

HEADWAY

SINCE 2007

NEWS ON ADVANCES IN THE PREVENTION, DETECTION, AND TREATMENT OF HEAD AND NECK CANCERS

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Support system and well-being in patients with head and neck cancer

By Fendi Obuekwe, BS; Jonas T. Johnson, MD, FACS;
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Receiving the diagnosis of head and neck cancer, undergoing treatment, and managing disease- and treatment-related side effects is a difficult, life-long journey. Patients often lean on family members, close friends, and caregivers for physical, social, emotional, and financial support. Though our head and neck cancer clinic offers professional support from various providers, patients heavily rely on social support from their community or personal support system.

Social support may be emotional, instrumental, appraisal or informational. Low social support is associated with poor health-related quality of life and increased psychological distress. Social support, especially emotional support and spousal support, protects against depression, anxiety, and loneliness in the general population. While studies show that greater social support is associated with decreased psychosocial distress in patients with head and neck cancer, the relationship between social support and quality of life is inconsistent. Some studies report that higher social support is associated with better quality of life, while others report that there is no association. Lower quality of life is associated with increased symptoms of depression and anxiety and elevated feelings of loneliness in patients with head and neck cancer. As head and neck cancer causes disease- and treatment-related difficulties with speech, swallowing, movement, and facial disfigurement, which impact quality of life and may lead to social isolation, the relationship between social support and quality of life, depression, anxiety, and loneliness should be explored in our patient population.

Moreover, while studies evaluating perceived social support in patients with head and neck cancer exist, data on the composition of support systems and satisfaction with received support is limited. Though some patients may have an extensive personal support system, others may have limited or nonexistent support. The quality of received support may also differ from the quantity of available support. Understanding not only the availability of social support but also the makeup,



Fendi Obuekwe

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Having a voice in the fight against cancer

By Marina Posvar
*Patient Navigation Services Coordinator,
UPMC Hillman Cancer Center*



Marina Posvar

As a two-time breast cancer survivor, I am the first to admit that pink is everywhere – and not just in October. But when I was diagnosed with cancer, there weren't enough

pink ribbons in the world to alleviate my fears of leaving my 3- and 5-year-old sons without a mother. Thankfully, I survived each diagnosis and got to see my boys grow into fantastic men!

I started working at UPMC Hillman Cancer Center when it first opened in 2002, shortly after I went through treatment. I am still a member of the Hillman team, connecting patients to education, services, and support as a Patient Navigation Coordinator. When I arrived at Hillman, I quickly learned that there are many more colors of ribbons than just pink, and, with that, I became aware of the lack of funds for lifesaving and groundbreaking medical research across cancer diagnoses and the disease spectrum. This revelation began my journey of being an advocate and speaking up not only for myself and my boys but for anyone who has been or will be touched by cancer.

While volunteering with the American Cancer Society (ACS) I learned about their nonprofit nonpartisan advocacy affiliate, the American Cancer Society Cancer Action Network (ACS CAN). It is the nation's leading advocacy organization dedicated to passing evidence-based laws that contribute to the fight against cancer and ensuring that cancer patients, survivors, and their families have a voice in public policy matters at all levels of government. ACS CAN works to encourage elected officials and candidates to make cancer a top priority.

I have never been politically inclined or interested, frankly. But through ACS CAN, I learned that many of the most important decisions about cancer are not made in the doctor's office but, rather, in state legislatures, Congress and the White House. So, I became an ACS CAN volunteer. Now I have a voice in the fight against the disease – not just with pink ribbons – but with every color of ribbon representing all cancers.

At the federal, state, and local level, ACS CAN works to improve cancer patients' access to care, removing barriers to the latest prevention and early detection measures, treatments, and follow-up care that are proven to save lives. ACS CAN also prioritizes policies that reduce health disparities, ensure clean indoor air and access to smoking cessation programs, promote the importance of clinical trials and secure funding for cancer research, and more.

As a volunteer, I am provided many tools to be a successful and impactful advocate. For example, I may receive an email containing a call-to-action about a specific issue or bill that I can send directly to my lawmakers. In my visits with legislators, I am prepped on and provided with extensive information about our legislative goals and how they will benefit the cancer community. But ACS CAN knows that the greatest resource we have to persuade lawmakers to support policies benefitting cancer patients is our story; by telling your Congressperson, Councilmember or State Representative or Senator how cancer has impacted your life or that of your family, you communicate the impact such policies can have.

Volunteering with ACS CAN is incredibly rewarding, and it is so fun to work alongside other volunteers who are as passionate as I am to change the face of cancer. I urge anyone who's been touched by cancer to join me in this fight. To learn more about the work of the American Cancer Society Cancer Action Network or get involved, you can visit www.fightcancer.org.

Supporting patients, caregivers and staff through meaningful connections

By Amber Miller
*Director, Volunteer & Guest Services,
UPMC Hillman Cancer Center*

If you've visited UPMC Hillman Cancer Center in Shadyside, Pittsburgh, you may have encountered someone donning a jade green jacket at our main entrance eager to assist you when entering the



facility. Our volunteers welcome you with a friendly smile, whether you see it or not under their masks! We aim to take away the burden of navigating through the building by escorting new patients to their appointments while acclimating them to the 'lay of the land' in the cancer center. Additionally, our volunteers are there to assist with whatever the needs may be, such as providing a wheelchair and accompanying the patient and family to their destination while guiding them to whatever services and support they may need. The initial welcome we offer will hopefully ease the stress of coming to Hillman in what can be a very difficult time in a patient's and family's life. No one wants to have to go to a cancer center. Our volunteer program focuses on small gestures as these to provide comfort and calm during a trying time.

Throughout the facility, you will find volunteers working in a number of roles; such as assisting researchers in the discovery of new treatments in Labs located right at Hillman, serving lunches and snacks to patients during treatment, or fitting a patient with a new wig who

may be experiencing hair loss due to therapy, and in the Gumberg Family Resource Center providing educational, supportive materials, and direction to services in the cancer center and in the community.

The volunteer department collaborates with many departments such as clinical research, pharmacy, laboratory research, as well as our medical oncology clinics for volunteer opportunities. We work with each volunteer applicant to understand their interests and goals and then find the best fit for what they hope to achieve with their volunteer service. It is extremely important to us that the volunteer finds fulfillment in their volunteer work. The volunteer opportunities are diverse and are always evolving to meet the needs of the patients and staff.

Volunteers can also be found working behind the scenes in many departments assisting staff with administrative tasks or restocking supplies. In addition to the amazing 'people' volunteers, we have a robust program made up of our four-legged friends, our pet therapy dogs! The pet therapy program celebrated a 10-year milestone in 2022, with 73 dogs coming through the program, nine of which joined within the last year. The pet therapy teams make rounds in the common areas and visit with patients, visitors, and staff to help patients and families forget, even if just for a moment, that they are in a cancer center. We recognize that not everyone is a dog person, so the teams respect everyone's space and ensure to check for comfortability before approaching.



For the artists, and for those who want to discover their creative side for the first time, volunteers provide patients with the opportunity to paint a tile that will be placed in the Healing Wall display located



on the walkway between Hillman and Shadyside Hospital.

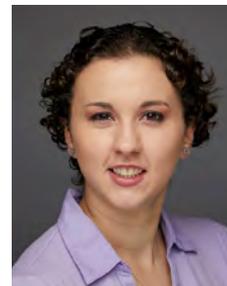
Perhaps, finding quiet and comfort is what is needed for a patient's day; you will find volunteers making rounds with the comfort and caring carts. With generous support from donors and community members, volunteers offer many items that may help to bring comfort or relaxation to the patients such as warm blankets, hats, mints, word/number puzzle books, lip balm, playing cards, backscratchers, just to name a few.

In addition to our main location in Shadyside, we support volunteers at numerous community cancer center locations in similar volunteer positions. We currently have active volunteers supporting our Uniontown, Washington, Beaver, and Somerset locations. Currently, the volunteers' ages range from 18 to 90, and we are always welcoming new volunteers! Right now, there are 140 active volunteers in our program and in the last year, the volunteers have given over 14,000 hours of service! We are continuing to rebuild the program post-pandemic and are extremely grateful to all our long-standing volunteers who have been with us for many years, and all the new people we are fortunate to meet every day. We strive to build quality and meaningful connections through the service work of these remarkably compassionate and giving individuals, our valued Hillman volunteers.

For questions, information, or interest in volunteering at any of our locations, please send an email to hccvolunteer@upmc.edu or call 412-623-4636 or 412-623-3478.

A better tool for identifying malnutrition

By Alyssa Weinfurther, MS, RD, CSO, LDN
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Alyssa Weinfurther

A dietitian is an expert in the field of nutrition. They work in a variety of settings and help patients with many different problems that they encounter related to eating. Dietitians are

especially helpful to patients who have head and neck cancer. They also help patients identify if they are getting enough nutrition or need to make any adjustments to their diet to help improve their overall health. One way they can do this is by using a newer tool for identifying malnutrition (meaning: bad nutrition). Malnutrition is most commonly referring to not eating enough nutrients to maintain weight or muscle status. This newer component of nutrition assessment, called the Nutrition Focused Physical Exam (NFPE), was created and is used by dietitians to help identify malnutrition.

Prior to being trained in NFPE, malnutrition was identified by having weight loss (of varying amounts) and decreased nutrition intake. While these are very important parts of nutrition, the missing piece in nutrition assessment was assessing muscle and fat sites to determine if someone is well-nourished or malnourished. NFPE is a hands-on exam evaluating various muscle and fat sites throughout the body to assess for degrees of muscle or fat wasting. This exam takes only a few minutes and incorporates areas on the face, shoulders, back, arms, and legs. During this exam, the dietitian will touch specific parts of these body parts and may ask you to engage the muscles by biting down like you are chewing, pushing on their hands, or moving your legs like you are marching. By engaging the muscles, dietitians can feel the muscles to determine if there is any muscle loss present.

The Head and Neck Survivorship Clinic at UPMC sees patients throughout all stages of their cancer journey. This clinic contains two registered nurses, one ear nose and throat surgeon, three speech language pathologists, one physical therapist, one registered dietitian, one dentist, one audiology assistant, and two research coordinators. NFPE was implemented on all patients who were getting ready to start chemo and/or radiation from August 5, 2021 through July 7, 2022 to determine if more patients could be identified as malnourished using these additional criteria. By incorporating this malnutrition screening tool, 42% more patients were able to be identified as having malnutrition than just using weight loss and decreased nutrition intake. In the survivorship clinic, this information was used to help start focusing on improving nutrition intake after this initial visit, but before the patient starts treatment and develops side effects that may worsen their nutrition status. If using NFPE showed that a patient had malnutrition, they were encouraged to focus on increasing intake of calories and protein foods. By eating more calories and protein, patients can improve their weight and muscle mass before starting treatment. Once patients start treatment, they often have some degree of side effects (like nausea, vomiting, chewing/swallowing difficulty, and taste changes). Many of these side effects can make eating more challenging.

By starting the focus on improving nutrition before starting treatment, patients may have more strength and less breaks in treatment as they move on to chemo and/or radiation. Dietitians are an important part of this. If you are interested in meeting with a dietitian to help with your individual nutrition needs, ask your

medical oncologist, ENT surgeon, or the Head and Neck Survivorship clinic to send a referral for medical nutrition therapy or nutrition consultation.

Advancing survivorship care through research

By Marci Lee Nilsen, PhD, RN, CHPN, FAAN
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Otolaryngology, School of Medicine*



Marci Lee Nilsen

For patients who have undergone surgery or radiation for head and neck cancer, it's important to recognize the potential changes that may occur in your shoulder and neck area. Around

half of survivors report experiencing pain, including stiffness and cramping, in their neck, which can impact daily activities like driving or working. These changes often stem from scarring or stiffening of the skin, tissue, and muscles, a condition known as fibrosis. This alteration in skin and muscle can restrict movement, making it challenging to turn your head or causing slower movements to avoid discomfort. Additionally, some patients facing neck pain may also experience difficulties with swallowing. These physical changes together can affect the overall quality of life for individuals who have undergone treatment for head and neck cancer. It's essential to be aware of these side effects of treatment and seek support or guidance from healthcare professionals to manage and alleviate these challenges.

As healthcare providers, our goal is to closely monitor changes in patients and offer therapies like physical therapy so you can maintain or improve your function. At present, we lack specific strategies to prevent these side effects from arising altogether. With the impact these changes have on the lives of people with head and neck cancer, it is important we continue to better understand these issues and work to develop novel interventions that are accessible to all patients. In order to grow the knowledge in this area, I was

awarded a research grant from the National Cancer Institute. This grant enables us to delve deeper into understanding the causes, including genetic markers, of fibrosis and its accompanying symptoms, such as neck pain, stiffness, and difficulties with swallowing. We'll be tracking patients throughout their treatment and for two years afterward to assess any changes. Our research team, comprising physicians, physical therapists, and swallowing therapists, is dedicated not only to uncovering insights but also to creating innovative solutions that address these challenges. Our collective goal is to enhance the lives of those affected by head and neck cancer.

Building head and neck cancer care around the best functional outcomes for patients

By Lisa A. Goldstein
Writer, Eye & Ear Foundation

Under the leadership of Dr. Zevallos, one of the big changes that is moving forward for the Department of Otolaryngology is to hire otolaryngology head and neck surgeons to perform complex head and neck reconstruction. Microvascular reconstructive surgery involves using tissues from other parts of the body and transplanting them to fix defects in the head and neck. This can include using bone from the fibula bone to reconstruct the mandible after cancer surgery, and skin and muscle from the thigh or forearm to reconstruct the tongue, among many other applications.

The Department of Otolaryngology has recruited Matthew Spector, MD, one of the most experienced and accomplished head and neck microvascular surgeons in the United States, to lead this effort. As the Director of Head and Neck Surgical Oncology & Microvascular Reconstruction, the goal is to build a cutting-edge head and neck reconstructive surgery program at UPMC based in the Department of Otolaryngology. Kevin Contrera, MD, MPH, a head and neck surgical oncologist and microvascular reconstructive surgeon trained at MD Anderson Cancer Center,

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For additional topics on the prevention, detection and treatment of cancer, including head and neck cancer, visit www.hillmanresearch.upmc.edu/about/news/publications for archived issues of Headway.

YASU: a supportive lifeline for young adults impacted by cancer

By Stephanie Samolovitch, MSW
YASU founder and Executive Director



Stephanie Samolovitch

Recently, I dined out at a new restaurant in downtown Pittsburgh with four other women as we celebrated a 10 year anniversary of one of them having stage 4

breast cancer since day one. Ironically each one of them is a young adult breast cancer survivor, diagnosed in their 20s and 30s. Navigating through treatments, surgeries, lack of finances, parenting, anxiety and depression, job disruptions, and so many other factors that contribute to how and why all of us have a special bond. We understand and appreciate each other.

Sitting across from the 10 year cancer survivor was a 40-year-old breast cancer survivor of seven years. Two weeks prior to our dinner celebration, she was diagnosed with a recurrence and now has stage 4 breast cancer. We didn't know how the evening would turn out. Do we celebrate the anniversary and ignore the recurrence? Do we acknowledge both? Do we reschedule dinner for the time being?

This dinner was an incredibly special memory maker because everyone was supported, regardless of life circumstances.

In 2020, I founded Young Adult Survivors United (YASU) after overcoming my own Leukemia diagnosis in 2005 at the age of 20. This was a chance to fill a significant gap with many unmet needs. The pandemic immediately forced us to build a virtual platform, which I never imagined being as impactful as it's been. Our model starts with three pillars of providing emotional, social, and financial support. Virtual support group chats is the safe space for them to disclose without judgement and feel united with their peers. Socials are the perfect distraction from everyday

stress and engages them without feeling obligated to talk about cancer. Financial toxicity is among the greatest challenges experienced by this population. We contribute \$500 towards their medical bills, rent or mortgage, utility bills, fertility preservation costs, integrative oncology services, or for basic need support (groceries and gas gift cards).

In 2021, we launched the Rae of Hope program, offering free daylong or overnight respite trips for our members. This program was created in honor of a YASU member who had breast cancer for 10 months but sadly passed away. These trips are memory makers. They give our members a chance to get away, relax, and recharge. Without this program, members simply can't afford such trips. Think about what it does for their mental health as well. It's not just about a fun trip. It's about self-care and much needed breaks from everyday stressors and worries.

Some of the other ways we support young adult cancer survivors only happen thanks to our amazing partnerships with companies such as Calm Pittsburgh and iZORA. Thanks to them and supporters like The Pittsburgh Foundation, we're able to provide free counseling for our members. The generous staff at iZORA provide free microblading or semi-

permanent eyeliner to our members as long as they provide approval on letterhead from their oncologist. One of our most popular programs is the monthly Self-Love Workshop. Such programs increase self-awareness and confidence as young adult survivors transition through treatments, surgeries, and hopefully back into life post-cancer. We're the helping hands supporting them throughout the entire journey.

As you can see, YASU makes every effort to build and strengthen this community, provide various programs that encompass the age appropriate tools, programming, and support needed to confront and overcome cancer with those who understand and can relate. Regardless of age, if you've been impacted by cancer, I highly encourage you to find a community that's relatable to you; whether it be the same diagnosis, age, location, etc. I am a firm believer that medicine can help but it is much easier and rewarding to cope when you aren't alone. If you don't know where to turn, start with your medical team; especially nurse navigators. All of us are here to make your journey less stressful and more meaningful. You are never alone, I assure you.

Support system

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magnitude, and satisfaction with support will allow providers to identify deficiencies in support, and to mitigate negative outcomes associated with inadequate support. Furthermore, understanding which patients desire to expand their support system and in which domains will allow for effective interventions, such as cultivating peer-to-peer connections and increasing enrollment in head and neck cancer support groups.

The Survivorship Clinic plans to explore the association between personal support system and physical-psychological-social-emotional well-being in patients with head and neck cancer in all stages of the survivorship trajectory. Participants will complete a survey assessing sociodemographic characteristics, composition of personal and professional support systems, availability of social support,

satisfaction with received support, willingness to expand personal support system, health-related quality of life, symptoms of depression and anxiety, and feelings of loneliness. As quality of life changes over the course of survivorship and sociodemographic factors influence health outcomes in patients with head and neck cancer, we will study support and well-being in patients at various stages of the survivorship trajectory with diverse sociodemographic characteristics.

We believe that having a strong support system is imperative to a favorable well-being in patients with head and neck cancer. We hope to expand and strengthen social support to reduce psychosocial distress and improve health-related quality of life in our patient population.

Building head and neck cancer care

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was also hired for the same reason. These changes are in line with national trends at most major academic cancer centers across the United States, where highly trained head and neck microvascular reconstructive surgeons based in Otolaryngology perform the majority of these complex cases.

"The major goal of the head and neck reconstructive program is to improve on the functional outcomes of patients who undergo reconstruction at UPMC," Dr. Spector said. "Between Shaum [Sridharan], Kevin, and I, we have a wealth of skill and knowledge to perform these surgeries. We have trained across the country to bring in this expertise. When performing these complicated reconstructions, there are a number of goals. The overarching goal is to improve the speaking and swallowing outcomes of patients, to bring an individual back to their employment, and to maximize the cosmetic outcome, to name a few."

The group will be able to not only provide these complex services, but also do further research on how to maximize these outcomes. They partner closely with Dr. Steve Kim, Dr. Zevallos, Dr. Jessica Maxwell, and Dr. Ferris, as well as the multidisciplinary team that includes speech-language pathology, medical oncology, and radiation oncology. They have interests in tongue reconstruction, soft tissue reconstruction after cutaneous cancer surgery, parotid reconstruction after salivary gland surgery, voice box reconstruction and throat reconstruction after larynx cancer surgery, reconstruction after trauma, and management of difficult head and neck wounds – among others.

"Our goal is to maximize function and minimize the morbidity of surgery using cutting-edge reconstructive techniques," Dr. Spector explained. "We want to provide an individualized approach for each patient, understanding their goals and needs to provide the best outcome."

Head and Neck Cancer Program website

Looking for more information about patient services, current research, clinical trials, news and events, and other valuable information pertaining to head and neck cancers? Check out the website for the Head and Neck Program of UPMC Hillman Cancer Center at UPMCHillman.com/headandneck.

Contact information

American Cancer Society.....	1-800-227-2345 cancer.org
Breast Cancer Support Group – UPMC	412-647-2811
Cancer Bridges.....	412-338-1919 <i>Counseling, support groups, health and wellness, family programs</i> cancerbridges.org
Center for Counseling and Cancer Support – UPMC.....	412-623-5888
Division of Sleep Surgery – UPMC Mercy.....	412-232-3687
Monroeville.....	412-374-1260
Eye & Ear Foundation	412-864-1300 eyeandear.org
Face2Face Healing.....	724-935-3580 face2facehealing.org
Gumberg Family Library and Resource Center	412-396-6130
Hillman Cancer Center – UPMC.....	412-647-2811 <i>Research, clinical trials, referrals, patient resources, and support</i> hillman.upmc.com
Hopwood Library at UPMC Shadyside	412-623-2620
Hyperbaric Oxygen Therapy – UPMC.....	412-647-7480
Immunotherapy – Cancer Research Institute.....	800-992-2623 cancerresearch.org
Mrs. Claus Club of North Hills	412-992-7339 mrsclausclub.org
Nutrition – American Institute for Cancer Research.....	aicr.org
Prostate Cancer Support Group – UPMC.....	412-647-1062
Swallowing Disorders Center UPMC Eye & Ear Institute (Oakland).....	412-647-6461
UPMC Shadyside.....	412-621-0123
Young Adult Survivors United.....	724-719-2273 yasurvivors.org

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