

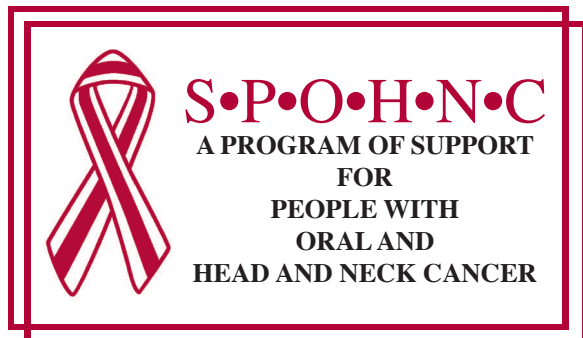
NEWS FROM S·P·O·H·N·C



VOL. 28 NO. 5

SUPPORT FOR PEOPLE WITH ORAL AND HEAD AND NECK CANCER, INC.

FEBRUARY 2019



Head and Neck Cancer Pain: Opioid Use and Alternatives

Introduction

Anyone who currently has or who has survived head and neck squamous cell cancer (HNSCC) can tell you that the cancer



itself and the treatment involved can cause significant pain. The location of the tumors as well as the therapies to treat them, including large surgeries, radiation, and chemotherapy, all contribute to this pain. As we are finding more effective treatments for this disease resulting in higher cure rates, it is important to keep in mind

short- and long-term side effects and quality of life issues. This article will describe the pain caused by HNSCC treatment, opioid use during this process and why it sometimes can be of concern, and alternative methods to manage pain.

HNSCC pain

HNSCC typically involves sites including the oral cavity (gums, palate, tongue), oropharynx (base of tongue, tonsils), hypopharynx (throat between pharynx and larynx), larynx (vocal cords and surrounding areas) and nasopharynx (are behind the nose). These areas have many nerves, blood vessels, and soft tissue that we need for important functions such as facial movements, swallowing, chewing and talking. Unfortunately, when tumors grow in these sites, they disrupt the nerves and blood vessels which can result in significant pain. Surgical procedures to remove these tumors can exacerbate the pain by direct damage to tissue causing irritation, swelling, inflammation, infection and nerve injury. Radiation, typically given over a multi-week period, also causes pain from

inflammation of the mucosa (mucositis) and skin (dermatitis), nerve injury, and fibrosis (scarring). Chemotherapy given with radiation enhances the radiation effect and worsens these side effects. On their own, chemotherapies often used in HNSCC such as cisplatin, docetaxel, and paclitaxel can also cause neuropathy (nerve injury) and muscle aches. The vast majority of patients report pain during HNSCC treatment and a third of patients report persistent pain or other issues effecting quality of life six months out from treatment. Post-treatment pain can be aggravated by cancer recurrence, infections, ongoing tobacco use, dry mouth, acidic or spicy foods and dry air.

Opioid pain medication use during HNSCC treatment

Our group used a national database (SEER-Medicare) of patients to look at opioid use during and after curative-intent HNSCC treatment. Prescribed opioid medications include codeine, fentanyl, hydrocodone, hydromorphone, meperidine hydrochloride, morphine, nalbuphine, oxycodone and tramadol. We found that 83% of patients required at least one opioid prescription during HNSCC treatment. 15% of patients were still requiring continuous opioid prescriptions at 3 months and 7% at 6 months despite being cancer free. While this may not seem like an extremely high number, this is double the national rate of chronic opioid use which is closer to 3-4% of the American population. Our study likely underestimates the true rate of opioid use during and after HNSCC treatment as we were only able to include patients over the age of 65 due to the nature of our database. Younger age is a significant risk factor for persistent opioid use and including younger populations would likely have higher rates. Smaller studies on HNSCC patients have shown rates as high as 30-40% of patients still requiring opioid prescriptions at 6 months after treatment completion. Beyond young age, other risk factors of chronic opioid use include tobacco use, alcohol and other drug use, underlying psychiatric conditions, type of opioid used and length of time on medications.

Why do we care about opioid use for our HNSCC patients?

While nobody wants our HNSCC patients to be in undue pain, and opioids certainly have their place as part of our treatment, they also have concerning short- and long-term effects that should be taken into consideration. In the short-term, opioid medications can cause symptoms such as constipation, nausea, vomiting, headaches, rashes, insomnia, fatigue and lack of appetite. Older patients can have slowed and less effective breathing. Overall quality of life is also reported to be lower compared to similar patients not taking opioids.

Along with a continuation of the short-term side effects, chronic opioid use can result in depression, sleep-disordered breathing, cardiovascular issues, sexual dysfunction and other

OPIOID USE continued on page 2

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endocrine issues, and increased sensitivity to pain. Some studies even show decreased survival rates for cancer patients on opioids and increased growth of cancer cells in the presence of opioids in the laboratory. Of course, there are also the additional concerns for addiction and overdose. 2.5 million Americans have an opioid use disorder and on average 130 people die in the United States daily from opioid-related issues. 40% of these opioid overdose deaths involve prescription opioids. It is important to distinguish between opioid dependence and addiction (or opioid use disorder). A physical dependence can occur when people have been on an extended course of opioids and the body requires external opioids to prevent withdrawal. This can typically be managed with a slow taper off of the medication. Opioid use disorder, on the other hand, can present as uncontrollable cravings for the drug or inability to control drug use despite possible harm to oneself or others. This is more difficult to treat and often requires the combination of medication use (such as methadone and buprenorphine), therapy, and close follow-up with a pain and addiction specialist. Risk factors for developing an opioid use disorder include high doses of opioids, use > 90 days, age <65 years old, current pain, insomnia, anxiety/depression and illicit drug use.

Beyond the short- and long-term side effects of opioids, multiple studies have shown that they may not be very effective at managing chronic pain. While they can allow for better pain control in the acute setting, there is not good evidence that they provide long term pain control benefits compared to non-opioids and non-pharmacological methods of pain management.

If it is determined that opioids are needed for pain control as part of a treatment strategy, then a careful plan should be put in place to manage short- and long-term side effects. If feasible, an eventual plan for weaning off of these medications should also be addressed when the worst effects of treatment are waning. If the HNSCC is persistent or recurs, then use of opioids may be unavoidable and weaning not possible.

What other strategies can we use to manage HNSCC pain?

There are multiple other medications and therapies that can be used as an alternative or in addition to opioids to manage and prevent pain due to HNSCC and its treatment.

Acetaminophen and Non-Steroidal Anti-Inflammatory Drugs (NSAIDS)

Acetaminophen (Tylenol) and NSAIDS (including Aspirin, Ibuprofen, Naproxen, Celocoxib, etc.) are often useful in mild to moderate pain, particularly with an inflammatory or musculoskeletal component. These medications can often be used before treatment pain becomes severe or as a bridge off of opioid medications. Several studies have also found that use of NSAIDS or acetaminophen alongside opioid medications may increase pain control and allow for lower opioid doses. NSAID use should be monitored for gastrointestinal side effects (nausea, cramps, ulcers, etc.) and kidney function, particularly if taking around the clock. Acetaminophen use should be kept to less than 3,000-4,000 grams per day and monitored for liver injury.

OPIOID USE continued on page 3

OPIOID USE continued from page 2*Gabapentin/Pregabalin*

Gabapentin (Neurontin) and Pregabalin (Lyrica) are medications categorized as anticonvulsants as they were initially developed to stop seizures. They are typically used in the pain field to address nerve-related pain and have been largely studied in patients with diabetic neuropathy, though both have been looked at in HNSCC. Gabapentin is usually started at a low, nighttime dose and is titrated up to be taken as much as 3 times a day if tolerated. It has been shown to decrease pain and mucositis after radiation and improve swallowing outcomes.

Some people do have difficulty tolerating gabapentin due to side effects of dizziness, drowsiness and fatigue. Pregabalin is more expensive and typically reserved by most insurances for second-line treatment for people that do not tolerate gabapentin or in whom it does not work. When studied in HNSCC patients receiving radiation, it was found to significantly decrease pain severity and improve mood and quality of life. Pregabalin is generally tolerated better than gabapentin, but can also cause the side effects of dizziness, drowsiness and fatigue.

Antidepressants

Several drugs developed as anti-depressant medications have also been found to have some effect in cancer pain management. The two major groups are tricyclic antidepressants (TCAs, such as amitriptyline and nortriptyline) and serotonin and norepinephrine reuptake inhibitors (SNRIs, such as duloxetine and venlafaxine). Neither type has specifically been studied in HNSCC, but both have been shown to significantly reduce nerve pain as well as improve anxiety, depression and insomnia in other types of cancers. TCAs can have significant side effects such as drowsiness, dizziness, dry mouth, and constipation that can occasionally limit their use. The SNRIs tend to be better tolerated though can still cause nausea, drowsiness, and dry mouth.

Corticosteroids

Corticosteroids, including dexamethasone and prednisone, can sometimes be given in short courses, or bursts, to help decrease inflammation contributing to pain. They can relieve the mucositis and swelling in the

mouth, neck and throat and often can help with appetite and energy levels.

Typically, patients should not be left on steroids for more than a few days to several weeks as long-term use can result in many issues including high sugar (glucose) levels, infection risk, poor healing, swelling, gastrointestinal issues, etc.

Rehabilitation

Physical therapy (PT), occupational therapy (OT), and speech therapy (ST) all have multiple positive effects on functional outcomes and quality of life during and after HNSCC treatment. HNSCC patients that participate in these therapies have improved swallowing outcomes, better nutrition, higher physical function and muscle endurance, and less fatigue. By increasing function and decreasing swelling and scar tissue, these therapies have repeatedly shown to prevent and decrease pain. If possible, meeting with these therapists early in the treatment course before symptoms develop can prevent or decrease some of these side effects and certainly should be incorporated as part of a post-treatment HNSCC survivor plan.

Exercise

Physical activity, whether done as an individual or under guidance, is increasingly thought to be an important part of cancer treatment and survivorship. Activities such as walking, yoga, swimming, low-impact cardio, and non-heavy weight lifting have all shown similar benefits to rehabilitation as well as improvements in mood and tolerance to treatment. Consistent exercise participants regularly report lower levels of pain.

These patients also have lower rates of cancer recurrence and cancer deaths. It is important to discuss type and rigor of planned exercise with your doctor, but most low impact activities should be well tolerated during and after HNSCC treatment.

Alternative/Complementary Medicine

There are many other alternative and complementary medicines and techniques that may impact cancer and treatment related pain. Massage and acupuncture in particular have been studied in cancer patients and may provide significant pain relief to some. Many other devices and medications such as herbal remedies, antioxidants, and cannabinoids can be purchased for possible pain relief.

Most of these are not well studied or regulated yet, though scientists and doctors are increasingly looking at these for possible non-opioid options. Your doctor should be aware if you are using any of these remedies to ensure they will not interact with your current medications and treatments.

Conclusion

Most patients with HNSCC report pain at some point due to the location of their cancers and the rigorous treatments they are put through. Opioid medications have been widely used to manage this pain, but we are becoming increasingly aware of the short- and long-term side effects as well as the risk of disordered chronic use. It is very reasonable to continue to use opioids for HNSCC, particularly for severe pain, but patients and their doctors should be aware of the risks and have a long-term pain management plan in place. Using non-opioid medications and therapies alongside opioids may reduce the opioid doses needed and may target the pain in different ways (such as addressing nerve pain). These other medications and methods can also be used to help taper off of opioids as tolerated when the treatment-related side effects start to decrease.

Managing pain control is best done as a multi-disciplinary team with patients heavily involved to avoid suffering while also being mindful of all the modalities to address it.

Editor's Note: Jessica McDermott, MD received her MD at Medical College of Georgia followed by residency at Emory University and fellowship in hematology/oncology at the University of Colorado. She is currently an assistant professor of medicine at the University of Colorado and also works at the Denver VAMC. Her clinical and research focus is on head and neck cancers - participating in and developing clinical trials and researching ways to improve quality of life and long term outcomes in these patients.

“SPOHNC is a great patient advocate group and team working effortlessly to meet the needs and raise awareness.”

~ Julie A.

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HEAD AND NECK CANCER NEWS

Cetuximab with radiation found to be inferior to standard treatment in HPV-positive oropharyngeal cancer

August 14, 2018 - An interim analysis of data from a randomized clinical trial of patients with human papillomavirus (HPV)-positive oropharyngeal cancer found that treatment with radiation therapy and cetuximab is associated with worse overall and progression-free survival compared to the current standard treatment with radiation and cisplatin. The trial was designed to see if cetuximab with radiation would be less toxic than cisplatin with radiation without compromising survival for patients with the disease.

The phase 3 trial, which closed enrollment in 2015, was funded by the National Cancer Institute (NCI), part of the National Institutes of Health, and led by NRG Oncology, part of NCI's National Clinical Trials Network. The data monitoring committee overseeing the trial recommended releasing the data after an interim data analysis showed that cetuximab with radiation was associated with inferior overall and progression-free survival, compared to cisplatin and radiation. The U.S. Food and Drug Administration has previously approved cetuximab with radiation for patients with head and neck cancer, including oropharyngeal cancer. Cetuximab with radiation is an accepted standard of care, especially for patients who cannot tolerate cisplatin.

"The goal of this trial was to find an alternative to cisplatin that would be as effective at controlling the cancer, but with fewer side effects," said Andy Trotti, M.D., of the Moffitt Cancer Center in Tampa, Florida, a lead investigator of the trial. "We were surprised by the loss of tumor control with cetuximab."

There has been a lot of recent interest in the cancer clinical research community in evaluating the "de-escalation" of therapies for cancers that have a good prognosis, such as HPV-positive cancer of the oropharynx (the part of the throat at the back of the mouth, including the soft palate, the base of the tongue, and the tonsils). The goal is to improve patients' quality of life and reduce long-term toxic effects without compromising treatment efficacy. HPV-positive oropharyngeal cancer is frequently

diagnosed in individuals in their 50s and 60s, and is associated with high survival rates, providing the incentive for this trial. Moreover, the incidence of this type of cancer has increased rapidly in recent years in the United States.

"Clinical trials designed to test less toxic treatment strategies for patients without compromising clinical benefit are a very important area of interest for NCI and the cancer research community," said Shakun Malik, M.D., of NCI's Division of Cancer Treatment and Diagnosis.

This trial's primary objective was to determine whether the substitution of cetuximab for cisplatin with radiation would result in comparable overall survival while reducing toxic side effects with improved long-term quality of life. The trial enrolled 849 patients with HPV-positive oropharyngeal cancer who were randomly assigned to receive either cetuximab or cisplatin with radiation. The study had three planned interim analyses.

The third and final interim analysis, done after a median follow-up of 4.5 years, found that overall survival on the cetuximab arm was significantly inferior to the cisplatin arm. Overall rates of serious (grade 3-5) adverse events were similar for patients in both groups. However, as the researchers expected, toxic side effects were different, with adverse events of renal toxicity, hearing loss, and bone marrow suppression more common in patients in the cisplatin arm, while body rash was more common in the cetuximab arm. All patients in this trial had completed therapy at the time of this analysis.

"This trial is the first randomized clinical trial specifically designed for patients with HPV-positive oropharyngeal cancer, and it establishes cisplatin with radiation as the standard of care," said Maura Gillison, M.D., Ph.D., of the University of Texas MD Anderson Cancer Center in Houston, the other lead investigator of the trial.

Full study details were presented in the plenary session at the American Society for Radiation Oncology (ASTRO) Annual Meeting (link is external) in San Antonio, Texas. Findings from the trial will later be

published in a peer-reviewed journal.

For more information on the trial: <https://clinicaltrials.gov/ct2/show/NCT01302834>

About the National Cancer Institute (NCI): NCI leads the National Cancer Program and NIH's efforts to dramatically reduce the prevalence of cancer and improve the lives of cancer patients and their families, through research into prevention and cancer biology, the development of new interventions, and the training and mentoring of new researchers. For more information about cancer, please visit the NCI website at cancer.gov or call NCI's Contact Center (formerly known as the Cancer Information Service) at 1-800-4-CANCER (1-800-422-6237).

About the National Institutes of Health (NIH): NIH, the nation's medical research agency, includes 27 Institutes and Centers and is a component of the U.S. Department of Health and Human Services. NIH is the primary federal agency conducting and supporting basic, clinical, and translational medical research, and is investigating the causes, treatments, and cures for both common and rare diseases. For more information about NIH and its programs, visit www.nih.gov.

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IN MEMORIAM

David Kabat

SPOHNC was deeply saddened to learn of the recent passing of a dear member of our SPOHNC family...David Lee Kabat, on Dec. 29, 2018.

Longtime member of SPOHNC, David had been a valued and very supportive volunteer for SPOHNC since 2003, when he joined our National Survivor Volunteer Network as a match volunteer. David wanted to make a difference in the lives of those touched by head and neck cancer, and he surely did that. During his time as a volunteer, David helped and gave hope to many newly diagnosed patients as they travelled their own cancer journey. He offered support and a caring heart to those who were seeking inspiration and looking ahead.

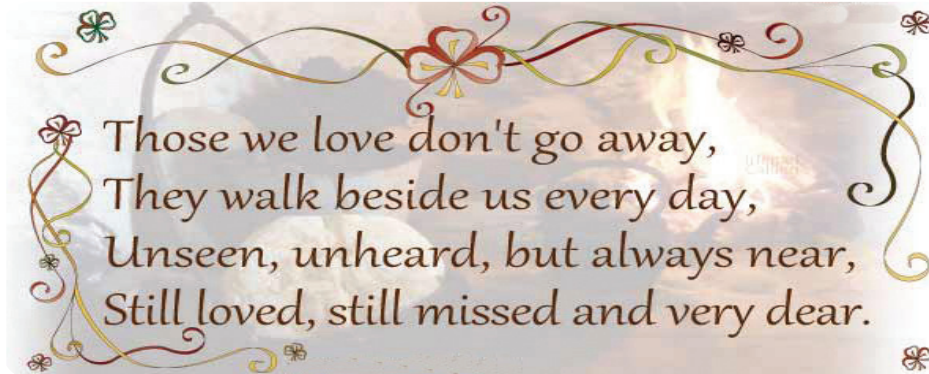


made many lifelong friends. He also served in the Army Reserves for six years during the Vietnam era.

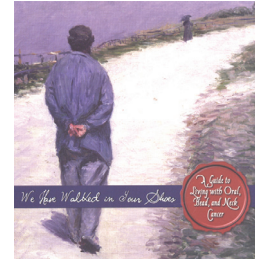
Specializing in construction law, commercial real estate law, and banking law, he also had specialized skills in contract negotiation and litigation.

David was dedicated to all that he was involved with. His family and his work, were his greatest loves and his priorities in his life. His loving wife, children and grandchildren were the center of his Universe and that was apparent to all who knew him. He was a much-loved figure in his community and highly respected in his field of work. Tributes received by SPOHNC from family and friends are a testament to just how special he was, to so many people.

SPOHNC will miss David's caring and compassionate heart, and we will keep David and his family in our thoughts and prayers.



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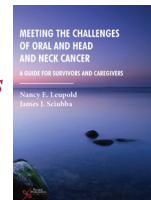
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SPOHNC IS CELEBRATING YOU!

SPOHNC has many birthday wishes to share this month. Some are belated, since we don't publish a January issue, but that doesn't mean they're not sincere. We wish all of you the very best for this coming year!

One very special lady celebrated her New Year's Eve birthday in California this year – our own Executive Director, Mary Ann Caputo! Mary Ann travelled to San Diego for a very special birthday gift – the gender reveal party for her son, Larry and his lovely wife Megan, who are expecting a baby this Spring! Congratulations to the happy couple, who will be welcoming a baby boy in June! This little bundle of joy joins Mary Ann's East Coast grandsons, Frankie and Ayden. Congratulations to the entire Caputo Family on this upcoming joyous occasion – and what a great birthday gift for Mary Ann. Happy Birthday!!!!



SPOHNC also sends belated birthday wishes to our Treasurer, Walter Boehmler, who celebrated a birthday on January 8th. Walter has been a volunteer on SPOHNC's Board of Directors since the founding of the organization, almost 30 years ago. He is our money watcher, and keeps us in line when it comes to budgets and spending. Kind, dedicated and a wonderful man, he has always been a good friend of SPOHNC and we are honored to count him among our SPOHNC family.

We hope that Walter took a break from his duties as Treasurer, to celebrate his special day. SPOHNC wishes you all good things for the coming year!

Dorothy Gold has been a valued member of our Board of Directors for many years. She also facilitates our SPOHNC Chapter in Maryland at the Milton J. Dance, Jr. Head and Neck Center.



All this while also holding a position there as an Oncology Social Worker...Dorothy is one very busy lady! Dorothy celebrated her birthday on February 1st! Dorothy – we truly hope you took a break from your busy work and volunteer day, to do something fun, and something nice for yourself. Someone who gives so much should have some time to enjoy a very special day. Thank you for all you do for the patients and families that you help each and every day, and for SPOHNC!

Survivor and SPOHNC member, Debbie Amorese will be celebrating her birthday on February 26th. Debbie wrote to SPOHNC to tell us about her birthday, so we could shout it from the rooftops. Debbie said in her note "My mantra after surviving squamous cell carcinoma of the tongue is to "Celebrate the Good Stuff!" Well, Debbie, we hope that you will be celebrating lots of good stuff on your special day! Happy, happy birthday to you!

CHAPTER NEWS

From Palm Coast, FL

Here's how SPOHNC Palm Coast, FL celebrated the holidays this year. From the desk of Chapter Co-Facilitator, Amy Beilman.

Our holiday meeting this month was "heartwarming" There were 22 of us dressed in festive colors. We each brought presents, and the gift table looked bountiful and pretty. The holiday treats to share were overflowing.

Everyone was just so grateful to be there. With all the problems and issues we have all experienced in our journeys, the business of survival is what really counts. We are all survivors.

This year we went around the room and shared a story of the most memorable gift you can remember receivingIt could be anything at any point in your life that stands out. By listening to everyone's stories it gave us all an extra peek at who we are, how we grew up, and how we got to be where we are today.

One person mentioned how poor they were growing up and that there was

no money for gifts....and when a fruit basket arrived, it had to be shared with 14 children. Wow! The fruit was cut carefully.

One person wanted a puppy more than anything in the world, and she got a leash and a collar (without a live dog). She walked that leash and collar around the market place and people petted her "dog".

One person said they were spoiled and got anything they wanted for Christmas. One person got a super-duper red Corvette which she still has.

One person got a Bulova watch from her husband, with two little hearts.....in order to help her tell time to nurse her first-born child.

One person got a cook book from his Mom with all her favorite recipes which he cherishes and still uses to this day.

One person got the doll house she always wanted, but then she was told she had to share it with her sister.

One Christmas Lewis as a child found hoof prints on the roof of his snowy house. No one ever lived up to it.

And on and on the stories went.

We also presented Gloria with the first annual NURSE RATCHIT AWARD for duties above and beyond this past year for Art. Congratulations Gloria!

We ended our meeting with a "Chinese" grab bag, and because this group is soooo kind there was very little "stealing" of the sought-after gifts. Angela was last and could pick anything she wanted. In the end, she grabbed the assorted box of gourmet cocoas.

We are so very grateful to be a part of this group. Seeing everybody for an hour and a half a month validates what we've all been through and yet, that life is good.

We haven't had very many new throat cancer patients this year, but maybe that's the good news.

Thank you all for supporting each other.

Be Well. Happy Healthy New Year. See you in 2019.

Much Love,
Amy and Lewis

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Eat Well Stay Nourished A Recipe and Resource Guide for Coping With Eating Challenges

compiled by Nancy E. Leupold, Survivor, Founder and President Emeritus

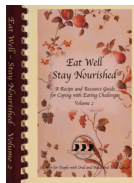


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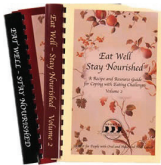
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Flirty February Recipes from “Eat Well Stay Nourished A Recipe and Resource Guide For Coping With Eating Challenges”

Compiled and Edited by Nancy E. Leupold, Survivor, Founder & President Emeritus

Hot Crab and Avocado Casserole (from Volume Two)

- 1/3 c. chopped onion
- 1/3 c. chopped red bell pepper
- 1 tsp. dried thyme leaves
- 2 Tbsp. butter
- 2 c. milk
- 3 Tbsp. flour
- 3 (5.5 oz) cans crabmeat, drained and flaked
- 2 small avocados, peeled pitted and chopped
- 2 Tbsp. lemon juice
- Salt and cayenne pepper (optional) to taste



Saute onion, bell pepper and thyme in butter in medium saucepan until tender – about 5 minutes. Stir in flour and cook one minute. Add milk gradually. Heat to boiling over medium heat, stirring constantly. Stir in crabmeat, avocados and lemon juice. Season to taste with salt and (optional) cayenne pepper. Spoon into lightly greased 1 quart casserole. Sprinkle with cheese. Broil for 2 minutes or until golden. Serves 6. 259 calories per serving.

~ Meg M., NY

Favorite Cheesecake (from Volume One)

- 4 – 8 oz. pkg. cream cheese
- 6 eggs
- 2 c. sugar
- 2 c. sour cream
- 2 Tbsp. cornstarch
- ½ stick melted butter
- 1 tsp. vanilla
- 1 tsp lemon juice



In a large bowl, beat cream cheese until creamy. At medium speed, add sugar gradually. Add eggs one at a time, beating in between. Add sour cream and beat. When well blended, add the remaining ingredients. Pour into a 10” springform pan. Place pan in larger pan filled ½ full with water. Bake 30 minutes at 400 degrees. Lower oven to 325 for 30 minutes more. Cool thoroughly before removing from pan. Chill 6 hours or overnight. Yields 12 servings. 548 calories/serving.

~ Nancy L., NY

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TIME FOR SHARING... My Journey

In the summer of 1999, at age 43, I developed an annoying snuffle and sensation that my nose was constantly running that would not go away. Additionally, if I became cold, my nose would close up and I had to breathe through my mouth. My boyfriend, now husband, insisted that I see a doctor



and thereby saved my life. I underwent CT scan that showed a possible sinus polyp, was placed on a steroid taper, and discontinued a decongestant nasal spray which by now I had in my office and

both floors of my house. I was told if the polyp came back once I was off steroids, I should have it removed. So when the polyp came back, I had it removed. To my surprise, pathology confirmed a “sinonasal undifferentiated carcinoma” or SNUC. As I sometimes say, cancer SNUC up on me.

Perhaps because I am a medical oncologist, and also because I have compassionate friends, I was able to get an appointment with one of my radiation colleagues the afternoon I found out I had cancer. That doctor told me he had only seen one SNUC in his career, about 12 years prior, and referred me for a second opinion out of town. I learned from that second opinion that my margins were not clean, meaning some cancer may have remained in the sinus. Fortunately, that doctor said, I lived near two universities with excellent head and neck cancer centers, otherwise he would have treated me himself. So I returned home and underwent a second endoscopic en bloc excision of the cancer bed obtaining clean margins, followed by external beam radiation therapy. I completed radiation and my sense of taste returned just in time for the wedding of the century, my own in May 2000!

I underwent routine follow up for the next few years until one day I started feeling

as though my breathing was obstructed again. I could feel my breath passing over something in the left nasal passage, too far back for me to see. I saw my ENT physician who biopsied the obstructing mass in his office. When he saw it, he started cursing. Pathology again confirmed a SNUC and a few days later I underwent random biopsies of the base of the skull in the operating room to determine the extent of disease. When they all came back positive and a PET scan confirmed cancer in my left upper jaw, it was recommended I undergo craniofacial resection (CFR) and removal of the left upper jaw or maxilla and palate. Following this surgery, I underwent proton beam radiation away from home, then returned for 4 cycles of chemotherapy with taxotere, ifosfamide, and carboplatin with an AUC of 7 (!) Chemotherapy more than any other treatment kicked my you know what and I elected to receive only 3 cycles of the planned 4.

Much of my treatment was away from home and during that time I practiced integrative/holistic medicine on myself without even knowing it's name. Integrative medicine is the combination of conventional or allopathic medicine, that is, the surgery, radiation, and chemotherapy I was receiving, and evidence based complementary therapies. Importantly, integrative medicine uses BOTH conventional and complementary care to achieve the best care. It is NOT alternative medicine. The National Center for Complementary and Integrative Health, a branch of the National Institutes of Health, divides complementary therapies into five areas: mind-body medicine, whole medical systems, biologically based therapies, manipulative and body based therapies, and energy therapies. Mind body therapies I practiced to help me stay calm and fearless included forming an online support group of friends and family with whom I corresponded, finding a church home away from home (spirituality and prayer), and renting an electric piano on which I played hymns and Broadway show tunes. My husband could not be with me during proton treatments out of town and family members

would come spend at least a weekend with me. Biologically based therapy refers to nutrition and dietary supplements. Radiation to the head and neck area caused me to have a dry mouth and lose my sense of taste. I sought ways to increase fat, protein, and calories, but not too successfully as I still lost 17 pounds. Manipulative and body based therapies include exercise and acupuncture among other modalities. I was actually too worn out to perform any exercise besides a 10 minute walk to radiation and back to my apartment each weekday. I have since learned the benefits acupuncture can provide to cancer patients in terms of improving energy, enhancing a sense of well being, alleviating nausea, neuropathy, pain, and other side effects of treatment. Ayurveda and Traditional Chinese Medicine are examples of whole medical systems. Reiki and healing touch are examples of energy medicine. I did not use any of those modalities. My experiences the second time I had cancer ultimately led me to do a fellowship in Integrative Medicine with Dr. Andrew Weil, to learn medical acupuncture (an abbreviated course of study for physicians), meditation and clinical hypnosis. I felt if integrative therapies had helped me thorough cancer, I needed to share them with my patients.

I returned to work in May 2004, 13 months after the CFR. Over the course of the next ten years, I was able to work full time. During those years I underwent multiple dacrocystorhinostomies—surgeries to insert small tubes that bypassed my scarred down tear ducts and diverted tears to drain into my nose, myringotomies—insertion of tubes through the ear drum to drain fluid collections and restore hearing, and endoscopic surgeries performed through the nose to debride or remove areas of osteoradionecrosis, dead, infected bone in the radiation field at the base of skull. I had two courses of hyperbaric oxygen therapy to promote healing after the debridements.

In 2014, the infection in the dead bone became worse and my doctors recommended I undergo maxillectomy and reconstruction with the right fibula, a bone in the outer

lower leg, and its blood supply. It took me a

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few months to work myself into the right state of mind to face such aggressive, elective surgery. Once I decided to undergo the reconstruction, I used integrative medicine to prepare. I worked with a personal trainer to get my heart and lungs in top shape, saw a nutritionist for dietary advice to best promote postoperative healing, and prayed for the best outcome. Together, a friend who is a Consultant of the American Society for Clinical Hypnosis and I prepared a recording that I listened to regularly both pre and postoperatively. The recording told my body that it knew how to heal, I would recover quickly from anesthesia, would not bleed excessively, would remain comfortable in terms of pain or nausea after surgery, and reminded me that my surgeon had done this surgery successfully many times before. I was in excellent hands.

Reconstruction was a process that took three surgeries over roughly 15 months for me to complete. I did not have upper teeth till the end of that time so my speech was not very clear. I went on disability and chose not to return to work after completion of surgery and three months of physical rehabilitation. Balance remains a minor issue, but I haven't fallen in three years. I don't feel I would have the stamina to practice medicine now and parts of my brain have been irradiated twice. My memory and mental quickness are not what they used to be. Fortunately the disability company seems to agree.

I miss some aspects of practicing medicine, but retirement/disability is wonderful. I have finally had time to learn how to throw pottery on a wheel, I volunteer as a co-leader of a SPOHNC support group and lead a monthly nutrition "conversation" for patients at Caring House, the local medical center's guest house for out of town cancer patients. My husband and I have been able to travel a bit. I also take every opportunity to advocate for integrative care for people with cancer and everybody else.

As the ENT physician who performed CRF put it when he released me from routine scans and follow up last year, 18 years after initial diagnosis, it took a small army to bring me through cancer. I am forever grateful to him and all the troops.

~ Sharon Taylor
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HEAD AND NECK CANCER NEWS

Head, Neck Cancers Up Among 9-11 Responders

Feb. 1, 2019 (HealthDay News) -- Head and neck cancers among a group of first responders to the 9/11 World Trade Center terrorist attacks are significantly higher than expected, a new study says.

Rutgers University researchers found that diagnoses of these cancers increased 40 percent in a group of WTC workers and volunteers over a four-year period.

The findings suggest there are emerging health risks among those first responders that require ongoing monitoring and treatment, according to the study.

"This excess occurrence in head and neck cancers is plausible since first responders inhaled debris clouds containing many known carcinogens," said study author Judith Graber. She's an associate professor in Rutgers' School of Public Health and a researcher in the Environmental and Occupational Health Sciences Institute.

"In addition, these carcinogenic exposures might add to or increase the effect of known personal risk factors for some head and neck cancers, such as tobacco smoking, heavy alcohol use and oral HPV infection," Graber added in a university news release.

Graber's team compared the incidence of head and neck cancers from 2003 to 2012 among 73 first responder workers and volunteers enrolled in the

World Trade Center Health Program with the number of expected cases based on the N.J. State Cancer Registry. (The health program involves nearly 34,000 in all).

They found a 40 percent increase in diagnoses of head and neck cancers among first responders between 2009 and 2012, according to the study. The results were published recently in the *International Journal of Cancer*.

Since cancers develop over time, the findings of significant excess cancer in this period "point to a newly emerging trend that requires ongoing monitoring and treatment of WTC-exposed persons," Graber said.

The findings stem from a two-year study examining whether WTC first responders were at greater risk of human papillomavirus (HPV)-related throat and tongue cancer because of their Ground Zero exposure. The U.S. Centers for Disease Control and Prevention funded the study.

The most notable increases were seen in throat cancers often associated with HPV infection, but not in mouth and nasal cancers.

The study also found that head and neck cancers were most common among first responders who were over 55, white, or members of the military or protective services and involved in rescue and recovery and maintaining the perimeter after the terrorist attacks.

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HEAD AND NECK CANCER NEWS

Minimally-Invasive Treatment Option for Early Stage Oral Cancer Reduces Recovery Time, Improves Survival

DETROIT – Henry Ford Cancer Institute is a leader in providing a minimally invasive procedure called a sentinel lymph node biopsy for patients with early stage oral cancer. The biopsy can be performed at the same time oral cancer is surgically removed, and it can determine if the cancer has spread to nearby lymph nodes.

For Henry Ford patient Marlene Calverley, the biopsy meant having three lymph nodes removed versus 30-60 lymph nodes, and a two-inch scar instead of a five-to-six-inch scar. It also meant no neck drains, no physical therapy, and a decreased risk of complications.

“We are one of the few – if not the first – medical center in the State of Michigan to adopt this new paradigm for treating early oral cavity squamous cell cancers,” says head and neck cancer surgeon Tamer A. Ghanem M.D., Ph.D., director of Growth, Access, and Service for the Department of Otolaryngology at Henry Ford Cancer Institute. This new paradigm is based on a standard treatment for breast cancer and melanoma skin cancer.

The early data shows that sentinel lymph node biopsy may improve patients’ survival rate. Research also demonstrates a significant decrease in recovery time, complications, and effects attributed to a treatment, says Steven Chang, M.D., director of the Head and Neck Oncology program and the Microvascular Surgery Division at the Henry Ford Cancer Institute. Head and neck cancers are among the most common cancers in the U.S. and globally. At the time patients are first diagnosed with oral cancer, about 15-25 percent of them have hidden microscopic cancer cells in the lymph nodes of the neck.

During a routine dental exam, Calverley was told to watch a small spot on her tongue. Three years later, an oral surgeon discovered cancer. Knowing there was a significant chance of cancer spreading, the surgeon recommended a neck dissection to remove all the lymph nodes.

At Henry Ford, Dr. Chang would offer a new and more precise treatment approach. Traditionally, when oral cancer is found, neck surgery is performed and all the lymph

nodes are removed, whether they are known to be diseased or not. However, about 75-85 percent of the patients do not need this surgery. After surgery, patients may require neck drains, and some will experience shoulder and lip weakness caused by exposing and manipulating the nerves, says Dr. Chang. Also, patients will have a large scar and longer recovery time.

In the past, patients who had early oral cavity lesions and who were at risk for hidden cancer in the lymph nodes were routinely offered extensive neck surgery to find any diseased nodes. Now, we are offering a simple sentinel node biopsy to select patients to find diseased nodes, says Dr. Ghanem.

Calverley was one of those select patients. To eliminate the cancer, one-quarter of her tongue would need to be removed. When doctors at another medical center initially recommended having all of levels 1-4 removed – which could consist of 30-60 nodes in her neck – and grafting donor tissue onto her tongue, she sought a second and third opinion.

“Dr. Chang was the only one who offered to do the sentinel node biopsy and to have my tongue heal on its own,” says Calverley, a 72-year-old Rochester resident.

When Dr. Chang explained that the sentinel node biopsy is also done for women having a mastectomy, it was an easy decision for me, she said.

“I went home and prayed and spent two days talking to people about my decision,” she says. “Friends in the medical field agreed with me and asked, ‘Why would you have all the lymph nodes in your neck removed if they aren’t cancerous, and then deal with all the repercussions? It’s not necessary.’”

“I had my surgery in November, and my tongue is healing beautifully,” says Calverley. “Only three nodes were removed, and my scar is only about two inches. It’s right in line with a wrinkle on my neck, and you can barely see it,” she says.

“Within three days, I was up and making pumpkin rolls for Thanksgiving,” says Calverley. She spent only one night in the hospital after the surgery.

The benefits of the biopsy are important.

Compared to surgery that removes all the lymph nodes, sentinel lymph node biopsy lowers the risk of lymphedema, which causes a buildup of fluid and swelling in the body. Additionally, the biopsy involves mapping lymph nodes in the lower neck and opposite side of the neck – areas not typically included in the traditional approach. For cancer in the middle area of the head or neck, patients can avoid surgery on both sides of the neck.

The sentinel node biopsy procedure involves injecting into the oral cancer site a weak radioactive substance that marks white blood cells. The substance acts as a tracer and is picked up by the lymph vessels, travelling along the path most likely used by any cancer cells that might drain from the tumor to the lymph nodes. Depending on the patient, cancer cells may travel in different paths or patterns. The first lymph node that the substance goes to is called the sentinel lymph node. Imaging will find it and any other nodes containing the tracer.

The surgeon will remove the suspected lymph nodes along with the oral cancer, and a pathologist will immediately examine the tissue to determine if cancer is actually present in the nodes. If it is, the surgeon will perform a neck dissection to remove the diseased lymph nodes.

However, if the nodes are negative for cancer, then we will avoid a full neck surgery for the patient, says Dr. Ghanem.

By using minimally-invasive procedures and personalized medicine, doctors at Henry Ford continue to advance their mission of improving patient outcomes.



Photo courtesy of PJ Jordan, NSVN Caregiver Volunteer

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