

NEWS FROM S·P·O·H·N·C



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S·P·O·H·N·C
A PROGRAM OF SUPPORT
FOR
PEOPLE WITH
ORAL AND
HEAD AND NECK CANCER

Cure is Not Enough: Why Survivorship Matters for Head and Neck Cancer Patients

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What is cancer survivorship?

Survivorship focuses on the health and life of a person with cancer from initiation of treatment until the end of life. It covers the physical, psychosocial and economic issues of cancer, beyond the diagnosis and treatment phases. Survivorship encompasses considerations related to the ability to obtain health care and follow-up treatment, late side effects of treatment, second cancers,



lifestyle factors and quality of life. Both patients and providers alike play equal roles in the survivorship process. Family members, friends and other sources of social support are also considered part of the survivorship experience.

Why is survivorship important for head and neck cancer?

Survivorship begins at diagnosis. Survivorship is living with, through and beyond cancer and its treatment. Adjusting to a “new normal” and learning to cope with an umbrella of physical and emotional changes after cancer treatment is essentially what defines survivorship. This is particularly important in the setting of head and neck cancer due to the spectrum of physical and psychosocial changes that frequently accompany the diagnosis and treatment of these malignancies. Since patients with head and neck cancer are often treated with a combination of surgery,

chemotherapy, and/or radiation therapy, the functional and quality of life implications associated with these modalities must be considered.

There is a need for patients to be educated regarding the long-term and late effects of cancer, interventions available to them to prevent or treat these problems, as well as ways to stay as healthy as possible after treatment. Survivors may be cancer free but the treatment can cause long term and late side effects that in some cases might be worse than the actual cancer treatment itself.

New Commission on Cancer Accreditation Standards require survivorship care plans be given to and discussed with patients treated with curative intent who are finishing active treatment and patients to be screened for distress and psychosocial health needs. As a result, these practices are becoming the standard of care.



What does a “new normal” mean after cancer treatment?

The end of cancer treatment, while a time to celebrate, can often represent a challenging time for patients. This is largely because of fears regarding the unknown. Given how life changing treatment can be, transitioning to a “new normal” takes adjustment and involves both physical and emotional considerations. For head and neck cancer patients in particular, this “new normal” may include changes in the way one eats and the activities in which one can participate; new or different forms of social support; cosmetic and/or physical changes on the body; emotional scars from having recently undergone such an intense experience. In addition, learning how to cope with natural fears of recurrence can take time.

How can one cope with fear of recurrence?

Fear of recurrence is normal and often lessens over time. However, even years after treatment, some events may cause patients to become worried. Follow-up visits, certain symptoms, the illness of a loved one, or the anniversary of the date one was diagnosed can all trigger concern. An important step patients can take is to be informed. Even though you can't control whether or not your cancer recurs, there are steps one can take to help cope with fears and to provide a greater sense of control: Find out about support/health care services available to you; communicate pro-actively with your health care team; keep notes on any symptoms you may have; make sure you maintain and comply with a follow-up care plan.

SURVIVORSHIP continued on page 2

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Chris Leonardis

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IN THIS ISSUE

Time for Sharing.....5
 Thoughts From a Facilitator/Caregiver.....7
 The Recipe File.....8
 Chapter News.....9
 Head and Neck Cancer News.....9,10

SURVIVORSHIP continued from page 1

What are some late physical effects from head and neck cancer treatment that influence survivorship?

Musculoskeletal/Neuromuscular Dysfunction

Damage to the spinal accessory nerve can be a major cause of shoulder dysfunction and pain in survivors, especially among those who underwent neck dissection. Referral to rehabilitation specialists such as a physical therapist to strengthen the affected shoulder and improve or maintain range of motion is one intervention. Additionally, there is nerve stabilizing medication for pain and spasm management. Survivors may also develop cervical dystonia which affects the muscles of the neck and upper back. Cervical dystonia can result from neck dissection that disrupts the cervical anatomy and damage nerve roots. Survivors who underwent radiation can also develop fibrosis in the neck causing pain and range of motion limitations as well as neuropathies leading to numbness, tingling and weakness involving the upper extremities.

Trismus

Trismus is the inability to fully open the mouth. This is a common complication of treatment and has a detrimental impact on quality of life. This can cause difficulty with eating, speaking and maintaining oral hygiene. Physical therapy and jaw motion stretching exercises are interventions that could potentially help with this symptom.

Dysphagia/Difficulty Swallowing

Difficulty swallowing is most commonly characterized by inefficiency moving solid food through the mouth down the throat. This can result in aspiration. Patients should also be aware of a high risk of subclinical “silent” aspiration. This can be assessed by video fluoroscopic swallow study also known as the modified barium swallow or the fiber optic endoscopic evaluation of swallow. Aspiration is an independent predictor of pneumonia in cancer survivors and can be lessened by a speech language pathology referral.

Reflux

It is recommended that head and neck cancer survivors be aware of the potential to develop worsening reflux disease. Proton pump inhibitors or antacids, sleeping with a wedge pillow, and not eating or drinking fluids for 3 hours before bedtime, tobacco cessation, and avoidance of alcohol are ways to control symptoms. Chronic reflux can injure the teeth by damaging the enamel and/or even lead to permanent damage to the esophagus.

Lymphedema

Secondary lymphedema is a common late effect of treatment which causes swelling around face, neck, or internally around the throat. Swelling can have cosmetic and psychosocial consequences and can cause pain, infections, breathing or swallowing difficulties. Use of compression garments is one intervention that could improve this late effect.

SURVIVORSHIP continued on page 3

SURVIVORSHIP continued from page 2

Fatigue

Decreased energy is common among survivors who have undergone head and neck cancer treatment. This can interfere with quality of life. A regular exercise regimen can help survivors reduce fatigue, feel better physically and emotionally and generally cope better with related symptoms. Cognitive behavior therapy additionally lessens fatigue. Head and neck cancer survivors should be regularly screened for biological causes of fatigue including anemia, hormonal dysfunction, and cardiac dysfunction.

Hypothyroidism

The thyroid gland is exquisitely sensitive to the effects of therapeutic radiation and is also known to naturally decline in function over time. It is recommended that patients who received radiation to the neck have their thyroid function checked with labs on a regular basis after treatment. Common side effects of hypothyroidism include fatigue, weight fluctuations, sensitivity to hot or cold, mood changes, and impaired concentration, among others.

Xerostomia (Dry mouth)

While some salivary gland tissue can be spared with newer techniques, dry mouth complications should still be expected. Dry mouth can be transient or permanent. Saliva changes compromise protective features and can result in increased incidence of dental caries, sensitivity of non-decayed teeth, attrition, erosion of dentition, mucosal injury, altered taste, inability to wear dental prostheses, and increase risk of oral infection. Alcohol-free mouth rinses are recommended for head and neck survivors. Recommendations for a low-sucrose diet, avoiding caffeine, spicy and highly acidic foods are encouraged. Medications such as pilocarpine and cevimeline may be beneficial in certain situations to help stimulate salivary flow.

Altered Taste

Altered taste can be among the most common and burdensome toxicity for survivors. Taste disturbance is most pronounced around 2 months after end of radiation and recovery is expected over the course of years. It is important that survivors stay in regular contact with their

dietitian or nutritionist to optimize their food intake if altered taste is particularly prominent.

Speech/Voice

Speech, voice, or resonance disturbance may alter understandability or acceptability of verbal communication in survivorship. Both surgery and radiation therapy can lead to anatomical changes which make articulation and/or phonation more challenging. Survivors can be referred to a speech language pathologist for assessment and management of speech, voice, and resonance disturbance.

Oral/Dental Health

Ongoing, diligent attention to oral health is essential in survivors treated with radiation. Survivors should brush with a soft toothbrush, floss after each meal, do daily fluoride treatments using 1.1% sodium fluoride paste as a dentifrice or in customized delivery trays and have regular dental cleanings. There is an increase in oral complications after treatment with caries, gingival disease, gum disease and rare but possible, osteonecrosis of the jaw. Close monitoring of dental and oral health should continue as long as salivary flow is reduced.

How do psychosocial factors influence survivorship?

Treatment may dramatically change body appearance and alter the survivor's perception of self. Both body image concerns and diminished self-perception among survivors have been shown to be high. Survivors often report ongoing difficulties in recovery and returning to "normal" after treatment. Some survivors experience fear of recurrence, which contributes to significant mental health problems for which they already have an increased risk, including distress, depression, and anxiety. The consequences of untreated depression can be severe. For instance, several reports have demonstrated that the incidence of suicide in cancer patients may be significantly higher than among the general population. From a therapeutic standpoint, untreated depression has been demonstrated to affect compliance to prescribed therapy, wound healing, appetite and contribute to

prolonged hospital stays, sleep disruption, decrease motivation and less fulfilling social lives. Providers should be familiar with the mental health concerns that patients may experience. The utilization of tools to screen for symptoms and the development of resources to care for the survivor are of utmost importance.

Why is a survivorship care plan needed?

Providers should institute evidence-based survivorship care plans to standardize ways of follow-up so that follow-up for head and neck cancer patients is optimized after treatment. Surveillance and screening for recurrent disease forms the primary basis for follow-up and should be performed on a regular basis, incorporating imaging as needed. Other recommendations from the American Cancer Society survivorship guidelines include healthy weight maintenance, smoking cessation, education on signs of recurrence, engaging in physical activity, achieving a well-balanced diet and avoiding alcohol consumption. The number of cancer survivors is growing drastically with aging of the baby boomer population. Cancer survivors face physical, psychosocial, emotional and mental impacts from cancer and treatment. Survivors deserve comprehensive, high quality and coordinated clinical follow up care. There is a need for partnership between the survivor's primary care physician and oncologist to provide this. Survivors and caretakers should be provided with tools and resources to live beyond cancer treatment. Knowing what to expect after cancer treatment can help patients make plans, lifestyle changes, and important decisions about the future. Cure is simply not enough.

How can patients take charge of survivorship?

Survivors may experience a mixture of strong feelings, some of which appear contradictory. These include joy, concern, loneliness, relief, guilt and fear. Some people say they appreciate life more after a cancer diagnosis and have gained a greater acceptance of themselves. Others become very anxious about their health and uncertain of how to cope with everyday life. It is natural for patients to express feeling isolated after learning that their treatment has concluded and that relationships which

SURVIVORSHIP continued on page 4

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SURVIVORSHIP continued from page 4

were built with the cancer care team are drawing to a close. This is often because patients have developed a bond with the care team which has provided a powerful sense of security during treatment.

Additionally, new worries and challenges surface over time, such as any late effects of treatment, emotional challenges including fear of recurrence, sexuality and fertility concerns and financial and workplace issues. Every survivor has individual concerns and challenges. With any challenge, a good first step is being able to recognize a cancer survivor's fears and to feel comfortable talking about them. Many survivors find it helpful to join an in-person support group or an online community of survivors. This allows a sense of communication and shared dialogue with people who have had similar first-hand experiences. Other options for finding support include talking with friends or members of the health care team, individual counseling, or asking for assistance at the learning resource center of the center where treatment was provided.

You can find help through Support For People with Oral and Head and Neck Cancer (SPOHNC). Concerns such as emotional and psychosocial needs are addressed through SPOHNC's many programs, including its National Survivor Volunteer Network matching program (more than 200 volunteers strong), and its more than 125 SPOHNC Chapter Support Groups located throughout the United States.

As mentioned in this article, there can be many debilitating side effects following treatment for oral, head and neck cancer. You can find additional information in SPOHNC's print resources as well. These print resources include "News From SPOHNC," SPOHNC's Product Directory, *Volume 1 & 2 of Eat Well Stay Nourished A Recipe and Resource Guide For Coping With Eating Challenges, Meeting the Challenges of Oral and Head and Neck Cancer – A Guide for Survivors & Caregivers* and *We Have Walked in Your Shoes, A Guide to Living with Oral, Head and Neck Cancer – Second Edition*.

SPOHNC's programs and print resources are a wealth of much needed support and information for survivorship and survivorship care following the diagnosis and treatment of oral, head and neck cancer.

To find out more, contact SPOHNC at 1-800-377-0928, or e-mail info@spohnc.org.

What should a follow-up care plan consist of?

All patients who conclude cancer treatment should be provided a follow-up care plan. The National Cancer Institute and other cancer organizations recommend this document for people who have finished treatment. The details of this plan will depend on the type of cancer and type of treatment, along with the patient's overall health. It is usually different for each person. In general, survivors return to the doctor every 3 to 4 months initially, and once or twice a year after that. Studies have also shown that patients who received a copy of their treatment summary were more likely to report having good care and communication from their doctor. This information is invaluable to share with the primary care physician and any other doctors involved in providing care. It is important that patients keep this summary with their medical records so that key facts about treatment are always in the same place and secure.

What questions should patients ask during follow-up?

All patients should have follow-up care after treatment for head and neck cancer. Follow-up care means returning to see a doctor for regular medical checkups once treatment has concluded. The purpose of follow-up is to not only survey for signs and/or symptoms of cancer recurrence but also to discuss ways to optimize quality of life. Checkups are the time to check for physical and/or emotional effects that may develop months or even years after treatment ends. Patients should be encouraged to be pro-active about follow-up care. Common questions to ask include the following:

- What are symptoms or other 'red flags' I should be watching for?
- How can I be pro-active about screening for cancer recurrence?
- How often do I need to see the doctor?
- How often should tests and/or blood draws be performed? What can I do from a lifestyle standpoint to optimize quality of life?

- What can be done to relieve pain, fatigue and/or other side effects after treatment?
- How long will it take for me to recover and feel more like myself?
- Is there anything I can do to keep the cancer from coming back?
- Are there foods or drinks I should avoid?
- Are there any support groups I can attend?

Editors Note: Dr. Allen Chen is Professor and Chairman in the Department of Radiation Oncology at the University of Kansas School of Medicine. He is a graduate of Cornell University, earned his Medical Degree from Yale University School of Medicine, and completed residency training at the University of Texas MD Anderson Cancer Center and the University of California, San Francisco, School of Medicine. Dr. Chen is a leading expert in the management of head and neck cancers and is a frequently invited speaker for conferences across the world. He has particular interests in clinical trial development, medical education, and bioinformatics.

Liza Murray is a nurse practitioner in the Department of Radiation Oncology at the University of Kansas School of Medicine and has a particular interest in survivorship and quality of life for patients undergoing cancer care. After completing her Bachelor of Science degree at the University of Kansas, she earned a Master's of Science Degree in nursing at the University of Kansas. Liza was the recipient of the Colleen P. Kosiak Clinical Excellence Award during her master's program and has also been honored with the "Outstanding New Graduate Nurse Award" and the "Hematology and Oncology Nurse Excellence Award" during her tenure at The University of Kansas Hospital.

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A TIME FOR SHARING... A Light at the End of the Tunnel!

As a wife, mother, grandmother and registered nurse, family is everything to me. I have a variety of hobbies and interests. We have a pond and waterfall in our backyard where my husband Lee and I garden, or sit on a bench and just relax and enjoy. I'm in the middle of writing a novel. I also enjoy making natural skin care products. Besides family, I love hanging out with our two Silky terriers, Lexi and Lola, who are family too.

The highlight of my life was in 2000, when Lee and I, along with daughter Toni and son Jon, took my mother to Hilo, Hawaii for her 80th birthday. Born and raised in Hilo, she left the Big Island during World War II,

when she was twenty. Sixty years went by before she returned. Now the oldest of a huge clan, it was quite a celebration. Although she



was never to return, it was the trip of a lifetime – a time of unforgettable memories.

In early 2007, my mother passed away. I was devastated. Several months passed until I was ready to return to work. Before I began my job search, though, we took the family to Rehoboth Beach, DE, our “go to” beach town where we vacationed almost every year since we were first married. This time, we had all 3 grandchildren along and had a wonderful time together.

Two weeks later, I absentmindedly touched the side of my neck for no particular reason, and... *what is that?!* A look in the mirror showed a raised lump on my neck. *Where did that come from?* As a nurse, I was immediately alarmed. One moment there was nothing there, and the next ...?

A couple of days later, I saw my family doctor, who immediately ordered an Ultrasound Scan of my neck, followed by a CT. Conclusion: there was a left-sided neck mass coinciding with a palpable lesion, 2.5 x 2.3 cm. Its nature was unclear. We were referred to Penn State Health Milton S. Hershey's Chief of Otolaryngology, Head and Neck Surgery. *An oncology surgeon?! This was not supposed to happen to me!*

Nobody in my family ever had cancer. It was so surreal.

October 2007: Despite various diagnostic tests, my doctor was unable to determine whether or not the mass was malignant. As a precaution, I went into surgery, hopefully for just an incisional biopsy. I contacted my employment agency, explaining I was having a small procedure done – no big deal. I was sure it was nothing. I would call them in a day or two, at which time they could start setting up interviews. It never happened. The nightmare had begun.

Lee sensed there was a problem, but was stunned when the doctor gave him the news: the mass was cancerous. I came out of surgery with a modified radical neck dissection and a very uncomfortable incision from behind my left ear to midline of my neck. Thirty two lymph nodes were removed, one in which metastatic squamous carcinoma was present. Because the primary source was unknown, a second surgery was done two weeks later to remove my tonsils, which were suspected to be the primary source.

A treatment plan was established, starting with a feeding tube, as there was a good possibility I would have difficulty eating and swallowing during or after treatment. *Thanks, but no thanks!* I had had patients with feeding tubes before, and did not wish to have one. I finally gave in – it would be better to get one before the chemo and radiation than after, when my immunity would be down and I would be more susceptible to infection.

The beginning of my road to recovery was rocky. I am not going to paint a pretty picture about it – I had never felt more miserable in my entire life.

December 2007: I was hospitalized for my first round of Cisplatin. Discharged the following morning, I received my first of 30 radiation treatments. It wasn't long before my throat was so sore, I couldn't swallow, and I lost my sense of taste. It's extremely hard to eat when your food tastes like cardboard. While the family enjoyed a delicious Christmas dinner, I ate a couple of spoonfuls of mashed potatoes. Period. I tried a little vanilla ice cream – it tasted like cold, hard plastic. Guess it was good I got that feeding tube after all! I soon became

accustomed to it, and wasn't bothered at all by others eating in front of me. I learned to enjoy and be satisfied with just the smell of food. Ten months went by before I had it removed.

December 26: I received my second round of Cisplatin, with radiation continuing 5 times a week. My tolerance for this assault on my body was fading fast, and I became extremely weak. Getting up and going to the bathroom, which was right around the corner from my bedroom, became a challenge. I'd get out of bed but had to stop and rest before continuing. I felt extremely nauseated. My husband says that I was really out of it, and once asked “Who's that boy?” I couldn't remember my own son's name!

I hallucinated a number of times while crawling up the stairs following radiation. Suddenly, there were bugs all over the carpet enmeshed in an intricate web. I developed thrush – white patches inside my mouth that became increasingly sore. Despite rinsing my mouth with an anti-fungal rinse, it returned 11 times!

You think you have everything all figured out and are traveling along the road of life as planned. Then suddenly, you meet this huge obstacle and have to make a detour, and you're forced to take an alternate route – a dark hazardous route that you had never taken before. I knew a positive attitude was essential in getting through my treatment; however, this was easier said than done.

It was during this time that my mother came to me in a dream. She wanted me to know she was watching over me, and that I was going to be alright. From that moment on, I never worried about the cancer itself. I had complete faith in my doctor. It was the cancer treatment I was so apprehensive about!

January 2008: Feeling awful. I cancelled my 3rd Cisplatin, but was told I'd have to make it up. I also skipped a week of radiation. I had developed a horrendous case of “mucus mouth,” which lasted for months. I was afraid to go to sleep at night because I would often wake up choking on it. It was tenacious and would proliferate faster than I could rinse my mouth, resulting in huge blobs of mucus. This made me more anxious. I tried many different products but nothing worked, except for lemon lime seltzer water.

continued on page 6

continued from page 5

which was helpful, but only for a little while. In time, I discovered that paper towels were the only thing that reduced my discomfort. I would fold one so it fit into my mouth and helped absorb the secretions. I returned to radiation, but by the end of the month, I quit at 25. I just couldn't take it anymore. I do not recommend this to anyone. My radiation oncologist was not happy.

So, I spent most of January and February in bed, Lexi and Lola at my side. I felt so isolated, and for a time, I lost complete sight of the light at the end of the tunnel. Would I ever feel "normal" again? I was beginning to doubt it.

February: By the end of the month, my hair had completely fallen out. It didn't bother me nearly as much as I thought it would. When it started growing back in, I decided to wear it short and punky, something fun and different. I had a wig and some cute hats that I wore occasionally, but it was really not a big deal. More important things to worry about than a bald head!

March-April: In place of Cisplatin, I was given Carboplatin and Taxol, which, unfortunately, made my "mucus mouth" flare up again. With Taxol, the soles of my feet immediately became numb and tingling, which are symptoms of peripheral neuropathy. This has not improved with time. On a more positive note, I was beginning to feel a bit better.

Post treatment: I can't stress enough how important good dental and mouth care are. Find the best dentist you possibly can, see him regularly, and be meticulous with caring for your teeth and gums. Radiation caries is a huge problem. Dry mouth creates a hotbed of decay. Til I was done with my treatment, every single tooth in my mouth had radiation caries. I eventually had to have them all crowned, which was very costly. Problems continued, and I had to have hyperbaric treatments before my radiation oncologist would allow me to have dental implants. It was too risky. The integrity of my jaw could have been seriously compromised, resulting in irreparable damage.

I had been invited to a head and neck cancer support group in April 2008 (an affiliate of SPOHNC), but it wasn't until October that I finally worked up the courage to attend ... and found a small group of people who welcomed me and who knew exactly what I'd gone through because they

had been through the same thing. Suddenly, I didn't feel so alone anymore. I had support, and I learned I was a lot stronger than I thought I was. I began to heal, and in time, I realized that there is life after cancer... a good and fulfilling and productive life. Although I had lost my way for a time and my life had not returned to the way it used to be, I found a new "way" for myself, and I created a new "normal." There is a light at the end of the tunnel!

Nine years out, I am cancer free. I do sometimes have trouble swallowing food, like beef or chicken, due to the radiation. I am sometimes forgetful or have difficulty comprehending things (chemobrain!) Other than that, I am feeling well.

Never in my wildest dreams would I have imagined that one day, I would help launch and facilitate the SPOHNC Penn State Health Head and Neck Cancer Support Group. But here I am... and I love it! It's the group that inspires me: people sharing stories about their experiences and struggles, **p e o p l e** **l e a r n i n g** that they are stronger than they thought they were. I'm especially inspired by a few long-time survivors who go out of their way, time and again, for those just beginning treatment who have particular needs or are in need of additional support. They've inspired me to reach out to others as well in providing encouragement, hope, and information to those whose shoes I have walked in.

We often have guest speakers at our meetings. Other times, we just get together and talk about whatever's on our minds, share our stories, concerns, and coping strategies. We're not only for newly diagnosed patients, but also for long-time survivors and their families, caregivers and friends. It's a very positive experience. My wish for everyone who has ever been diagnosed with this horrible disease is for them to know that they are not alone... there are others just like them who understand, who share their experiences and are here to encourage and offer their support - *That there is light at the end of the tunnel, and that this diagnosis does not mean their lives are over!*

We meet at the University Fitness and Conference Center, Room 302b, on the Penn State Health campus, on the fourth Sunday of the month from 2pm to 3:30-4 pm.

There are a number of people who I'm inspired by: my son, Jon, a very talented artist and musician who just celebrated 4 years of sobriety. We are so proud of him. I'm inspired by my wonderful mother, who taught me I could do anything I wanted to; and by Lee, for supporting me every step of the way with not just my 'journey,' but with the support group as well. I'm also inspired by Dr. David Goldenberg for his openness, dedication and tenacity. He continues to bring his patients hope, working tirelessly to find a cure for this horrible disease - and Betty Cek, his nurse, for greeting everyone with a big hug and a smile, making everyone feel special and cared for. A big thank you, too, for all of her support with the group.

Would I have chosen to have head and neck cancer if I could? I can't answer that question. I've been deeply blessed by many wonderful people I never would have met if not for this cancer. Many I now call 'friend.' I've learned a lot about life and about myself, and have grown and changed in so many different ways. It certainly changed the course of my life, but in a good way. Sometimes things happen for a reason. Sometimes, you find your inspiration.

~ Patrice Saurman
pennstateheadneck@gmail.com



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WHEN CANCER KIDNAPS YOUR LIFE

Amy Beilman – SPOHNC Palm Coast Northeast, FL Chapter Facilitator

If you're reading this article, it would make sense that you or someone you love has been diagnosed with cancer.

Finding out you have cancer is like finding out that your life has been kidnapped.....Now, you only care about one thing. What kind of "ransom" do I have to come up with to get it back?

My husband is a throat cancer survivor. When he was diagnosed, we were catapulted into a state of shock. Within 48 hours, we were waiting for "the ransom note." How much do we need to come up with?

Unfortunately, sometimes, things aren't printed clearly: as in bring \$50,000 in unmarked bills to the nearest Wendy's.

No, your ransom note reads something like....we'll need to do surgery/maybe follow up with radiation and chemo, and we won't be able to give you a definitive answer until all the test results are back. WHAT are you saying? That there's nothing right now that we can do? Be patient... be positive... eat a lot of fruit and vegetables? We hate lima beans. Now what?

Living in a new world, a world that seems "controlled" by cancer is difficult. Your challenge is to buckle up securely and hold on.

How could two people, who just yesterday were worried that their dishwasher might break down, wind up with a REAL worry? I remember my Dad saying to me that the only worry that's real is a worry that money can't fix.

There are so many survivors out here... survivors that have been cancer free for years and years... So, how long did it take some of these people to "get their life back?" The longer you go with no sign of cancer, the better you trust your body, the better you feel about life.

Some of the dark days of early diagnosis and treatment start to fade, and little by little, your old life seeps back and you start to have a "New Normal." It's interesting to suddenly realize that your life has changed, but it's all good.

All of the feelings that come along with a cancer diagnosis are NORMAL. Feeling like a deer in the headlights is normal. Feeling agitated, or anxious, or scared is normal. Keep the faith that this too shall pass. Cancer can kidnap your life temporarily, but in the long run, your life is yours to live. Live it the best way you know how.

YESTERDAY IS HISTORY
TOMORROW IS YOUR FUTURE
TODAY IS YOUR LIFE
LIVE IT



photo courtesy of Don Thiemann

Terre Haute, IN Chapter Facilitator – SPOHNC Is Celebrating YOU!

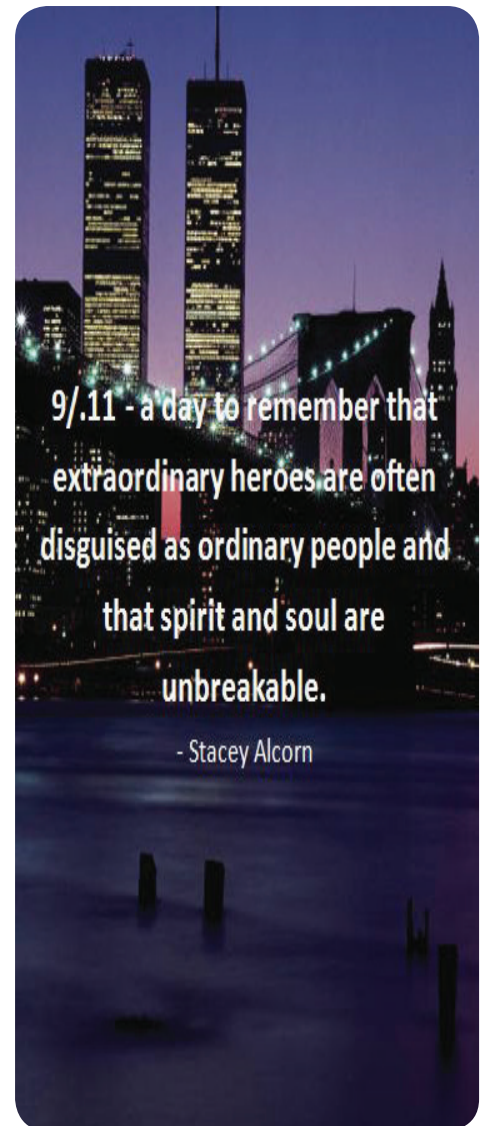
While we were all enjoying a lovely summer, one of our own SPOHNC Chapter Facilitators was celebrating and enjoying her own special day.

Happy Birthday Sister Mary!

On July 15th, Sister Mary Ryan, Survivor, celebrated a birthday. Sister Mary has been the dedicated Facilitator of the SPOHNC Terre Haute, Indiana Chapter since 2009.

SPOHNC thanks you for your continued commitment to those who are seeking hope, help and support. Your experience as a survivor, coupled with your professional experience and your very special calling, have made you an asset to the community, and to your SPOHNC Chapter Support group as well.

All good wishes for an amazing year, from your SPOHNC family!!





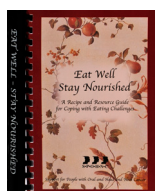
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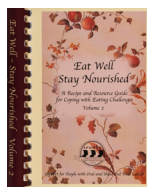


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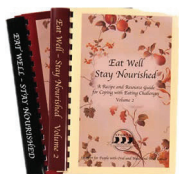
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**Super Soft September Recipes from
Eat Well Stay Nourished A Recipe and Resource Guide
For Coping With Eating Challenges**

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

If you have difficulty with chewing and swallowing, try these recipes from Volume Two.

Sweet, and savory!

Berry and Beet Smoothie

- ¾ c. cranberry juice, chilled
- ¼ c. cranberries (fresh or frozen)
- 1 small beet, steamed
- 1/3 c. frozen strawberries
- 2 tsp. honey or other sweetener to taste
- 2/3 c. ice cubes



Place all ingredient into Vitamix container in order listed and secure lid. Select variable 1. Turn machine on and slowly increase speed to Variable 10, then to high. Blend for 1 minute or until desired consistency is reached. Serves 2 - 3. 349 calories/serving.

~ Sean G., CO

Roasted Cauliflower and Aged White Cheddar Soup

- 1 small head cauliflower, cut into florets
- 2 Tbsp. oil
- salt and pepper to taste
- 1 Tbsp. oil
- 1 medium onion, diced
- 2 cloves garlic, chopped
- 1 Tbsp. thyme, chopped
- 3 c. vegetable broth
- 1 ½ c. aged white cheddar cheese, shredded
- 1 c. milk or cream



Toss cauliflower in oil with salt and pepper in a bowl then arrange in single layer on a baking sheet, Roast at 400 degrees til lightly golden brown (20 to 30 minutes). Heat one tablespoon oil in large saucepan over medium heat. Add onion and sauté til tender. Add garlic and thyme and sauté til fragrant. Add broth and cauliflower and bring to boil. Reduce heat and simmer, covered, for 20 minutes. Puree soup until it reaches your desired consistency. Mix in the cheese, let it melt and season with additional salt and pepper to taste, add milk or cream to make it creamier. Remove from heat and serve. Serves 4. 390 calories/serving.

~ Judy T., MD

*SPOHNC apologizes for an error
in the April 2017 issue of “News from SPOHNC.”*

Dave Noble

should have been listed as a

Sponsor

in the Donation Category section of the newsletter.

Find SPOHNC on Twitter

HEAD AND NECK CANCER NEWS

New Experimental Drug Kills Cancer Cells When Combined With Chemotherapy

Although the traditional chemotherapy drug, cisplatin, is somewhat successful in its own right, researchers have discovered that when combined with a new experimental drug the results are astounding. In a recent University of Michigan study carried out using mice, researchers found that when this combination was used in mice it destroyed a rare form of salivary gland tumor and stopped it from recurring within a 300 day period.

This rare form of cancer in question is called ***adenoid cystic carcinoma**, or ACC for short. It affects around 3,000 to 4,000 people annually and is most commonly found in the salivary glands. Unfortunately, it's one of those cancer's that isn't usually detected until it's at an advanced stage, is very resistant to therapy, and as of yet has no cure. Normally these type of tumors is treated with surgery and radiation. Chemotherapy is usually avoided as ACC is very slow-growing and chemotherapy is better used on rapidly growing tumors, confirmed Jacques Nor, a UM professor of dentistry, otolaryngology, and biomedical

engineering, and principal investigator on the study.

The experimental drug used in the study is called MI-773, and when combined with cisplatin, is very effective at warding off cancer. It does this by preventing the interaction taking place that disarms the vital cancer-fighting protein, p53. As the researchers explain it, by blocking that interaction, ACC cancer cells become sensitized to cisplatin. "This drug MI-773 prevents that interaction, so p53 can induce cell death," says Nor. "In this study, when researchers activated p53 in mice with salivary gland cancer, the cancer stem cells died."

As part of the study, researchers carried out two different types of experiments in order to fully test how much the ACC tumors were reducing in size as well as their recurrence patterns. The first experiment involved treating tumors in mice with the combination of

MI-773 and cisplatin. The results were that the tumors shrank considerably from around the size of an acorn to almost nothing. In the second experiment, researchers removed the acorn sized tumors surgically and followed it up with one month's worth of MI-773 treatment.

"We did not observe any recurrence in the mice that were treated with this drug after 300 days (about half of mouse life expectancy), and we observed about 62 percent recurrence in the control group that had only the surgery," said Nor. "It's our belief that by combining conventional chemotherapy with MI-773, a drug that kills more cancer stem cells, we can have a more effective surgery or ablation." One slight drawback to the study is that it is based on an observational period of 300 days, whereas nearly half of all ACC tumors recur only after around 10 years. It's still early days for the drug combo in terms of being used on human patients but is still a good place to start nonetheless.

Chapter News

from SPOHNC Dayton, Ohio

CELEBRATING On August 14th,
10 years SPOHNC's
Dayton, Ohio
Chapter celebrated a milestone. Happy 10th
Anniversary!

The SPOHNC Dayton, Ohio Chapter has been facilitated by survivor Hank Deneski, since its inception 10 years ago. Following Hank's treatment for base of tongue cancer in 2005, he attended SPOHNC's 15th Anniversary Conference in New York, where he learned about the organization and the services and programs of support offered. Hank saw a need in his community, and was driven to help, by starting up a SPOHNC Chapter. With the support of SPOHNC, Hank's group has flourished, and continues to grow and inspire those who are seeking hope and help. Thank you Hank, for your dedication.

SPOHNC wishes Hank, Lil and all of the past and present attendees of the Dayton, Ohio SPOHNC Chapter Support group, a very Happy Anniversary. Here's to many more years of support!

SPOHNC Chapter News

Our SPOHNC Chapters are growing and our reach is expanding every day. Nothing can compare to the support of a group of people who are going through a similar experience, to give hope. This summer, SPOHNC was contacted by more than 5 states across the country, to inquire about how to start a SPOHNC Chapter. SPOHNC is pleased to offer our support to new and existing Chapters!

If you feel there may be newly diagnosed patients in your area who are not aware of a SPOHNC Chapter nearby, SPOHNC is glad to help. We can update your meeting flyer and send it to you, for inclusion in a community newspaper or to post in the local library, in addition to healthcare

facilities in your area. SPOHNC can also do a zip code radius search of our own database, so that we can mail out the flyer to newly diagnosed patients and survivors who live within a 30 mile radius of your

meeting location. Let us know if we can help you grow your support group by calling SPOHNC at 1-800-377-0928.

If there is no SPOHNC Chapter nearby, and you would like to find out how to start a Chapter, please give SPOHNC a call. We will help you through the process and provide you with guidelines, materials and administrative support, to help you get the word out about your new SPOHNC



Chapter. SPOHNC provides continuing help and information along the way. We have also created some new initiatives to communicate and share ideas and best practices among Chapter Facilitators.

SPOHNC looks forward to hearing from you, sharing information with you and hearing about all of the good things that are happening in our SPOHNC Chapter Support Group. Please keep in touch! We want to hear from you!

Connect with SPOHNC's "group" on Facebook

HEAD AND NECK CANCER NEWS

Newly developed nomograms provide accurate predictions for patients with oropharyngeal cancer

NRG Oncology researchers recently developed and validated a nomogram that can predict 2-year and 5-year overall survival (OS) and progression-free survival (PFS) for patients with local-regionally advanced oropharyngeal squamous cell carcinoma (OPSCC) treated primarily with radiation-based therapy. This nomogram was developed with data from clinical trials NRG Oncology/RTOG 0129 and 0522. Results were published online in the *Journal of Clinical Oncology* on August 4, 2017.

A nomogram is a graphic depiction of models that can be utilized to estimate the numeric probability of death, disease progression, or other events for a particular patient. Validated nomograms can be advantageous in determining social or biological factors that could be associated with survival. NRG Oncology's validated nomogram for prediction of survival in oropharyngeal cancer can be found on the NRG Oncology website under the Resources tab.

"Nomograms offer the ability to personalize survival estimates for patients based upon a host of factors that are clinically relevant when we meet patients," stated Carole Fakhry, MD, the study's lead author and an associate professor in the Department of Otolaryngology Head and Neck Surgery at John Hopkins University.

Researchers developed and validated the nomograms for OS and PFS using a derivation cohort and the models were applied to a validation cohort. The

derivation cohort included 493 patients with OPSCC, a known tumor p16 status, and a smoking history measured in pack-years, who were randomized into two clinical trials: NRG Oncology/RTOG 0129, a phase 3 trial that evaluated standard fractionated (SFX) vs. accelerated fractionated (AFX) radiotherapy with cisplatin; and, NRG Oncology/RTOG 0522, a phase 3 trial that evaluated the addition of cisplatin to AFX radiotherapy and concurrent cisplatin. The validation cohort included 153 patients with OSPCC, a known tumor p16 status, and a smoking history who were randomized into NRG Oncology/RTOG 9003, a phase 3 study that evaluated SFX vs. concomitant boost vs. split-course accelerated vs. hyperfractionated radiotherapy. The Cox model was used to determine if the survival distributions differed among the three risk groups.

Both models included age, Zubrod performance status, pack-years, education, p16 status, tumor and nodal stage; however, the OS model also included anemia and age to-pack-year interaction, while the PFS model included marital status, weight loss, and p16 to Zubrod interaction. Predictions correlated well with observed 2-year and 5-year outcomes.

"These nomograms will help in providing patient-specific estimates of survival that can be used for risk-stratification and discussions of prognosis with patients," added Dr. Fakhry.

###



Photo courtesy of PJ Jordan, NSVN Volunteer

*It doesn't matter
what the situation looks like
or how difficult the challenge.*

*Scripture promises us that
"Hope is a strong
and trustworthy anchor
for our souls"*



(Hebrews 6:19, NLT)

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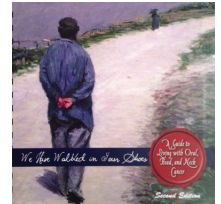
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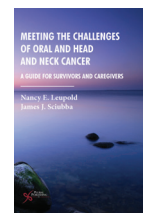
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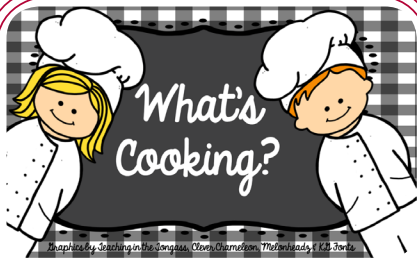
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