Adherence to Swallowing Exercises in the Prevention of Radiation-Related Dysphagia

Eileen Shinn, PhD

When faced with cancer, patients and their caregivers draw upon all their mental, physical, financial and social resources in order to rise to the challenge. As Dr. Glenn Peters, a head and neck cancer surgeon at the University of Alabama observed, “Cancer seems to bring out the strengths in a person just when their life seems to be falling apart. It will always be a source of constant amazement to me just how intensely patients rise to the occasion when faced with such devastating prospects. I have yet to meet a quitter - ever! You folks are the gutsiest, most determined bunch of folks I have ever met in my life.”

The number of throat cancer patients in the U.S. is rapidly rising: within the past 20 years, the number of human papillomavirus (HPV)-positive oropharyngeal cancers has more than doubled, due to a U.S. epidemic of HPV infection. In 2014, 27,040 new cases of laryngeal or pharyngeal cancers are expected in the U.S. Because these tumors are very difficult to detect until they have grown quite large, most cancers of the larynx and pharynx are not diagnosed until they are in the late stages (stage III-IV). However, cancers of the larynx and pharynx are highly curable, with overall 5-year survival rates ranging from 61% - 78%. Nevertheless, as most patients and caregivers already know, treatment is challenging and causes both acute and long-term effects. High-dose radiation treatment is almost always used and the radiation field often includes the glands that produce saliva as well as important swallowing muscles in the throat. While modern techniques in radiation allow clinicians to precisely shape the photon beam to minimize exposure to the salivary glands and swallowing muscles, radiation doses to the tumor are almost always over 68 Gray [Gy], which increases the risk of scarring of connective tissues and blood vessel linings within swallowing muscles.

Aftereffects of Radiation
When these tissues become scarred after radiation, head and neck cancer survivors may experience difficulties with their swallowing, or dysphagia. Unfortunately, once it occurs, problems with swallowing tend to be permanent. Radiation-induced dysphagia occurs in up to 39% of patients. In a recent Danish study of 647 pharyngeal and laryngeal cancer patients who had been treated with a modern radiation technique called Intensity Modulated Radiation Therapy (IMRT), 22% of the long term survivors had moderate-to-severe problems with swallowing as measured by gold-standard videographic x-ray swallow study. While typically underappreciated at the time of cancer diagnosis and treatment, difficulty with swallowing is devastating to survivors’ quality of life and may lead to further problems with maintaining adequate nutrition and increased risk of choking while eating or swallowing.

As stated previously, once scarring of the swallowing muscles develops, there is little hope of restoring normal function, and strategies to improve swallowing muscle function after scarring has already developed have not proven to be effective for large numbers of survivors.

The Importance of Prevention with Swallowing Exercises
Therefore, prevention of swallowing problems is critically important for head and neck cancer survivors. In addition to the modern surgical, chemotherapy and radiation techniques that doctors can use to spare key swallowing structures, swallowing exercises during radiation are also effective in preventing dysphagia. These exercises target the base of tongue, pharyngeal constrictors and suprathyroid strap muscles to promote strength, mobility and endurance and have become a standard preventive regimen delivered by speech pathologists in comprehensive cancer centers nationwide. Studies confirm that motor exercise before and during RT reduce the incidence of long-term dysphagia in advanced HNC patients. One group of healthcare professionals found that adherence to swallowing exercises during RT was significantly related to patients’ self-report of their ability to swallow and eat normally when assessed 1 and 2 years after their radiation (this study followed 109 oropharyngeal cancer patients).

Low adherence to swallowing exercises is a persistent problem. Importantly, the swallowing exercises are ineffective for all but the smallest of tumors once radiation-induced scarring is established. For patients, this means that swallowing exercises...
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should be started and maintained during radiation and beyond. However, since radiation is physically and emotionally challenging for patients, most patients do not adhere to their swallowing exercises during radiation. This same group found that patients reported low adherence to swallowing exercises during radiation: 13% of 109 oropharyngeal cancer patients completed all of their prescribed exercises, compared to 32% who tried the exercises sporadically before quitting and an additional 55% who never tried the exercises. When asked individually, nonadherent study participants invariably explained that they could not feel nor detect any decline in their swallowing function, and thereby concluded that their personal risk for post-radiation dysphagia was low. This limited sense of urgency was striking in light of the fact that all participants attended at least two speech pathology appointments to receive training in preventive exercises and their rationale.

WHY SHOULD I DO MY SWALLOWING EXERCISES?
• 22-39% of all head and neck cancer survivors will develop swallowing problems after radiation.
• These exercises are highly effective before you develop a swallowing problem. They are not as effective once you have a swallowing problem; therefore, it is extremely important to do them.
• By the time you get to the point where you need help, it is almost too late.
• If you develop a swallowing problem, you must see speech pathology, because they can help you.

Because not enough research has been done to predict who will end up with a swallowing problem and who won’t, everyone undergoing radiation to the throat for Stage III-IV cancer should perform swallowing exercises during radiation. If a patient’s hospital does not have a speech pathologist who can teach these exercises, then patients should ask their head and neck cancer surgeon to refer them to a speech pathologist who specializes in adult dysphagia. It is important to remember that these exercises are different from your neck exercises (e.g., turning your head from side to side).

Helping Patients to Complete Their Swallowing Exercises
At one comprehensive cancer center in the United States, a group of physicians developed a research program called PREPARE to help patients start and maintain their swallowing exercises during radiation. The team has completed one randomized trial testing the efficacy of PREPARE in oropharyngeal cancer patients and are in the final year of a second randomized trial testing the efficacy of PREPARE in patients with laryngeal, hypopharyngeal and nasopharyngeal cancer. Immediately before beginning radiation, a total of 325 patients were randomized to receive the PREPARE intervention or enhanced usual care (control). PREPARE’s high recruitment success and intervention retention rates (88% and 97%, respectively) indicated that patients recognized the value of this project. Of the 325 patients who were recruited, twelve patients died during the study period, and 263 patients completed the first follow-up assessment time point (84%). Half of the patients...
Follow-up data at later time points also indicated that PREPARE positively impacted swallowing-related outcomes. At 3 months post-radiation, 25% of patients randomized to the PREPARE program were able to eat a normal diet compared to 13% of the patients who were randomized to the control group. When examining rates of patients who were tube-dependent at 6 months post-radiation, 26% of PREPARE patients reported tube-feeding vs. 41% of the Control patients. Two of the behavioral methods that were employed in the PREPARE research project to maintain adherence were: 1) behavioral contracts to perform exercises and 2) teaching communication strategies. These are briefly explained below.

Making a Commitment
During radiation, patients are asked to perform each of their swallowing exercises about 8 to 10 times each, at least four times a day. Doing these exercises daily requires a strong commitment. In the PREPARE research project, patients were asked to sign a contract with themselves, promising that they would do their swallowing exercises and keep track of the number of exercises. Some type of method to track progress is key in improving adherence to any behavior. Another important tool for improving adherence is to ask patients to set goals for themselves throughout treatment, such as, starting their exercises, drinking or swallowing a certain type or amount of food or drink, or reaching a certain number of exercises per day. Many PREPARE research participants used checklists or apps that they downloaded onto their computers or phones. Last but not least, it is important to congratulate patients and reward them when they have met a goal.

Staying Positive
After the initial shock of diagnosis, most patients want to research their condition on the Internet. While some medical websites contain helpful information, what most patients want to know at the onset is whether they will survive or not. It is very difficult to obtain accurate information in this regard. Much of the information on most websites are general and do not take into account each patient’s individual characteristics and health status. Therefore, it is always best that patients and caregivers go directly to their physicians with questions and worries, because they know important factors such as the size and location of the tumor(s), whether all of the treatments are being completed, and whether other health conditions are impacting treatment. Patients would be well served to bring notebooks to jot down questions before the visit and answers once they are in the exam room. Some patients even audio record their visits so that they can process the information in a more relaxed setting after the visit. It goes without saying that asking plenty of questions, following their doctors’ instructions, and maintaining good communication with caregivers will help patients maintain a positive attitude.

Communication
Treatment is quite stressful and maintaining good communication between caregivers and patients can be challenging. In our research program, we teach patients to be clear, specific and detailed in their communication whenever possible. We also advise patients and caregivers to pay attention to their nonverbal behaviors. We tell them, “It is not always what you say, but how you say it.” Sometimes a person’s tone of voice, facial expressions and body language are just as important as the words being spoken. It is also important to teach both patients and caregivers the art of listening. This often means learning to tolerate silences and lulls in conversation in order to give the other person the space they need to open up. Another powerful tool to improve communication is to simply reflect back what was said and once the other person confirms that is what was meant, to venture further and make a guess at the feeling underneath the spoken words. We also teach patients and caregivers to resist the urge to jump in with advice or suggestions, since this often results in people feeling that their situation is not understood or worse yet, is being minimized. Finally, we teach patients and caregivers to try to use “I” statements as a way to communicate without placing blame or being drawn into a defensive argument. The “I” statement tells the other person how you feel, in contrast to the “You” statement, which places the blame on the other person. For example, instead of saying, “You need to stop nagging me to do my swallowing exercises,” it may be more effective to say instead: “When you tell me to do my swallowing exercises, I feel like I’m not doing enough to pull my share around here. I feel guilty about putting you through this.” Or, if the caregiver wants to try making an “I” statement, instead of saying something like, “You never do your swallowing exercises. You know what the doctor said could happen!” it may be more effective to say something like, “I feel anxious when I don’t see you doing your swallowing exercises. Is there something I can do to help you get them done, or would you like to work on your exercises while I do some situps/stretching/fill-in-the-blank.”

Since cancer treatment is such a fraught time, we also give patients and caregivers suggestions in dealing with conflict. They are:

• Pick appropriate times to express your feelings.
• When expressing your feelings use “I” statements, instead of accusatory statements.
• When you are upset or angry try using a calm tone of voice.
• Avoid negative communication styles such as name-calling, criticism, sarcasm and yelling.
• If the discussion becomes too intense or difficult, take a time out.
• It’s important to realize that it is not your job to solve all of his or her problems.
• The best way that you can help is to be an active listener. Active listeners make frequent eye contact and ask questions to show that they are listening.
• If your loved one is pressuring you to solve his or her problems, you might want to take a break from the conversation.
• Here is an example of something you could say: “I’m trying to be helpful, but I’m reaching my limit. Let’s please talk about this when we’ve both had some rest.”

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Editors Note: Eileen Shinn, PhD, is an Assistant Professor in the Department of Behavioral Science at the University of Texas MD Anderson Cancer Center. Her research interests include health behaviors and health outcomes, adherence and coping with cancer treatment and prevention of late-term effects, stress-mediated cancer outcomes, and dissemination of efficacious screening and diagnostic technologies in cancer.

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Conclusion

Patients have an intense desire to not only beat their cancer, but to live as full a life as possible once their treatment is over. While highly curable, up to 39% of throat cancer survivors will experience some type of permanent swallowing problem. Dysphagia delays patients’ return to work, leads to inadequate nutrition and increases risk for choking during swallowing. To prevent this, patients can perform targeted swallowing exercises during radiation. Unfortunately, even at a comprehensive cancer center where patients experience top-of-the-line care with multidisciplinary treatment providers, adherence is very difficult. Patients are nonadherent because their side effects during radiation are painful. Therefore patients and caregivers need support during radiation to improve adherence to preventive swallowing exercises.

REFERENCES:


Imagine John...

John just received the call from his doctor - the call that every newly diagnosed patient is overwhelmed by. John was diagnosed with oral, head and neck cancer, and he needs your help. He needs OUR help... because John, unfortunately, does not have the comfort of being able to refer to a resource that you had when you began your cancer journey...when someone handed you We Have Walked In Your Shoes - A Guide to Living With Oral, Head and Neck Cancer.

SPOHNC recently began a campaign to bring back this much-loved source of support and comfort - We Have Walked in Your Shoes.

In the past, SPOHNC has been able to distribute thousands of books – to newly diagnosed patients, caregivers, and healthcare professionals along the way. Those books are no longer available, and a new and updated edition needs to be republished for those who are just about to begin their journey of their own.

“We Have Walked In Your Shoes” is a tremendous resource for oral, head and neck cancer patients. As the 14-year facilitator for SPOHNC San Diego, I have handed out countless numbers of these terrific books. When I make up an info packet for a new patient, “We Have Walked In Your Shoes” is the first thing that goes in. For a newly diagnosed patient, or a survivor trying to make sense of the lingering side effects of treatments, it’s an invaluable source of information. It is so well organized, and contains a wealth of information relevant to our type of cancer (I’m a survivor too). I’ve had so much feedback, over the years, on how helpful this book is. I cannot wait to get the new edition.” ~ Valerie Targia, SPOHNC San Diego Chapter Facilitator

Imagine you are John...now imagine what you can do to support John on his cancer journey. Thanks to compassionate donors like you, our campaign is moving forward. Many of you have generously given in support of We Have Walked In Your Shoes - A Guide to Living with Oral, Head and Neck Cancer, but we still need more help to reach our goal of providing guidance and comfort to newly diagnosed patients.

Imagine John, with We Have Walked In Your Shoes in his hands. Imagine how hopeful he is, after reading through the resource that brought you so much encouragement when you were on your cancer journey.

Visit www.spohnc.org or call 1-800-377-0928, and give a gift today.

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Chapter News
SPOHNC Baltimore Chapter Makes Music Together

Although the journey down cancer’s trail can include some terrifying twists and turns, just around the next bend you may meet some fellow travelers who become your steadfast companions. With their empathy and generosity of spirit they give you hope, lift you up and cast a golden glow on the future. Thus it was for George Reeder, Don Peyton and Jeff Wilson. George was diagnosed with tongue cancer in 2013, Don with tonsil cancer in 2010 and Jeff with tonsil cancer in 2008. That they are all three head and neck cancer survivors is only one circumstance they share. The more joyful commonality is that they are all musicians who joined together to create a trio that George’s wife, Lynn, has irreverently dubbed The CarcinoGents.

George currently plays sax in three different bands and is actively involved in various support opportunities at GBMC. Determined to face his cancer head on, he met Don Peyton at SPOHNC’s Baltimore - GBMC Chapter Support group meeting almost immediately after his diagnosis. Don has enjoyed a long career playing and restoring stringed instruments and is also an active SPOHNC volunteer, providing support to other head and neck cancer patients. Last year Don introduced George to Jeff, who for 40 years has been gigging steadily as a piano player in the Baltimore/Washington area.

On June 8th, The CarcinoGents trio provided some delightful musical entertainment at GBMC’s Cancer Survivorship Celebration. The trio got an extra boost of talent with the addition of radiation oncologist Dr. Geoffrey Neuner on guitar and vocals, cancer survivor Rob Schroeder on harmonica, and Lynn Reeder on percussion and vocals. Dr. Gary Cohen, the medical director of the Sandra & Malcolm Berman Cancer Institute also sang and played guitar. All three CarcinoGents profess their undying (pun fully intended!) gratitude to GBMC for the excellent care they received. They hope that their musical collaboration inspired optimism in the other survivors at the celebration. Life does go on despite a cancer diagnosis, and sometimes it even gets sweeter…especially if you carry a little song in your heart.

~ Lynn Reeder
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SURVIVOR NEWS

Life Goes On... by Brian McMahon, Survivor and Syosset, NY SPOHNC Chapter attendee

Have you begun a new and different kind of journey since your diagnosis and treatment? Maybe you’ve taken up a hobby that you always wanted to try but never seemed to have the time? SPOHNC has heard from some of you, that you’ve discovered new things, about yourself - about the world around you – and we want to share the good news with all of our readers.

Look for features in the coming months - and share your hobbies and interests with SPOHNC. Send pictures too – everyone loves to look at pictures! Send your stories to info@spohnc.org, or PO Box 53, Locust Valley, NY 11560.

Just to give you all my background, I’m now just about 59 and had cancer in my right soft palate area. I finished radiation and chemo in September 2011. I had reconstruction forearm free flap surgery afterwards to repair the damage from radiation and help me to eat again, but the surgery made things worse. I’ve accepted that it is what it is, and it’s up to me to work at making things better. I still see small progress each month; the human body is amazing in its ability to adapt. All in all, I’m glad to still be here!

I’ve always done a pretty good job keeping myself entertained and I wanted to share my latest hobby with you all. I’m close to my sister and she would often mention that she saw a new bird and tell me a little about it. As I did my trismus exercises (I use a tablespoon) for about 10 minutes in the morning, I’d look out the back window and watch an occasional bird land in the backyard. To make things more interesting, I put up a bird feeder. After about 2 weeks, it started attracting a crowd. I got myself a nice pair of binoculars, books on birds, and started identifying what I saw. I always enjoyed photography but I didn’t get around too much to find new things to photograph.

Birds were the perfect subject!

I added a few more attractions for the birds, like water and suet (cake of bird food that hangs) and activity around the feeder grew more as word got out this was a friendly stop, and I was snapping away…

My 10 minutes a day turned into an hour as I watched every time I passed a window or went outside. I work from home so I have to be careful about how quickly time goes by. When I go outside to watch the birds, I found another added benefit: I have to stretch my neck to look up in the trees and when I see something good, hold that stretch as long as I can to keep it in my sights. This helps me a lot as I could hardly turn my head for quite some time after surgery. I started in late November when it was already quite cold out. It amazed me how these little birds could handle the brutally cold and windy winter we had. Rain, snow or shine, they were out there! They would fluff up their feathers on the extreme cold days – truly amazing to see their transformation. As the months went by, I saw new birds arriving at my feeder. Wait – what’s that? Never saw one of those before – beautiful, snap, snap, snap! I’d observe all of the features and then go to my books and apps and figure out which bird it was. It’s a Red-breasted Grosbeak, or - Wow! - look everyone’s hiding now… there’s a Coopers Hawk! If all else fails in my quest to identify the bird, I can always consult with my sister and photographed over 40 types of birds, males (now in their breeding plumage) and females, and their young. I’ve been on a few bird walks at Massapequa Preserve and I had a guided group walk in May. My wife is now anxious to see a new bird too and while out on her long bike rides (another hobby of ours) she’ll snap a shot with her phone

That special new bird always seems to appear just as I’m getting ready to go out the door or back to work, and I have to calculate how long it will take me to get good shots, or if it will still be there when I get back. Oh, and now that it’s getting nice out - you can see them putting on a show for each other to attract a mate and start a family. It’s amazing what they can do with their feathers! I never knew there was so much going on in my backyard. I’ve identified and photographed over 40 types of birds, males (now in their breeding plumage) and females, and their young. I’ve been on a few bird walks at Massapequa Preserve and I had a guided group walk in May. My wife is now anxious to see a new bird too and while out on her long bike rides (another hobby of ours) she’ll snap a shot with her phone

Don’t wait for extraordinary opportunities. Seize common occasions and make them great.

~ Orison Swett Marden
HEAD AND NECK CANCER NEWS

U-M researchers find protein that fuels repair of treatment-resistant cancer cells

ANN ARBOR—Imagine you’re fighting for your life but no matter how hard you hit, your opponent won’t go down.

The same can be said of highly treatment-resistant cancers, such as head and neck cancer, where during radiation and chemotherapy some cancer cells repair themselves, survive and thrive. Head and neck cancer is the sixth most common cancer in the world, but the late detection and treatment resistance result in a high mortality rate.

Now, University of Michigan researchers have found that a particular protein—TRIP13—encourages those cancer cells to repair themselves. And they have identified an existing chemical that blocks this mechanism for cell repair.

“This is a very significant advance, because identifying the function of the protein that fuels the repair of cancer cells and having an existing chemical that blocks the process, could speed the process of moving to clinical trials,” said principal investigator Nisha D’Silva, U-M professor of dentistry and associate professor of pathology.

Typically, if scientists discover a promising drug therapy target, it takes years to develop drug compounds from scratch and move these into clinical trials.

If cell DNA is damaged and the cell cannot repair the damage, the cell dies. In head and neck cancers, D’Silva and colleagues showed that cancer cells that overexpress TRIP13 were able to repair their DNA enough to survive and continue to grow as cancer.

“Targeting this repair mechanism with specific drugs could increase effectiveness of treatment and improve survival of cancer patients,” D’Silva said. “And given the overexpression of TRIP13 in several treatment-resistant cancers, this strategy will likely be important for multiple cancers.”

The study, “TRIP13 promotes error-prone nonhomologous end joining and induces chemoresistance in head and neck cancer,” appeared online July 31 in Nature Communications.

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Blood and saliva tests help accurately predict recurrences of HPV associated oral cancers

August 1, 2014 - Physicians at Johns Hopkins have developed blood and saliva tests that help accurately predict recurrences of HPV-linked oral cancers in a substantial number of patients. The tests screen for DNA fragments of the human papillomavirus (HPV) shed from cancer cells lingering in the mouth or other parts of the body. A description of the development was published in the July 31 issue of JAMA Otolaryngology - Head & Neck Surgery.

“There is a window of opportunity in the year after initial therapy to take an aggressive approach to spotting recurrences and intensively addressing them while they are still highly treatable,” says Joseph Califano, M.D., professor of Otolaryngology - Head and Neck Surgery, member of the Johns Hopkins Kimmel Cancer Center, and medical director of the Milton J. Dance Jr. Head and Neck Center at the Greater Baltimore Medical Center. “Until now, there has been no reliable biological way to identify which patients are at higher risk for recurrence, so these tests should greatly help do so,” he adds.

Patients with HPV-associated oropharyngeal cancers are generally examined every one to three months in the first year after diagnosis. Recurrences are often found when patients report ulcers, pain or lumps in the neck. But imaging tests are unreliable in detecting cancer recurrence earlier, and the location of oropharyngeal cancers - in the tonsils, throat and base of the tongue -- make it difficult for physicians to spot budding lesions.

Califano says survival rates for patients with early-stage, HPV-related oral cancers are as high as 90 percent within the first two years, and a study reported by Johns Hopkins experts in February showed that, even after recurrence, more than 50 percent of patients survive two years after their recurrence. The new blood and saliva tests have the potential to improve these rates, he adds.

For the study, the Johns Hopkins team analyzed blood and saliva samples from 93 oropharyngeal cancer patients who were treated with surgery, radiation alone, or combined chemotherapy and radiation at The Johns Hopkins Hospital or Greater Baltimore Medical Center. Samples were collected before and after treatment. Some 81 patients had HPV-positive tumors. The researchers selected patients with a variety of early-to-advanced stage cancers; none of the patients had distant metastasis.

The blood and saliva tests were performed using polymerase chain reaction, which amplifies certain portions of DNA and measures its amount. The scientists found that HPV DNA detected in patients’ saliva after treatment was predictive for recurrence nearly 20 percent of the time in a subset of the patients. When the scientists looked for HPV DNA in the blood of another subset of patients, the accuracy of a recurrence prediction rose to more than 55 percent. In a third subset of patients, finding HPV DNA in both blood and saliva samples after treatment accurately predicted recurrence 70 percent of the time.

Despite the encouraging results, Califano says, further refinements are still badly needed to improve detection of possible recurrences because HPV is highly prevalent in our bodies, and “we can’t be sure our test results are cancer-specific and not due to other forms of HPV infection or exposure.” His team is looking for other genomic biomarkers that would increase the specificity of HPV DNA testing in blood and saliva. Califano also cautioned that the current study was too small to link test results to the severity of recurrence.

Rates of HPV-related oropharyngeal cancer are on the rise in the United States, outpacing oropharyngeal cancers due to tobacco and alcohol use, according to Califano. Some 70 percent of nearly 30,000 oropharyngeal cancers diagnosed in the U.S. are caused by HPV. Source: National Institutes of Health’s National Cancer Institute

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A TIME FOR SHARING... This is My Story

My story of cancer really started just about 20 years ago when my husband, James Metropoulos, was diagnosed with diffuse, small cell lymphoma. In 2001, he was also diagnosed with rectal cancer, not related to the lymphoma. He battled the diseases for eight and a half years, dying in 2002.

In 2004 I met the man I would marry – Richard Glomb. In 1994 Richard underwent a nephrectomy because of renal cancer. When we met, we both had lost a spouse to cancer. Richard’s wife, Virginia, had died of multiple myeloma in 2001.

We were wed in August of 2005, and at the time of our wedding we knew he was having some type of problem, but it was very difficult to diagnose. He finally received a diagnosis of follicular lymphoma the following November. After undergoing chemotherapy and several years of rituxin, he is now cancer free for 3 years.

In May of 2011, we were travelling to Kentucky to see my youngest son receive his masters degree in divinity from Asbury Theological Seminary. Mark is a Methodist pastor in Central Pennsylvania. On the drive up, I felt a small lump in the left side of my neck. I did not tell my husband until the next day, and we decided not to say anything to the family until I had it checked when we returned home.

On the day we left Kentucky, I contacted my internal medicine doctor back in Florida and he saw me the day I came home. He thought it might be a viral infection and gave me antibiotics to take for 10 days. When I returned to him, the soft lump had become much smaller and very hard. We immediately made an appointment with my husband’s oncologist. I was then sent to an ENT doctor who could not find anything in my throat that was suspicious. He was more concerned that I used a q-tip in my ears when I showered!

He wanted to have a CT scan done and ordered blood work. An appointment was set up for me to have the CT scan. Thankfully, the technician doing the CT scan read the blood work and realized if he injected me with dye, he would have probably shut down my kidneys.

No one in the ENT office had bothered to read the blood test results – they just sent it over to the radiation oncology office. Needles to say I did not return to that office.

A biopsy was next, with a wonderful doctor who had a great deal of difficulty accessing some tissue. That hard little nodule insisted on moving. A couple of days later I received the call with the results everyone dreads…It was malignant, squamous cell.

My oncologist sent me to an excellent ENT doctor in Orlando for a neck resection and biopsies. My daughter is a physician’s assistant and she knew the PA who was my doctor’s assistant. Her presence was very reassuring. My doctor explained I would have up to 9 biopsies in my throat and neck surgery on the left side. It wasn’t the most pleasant experience but wonderful aftercare helped a great deal.

At my follow up appointment with the surgeon I was told the surgery showed I had cancer in the tonsil area and at the base of my tongue. It was stage 3 – not what anyone wants to hear. The after effects and what was going to be involved including radiation and chemo were thoroughly explained. I asked my doctors if going through the treatments were worth it and I was assured it was. Probably the worst after effect from the surgery was the numbness and pain in my neck. The numbness gradually faded away, and about a year later it was gone completely.

By September, I was ready for chemo and radiation. Thirty-nine doses of radiation and 6 rounds of Erbitux, which is a monoclonal antibody, were prescribed.

I was fortunate to have doctors who were very upfront about what was going to happen and what side effects to expect. Being a trifle vain, I wasn’t very happy to hear that I could possibly have widespread facial acne from the Erbitux, but I was prescribed a topical cream and antibiotics, which limited my breakouts to only three small areas.

So, at 74 years young and with lots of moral support from family and friends along with lots of prayers being said for me, off we went. I say “we” because it was going to affect my husband and family almost as much as it was going to affect me. Cancer patients do not go through this journey alone. It takes many people to help you.

The next step was being fitted for a mask for radiation. Now that is a real trip, when you realize exactly what that means! I was shown the material which formed the mask. Probably the second hardest thing I went through during treatment was lying still while this material hardened around my face. It took all I had in me to not say “ok I’m done – I’m leaving” – but I did get through it, as everyone does who has head and neck cancer.

I started radiation in September – so fortunate to have caring doctors and technicians who walked me through it all. The first 2 – 3 times I heard the clicks which meant I was now attached to the table and my head was not going anywhere – it took all I had not to freak out, but I got through 5 days of radiation, a day of x-rays and another 5 days of radiation and on it went. I made a game of it in a way. I kept a small notebook and in it I would write down how many days of radiation I had – I did not write down how many more I had to come, but said “ok, as of today I have finished 10%, 20%, 50%” and so on. The few minutes of treatment each day goes by so slowly, so I started saying a series of prayers and soon I knew when the treatment was ending – when I said my last prayer. My daughter gave me a bracelet with charms on it – an angel, a faith charm and a cross charm.

I opted not to have a port put in. I can’t say today if this was a good idea or not. I have large veins in my hands and they were easy to access and the Erbitux was not as hard on veins as some chemo’s can be. I didn’t realize how many times I would have to be hydrated, nor did I have a feeding tube. This is such an individual decision.

After about 3 weeks of radiation my throat was a mess. I existed on Ensure, Carnation Instant Breakfast, Grapenut custard pudding, Lipton noodle soup and lots and lots of water. Until my throat was too sore and the cold felt like a burn, I enjoyed Steak N Shake milkshakes – the shakes have a lot of calories. At Thanksgiving, my

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daughter and son in law brought an entire Thanksgiving dinner to our house. At least we could all be together. I had a taste of mashed potatoes, but that was all. It felt so good to have my family around me. Our house was full of love.

Time passed and treatment was finally coming to an end. The pain, dry heaves and mucous problems were abating. At the end of November, I passed out and was taken to the hospital, as I hit my head on the kitchen floor and had a rather large lump. I said to myself “now you’ve done it”. All was well though – no concussion. I’m thankful I’ve always had a hard head. I stayed for 2 days – the dietician was wonderful. She came to me and asked in great detail what she could feed me.

My last radiation treatment was December 9, 2011. I went to the radiology office that day saying I just couldn’t finish. I was done – I quit. My wonderful, caring office that day saying I just couldn’t finish. Today, I’m so glad I had the treatment and care I received. I feel better than I’ve felt in many years. My energy has returned, along with my appetite and a new appreciation for food. I’ve learned to eat slowly and savor every new taste. The taste that was the last thing to come back was for chocolate – somehow that doesn’t seem quite fair! As more time passes, I am able to eat more and more foods without discomfort.

During this entire time, my husband and I cried together twice – once when we received the phone call saying I had cancer, and the second time was when we were told I was cancer free.

For two and a half years now I have

**First Annual Trisha’s Memorial Ride**

On Sunday, July 27th, the First Annual Trisha’s Memorial Ride, held in memory of Trisha Adamski Appelhans, took place in Perrysburg, Ohio. Trisha, a long time volunteer for SPOHNC’s National Survivor Volunteer Network match program, sadly lost her battle with salivary gland cancer in June of 2013, and her family vowed to carry on what she had started, by holding the Bike Run.

It was a great day for a ride, as shining Harleys gleamed in the late morning sun. Bikers gathered at the start as the police escort arrived to ensure the safety of the riders and their passengers as well. The conversation was all about Trisha. Bikers remembered her as the girl who was always ready with a helping hand, even as she fought her own battles. She was a special woman – passionate about SPOHNC, and the many other organizations that she volunteered for. Trisha’s husband Matt, and their daughters Jordan and Josie were there, assisting with the event. The girls loved participating, and doing this for their mother. They made everyone smile as they remembered their beautiful and caring Mom.

The run began with the thunder of bikes as they left the starting point. The 61 mile ride culminated at Dolly & Joe’s - a local place, well known to those in the area. A bbq lunch, raffles, and a silent auction of items donated by local businesses, all contributed to the success of the First Annual event. Trisha’s brother, Josh, thanked the hundred of supporters who gathered there. He spoke of his sister’s amazing spirit and shared heartfelt words, encouraging those in attendance to “hug and kiss and tell your loved ones how much you love them - because it can be over at any second...” Trisha’s mother and father also attended the run.

Proceeds from The First Annual Trisha’s Memorial Ride benefited SPOHNC, and provided the initial deposit for a scholarship fund formed for Trisha’s daughters, toward their college education. Plans are to continue the tradition in Trisha’s memory, and to grow the event each year, while promoting awareness of oral, head and neck cancer, and the support and encouragement offered by SPOHNC.

The event was a fitting tribute to a woman who will be remembered for her kind and caring nature, and the way she was always ready and willing to help others.

Shirley Glomb  
Flacubman@icloud.com

*SPOHNC*  
http://www.spohnc.org  
E-mail-- info@spohnc.org
# Chapters of SPoHNC

(120+ and growing!)

Contact SPoHNC at 1-800-377-0928 for Chapter information & Facilitator contact information

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