Audiology services in UPMC’s Head & Neck Cancer Survivorship Clinic

By Lori Zitelli, AuD; Catherine Palmer, PhD; Marci Nilsen, PhD, RN; Elizabeth Dervin, BA

Patients with head & neck cancer are often treated with a combination of chemotherapy drugs and radiation. There are specific types of chemotherapy that are known to be toxic to the hearing and balance systems. One such commonly-used drug is called cisplatin, which is often used with radiation during treatment. Many patients being treated with cisplatin and radiation experience problems related to hearing loss, tinnitus (ringing or other noises in your ears or head), and balance.

In UPMC’s Head & Neck Cancer Survivorship Clinic, there is an interdisciplinary team of professionals who aim to help cancer survivors manage the effects of their disease and treatment. One of these providers is an audiologist who screens every patient for hearing loss and problems with tinnitus. On the day of this appointment, the audiologist has two goals: screen for hearing problems that may interfere with communication during the office visit, and connect patients to resources that can help them manage hearing loss or tinnitus that they may be experiencing as a result of their treatment.

The reason that we care about patients’ hearing status during Survivorship appointments is that people who have hearing loss but do not wear hearing aids are at risk for miscommunication with their doctors and other providers. Only about 20% of individuals who need hearing aids actually use them. To ensure that significant hearing loss is addressed on the day of clinic, the hearing screening occurs first. If needed, we provide communication strategies and non-custom amplification for use on that day. Other providers from the team are instructed in strategies such as using clear speech, remaining face-to-face, ensuring good lighting in the room, and reducing all sources of background noise when communicating with patients who have hearing loss. If a patient requires an amplifier to communicate, the amplifier is assembled, the headset is placed on their ears, and the microphone is clipped to their lapel so that they don’t have to carry it. If the individual has personal hearing aids, we ensure that they are functioning properly. Simple repairs can be done on site and can reduce additional clinic visits that would otherwise be required to address problems with hearing aids. A list of clinics throughout western Pennsylvania is provided for more convenient access to follow-up audiological care.

As of March 2019, 892 patients have been screened by the Survivorship Clinic audiology team. 23% have passed the hearing screening (hearing all of the sounds), 59% have...
Young adult cancer: a personal story that changed everything
By Stephanie Scoletti

As a 19-year-old college student, the last thing I expected was to be a cancer patient. On August 24, 2005, I was admitted to Shadyside Hospital. Two days later I had a bone marrow biopsy. The next day, they confirmed that I had A.L.L. Leukemia. Chemotherapy started and I was scared. I didn’t even know how chemo was administered or if I’d survive. All I knew was that I’d soon be bald and my future may be without children.

Thankfully, my family and a few friends were my backbone, my army of support, my everything. We celebrated my 20th birthday in the hospital, covered the walls in my room with an overwhelming amount of cards I received, and counted down every day until this first stage of treatment ended. This was only the beginning. Something happened during that hospitalization that triggered me in a way I never expected.

Yes, losing my hair was traumatizing. I knew my family was emotionally crushed and we all feared for my life. Somehow, deep within, I decided to make a choice. My fighting spirit and determination along with my support system is what led me to change my major to Social Work, knowing my purpose in life was to work in oncology. I was introduced to the Cancer Caring Center in 2008 when searching for an internship. Who? At this point I’m a 3-year survivor and never heard of them. I was shocked. Thankfully, it was the right fit! My passion only grew and I secured another internship during my graduate degree program. Fast forward to January 2011, I became the Director of Support Services for the Cancer Caring Center after earning my Master’s Degree in Social Work.

Within that year, I founded the Young Adult Cancer Support (YACS) program which offers emotional, social, and financial support to 18-39 year-old cancer survivors in Western Pa., I saw first-hand the lack of support for this population and had to change that. As young adults, we experience many unique issues when diagnosed with cancer. Eight years later, YACS remains the only support program of its kind in Western Pa. It’s been an amazing journey seeing this program grow over the years. I continue to meet some of the most inspiring individuals.

I’ve celebrated my survivorship for 13 years. Looking back, I believe this was my calling. Yes, the chemotherapy, the brain radiation, the spinal taps, and all the side effects that came long with it were brutal. Through that I always focused on what I was thankful for and what I could control. One day during my initial hospitalization, I was permitted to go outside for a brief moment. My mom escorted me by wheelchair and feeling the sun shine on me was one of the most gratifying experiences. That moment will always remind me to appreciate the little things in life. I met my soulmate in 2012 and have been married for over two years now. Matt, my husband, is my hero and really defines what it means to live life to its fullest. He has voluntarily raised over $50,000 for YACS while participating in some of the most physical challenges worldwide. Every day I’m reminded how blessed I am!

How we choose to live is up to us. It takes time to find a new normal, once treatment ends or if treatment never ends. The best advice I can give is to be gentle on yourself. Be patient. Allow yourself time to grieve what cancer stripped from you. It’s just as important to celebrate every single day. Roses can’t bloom without sunshine and rain. Remind your loved ones how much you appreciate them. Remember to smile because it’s contagious. Finally, I encourage you to share your story because it will inspire others. “Alone we can do so little. Together we can do so much.” –Helen Keller.

Occupational therapy: a supportive service in cancer care
By Rachelle Brick, MSOT, OTR/L
University of Pittsburgh, Department of Occupational Therapy

Cancer and cancer-related treatments may lead to changes in daily life. For example, cancer and cancer-related treatments have been associated with symptoms such as fatigue, pain, nausea, and changes in thinking skills. The cancer experience may also impact the activities you want and need to do – work, leisure, social and family obligations, caregiving, and more. Due to the uniqueness of the cancer experience, each person may experience different limitations throughout the course of the disease.

What is occupational therapy?
Occupational therapy practitioners are skilled rehabilitation professionals that can address changes in activity engagement and symptom management. Occupational therapy is the only profession that “helps people across the lifespan to do the things they want and need to do through the therapeutic use of daily activities (occupations).” The goal of occupational therapy services is to prevent decline, maintain performance in meaningful activities, and restore day-to-day function. Occupational therapy practitioners use a collaborative, client-centered approach that supports individuals to identify meaningful goals and engage in therapeutic intervention.

Occupational therapy services are appropriate for individuals across the cancer continuum including those who are newly diagnosed, undergoing treatment, receiving hospice or palliative care, or in the survivorship phase. Occupational therapists can also offer caregivers the tools to offer support and assistance to their loved ones in performing daily activities.

What does occupational therapy look like?
Occupational therapy intervention aims to maximize quality of life and independence through the following methods:

For additional topics on the prevention, detection and treatment of cancer, including head and neck cancer, visit http://www.upmcancercenters.com/portal_ headneck/publications.cfm for archived issues of Headway.
• Management of activities of daily living (ADLs) such as bathing and dressing through skills training, adaptive strategies, environmental modification, and assistive technology training.
• Engagement in instrumental activities of daily living (IADLs) such as caregiving, meal preparation, paying bills, laundry, and medication management using work simplification techniques and activity scheduling.
• General symptom management to address lymphedema, chronic fatigue, peripheral neuropathy, pain, and cognitive impairment through lifestyle redesign, exercise programs, energy conservation strategies, cognitive strategies, and relaxation management.
• Environmental modification to minimize fall risk, promote energy conservation, and improve accessibility to daily needs.

Where do I go for occupational therapy? Occupational therapy practitioners serve those across the cancer continuum:

• Hospital Setting: Occupational therapy practitioners may focus on activities of daily living such as dressing, bathing, transfers, or using adaptive equipment to maintain one’s highest level of independence. They may also provide home exercise programs and play a role in determining safe discharge recommendations.
• Rehabilitation Centers or Skilled Nursing Facilities: Occupational therapy services may continue to work on activities of daily living, but also incorporate education and training in environmental modification and engagement with leisure activities, community participation, and return-to-work activities.
• Outpatient Rehabilitation: Occupational therapy services target activity engagement and symptom management impacting day-to-day routine. The structure of services may address lymphedema management, cancer-related cognitive impairment, chemotherapy-induced peripheral neuropathy, fatigue, upper extremity limitations, lifestyle redesign, and assistive technology training.
• Hospice and Palliative Care: Occupational therapy services focus on quality of life and maximizing a person’s ability to perform meaningful activities. Occupational therapy may also include positioning and pain management strategies.
• Home Health: Occupational therapy practitioners may address home modifications and caregiver education to maximize one’s safety and independence. The structure of this service targets valued and necessary activities to promote day-to-day function.

If you have noticed changes in your day-to-day routine, occupational therapy services may be of assistance. To find out more, contact your doctor for more information on an occupational therapy evaluation.

Rachel Brick is an occupational therapist and pre-doctoral student within the Department of Occupational Therapy at the University of Pittsburgh. She can be contacted at rsb50@pitt.edu.


Caring for and supporting a loved one with cancer

By Donna Feltz

In many ways it is so true how a phone call or a knock on your door can change your life forever. In my case, it was a knock on my front door. In the cool morning of late October 2017, my sister Karen stood on my front porch holding a white binder. She came in and we talked for a minute, then she said, “I felt like I was supposed to stop to see you and ask if you would help me through this.”

At that point she turned the white binder around and all I saw were the words “cancer” on it. Karen was diagnosed with stage 3 breast cancer. We cried, and we prayed, and our journey began.

Looking back over the past 16 months, our journey seemed like a long time, but through it all God was so faithful. His grace and strength were with us at every step. During this time, I learned many things as a caregiver/support person and thought to share three of the main things that I learned.

First, I learned the importance of listening and encouraging. When Karen was first diagnosed with breast cancer, she was going through a lot of emotions and thoughts. I needed to give her the freedom to express her thoughts without judgment or advice. I needed to be quiet and just listen.

Encouragement was also important throughout the whole process. After we would go to doctor appointments, tests or the chemo treatments, I would try to always find something encouraging to say. When we would hear difficult news, it was important to speak life and hope to her.

Second, I learned the importance of just being there – from taking Karen to her appointments, sitting with her when she got her chemo treatments, being with her at home after her surgery, and holding her hand and telling her how much I loved her to just being there so she did not feel alone.

The third one that I am going to share surprised me. It is the importance as a caregiver/support person to allow yourself to grieve. When Karen first told me about her diagnosis, I cried for several weeks and prayed and prayed and prayed. Then I started to read a lot about breast cancer and took notes at all the appointments. I wanted to be proactive. This might sound odd, but I was preparing myself to fight and to fight hard for her. But what I did not realize was that I started carrying a burden I was not meant to carry. It was not until my dear husband and precious friend told me what they saw and encouraged me to release the burden to The Lord. Once I surrendered my fears and grief to God, I had peace and a new strength to do what I was meant to do.

Out of all of this, I learned that The Lord is so deliberate in His plan for each of us – deliberately walking through the darkest valleys with us and faithfully carrying us...
Head & neck cancer support groups

- A cancer support group, primarily for head and neck cancer patients, family members, and caregivers meets the first Wednesday of each month at UPMC Cancer Center, Upper St. Clair, 200 Oxford Drive, Suite 500, Bethel Park, Pa. To register, call 412-622-1212.

- Let’s Talk Laryngectomy Support Group – Meetings are held the first Tuesday of each month at 7:00 pm, Forbes Regional Hospital, 2570 Haymaker Road, Monroeville, Pa. Contact: Rich Boguszewski at rbogos@gmail.com or Dan Evans at djevans222d@gmail.com. https://LetsTalkGroupPgh.wixsite.com/LaryngectomyHelp.

During our weakest moments. It was a challenging year, but after the chemo treatments, surgery, and radiation, my sister is doing well. Yes, that knock on my front door changed my life forever, taking me where I did not expect to go. But I can say this with confidence, these three lessons I learned along this journey enabled me to become the kind of caregiver/support person my sister needed me to be in her time of greatest need.

Roller coaster ride: surviving and thriving through your cancer journey

By Wendy A. Myers, MSW, LCSW
Director of Counseling-Cancer Caring Center
Owner/Licensed Clinical Social Worker-Find Your Balance, LLC
wendyamyers@gmail.com

There are many ups and downs throughout your cancer journey which can feel like riding a roller coaster. Life becomes very unpredictable and out of control. When there are more moments of feeling out of control then it is helpful to raise your red flag to ask for help and support. Seeking support from family, friends, your medical team and the community can help you regain some of this lost control and ultimately life balance through this journey.

Survivors and their caregivers can begin to look at four areas of their lives in which they CAN gain control. These are COURAGE, ACCEPTANCE, HOPE and JOY.

COURAGE is gained through facing the fears of you and your loved ones. This requires an open and honest discussion of the facts of your illness, plans of treatment, and most importantly talking about each of your fears and concerns. Survivors need their feelings validated, even if they are negative at times-family members and friends hesitate to do this as they believe that the survivor will lose hope, but in the end it allows the survivor to feel heard so that they can have some control back to plan for their future. This enables them to gain control over their fears and face them so that they can go on to live focusing on the hope and knowledge of their treatment plan. The goal being an appreciation for each day they are able to spend with family and friends.

This in turn leads to ACCEPTANCE of not necessarily the cancer but of where they are in their cancer journey – what’s important and what they can control.

Soon thereafter HOPE develops for both the survivor and their loved ones as a treatment plan is set into motion and there is some time for planning activities to look forward to with family and friends.

The ultimate goal is to find JOY in recognizing how precious the present moment is thus finding enjoyment and pleasure in your life. Hopefully, to develop an awareness of the positives in your life, despite the co-existing negatives.

Maintaining these four areas of balance may be further enhanced by also focusing on six additional areas that you and your caregiver can gain control of within your life. These areas include EXERCISE/ADLs, activities of daily living like NUTRITION, REST, STRESS LEVEL REDUCTION, SPIRITUALITY and INTIMACY/SOCIAL CONNECTIONS.

EXERCISE/ADLs can entail moving through walking, yoga, stretching or taking a class. Also included can be a consult from your physician for physical therapy and occupational therapy to help to regain your strength and possibly come up with other ways to do daily tasks that have been hindered due to cancer or ongoing treatment side effects.

Creating a daily routine, making a calendar with medical appointments as well as social activities to look forward to and organizing your legal/financial affairs can be very empowering.

NUTRITION should be thoughtful. Thinking about what you are able to eat and feel like eating will provide you with much energy to get through your treatment and daily life activities-talking with a dietician can always be helpful for meal plans and snack suggestions.

REST is important and not talked about enough. Rest can provide numerous health benefits to restoring your energy and helping to actively fight your cancer by boosting your immune system in the same way that good nutrition can help with recovery. Taking naps, relaxation, breathing exercises and meditation apps are available now that can help to promote healthy sleep habits.

Lowering your STRESS LEVEL in all areas of your life can be beneficial as cancer does not exist in a vacuum. It can be helpful to enlist the support of a counselor to talk about present and past life concerns as well as to plan for your future. This can help give you a more positive view of dealing with nagging issues. This also helps in boosting your immune system.

SPIRITUALITY can encompass many areas, not just religion, but for many their religion is a guiding light. Getting out into nature, meditation and finding a peaceful quiet place to reflect can be healing. Also included in this area is finding forgiveness for past issues whether it is forgiving yourself or others. This can allow a release of negative thoughts and feelings that are also a boost to help to fight off illness.

Finally, finding INTIMACY OR SOCIAL CONNECTIONS with those in your life allows you to focus on others’ needs and concerns rather than always fixating on the negative and worrisome issues that you are facing-this allows you to feel a sense of empathy and hope along with peace and joy. Saying thank you to others who have helped you along your journey can be helpful for all involved.

Words to thrive by include a quote by the late Randy Pausch, CMU Professor and author of The Last Lecture... “We cannot change the cards we are dealt, just how we play the hand.” Life is full of journeys that we don’t plan. Even the difficult ones have a high road worth seeking.
Recover from surgery: hard to swallow?

By Tami Wasserman-Wincko, MS, CCC-SLP
Director, Speech-Language Pathology Division, UPMC Department of Otolaryngology

Difficulty swallowing, also known as dysphagia, can impair quality of life and can lead to aspiration pneumonia, which is life-threatening. Dysphagia is often associated with specific medical conditions such as stroke, neurological disorders (ALS, Parkinson’s Disease, Multiple Sclerosis), dementia, respiratory disease, and head and neck cancer. Difficulty swallowing can also occur in hospitalized patients after complex surgeries.

The team of clinicians in the Department of Otolaryngology, Division of Speech-Language Pathology has identified quality improvement initiatives to minimize aspiration risk in specific populations. This work demonstrates the importance of speech-language pathology intervention and how aspiration-related illness may be reduced.

Lung Transplant

Brooke Baumann, MS, CCC-SLP and Sara Byers, MA, CCC-SLP evaluated swallowing on 220 single- or double-lung transplant patients. They found that the clinical bedside swallow evaluation alone is not sufficient for detecting aspiration (food and/or liquid entering the airway) in this population. Aspiration risk was higher for patients intubated > 72 hours and who had undergone tracheostomy placement. The data supports that lung transplant patients need special swallowing placement. The data supports that lung transplant patients need special swallow- ing placement. The data supports that lung transplant patients need special swallow- ing placement. The data supports that lung transplant patients need special swallow- ing placement. The data supports that lung transplant patients need special swallow- ing placement. The data supports that lung transplant patients need special swallow- ing placement. The data supports that lung transplant patients need special swallow- ing placement. The data supports that lung transplant patients need special swallow- ing placement. The data supports that lung transplant patients need special swallow- ing placement. The data supports that lung transplant patients need special swallow- ing placement. The data supports that lung transplant patients need special swallow- ing placement.

In the second phase of their work, they identified 143 patients with oropharyngeal dysphagia. Twenty-one patients were not safe to resume an oral diet after the initial swallowing evaluation. However, 122 patients did resume an oral diet by interventions implemented by the speech-language pathologist. These include: diet texture modification and/or postural behavioral strategies.

Liver Transplant

Leah Nestlerode, MA, CCC-SLP and Erin Lucatorto, MS, CCC-SLP evaluated swallowing on 53 patients following liver transplantation. They found a high rate of dysphagia (47%) on bedside swallow assessment, and on the x-ray swallow, 17% demonstrated food and/or liquid entering the airway. Frailty and deconditioning are complications of liver disease and this can cause decline in swallowing function. These findings suggest that early assessment and intervention by a speech-language pathologist is important and may reduce aspiration events following surgery.

Esophageal Surgery

Brooke Baumann, MS, CCC-SLP, Leah Nestlerode, MA, CCC-SLP, Amanda Levitt, MS, CCC-SLP, and Erin Lucatorto MS, CCC-SLP collected baseline data which revealed that aspiration can be common in the early period after esophagectomy. Over a 6-month period, speech-language pathology completed an x-ray swallow test, also known as the modified barium swallow, on 25 patients following surgery. Of the patients evaluated, 14.8% developed aspiration pneumonia within 30 days and 60% demonstrated food/liquid entering the airway. Patients with high and low risk factors had similar incidence of aspiration on exam. As a result, speech-language pathology is now evaluating swallowing on all patients following esophagectomy and will continue to study why aspiration is a problem for these patients.

These studies serve to emphasize the prevalence of swallowing disorders in people in whom the primary problem is not the throat. Illness and weakness can cause swallowing difficulty. Aspiration can lead to pneumonia; therefore, prevention is important.

Tami Wasserman-Wincko receives 2019 ASHF DiCarlo Award

By Edward I. Harrison and Jonas T. Johnson, MD

Tamara “Tami” Wasserman-Wincko, CCC-SLP, is the recipient of the 2019 DiCarlo Award. This distinction, conveyed by the American Speech-Language-Hearing Foundation (ASHF), recognizes individuals for outstanding contributions in advancing clinical knowledge or practice in speech/language pathology and audiology. The award is only presented when a “worthy” person is nominated and selected. Based on her contributions to the field of Speech Language Pathology, her patients, and the University of Pittsburgh, she is certainly deserving.

Ms. Wasserman-Wincko is the Director of Speech-Language Pathology for the University of Pittsburgh Medical Center in the Department of Otolaryngology. She also holds appointments in the University of Pittsburgh’s Schools of Medicine and Health and Rehabilitation Sciences. Tami is a thoughtful and innovative clinician, educator, and researcher. She focuses her practice and research on the evaluation and treatment of patients with swallowing difficulties, in particular, survivors of head and neck cancers.

In 2016, Ms. Wasserman-Wincko partnered with Jonas T. Johnson, MD, Chair of the University of Pittsburgh Department of Otolaryngology and Marci Nilsen, PhD, RN, Assistant Professor of the University of Pittsburgh School of Nursing, to establish the UPMC Head & Neck Cancer Survivorship Clinic. This unique care resource is the first in the nation to address the needs of survivors of head and neck cancer with an integrated team-based approach. Multiple clinical issues are addressed during a single visit, at one physical site, and with a singular, respectful co-payment.

Ms. Wasserman-Wincko has played important roles in developing and directing the care team, defining clinical processes, writing educational materials, and collecting data. More than 1,200 patients have received care through the Survivorship Clinic. Ms. Wasserman-Wincko has personally cared for many of them. She has done so with compassion and the aim to continuously improve the value of services provided. In addition to providing patient care, Ms. Wasserman-Continued on page 6
Audiology services
continued from page 1

failed the hearing screening (missing one or more sounds), and 18% have significant hearing loss (missing all of the sounds).
This group either already has their own hearing aids or were offered an amplifier to use during their appointments in order to improve communication with the care providers.

Patients with head and neck cancer are a unique group. When comparing the rates of hearing loss and tinnitus to what is expected in the general population in America, patients with head & neck cancer are at a higher risk to experience these issues. In our clinic, we have learned that many patients are not informed of these risks prior to beginning treatment. If you are a head & neck cancer survivor, please call our office at (412) 647-2030 to schedule a hearing evaluation and begin the process of managing hearing loss and tinnitus.

Contact information
American Cancer Society.................................................. 1-800-227-2345
Assistance with Coping.................................................... 412-623-5888
Cancer Caring Center........................................................ 412-622-1212
Cancer Information and Referral Services....................... 412-647-2811
Clinical Trials................................................................. 412-864-1728 or 412-864-3759
Eye & Ear Foundation...................................................... 412-383-8756
Face2Face Healing......................................................... 1-844-323-4325
Family Care Giver Education and Support...................... 412-623-2867
Gumberg Family Library.................................................. 412-623-4733
Head and Neck Cancer Support Group............................ 412-622-1212
Heart and Hands Ministry ............................................... 724-935-3636
Hopwood Library at UPMC Shadyside............................. 412-623-2620
Hyperbaric Oxygen Treatment...................................... 412-647-7480
Our Clubhouse............................................................... 412-338-1919
Pain and Supportive Care................................................. 412-692-4724
Prostate Cancer Support Group..................................... 412-647-1062
Satchels of Caring Foundation........................................ 412-841-1289
Swallowing Disorders Center
UPMC Eye & Ear Institute (Oakland)......................... 412-647-6461
UPMC Shadyside............................................................ 412-621-0123
UPMC Division of Sleep Surgery
Mercy............................................................................. 412-232-3687
Monroeville.................................................................... 412-374-1260
American Cancer Society website.................................. www.cancer.org
Head and Neck Cancer Program website....................... UPMCHillman.com/headandneck

Head and Neck Cancer Program website
Looking for more information about patient services, current research, clinical trials, news and events, and other valuable information pertaining to head and neck cancers? Check out the website for the Head and Neck Program of UPMC Hillman Cancer Center at UPMCHillman.com/headandneck.

Clinical trials
For more information about head and neck clinical trials, contact Amy at 412-864-1728 or Denise at 412-864-3759.