

HEADWAY

NEWS ON ADVANCES IN THE PREVENTION, DETECTION, AND TREATMENT OF HEAD AND NECK CANCERS

Page 1

Excellence in ears, nose and throat surgery

Page 2

Cancer, college and a career
The pitfalls and promises of sleep

Page 3

Cancer: a family affair

Page 4

Helpful ideas about the management of changes after treatment

Page 5

Swallowing difficulties during and after chemoradiation therapy for head and neck cancer

Page 6

Swallowing Disorders Center
Clinical trials
Contact information
Head and Neck Cancer Program website

Excellence in ears, nose and throat surgery

By Jonas T. Johnson, MD

Chair, Department of Otolaryngology, Eye and Ear Institute

In recent years, there have been a proliferation of public sites which attempt to rate quality among doctors and hospitals. Perhaps the most well-known and one of the most enduring reports is issued annually by the magazine “US News and World Report.” They began ranking hospitals and academic departments in 1990. The rankings are generated through solicitation of opinion from qualified doctors across the country. More recently the scoring system has been modified to take into account outcomes of treatment and patient satisfaction. The University of Pittsburgh Medical Center (UPMC) has been recognized among the top academic medical centers in the United States for the last several years. In 2015, UPMC was ranked #13 nationally. UPMC Presbyterian-Shadyside Hospital is ranked as the best in our region with 10 disciplines, including cancer care, ranked near the top. The Otolaryngology Department was ranked #6.



I hope that our patients and friends recognize that the Department of Otolaryngology has been ranked in the top 10 since the inception of these reports. Currently there are approximately 125 departments of otolaryngology (Ears, Nose and Throat) in the United States. In 1997, we ranked #5 in the country. In the subsequent 18 years, we have gone as low as #7 and high as #2 in the country.

The Department of Otolaryngology is a team of over 35 expert surgeons, another 35 doctors in training and approximately 25 scientists. Our mission is to provide outstanding patient care in an environment of research and education. Currently our research program is #3 in funding from the National Institutes of Health. Our residency program is, similarly, ranked in the top 5 in the country. Pittsburgh is a wonderful place to live, to raise a family, and it also represents a safe and effective place to seek healthcare.



Cancer, college and a career

By Joseph Gault

My senior year of college, I had just finished moving back to campus and unpacking the last box. I felt an odd pain in my left side, and just assumed I had hurt something during the move. However, the next day the pain was worse, and I noticed a lump in my left breast. I decided I had to have it looked at.



Joseph Gault with his fiancée.

The doctor ordered an ultrasound and mammogram for me. When I went to the doctor for the mammogram, there was a sense of surprise on the other patients' faces when my name was called back to see the doctor. Needless to say, the mammogram was an uncomfortable experience. But, the results came back negative; just dense tissue according to my doctor. But, just for safety, he ordered a myriad of blood work. A couple of weeks passed, and I hadn't heard anything yet. Then, one afternoon, my doctor called me as I was in class and demanded I see him that afternoon.

When I arrived in the doctor's office, he looked at me blankly and said, "Joe, you have testicular cancer." Wow. A million thoughts raced through my mind all at once. I never knew anyone personally who had battled cancer. There was no history of it in my family. How was this possible?

Well, the doctors and surgeries commenced. A few weeks later, my urologist called and confirmed from the biopsy that I had stage 1 testicular cancer, and would need to undergo six weeks of BEP chemotherapy. The very next day, I was offered a full time position at Citizens Bank, and I was working on finishing my senior year of college. As if I didn't have enough going on, now I needed chemotherapy? Well, I figured I should just make the best of it.

I did a fair amount of research on my chemotherapy, and learned that my hair would almost certainly fall out. So I decided to shave it before it could fall out. In my mind, this was my way of being a step ahead of the cancer. It was an odd adjustment, but keeping a positive attitude, I decided to brand myself as the "bald banker."

In mid October, I began my chemotherapy. My schedule was two 3-week sessions. Week one consisted of Monday through Friday from 8-5, and the next two weeks on Tuesday from 8-12. Then repeat for one more cycle. The first few days were okay, and I didn't really feel any side effects from the chemotherapy. However, after the first two weeks, the effects started to hit me. The worst was fatigue.

Some days, I had the energy to get out of bed and walk to my desk in my dorm room. After that, I was finished for the day. But I had to muster up the energy to go to work, keep up with classes, and somehow make it through treatment. It seemed impossible at times, but I continued through.

The tough part with cancer and chemotherapy is that the disease is so often not obvious to an outsider. What I mean is that anyone who just looked at me on the street or in my office wasn't able to tell I was battling cancer. They couldn't understand the physical toll chemotherapy takes on your body, wiping out that last ounce of energy you wish you had. Luckily for me, I had the world's greatest support system.

One month prior to being diagnosed with cancer, I began a new relationship with a young woman. While I was afraid how she'd respond, I knew I had to tell her about my diagnosis. Rather than running away, she simply stated that we'd make it through and she'd always be by my side. We are now engaged and excitedly planning the rest of our lives together.

My mother also gave selflessly of her time and took me to all of my treatments, never once leaving my side. It was hard some days to even smile, but having her by my side was better than any dose of medicine.

My brother and my friends made me smile and forget about cancer on countless occasions. The medicine and chemotherapy were strong. The love and support of my family and friends was even stronger. And because of that, I am in my 15th month of remission, and looking forward to a healthy, happy and (hopefully) cancer-free future.

The pitfalls and promises of sleep

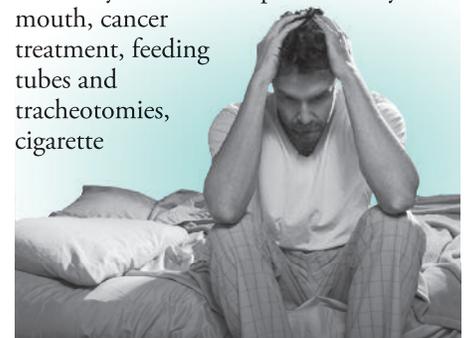
By Laura B. Samuelsson, M.S.
Doctoral Candidate

By now, we are all aware of the importance of sleep: we are exhorted by our doctors and spouses and even the mainstream media to get "a good night's sleep," to aim for eight hours of sleep per night, and told that this is especially important for anyone dealing with an acute or chronic illness. Quality sleep is foundational for maintaining optimal physical, mental, and emotional health, yet "a good night's sleep" often feels like an unobtainable goal for a patient with head and neck cancer. It is critically important for head and neck cancer patients to understand:

- *the pitfalls of sleep* – what sleep complaints and disorders are common in HNC?
- *the promises of sleep* – what can HNC patients with sleep complaints or disorders do to improve their sleep?

THE PITFALLS OF SLEEP

Pain, fatigue, and sleep disturbances are some of the most common symptoms experienced by HNC patients. Importantly, pain can interfere with quality sleep, and poor sleep quality can further contribute to feelings of daytime fatigue and increased sensitivity to pain, creating a vicious cycle for HNC patients. Dry mouth, cancer treatment, feeding tubes and tracheotomies, cigarette



smoking, and alcohol consumption can also significantly interfere with your sleep. Many HNC patients meet criteria for insomnia disorder, which means they experience severe sleep problems, including frequent difficulty falling asleep, difficulty staying asleep, or unrefreshing sleep, several nights a week over many weeks. If you find yourself frequently unable to fall asleep within 30–45 minutes or lying awake for long periods of time throughout the night, you may have insomnia.

If you notice severe dry mouth upon awakening, extreme daytime sleepiness or fatigue, and heavy or frequent snoring (or if your bedpartner tells you that you snore, gasp, snort, or stop breathing during your sleep), you may have obstructive sleep apnea (OSA), a sleep disorder that can occur in up to 80% of HNC patients as a result of surgery or radiation therapy.

Even if you feel you don't necessarily have insomnia or OSA, you should know that milder symptoms of sleep disturbance deserve your attention. You should never feel that you have to suffer your symptoms in silence.

THE PROMISES OF SLEEP

Happily, there are many things you can do to work towards “a good night's sleep,” regardless of your sleep problem. If you're struggling with the occasional bouts of sleepless nights or daytime sleepiness, try making a few adjustments to help improve your sleep:

- Pick a sleep-wake schedule and stick to it. Get into bed and out of bed at the same times every night and morning. Yes, even on weekends or free days!
- Don't lie in bed awake. If you've been in bed and awake for more than 30 minutes, get out of bed and leave the bedroom. Do something boring in low light in a different room, like knitting, working on a puzzle, or reading an old John Deere tractor maintenance manual.
- Keep your bedroom environment cool and dark. This will help you sleep more soundly.
- Avoid caffeine, tobacco, and alcohol – especially right before bed.
- Get plenty of sunshine and fresh air, especially first thing in the morning.

Take a shower, go for a walk, or just sit in the sunlight when you first wake up. This will help your body find a good natural rhythm, and will help you feel more alert and less sleepy throughout the day.

- Keep all non-bed activities out of the bedroom. Use your bed for sleeping and sex only. Watch TV, read, crochet, browse your phone or tablet, or paint your nails in another room, not in bed.
- If your doctor approves, try some gentle exercises, yoga, or stretching in the late afternoon. This can help decrease your pain and make you feel sleepier when it's time for bed.

If you suspect that you have OSA, call the UPMC Sleep Medicine Center at (412) 692-2880 and request an evaluation. The experts there can help determine whether you have a problem and work with you to find the optimal treatment, such as using a continuous positive airway pressure (CPAP) machine at night.

If you suspect that you have insomnia, or if you're struggling with poor sleep quality night after night, call the UPMC Cancer Sleep Clinic at (412) 623-5888 to learn more about their behavioral sleep medicine treatments to improve sleep in cancer patients and survivors.

Cancer: a family affair

By *Eva Grayzel*



Eva Grayzel (third from left) with her family.

When I returned from the hospital, my children Jeremy and Elena, 7 and 5 years old, could barely look at me. I understood. I could hardly look at myself even though I kept my sutures covered with scarves and bandages. My children shied away from my touch. How could I blame them? I couldn't touch my own wounds.

I could barely eat and took pleasure in serving my family nourishing food, feeling in some way it nourished me as well. Elena inspected everything I served carefully. “Mommy, did you take a taste with this fork?” “No honey,” I said, “I touched it to my lip to see if it was too hot for you.” “I don't care. I don't want it.” she said. We explained to her several times she wouldn't become ill from sharing with me.

Often, Elena became angry at me for no reason. She would hit me out of the blue, stick her tongue out, kick my shins. One day, I sat her on my lap and with my radiated raw vocal chords I said, “Elena, tell me why you are angry. What did I do?” She ran away saying “bad mommy.”

My husband put Elena to bed because she didn't want me to do it anymore. One night, she called out “I want my mommy.” Ecstatic, I hurried to her room and said in my hoarse whisper, “It's me, Mom.” “I want my Mommy,” she cried out.

I thought she didn't hear me. I leaned closer, rubbed her back like I always did, and repeated, “Honey it's me. It's Mom.” “But, I want my Mommy,” she said. I got it. She wanted her old mommy back. We all did.

I suppose it was good that Elena expressed her feelings. Jeremy was the opposite. He would play by himself with his astronaut figures and space machines on the living room floor while I rested on the sofa. When I suggested he call a friend, he would resist unless they could play at our house. He never wanted to be too far from me. He never asked any questions even when I reminded him that I would get better soon. I know he was scared because every time I had a coughing attack, he ran out of the room with fear. The emotional trauma to my children lasted long after I recovered and re-engaged with life.

My daughter didn't kiss me for two years. She was intuitive. She knew she could lose me so she didn't want to commit to one more day of loving me. We learned how to kiss again with a game I made up called “The smallest kiss in the world.” It was a competition between my children about who could give me the smallest kiss. Elena took any opportunity to

compete with her brother. She angled my face just right and kissed me. I didn't even feel her kiss, yet told her it was too big. This game put us on the road to recovery.

Three years after I had recovered, Jeremy was with my mother looking for birthday cards. He found a get well card and said, "Grandma, lets buy this for Mom." She had to remind him that I wasn't sick anymore.

My children were deeply affected by watching me struggle with the public and devastating effects of treatment for oral cancer. Their fear of losing me was deep, real and bottled. I regret not seeking professional counseling for them, but I didn't think of it, and it wasn't suggested by my healthcare providers. The pain my disease caused my children hurt me more than my disease. This is my illness – keep my children out of it! But it doesn't work that way. Cancer is a family affair.

When I regained my voice after radiation therapy, I wanted my children to know how special they were on a regular basis. Also, I wanted to bring faith into their lives, even though I questioned my own. So, I started blessing them every night, just before their goodnight kiss. "Thank you for blessing me with my son Jeremy who..." I would say. I would also praise him with phrases like "...who is sensitive of others' feelings," or "...calls his grandma without me asking." Then I would continue the blessings, "...help Jeremy find the strength to..." adding whatever I wanted him to work on, like be kind to his sister or remember to lift the toilet seat. One night he asked why lifting the toilet seat mattered. Rather than respond in the heat of anger after sitting in his urine yet again, I answered his question with warmth and sincerity. We had meaningful and productive conversations. And, he never forgot to lift the seat again!

One day Jeremy asked me who blesses me. I told him the truth – no one. He put his hands on my head that night and blessed me. That gesture made a lifelong imprint on my soul. It doesn't matter what age you attain, the education you acquire, or the profession you practice; you can bless and enrich another person's life.

This revelation led to a weekly charity box

ritual. We put a dollar in the charity box to recognize an act of kindness, like when I reached out to a cancer patient, or when my daughter drew a picture for her grandma for a friend in the hospital, or when Jeremy was captain of the kickball team and chose first the kid who was always chosen last, or something as simple as my husband smiling at a stranger. We are all role models, performing good deeds every day, but often without a tradition or special way to share our kind acts with those we love. The charity box became an opportunity to instill my values of giving charity as well as reaching out to others.

When I reached my 10 year cancer-free anniversary, I wanted to mark the occasion. What better way than to empower children of cancer survivors with coping skills and communication strategies? I wrote two children's books in the Talk4Hope Family Book Series: *Mr. C Plays Hide & Seek* and *Mr. C the Globetrotter*. These books are everything I wished I had for my children.

Eva Grayzel is a motivational speaker, master storyteller, and author. A champion for early detection, Eva founded SixStep Screening.org, an oral cancer awareness campaign for which she was recognized by the American Academy of Oral Medicine. She is also the author of two books for children of cancer survivors available at Talk4Hope.com and the iTunes store. Learn more about Eva at EvaGrayzel.com.

Helpful ideas about the management of changes after treatment

By Marci Nilsen, PhD, RN
University of Pittsburgh School of Nursing

While your cancer treatment may be complete, it is possible for you to experience side effects from treatment months to years later. These effects are commonly referred to as long-term or late effects of treatment and may come from any of the three main types of treatment: surgery, chemotherapy, and/or radiation. Surgery can cause both scarring and numbness, while radiation may create changes in saliva and taste. Radiation can also contribute to fibrosis or stiffness. It is important to note that not everyone

experiences the same effects of treatment. Most commonly people report changes in eating and speaking, dry mouth, an increase in cavities and tooth decay, loss of hearing and stiffness in the jaw or neck and shoulders.

It may take time to adjust to the effects of your treatment. While these late effects may be frustrating, there are activities you can do to help manage them.

Changes to eating and speaking

Speech-language pathologists can help you with issues related to swallowing and speaking. They can also provide you with swallowing and speaking exercises that you can do at home. Most people require 1800-2200 calories a day to maintain their weight. If you are unable to eat large meals or dense solid foods, you may have to eat smaller, moister meals and eat more frequently to achieve your daily nutritional needs. The goal of 1800-2200 calories remains in place, but liquid materials require more volume. Many people find that snacking between meals helps them to meet daily goals.

Dry mouth

It is important to keep your mouth moist. Things that may help include: drinking enough water, using gum or hard candies, and using a saliva substitute such as Biotene. Some people are helped by drugs such as Salogen or Evozac.

Cavities and tooth decay

It is important to keep your mouth and teeth healthy during and after treatment. Brush your teeth, gums, and tongue with a soft toothbrush after every meal and at bedtime. Follow-up with your dentist on a routine basis. Most people benefit from regular application of topical fluoride.

continued on page 5

For additional topics on the prevention, detection and treatment of cancer, including head and neck cancer, visit http://www.upmccancercenters.com/portal_headneck/publications.cfm for archived issues of *Headway*.



Swallowing difficulties during and after chemoradiation therapy for head and neck cancer

By Tamara-Wasserman-Wincko,
MS, CCC-SLP

Director of Speech-Language Pathology,
Department of Otolaryngology, UPMC

Why am I having difficulty swallowing?

Swallowing difficulties, also known as dysphagia, are quite common during and after chemoradiation therapy for head and neck cancer. The early side effects of treatment cause pain with swallowing, sore mouth, dry mouth, thick saliva, and loss of taste. These expected side effects often lead to swallowing difficulties. Common swallowing symptoms are: coughing and throat clearing when eating and drinking and the sensation of food sticking in the throat. Swallowing changes can occur as early as the 3rd or 4th week of treatment and typically worsen toward the end of chemoradiation. It then sometimes takes three to four weeks before swallowing starts to feel better.

What can I do?

All patients with head and neck cancer should be seen by a speech-language pathologist who specializes in dysphagia. Your cancer team can help with this referral.

A swallowing evaluation determines the severity and the cause of the swallowing problem. This is done by either doing a modified barium swallow study, also known as MBS (x-ray), or using a fiberoptic endoscope that is passed through the nasal passage to view the throat when swallowing. During the exam, the speech-language pathologist will test your swallowing by giving you water, pudding, and a cookie. Different swallowing techniques will be tried to determine if you can swallow easier. For example, if you have discomfort on the right side of your throat and there is food sticking primarily on that side, a head turn to the right may improve swallow function. If there is accumulation of food in the throat, a liquid wash may be helpful to clear it. Following the exam, the speech-language pathologist will

Head & neck cancer support group

A cancer support group, primarily for head and neck cancer patients, family members, and caregivers is available in the Pittsburgh area. The group 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.

develop a treatment plan that will include range of motion and strengthening exercises. Eating is part of the exercise program and research has shown that patients who eat and exercise during the course of treatment swallow better than those who do not swallow and exercise during cancer treatment.

What should I expect during treatment?

It is common to change the texture of certain foods if mouth sores or pain interfere with swallowing. If the tongue is sore, it will not generate enough pressure to push the food where it needs to go. This often results in food sticking and multiple swallow attempts to clear, which can be frustrating. High calorie drinks can be used to replace lost calories when diet modifications are made and eating small amounts or having snacks throughout the day can help. The mouth and throat are usually sensitive during treatment, so it is important to avoid food and drinks that are spicy and acidic to prevent further irritation. These include: juices, sauces, spices and alcohol. You can also expect thick secretions during and after the course of treatment, so it is important to drink water to help your throat stay clear if this is recommended by your speech-language pathologist. Water will also help with dry mouth, also known as xerostomia.

What happens after chemoradiation is completed?

A repeat swallowing evaluation will show the changes that have occurred from the treatment and will also determine if the swallowing treatment/exercise plan needs to be changed. At this time, you will learn what your “new normal” will be. Everyone will have their own “new normal” and for some, a drink may need to be taken more often during the meal to help clear the food that remains in the throat. For others, it may mean an extra

push with the tongue to get the food down most efficiently. Whatever the “new normal” is, your speech-language pathologist will help guide you to maintain a functional and safe swallow. If you were not able to complete all of the swallowing exercises during chemoradiation due to pain or other complications, you will have another opportunity to do them when you are feeling better. It is never too late to do exercises; in fact, it is recommended that exercises are done forever to maintain function. Eating is one of the best exercises.

Helpful ideas about the management of changes after treatment

continued from page 4

Loss of hearing

Radiation therapy can also contribute to hearing loss in some individuals. Audiologists can test your hearing and recommend strategies or devices such as hearing aids.

Stiffness in the jaw or neck and shoulders

Gentle jaw stretching and mouth opening exercises can be used to improve the stiffness of your mouth. Daily active range of motion or assistive range of motion of your neck and shoulders can help prevent further stiffness to those joints. Physical therapists can provide specific stretches with the goal of empowering you to do these exercises yourself.

Your physician or surgeon can also help identify additional activities or specialists who may be able to help you in managing these bothersome effects of treatment. Most importantly, if you notice symptoms worsening, talk with your doctors about what you are experiencing, and they can help you find professionals and resources to help.

Swallowing Disorders Center

The UPMC Swallowing Disorders Center is dedicated in helping patients with swallowing problems as they undergo treatment for head and neck cancer. Early intervention with swallowing exercises has been linked to better quality of life outcomes. It is highly recommended that patients be seen by the swallowing team to begin a therapy program as soon as the plan for treatment has been identified.

The process begins with a swallowing evaluation to assess baseline swallowing function and to identify if posture changes, swallowing strategies, and/or diet modification will help the patient swallow better. While some patients require a feeding tube during the course of treatment, the ultimate goal is to return to eating and drinking as soon as possible. We provide assistance during the transition from a modified diet or tube feedings back to a regular diet. When returning to a regular diet is not possible, we help to develop an individualized plan to take certain foods or liquids safely.

We recently completed a study in which weekly questionnaires were given to eleven patients as they underwent chemo-radiation therapy to help us better understand what patients experience during the phases of treatment. This type of information is helping us tailor our therapy approaches to achieve better outcomes. For most, increased difficulty with swallowing occurs toward the end of treatment and may even last a few weeks after the completion of treatment. Once patients are feeling better, the goal is to re-establish the exercise program and begin aggressive intervention so patients can return to an oral diet safely. The team is also participating in a multi-center study involving a special device to exercise the tongue. The device measures baseline tongue pressures so patients can improve strength with practice and meet specific target goals. Grip strength assessments are also being used in the center to determine if there is a relationship between weakness and dysphagia (difficulty swallowing).

The UPMC Swallowing Disorders Center has two locations:

- **UPMC Eye & Ear Institute**
(Oakland)
412-647-6461
- **UPMC Shadyside**
412-621-0123

Clinical trials

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

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
Family Care Giver Education and Support	412-623-2867
Gumberg Family Library	412-623-4733
Head and Neck Cancer Support Group.....	412-622-1212
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

www.upmccancercenters.com/headneck
Hillman Cancer Institute website

www.upci.upmc.edu

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 Cancer Program of UPMC Cancer Centers at www.upmccancercenters.com/headneck.

University of Pittsburgh Department of Otolaryngology

Head and Neck Oncology
Eye & Ear Institute
203 Lothrop Street, Ste. 300
Pittsburgh, PA 15213
P: 412-647-2100

Robert L. Ferris, MD, PhD
UPMC Endowed Professor
Chief, Division of Head and Neck Surgery
Co-Principal Investigator,
University of Pittsburgh SPORE grant

Jamie DeRusso
Head and Neck SPORE Grant Administrator