



SUPPORT FOR PEOPLE WITH ORAL AND HEAD AND NECK CANCER | EST. 1991



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New information and special programs, new treatment options, new volunteers and new SPOHNC Chapters will come your way in 2023.

Keep in touch, check our website, and open your emails from SPOHNC.

May the New Year bring you good health, happiness and prosperity.

“Together, WE Heal”

Medicare Dental Update!

Find out more on page 7.

Hoda and Jenna Welcome a Guest!

Find out who on page 8.

SPOHNC Salutes You

Read about a survivor volunteer whose motto is “baby steps and small victories.” Turn to page 10.

Nutrition Management in Patients with Head and Neck Cancer

Alyssa Weinfurther, MS, RD, CSO,

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SPOHNC is dedicated to raising awareness and meeting the needs of oral and head and neck cancer patients through its resources and publications.

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Nutrition Management in Patients with Head and Neck Cancer

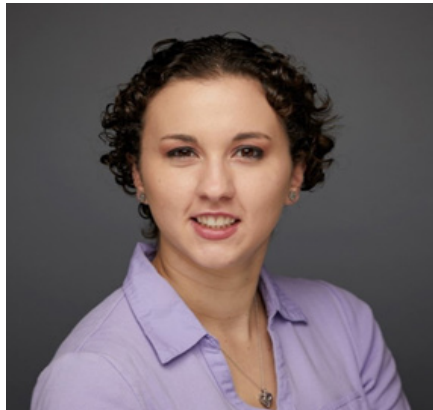
Alyssa Weinfurther, MS, RD, CSO, LDN

It is important for patients to treat food like medicine since it is such an important part of their treatment journey.

Proper nutrition is crucial to patients with head and neck cancer before, during, and after treatment. Getting adequate nutrition can help prevent weight loss, help patients feel stronger, and even result in better outcomes during treatment. It is important for patients to treat food like medicine since it is such an essential part of their treatment journey. However, eating can sometimes be difficult due to loss of appetite in addition to numerous side effects of treatment.

Nutrition should be prioritized for patients at all stages of treatment. If appetite is decreased, patients are encouraged to eat small meals every 2-3 hours. The smaller portion sizes can seem more manageable to achieve at each meal, and at the end of the day, makes it easier to meet nutrition goals. Patients can also supplement their meals with nutrition drinks or high calorie and protein milkshakes if eating becomes too challenging for them.

If a patient is unable to eat enough, a feeding tube can be placed to help provide additional nutrition.



Why is Nutrition Important?

Food is an essential component during cancer treatment. A patient who has cancer tends to need more calories and protein than someone without cancer, as their bodies burn more calories to fight the disease. As a result, they are more likely to have difficulty maintaining weight, especially if there are no changes to the amount of food or calories they are eating.

Food also provides nourishment and can improve strength throughout treatment. The main nutrition goals for patients during cancer treatment include increasing calories and protein, maintaining weight, and food safety. Also, managing treatment side effects is also an important part of nutrition care during the treatment stage.

An interdisciplinary care team can provide more cohesive recommendations for patients, which can result in better outcomes. This team could include oncologists, surgeons, nurses, speech language pathologists, dietitians, physical therapists, occupational therapists, and dentists. Having a team like this involved in cancer care can provide the best outcomes for patients, because some recommendations may overlap between disciplines.

Nutrition Related Side Effects of Treatment

There are many side effects of cancer treatment that can cause difficulty eating, like loss of appetite, nausea,

vomiting, constipation, diarrhea, dry mouth, sores in the mouth or throat, swallowing difficulty, and taste changes.

Any combination of these side effects can make eating less desirable and more challenging. Sometimes patients need to make changes to what they eat to help with these side effects and to be sure that they are getting adequate nutrition.

Management of Side Effects

One of the most important things to do during treatment, especially if there is difficulty eating or decreased appetite, is to focus on increasing intake of higher calorie and protein foods. By eating enough calories and protein, patients can maintain their weight and preserve muscle mass. This can be achieved by choosing foods that are high in calories and protein or supplementing with high calorie/protein shakes. There are many commercial products at the grocery stores and drug stores that can help supplement the diet. Some of the most well-known nutrition supplements are Ensure, Boost, and Premier Protein. While these products have their benefits, they can be costly if needed in larger amounts. Homemade high calorie/protein shakes may be equally beneficial. By combining ice cream, milk, or yogurt with protein powder and fruits/vegetables in a blender, a high calorie nutrition shake can be made at home. If appetite is decreased, eating small meals every 2-3 hours can be more achievable, increase overall caloric intake in a day, and prevent weight loss from occurring.

A side effect most associated with cancer treatment is nausea and/or vomiting. By choosing to eat small meals every 2-3 hours, eating may be easier to accomplish. This frequent intake of food can help prevent nausea from being caused by an empty stomach. Choosing to eat foods that are cold or at room temperature generally do not provide as strong of a smell as hot foods,

which in turn can help reduce nausea caused from the smell of food. If nausea medication is prescribed by the oncologist, taking these medicines shortly before meals can provide relief from nausea and allow for larger intake of foods at each meal.

Also, avoiding foods that are fatty or greasy, and choosing bland foods may prevent nausea from worsening at meals. Remaining upright in a sitting position for at least 30 minutes

Food also provides nourishment and can improve strength throughout treatment.

after meals can help reduce nausea as well. If these lifestyle changes do not provide enough relief, reaching out to the oncologist to provide recommendations for anti-nausea medications would be best.

Constipation may be another side effect of cancer treatment resulting from chemotherapy or not eating an adequate quantity of food. If patients are not eating enough food, they will have less frequent bowel movements. If this is the cause of constipation, eating more often and trying to increase daily food intake can be a good first step to resolving constipation.

Additionally, increasing the amount of fiber found in fruits, vegetables, beans, and whole grains and water in the diet may be helpful. On average, women should intake 25 grams of fiber each day and 38 grams of fiber are recommended for men. In addition, the average fluid intake is between 8-10 cups per day. Fiber and water intake should increase simultaneously and gradually. Also, drinking a hot beverage or eating hot cereal first thing in the morning, can stimulate the digestive system to have a bowel movement. Finally, doing some light activity, like going for a walk, can also help

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increase frequency of bowel movements. If these lifestyle changes do not provide enough relief, reaching out to the oncologist to provide recommendations for laxatives or stool softeners would be best.

Diarrhea is another very common side effect of chemotherapy and can sometimes be a problem even after treatment is complete. Eating small, frequent meals can provide relief by decreasing the amount of food going into the stomach at one time, which can slow down diarrhea. Choosing foods that are low in fiber, low in fat, and avoiding gas forming foods (like broccoli, cabbage, beans, etc.) and carbonation can be easier on the stomach and improve diarrhea. If diarrhea is present, it is important to increase water intake to prevent dehydration. The recommendations for liquids are the same as for constipation (8-10 cups/day) with the addition of 1 cup for every loose bowel movement. Even though low fiber foods are generally recommended, adding in soluble fiber food, like applesauce, bananas, oatmeal, potatoes, and rice, can bulk up the stool and lessen diarrhea. If these lifestyle changes do not provide enough relief, reach out to the oncologist to provide anti-diarrheal medication or soluble fiber supplement recommendations.

Radiation treatment commonly causes dry mouth and may be a significant challenge to efficient eating and swallowing. Dry mouth can make chewing and swallowing difficult because saliva often becomes very thick and difficult to clear. The thickness of the saliva can affect the texture of food in the mouth.

In these instances, choosing softer foods and making sure that the foods are moist can help with swallowing. Adding broth, sauce, or gravy to moisten foods may make them easier to eat. Another tip for easing this side effect is alternating bites of food and sips of liquids, which can help prevent dry mouth from causing difficulty swallowing. Sipping liquids frequently throughout the day can improve dry mouth.

Painful sores or ulcers may occur in the mouth as another challenging side effect of chemotherapy and/or radiation and can interfere with the desire to eat. To help prevent causing more discomfort, choosing foods that are bland and avoiding spicy, acidic, or heavily seasoned foods can make eating a little easier. Softer textured foods can be more comfortable because there is less rubbing on the sores. Foods that are room temperature or colder can be more soothing than foods that are a hot temperature. If the mouth sores are located in the front of the mouth, drinking with a straw may potentially bypass the sore and be more comfortable.

Additionally, sometimes regular consistency foods can be harder to eat if chewing and swallowing is more challenging based on the location of the tumor, in conjunction with side effects from chemotherapy, radiation, or surgery. If this occurs, choosing softer foods (requires little chewing) or more pureed foods (smooth and requires no chewing, like pudding) is generally recommended. These foods tend to be easier to eat and can make eating less challenging or time consuming.

Working with a Speech Language Pathologist (swallowing therapist) can provide recommendations for the most appropriate consistency and swallowing strategies for each patient. Sometimes these changes to the consistency of food are temporary, but sometimes it can be needed long term.

The desire to eat often reduces because of changes to the senses of taste or smell following cancer treatments. These changes are different for every person, so recommendations are individualized depending on the situation. Most commonly, foods tend to have no taste or taste different

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than normal (metallic, salty, bad, etc). There are different strategies, such as using lemon candy prior to a meal, eating with plastic utensils, or using a water, salt, and baking soda mouth rinse prior to meals may help improve some of these changes to taste. If the smell of food is unappetizing, avoiding cooking areas and choosing cold or room temperature foods can be more appealing. In addition, drinking liquids from a cup with a lid and straw can decrease the smell of these beverages and may be more appealing.

Depending on the severity of side effects and if weight loss occurs, a feeding tube may be recommended by the oncologist or dietitian.

Feeding tubes can be inserted into the nose or stomach to help provide all nutrition if the patient cannot eat anything by mouth, or partial nutrition in combination with foods that are consumed by mouth. This is a good option if eating is challenging, because it can take away the stress of eating enough calories and supplementing nutrition through tube feeding. Feeding tubes can also help with hydration, especially if thickened liquids are recommended. There are many formulas that can be administered through a feeding tube.

The dietitian will suggest the optimal formula based on medical history (diabetes, kidney disease, GI distress, etc.). Tube feedings can be run through a pump on a cycle for multiple hours at one time, with several hours off the feedings. For example, the pump can run for 10 hours overnight, which would then allow for it to be turned off for 14 hours during the day. Another method of tube feedings is bolus feedings, which is done through syringe multiple times throughout the day to mimic mealtime feedings (example 2 cartons of formula 3 times/day). If eating is challenging and weight loss continues to occur, it is best to talk to the dietitian and the oncologist to see if a feeding tube is a feasible option to support nutrition.

Recommendations for Eating Over the Holidays

Add extra gravy, sauce, or broth to foods to help make them easier to swallow. Here are some food examples that may make planning for the holidays a lot easier:

Protein: turkey or chicken with gravy, lamb, beef stew, pulled pork, cod, salmon, deviled eggs, souffle, quiche, meatloaf, and gravy

Starch: mashed potatoes with gravy, stuffing with gravy, well cooked pasta with sauce or broth, macaroni and cheese, potato casserole

Vegetables: cooked carrots, sweet potatoes, most canned vegetables, well-cooked green beans

Fruits: applesauce, fruit cocktail, soft cut up fruit, cranberry sauce

Dairy: pasteurized eggnog, hot cocoa, creamed soup

Desserts: cheesecake, ice cream, pie (if the crust is too much, can have just the filling), mousse, pudding

The holidays, a time surrounded by celebratory events that involve eating and drinking, can provide added stress to cancer survivors with altered ability to eat and drink during or following treatment. Planning a holiday menu that considers necessary liquid and food modifications may ease some of this stress by allowing you to eat the same meal as your guests.

Editors Note: Alyssa Weinfurther is a lead dietitian at University of Pittsburgh Medical Center Hillman Cancer Center. She obtained a Bachelor of Science degree in Nutrition from Seton Hill University and a Master of Science degree in Nutrition from Indiana University of Pennsylvania. She is a Board Certified Specialist in Oncology. She is currently serving as secretary of the Pennsylvania Academy of Nutrition and Dietetics and a Trustee for the Pennsylvania Academy of Nutrition and Dietetics Political Action Committee and is also an adjunct professor in the Nutrition department at Seton Hill University.

“I am blessed and thankful
to be a member of this group.
God bless you all.”

~ Beth

Get Cozy with Comfort Food



Nutty Sweet Potato Soup — RECIPE —

INGREDIENTS

6 large sweet potatoes, peeled & thinly sliced
 2 sweet onions, chopped
 4 Tbsp. butter
 4 Tbsp. olive oil
 3 qt. chicken or vegetable flavored Better than Bouillon broth
 2 c. salted cashews

Nutritional Information Per Servings:

Calories 162(kcal), Total Fat 10(g), Saturated Fat 3(g),
 Cholesterol 5(mg), Sodium 285(mg), Carbohydrate 13(g),
 Dietary Fiber 2(g), Protein 8(g).

Melt butter & oil in a 12 quart pot. Add chopped onions & sauté until soft. Stir in sweet potatoes, thoroughly mixing them in with the onions.

Add broth & cashews. Bring to a boil & reduce to simmer. Cook until sweet potatoes and cashews are soft, about 45 minutes. Allow to cool. Puree smooth.

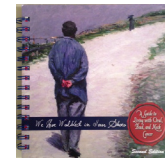
Yields 24 (8 ounce) servings.

SPOHNC's RESOURCES

We Have Walked In Your Shoes: A Guide to Living With Oral, Head and Neck Cancer
 - by Nancy E. Leupold & James J. Sciubba, DMD, PhD

DIGITAL EDITION available now on our website for \$7.99

PRINT EDITION \$14.95 includes shipping and handling



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Eat Well Stay Nourished
 A Recipe and Resource Guide for Coping With Eating Challenges
 compiled by Nancy E. Leupold, Founder

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Medicare Dental Update

On November 1, 2022, the Centers for Medicare & Medicaid Services (CMS) finalized a rule (CMS-1770-F) that expands Medicare coverage for “medically necessary” dental services. The rule sets forth a coverage standard that allows Medicare payment for certain dental services that are “inextricably linked to, and substantially related and integral to the clinical success of, a certain covered medical service.”

Under the new rule, Medicare will in 2023 begin to cover a dental or oral examination performed as part of a comprehensive workup prior to a Medicare-covered organ transplant (including stem-cell and bone marrow transplant), cardiac valve replacement, or valvuloplasty procedure, as well as medically necessary diagnostic and treatment services to eliminate oral and dental infections prior to, or at the same time as, these procedures.

Beginning in 2024, Medicare will pay for certain necessary dental services, performed as part of a comprehensive workup prior to and during the treatment for head and neck cancers. Over the next year, CMS will further define and develop guidance concerning this particular coverage.

Aside from these and a few other clinical examples recognized by the agency, regional Medicare Administrative Contractors can determine, by applying the coverage standard on a claim-by-claim basis, if payment can be made for dental services in other clinical scenarios.

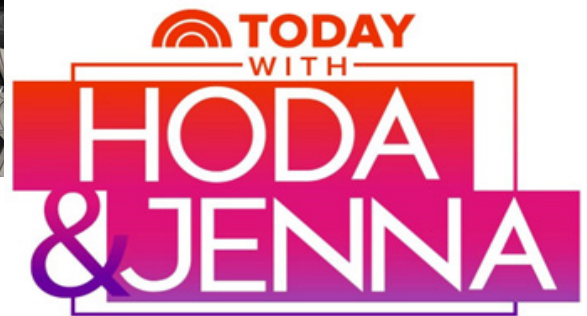
Other important information

It is important for Medicare beneficiaries to understand that coverage under this rule would depend upon their medical and dental providers coordinating services and exchanging information. Each provider must also be enrolled in Medicare and meet all other requirements for billing. Medicare payment may also be made for ancillary services and supplies needed for the covered dental services-- such as anesthesia, diagnostic x-rays, and use of operating rooms.

A Star is Born!

Mason Folchetti-Puglin has made the big time!!! ...and his grandmother would be so proud!

Mason is the son of Deana Folchetti-Puglin and Julianne Puglin-Folchetti, and the grandson of Maria and Tom Folchetti. The Folchetti's are a very special part of our SPOHNC family. You read about them in a recent issue of "News from SPOHNC" when they attended the LI Ducks game with the Syosset, NY SPOHNC Chapter support group. Those Folchetti's do get around!!



Mason recently had the exciting opportunity to appear in the segment about Hot Holiday Toys as a special guest on TODAY with Hoda & Jenna!

We remember Mason as a baby...so to see him now is really special for us too!! Looking dapper in his sweater, handsome with his hair all gelled up, Mason and a group of other kids ranging in age from 4 to 10 were on the show, playing some fun games, and having a great time. The segment was live!!



Apparently, Hoda has a special place in her heart for Mason, and he will be invited back again!!

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to find out how.

Head and Neck Cancer News

Less Invasive Treatment for Head and Neck Cancers

November 29, 2022 - Original story from the University of Colorado

A new study from researchers at the University of Colorado Anschutz Medical Campus has identified a less invasive way to treat a subset of head and neck cancers that could potentially change the standard of care for patients.

HPV-unrelated head and neck squamous cell carcinomas (HNSCC) typically do not trigger immune responses and have not responded well to immunotherapies. The current standard of care for these tumors begins with surgery that can require tongue or jaw removal and other facial and oral complications, followed by six weeks of radiation with or without chemotherapy

In a new study, just published in *Nature Cancer*, Anschutz researchers detail a different approach to treat these tumors that uses radiation combined with immunotherapy to invigorate the patient's immune response and reduce immune exhaustion.

This approach, combined with just one cycle of the drug Durvalumab within a specific pre-operation timeframe primes the immune system to kill most or all of the cancer before surgery. The level of success observed in this preoperative marriage of treatments is remarkable.

Of the 21 HNSCC patients participating in the Phase I/Ib dose-escalation study, major pathological responses or complete responses was 75%, and 89% for those in the expansion cohort who received the optimal radiation dose. And for those on the expansion cohort with MPR/CR, none of them received adjuvant radiotherapy or chemotherapy despite large tumors

at presentation and none have recurred to date. Time to surgery was also a critical element in allowing response to be observed and for immune system priming to happen.

“The response in our patients to this dual-treatment protocol surpassed our expectations,” says Sana Karam, MD, PhD, corresponding author, and member of the CU Cancer Center. “By combining treatment modalities, we were able to spare our patients’ lymph nodes and prime their immune systems, ultimately resulting in a less morbid treatment regimen.”

In conducting the translational analysis, Anschutz MD/PhD student Laurel Darragh observed a major increase in T-cell infiltration in the tumor and several biomarkers in the blood. The blood correlates could be detected preoperatively such that it was clear pre-surgery who was going to respond to the treatment. All patients went on to receive 4 additional cycles of postoperative Durvalumab, but those who failed the treatment did so despite the adjuvant treatment.

“Our biggest takeaway from these results is hope for our patients,” says Karam. “The response rates here are truly unparalleled, so we are hopeful that this work will lead to a significantly improved standard of care in how we treat these types of cancers.”

Researchers hope to move forward with these results to validate potential biomarkers in a larger, ongoing Phase II trial.



Winter Champion of Hope

Jim Vazzana

Our Winter Champion of Hope believes in “baby steps and small victories!”

Jim was first introduced to SPOHNC in 2011, when he placed an order for our book called *We Have Walked in Your Shoes*. He had been diagnosed with stage 4 base of tongue cancer in 2009. His treatment, which he wrote about in the May 2013 issue of *News from SPOHNC*, was grueling, but successful, and he decided he wanted to give back to SPOHNC. He became a volunteer for our National Survivor Volunteer Network in 2013.

As an ex-Marine, Jim has informally been dubbed our resident expert in military and law enforcement patients and survivors. He has built an informal network of all of those that we have matched with him, and he keeps in touch with them, and they keep in touch with each other. It's a special kind of connection...a

“brotherhood”. Jim has happily served as the support system for more than 20 newly diagnosed patients and survivors since joining the match program. SPOHNC is grateful!

Jim and his wife were living on Long Island when he was diagnosed and treated for his head and neck cancer. He had a long career in landscape architecture, and most deservedly, he and his wife decided to relocate to Florida for his retirement in 2019 and they have been enjoying retirement and loving life on the Treasure Coast ever since. As if being a SPOHNC volunteer wasn't enough, in his retirement, Jim also decided to volunteer at the Sculley Walsh Cancer Center for quite some time. It must be true what they say about retirement being busier than working

life. Jim also loves riding his motorcycle (a custom rebuilt Harley that he reworked himself!), and when he's not doing any of those things, he is boating, fishing, and spending time at the beach. He says “Life is good and I am so grateful for it all.” That's just Jim...and he is amazing.

Despite some recent health challenges, Jim is still actively volunteering and recently looped SPOHNC in on an email exchange with a fellow veteran that he is helping. Sadly, so many veterans who were stationed at Camp LeJeune have been diagnosed with cancer that has been linked with the water at the base, and Jim has been advocating on their behalf to obtain financial assistance and to make this horrible injustice more well known outside the military. He remains dedicated to the time he served, and those he served alongside as well.

In the last paragraph of Jim's sharing story in *News from SPOHNC*, he says, of his cancer journey...”**2011**: My journey, at least the most difficult part, is over. It has made me a different person...life will never be the same. I have been given a second chance at life and it will be lived with more love, compassion and understanding of all the blessings I have...and always did have, but was never so keenly aware of...until now.”

Jim is always at the ready to help, and he consistently expresses his gratitude to SPOHNC for the opportunity to serve.

“I think I might have been an inspiration and for that I am feeling grateful that I might have been a catalyst and that I did something to ‘pay it forward’ for all the love and support that was given to me. Thank you for allowing me the opportunity to do some good.”

~ Jim Vazzana

Also Jim's words...“Baby steps and small victories” which he has used time and time again, in his sharing story, his emails to SPOHNC and likely to those he has connected with by phone, ring so true, and they are the best words of advice for those who are dealing with the diagnosis and treatment of oral, head and neck cancer.

Jim, we thank YOU, for all that you have done, and continue to do, to support and inspire those who come to SPOHNC, and to you, seeking advice, friendship and a listening ear. It is truly SPOHNC's honor, to honor you, as our Winter Champion of Hope. Thank you for your service, to our country, and to those you help through every connection.



CHAPTERS OF SPOHNC

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PLEASE NOTE: Some Chapters are not holding meetings in person at this time due to COVID-19.

Many groups have found other creative ways to support one another during this time of need.

Call to SPOHNC to find out more.



Featured above is SPOHNC's Minneapolis, MN Chapter Support group.

Send us your SPOHNC support group photo (with permissions) to be featured here in a future issue!

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