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Information provided by the IAL News is not intended as a substitute for professional medical help or advice, rather as an aid in understanding problems experienced by laryngectomees and the state of current medical knowledge. A Physician or other qualified healthcare provider should always be consulted for any health problem or medical condition.

The IAL does not endorse any treatment product that may be mentioned in this publication. Please consult your physician and/or speech language pathologist (SLP) before using any treatment or product.

The opinions expressed in the IAL News are those of the authors and may not represent the policies of the International Association of Laryngectomees.

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* IAL Brochures
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* “Laryngectomees Loving Life” DVD (35Mins) ($10 donation requested) May also be watched on website.
* “First Steps” Available to download from the IAL website

Order From: IAL in Atlanta or email: theialoffice@gmail.com

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We thank all of our vendors for their support. Please contact them with your questions or comments. They are always ready and eager to help with any problem.

Contact Allison Reber Wurz, theialoffice@gmail.com, for all updates to the IAL website, club postings, changes to club contacts and professionals, in addition to resources you may need from the IAL office.

Thank You!
My Journey

by Tom Olsavicky

It was April Fool’s Day, April 1, 2008, when most everyone was having fun by pulling practical jokes on friends and relatives but I was on my way to a life changing operation. This journey started in the summer of 2006 shortly before I turned 64 years old. I awoke one morning with a hoarse voice. There was no obvious reason and there was no pain or discomfort so I didn’t think anything was wrong. A few weeks passed but my voice was not improving. My General Practitioner couldn’t find a reason and didn’t have any answers so he referred me to an Ear, Nose and Throat Specialist. A view of my voice box showed that my right vocal chord was not moving. Since I was not a smoker or drinker and there were no lumps or obvious causes, it was blamed on allergies or some other non-critical reason. Months passed, allergy testing completed, and a biopsy performed. All were negative yet my voice did not improve. In 2007 a second biopsy, deeper into the vocal chord, revealed the presence of cancer. A team of doctors thought it could be taken care of with radiation. After 35 treatments, four months of healing and still no improvement in my voice, a 3rd biopsy revealed the cancer was still present and the only cure would be a "total laryngectomy". At that moment I could barely spell the word let alone know what it meant.

A crash course on the computer in an attempt to learn all that I could still left me with many questions. I was scared, frustrated and asked many times, "why me?" I began looking back at my life to see what may have brought this on. I had spent 20 years in the US Air Force working in ground radar maintenance and came in contact with several harmful chemicals, I worked a couple of years in a smoke filled bowling alley, and spent 14 years, before retirement, at Newport News Shipbuilding in Nuclear Instrumentation and again worked with potentially harmful chemicals. Any of these situations could have been the root cause but not one place or condition could be labeled as the primary cause of the cancer. When I was younger, I had a cousin and an uncle who had developed throat cancer but it was then thought that smoking caused their problem. Now I wondered if it was genetically related. However since no definitive answers were able to be pinpointed, all I knew was that if I wanted to live a little longer and a laryngectomy would give me the best opportunity.

Still being apprehensive about life after surgery, I wanted to talk to other individuals who had made the same decision. They had "been there, done that" and could give me the best advice. I had never heard of Lost Chord Clubs until I spotted a brochure in a doctor’s waiting room. I then made one of the most important decisions to enable me to face the day of the operation and my future. I attended a meeting of the Tidewater Lost Chord Club in Virginia Beach. They showed me that I wouldn’t be writing everything I had to say. I would definitely speak again although I would never sound the same. They convinced me that I would have a "new normal" life and could still do 95% of the things I did before surgery. My fears, although still present, were greatly reduced. My wife, Sandy, and I were provided with all the information necessary to enable us to confidently handle the recuperation period. They helped so much that I immediately made up my mind to do what I could to help those individuals who would be facing the same decisions in the future. To accomplish this, approximately one year later, I began the Peninsula Lost Chord Club at the Riverside Cancer Care Center in Newport News to support those individuals in this area. We meet on the first Wednesday of each month and with the help of our other Laryngectomees, I feel we have made a big difference in providing hope for the future for many new throat cancer patients. Of course, for the last ten months, Zoom meetings have been the way we keep in contact and provide guidance for new patients who are able to join us.

It has now been thirteen years since my total laryngectomy. I consider myself in good physical health for a 77 year old who has recently had a hip joint replacement. I speak by using an Electro-Larynx (EL) placed under my chin and can be understood even on the phone. Most importantly I am able to enjoy my 5 grandchildren. The two youngest ones have never heard me speak any other way, so they totally accept me as I am. They even enjoy using my EL.

My voice box is gone but I am very thankful to still be alive and able to talk. I do not regret making this life changing decision and believe that everything happens for a reason. Over the years, I have had the opportunity to speak at some of the WebWhispers Dinners at the annual IAL Conferences and since 2011, thanks to Pat Sanders, have enjoyed being a Moderator for WebWhispers. My club and I were the host of the IAL Conference in 2017 in Newport News, Va. I have been fortunate enough to participate in several training classes at many IAL Conferences. In Jan. 2018, I was the guest speaker at the Texas Laryngectomy Conference. As an added bonus, I have met many courageous people throughout this journey and will continue to strive to educate anyone who wishes to have more information concerning a Laryngectomy.

Editors Note: Tom is currently President of the Peninsula Lost Chord Club and Vice President of the Tidewater Lost Chord Club. He has held both clubs together by providing Zoom meetings twice each week. He does pre and post op visits when called on and is always ready and willing to help anyone in need. Truly an inspiration to many. Thank You Tom.
New technology from Purdue University and Indiana University School of Medicine innovators may one day help patients who suffer devastating vocal injuries from surgery on the larynx.

A collaborative team consisting of Purdue biomedical engineers and clinicians from IU has tissue-engineered component tissue replacements that support reconstruction of the larynx. The team's work is published in The Laryngoscope.

The larynx is a very complex human organ consisting of outer cartilage for structural support, inner muscle that contracts to permit voicing, swallowing, and breathing, and inner vibratory lining.

Currently, thousands of patients each year with laryngeal cancer or trauma require a procedure called total laryngectomy in which the entire larynx is removed, and patients are left without a human voice and breathing through a hole in their neck called a stoma.

"There are very few options for laryngeal reconstruction and no options for restoration of laryngeal appearance, structure and function," said Stacey Halum, a fellowship-trained laryngologist specializing in head and neck surgery. "While surgeons occasionally use local or free tissue transfers to repair laryngeal defects, these local or regional tissues just 'plug holes' or close the defects without really restoring function because the transferred tissues are not dynamic they do not move or contract. They also tend to lose bulk and scar over time."

Halum, along with Sherry Harbin, a professor in Purdue's Weldon School of Biomedical Engineering, led the innovation team.

The innovators used a patented collagen polymer developed by Harbin's lab to fabricate the three regenerative replacement tissues for the laryngeal reconstruction procedure.

"Our approach is unique in that we are using customized engineered tissue replacements, with the muscle component fabricated using the patient's own muscle progenitor cells. We believe these engineering approaches will provide patients with better options for reconstruction so that total laryngectomies become something of the past."

Sherry Harbin, Professor, Weldon School of Biomedical Engineering, Purdue University

Harbin and Halum believe the technology has widespread applications for custom fabrication of engineered tissue replacements for tissue restoration in other parts of the body.

Harbin founded GeniPhys, a Purdue startup focused on the commercialization of the collagen polymer technology.
Policy for COVID-19 testing of patients with pre-existing tracheostomes (Tracheostomy/laryngectomy)  By Dr. Itzhak Brook, M.D., M.SC.

Background: Based on what is currently known about COVID-19 and what is known about other coronaviruses, spread is thought to occur mostly from person-to-person via respiratory droplets among close contacts.

• being within approximately 6 feet (2 meters) of a person with COVID-19 for a prolonged period of time.
• having direct contact with infectious secretions from a patient with COVID-19. Infectious secretions may include sputum, serum, blood, and respiratory droplets.


Early reports suggest person-to-person transmission most commonly happens during close exposure to a person infected with COVID-19, primarily via respiratory droplets produced when the infected person coughs or sneezes. Droplets can land in the mouths, noses, or eyes of people who are nearby or possibly be inhaled into the lungs of those within close proximity. The contribution of small respirable particles, sometimes called aerosols or droplet nuclei, to close proximity transmission is currently uncertain.


Approximately 100,000 people in the US undergo a tracheostomy each year, and a portion of these are permanent. About 12,000 people per year are treated for laryngeal cancer and as many as 1000 per year will undergo laryngectomy. This population have altered anatomy; because they are neck breathers they may have two potential sites of colonization/infection with the novel coronavirus that may be isolated from each other. Nasopharyngeal (NP) colonization - even if no airflow is occurring through the nose, hand contamination and face touching could lead to contamination at the anterior nasal surface and mucociliary transport could result in NP colonization. Tracheal colonization - the stoma could become colonization through either hand contamination/touching as is required during phonation and routine trach care, or from aerosolized exposure should they be close to an individual carrying the virus who sneezes or coughs.

For initial diagnostic testing for COVID-19, CDC recommends collecting and testing upper respiratory tract specimens (nasopharyngeal swab). CDC also recommends testing lower respiratory tract specimens, if available.

Criteria for testing will vary by local supply and practices and is outside the scope of this policy.


Recommendation: When a patient with a pre-existing tracheostomy meets criteria for testing per local protocols based upon local testing availability, specimens for testing should be collected from both the upper aerodigestive track (NP swab), and the lower respiratory track (tracheal swab).

Points for consideration:

• NP swabs may be collected in standard fashion
• Full PPE should be worn while collecting tracheal swabs (gown, gloves, n95 respirator, face shield/goggles, head and shoe covers) because of the risk of aerosolization should a cough be induced during specimen collection.
• Tracheal swabs must be collected while trying to minimize the risk of coughing/aerosolization during collection.
• No effort should be made to induced sputum.
• If a tracheostomy tube is present that contains an inner cannula, this inner cannula may be removed and the distal end swabbed for any visible mucous.
• If the patient does not have a tracheostomy tube with an inner cannula but has a tube in the stoma, while stabilizing the tube with one hand to prevent motion, a swab should be gently inserted through the inside of the tube with the intent of reaching the distal end of the tube (5 cm for a standard laryngectomy tube, 7 cm for a standard Adult size 6 tracheostomy tube). The swab should be rotated 360 degrees and then removed and inspected. If there is no visible mucous on the swab the procedure should be repeated with careful attention to getting the swab deep enough, to obtain visible mucous on the swab.
• If a cough is stimulated any expectorated mucous may be used for the swab.

While test results are pending (patient under investigation status), a HME should be worn over the stoma/tracheostomy tube, to prevent potential spread via aerosolization.

See how far you've come?
Be proud of yourself.
If nothing else, one day, you can look at someone straight in the eye and say:
“But I lived through it and it Made me who I am today.”
My Positive Outlooks.com
Raffle Baskets
For the 2021 IAL AM/VI
By Susan Bruemmer, M.S., CCC-SLP, Retired

As a new member of the IAL Board, I was excited to participate in planning our 2020 meeting in Charlotte, NC, June 10-13, 2020 at the Crowne Plaza Hotel in the Charlotte Executive Park. However, that did not happen due to the Covid-19 Pandemic.

We are hoping to get a good number of attendees at the 2021 meeting September 28 thru October 2, 2021 as we are ready to get back to “normal activity”. We usually had a silent auction during the meeting that was made of of donations from the local host club. That was a big undertaking.

Instead, I would like to see raffle items and/or baskets from any person representing their hometown club attending the IAL AM/VI in Charlotte. We have asked for baskets with items from your home state. I had gotten confirmation from clubs in California, Texas, New Mexico, Washington, Virginia and Arizona and am looking forward to seeing what each of those baskets contain from the different states. We could use a few more baskets representing attendees’ local areas. My club in Kennewick, WA is already planning to put together a Washington basket so we can let people know about our area of the country. (There will be no food involved.) If there will be no member attending from your local club, please think about donating a basket anyway and sending it to:

Susan Reeves, IAL Manager, 18 West College, San Angelo, Texas 76903

We would love to have all clubs represented. Please let me know if your local club can help out. My email is: sbruemmer3@gmail.com

This will be a great fundraiser for the IAL and should be a lot of fun. Thanks in advance.

We will also be holding a 50/50 raffle at our event. Save up some cash to take a chance on winning a nice big pot of money.

Being a Caregiver
By: Donna Schmidt-Green

Just because my husband and I are now divorced and no longer live together, I am still looking after him and much of his care. I do a lot of appointment planning, ordering supplies through ATOS, other doctors appointments etc. He doesn’t like talking on the phone using his electro-larynx because it is hard for people to understand him and that can get him pretty frustrated. I do help him out financially when I know he’s struggling because we still care a lot about each other.

He does take care of his stoma, and to tell you the truth, the actual taking care of his stoma would be hard for me. I have a weak constitution.

I was there for him during the surgery, and stayed at the hospital all week. I’ve been going with him for his check ups, 3 1/2 hours one-way.

One thing to remember is they don’t remember a lot of what has happened to them the first week because of all the drugs for the pain. So don’t take offense to things they might say because they probably don’t even remember that! At least that’s how it was with us. At times it can be trying and you do need a lot of patience. I just know he would be there for me if the shoe was on the other foot so to speak. I try not to meddle too much, but I’ve always been a mother figure in some ways, that’s my nature. I try to be proactive instead of reactive, and that doesn’t always work either! Sometimes I just have to be silent because he doesn’t want to hear my suggestions.

I will always care about him and want the best for him and I’m so thankful he finally quit smoking. It is just so sad, that this was the only way he was going to do it because of his first cancer. When we got the diagnosis that he needed a laryngectomy it hit as hard as the first cancer diagnosis nine years before. I’ve tried to stay positive and remind him that this was life-changing but not life-ending! You have survived this!

I think the best thing for him, was the nurse he had most of the time in the hospital. She made him take care of himself, she showed him, she had him do it so he could be self-sufficient. It is a good thing, especially because my nerves would probably make me pass out if I had to do the actual cleaning of his stoma.

To all those going through this struggle, there are good days and there are bad days! But, you can survive. Just try to be thankful, because so many people can lose their life because of this. I do believe, for the person who does pass, if they believe in God there is nothing but joy! It’s the ones who are left behind that are suffering with the loss. So I pray every morning for peace for those who lose a loved one, and the ones that make it that they appreciate those who have helped them get through it. None of us are guaranteed tomorrow, so we should always be humble, always be kind and always let the people we love know that! May God bless everyone who is going through a struggle no matter what it be! Thank you for letting me share!
President’s Message

At long last we will be meeting in Charlotte, NC on September 28 thru October 2, 2021. I am really excited and I am looking forward to seeing all of my old friends and making many new friends.

Registration and hotel information are located in the back of this newsletter. We will have registration on line, but unfortunately the hotel does not have online reservations for our group. They do have an 800 number to call and it is located on the back inside cover. We are hoping that everything will be much more open by the time we meet and that we can enjoy all of the face-to-face time we want. We have not settled on a Friday afternoon outing yet. We are looking at all options to see what will be best for our event. Our next newsletter will be out in August and will have all of the details.

Registration should be available on our website by May 1st. Our webmaster, David Cleveland has been working to get it up and running as soon as he can. I hope you have checked out our website (theial.com) to see the changes that are being made and hopefully you will find it more user friendly and easier to navigate. We are always open to suggestions for improving our site and would be happy to hear from you. If there is any other information you would like to see posted, please let us know.

When you visit our website you will find we have individual memberships. These memberships are only $5 a year and that helps to defray the cost of the Newsletter printing and mailing. It is very easy to sign up and become a member. I want to recognize the people that have signed up for individual membership though April 16, 2021. Thanks to Peter Sortwell from San Mateo, CA; Terance Smith from Fremont, IN; Mary Rose Pearl from Killeen, TX; Aaron Wayne from Inglewood, CA., and Bill Franklin Garber from Rio Rico, AZ.

There are some things everyone needs to be thinking about. We will have our delegates meeting on Saturday morning October 2. Everyone currently on the Board of Directors have served their two year terms and will be up for re-election. This includes all of the officers as well. I do not want to remain as president, as I’ve had some health problems, and I am sure hoping that someone will step up and take my place. If there is anyone out there interested in being an active board member or officer of the IAL, all you have to do is submit a picture with a bio and an endorsement from your local club. You can mail that to the IAL office in Atlanta and you will be added to the slate of candidates. We recently lost a member of our Board. I am sorry to report that Karen White passed away and will be missed by many. She served on the board for two years and was an active member. I recently appointed John Ready to fill her term, until our next delegate meeting in September.

We are planning a great Annual Meeting/Voice Institute in Charlotte and hope all of you that possibly can will attend. It will be fun and informative for all. Please go ahead and register so we can get a good idea of our attendance.

I want to thank all of our vendors for their continued support. Things have not been easy through the Covid Pandemic but you have all stuck with us. A special thank you to Atos Medical and InHealth Technologies. They have gone that “extra mile” in helping us stay connected by conducting on Zoom meetings and online events. Please check out facebook and log on to these wonderful learning events. They surely are keeping us connected to each other and helping in any way they can.

It has been a pleasure to serve as the president of the IAL and I look forward to seeing many of you in September.

By: Helen Grathwohl
MY WINTERTIME

By Joyce Hurd in St. Louis

Time has a way of moving quickly...it catches us unaware of the passing years. Indeed, it seems like just yesterday I was young and embarking on a new life in college and yet, it also seems like eons ago, and I marvel at how fast the time flew by.

I believe that I lived well since I catch fleeting glimpses of my past hopes and dreams...but, I find myself in the the winter of my life... caught unawares and off guard. How didst I get here so quickly? Where hath the time gone? My youth...slipped through my fingers.

I remember seeing people and thinking that they were ever so much older than I. I was invincible...I was in my summer season! Winter was so far off that I could not comprehend it or imagine what it would be like.

But time sped on...my friends retired and are getting grey... they move slower, yet still faster than I. Many are in better physical condition than I, although the ravages of time are beginning to show and suddenly we have become those old folks we used to see and never thought we'd be. I look in the mirror and don't recognize the visage that looks back at me. My thick, lustrous tresses have become thinning grey strands...my once taut chin now sags...laughter lines crease my face...

Now-a-days I find that just taking a shower is a real accomplishment! Having a nap is not a treat anymore... it is mandatory, because if I don't take one willingly... I just fall asleep where I sit!

And so... now I enter this new season of my life, unprepared for all the new aches and pains. I am embarrassed by my loss of strength. Oh how I wish I had done so many things that I never did!! How did I pass through my Autumn without knowing it? But at least I know that though the winter has come... and I'm not sure how long it will last... that when it's over on this earth... it's over...and a new adventure will begin!

Yes, I have regrets as there are things that I wish I hadn't done...and there are things that I wish I would have done...but indeed, there are also a lot of things that I'm happy I did get done. In many respects, I have survived more than most people and have accomplished a wide variety of various and sundry things. I have earned too many degrees, some say, and not been consistent in my employment. I have loved too passionately and laughed too loudly...my choice of dress is not the norm...and yet, I remain true to myself and the God who saved me.

So, beloved, if you are not in your winter yet... let me remind you, that it will be here faster than you think. Take my advice... whatever you would like to accomplish, do it... don't put it off for too long as life goes by so very quickly. Do what you can as soon as possible since you may never be sure whether or not this is your wintertime.

Remember that you have been given no promise that you will see all the seasons of your life... so, I advise you to obey God and do all Christ asks of you to the best of your ability. Speak to your family and say everything you want your loved ones to remember...pray that they appreciate and love you for who you are, not for all the things that you have done for them.

"Life" is a GIFT to you. The way you live your life is your gift to God! Make it a fantastic one... one that makes the Lord smile.

Remember: The relationship you have with Christ Jesus is the real wealth not pieces of gold and silver...for where our hearts are - there is our treasure.

Enjoy the little things in Life,
For one day you'll look back
And realize they were the big things.

Kurt Vonnegut
Tonya T. Jones: Healing and Hope

For me, Tonya Jones, overcoming has been the only option.

In 1978, after struggling with a raspy voice for months, I was diagnosed with vocal cord cancer and would need surgery immediately.

It was not going to be surgery with a quick fix. The removal of my larynx and thus the loss of my ability to talk.

My physician advised that with a successful surgery, I could undergo speech therapy to regain speech through esophageal voice and/or an electronic device.

During the time leading up to the diagnosis and surgery my church was overwhelmingly supportive. Prayers, visits, gifts, cards, and phone calls were my constant encouragement. My pastor and his wife, my dear friends, gave counsel and prayed for a miracle.

The therapy of learning to speak again was difficult; my determination to do whatever was required would be done and succeed. My career with Georgia Power had begun a year and a half before, and I was the proud mother to a beautiful 3-year-old daughter. I was also active in my local church teaching preteen girls, giving periodic devotions to my adult class, and singing with the choir. I could not see myself speechless.

A few weeks into my speech therapy, I made the decision to return to work. My management was very gracious providing me with a private office and having others take my calls.

During my convalescent period, a woman from the Greater Atlanta Voice Masters called me. After a brief conversation, she asked to visit, however, I was devastated with how she sounded as a laryngectomee. I was deflated. When she and her husband arrived, having traveled from Decatur to Austell, I was awed by her beautiful smile; her visit greatly encouraged me. Jane Del Vecchio became a friend and because of her, I joined the GAVM and became a trained patient visitor. During the years with GAVM I met many laryngectomees but no one even close to my age. However, meeting these people who struggled as I did, and many of them used a device of some sort, was a delight and a reminder there is life after laryngectomy surgery.

Jane introduced me to the American Cancer Society Decatur office. Through our connection I was invited to speak at various groups and share my story. I agreed to this venture with the inclusion my audience would know I was a non-smoker and that I would always share my faith. At this time, I answered my phone calls at the office, and had returned to life as it was with one exception: Me as a laryngectomee, a young woman with a very pronounced “disability”, who was pointed out time and again because of my unique voice, not always kindly.

The speaking engagements became more frequent and Georgia Power agreed to allow me to use work time when “necessary. I spoke to student nurses, cancer survivors, church groups, unwed mothers, my own company, Ga. Power, and many others.

As I was mastering esophageal voice, I was very unhappy with the quality of my voice. As a young woman who trained as a fashion model to walk the runway and who was fastidious about dress, makeup, and hair this was a blow. In addition, due to my youth, many who heard me speak would comment or look very perplexed. This became a thorn in my side, frankly, it was a rough period in my life. But things changed. It seemed men found me interesting and attractive. I began to date again. And my voice profoundly improved.

As difficult as the adjustment was for me as a new laryngectomee, the walk strengthened me, God’s purpose was at work. For this article I am compelled to acknowledge my deep love of God, the grace He bestowed upon me to walk through this period of life, and the supernatural ability He gave me to speak fluently. My faith was alive and walked out in Scripture, “I can do all things through Christ who strengthens me”, and “All things work together for the good to those who love God and are the called according to His purpose”. It was not my strength or ability or anything in me that gave hope and encouragement for this life, but God alone. Because of His purpose in my life, I continue to give Him praise for allowing me to touch others with hope.

As I continued to speak to various groups, I learned that people in my audience faced traumatic episodes in their lives, not only to cancer. These people needed to hear and see someone who had faced a trauma and adjusted to a drastic change, who in fact, became an overcomer not a victim. Many would come to me and share a terrible situation and how my story impacted their lives and how I did so with a smile (thanks Jane).

During my time with GAVM, the International Association of Laryngectomees hosted the convention in Atlanta and our group was involved in that effort. I was asked to take part on a panel regarding issues of laryngectomees. We also performed a Gone with the Wind themed skit and I played Scarlett O’Hara. This was a thrilling experience for me and although I have not attended another convention, I look forward to doing so in the future.
Because my voice became more fluent and less raspy, I began speaking without even thinking of the mechanics of doing so. I had far less comments about my voice and was much more comfortable being “me” and not worrying about perceptions of others.

Life continued and I was blessed with a baby boy four years after my surgery. With two children, working full time, our church involvement I had less time for GAVM and speaking engagements.

Eventually I retired from Georgia Power after 32 years and moved to a rural area. A few years after retirement, I wanted to re-enter the workforce, but could not find a job – even with all my experience and skills.

Through the prior years I had experienced some prejudice because of my physical challenges; there was rejection, and I was marginalized as a person especially when I wanted to speak. People would speak over me not only in business meetings but in personal situations. I struggled with having people and employers view me as a ‘disability’ rather than viewing me as a whole person with skills and experiences and capabilities. Even after the Americans with Disabilities Act 1990 was implemented, there was still quite a bit of prejudice. Thankfully, there is a greater understanding and acceptance of people with impairments today.

Through working with the Goodwill Career Center, I was hired by Three Rivers Regional Commission Area Agency on Aging in December 2013. I was the new GeorgiaCares Volunteer Coordinator; I also trained and became certified as a Medicare Counselor within a year. This job required a great deal of face to face and phone work with Medicare clients.

During my involvement with Goodwill Career Center, I was invited to take part in a televised interview for their training center. Immediately after I was invited to speak to their Board of Directors sharing my experiences as a challenged individual. Since the interview took place at Three Rivers, the Board of Directors invited me to share my experiences.

Presently, I am retired, a grand mother, and most recently a great grandmother. To sum up my life thus far, it has been a life well lived, blessed of God, loved by family.

Having cancer and becoming a laryngectomee, did not stop my life or make it easily dismissed, rather the experience gave me a depth and deeper understanding of life’s purposes. Would I do it all again? Yes, a thousand times yes. The miracle came in an unexpected way and was far better than I could have asked.

Submitted by Tonya T. Jones, February 2021

Understanding Medicare Coverage for Stoma Care Supplies

Much confusion exists regarding insurance coverage, especially Medicare coverage, for laryngectomee supplies. Some are under the impression that Medicare “doesn’t cover” their supplies, which is incorrect. The confusion is due to the complexities of the Medicare reimbursement system, as well as the development of new products and supplier adaptations to market forces.

The Center for Medicare and Medicaid Services (CMS) assigns a HCPCS (Healthcare Common Procedure Coding System) code to designate classes of medical supplies for filing reimbursement claims. For example, the HCPCS code for laryngectomy tubes (InHealth StomaSoft and Atos LaryTube) is A7520, and the code for HME cassettes is A7507. CMS assigns an “Allowable Reimbursement” for each code, which is the amount that Medicare will reimburse for a supplied item, subject to a 20% copay amount and an annual deductible.

There may be slight variation in these allowable amounts based on location, but according to the current fee schedule, the CMS Allowable amount for a laryngectomy tube is typically $55.27. Assuming a patient has met their annual deductible, Medicare would reimburse the supplier 80% of the allowable amount ($44.22) and the patient would pay $11.05 (20% of $55.27) out of pocket for a laryngectomy tube if purchased from a supplier who has agreed to accept Medicare assignment for the item, regardless of the customary price that the supplier charges for it.

If the supplier does not accept Medicare assignment, the laryngectomee will usually be required to pay the supplier full price when ordering (estimated $135.00), the supplier files a Medicare claim on the patient’s behalf, and then CMS reimburses the patient $44.22 (80% of the Allowable $55.27). Please note that these are estimated costs, as prices vary with the manufacturers and distributors and Medicare reimbursement levels are subject to change at any time. Also, if a patient has a supplemental insurance plan, the annual deductible and these out-of-pocket expenses may be covered in whole or in part.

CMS has designated HCPCS code A7508 for all one-piece adhesive baseplates (InHealth and Atos) regardless of the style, and doesn’t make a distinction between the Flexiderm, Optiderm, Luna, Stabilibase, AccuFit, HydroFit, etc. There is one HCPCS code for HME cassettes, HCPCS code A7507. Again Medicare doesn’t make a distinction between EasyFlow, XtraMoist, Luna, Micron, etc.

Medicare will ‘cover’ all one-piece adhesive baseplates and HMEs. But because Medicare doesn’t distinguish between the various products, they have one set amount that they reimburse, regardless of how much the manufacturers or distributors charge for them. For example, ATOS takes ‘Medicare assignment’ on Flexiderm, Optiderm and Luna baseplates, meaning they agree to accept whatever Medicare will reimburse and can only bill the patient for the 20% copay. They do not take Medicare assignment for other products such as Stabilibase XtraBase, or Micron filters, so you pay the full amount up front and will receive a partial reimbursement on your Medicare claim some weeks later. InHealth accepts Medicare assignment for their AccuFit and HydroFit baseplates and HME cassettes.

So it is NOT a case where Medicare ‘doesn’t cover them’. Medicare covers all of them. It is that the SELLER has decided that the Medicare reimbursement is too low for particular items so they will not accept Medicare’s assigned reimbursement for them as full payment.

Carla DeLassus Gress, ScD, CCC-SLP
Nebraska Methodist Hospital
Omaha, NE
Benefits of Pet Therapy

By: Stacey Brill,

Interacting with a pet can aid with physical and emotional issues, whether as an owner or as a therapy patient. For the purposes of this column, the focus is on therapy. Therapy dogs are trained canines that are registered by different corporations to help patients with a variety of different mental and physical illnesses. Currently there are more than 50,000 therapy dogs used in pet therapy in the United States. Numerous benefits of pet therapy have been reported, including alleviation of pain, reduced blood pressure, and an overall improved mental state. Additionally, therapy with pets can help with improving joint movement and motor skills, social skills, increasing motivation for exercise and decreasing isolation and loneliness. One of the biggest benefits of pet therapy is the reduction of stress and anxiety levels. When interacting with a friendly animal, the human brain releases “feel-good” chemicals called endorphins that make the patient feel relaxed and more at peace.

Many of you may have experienced pet therapy while you were hospitalized. Think about how you felt being in the hospital and when the therapy dog came to visit how that brightened your day. Many of you with extended hospital stays may have looked forward to a certain day of the week knowing that was pet therapy day. Knowing this led me to the decision to work with my personal dogs to see if I could use them as an adjunct to my therapy and as a support to my patients. It worked-- my therapy dogs have met many patients over the years and have forged many bonds with patients and families. In fact, patients come back to the clinic just to visit the dog not me, their clinician! When patients were asked in surveys what the highlight of their therapy was, overwhelmingly their reply was having a dog present to give them comfort.

16 years ago, I started bringing my English Bulldog, Daisy, a trained therapy dog, to the hospital with me. Daisy had a bond with my patients as she too was a head/neck cancer survivor. Daisy was diagnosed with Squamous Cell Carcinoma of her jaw and went on to have a partial mandibulectomy. It was a diagnosis and operation to which my patients could relate, and, in a way, she inspired them. Since then, I have trained five of my personal English Bulldogs to become registered therapy dogs. I have incorporated the dogs into therapy sessions and have noticed reduced stress and anxiety in the patients, as well as in family members. There is something about a cute, wrinkly bulldog greeting you that you can’t help but smile.

My patients who have interacted with the dogs share feelings and experiences seemingly with more ease and comfort. Patients have used the dogs in the room to create purposeful speech and to practice using their artificial larynx or TEP. They report feeling comfortable engaging with the dog as do not feel judged about the clarity of their speech. Many of my patients have dogs at home and have conveyed that they want to be able to talk to their dog using clear voicing with their TEP or artificial larynx. These patients feel having a dog present in the therapy session is helpful for them to practice naming their commands they give their own dogs. The dog’s presence seems to motivate patients to do more, makes them feel relaxed and more motivated to come to therapy.

After head/neck cancer treatment, many patients have difficulty swallowing and are afraid about eating. Having the therapy dog present during therapy while doing po trials has been beneficial at reducing their fear. I have taken blood pressure readings prior to therapy and post therapy with the dog present and found consistently patient blood pressure has dropped, indicating less stress. In many cases, the dog is a good distraction for the patient and gives them something to focus on, rather than the potentially anxiety producing task at hand. Most of my patients have requested to have their photos taken with the dog I have at the time and have shared stories with their families about having a therapy dog present during their speech therapy sessions.
I firmly believe that dogs can sense when a person needs their comfort. My current therapy dog, Harlow, will sit with patients allowing them to pet her while they are completing therapy tasks. She will give a lick or a paw to those that she senses need a little extra push in therapy routine. It is as if she is saying “keep up the good work you can do this”. Watching the joy that my therapy dogs have brought to patients and families and seeing the smiles on their faces makes my job as a Speech Pathologist even more rewarding. I love the fact I can help patients with their rehabilitation and bring them happiness as well.

One of my favorite stories is of a patient that underwent a total glossectomy. His tongue and throat were rebuilt, he had bilateral neck dissection and underwent chemo-radiation. This gentleman endured so much and had a long road to recovery. He always looked forward to therapy days knowing Harlow would be there with him. He worked extremely hard to regain his speech and swallowing ability. She distracted him from the pain he was having. Harlow would sit with him, listen to him talk, give him kisses for his accomplishments and was a great support mechanism for him. For her second birthday he brought her a birthday party to his therapy session and even used his new speech skills to sing her happy birthday.

Harlow has been with another patient from the start. She was with him for pre-op education for his laryngectomy to his therapy appointments training him to use his artificial larynx, and then how to manage his TEP. He would practice voicing by telling her stories. He always requests a TEP change on days he knows she will be in the clinic as he enjoys seeing her and has said she brings him peace and a sense of calm.

Pet therapy can be provided in a variety of different settings and with a variety of different animals. I can honestly say providing pet therapy for the past 16 years with my personal dogs has been a highlight of my career. I encourage others to do the research and establish or participate in a pet therapy program where they live. As Christopher Morley once said “No one appreciates the very special genius of your conversation as the dog does”
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Can We get Motivated in a Pandemic?

Written by Sean Dietrich
Submitted by David Kinkead

Motivation. What is motivation? Where did it come from? Where did it go? When will it come back? Why am I still wearing the same pajamas I was wearing in March 2020? Why am I beginning a paragraph with rhetorical questions?

Because I have no motivation.

If you don’t have any motivation either, welcome to the club. There is a logical reason for why we’re feeling like such losers. And here it is: These are sucky times.

I know of no other way to put it. This is not a normal era, so expecting to feel normal and “productive” is like expecting to turn into a turtle. It’s not going to happen.

This pandemic era is like one giant funeral. If you have ever experienced the death of a loved one, you already know what I mean.

A funeral will sap your energy and leave you totally exhausted. And it doesn’t end after the funeral ceremony. Once the funeral ends, friends will incessantly call to check on you, but you’ll have no enthusiasm to speak to them, so you’ll blow them off because conversations take energy.

Eventually, friends quit calling because you never answer your phone. So you end up isolated. Which means that now you’re REALLY lost. The further you sink, the faster your motivation disappears. Sound familiar?

Here’s the thing. What I just described isn’t called motivation loss. This is classic grief.

Which is exactly what you’re experiencing right now, “collective grief”. And before you tell me I’m an idiot for using this phrase, I didn’t make up that term. Mental health experts did.

We are grieving the loss of a world we grew up in. And we’ve lost a lot. We’ve lost travel, parties, concerts, church services, holidays, buffets, handshakes, indoor dining, gainful employment, company picnics, Little League, hugs, movie theaters, and just when it couldn’t get any sadder, Hank Aaron died.

To make things worse, there are still folks out there who claim they’re doing just peachy. Like my friend John, who says this pandemic has been no problem for him. John says he started a new diet, a new workout routine, a new business, and he probably claims he’s found spiritual fulfillment through the teachings of Englebert Humperdink.

“I’m doing great!” says John. Well simply put, my friend John—and I mean this respectfully—is full of doo. And people like him ought to quit bragging about how wonderful their life is or else friends might write about them and use their real name.

This morning I interviewed a mental health therapist while doing research for this column. The doc had this to say about people who claim they aren’t having any pandemic related problems: “I don’t its possible not to suffer during this period”.

He explained why. I’m paraphrasing Here: “Imagine you standing outside during a tornado. During the storm, someone tells you that you have just won the lottery. Thus, while and F5 cyclone the size of a rural school district destroys your hometown and harms your family members, you’ve just discovered you’re a millionaire”.

Now I ask: In this scenario can you be truly happy?

Well brain science tells us the answer to all this depends on the gross total of your lottery winnings after taxes. NO! WAIT! I mean brain science tells us you can NOT be truly happy in this chilling scenario. How could you? Your whole world is falling apart, what good is a pile of cash? You have bigger priorities here.

Which leads us right back to motivation. Maybe you’re not lazy, maybe your priorities have changed.

Which is why I asked the mental health therapist what sort of things people could do to overcome our lack of motivation. The expert said this: “My advice to my patients is to roll with it. Be unmotivated. If you don’t want to wash your hair, don’t. The worst thing you can do is fight the way you feel. Listlessness and lethargy are basically symptoms of depression. Resisting them is like saying, ‘Hey, I can make this bad stuff disappear if I try real hard.’ That’s not true. And putting pressure on yourself to be productive is the worst thing you can do. Give yourself a break.”

So if you’ve had the motivation to read this far, the doctor’s advice pretty much boiled down to this: Relax. Quit punishing yourself. This is a hard time to be alive. But you are indeed alive and your life is a gift.
BACK TO BASICS - THE IMPORTANCE OF COVERING THE STOMA

SLP Zilpha Basone, Ph.D. has probably attended more IAL Annual Meetings than any other professional as a faculty member of the Voice Institute, major speaker, honoree, or just another attendee visiting with many of her laryngectomee and professional friends. Her dedication to laryngectomees has been a permanent fixture of her life. She lives in Northern Virginia and is retired from the VA hospital system.

When asked what she considered to be the most important advice to give to laryngectomees she did not hesitate but said (1) develop the best and more effective method of communication you can, and (2) cover your stoma 24/7. What follows is a reprint of an article appearing in the IAL News in September, 2001:

It is important from a health standpoint for laryngectomees to cover their stomas at all times.

While there is contradictory advice from equally knowledgeable experts on many issues facing laryngectomees, this is not one of them. The consensus of expert medical opinion overwhelmingly supports the wearing of stoma covers. The reason is found in an understanding of how the laryngectomy surgery changed our anatomies.

The laryngectomee operation bypassed the entire upper half of the respiratory system. It did this by bringing the trachea tube which used to connect our lungs with our throats, mouths and noses directly to the outside via a surgically created hole, the stoma. We thus lost the breathing function of the upper half of the breathing system.

Our noses, mouths, and throats served a number of important purposes in breathing. They served to perform these functions for incoming air: (1) filter it, (2) humidify and help retain moisture from exhaled air to reuse, (3) warm it, and (4) provide resistance so that our lungs fully inflated.

Prior to the laryngectomy, air would enter through the twin nostrils in an upward direction. The first line of defense in filtering out dirt particles was nose hair. Incoming air was also forced against the curved part of the nasal cavity where it encountered turbinates, or flesh covered bony [cartilage] structures in the nose. Covered with sticky mucous, these trapped more impurities from the air, warmed the air, and provided resistance to incoming air. The air also picked up water vapor from their mucous linings.

The back of the nose and mouth and upper part of the esophagus provided still more filtering, warming, humidifying and resistance as the air traveled downwards. By the time the air reached the lungs, it had almost 100% relative humidity, or was holding all of the moisture it could hold. Additionally, the temperature was now close to the body temperature of 98 degrees.

When we exhaled, the air coming from our lungs would deposit most of the moisture in it back into the mucus lining for reuse. After laryngectomy, we lose virtually all of this moisture in exhaled air through the stoma unless we cover it.

Stoma covers help to replace functions previously carried out by the nose and mouth in:

- Filtering airborne dirt particles, bacteria, viral and other biological agents from entering the lungs via the stoma.
- Retaining some of the moisture from the lungs which would otherwise be lost in exhaled breath.
- Keeping some warmth from escaping in exhaled air
- Restoring some resistance to inhaled and exhaled breath which is helpful in retaining better lung function.

There are a great many potential negative consequences for not wearing a stoma cover including:

- Increased danger of respiratory illnesses including pneumonia
- Greater mucous production
- Increased coughing
- Greater possibility of potentially life threatening mucous plugs
- Chapped irritation from the stoma wall drying out
- More crusting and potential blockage of airflow through the stoma
- An enhanced potential for dehydration from loss of humidity in exhaled breath
- Reduced lung function from the loss of resistance

If you do not presently wear a stoma cover you may find it easiest to begin with an open weave knit or crocheted stoma cover, and gradually work up to a closer weave, foam cover, or HME (heat/moisture exchange) filter. Although the research is not complete, the HMEs are probably superior in providing for all of the previous functions of the nose in filtering, humidifying, heating air and providing resistance for improve lung function.

(Thanks to SLPs Julie Barkmeier, Carla Gress, Vera Karger, and Brian Shute for contributing ideas and editorial suggestions).
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