Rehabilitation of Eating and Swallowing After Oral Head and Neck Cancer

Nancy A. Hutchison, MD

Advanced surgical, radiation and chemotherapy techniques have revolutionized the treatment of oral head and neck cancers (OHNC). Treatments are now less disfiguring and have better local control and survival. Some tumors are treated with radiation alone or radiation plus chemotherapy at the same time. When surgery is necessary, chemotherapy and radiation therapy allow for smaller, organ preserving, surgeries.

When medical professionals use the term “organ preservation”, this refers to the fact that a structure is left in place and not surgically removed. Traditionally, organ preservation referred to avoiding laryngectomy (removal of the voice box or larynx), but it is more accurate to think of organ preservation in a larger sense. All of the structures of the mouth, face, neck, jaw, throat and respiratory tract are necessary for effective eating and swallowing. Treatment of OHNC aims to destroy or remove the tumor with the least amount of damage to uninvolved surrounding structures. Organ preservation in this sense should be thought of as leaving intact as much of the mouth, tongue, mandible (jaw bone), larynx (voice box), pharynx (muscular structure behind the mouth and nasal cavity leading to the respiratory and GI tracts), neck structures (including nerves, muscles, some lymph nodes) and the upper part of the esophagus (muscle tube leading to the stomach).

Organ preservation is a structural concept, not a functional one. When a car is constructed, it consists of parts and coverings. It does not move without electricity, power, lubricants, and finely tuned interactions of all the parts moving together. Similarly, organ preservation does not make the head and neck structures function. Muscles and nerves must work in a specific sequence.

Lymph fluid and blood need to flow. As a car cannot be left to rust, the structures of the head and neck cannot be left to weaken or become stiff. When soft tissues of the body become stiff, or fibrotic, they won’t move even if a power source is available. In the mouth, face, throat and neck, surgery and radiation can create scarring and loss of lubrication that causes the preserved structures to freeze and immobilize. Lack of use leads to weakness and contracture (soft tissues locked in a tightened position). Dysphagia is an abnormality in any aspect of swallowing liquids or solids. In oral, head and neck cancer dysphagia is most commonly caused by functional failure in spite of organ (structural) preservation. Much of the functional failure is from fibrosis (scarring), weakness and lymphedema (areas of trapped fluid).

Surgical techniques for OHNC can involve reconstruction of the tissues of the mouth and throat. These reconstructions bring flaps of living muscle tissue from other parts of the body, usually arm or leg, into the mouth and throat to fill in large areas of surgically removed diseased tissue. These reconstructions are referred to as free flaps. A Plastic Surgeon assists the ENT surgeon in placing the free flap. These techniques are responsible for the excellent cosmetic results we see today after surgeries to remove larger tumors. These free flaps, however, have no innervation. That is, the free flaps are not connected to a motor nerve so they do not contract like normal muscle. They are present as a place holder, a way to fill in a large defect that could not have been closed otherwise. Because of their lack of function, free flaps are susceptible to fibrosis (scar), contracture (shortening) and lymphedema (filling with lymph fluid and not able to push it out).

Experience with organ preservation and concurrent chemotherapy/radiation therapy has discovered that as many as 60% of individuals undergoing radiation therapy will have progressive dysphagia. (Nguyen, N et al: Long Term Aspiration Following Treatment for Head and Neck Cancer. Oncology 2008;74:25-30. Greven, K et al. Swallowing Dysfunction is a Common Sequelae After Chemoradiation for Oropharynx Carcinoma. Am J Clin Oncol 2008; 31:208-212.) Usually there is some early improvement in eating after the acute effects of radiation (mucositis, pain) subside, but there can be lack of recovery of swallowing. Also, there may be a delayed onset of dysphagia after 6 to 12 months due to functional failure of the structures from progressive fibrosis. (Langerdijk J et al. Impact of Late Treatment-Related Toxicity On Quality of Life Among Patients With Head and Neck Cancer Treated with Radiotherapy. J Clin Oncol 2008; 26: 3770-3776. ) Studies have shown that specific exercises of the face, jaw, neck and throat help to maintain function and reduce fibrosis. (Kulbersch et al: Pretreatment, Preoperative...
IMPROVED TREATMENTS continued from page 1

Swallowing Exercises May Improve Dysphagia QOL. Laryngoscope 2006;116:883-886

Chewing and swallowing as much as possible during chemotherapy and radiation therapy are important. Even for people who need a feeding tube for nutrition, it is recommended to continue to talk, chew and swallow as much as possible during chemotherapy and radiation therapy to preserve function in the mouth and throat structures. If eating by mouth is not possible or safe, it is recommended to continue with specific exercises. Range of motion of the face, jaw and tongue should be performed daily. Specific swallow exercises should be done to keep the swallow structures from becoming weak and stiffened or fibrosed. (Lewin, JS: Dysphagia After ChemoRadiation: Prevention and Treatment. Int J Radiation Oncol Biol Phys 2007; 69:S86-S87. Rosenthal D et al: Prevention and Treatment of Dysphagia and Aspiration After Chemoradiation for Head and Neck Cancer. J Clin Oncol 2006; 24: 2636-2643.)

Physical Medicine MDs who work in cancer rehabilitation are familiar with using techniques to address all aspects of eating, swallowing and speaking that can be affected by OHNC. These techniques address myofascial disorders (muscle and connective tissue scars, spasm and contractures), lymphedema, neck, shoulder, lip, tongue, facial and respiratory muscle weakness, along with specific aspects of speech and swallow dysfunction. It is important to address the system as a whole for best outcomes. We work with a team of Speech Language Pathologists, Physical Therapists, Occupational Therapists and the other treating MDs to individualize rehabilitation to best effect.

Rehabilitation therapy for OHNC has become complex and is different from traditional speech therapy. Most speech-language pathologists (SLPs) have been trained to treat speaking and swallowing disorders for people with neuromuscular diseases such as stroke and Parkinson’s disease. With the revolution in treatment for OHN cancers, not all SLPs are familiar with the methods used for this population. It is important for the SLP to work closely with a Physical Medicine Cancer Rehabilitation MD or the ENT physician. The SLP must become informed on the area of surgery, field of radiation, location of free flap reconstruction, areas of lymphedema, myofascial restrictions and how these affect eating.

If there is a laryngectomy, the SLP must also be familiar with alaryngeal speech. Methods of alaryngeal speech include electrolarynx, tracheoesophageal prostheses and synthesized speech devices. Neck contractures and lymphedema can make swallowing and speaking ineffective so the SLP might need to work with a Physical or Occupational Therapist certified in lymphedema and myofascial techniques. The Modified Barium Swallow (MBS) or videoswallow in OHNC is used to assess the function of the muscular structures from the lips to the esophagus as well as to assess abnormalities that can lead to aspiration or lack of transit of food. For the person with OHNC the MBS is like a muscle test and speaking ineffective so the SLP might need to work with a Physical Medicine Cancer Rehabilitation MD or the ENT physician. The SLP must become informed on the area of surgery, field of radiation, location of free flap reconstruction, areas of lymphedema, myofascial restrictions and how these affect eating.

Swallowing can be improved using specific exercises. For those with OHNC, the SLP must work closely with a Physical Medicine MD to address the system as a whole for best outcomes. We work with a team of Speech Language Pathologists, Physical Therapists, Occupational Therapists and the other treating MDs to individualize rehabilitation to best effect.

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may be needed to regain function. The most common suprahyoid exercises are the Mendelsohn and Shaker. The Mendelsohn raises the larynx like an elevator from the bottom to the top of the neck and holds it as high as possible for as long as possible. This exercise works the muscles that power the shaft of the hammer (base of tongue). The Shaker exercise involves lying flat, lifting and holding the head to look at the feet as a means of strengthening the front of neck muscles involved in swallow. The Masako exercise moves the tongue base while swallowing to bring together the posterior pharyngeal wall and muscles that raise the larynx. The exercises are not done with food in the mouth. Special swallow exercises that are used with food include the supraglottic swallow that uses breath holding during the swallow and airway clearing after the swallow. None of these exercises or swallow techniques will be effective if there is significant skin fibrosis, lymphedema or muscle contracture.

Just as traditional physical rehabilitation uses neuromuscular electrical stimulation (NMES) for weak arm and leg muscles after surgery, swallow therapists can utilize NMES for weak suprahyoid muscles. One NMES device that has received recent attention is the VitalStim machine. The VitalStim machine provides NMES to the suprahyoid muscles as an adjunct to comprehensive eating and swallowing therapy. VitalStim is not a stand alone treatment. The principle of NMES to the suprahyoid muscles is to provide an electrical “boost” to help these muscles contract with enough force, in the proper sequence and rate to work more effectively with the other muscles of swallow. NMES is done during the act of eating in therapy to rehabilitate weak swallow muscles in the same way it is used in Physical Therapy during active exercise. SLPs who use Vital Stim must have special certification to use this device. Preliminary studies with small numbers of OHNC patients have shown some encouraging results for NMES as an adjunct to traditional dysphagia therapy but more research in this area specific to OHNC is needed. Not all patients are candidates for NMES therapy so a doctor’s evaluation and prescription is required (Ryu et al. The effect of electrical stimulation therapy on dysphagia following treatment for head and neck cancer. Oral Oncology. Vol 45. #8. pp 665-668. Lin et al, Effects of functional electrical stimulation on dysphagia caused by radiation therapy in patients with nasopharyngeal carcinoma. Supportive Care in Cancer. Published Online November 29, 2009 Springer-Berlin/Heidelberg).

The treatment for Oral Head and Neck Cancers has come a long way in recent years. Specialized rehabilitation techniques for the unique problems of survivors have been emerging. These techniques involve a comprehensive program of myofascial release, lymphedema therapy, strengthening and range of motion exercises for the face, neck, mouth and throat along with specialized swallow therapy that can include NMES. As more rehabilitation physicians and therapists begin to use these techniques, the care and quality of life for OHNC survivors will continue to improve.

Editor’s Note: Nancy A. Hutchison, MD is a specialist in Physical Medicine and Rehabilitation and is the Medical Director for Cancer Rehabilitation and Lymphedema at the Sister Kenny Rehabilitation Institute and Virginia Piper Cancer Institute, 800 East 28th Street, Minneapolis, MN 55407

Meeting the Challenges of Oral and Head and Neck Cancer: A Survivor’s Guide
http://www.spohnc.org
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Let’s begin my story with “My Matt”. He is my great nephew. Matthew was born a day before my birthday on January 2. From the day he was born, we had a special connection and shared our birthdays. It was not a surprise that he was the one who had an active part in my story as follows.

In September 2006, Matt and I were watching cartoons. He was behind me as I was lying on my side on the couch. He accidentally slipped and his elbow jabbed into my neck pretty hard. For the next 2 days, my neck was sore. The third day I noticed a lump the size of a golf ball. I showed my sister who felt it and shouted, “It’s hard.” I wasn’t startled because the way the incident happened, it didn’t register with me that it could be cancer. However, I went to my physician right away and had a blood test and a CAT scan.

Nothing unusual from the blood test but the scan showed a mass. Again, no surprise. When I went to see an ENT specialist, he found my story rather odd so he sent me for a needle biopsy. The needle biopsy showed that cancer was present. The ENT suggested I see a surgeon right away!

A Moment in Time

My family was very supportive at this time, which helped me go through this shocking moment. I made an appointment at a cancer center in New York City. My sister Patty and friend Linda came with me to the city to see a head and neck surgeon. Mind you, my sister is a foreigner to New York City and it was amusing to see her there. We were brought up on neighboring Long Island, and I was the only adventurer who frequented the BIG city.

Also the surgeon and his nurse were very comforting and informative. The surgeon told me that my lump was the secondary spot for squamous cell carcinoma, or Head and Neck cancer. It was in stage 3, and there are only 4 stages. I couldn’t believe it! My little Matt, only 4 years old, was my lifesaver, my angel! I never would have known I had cancer if it weren’t for him! I had no symptoms. I’m grateful to him and for my treatments.

What Comes Around

I was living a healthy lifestyle, eating organic foods and being aware of what I was exposing myself to. As I found out, it is not what you are doing now, it’s what you did before that comes out now. I was a DJ for 10 years, partying and exposed to smoke and alcohol, the major causes for this type of cancer.

The surgeon told me he needed to find the primary tumor and suggested a PET scan. The PET scan didn’t reveal the primary tumor. I was scheduled for surgery with the possibility of a radical neck dissection if the primary wasn’t visible during exploration. The primary site was found in my tonsil and the base of my tongue, and was removed without having the neck dissection. The lump in my neck was treated with 2 chemotherapy and 33 radiation therapy sessions.

I was out of work for 4 months without a paycheck. It wasn’t easy but with the help of my sister and brother-in-law, it was as smooth as it could be. My brother-in-law took me for my treatments every day; my sister, on her days off. My mother opened her home to me and I stayed with her during my treatments. I am very blessed to have family, friends, and coworkers who care as much as for me as they do. I didn’t realize how much until this time. Thank you to all of you!

I think the worst part of the whole experience was the feeding tube. They had to insert a feeding tube in my stomach so I could eat and hydrate myself since I couldn’t swallow very well at the time. Unfortunately, the nutrients they recommended didn’t agree with me and my healthy organic body. I got sick a lot from the nutritional supplements, and I had to take medicine to help me keep the “food” down, as it would come back up as soon as I took it. As for the chemo, I didn’t get sick from it, only tired.

A Long Haul

It was a long haul, and I used to come home every night and mark off another day on the calendar to track my progress. It helped. I kept a positive attitude all along but questioned why? Why me? I guess that’s normal. I accepted the reality because I didn’t feel I had any other choice. So I just went along, day by day, living in the present and thinking this is where I was meant to be at this time.

I couldn’t wait for the feeding tube to be taken out, on the other hand. It was the strangest thing to have this foreign object in my body. My sister Patty came with me when they took the feeding tube out. She sat across from me as they just deflated the ball from the inside and pulled it out, just like that! I thought they would at least deaden the area or put me out, No! Just like that! It hurt for a half hour after. But, I made it through.

New Light

It was a growth experience in many ways. We take so many things for granted until we can’t do them any longer. To be able to eat, chew, swallow, taste...I would sit and watch people eat and wish I could taste and swallow like them. I lost 30 pounds and went down 3 sizes. I feel great and look just as good in my size 8 clothes! At this point, my tastes buds are 75% returned and my saliva 60%. I have to have a water bottle with me at all times.

I finished all my treatments finally and went back for another PET scan and all is well again. I am cancer free and a new person. I feel like the experience was so surreal. I had to embrace myself in a whole new light. Now I am doing a lot of things I wanted to do and didn’t. I appreciate every day and every new experience. I don’t take my life for granted, not that I ever really did. I don’t drink any alcohol, even though I used to love red wine now and again. I rather not take the chance of going thorough this again. I am one of the lucky ones, thanks to Matt, my angel!
HEAD AND NECK CANCER NEWS

FDA Clears TransOral Robotic Surgery –
Developed at Penn – for Tumors of Mouth, Throat and Voice Box
Minimally Invasive Procedure Shortens Recovery, Improves Outcomes

PHILADELPHIA – A minimally invasive surgical approach developed by head and neck surgeons at the University of Pennsylvania School of Medicine has been cleared by the U.S. Food and Drug Administration (FDA). The da Vinci Surgical System (Intuitive Surgical, Inc., Sunnyvale, California) has been cleared for TransOral otolaryngologic surgical procedures to treat benign tumors and select malignant tumors in adults.

Drs. Gregory S. Weinstein and Bert W. O’Malley, Jr. of the University of Pennsylvania School of Medicine’s Department of Otorhinolaryngology: Head and Neck Surgery founded the world’s first TransOral Robotic Surgery (TORS) program at Penn Medicine in 2004, where they developed and researched the TORS approach for a variety of robotic surgical neck approaches for both malignant and benign tumors of the mouth, voice box, tonsil, tongue and other parts of the throat. Since 2005, approximately 350 Penn patients have participated in the world’s first prospective clinical trials of TORS. These research trials comprise the largest and most comprehensive studies of the technology on record.

“TORS has dramatically improved the way we treat head and neck cancer patients, completely removing tumors while preserving speech, swallowing, and other key quality of life issues,” said Bert O’Malley, Jr., MD, professor and chairman of Penn Medicine’s Department of Otorhinolaryngology: Head and Neck Surgery. “It is very exciting that a concept conceived at Penn, evaluated in pre-clinical experimental models at Penn tested in clinical trials at Penn, and then taught to key surgeons and institutions both within the U.S. and internationally has been officially recognized by our federal governing agencies and peers around the world as a new and improved therapy for select neck cancers and all benign tumors.”

45,000 Americans and approximately 500,000 people worldwide are diagnosed with head and neck cancers each year. Head and neck tumor treatments often involve a combination of surgery, radiation therapy, and chemotherapy. In many cases, surgery offers the greatest chance of cure; yet conventional surgery may require an almost ear-to-ear incision across the throat or splitting the jaw, resulting in speech and swallowing deficits for patients. In comparison, the minimally invasive TORS approach, which accesses the surgical site through the mouth, has been shown to improve long term swallowing function and reduce risk of infection while speeding up the recovery time. When compared to traditional surgeries, after their cancers have been removed successfully, patients have been able to begin swallowing on their own sooner and leave the hospital earlier. TORS outcomes are markedly improved when compared to standard chemotherapy, radiation or traditional open surgical approaches for oropharyngeal cancer.

“Based on our data and patient outcomes, coupled with the national and international enthusiasm and interest for TORS, we are changing the way oropharyngeal cancer and tumors will be treated now and in years to come,” noted Gregory Weinstein, MD, FACS, professor and vice chair of the University of Pennsylvania School of Medicine’s Department of Otorhinolaryngology: Head and Neck Surgery, director of the Division of Head and Neck Surgery and current president of The Society of Robotic Surgery. “We are already investigating new TORS treatments for other conditions such as sleep apnea, and collaborating with colleagues in Penn Neurosurgery to use TORS to remove skull base tumors and repair cervical spine disease.”

The Penn TORS program developed an international training program that has trained numerous surgical teams from 12 different countries, many of whom have started establishing TORS programs at their respective institutions. With the FDA clearance of the da Vinci System for transoral otolaryngology, Penn Medicine will immediately expand its well established training program to include surgical teams from the United States.

For more information about the Penn TORS Program, please visit http://www.uphs.upenn.edu/pennorl/research/tors or call 215-349-5390. A Penn Medicine press release on TORS can be found online at: http://www.uphs.upenn.edu/news/News_Releases/may05/TORS.

Oral and Head and Neck Cancer Awareness Week

April 12th - April 19th 2010

Please check with your local chapters for upcoming events.
For listings of locations offering free oral screenings visit: www.headandneck.org

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Caregivers Corner...by Phyddy Tacchi

“I work all the time, but still feel like I’m behind.”

One of the chief concerns of caregivers is fatigue, both physical and emotional. Many caregivers complain of sleep deprivation. Because of the all-encompassing duties that caregivers must absorb, fatigue and self-doubt may set in. The more tired caregivers begin to feel, the more they may question their ability and self-confidence. If this fluctuating sense of physical and emotional fatigue has happened with you, don’t lose heart. This reaction has been the experience of many caregivers. It is important to take care of yourself during these difficult periods, even for small blocks of time.

The Tough Times: Caregiver Doubts

Which of the following thoughts of self-doubt can you most identify with?

- “Why can’t I keep up?”
- “Why can’t I do everything that needs to be done?”
- “Why can’t I get him/her to eat? To drink? To walk?”
- “Is there something wrong with me because I can’t get him/her better?”
- “Why doesn’t he/she talk with me?”
- “Why can’t I control things?”
- “I’m working as hard as I can and he/she still feels bad.”
- “I don’t have time for anything.”
- “I feel defeated and burned out.”
- “My loved one is so irritable with me, I just don’t know how to handle it.”
- “My loved one doesn’t want anyone else to care for him/her other than me. I’m getting worn out.”
- “My loved one won’t follow my advice.”
- “I let picky things get to me.”

The Emotions of Caregiving

As you may already know, there are many fluctuating emotional aspects of caregiving. Read what other caregivers have experienced:

- “My loved one is so irritable with me, and I’m working as hard as I can to help. All I want to do is go home.”
- “I don’t have time to take care of myself.”
- “Even if I did, I don’t know where to go or what to do.”
- “I just want things to return to normal, to the way things used to be.”
- “Sometimes, I just have to get away.”

Sound familiar? Sometimes caregivers feel as if their mood changes in conjunction to managing the fluctuating nature of day-to-day medical circumstances.

- “Help! I’m on an emotional roller coaster and I can’t get off.”
- “Sometimes at night, I just lay there waiting for the next earthquake.”
- “If I don’t sleep at night, I end up crying the next day.”

Caregivers often work overtime to provide care to their loved ones. This schedule has its pitfalls and blessings. It’s often a job requiring 24/7 attention with many physical and emotional demands, filled with highs and lows. The most common complaints of caregivers are emotional and physical fatigue, exhaustion and sleep deprivation. The time and effort it takes to care for your loved one each day can, over time, become very stressful with a gradual wearing down of energy.

There’s a high correlation between fatigue and depression in caregivers. When you’re under such tremendous chronic stress, you can experience many emotional ups and downs on any given day. One minute you feel as if you have it all together and the next minute it seems like you’re falling apart. Not only is physical fatigue a factor, but emotional overload is as well.

The Volcanic Feelings of Caregivers: Emotions to the Max

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The “Forbidden” Feelings of Caregivers

“Sometimes, I can’t talk to anyone about how I feel. I don’t want to burden them or take away the hope of my loved one. No one understands what this is really like unless they’ve been through it.”

It’s not unusual for caregivers to have intense feelings that they’re hesitant to talk about, especially to their patient as caregivers may wish to protect their loved one from hearing about their distress. These feelings can be strong and seemingly in conflict with what you’re trying to do. Although others may tell you to “think positive or be optimistic,” there are times when this just doesn’t seem possible.

Which of these “forbidden” feelings can you identify with?

- Yearning for “normal”
- Doubt
- Resentment
- Anger
- Guilt, feeling trapped
- Fear
- Hopelessness
- Helplessness
- Worry
- Sorrow
- Grief
- Loneliness

In the next issue of News From SPOHNC we will talk about the 6 Basic Steps for Caregiver Self-Care.

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Managing the Cost of Cancer Care
Practical Guidance for Patients and Families

INTRODUCTION
The cost of cancer care can be high. There may be expenses that you hadn’t planned for during your care. Financial costs can be a burden for people with cancer today, and these costs may affect the medical decisions that you and your doctor make.

The American Society of Clinical Oncology (ASCO) is working with oncologists across the country to increase doctor-patient communication on this crucial topic. ASCO is the world’s leading professional organization representing doctors who care for people with cancer.

If you are a person with cancer, understanding what costs to expect before starting treatment can help you manage the financial impact of cancer in the most effective way possible. ASCO created this guide to help you talk with your health care team about coping with the costs of cancer care. The guide includes tools and resources to assist you in financial planning before, during, and after treatment.

Whether you have private health insurance, government insurance (such as Medicare or Medicaid), or no insurance, it is important for you to talk openly with your health care team soon after diagnosis about the costs of your care. This may include medical costs — such as the price of a specific drug — as well as additional costs — such as transportation costs to and from the cancer center — that could make getting the best cancer care more difficult.

Out-of-pocket expenses can quickly add up and affect your family budget. These costs are also the reason some people don’t follow or complete their cancer treatment plan. However, not following your treatment plan for any reason could put your health at risk and lead to even higher health care costs in the future.

Your health care team can help you identify costs related to your treatment options, suggest ways to help reduce or manage medical and associated costs, and refer you to support services that address the financial difficulties many people with cancer face.

UNDERSTANDING COSTS RELATED TO CANCER CARE
After you are diagnosed with cancer, it is important to think about the different types of costs that could add up during your treatment and recovery periods. This will help you determine what kind of budgeting, support, or financial assistance you may need. Your personal costs will depend on several factors, including the length and type of your cancer treatment plan and the extent of your health insurance coverage.

Some costs may be more obvious to you than others. For instance, many people quickly think about how much a particular medication will cost for them based on their insurance coverage. However, there are also other costs — often called “hidden costs” — you will need to consider. These are the costs of daily living that increase due to the illness and its treatment.

For instance, your expenses for gasoline and parking fees will go up a lot if you need to receive daily radiation therapy at a facility 20 miles away from your home. Or, a new expense is added to your budget if you need child care every Tuesday so you can go to the doctor’s office for chemotherapy. At the same time, you may need to work less — and earn less money — because of the demands of the treatment schedule.

To get started, it may be helpful to group the different types of costs based on your budget and needs. Common financial categories for cancer care include:

• Doctor Appointments: This includes payments for the medical care you receive at each doctor visit, such as a physical examination or check-up. In most situations, your insurance provider requires you to pay a fee called a co-payment, or co-pay, each time you visit the doctor. The amount of the co-pay is set by the insurance company, not the doctor or doctor’s office. In addition, there will typically be a separate payment needed for each laboratory test, such as a blood or urine test, done as part of your appointment.

• Cancer Treatment Costs: This includes payments for the medical care you receive during your cancer treatment, such as each radiation therapy session. If you’re participating in a clinical trial, there may be other cost-related factors to consider. Some aspects of your treatment may not be covered by insurance. In general, cancer treatment can take anywhere from a few days up to months or years, so you will need to map out, with the help of a doctor or nurse, how often and for how long you may have these out-of-pocket costs.

• Medication Costs: This includes payments for the specific medicines prescribed during your treatment period, such as chemotherapy and drugs to help relieve common side effects.

• Transportation Costs: This includes expenses you may have due to traveling to and from the doctor’s office and/or treatment facility, whether it is by car, bus, train, or airplane. This category may also cover the price of hotels or other lodging needed.

• Family and Living Expenses: This includes costs related to running your household and caring for your family during your cancer treatment, such as child care, elder care, and coping support.

• Caregiving, At-home Care, and Long-Term Care: This includes additional costs of the care that a person with cancer may need, such as fixing meals or driving the patient to each medical appointment. It could also include extended nursing care at a specialized facility.

• Employment, Legal, and Financial Issues: This includes the costs that arise when a patient needs professional guidance on employment, legal, or financial issues related to their diagnosis. This includes such topics as addressing loss of wages of the patient or caregiver, learning about employment rights under the law, figuring out medical expenses during income tax filing, or writing a will.

Once you’ve outlined your cost categories, you can begin to think about the specific, individual costs in each one. If you feel overwhelmed, ask for help from a trusted family member, friend, or member of your health care team.

Reprinted from the booklet “Managing the Cost of Cancer Care: Practical Guidance for Patients and Families” with Permission from The American Society of Clinical Oncologists
Chronic periodontitis, a form of gum disease, is an independent risk factor for head and neck squamous cell carcinoma. This suggests the need for increased efforts to prevent and treat periodontitis as a possible means to reduce the risk of this form of cancer.

“Prevent periodontitis; if you have it already, get treatment and maintain good oral hygiene,” said Mine Tezal, D.D.S., Ph.D., assistant professor in the Department of Oral Diagnostic Sciences, School of Dental Medicine, University at Buffalo, and NYS Center of Excellence in Bioinformatics and Life Sciences at the University of Buffalo. She is also a research scientist in the Department of Dentistry and Maxillofacial Prosthetics at Roswell Park Cancer Institute, which is where the study was conducted.

Results of this study are published in *Cancer Epidemiology, Biomarkers & Prevention*, a journal of the American Association for Cancer Research.

Chronic periodontitis is characterized by progressive loss of the bone and soft tissue attachment that surround the teeth. The researchers assessed the role of chronic periodontitis on head and neck squamous cell carcinoma, as well as the individual roles on three subsites: oral cavity, oropharyngeal and laryngeal. They used radiographic measurement of bone loss to measure periodontitis among 463 patients; 207 of whom were controls.

Findings showed that chronic periodontitis might represent a clinical high-risk profile for head and neck squamous cell carcinoma. The strength of the association was greatest in the oral cavity, followed by the oropharynx and larynx, according to Tezal.

When they stratified the relationship by tobacco use, they found that the association persisted in those patients who never used tobacco. The researchers did not expect the periodontitis-head and neck squamous cell carcinoma association to be weaker in current smokers compared to former and never smokers, according to Tezal. However, this interaction, although statistically significant, was not very strong.

“Confirmatory studies with more comprehensive assessment of smoking, such as duration, quantity and patterns of use, as well as smokeless tobacco history are needed,” she said.

“Our study also suggests that chronic periodontitis may be associated with poorly differentiated tumor status in the oral cavity. Continuous stimulation of cellular proliferation by chronic inflammation may be responsible for this histological type. However, grading is subjective and we only observed this association in the oral cavity. Therefore, this association may be due to chance and needs further exploration,” Tezal added.

Andrew Olshan, Ph.D., said these results lend further support to the potential importance of poor oral health in this form of cancer. Olshan is professor and chair of the Department of Epidemiology at the Gillings School of Global Public Health, and professor in the Department of Otolaryngology/Head and Neck Surgery, School of Medicine, University of North Carolina at Chapel Hill.

“The study of poor oral health including the possible carcinogenic role of microorganisms is part of a rapidly growing interest in how a community of microbes that live in the various environments of the human body can affect health,” Olshan said. “Although the study is comparatively small, the researchers were able to also see an association between bone loss and the risk of head and neck cancer.”

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**Prevent Periodontitis to Reduce the Risk of Head and Neck Cancer**

Visit SPOHNC’s new web site at www.spohnc.org

Our Mission
SPOHNC is dedicated to raising awareness and meeting the needs of oral and head and neck cancer patients.

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CHAPTERS OF SPOHNC

ARIZONA-CHANDLER
Cancer Center at Chandler Reg. Med. Ctr.
1st, Wednesday: 5:30 – 7:30 PM
Monica Krise, MSW  480-728-3613
monica.krise@chw.edu
Dick Snyder  480-895-6019
rsnyder326@aol.com

ARIZONA-PHoenix
Banner Desert Medical Center
1st, Wednesday: 4:30 -6:30 PM
Keri Winchester, MS, CCC-SLP
480-512-3627
Keri.Winchester@bannerhealth.com
Dick Snyder  480-895-6019
rsnyder326@aol.com
Bette Denlinger, RN 480-838-5194
betteldenlinger@cox.net

ARIZONA-SCOTTSDALE
Virginia G. Piper CA Center
3rd, Thursday: 6:30-8:30 PM
Chris Henderson, MS, CCC-SLP
602-312-9226
chenderson2@shc.org
Sandy Bates, RN  805-652-5459
sandy.moff@cox.net
Les Norde  602-439-1192
elnorday@cox.net

ARKANSAS-NORTHWEST
WVA Cancer Support Home
3rd, Saturday: 10:00 AM-12:00 PM
Jack Igleburger  479-876-1051/586-4807
tmplnjak@cox.net

CALIFORNIA-LOS ANGELES-UCLA
UCLA Med. Pla., RadiOnc
Conf. Rm, B-265
1st, Tuesday: 6:30-8:00 PM
Pam Hoff, LCSW  310-825-6134
jhiggins@uci.edu

CALIFORNIA-PASO ROBLES
The Wellness Community
1st, Tuesday: 6:00 PM
Kenda Kellawan  805-238-4411
kenda.kellawan@wellnesscommunityhope.org

CALIFORNIA-SAN DIEGO
45 Ranch Library
1st, Saturday: 1:00 PM
Valerie Targia  760-751-2109
vtargia@yahoo.com

CALIFORNIA-SAN FRANCISCO
UCSF Comprehensive Cancer Ctr.
3rd, Wed., 1:00-2:30 PM, Rm. H3805
Daphne Stuart, LCSW  415-885-7394
daphne.stuart@ucsfmedctr.org

CALIFORNIA-SANTA MARIA
Marion Rehab. Center
Every other Tues., Alternate Months
Aundie Werner, MS, CCC-SLP
805-739-3185
aundiew@mail.com

CALIFORNIA-STANFORD
Stanford Cancer Center
1st-Tuesday: 4:00 - 5:30 PM
Jan Porter, LCSW  650-725-4765
jporter@stanfordmed.org
Ann Kearney, MA, CCC-SLP  650-736-0469
akearney@ohms.stanford.edu

CALIFORNIA-VENTURA
The Cancer Resource Center of
Community Memorial Hospital
Kathleen Horton 805-652-5459
khorton@cmhhospital.org

COLORADO-DENVER
Porter’s Adventist Hospital
Cottonwood Springs Conf. Rm, 1st, Fl.
Last Tuesday: 6:30-8:00 PM
Jeanne Currey  303-778-5832
jeannecurring@sentura.org

CONNECTICUT-NORWICH
William W. Backus Hospital
Medical Office Building, MOB Conf. Rm.
3rd, Tuesday: 5:00-6:00 PM
Darlene Young, RN, OCN
860-892-2777
dayoung@wwbh.org
Kathy Gernhard, RN, OCN
860-892-2777
kgernhard@wwbh.org

DC-GEORGETOWN
Lombardi Cancer Center.
3rd, Monday: 12:15-1:45 PM
Joanne Assarsson, MSW, LICSW
202-444-3755
assarssj@gunet.georgetown.edu

DC-WASHINGTON
Washington Hospital Center
Washington Cancer Institute
Call for Additional Information
Catherine McCarthy, LCSW
860-444-3744
cmmccarthy@lhmhop.org

CONNECTICUT-NEW LONDON
Lawrence & Memorial Hospital
Community Cancer Center
Call for Additional Information
Catherine McCarthy, LCSW
860-512-3627
kgernhard@wwbh.org

FLORIDA-ENGLEWOOD
Englewood Community Hospital
3rd, Thursday: 10:30AM-12:00 noon
Joseph Bauer  941-474-0099

FLORIDA-FT WALTON BEACH/NW FL.
Call for Location
4th, Thursday: 5:00 PM
Ryan Ennis, MA, CCC-SLP
850-863-8275 rennis@white-wilson.com
Shannon Leach, MA, CCC-SLP  850-362-9200
sleachslp@yahoo.com

FLORIDA-GAINESVILLE
Winn Dixie Hope Lodge
2nd, Monday: 6:00-7:00 PM
Carol Glavin, MSW, LCSW  352-371-8695
cfglavin@cox.net
No calls after 9:00 PM, please

FLORIDA-LECANTO
Robert Boissoneault Oncology Institute
3rd Wednesday: 11:30 AM-1:00 PM
Patrick Meadors, PhD, LMFT  352-342-1822
pmeadors@bci.com

FLORIDA-MIAMI
The Wellness Community
3rd, Wednesday: 7:00-9:00 PM
Gary Mallinichodr  305-668-5900
gcm4@yahoo.com
Russell Nansen  305-661-3915

FLORIDA-MIAMI
UM/Sylvester at Deerfield Beach, Ste.100
2nd, Tuesday: 1:30 PM-3:00 PM
Penny Fisher, MS, RN, CORLN  305-243-4952
pfisher@med.miami.edu

FLORIDA-NAPLES
NCH Healthcare System/Downtown
1st, Wednesday: 3:00-4:30 PM
Karen Moss, MS, CCC-SLP  239-436-4712
Karen.moss@nchmd.org

FLORIDA-OCALA
Robert Boissoneault Oncology Institute
1st, Monday: 11:00 AM-12:00 Noon
Patrick Meadors, PhD, LMFT  352-342-1822
pmeadors@bci.com

FLORIDA-SARASOTA
The Wellness Community
2nd, Thursday: 5:30 PM
Julie O’Brien, LMHC  941-921-5539
julieobee@verizon.net
John Kleinbaum, PhD  941-921-5539
hope@wellness-swfl.org

FLORIDA-WELLINGTON
Wellington Cancer Center
4th, Tuesday: 6:30-8:00 PM
Catherine DeStefano, RNC, OCN
561-793-6500
angelicanel1@bellsouth.net

GEORGIA-ATLANTA
St. Joseph’s Hospital
2nd, Monday: 6:30-8:00 PM
John Sandidge  678-843-5585
jsandidge@sjha.org

GEORGIA-ATLANTA-EMORY
Winship CA Institute (Bldg. C)
Last Monday: 6:30-7:30 PM
Arlene S. Kehir  404-778-2369
Arlene.Kehir@emoryhealthcare.org

http://www.spohnc.org
E-mail-- info@spohnc.org
CHAPTERS OF SPOHNC

GEORGIA-AUGUSTA
MCG Health Children’s Medical Center
Family Resource Center
1st Tuesday: 6:00-7:30 PM
Lori M. Burkhead, PhD, CCC-SLP 706-721-6100
Lburkhead@mcc.edu
Leann Dragano
dragano@bellsouth.net

ILLINOIS-CHICAGO
DuChesnay Ctr. for Advanced Medicine
4th Tuesday: 1:00 PM
Mary Herbert 773-834-7326
mherbert@medicine.bsd.uchicago.edu

ILLINOIS-MAYWOOD
The Cardinal Bernardin Cancer Ctr.
MAINE-AUGUSTA/CENTRAL
Harold Alfond Center for Cancer Care
Call for Additional Information
Therese Berniger, SLP-CCC
207-872-4051
therese.berniger@mainegeneral.org

MARYLAND-BALTIMORE-GBMC
Milton J. Dance Head & Neck Center
Physicians Pavilion East Conf. Ctr.
3rd Tuesday: 7:00 PM
Dorothy Gold, LCSW-C, OCW-C 443-849-2980
dgold@gbmc.org

MARYLAND-BALTIMORE-JHMI
Johns Hopkins – Greenspring Station
2nd Wednesday: 7:00-8:30 PM
Kim Webster 410-955-1176
Kwebster@jhmi.edu

MASSACHUSETTS-BOSTON
Massachusetts General Hospital, One Tuesday each mo.: 6:00-7:30 PM
Valerie Hope Goldstein 617-731-1703
Fernval@aol.com

MASSACHUSETTS-DANVERS
MGH Northshore Cancer Ctr.
2nd Tuesday: 5:30-6:30 PM
Mary Anne Macaulay, LCSW 978-882-6002
mmacaulay@partners.org

MICHIGAN-DETROIT
Henry Ford Hospital
Josephine Ford Cancer Ctr. Rm. 2038D
1st Wednesday: 11:30 AM
Amy Orwig, MSW 313-916-7578
aorwig1@hfhs.org

MICHIGAN-ST. JOSEPH
Lakeland Healthcare
1st Monday: 5:00-6:00 PM
Jennifer Christopher, MA, CCC-SLP
269-428-2799
jchristopher@lakelandregional.org

MICHIGAN-TROY
Beaumont Hospital
Wilson Cancer Resource Center
4th Thursday: 6:30 PM
Carrie Eriksen, LCSW, 248-964-3430
CEriksen@beaumonthospitals.com

MINNESOTA-MINNEAPOLIS
Hennepin/Southdale Library
1st Monday: 7:00-9:00 PM
Colleen M. Endrizzi 952-545-0200
CEriksen@beaumonthospitals.com

MISSOURI-COLUMBIA/MID-MO
Ellis Fischel Cancer Center
2nd Wednesday: 5:30-7:00 PM
Laura M. Neal, MSW, MPH, LCSW
573-884-1509 neallm@health.missouri.edu

MISSOURI-ST. LOUIS
St. Louis University Cancer Center
4th Friday: 10:00 AM - 12:00 noon
Deborah S. Mapne, MSN, RN, RN, OCN
314-577-8880; manned@slu.edu

MONTANA-BOZEMAN
Bozeman Deaconess Hospital
3rd Thursday: 12:00 Noon-1:00 PM
Doug Stiner 406-586-0828
nancydoug@theglobal.net

NEBRASKA-OMAHA
Methodist Cancer Center
1st Tuesday: 12:00 noon
Susan Stensland 402-559-4420
sstensland@nebraskamed.com

NEW JERSEY-MANHATTAN
Mount Sinai Medical Center
3rd Tuesday, 3:00 PM
Stephanie Eisenman, LMSW
212-241-7962
stephanie.eisenman@mountsinai.org

NEW YORK-Albany
Gilda’s Club
3rd Thursday: 7:00-9:00 PM
Joseph Ciccarelli 618-882-9742
jciccarelli001@nyccap.org

NEW YORK-Buffalo
Roswell Park Cancer Institute
3rd Tuesday: 4:30-6:00 PM
Amy Sumbrum, SLP 716-845-4947
amy.sumbrum@roswellpark.org
Jim Smallidin 716-845-4472
james.smallidin@roswellpark.org

NEW YORK-MANHATTAN
Beth Israel Head and Neck Institute
4th Tuesday: 1:30-3:30 PM
Jackie Mojica 212-844-8775
jmojica@chpnet.org

NEW YORK-Phila/phila
University of Pennsylvania Hospital
1st Wednesday: 9:30-11:00 AM
Micki Naimoli 856-722-5574
Tracy Lautenbach 215-662-6193
lautenbach@xart.upenn.edu
Mia Benson Smith, MS 215-662-4641
mia.bensonsmith@uphs.upenn.edu

NEW YORK-TOMS RIVER
Community Medical Center
Last Thursday: 3:00 PM
Sherry Laniado, MSW, LCSW 732-557-8270
slaniado@sbhcs.co

NEW MEXICO-Albuquerque
Norma Neapolitano 505-683-9518
neapolitano@nmc.org

NEW YORK-ALBANY
Gilda’s Club
3rd Thursday: 7:00-9:00 PM
Joseph Ciccarelli 618-882-9742
jciccarelli001@nyccap.org
Norma Neapolitano 518-683-9518
nneapolitano@nmc.org

NEW YORK-Buffalo
Roswell Park Cancer Institute
3rd Tuesday: 4:30-6:00 PM
Amy Sumbrum, SLP 716-845-4947
amy.sumbrum@roswellpark.org
Jim Smallidin 716-845-4472
james.smallidin@roswellpark.org

NEW YORK-MANHATTAN
Mount Sinai Medical Center
3rd Tuesday, 3:00 PM
Stephanie Eisenman, LMSW
212-241-7962
stephanie.eisenman@mountsinai.org

SPOHNC
P.O. Box 53
Locust Valley, NY 11560-0053
1-800-377-0928
CHAPTERS OF SPOHNC

NEW YORK-MANHATTAN
NYU Clinical Cancer Center, 11th flr
1st, Tuesday: 2:00 PM
Carole Wind Mitchell, RN 212-731-6002
carole.mitchell@nyumc.org

NEW YORK-ROCHESTER
Strong Memorial Hospital
1st, Thursday: 4:30-6:00 PM
Sandra Sabatka, LMSW  585-276-4529
Sandra_Sabatka@URMC.Rochester.edu

NEW YORK-STONY BROOK
Ambulatory Care Pavilion
1st, Wednesday: 7:30-9:00 PM
Dennis Staropoli 631-682-7103
den.star@hotmail.com

NEW YORK-SYOSSET
NSLII-Syosset Hospital
2nd, Thursday: 7:30-9:00 PM
Christine Lantier 631-757-7905
clantier@optonline.net
Mary Ann Caputo 516-759-5333
mary.ann.caputo@spohn.org

NORTH CAROLINA-ASHVILLE
Hendersonville/WNC
2nd Thursday: 5:00-6:30 PM
Mark Tenzer 914-328-2072
mark.tenzer@optonline.net

NORTH CAROLINA-CHARLOTTE
Blumenthal Cancer Center
2nd & 4th Thursday: 1:30-3:00 PM
Meg Turner 704-355-7283
meg.turner@carolinashealthcare.org
Terri Painchaud 704-364-7119
trapppb@yahoo.com

NORTH CAROLINA-CHAPEL HILL/DURHAM
Cormacopia House
3rd, Wednesday: 6:00 PM
Dave Gould 919-493-8168
dave@da.org

NORTH CAROLINA-CHARLOTTE
P.O. Box 53            Locust Valley, NY 11560-0053           1-800-377-0928
Jfbrelsford1@mmm.com

OHIO-CLEVELAND
Cleveland Clinic at Fairview Hospital
Tom Wurz 440-243-6201
2nd, Thursday: 4:00 PM
roc8@hotmail.com
Gwen Paull, LISW 216-476-7241
gwen.paull@fairviewhospital.org

OHIO-LIMA
St. Rita’s Regional Cancer Ctr.
The Allison Rad/Onc. Ctr.
3rd, Tuesday of even month: 5:00 PM
Holly Metzger, LMSW419-996-5606
hmetzger@health-partners.org
Linda Gliorioso 419-996-5616
lgliorioso@health-partners.org

OCEAN-NEW-JERSEY
The Chapel Room
One Elizabeth Place
Hank Deneski 937-832-2677
2nd, Monday: 6:00-8:00 PM
hdeneski@ mindspring.com

OKLAHOMA-TULSA
Hardesty Public Library
1st, Tuesday: 6:30 PM
Christine B. Griffin, RN 918-261-8858
beritrigger@cox.net

OREGON-MEDFORD
Providence Medical Center
2nd, Friday: 12:00-1:30 PM
Richard Boucher 650-269-8323
richard.boucher@hp.com

OREGON-THE WILLAMETTE VALLEY
Samaritan Reg. CA Ctr. Library
2nd Wednesday: 5:00-6:30 PM
Lisa Nielsen 541-757-9882
HNCsurvivor@comcast.net

 PENNSYLVANIA-HARRISBURG
Health South Lab
3rd, Tue: 6:30 PM
Joseph F. Brelsford 717-774-8370
jfbrelsford1@mmm.com

 PENNSYLVANIA-MONROEVILLE
Inter Community Cancer Center
Last Friday of month: 3:00 - 4:00 PM
Beth Madrishin 412-856-7740
bmadrishin@wpahs.org

 PENNSYLVANIA-YORK
Apple Hill Medical Center
2nd, Wednesday: 5:00 PM
Dianne S. Hollinger, MA, CCC-SLP
717-851-2601
Dhollinger@wellspan.org

 PENNSYLVANIA-MONROEVILLE
Health South Lab
3rd, Tuesday: 6:30 PM
Joseph F. Brelsford 717-774-8370
jfbrelsford1@mmm.com

 TENNESSEE-CHATTANOOGA
Memorial Hospital
1st, Monday: 4:00-5:30 PM
Jeanne Richelson 423-894-9215
Jeanne1255@aol.com

 TEXAS-DALLAS
Baylor Irving-Coppell Medical Center
2nd Saturday: 10:00 AM
Dan Stack 972-373-9599
danstack@aol.com

 TEXAS-DALLAS
Cvetko Ctr. at Sammons Cancer Ctr.
2nd Tuesday: 11:00 AM-12:30 PM
Jack Mitchell 972-496-6561
jackmitchell5225@aol.com

 TEXAS-FORT WORTH
Moncrief Cancer Resources
2nd, Wednesday: 3:30-5:00 PM
Valerie Oxford, M.S.S.W
817-927-6364/838-4863
valerie.oxford@moncrief.com

 TEXAS-HOUSTON/TOMBALL
Tomball Regional Hospital
2nd, Tuesday: 12:00 Noon-1:30 PM
Lynda Tustin, RN 281-401-5900
ltustin@tomballhospital.org

 TEXAS-McALLEN
Rio Grande Regional Hospital
3rd, Tuesday: 6:00 PM
Stephanie Leal, MA,CCC,SLP
SAL1275@aol.com
Cheryl Lopez, MS, CCC, SLP 956-632-6426

 TEXAS-PLANO
Regional Medical Center at Plano
1st, Tuesday: 6:00-8:00 PM
Polly Candela, RN, MS 214-820-2068
polly.candela@baylorhealth.com
Emily J. Gentry, RN 214-820-2068

 VIRGINIA-CHARLOTTESVILLE
Dep. of Forestry Building, Suite 800
Last Thursday: 11:30-1:00 PM
Vikki Bravo 434-982-4091
vsb4v@virginia.edu

 VIRGINIA-FAIRFAX
Inova Fairfax Hospital, Radiation/Oncology
2nd, Wednesday: 5:30-7:00 PM
Corinne Cook, LCSW 703-776-2813
Corinne.cook@inova.com

 VIRGINIA-NORFOLK
Sentara Norfolk General Hospital
3rd, Monday: 7:00 PM
Cynthia Gilliam 757-652-6653
beachdolphin@aol.com
Dee Gibson 757-481-0705
Deel1141@cox.net

 WASHINGTON-SEATTLE
Evergreen Hospital Medical Center
Call for Additional Information
Kile Jackson 425-788-6562
kile.jackson@hotmail.com

 WASHINGTON-SEATTLE
Virginia Mason Cancer Institute
Correa C Conference Rm.
3rd, Thursday: 6:00-7:30 PM
Susan (Sam) Vetto, BSN, RN, BC 206-341-1720
susan.vetto@vmmc.org
Joanne Fenn, MS, CCC-SLP 206-215-1770
joanne.fenn@swedish.org

 WISCONSIN-MADISON
Univ. of Wisconsin Hospital
ENT Clinic Rm. G3/206
1st, Wednesday: 11:30-1:00 PM
Rachael Kammer, MS, CCC,SLP 608-263-4896
kammer@surgery.wisc.edu
Peggy Wiederholt, RN 608-265-3044
wiederholt@humonc.wisc.edu

 WISCONSIN-MADISON
Medical College of Wisconsin
Conference Rm. J, Rm. 1010
3rd, Thursday: 12:00-1:00 PM
Tammy Wigginton, MS, CCC/SLP414-805-5662
twiggint@mcw.edu
ANNUAL MEMBERSHIP

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❏ $25.00 individual       ❏ $30.00 family
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