Navigating the Holidays When the Food Tastes the Same as the Plate…

Shayne Robinson, RD, CSP, CDN

The holidays are upon us! You have been invited to holiday parties and family dinners, but you can’t taste, are having trouble swallowing or have lost so much weight your clothes don’t fit. Your first instinct may be to stay home. But, the holidays are as much about spending time with friends and family, as they are about food. Managing your eating during the holidays can be a challenge, but celebrating the holidays is an important part of your treatment and recovery.

Head, neck and oral cancers can often make it difficult to eat. On average 50 percent of patients suffer from dysphagia (painful or difficulty swallowing) for 6 and 12 months after treatment is complete, with 15 percent having moderate to severe dysphagia for more than a year. Concomitant chemoradiotherapy (both chemotherapy and radiation therapy at the same time) increases the frequency and severity of dysphagia. Dysphagia influences quality of life and appetite. In addition to dysphagia, a recent marketing research study showed about 40% of cancer patients have increased taste sensitivities; 90% of patients treated with curative dose of radiation will experience significant taste impairment. According to one study, 48% percent of head and neck cancer patients are malnourished at the time of diagnosis, while other studies show rates of malnutrition up to 80%.

Malnutrition is typically related to an inability to eat due to the disease itself and/or the side effects of cancer treatment. Malnutrition in cancer patients is associated with shortened survival and, reduced benefits of treatment such as surgery or medical therapies. It also results in a poorer tumor response to chemotherapy, increased side effects from chemotherapy, and poorer quality of life.

The bottom line is that head and neck cancer patients need to maximize their nutritional status. There is no point in doing this alone since clinical studies have shown that nutrition, guided by a trained specialist, can have an impact on nutrition status.

A study conducted with 64 head and neck cancer patients undergoing radiation therapy at the Radiotherapy Clinic of the Department of Nutrition and Dietetics of the Institute of Radiology, Clínicas Hospital, University of São Paulo Medical School, demonstrated the benefits of working with a nutritionist. These patients were provided nutrition care by a nutritionist, as an integral part of the interdisciplinary team. The patients were evaluated for calorie and protein intake, weight, height, body mass index (a measure of body fat based on height and weight), body muscle mass and laboratory indicators. All patients were counseled by a nutritionist to maintain a very high caloric intake during the treatment period. The researchers found that the patients were able to increase their calorie and protein intake. The authors concluded that nutrition intervention by a nutritionist can help increase calorie and protein intake. They encourage routine nutrition evaluation and dietary care in order to prevent the nutritional deterioration and anorexia that often accompany radiation therapy.

In another study of 36 patients receiving radiation therapy in a radiation facility in Queensland, Australia, to the head and neck area, patients were randomized (selected in a random manner to reduce bias) to a nutrition intervention group or a usual treatment group for comparison. The nutrition intervention group received nutrition counseling by a Registered Dietitian (RD). Nutrition therapy was individualized, and supplements were provided as needed. Patients were seen weekly for six weeks, then bi-weekly to the end of the study. The control group received general nutrition advice from the nursing staff, a booklet on nutrition during radiation therapy, and supplement samples as needed. Weight and body composition were monitored. Researchers found that the intervention group that worked with the RD lost significantly less weight and muscle mass than the group that received the nursing guidance. They concluded that intensive nutrition therapy/counseling provided by a RD minimized weight and muscle loss.

A similar study looking at 60 patients found the group working with a RD had significantly higher calorie and protein intakes. They also had a better quality of life and physical function.

While reading articles and searching the web may offer advice, general information is often simply not adequate to address the full scope of concerns that are unique to head, neck and oral cancers. RD’s who are also Certified Specialists in Oncology Nutrition (CSO) have the expertise to meet the needs of oral, head and neck cancer patients. CSO’s are trained to understand your medical information and discuss your case with your health care team. They will recommend a nutrition plan specific to your preferences, needs, and abilities. They follow you throughout your treatment period. The researchers found that the patients were able to increase their calorie and protein intake. The authors concluded that nutrition intervention by a nutritionist can help increase calorie and protein intake. They encourage routine nutrition evaluation and dietary care in order to prevent the nutritional deterioration and anorexia that often accompany radiation therapy.

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Managing alterations in your sense of taste and texture to maximize your nutritional status

Food may taste the same, have less taste, no taste, or just taste bad. Your perception of the texture of food can change too. Alterations in sense of taste usually occur as a result of radiation. The high doses of radiation used to kill cancer cells can also damage healthy cells in the treatment area. Most often your sense of taste will return in the 2-6 months following treatment.

Chemotherapy, oral infections, mouth sores, surgery and the cancer itself may also cause alterations in your sense of taste and texture. Patients often report a metallic taste from chemotherapy. Oral infections such as thrush, can dull your taste buds, and should be reported to your doctor or nurse. Mouth sores, often painful, can make your mouth sensitive to rough textures or acidic foods.

To alleviate these problems, choose foods that look and smell good to you and focus on your other senses. If you have lost the ability to taste one flavor but not another, choose the flavor that you can taste. Choose stronger flavors if your sense of taste has decreased. For example, if you have a decreased ability or have lost the ability to taste salty food, but can taste sweet, then choose sweet seasonings, such as fruit chutney, duck or cranberry sauce on meats, poultry or fish. You can marinate foods in a teriyaki sauce or honey-based marinade and if making a soup or stew, add in dried fruit.

The holidays are the time to try new foods. Often foods are more acceptable when you don’t have a pre-conceived notion about what they should taste like. Holiday gatherings are a great opportunity to taste new recipes.

Remember there is more to foods than just the flavor. Concentrate on the color, texture and odor of food. The eating environment and the company you keep at holiday meals may be more enjoyable than the foods themselves, so focus on the pleasurable part of the holiday experience.

Take advantage of pleasant memories around holiday foods such as egg nog. Allow the memories, odors and sounds of the holidays satiate your appetite.

Try rinsing your mouth with tea, ginger ale, salted water, or baking soda and water to cleanse taste buds before eating.

Use herbs and spices like basil, oregano, rosemary, tarragon, or mint for extra flavor. For example, try adding mint to hot cocoa and garnish with a candy cane for a festive holiday treat. If you are using a hot cocoa mix, don’t mix it with water, but instead mix it with milk, almond milk, soy milk or coconut milk to give extra flavor, protein and calories.

Tart foods can be effective at enhancing flavors. Try marinating your holiday ham in orange juice and garnish with pineapple. Try a lemon sauce on poultry or fish. Use your leftover holiday turkey, mayonnaise and chopped pickles to make turkey salad.

Sometimes you can rid your mouth of undesirable tastes that linger by eating strong flavored foods that leave their own tastes. Pineapple, green apples, candy canes, or sour candies are good examples. Remember to brush your teeth after eating sugary candy.

Tart and strong flavored foods should be avoided if you have
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mouth sores or a sore throat or are on radiation to the head and neck and have the potential for mouth sores.

Managing Difficulty with Swallowing
Don’t allow dysphagia to make you a party pooper. If you need soft or pureed foods and are not sure you will be able to eat at your holiday celebration, offer to bring a soft dish that you can eat, such as a soufflé or mashed root vegetables.

In the event that the food served at a party may not be the right texture for your needs, or you are tube fed, or if you eat really slowly then choose to eat or feed before the event. It is acceptable to just snack, or have a beverage at the event. Everyone knows you can’t talk with food in your mouth, so if you are not eating, you can be the life of the conversation at the party!

Try not to miss out on foods that are a holiday tradition. It is easy to soften foods to make them acceptable. For example, if your family has a traditional pancake breakfast Christmas morning. Put your pancakes in a bowl; pour some warm milk and syrup on top to soften. Or if you love pumpkin pie but can’t swallow the crust, then put the pie in a blender with milk (or soy milk, almond milk, coconut milk or a nutrition supplement) to make a pumpkin pie smoothie. Try softening (and moistening) foods with gravy, olive oil or other healthy oil to make them easier to swallow and to add the extra calories you need.

Avoiding and/or Reversing Weight Loss
Holiday meals can be packed with calories, so this may be your chance to gain back some of the weight you have lost. Mashed yams, mashed potato, pumpkin soup and stuffing are all high calorie traditional holiday dishes. Add a healthy fat like olive oil to your portion to further increase the calories and help it slide down easily.

Just because the meals are packed with calories, doesn’t mean you can skip snacking, especially if you have lost weight. Holidays are a perfect time to snack on leftovers. If you find you can’t finish a meal at the holiday party ask for a doggie bag. Holiday leftovers make a perfect snack.

To increase calorie intake incorporate extra healthy fats, like avocados, nut butters (peanut butter, almond butter, sunflower seed butter) tahini, olive oil, coconut oil or canola oil. For example, mash a hard-boiled egg with avocado and olive oil or stir almond butter into your mashed yams. The nut butters are also a great source of protein.

When recipes call for water, such as hot cereals, hot cocoa and even soups, replace it with juice, milk, soymilk, rice milk, coconut milk, almond milk or even nutrition supplements.

In my experience, patients that routinely consult with a RD CSO as part of their interdisciplinary team are better equipped to manage eating challenges and make the most of the holidays. The holidays are about spending time with loved ones. Although celebrations often revolve around food, you have the tools and strategies to make the most of your events. Taste changes, difficulty swallowing and weight changes can make these events more challenging, however, with the right planning, you too can get into the holiday spirit. Bon Appétit!!!!

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Editors Note: Shayne Robinson RD CSO CDN is the Oncology Dietitian in the infusion center and radiation oncology practices of New York Presbyterian’s Ambulatory Care Network. She is a registered dietitian, board certified in oncology nutrition. She received her bachelors degree from the University of Maryland at College Park and completed her internship through the New York Institute of Technology at the Good Samaritan Medical Center. Shayne has worked as an oncology dietitian for over 10 years at The Beth Israel Comprehensive Cancer Center, Saint Vincent’s Comprehensive Cancer Center and most recently Albany Medical Center.

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TIME FOR SHARING... CANCER? YOU’RE KIDDING!

“I don’t care. We’re going to New York and that’s it! This is our time to go home, grab the Radio City extravaganza, catch the Nutcracker at the Met, ogle the windows on 5th Avenue and eat roasted chestnuts while staring at the Rockefeller Christmas Tree time, and nothing’s going to get in the way. The cancer will just need to take care of itself for the weekend.”

And that’s how it started...

I’ve never been a good pill taker. Somehow pills have always been a difficult swallow for me, unlike my wife, who can toss a handful of multi-sized pills into her mouth, grab a swig of water and BOOM - gone! I’d stick one pill at a time way back in my throat then quickly chug a mouthful of water and hope for the best. So, when it became a little more difficult to swallow my morning vitamins etc. I, except for kiddingly accusing my wife of buying larger sized pills, hardly paid attention. It was only after it became a real pain, that I set up an appointment with my local ENT guy.

So, he didn’t like the look of the base of the left side of my tongue. Okay. So, he didn’t like the look of the chunk of my tongue (he swears it was a miniscule sliver of tissue, but I know better) he took for a biopsy. Okay. So, the folks, who examined the tissue, didn’t like the look of the tissue either. Okay, so nobody likes my tissue. But Cancer? Cancer? You’ve got to be kidding me.

Okay, so no one was kidding me, but for a month we’d planned our trip to my hometown, and Cancer or no Cancer, we were going to The City for a weekend. Period. End of report.

You know, no one gets up in the morning and says, “Let’s see how much bad news I can uncover today.” Most of us just get up and go about our daily grind: a little bit of fun, a little bit of joy, a little bit of unpleasantness and boom! The day’s over, we settle in and before you know it it’s tomorrow and off we go once again. Standard procedure. So when someone comes in and says, “Hey man, you’ve got a serious case of tongue cancer”, it can really ruin your day. If you let it. We went to New York and had one heck of a time.

Then it became time to pay the biopsy piper. So I sit down and get the news. The good news is no surgery is necessary. Okay! The bad news is the regime of chemotherapy and radiation is one big rollercoaster ride: Feel good; Boom! Feel lousy. Spirits up; Slam! Basement time! Okay, so it won’t be a sleigh ride, or a walk in the park. Okay. Let’s go for it.

Now, radiation is a touchy thing. The beam of whatever it is, needs to be carefully directed, otherwise bad things can happen to good tissue, so you need to be perfectly still and not move while being shot at. In order to make sure you are indeed stationary, a mask is molded to your face and clamped down to the table upon which you lie during treatment. Kind of like being a 21st Century Man In The Iron Mask. Oh. Did I mention that I’m claustrophobic? You’re going to do what? How? So, let me get this straight. You’re going to bolt me down to a table, after stuffing me into a mask molded to my face and hold me there while you shoot red beams at me. Yes? You are kidding me, right? No, you’re not, I see.

I could lie and say the first two sessions were uneventful, or tell you that a greater torture no one could devise. It was hell on wheels, until my darling wife suggested that we cut large eyeholes into the mask, so that it wouldn’t feel like I was being suffocated to death. From that point on, the radiation part of my treatment was a snap. I could snuggle into my mask, see out clearly and lay still for the short time it took to zap me. If you’re one of my kind and become unable to breathe just at the thought of playing the Man In The Iron Mask, you should discuss some options that could open-up your vision and keep you calm.

The Chemo portion of my treatment was a snap. Sit in a comfortable mini easy chair, cover up with some blankets, get an IV into your arm, which is attached to a bag of fluid, and be attended to by kind, considerate and cheerful nurses. This I could do standing on my head. So, the treatment began, and went full-course, and here’s the long and the short of it: things to do and, more importantly, things not to do...

I wasn’t ready for my prime-time presentation as the Italian Yul Brynner. In fact, I was almost two weeks into my Chemotherapy treatment, and my hair was as thick and full as ever. Looked to me like maybe the stuff I was getting didn’t do that “baldness” thing. And, who knows? If I didn’t take a shower every morning, maybe it wouldn’t have let loose all at once, but “BAM”, one morning I went in like the proverbial lion and came out like a little shorn lamb. Bald like that billiard ball everyone talks about. So, gird your loins and, early on, pick out a hat that you wouldn’t mind wearing, because wear it you will.

Chemotherapy knocks you down. Fact. So, what you want to do is pick a favorite spot in your home, one that you’d love to spend more time in if only you had the time, because you’re about to find that time. You’re not going to become an invalid: I managed about 2 to 3 hours a day of work time – an easy task, as I’m self-employed. If you’re thinking of going into the office for a few hours a day, put that thought aside. It isn’t going to happen. You are really going to really want to lie down and rest infinitely more than you ever thought possible. Me? I chose the couch facing the TV, because I never get a chance to watch much TV and I was worried that I’d slipped too far behind in the shenanigans of “As The World Turns” to be allowed to continue as a card-carrying member. As it turned out though, my main TV diet consisted of watching every program aired on The Food Network - or at least those that I was awake for, and that was because…

Up here in Maine, we use the word “wicked” in the superlative and we use it both up and down. So, someone can either be Wicked Bad; a real nasty character, or Wicked Good; so good it should be illegal. Radiation is Wicked Bad. It burns you, cooks you, fries you, and… it keeps doing so for days, months and years after your radiation treatment is done, which is why they mask you down and hold you still. They want that beam to go only where its damage is useful. But, despite everyone’s best efforts, there will be unwanted fallout, one of which is that it becomes painful to eat, and here is where...
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Superman must come flying in through the window. Lacking his appearance, your wife, girlfriend, boyfriend, best friend, Lassie, someone will need to step in and help you, encourage you, nay, force you to eat because, as it turns out, the muscles you use while eating, like many other muscles, needs to be constantly utilized, or like your arm muscles after you’ve stopped that great morning push-up routine you follow, they become weak and flabby and eating becomes an extremely difficult task to accomplish. I know. I didn’t, and then, I couldn’t, and so I did the next best thing, I chose to watch The Food Network. Vicarious eating. Who’d a thunk? So keep eating. No matter what. It’s way, way better that way.

Now, anyone who even hints that life after Tongue or Throat Cancer treatment is going to be the same as before, is right up there with Bozo The Clown: full of good cheer, lacking in reality. It won’t be. It will be different. Sometimes painfully different. But… although not the same, it can and will be most interestingly different, and in many ways differently better. For starters, you’ve made it through a really rough treatment regime. That takes strength and courage that many of us do not realize we possess. Having gone through however, puts that strength right smack in front of your eyes, waiting for you to utilize it. So grab it and go.

Today, I sound like Donald Duck, which is a big improvement over what I sounded like as I went through treatment. So, what do you do with a Duck’s voice? Why, become a radio personality - what else? I mean, how many radio personalities do you know sound like a manic duck? See my point? So, a friend of mine had a radio show on the local college radio system, during which time he would comment upon events, both world and local. Why we are friends is anyone’s guess, since we never seem to agree upon anything but, I thought, that could make for good radio.

So, I made a pitch. Sez I: “Here lies the opportunity for you to have not only a counterpoint opinion on the subjects you’re addressing, but one delivered by a manic duck!” How could he refuse? And you know, it’s worked, and, perhaps more personally important, it has provided me with many moments in the sun. People will hear me speaking, like say at the checkout counter of a supermarket, and they will tap me on the shoulder: “Excuse me, but aren’t you on the radio? I recognize your voice.” Seek and you shall find.

And while you’re seeking, look further out. Go for the “Aw, I don’t know. It’ll be a hard grind.” type of endeavors. You’ve paid your dues, now collect. Like, maybe, start running. Okay, so at first it’s only 50 yards and stop, but do it. Next week it’ll be a block, and the week after, 3 blocks. Then a Marathon beckons. Could be.

Buy a bike. Get cool with the fancy headgear and the smooth, slick wild-colored riding outfits. With all those gears available, you and your bike can be knocking out 10-miles, BAM! Just like that. After that you could dip your rear tire in the Atlantic Ocean and later, your front tire into the Pacific.

Better still buy a motorcycle. I did. Then go visit all your far-flung relatives. I rode 3,857 miles visiting family, some of which I hadn’t seen in quite a few years. It took two weeks, but it was two magnificent weeks.

Point is: you’ve survived a very rough treatment for a very nasty disease, which shows that you’ve got more in you than you may have thought. Now, armed with the power of that knowledge, expand your horizons. Change “What if?” into, “When are we leaving?”

Final words – of wisdom I hope: If you’re just starting your treatment, take heart. We others have gone before you and can report that it’s a steep, rock-strewn, muddy trail, but a doable one, and while you may come out grimy and worn, the pay-off will be enormous. If you’ve just finished your regime, congratulations. Now’s the time to grab a calendar and plan something. How about a ride through the Dakota Badlands? Or a climb up Devil’s’ Tower? A snap. I’m ready when you are.

~ Mike Torrusio, Jr.

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Be thankful
that you don’t already have
everything you desire,

If you did,
what would there be to look forward to?

Be thankful
when you don’t know something
For it gives you the opportunity to learn.

Be thankful
for the difficult times.
During those times you grow.

Be thankful
for your limitations
Because they give you
opportunities for improvement.

Be thankful
for each new challenge
Because it will
build your strength and character.

Be thankful
for your mistakes
They will teach you valuable lessons.

Be thankful
when you’re tired and weary
Because it means
you’ve made a difference.

It is easy to be thankful
for the good things.
A life of rich fulfillment
comes to those who are also thankful for the setbacks.

GRATITUDE
can turn a negative into a positive.
Find a way to be thankful for your troubles
and they can become your blessings.

Author Unknown
A specific subset of patients with oropharyngeal squamous cell carcinoma who undergo transoral robotic surgery and postoperative radiotherapy demonstrated an increased risk for late consequential surgical bed soft tissue necrosis, according to results of a retrospective analysis. Risk factors included tonsillar location, radiation dose to the surgical bed, depth of resection and severe mucositis, results showed.

John Lukens, MD, a radiation oncologist at The University of Pennsylvania, and colleagues sought to identify the frequency of and risk factors for the development of soft tissue necrosis (STN) in the surgical bed after completion of postoperative radiation therapy. Researchers defined soft tissue necrosis as ulceration of the surgical bed that developed more than 6 weeks after postoperative radiation therapy and required opioids, biopsy or hyperbaric oxygen therapy.

The analysis included 170 patients with oropharyngeal squamous cell carcinoma (OSCC) who underwent transoral robotic surgery and postoperative radiation therapy between 2006 and 2012. The cohort included 104 patients with tonsillar disease and 66 patients with base-of-tongue disease. All patients were followed for more than 6 months.

Overall, 47 patients (28%) were diagnosed with STN. Results showed tonsillar patients were more likely to develop STN than those with base-of-tongue OSCC (39% vs. 9%). Among patients diagnosed with STN, median tumor size was 3 cm (range, 1-5.6) and median depth of resection was 2.2 cm (range, 1-5.1). The median radiation dose was 6,600 cGy and the median dose of fraction to the surgical bed was 220 cGy. Thirty-one (66%) of the patients received concurrent chemotherapy.

Median time to soft tissue necrosis after postoperative radiation therapy was 2.5 months, and the median time to resolution was 3.7 months. Results of multivariate analysis identified several risk factors for STN, including tonsillar primary location (OR=4.73; P=.01), depth of resection (OR=3.12; P=.001), grade 3 acute mucositis (OR=3.47; P=.02) and total radiation dose to the resection bed (OR=1.51 per Gy; P<.01).

In May 2011, researchers avoided delivering more than 2 Gy per day to the resection bed mucosa. After that, only two of 26 (8%) patients developed STN. All cases were grade 2.

**Disclosure:** See the study for a full list of the researcher’s relevant financial disclosures.

Barbara Burtness – MD, HemOnc Today Editorial Board member commented: Lukens and colleagues draw on a large institutional experience with transoral resection of oropharynx cancers to make a very useful observation about the risk for late soft tissue necrosis after transoral resection and post-operative radiation. They report a retrospective analysis of 170 patients who underwent transoral resection with postoperative radiation. Twenty-eight percent of patients developed soft tissue necrosis at a median time from the conclusion of post-operative radiation of 2.5 months. The authors identified a number of possible risk factors, including larger tumor size, deeper extent of resection, grade 3 mucositis during radiation, tonsillar primary site and higher radiation dose. Higher postoperative doses resulted when there were positive or close margins, or during radiation boost to sites of extranodal extension.

The use of transoral resection is on the rise in parallel with increasing numbers of oropharynx cancers resulting from HPV infection. Thus, it’s important for treatment teams to be aware of this risk, how soft tissue necrosis presents, and the possibility of using hyperbaric oxygen to treat it. These data may indicate that caution is warranted in using this approach — which is FDA approved only for T1 and T2 cancers — for larger cancers.

The ECOG-ACRIN Cancer Research Group is conducting a clinical trial of transoral resection followed by risk-based postoperative radiation. A central question of the trial is whether patients with negative margins and no or minimal extranodal extension can achieve comparable cure and superior functional recovery if the postoperative therapy is delivered to 50 Gy rather than 60 Gy. Based on these data, a lower rate of soft tissue necrosis might be a further benefit of deintensifying adjuvant therapy. Pending the results of that trial, judicious patient selection based on T stage and preoperative evidence for extranodal extension — and vigilance for this complication — are warranted.

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CHAPTER HAPPENINGS
The University Miami Miller School of Medicine - Mort Silverblatt Sylvester Cancer Center SPOHNC Chapter

In the fall of 1997 Mort Silverblatt, a head and neck cancer survivor met with Dr. J.W. Goodwin, Director of the Sylvester Comprehensive Cancer Center and discussed plans to start a Head and Neck Cancer Support Group. It had some challenges but in 1999 Mr. Silverblatt and Dr. Goodwin and the Head and Neck nurse, Penelope Stevens Fisher, MS, RN CORLN, reached out to The American Cancer Society for the use of the Hope Lodge on campus. The meetings became monthly in the library and a support team was formed. The next milestone was the collaboration with SPOHNC when in March 2003 the group was named a SPOHNC chapter in honor of all the service Mr. Silverblatt provided for the many patients who also experience head and neck cancer. At that same time the Sylvester Comprehensive Cancer Center starting growing in surrounding communities with satellites services. The support group moved to the Sylvester Deerfield Clinic, where it continues to meet monthly. Currently a second support group is forming in the main campus to serve in conjunction with the new Head and Neck Cancer Survivorship Clinic.

The group has been active in survivorship care and in the community. Both Mr. Silverblatt and fellow survivor, Mr. Marty Mash, assisted in oral cancer screenings, educational displays, ACS Relay for Life and one on one supportive help for patients and families. The group remains strong and active. Support meetings have included dieticians cooking and bringing healthy foods; social workers explaining forms and listing community resources; physicians from medical and radiation oncology and head and neck surgeons have provided cancer care updates; counselors and practitioners in relationships, acupuncture, speech, swallowing, pharmaceuticals and research studies have been present for education and support. Fisher remains the facilitator and works with the survivors to meet the group’s and individual’s educational and supportive needs.

During the April 2014 Oral and Head and Neck Cancer Awareness Week the nursing staff of the UM/Sylvester Head and Neck Clinic, under the direction of Manager, Elia Fonte, RN; support group attendees and Fisher wore SPOHNC t-shirts while receiving 150 curious patients and visitors to the cancer center who viewed displays introducing SPOHNC, prevention, early detection, causes and treatment modalities for head and neck cancer.

~Penelope S Fisher MS RN CORLN
Facilitator - SPOHNC Miami, UM/Sylvester Chapter Support Group

HEAD AND NECK CANCER NEWS
Cancer diagnosis often adversely affects mental health - A cancer diagnosis can be traumatic

(HealthDay News) - One out of three people diagnosed with cancer also wind up struggling with a mental health disorder such as anxiety or depression, according to a German study published online Oct. 6 in the Journal of Clinical Oncology.

Anja Mehnert, Ph.D., a professor of psychosocial oncology at the University of Leipzig in Germany, and colleagues held face-to-face interviews with 2,141 Germans with cancer. The patients were between 18 and 75 years old. Standardized questions were used to determine if the cancer patients had mental health problems classified under the Diagnostic and Statistical Manual of Mental Disorders (DSM-V).

The researchers found that about 40 percent of patients with breast cancer (41.6 percent), head and neck cancer (40.8 percent), and malignant melanoma (39.0 percent) also had at least one mental disorder. The lowest rates of mental disorder, around 20 percent, occurred among patients with pancreatic (20.3 percent), prostate (21.6 percent), or stomach/esophageal cancers (21.2 percent). The most common mental disorders affecting cancer patients were anxiety disorders and adjustment disorders.

“[Our] findings reinforce that, as doctors, we need to be very aware of signs and symptoms of mental and emotional distress,” Mehnert told HealthDay. “We must encourage patients to seek evaluation, support, and treatment if necessary, as there are long-term risks often associated with more severe, untreated mental health disorders.”
HEAD AND NECK CANCER NEWS

Current tobacco use linked to oral HPV-16 infection

October 7, 2014 - Tobacco users demonstrated twice the risk for oral HPV-16 infection than former tobacco users or never users, according to study results.

HPV-16, a sexually transmitted infection, is considered the primary transmitted infection, is considered the primary reason for the sharp increase in oropharyngeal squamous cell carcinoma incidence in the United States during the past 2 decades.

“The practice of oral sex is common, but this cancer is rare. So there must be cofactors in the process that explain why some people develop persistent HPV-16 infections and HPV-positive oropharyngeal cancers when most other people don’t,” researcher Gypsyamber D’Souza, PhD, MS, MPH, associate professor of epidemiology at Johns Hopkins Bloomberg School of Health and Johns Hopkins Kimmel Cancer Center, said in a press release. “It appears that tobacco exposure increases the likelihood of having an oral HPV-16 infection, and although we do not yet know why, we suspect that the virus may not be cleared from the body as easily in people who use tobacco.”

D’Souza and colleagues evaluated data from 6,887 adults aged 18 to 59 years who participated in the National Health and Nutrition Examination Survey.

All participants completed computer-assisted self-interviews at baseline to assess current tobacco use — defined as use within the prior 5 days — and sexual behaviors. Slightly more than one-quarter (n=2,112; 28.6%; 95% CI, 26.5-30.9) of study participants were current tobacco users. Current tobacco users were more likely to be male, younger, have less education and have a higher number of lifetime oral sexual partners than non-tobacco users (P<.001 for all).

Researchers also conducted oral HPV DNA testing on all participants and detected oral HPV-16 in 63 participants (1%; 95% CI, 0.8-1.3%). Overall, the incidence of oral HPV-16 was significantly higher in current tobacco users compared with never or former users (2% vs. 0.6%; P=.004). Results of a multivariate analysis showed self-reported tobacco use was significantly associated with oral HPV-16 infection (OR=2.7; 95% CI, 1.35-5.41).

Researchers also evaluated the association between tobacco use and oral HPV-16 according to biologic biomarkers. They observed a significant association HPV-16 and levels of cotinine, a major nicotine metabolite (P=.02). They also observed a significant association between HPV-16 and levels of urinary 4- (methylNitrosamino)-1-(3-pyridyl)-1-butanol (NNAL), a tobacco-specific carcinogenic metabolite (P=.01).

A log increase in cotinine, which equates to approximately three cigarettes per day, was independently associated with oral HPV-16 (adjusted OR=1.31; 95% CI, 1.07-1.6). Researchers observed a similar trend for a log increase in NNAL, which equates to four cigarettes per day (adjusted OR=1.68; 95% CI, 1.23-2.28).

“We found that increasing levels of tobacco exposure were associated with higher odds of oral HPV-16 prevalence,” researcher Carole Fakhry, MD, MPH, assistant professor of otolaryngology — head and neck surgery at Johns Hopkins University School of Medicine, said in the press release. “These results may provide an additional reason for smoking cessation and suggest that even modest amounts of tobacco use are associated with higher oral HPV prevalence.”

Disclosure: The researchers report research support from and consultant roles with GlaxoSmithKline and Merck.

In Memorium

SPOHNC was deeply saddened to learn of the recent passing of Sheryl Strear, of Monroe Township, New Jersey, on September 25th. Sheryl was a dedicated educator at JHS 71M and Seward H.S. prior to joining the social studies department of Tottenville H.S., and was fluent in several languages as well. She was also a devoted volunteer for many organizations.

Sheryl and her husband Mitch have been long time supporters of SPOHNC, and attended our recent 20th Anniversary Conference & Celebration here in New York. We will keep Sheryl’s family in our thoughts and prayers.

We Have Walked in Your Shoes

“I have given many copies of “We Have Walked In Your Shoes” to patients beginning their journey in oral cancer--the feedback has been outstanding. As an oral, head and neck surgeon I consider this book one of the most valuable resources I can provide to help educate and empower our patients and families battling oral, head and neck cancer.”

- Anthony Morlandt MD, DDS - Assistant Professor of Oral/Head and Neck Oncology and Microvascular Reconstructive Surgery, University of Alabama at Birmingham Oral and Maxillofacial Surgery

A newly diagnosed patient’s first point of contact is their doctor. The day you are diagnosed, there is an overwhelming feeling of helplessness. How do I know what to do next? Who do I turn to? What is the next step? Where will I find the information I need in order to make the best decisions?

SPOHNC continues to be there, offering hope, encouragement and information through resources like We Have Walked In Your Shoes. Many of you have generously given in support of We Have Walked In Your Shoes, but we still need more help to reach our goal of providing guidance and comfort to newly diagnosed patients. If you have already given, we would like to thank you for your kindness.

If you’ve been meaning to give a gift toward We Have Walked In Your Shoes, now is the time - Give in honor of a friend or loved one who has just been diagnosed, or give in honor of a survivor you know. Contact SPOHNC at 1-800-377-0928 make a donation today.

Our campaign is moving forward – please help us to reach our goal. Give today so we can help a newly diagnosed patient tomorrow.

Connect with SPOHNC’s “group” on Facebook
November – the beginning of the season of giving – always reminds us to be thankful and grateful.

SPOHNC is thankful for your support. In October, SPOHNC’s most important fundraising campaign was included in your newsletter. Our Annual Appeal reaches out to each of you - to help SPOHNC fund the development of more chapter support groups, new patient and caregiver matches, and to help us to continue the crucial work that we do – helping patients, survivors and caregivers who contact us each and every day seeking information, financial resources, referrals or just someone to talk to. Through your membership dollars, gifts and donations to our Appeal, in 2014 we have been able to continue our vision and mission. SPOHNC is dedicated to raising awareness and meeting the needs of oral, head and neck cancer patients through its resources and publications.

It is heartbreaking to hear the words “You have cancer”... and especially a rare cancer that no one has heard about. SPOHNC fills a critical need, by offering survivors, who have walked in your shoes, to help guide one through a difficult journey. Our SPOHNC volunteers give of themselves – time, advice, strong shoulders and invaluable information for newly diagnosed patients. SPOHNC is grateful for our volunteers.

Each of you has helped us to be where we are today. We extend our thanks, and our gratitude...for your help in enabling SPOHNC to keep providing the programs of support that are so essential to those who have been affected by oral, head and neck cancer. SPOHNC is thankful and grateful, for you.

Bon Appetit!

With Thanksgiving upon us, the season of giving will be here before you know it. If you’re looking for a unique gift for a patient, survivor or caregiver, SPOHNC can help. Eat Well Stay Nourished A Recipe and Resource Guide For Coping With Eating Challenges can be shipped to you (or your gift recipient) in time for the holidays. Order your books today!

**Tuscan Bean Soup**
(from Volume 2)
4 cans (15 oz) cannellini beans
6 c. chicken broth
1 ½ medium onions, diced
¼ lb. pancetta, diced (or bacon)
3 Tbsp. olive oil
6 cloves garlic, finely minced
salt and pepper to taste


~ Ed A. - Laguna Niguel, CA

May the good things of life be yours in abundance, not only at Thanksgiving, but throughout the coming year.

**Limited Time Offer Extended!!**
(while supplies last)

**Two Volume Set**
$40.00 includes shipping and handling.
- Recipes & Information About Eating Challenges and Nutrition
- Cancer Journeys of Survivors
- Suggestions and “Tips from the Pros”

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E-mail-- info@spohnc.org

http://www.spohnc.org
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(120+ and growing!)

Contact SPOHNC at 1-800-377-0928 for Chapter information & Facilitator contact information

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ARIZONA - PHOENIX
ARIZONA - SCOTTSDALE
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ARKANSAS - NORTHWEST
CALIFORNIA - CARLSBAD
CALIFORNIA - LOS ANGELES-UCLA
CALIFORNIA - NEWPORT BEACH
CALIFORNIA - ORANGE-UCI
CALIFORNIA - SAN DIEGO
CALIFORNIA - S. SAN FRANCISCO
CALIFORNIA - SANTA MARIA
CALIFORNIA - STANFORD
CALIFORNIA - VENTURA
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COLORADO - DENVER
COLORADO - PUEBLO
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CONNECTICUT - NORWICH
DC - GEORGETOWN
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FLORIDA - FT MYERS
FLORIDA - FT WALTON BEACH/ NW FL
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FLORIDA - JACKSONVILLE/FCO
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FLORIDA - MIAMI/UMS
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FLORIDA - PALM COAST/ NORTHEAST
FLORIDA - SARASOTA
FLORIDA - THE VILLAGES
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GEORGIA - ATLANTA-EMORY
GEORGIA - AUGUSTA
GEORGIA - COLUMBUS
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ILLINOIS - MORRIS
ILLINOIS - SPRINGFIELD
INDIANA - FORT WAYNE
INDIANA - INDY-NORTH
INDIANA - INDY-WEST
INDIANA - SOUTH BEND
INDIANA - TERRE HAUTE
IOWA - DES MOINES
KANSAS - KANSAS CITY
KANSAS - TOPEKA
LOUISIANA - BATON ROUGE
MARYLAND - BALTIMORE-GBMC
MARYLAND - BALTIMORE-JHMI
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Please help to continue SPOHNC’s strong history of patient support by making a contribution today to our Annual Appeal!

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☐ Leaders Circle, $10,000+  ☐ Visionary Circle $15,000+

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