

HEADWAY

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

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New surgical robot available at UPMC

By Umamasheswar Duwuri, MD, PhD

Director of Robotic Surgery,
Department of Otolaryngology, University of Pittsburgh

Minimally invasive approaches have become more common in many medical fields. One form of minimally invasive surgery is robotic assisted surgery (also called robotic surgery). Robotic surgery incorporates the use of robots in performing surgery. The first surgical robot was introduced in 1985. Since then, robotic technology has been developed rapidly. Conceptually, the robot allows the surgeon to access small anatomic areas, provide better visualization and to minimize physiologic tremors.

The most common surgical robotic system was initially developed for cardiac and abdominal surgery. However, surgeons from other fields like Otolaryngology: Head and Neck Surgery have used this system, albeit with some difficulty. Now, there is a new surgical robot that has been developed especially for Head and Neck surgery. This device is made by the MedRobotics Corporation and incorporates flexible robotic instruments. This technology has the advantage of 'looking around the corner', especially in hard to reach areas like the base of the tongue or the larynx. This new device was developed through collaboration between the University of Pittsburgh and Carnegie Mellon University. This collaboration led to the creation of the MedRobotics Corporation, which is now based in Boston, Mass.

These anatomic regions are very difficult to reach using conventional methods and such surgeries are associated with prolonged hospital stays and generally necessitate the performance of a tracheotomy. With the use of robot-assisted surgery, we can now access these areas through the mouth, with excellent visualization and surgical exposure.

Many cancerous and non-cancerous conditions can be treated with these methods. Recently, we have employed robotic technology to remove excessive tissue from the base-of-tongue for patients with severe obstructive sleep apnea (OSA). Preliminary results demonstrate that this is a safe and feasible procedure with minimal patient discomfort (all patients have left the hospital within 1-2 days, tolerating an oral diet). Some patients have experienced relief of symptoms and improvement of their sleep disturbance scores.

Most recently, a surgeon from UPMC traveled to Europe, specifically Phillips University in Marburg Germany to perform robotic operations using this new device. We successfully completed these operations, with the assistance of German surgeons. The program has now expanded to UPMC, especially after the recent FDA approval that was awarded to this device.

In summary, robotic-assisted surgery of the head and neck is an exciting novel method that allows us to offer patients an alternative to traditional open surgery. Our initial experience suggests that this method reduces patient discomfort and promotes early post-procedure discharge from the hospital.



Lucky or unlucky?

By Kathryn Seeley
Cancer Survivor

When people learn that I've been fighting metastatic cancer for 15 years, I'm often asked, "How do you cope with that? How do you stay so centered and positive?" My answer used to depend on my mood and the person asking. But the truth was, inertia. What choice did I have? Yes, I try to be positive and have a sense of humor, but I really have no choice about it. What comes to mind is, "We play the hand we're dealt."

I was diagnosed in 2000 with a very rare gland cancer called Adenoid Cystic Carcinoma (ACC). It usually strikes glands in the head and neck – salivary, sinus, tongue, throat, neck, ears, eyes, you name it. But it can strike anywhere, and mine was in a breast gland (ACC of the breast, ACCB), throwing me into the breast cancer camp of medical treatment, where I stayed until 2006, when 10 lung tumors were found and I began to question everything. I had the usual breast cancer protocol for a relatively small, low grade tumor: lumpectomy, radiation and chemotherapy "as a precaution." I was told I was cured. Lucky me! When the lung tumors were found, I discovered research that my original doctors should have found and applied to my treatment six years earlier. I didn't have breast cancer at all. After all those support groups, pink swag, and speeches I gave as a breast cancer survivor... According to the NCI, just over 1,000 people in the U.S. a year get ACC. A fraction of these cases are ACCB. It wasn't until 2013 that I found a support group, any type of swag or anyone knowledgeable enough to give a speech.

As I set out on a lonely course to figure out how to stay alive, I learned that my prognosis was not so great. ACC grows too slowly for any type of chemotherapy to be effective. It is unpredictable and it is relentless. With no systemic option for treatment, we are left to become our own experts and we often end up teaching our doctors about our disease. ACC travels through the vascular system, looking for



nerves to destroy. Because of the vast system of nerves in the face, many ACC patients undergo numerous surgeries, disfigurement and extensive reconstruction to achieve control of this monster. The presenting symptoms are so diverse and confusing, people often have pain for years before an accurate diagnosis is finally made. And this is only the first chapter. If it spreads, it usually spreads to the lungs and from there it's anyone's guess where it will show up. Treatment for metastatic ACC becomes an exercise in guesswork and faith. Not so lucky.

Since the first crop of lung tumors were found in 2006, I've had three lung resections, 11 ablations (radiofrequency and cryoablation) for 30+ tumors, and three radiation treatment plans to kill and control cancer in both lungs, right kidney, soft tissue and a rib. In the midst of all this, I was diagnosed with Acute Myeloid Leukemia (AML) in 2009, treated with high dose induction/consolidation chemotherapy, relapsed and received a donor bone marrow transplant in 2010. The "precautionary" chemotherapy I received in 2000 as part of my initial treatment for "breast cancer" caused secondary AML nine years later. I was given less than a 10% chance of surviving 12 months. After two years of brutal complications, often more dangerous than the AML, I recovered (I was *really* lucky!) and resumed the fight against a new crop of metastatic ACC tumors. (Cancel that.)

I left my full time job a year ago and decided to move to Pittsburgh, where my closest relative and best friend lives. I had no family near me up until now, although I had a wonderful support network around the country. This last January, as I planned my move, I was diagnosed with a third cancer – breast cancer. The most common type. The real, official, what-did-I-do-with-all-that-pink-swag, breast cancer. (Exit Lady Luck, stage left.) It was in the same breast as the initial ACC tumor, and after a successful mastectomy, I received no further treatment. I moved to Pittsburgh on May 1st and although I have chronic pain, progressing disease and difficulty breathing, I love my new home. I have much less stress and I

continue to travel to Johns Hopkins Hospital in Baltimore for the whack-a-mole approach to killing cancer that so many ACC patients pursue around the world. Both Allegheny Health Network and UPMC are participating in cutting edge research on genetic testing, immunotherapy and targeted treatments that hold exciting promise for all cancers, but especially for the rare orphan cancers like ACC.

When telling my story, I often laugh when I get to the third cancer. My longevity is a bit absurd. After all this, it seems that I really shouldn't still be here. It would take no effort to spend my days on the dark side feeling sorry for myself. But in 2013 I found the ACC Organization International, www.accoi.org, a global online patient website and discussion forum connecting ACC patients through support and the sharing of resources. This all-volunteer group gives people hope, information and a family who understands. (Re-enter Lady Luck, stage right.)

So when people ask me how I cope, my answer now includes a deeper understanding than it used to. I think of other ACC patients I've met who have it much worse than me. But I still resist when people say that I'm brave or courageous. Not so. Bravery implies you've made a choice to do something. I did not choose cancer and cancer does not make me brave. In fact, it often makes me cranky and impatient. I admire people who are always positive, never complain and are a constant inspiration to others. That's not me. What I will admit to is being fierce and determined. It comes from anger, which is a negative place. But I've learned to temper my anger by trying to help others, so if that's the outcome, so be it. How do I cope? By playing the hand I've been dealt. Does this make me lucky or unlucky? At the end of the day, I choose to think Lady Luck is on my side.

For more information, visit Kathryn's blog, www.anarecancerjourney.blogspot.com.

For more information on ACC, visit Adenoid Cystic Carcinoma Organization International, www.accoi.org and Adenoid Cystic Carcinoma Research Foundation, www.accrf.org.

A new era of personalized medicine

By Jonas T. Johnson, MD

Chair, Department of Otolaryngology,
Eye and Ear Institute

Doctors have always offered people personalized care. They recognize that individual problems vary and it is acknowledged that patients often have differing wishes. Nevertheless, a uniting goal has usually been the need to succeed in treating the disease. If we use throat cancer as an example, treatment options have gradually changed as we have come to understand this condition more clearly. Just a few years ago, squamous cell cancer of the mouth and throat was attributed almost entirely to exposure to tobacco. It was somewhat of a revelation when about 10 years ago, research was successful in demonstrating that some throat cancers were actually due to the human papilloma virus (HPV). Cancers caused by tobacco had seemed to respond through either surgery or irradiation. The cancers caused by HPV appear to be especially sensitive to the combination of irradiation and chemotherapy. Scientists now have proven that the biologic differences among patients with squamous cell carcinoma are even more complex. Literally dozens of differing mutations in the DNA of patients with cancer have been identified. This seems to explain why treatment which may work very well in one person may not be effective in the next.

A patient we recently encountered with cancer of the mouth serves to illustrate this point. This man agreed to participate in a trial of biologic therapy before he had surgery. The drug, which is approved for use in squamous cell cancer caused his tumor to completely disappear. Before and after biopsies allowed our investigators to identify the mutation which caused his cancer. The drug he was administered targeted that mutation and caused the cancer to regress. Unfortunately, the particular mutation expressed by this man's cancer is present in only 1% of patients with squamous cancer of the mouth.

These findings are exciting and important. It suggests that targeted

therapy or "personalized medicine" is a very real possibility. It also suggests that we need to understand these tumors even better. When the mutations which caused the cancer can be reliably identified and targeted, it offers the opportunity to provide effective therapy to patients with tumors sensitive to that therapy. This also offers the opportunity to avoid treatment which will not work. We remain optimistic that findings such as these will lead to improved outcomes for many people.

If I could only talk!

By Marci Lee Nilsen, PhD, RN

University of Pittsburgh,
School of Nursing

We typically think of patients and families as recipients of care, but patients undergoing surgery and their families are playing a key role in helping improve care through their participation in innovative research projects. Through a collaboration between The Department of Otolaryngology and University of Pittsburgh, School of Nursing, patients are involved in progressive research that focuses on improving the patient experience of having surgery for head and neck cancer.

Patients who undergo surgical treatment for head and neck cancer can lose the ability to communicate through oral speech. While for some people, this inability to communicate vocally is temporary, for others, this difficulty with communication can persist. During the postoperative recovery period, patients must rely on alternative methods to communication – like pen and paper or gesturing. Many patients report difficulty communicating their symptoms and needs. This frustration is shared by the healthcare providers caring for them and the family members trying to support them. With funding from the National Hartford Center of Gerontological Nursing Excellence and the Mayday Fund, we are studying several alternative communication tools, and finding out how easy and helpful it is for older adult patients to use them in the immediate post-operative period.

In order to find communication tools that work best for older adult patients, we recruited participants who recently had

surgery to treat their head and neck cancer and asked them to evaluate six communication tools, including three laminated paper communication boards and three communication apps on an iPad. The goal was to find the tools that they felt would be most useful and easy to use after surgery. Overall, participants found the laminated paper communication boards to be the easiest to use but they valued the voice output that two of the communication apps on the iPad provided. Feedback that was particularly helpful to us was hearing that participants wanted more time and training to feel comfortable with the iPad communication tools.

The tools that were selected by participants in the first phase of the study are now being offered to participants over the age of 60 who are scheduled to undergo head and neck surgery that is expected to affect their ability to speak post-operatively. Participants are provided training on the tools and the opportunity to practice with them prior to surgery. On the day of surgery, the tools the participants selected are brought to the bedside and set up for them. Participants receive daily communication support by a trained research nurse in order to help facilitate optimal use of the tools. Family members and nurses are also encouraged to utilize the communication tools with the participants.

While we are still recruiting patients into this study, the responses we have received so far have been encouraging. Participants have described how the tools have helped them to communicate their urgent needs, like pain and the need to be suctioned, and they really appreciate being able to communicate messages to both their families and nurses.

While the focus of this study is on the use of tools by older adults, we hope to expand the communication options and support to individuals of all ages in order to optimize communication during a time when patients are particularly vulnerable. In partnership with our patients, we are designing interventions in order to improve the care we provide. We recognize that this is a difficult and stressful point in their illness – but their contribution is so important.

Seven key fitness program components

By Fred S. Como, BS CPT, CWLS

In my 25 plus years of working in the health and wellness industry, there are certain key factors I feel are very important in client success. With respect to your health, you might first consider noting a difference between wellness and fitness.

Wellness may be defined as a progressive lifestyle change which eliminates or reduces risks to our health and well-being and enables us to balance emotional, spiritual, physical, intellectual, social and environmental well-being and bring us to a more satisfying quality of life.

Fitness, on the other hand, is an empirical achievement of standards based on age and sex. For example, The ideal body fat percentage range for a female 45 years of age is 21% to 25% (based on ACSM standards). In many cases, I tell clients to “know your numbers” and the healthy range you should work towards and maintain. Most of these numbers you are familiar with such as blood pressure, cholesterol etc. Some not so familiar are body fat percentage, waist and hip measures, flexibility, and cardiovascular endurance to name a few.

Knowing your numbers, and as much about your fitness levels and numbers is an ideal platform to well established goals. Be sure your goals are specific, measurable, attainable, realistic and timely. Having a numbers driven goal in mind can help keep you focused as well as motivated.

1. Cardiovascular training

Cardiovascular training, or simply cardio, is any type of activity or exercise which is related to or involving the heart and blood vessels. Cardiorespiratory involves the heart, blood vessels and lungs and may be more appropriate in terms of training and conditioning. Any activity which is 30 to 60 minutes in duration, and includes mostly a sustained heart rate is considered

cardio. Think of walking, biking, swimming, etc. Be sure its fun too. Nothing is worse than feeling chained to a piece of equipment you dread getting on to begin with.

2. Resistance training (RT)

Any time you apply force to your muscles can be considered resistance training. This is a component which provides muscle strength, endurance, increased energy and increased bone density. As we age, having stronger muscles and bones can help reduce the likelihood and severity of a slip and fall injury. You can use weight training machines, free weights, resistance bands, body weight, milk jugs or cans of soup. I get most of my equipment from garage sales and save versus buying new.

3. Flexibility and balance training

I put these two together because far too many people think we get worse at each as we age. NO! We get worse at each because we do not train for them. Incorporate them into a daily routine for best results. Yoga and Tai Chi are great substitutes for formal training exercises and can even help with muscle endurance training.

4. Planning

Most people start exercising without any plans. You need to plan your training to be sure you are getting the most out of your sessions. Planning is key for RT, cardio, meals, supplements, shopping, relaxation and stress management, progression and recovery periods as well as rewarding your successes.

5. Supportive diet

Knowing how many calories to eat per day is just as important as knowing what to eat. The meal planning guide I use with clients breaks the daily intake of calories into 60% quality carbohydrates (mainly fruits and vegetables), 30% quality proteins and 10% good fats. It doesn't have to be perfect percentages but the quality should be the best most of the time.

6. High quality nutritional supplements

You may think there is no difference in vitamin or mineral supplements. And you would be very wrong. Buy cheap and you

will get what you pay for. But does spending more always get you higher quality? No, unfortunately it does not. What you should look for is that formula and product are produced in a cGMP certified manufacturing facility. cGMP is defined as current Good Manufacturing Practices and are now regulated by the FDA as part of the DSHEA in 1993. This guarantees that every formula is produced using the best technology and utilizing the highest quality control standards. What this means for the consumer is that every product is 100% guaranteed for purity and potency.

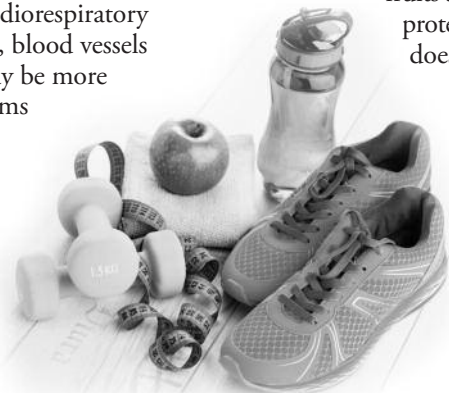
I tell clients this: “If you want to eat beef, you can either go to McDonalds or to Ruth's Chris Steak House. My nutritionals are Ruth's Chris quality.”

7. Sleep and stress management

Sleep plays a vital role in managing hormone levels which can affect your body's ability to shed stored fat weight amongst other system functions. Most people are not getting enough sleep or quality sleep and it needs to be addressed for balanced health and wellness. Stress management is part of a good night's sleep, but it's also necessary to manage your reaction to those things which stress you. Our society has developed an attitude of one-upmanship to see who is more stressed. It's not a competition! And if it is – the first one to the grave wins! Whaaaaat?! That's crazy. Manage it now before it alters your life completely.

And those are my seven key fitness program components. I hope it helps guide you towards a life of your design and management rather than a reaction to a life altered by poor health habits and choices. Keep in mind, if you've had health challenges, it's never too late to take action in a positive direction.

Fred Como, BS, owner of OneSource Wellness Coaching, is a certified Personal Trainer and Weight Loss Specialist through the National Academy of Sports Medicine. He can be reached at CoachFred@OneSourceWellnessCoaching.com, www.OneSourceWellnessCoaching.com or 724-713-1581.



The healing journey

By Karen Scuilli
Cancer Survivor

My name is Karen Scuilli, the Founder and Executive Director of the non-profit organization Face2Face Healing.

My journey began working as a registered nurse turned case manager and clinical consultant, working for one of the largest insurance providers in Pennsylvania. My life fit together like the pieces of a puzzle and I was both professionally and personally satisfied and thriving.

I was diagnosed with a late stage parotid tumor on the right side on May 16th 2012. The life I once knew was pulled



**Face2Face
Healing.**

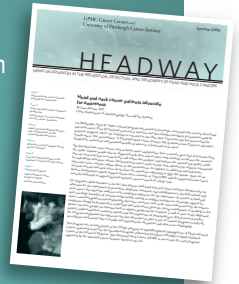
apart as if a grenade had rolled into my “life puzzle” and shattered the life I once lived. The pieces no longer fit. Some pieces were too big, too small or even missing.

As I began creating a new “life puzzle” with all the shattered pieces, I stumbled across a lot of barriers, both mentally and physically. Like many of you, I suffered many losses such as the loss of my identity with losing my job, my face and financial stability. I relied heavily on my faith to get me through these last three plus years. Don’t get me wrong, I did ask God why me? In fact, there were times when I screamed it. But I knew that God had a plan for me. He needed me to help others with their journeys.

We all face adversity in some way or another. It could be a disease such as cancer or other medical condition, the loss of a loved one, a divorce, loss of a job, etc. When facing any loss, we tend to focus on the loss instead of reminding ourselves what we are grateful for. For me, I learned to be grateful for what I have left. This is not an easy process. Sometimes it takes months or years. There is no correct timeframe when dealing with a loss, no matter what anyone tells you. I still have my days when I cry and it is normal. The important thing is to keep moving forward and “fake it until you make it.” You may not feel like doing something but do it anyway. Then before you know it, it will become part of your new routine.

Having a strong support system is very important. For me, some individuals supported me along my entire journey such as my family, a few close friends and my church family. Other individuals were there only when I needed them the most and for that I am grateful. The other individuals that I like to call my “angels”, were the many nurses, physicians, physical therapists, massage therapists, dentists, dental hygienists, and new friends I continue to meet along my care continuum. I initially pushed family and friends away from me and tried dealing with everything on my own. I beg you not to do this. It was not effective. Let your family and friends help you as much as possible. They too are sharing in your

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*.



losses and letting them help is part of their healing process.

I have found many gaps along my journey that have led me to my new mission, Face2Face Healing. My experiences allowed me to interface with the healing process in ways I never imagined. I have come to realize, along with many of my oncology and various service providers, that there are gaps in the care and recovery models.

My goal is to involve individuals, their families and service professionals to join an innovative healing network. Face2Face Healing creates the support network to give individuals and their families dealing with disfigurement the opportunity to meet and share with others through in person and on line support groups, an interactive website and activity based programs. Face2Face Healing’s mission is to build a community for individuals with disfigurement to promote healing through outreach, interaction, activity and education. I invite you to participate. Come visit me at Face2FaceHealing.org.

What Cancer Cannot Do



*It cannot lessen **love**.*

*It cannot fracture **faith**.*

*It cannot hinder **hope**.*

*It cannot prevent **peace**.*

*It cannot crush **confidence**.*

*It cannot kill **friendship**.*

*It cannot keep out **memories**.*

*It cannot corrode **courage**.*

*It cannot shatter the **soul**.*

*It cannot quench the **spirit**.*

*It cannot stop resurrection **power**.*

*It cannot erode **eternal life**.*

*Author Unknown
Adapted by June Hunt*

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.

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
Project of Love (comfort pillows).....	724-266-8007
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.

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