

SPOHNC

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



“Together,
WE Heal”

SPOHNC’s
Greenville, SC Chapter
support group recently held
a celebration to honor
their caregivers during February,
the month of love.

Massachusetts... We Need Your Help!

Find out more on page 7.

Chapter Happenings

Find out more on page 8.

SPOHNC Salutes a Gentleman

Find out more on page 10.

Understanding Scanxiety - Symptoms, Causes and Coping Techniques

Joanne Van der Veen

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

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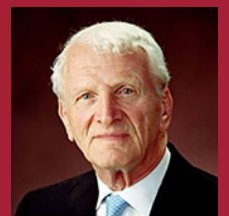
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Scanxiety

Understanding Scanxiety: Symptoms, Causes and Coping Techniques

Joanne Van der Veen

Scanxiety can occur at different levels.

Most people will experience the feeling of anxiousness to a lesser or larger degree throughout their life. Anxiety could present from a minor situation or a more significant life event, such as a cancer diagnosis.

For those with oral and head and neck cancer, undergoing imaging studies can lead to many emotions presenting. Feeling worried or stressed before, during, and after medical tests is common. These feelings of anxiety are termed “scanxiety” and can occur at different levels.

It is important to understand that scanxiety is normal and that many options are available to help you cope and manage your symptoms.

What Is Scanxiety?

Scanxiety is the anxiety and distress cancer patients experience before, during, and after a scan.

- Anxiety is feelings of unease, dread, and fear caused by stress.
- Distress is mental, emotional, spiritual, or social suffering, with emotions ranging from sadness, depression, loss of control, panic, and isolation.

For cancer patients, in particular, anxiety becomes chronic (present over a long period of time) and increases around the time a medical scan is required. A study of 222 cancer patients reported that 55% experienced some level of scanxiety.

Causes of Scanxiety

Cancer patients may experience scanxiety at different times surrounding a scan. Scanxiety can be caused by medical imaging machines such as an MRI, ultrasound, X-ray, and CT/CAT scan.

Before Scans

You may start to feel worried or stressed as soon as your scan has been scheduled and the days leading up to your appointment. You may also begin to feel anxious traveling to your appointment or in the waiting room.

During Scans

Depending on the area of the body that needs to be scanned, you may feel uncomfortable or claustrophobic in the medical imaging device. For example, the inside of an MRI can be small and cramped, leaving some patients feeling trapped and panicked.

The noises of medical imaging devices during scans can be overwhelming. Some scanners can also be uncomfortable and cold. These factors can add to the stress and anxiety surrounding scans.

After Scans

It is normal to experience some form of anxiety while waiting for your scan results to arrive. You may experience worrying thoughts, especially if it is a scan to check for cancer recurrence. Another situation that can increase stress is if the waiting period for your results takes longer than expected.

Other reported factors that cause high levels of distress in cancer patients include:

- Problems at home
- Unmet social or spiritual needs
- Difficulties with normal daily activities
- Physical problems, such as pain, nausea, or fatigue

Scanxiety Symptoms

For cancer patients, scans are an essential part of treatment and survivorship care. So it is important to identify scanxiety symptoms and the effects they may have. Identifying your scanxiety symptoms and causes can help you better understand your stress response and how to manage the symptoms or prevent them from occurring.

Symptoms of scanxiety may include:

- Insomnia, sleep disturbances
- Shortness of breath
- Changes in mood
- Muscle tightness
- Sweating
- Increased heart rate
- Restlessness
- Trouble eating or nausea
- Lightheaded, dizzy, or faint feeling

If you experience any symptoms of scanxiety, talk to your health care provider. They can help you manage symptoms and ensure your quality of life is not decreasing.

When Do Scanxiety Symptoms Occur?

Scanxiety symptoms can begin:

- Weeks, days, or hours before or after a scan
- During a scan
- Days and weeks before getting the scan results
- Waiting for a scan to diagnose cancer, monitor disease progression, or check if cancer has recurred

Coping Techniques for Scanxiety

Anxiety disorders may make coping with the stress of cancer and its journey more difficult. Fortunately, many types and levels of support and intervention can help you manage scanxiety.

Deep Breathing

Deep breathing exercises can help reduce anxiety and promote relaxation. It's a simple technique that can be practiced before, during, or after a medical scan. Inhale deeply through your nose and slowly exhale through your mouth. Repeat this for several minutes until you feel more calm and relaxed.

Here are some helpful deep breathing exercises:

- **Diaphragmatic Breathing:** Sit comfortably with your back straight and

your feet flat on the floor. Place one hand on your chest and the other on your belly. Inhale slowly through your nose, allowing your belly to expand, and exhale slowly through your mouth, pushing all the air out. Make sure to breathe deeply from the diaphragm rather than shallow breaths from the chest.

- **Box Breathing:** Inhale for a count of four, hold the breath for a count of four, exhale for a count of four, and hold the breath for a count of four. Repeat this cycle several times,

Many types and levels of support
can help you
to deal with scanxiety

focusing on your breath and counting.

- **4-7-8 Breathing:** Inhale for a count of four, hold the breath for a count of seven, and exhale for a count of eight. Repeat this cycle several times, focusing on your breath and counting.
- **Belly Breathing:** Place one hand on your belly and one hand on your chest. Inhale deeply through your nose, allowing your belly to expand, and exhale slowly through your mouth, pushing all the air out.

Mindfulness

Mindfulness involves paying attention to the present moment without judgment. During a medical scan, try to focus on your breath, the sensations in your body, and the sounds around you. Be aware of your thoughts but try not to engage with them. This can help you stay present and reduce anxiety.

Here are some helpful mindfulness exercises:

- **Body Scan Meditation:** Focus on each part of your body, from your toes to the top of your head, and observe any sensations without judgment.
- **Mindful Breathing:** Focus on your breath as you inhale and exhale, noticing any sensations and distractions. When you notice your mind wandering, simply bring your attention back to your breath.

- **Loving-Kindness Meditation:** Focus on sending love, kindness, and hope to yourself and others to help cultivate feelings of compassion and positivity.
- **Grounding:** Focus on your surroundings by using your senses. Notice what you see, hear, smell, taste, and touch.
- **Mindful Movement:** Focus on your body movements as you engage in physical activities such as yoga, walking, or stretching.
- **Gratitude Practice:** Focus on what you are grateful for in your life to help shift your focus away from anxiety and negative thoughts.

It's important to note that mindfulness takes practice and patience. It may take some time to find the technique that works best for you. Consider seeking guidance from a mindfulness-based therapist or a trained mindfulness teacher to help you get started.

Distraction

Distraction techniques can be an effective way to cope with anxiety, particularly when used in combination with other coping strategies.

Here are some examples of distraction techniques:

- **Engage in a Creative Activity:** Art, music, journaling, or any other creative activity can be a great way to distract yourself from anxious thoughts. Focusing on something creative can take your mind off your worries and channel your energy into something positive.
- **Play a Game:** Playing a game, whether it's a board game, card game, or video game, can be a fun and effective way to distract yourself from anxiety. Games can help you focus on the present moment and give you a sense of control.
- **Exercise:** Physical activity is an effective way to take your mind off stressors and ease anxiety. When you exercise, your body releases natural mood boosters called endorphins.
- **Watch a Movie or TV Show:** Watching a movie or TV show can be a great way to distract yourself. When you're engrossed in a good story, you can forget about your worries for a while and give your mind a break.

Support Groups

Support groups can be a valuable resource for cancer patients with anxiety. They allow you to connect with others going through similar experiences, share your feelings and concerns, and offer and receive emotional support.

These groups can also provide valuable information about your diagnosis, treatment options, and other resources. This can help you better understand and learn how to manage your symptoms.

Communication

Talk to your doctor or technician about your anxiety. They can provide reassurance, coping skills, and details of what to expect during the scan. They can also recommend additional resources like integrative oncology services.

Before your scan, you can write down a list of questions to ask your care team, such as:

- Why is this scan being done?
- What should I do to get ready for my scan?
- How long will the scan take?
- What happens during the scan?
- How will I get my results?
- How long will it take to get my results?
- What are the next steps after the scan?

Final Thoughts

Remember, it is normal to feel anxious before a medical scan. These techniques can help you manage your anxiety and feel more comfortable during the process. It's important to find coping techniques that work best for you. Try different methods and see which ones help ease your symptoms.

Communicate with your health care team about your anxiety and any concerns you may have. They can provide additional support and resources to help you through this challenging time.

Editors Note: Joanne Van der Veen is an experienced Healthcare freelance writer with a passion for clinical research and medicinal chemistry. She is passionate about taking complex terminologies and concepts and creating easily digestible, informative, and factually correct articles.

Head and Neck Cancer News

Conundrum solved over HPV link with head and neck cancer

FEBRUARY 13, 2023 - by University of Birmingham

A major international trial published in *The Lancet Oncology* has looked at studies from 13 head and neck cancer centers from nine countries around the world. Using the data of 7,895 patients, a research team has found that there is a significant number of people who have discordant results in which two different tests for HPV show different results.

The study found that for one in ten of patients who have discordant HPV results, they saw significantly worsening outcomes compared to those who tested negative in both tests.

In those cases, 5-year overall survival rates were:

- 81% for patients among double positive tests
- 53% for patients with p16-/HPV+ test
- 54% for patients with p16+/HPV- tests

Testing for whether a cancer is HPV-related involves two types of tests. The first, which is called HPV testing, looks for the actual virus within the tumor. The second type of test looks for a protein called P16, which has been established as a commonly used biomarker for HPV. P16 is easier to use, and so most people use it as the standard.

The study brought together collaborators from across Europe, coordinated by Professor Hisham Mehanna at the University of Birmingham.

Prof. Mehanna, Professor of Head and Neck Surgery, and lead author of the paper, said, “Through an international collaboration we have been able to answer a question that has perplexed the head and neck cancer community for over two decades. In that time there has been an emergence of a new type of head and neck

cancer: this cancer called Human papillomavirus (HPV)-related head and neck cancer, caused by the same virus that is often responsible for cervical cancer.

“What is remarkable is that patients with HPV head and neck cancer respond much better to current therapies than patients who are not HPV-related. As a result, we are trying to look for less toxic treatments for these patients to reduce the burden of toxicity. For patients who are HPV negative, we are doing clinical trials to increase the intensity of treatment—to try to improve outcomes.

“Therefore, testing for HPV in head and neck cancer patients has become a real priority and this new research has solved the conundrum puzzling the international community about why some patients respond much better to treatment than others.”

Patients with discordant tests who smoked were at much higher risk of worse outcomes, as the study found that their cancer behaved like HPV-negative cancers. On the other hand, patients with discordant tests who did not smoke had tumors that yielded good outcomes, like HPV-positive cancers.

Professor Mehanna said, “This has significant implications on how we test head and neck cancer patients moving forward, especially in regions where smoking is still prevalent and HPV disease is not prevalent; for example, southern Europe and countries in the east. It also has significant implications for how we choose which studies to enroll these patients in, and in [the] future what treatment they get.”

How Can SPOHNC Help You?

Join a SPOHNC Chapter Support Group

Connect with a Survivor or Caregiver Volunteer

“Together, WE Heal”

Contact SPOHNC today at 1-800-377-0928

or at info@spohnc.org

Massachusetts Oncology Patients, Survivors and Supporters (MOPSS) Update



Massachusetts Oncology Patients, Survivors and Supporters (MOPSS) is working with elected representatives in Massachusetts on Bill # 1094 which if passed, would require insurers doing business in Massachusetts to cover medically related dental treatment.

MOPSS needs your help!

If you live in Massachusetts and would like to join the MOPSS Committee, we are actively seeking more committee members, so that our voices will be heard! Please contact Tom Healy at THealy1019@gmail.com or by phone at 781-686-3774 for details about the upcoming meetings, and how you can help!!

If this bill passes in Massachusetts, it can be the model program for other states to follow. Let's all make it happen!!

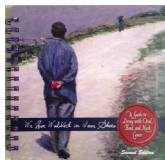
CALLING ALL MASSACHUSETTS HEAD AND NECK CANCER SURVIVORS!!

Are you looking for your insurance company to pay your dental expenses???

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SPOHNC's RESOURCES

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



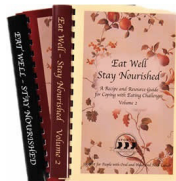
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Eat Well Stay Nourished
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Savory Shepherds Pie



<p>INGREDIENTS</p> <p>¾ lb. chopped meat ½ onion, diced 1 c. peas & carrots (frozen or canned, drained) 1 pkg. brown gravy mix (any brand)</p> <p>Ready made pie crusts (2 per pkg. Pillsbury or store brand) or 3 c. mashed potatoes (ready made or from dehydrated potato flakes)</p> <p>Nutritional Information Per Servings: Calories 251(kcal), Total Fat 12(g), Saturated Fat 5(g), Cholesterol 42(mg), Sodium 148(mg), Carbohydrate 23(g), Dietary Fiber 3(g), Protein 13(g)</p>	<p>Heat oven to 375. In a saucepan, brown chopped meat with onions. Add peas, carrots, gravy mix & enough water per package instructions. Cook until gravy thickens. Put one crust in a pie plate & add the meat & vegetable mixture. Spread mashed potatoes on top. For a two crust pie, top with a second crust & make two slits in the top crust to vent. Bake for 30 min. Serve with extra gravy & applesauce on the side. Serves 6.</p> <p>Jane Z. - NY</p>
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Go to sphnc.org to place your order today

Chapter News

From the desk of Linda Clyne, Co-Facilitator of SPOHNC Greenville, SC Chapter

Although Valentine's Day is considered by many to be all about romantic love, members of the SPOHNC Greenville, SC Chapter use their yearly February meeting to recognize a love that runs deeper than romance. We honor those who have loved us through some very tough times.

The Hebrew word hesed (חסד) may be the best description of the love our caregivers provide as we traverse the rocky road from that very first day cancer becomes part of our reality.

Many took on the "caregiver" title with fear and trepidation. Some were selfless, dauntless and full of grace from Day 1... and some had to be dragged, kicking and screaming, through the weeds with us.

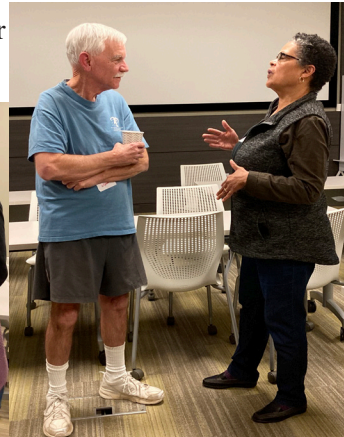
But by the grace of God these indomitable individuals hung with us. They persevered with us, continue to persevere with us, and — Lord willing — will persevere with us long into the future.

Hesed is not merely an emotion or feeling but involves action on behalf of someone who is in need. Hesed describes a sense of love and loyalty that inspires merciful and compassionate behavior toward another person.

Hesed surpasses ordinary kindness and friendship. It runs deeper than social expectations, responsibilities, fluctuating emotions, or what is deserved earned by the recipient. Hesed finds its home in committed, familial love, and it comes to life in actions.

Author Paul Miller describes hesed as "love without an exit strategy."

To all who commit to share the cancer journey with someone they love — with never a thought to an "exit strategy"... We love you. We celebrate you. We thank you!



Share yours
with our readers

Contact SPOHNC today
at
1-800-377-0928
or
info@spohnc.org
to find out
how.

Head and Neck Cancer News

SHARE YOUR PERSPECTIVE ON LIVING WITH HEAD AND NECK CANCER AND EARN \$200

IQVIA™ (www.iqvia.com), a healthcare research firm, is currently conducting a research project with patients 18 years of age or older, who have been diagnosed with advanced or metastatic head and neck cancer by their physician. The research will involve participating in two telephone interviews. Each of these interviews will last for approximately 60 minutes. In appreciation of your time, IQVIA is offering an electronic gift card voucher of \$200.

The research will focus on understanding your experience with head and neck cancer, as well as assess questionnaires designed to evaluate treatment benefits in a clinical trial. This research may help improve how the patient experience is accounted for in future clinical trials.

The study is strictly for research purposes; there will be absolutely no sales or promotional activities.



Share your experience living with Head and Neck Cancer

IQVIA

IQVIA wants to understand the experiences of patients living with locally advanced, locally metastatic or metastatic head and neck cancer through two compensated 60-minute telephone interviews

SCAN HERE TO SEE IF YOU QUALIFY

The advertisement features two women walking outdoors, one wearing a pink face mask and the other a purple one. The text is overlaid on the image, with the IQVIA logo in the top right corner. A QR code is located in the bottom right corner.

Head and Neck Cancer News

New immunotherapy strategies in targeting complexity in the tumor microenvironment

Alexandria, VA (March 18, 2023) – A symposium aiming to provide a better understanding of the tumor microenvironment, immune tolerogenic niches at cancer initiation, and novel immunotherapeutic strategies in head and neck cancer patients was featured at the 52nd Annual Meeting & Exhibition of the AADOCR, held in conjunction with the 47th Annual Meeting of the CADR. The AADOCR/CADR Annual Meeting & Exhibition took place at the Oregon Convention Center in Portland on March 15-18, 2023.

Cancer immunotherapy has arisen as a promising new treatment modality for head and neck cancer (HNC), built on an increased understanding of tumor immunology over the last two decades. However, it has become clear that not all tumors are created equal when it comes to their immune profiles, and many are resistant to immunotherapy. Thus, there is a need to better understand the complex tumor microenvironment to more accurately determine prognosis and design therapeutic strategies

capable of rendering tumors susceptible to immunotherapy and the immunologic effects of conventional therapies.

Organized by Simon Young of the University of Texas Health Science Center at Houston, this symposium provided a high-level overview of exciting developments in understanding the tumor microenvironment, both in terms of the complex immunosuppressive mechanics of the extracellular matrix, the creation of an immune tolerogenic niche at cancer initiation, and how novel immunotherapeutic strategies can target the adverse the tumor immune microenvironment in head and neck cancer. A broad spectrum of expertise was represented by featured clinician-scientist speakers: topics included current challenges in HNC surgical oncologic ablation strategies and formation of the immune tolerogenic niche at cancer initiation. This was followed by novel strategies to target fibrotic inflammation and biomaterial-based strategies for cancer immunotherapy and delivery of therapeutics to the immunosuppressive tumor microenvironment.

The symposium targeted dental students, post-graduate students, dentists, dentist-scientists, and scientists who wished to expand their knowledge of the tumor immune microenvironment and how cancer immunotherapy will impact head and neck cancer patients. This session was geared towards clinicians and researchers alike.

March Champion of Hope

Jack Igleburger

Our March
Champion of Hope
is an inspiration

Jack Igleburger – a gentleman, a scholar, and a survivor with a giving heart. Jack has been a member of our SPOHNC family since 2006, after moving to Northwest Arkansas from California, when he and his lovely wife and soulmate, Temple, began facilitating the Fayetteville, Arkansas SPOHNC Chapter. SPOHNC’s national office has received monthly meeting updates pretty much ever since then. We have gotten to know the group attendees through Jack’s very informative emails, so even though we can’t get to Arkansas, we feel like we know everyone.

Jack and Temple... a SPOHNC institution, until Jack’s beloved Temple passed away in 2021. They had been through so much together. Jack has held his head high through thick and thin and keeps pressing on as the strong and dignified man he is. He has a great spirit that won’t be broken.

Jack is a survivor of stage 4 base of tongue cancer. He had a recurrence and in 2018, underwent a laryngectomy. He made sure the support group didn’t miss a beat by appointing Gene Staggs to run the group while he recovered.

In 2012, Jack and Temple made the trip to New York to join their SPOHNC Family for the 20th Anniversary Conference and Celebration of Life. It was a wonderful weekend of camaraderie

and Jack and Temple had a great time connecting with other survivors and caregivers who attended this weekend long event. It was wonderful to meet them in person!

2012 was a busy year for Jack as he was also honored with the esteemed Gentleman of Distinction Award during the ninth annual Bill Fleeman Gentlemen of Distinction fashion show at the John Q. Hammons Convention Center in Rogers. Jack said of the award...“They usually are picking doctors and well-known dignitaries and philanthropists [for the award], people that are a little more well-known than Jack Igleburger. It was rather humbling that they thought I deserved it - that we deserved it.” SPOHNC featured this award and some great event photos in the December 2012 issue of **News from SPOHNC**.

Jack is a dedicated volunteer and has always taken his role as facilitator very seriously. He is a great provider of support and information for the group and always keeps the connections

going, even outside of meeting time. During the pandemic, he was able to pivot and offer the group the option of zooming, in order to stay connected during such a critical time. He is also much beloved by the SPOHNC national office for consistently encouraging group attendees to become members of SPOHNC!

Jack – we honor you this month as our March Champion of Hope. For more than 16 years, you have supported countless patients, survivors and

caregivers with your encouragement, optimism, understanding and patience. You are an inspiration to all!



“I feel very blessed to have found you...”

~ David

Don’t miss our upcoming
Spring issue, featuring Part 2 of the
Dental Implants feature article

CHAPTERS OF SPOHNC

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

PLEASE NOTE: Some Chapters are not holding meetings in person at this time.

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

Call to SPOHNC to find out more.



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

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

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