

## Coping strategies for head and neck cancer patients

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Receiving a diagnosis of cancer can disrupt all aspects of a person's life and result in feelings of anxiety, sadness, anger, loss, and physical pain. People with head and neck cancer face additional, unique challenges such as speech and communication impairments, difficulty breathing, physical disfigurement, and difficulty swallowing and eating that can cause self-consciousness, isolation, and discomfort.

Coping refers to strategies that deal with the disruption and distress associated with your cancer so that you can maintain good quality of life. No single strategy is helpful for all people in all circumstances, and the best approach is to have a flexible range of tools for managing your distress. The list can include:

- Seek information and resources to be actively involved in your treatment. You can find brochures at your physician's office, the Gumberg Family Library at Hillman Cancer Center, and from the American Cancer Society.
- Make healthy lifestyle choices about diet, exercise, smoking, and drug and alcohol use.
- If you are dissatisfied with aspects of your physical appearance, focus on the parts of yourself that you like, including external and internal qualities that may have remained unchanged or even improved by the cancer. For example, some

patients report that they have become more compassionate or more confident in their ability to handle whatever may come their way.

- Though it can be challenging at times, it helps to keep a sense of perspective and to take things one day at a time. One bad day does not equal failure. Don't lose sight of the progress you have made.
- Express your emotions, both negative and positive, rather than keeping them bottled up inside. Talk to friends, family, or other patients if possible, or write your thoughts and feelings down in a journal. If you're not used to expressing emotion, this might be difficult at first, but it generally becomes easier and more comfortable if you stick with it.
- Keep busy by engaging in pleasurable and distracting activities, such as reading or other hobbies.
- Find ways to relax, such as listening to music, practicing slow, deep breathing, or thinking about your favorite vacation or relaxation spot.

Experiment with these strategies to find the ones that work for you, and share them with your family members and other caregivers. It is normal to feel sad, fatigued, anxious, or hopeless at times when dealing with cancer; talk to your doctor if any of these symptoms last for more than two weeks. UPMC Cancer Centers' Behavioral Medicine has a team of psychologists who are able to work with you to learn more strategies for coping with cancer. We help patients with a variety of issues including: depression, anxiety, smoking cessation, body image issues, communication and relationship skills, insomnia, pain management, and a variety of other topics. For more information, call 412-623-5888.

## Contact information

Cancer Information and Referral Services (CIRS) is a free cancer information hotline staffed by oncology nurses. The service provides complete information on support groups, education, referrals, clinical trials, and a variety of cancer-related topics. Call 412-647-2811 Monday through Friday from 8 a.m. to 4 p.m.

## Support groups

The Department of Otolaryngology, UPMC Cancer Centers and the University of Pittsburgh Cancer Institute, is planning to form a support group in Spring 2008, for patients, survivors, family members, and caregivers who have been affected by head and neck cancer. If you are interested in participating, contact Tom Boyer, PA-C at boyertg@upmc.edu.

Support for People with Oral and Head and Neck Cancer (SPOHNC) meets at the Intercommunity Cancer Center, 2600 Haymaker Road on the last Friday of each month from 3 to 4:30 pm. For more information, call Sue or Beth M. at 412-856-7740.

Let's Talk, a support group for laryngectomees and their family members meets at Forbes Regional Hospital the first Tuesday of each month at 7 pm. Call Dolores Cush at 412-462-4741 for more information.

ThyCa Thyroid Cancer Support Group is a self-help group open to both patients and family members that meets the third Monday of each month from 7 to 8:30 p.m. at Panera Bread on the Blvd. of the Allies near Magee-Womens Hospital of UPMC. Call Arlene Kroll at 724-929-7582 for more information.

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# HEADWAY

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

## To our patients

The University of Pittsburgh Cancer Institute's (UPCI) Head and Neck Cancer program is focused on the development of new treatments of head and neck cancer that lead to substantial improvements in outcomes for patients. Although head and neck cancer remains a devastating illness, many recent advances have allowed for an optimistic view of the future.

The primary focus of UPCI's research activities has been the development of novel, molecularly targeted agents for the treatment of head and neck cancer. The advantage of these new treatments over traditional chemotherapy is that they can spare normal tissues and selectively attack the cancer cells. We have also learned that these new agents may enhance the effect of radiation or chemotherapy without significantly increasing the side effects. In the past few years, UPCI's head and neck program has been very active in clinical investigations. Our institution is among the pioneers in vaccine therapies for head and neck cancer. Innovative radiation techniques, such as stereotactic radiosurgery that delivers high doses of radiation in a small field avoiding healthy structures and targeting the tumor exclusively, are also being developed.

More than 10 clinical studies are ongoing that cover a wide spectrum of clinical settings, from early stage to advanced cancer. Common as well as rare types of head and neck cancer, such as salivary gland malignancies, are within the interest of our investigators. In 2006, approximately 100 patients with head and neck cancer were treated on various clinical protocols at UPCI. This makes our research program in head and neck cancer one of the largest in the country. Our goal is to sustain and increase this level of interest and participation from our patients. Having a large community network of satellite facilities in western Pennsylvania enhances our ability to make new treatments broadly available.

The head and neck cancer group recently presented multiple abstracts from innovative work at the prestigious American Society of Clinical Oncologists (ASCO) conference. A study with chemotherapy, cetuximab, and radiotherapy for locally advanced head and neck cancer that has now enrolled about 40 patients reported very high rates of tumor response. Moreover, studies with chemotherapy with the addition of bevacizumab, a drug that attacks the blood vessels that feed a tumor, showed prolonged periods of tumor control in recurrent head and neck cancer. Building on these observations, many new clinical investigations are planned for 2008.

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Sincerely,

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Co-leader, Head and Neck Cancer Program, UPMC Cancer Centers

## Clinical investigations update

by *Seungwon Kim, MD*

Otolaryngologists at the University of Pittsburgh are working with physician-researchers at the University of Pittsburgh Cancer Institute (UPCI) to develop new methods of fighting head and neck cancer. Epidermal growth factor receptor, or EGFR, has emerged as a promising target in this disease. EGFR is a receptor that triggers reactions that cause cancer cells to grow and multiply. EGFR is found at abnormally high levels in the surface of many types of malignancies. Several agents have been developed for the purpose of inhibiting EGFR and are undergoing clinical evaluations. Erbitux is one such agent that has been approved by the Food and Drug Administration for use against head and neck cancer. Erbitux is a cancer medication that interferes with the growth of cancer cells and slows their growth and spread in the body. Clinical trials using this agent have shown that radiation therapy is more powerful when combined with Erbitux and can extend the survival of head and neck cancer patients.

Another target that has shown promise in anticancer treatment has been the vascular endothelial growth factor receptor or VEGFR. This protein is expressed by the blood vessels and is involved in regulating the growth of blood vessels into head and neck tumors. It has been shown that blocking VEGFR stops formation of new blood vessels into tumors and, in essence, causes the tumor cells to starve and eventually die. Avastin, a drug that inhibits the VEGFR pathway, is in active clinical use in fighting colorectal and breast cancer and may be applied to fighting head and neck cancer.

Given the potent antitumor effects of Erbitux and Avastin, medical researchers have proposed that using both agents together may be effective in inhibiting the growth of human cancers. The researchers at the Department of Otolaryngology and UPCI are currently performing a clinical trial to study the efficacy of concurrently blocking both EGFR and VEGFR in head and neck cancer. The current study, led by Athanassios Argiris MD, and Jennifer Rubin Grandis, MD, FACS, is one of

several National Institutes of Health-supported Specialized Programs of Research Excellence (SPORE) projects at UPCI and UPMC Cancer Centers. This study will allow researchers to determine how effective this therapy is against head and neck cancer. In addition, tumor tissues obtained from this study will be used to study the ways in which the inhibition of the two proteins interact to produce the antitumor effects. Although the study has yet to release its conclusion, the two drugs have been shown to be safe and some patients have shown good response.

Clinical trials such as these are instrumental in developing new ways to treat head and neck cancer and are only possible through patient participation. Anyone interested in participating in this or other studies is encouraged to contact Carey Trent at 412-383-2084.

## A Miracle Named Jillian

*A Survivor's Story by Lynn Durkin*



In August of 2004 I was diagnosed with a rare form of head and neck cancer normally found in older people who drink and smoke. I don't drink and I quit smoking sixteen years earlier while I was pregnant with my son, Andrew. In September, I underwent surgery to remove my tonsils and 28 lymph nodes from the right side of my neck. I had a month to recover before chemo and radiation therapy started and I needed every minute of that time to heal.

Prior to starting therapy, I read all of the literature I was given. Having had a severe

reaction to a sulfa drug several years ago, I wanted to be prepared for any allergic reactions or adverse side effects. One of the first things I recall reading was that chemo and radiation therapy could make you infertile. Patients have the option of saving eggs through in vitro fertilization, but I laughed to myself. At 41 years old, I had no intention of having more children even if I could. I had been told 14 years earlier there was no way I could conceive and I reasoned with myself that I was meant to have just one child.

As anyone whom has ever gone through chemo and radiation therapy knows, it is traumatic. I only got through three of the six prescribed doses of chemotherapy when I had an anaphylactic reaction. Eventually, I had all 33 radiation treatments, and it took two months for the burns on my neck and the ulcers inside my mouth to heal. The radiologist told me I had to have a PET/CT scan every three months for the next two years. The first one was uneventful and showed no signs of cancer. However, at the second scan I was asked, "Can you be pregnant?" Though I knew it was impossible and answered, "No", something inside of me was unsure of the answer. Midway through treatment I received radioactive iodine and regretted not asking for a pregnancy test. As soon as that hot feeling of the injection came over me, I knew I was pregnant.

For the next month I was exhausted. I returned home from a week long vacation and slept for three days. I took a pregnancy test and it was positive. As you can imagine, I was thrilled, but a million thoughts were flashing through my head; the conversation with the doctor who told me I was infertile, the moment I was told, "You have cancer and it's bad," and then it hit me. Not only did I have a PET/CT scan, I also had to take a large dose of prednisone and Benadryl because I was sensitive to the radioactive iodine. What did I do to my baby? I had several more visits to specialists. One told me I should not go through with the pregnancy. Another said with all the risk factors there was a slightly higher risk than normal women my age of having a child born with a birth defect. Had the radioactive iodine and scan not caused a spontaneous abortion, which was a

possibility, I should be able to carry to term. There wasn't a moment of hesitation. The fact that I conceived at all was a miracle to me, whatever the outcome I was going through with my pregnancy.

As I went for follow-up visits with my doctors, it was pleasing to see the astonished looks on their faces when I told them I was pregnant. I gave birth to my daughter Jillian in February 2006. Upon her arrival the obstetrician discovered that she was born with the umbilical cord around her neck and there was a knot in it. Yet, she's perfect. When I look at her she's a constant reminder of the miracle I received. I'm so grateful for everyday of my life, and all the people who were in place to save me. I never want to have to go through anything that scary again, but if that's what it took to give me the daughter I never thought I'd have, so be it.

## Swallowing disorders

By *Roxann Diez Gross, PhD*  
Director, UPMC Swallowing Disorders Center

Universally, food and drink bring delight to our daily lives. We socialize and celebrate together over delicious foods with ample drinks. We comfort and nurture ourselves with food. Most take it for granted that our favorite foods and drinks will always be available... few can conceive of the possibility of being unable to swallow them.

As many head and neck cancer patients know, the simple, one-second act of moving food through the mouth and throat is not so simple. Swallowing is actually a rapid and highly complex motor pattern that requires a great amount of sensory input and muscle control. The movements change depending upon what is being swallowed. From the first glance at food, visual information begins the process.

Without really thinking about it, we ask ourselves if it looks good enough to eat. We smell the aroma to further confirm our desire. We place it in our mouths and should be rewarded with a taste that matches or exceeds our expectation. But, if one has low taste ability called hypogeusia

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(hi-po-goo-z-ah) or altered flavor sensation called dysgeusia (diz-goo-z-ah), there can be disappointment instead.

Altered taste sensation can occur as a result of surgery, radiation, or the combination of chemotherapy and radiation. When food is tasteless or the taste does not match our expectation, the natural response is to reject it. If everything we attempt to eat does not taste as it should and the enjoyment of food is lost, nutrition can become a burden instead of a joy.

Altered taste sensation is not the only challenge to obtaining adequate nutrition; swallowing function can become impaired. The medical term for a swallowing disorder is dysphagia (dis-fay-juh). There can be trouble getting food and drink through the throat or keeping it out of the airway. The need to swallow each bite several times or persistent coughing during meals signals a swallowing disorder. When eating becomes work, the amount that is consumed can decrease dramatically and nutrition can suffer.

Medical speech pathologists are trained to diagnose and treat swallowing disorders. They use clinical skills and other methods to identify the problem and design treatment plans. The UPMC Swallowing Disorders Center is unique in that speech pathologists and ear, nose, and throat physicians work side-by-side to evaluate and treat swallowing dysfunction. They also actively research new methods that can be used to treat swallowing disorders. The staff specializes in head and neck cancer and has found that working with patients before, during, and after treatment can greatly improve their ability to eat and drink safely. To learn more go to [www.upmc.com](http://www.upmc.com) and search under Swallowing Disorders Center, or call 412-647-6461 to make an appointment.

## Study Participants Needed

### SMILE Study

Physicians in the Department of Otolaryngology are participating with centers from around the country to study dry mouth which frequently occurs after treatment with radiation therapy. This is a multi-center randomized placebo-controlled design Study to assess the effectiveness of **ceviMeline to Improve oraL health** in patients with **xErostomia (SMILE)** secondary to radiation therapy for treatment of head and neck cancer.

Xerostomia, or dry mouth, is often a side effect of radiation therapy. SMILE's primary objective is to assess the impact of **cevimeline** on salivary flow. Participants will need to have completed radiation therapy during the past year. The study drug is FDA approved for other causes of dryness. Cevimeline will be provided free by the manufacturer. Participants will need to return for office visits twice (their regular visits) at which time they will be asked to complete questionnaires about dryness.

For more information, contact Dana Ivanco at [ivanocode@upmc.edu](mailto:ivanocode@upmc.edu).

### Fish Oil Study

Roxann Diez Gross, PhD, and Ricardo Carrau, MD are conducting a study to determine if fish oil can reduce or prevent swallowing problems that occur during or after the combination of chemotherapy and radiation therapy that is used to treat head and neck cancer. Individuals interested in participating in this study can call Dr. Gross at 412-647-6187.

### Clinical Trials

For more information about head and neck clinical trials, contact Carey Trent at 412-383-084 or search for clinical trials at <http://www.upmccancercenters.com/trials/index.html>.