living well *after* cancer

heal®

VOL.11 NO.1 / SPRING 2023

MANAGING CHEMOTHERAPY-INDUCED *Hair Loss*

Many survivors see significant hair changes during treatment, leaving a difficult reminder when they look in the mirror.

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GARDNER: CCM PHOTOGRAPHY; YOGA: NADIA_SNOPEK / STOCK.ADOBE.COM

Facing External Side Effects

SURVIVING CANCER CAN impact one's health in many ways, but the cosmetic changes people face after cancer treatment can be difficult to grapple with. Some doctors don't address these changes once disease is in remission, or patients struggle with feelings of shame or vanity for worrying about their looks after months or years of worrying about living through treatment.

ANTONIO RODRIGUEZ / STOCK.ADOBE.COM

In this issue of *Heal*®, we hear from patients about their experiences with losing their hair and the changes they've seen during regrowth, as well as the possible options patients and survivors have to preserve hair through chemotherapy.

A new space to be explored is the addition of an oncodermatologist, or a dermatologist specializing in treating patients with cancer. Maintaining hair texture and thickness begins with the scalp, which dermatologists are uniquely qualified to advise patients on.

The psychological effects of cancer altering one's physical appearance may also be tied to functional changes after surgery, especially so in survivors of head-and-neck cancers. These survivors have clear cosmetic changes to their faces, but body image distress includes the impact cancer has on talking, eating and making facial expressions as well. We speak to a biobehavioral specialist and a head and neck surgeon about the advances made in addressing lasting body image distress in survivors.

In our survivor spotlight, we also see how the effects of breast cancer surgery helped celebrity host Samantha Harris make a change in the opposite direction, where life after treatment reoriented her motivation to exercise from achieving aesthetic outcomes to cultivating a healthier body and mind.

However survivorship may have affected your appearance or your relationship with it, we hope this issue provides you with a new perspective on embracing your post-cancer body.

MIKE HENNESSY JR.
President & CEO
MJH Life Sciences®

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overheard on SOCIAL MEDIA

Advice From People Like You

We asked readers, **"How did cancer affect your relationship with your hair?"**

Here's what they said.

"I had long, blond, curly hair when I was diagnosed. Because of my upbringing, I tied my hair to my femininity. Losing it was very hard on top of losing my uterus and ovaries. People say it's just hair and it'll grow back. Not helpful. It has never been the same. I've coped with pretty scarves, sparkly beanies and now bright-colored hair like teal and purple. We need to validate women's feelings however they are impacted — or not. ***— KELLY***"

"I think it is easier being a male. The shock for me when my hair started falling out was how fast it occurred and in the first cycle. Given I had it cut quite short, I found the loose follicles very uncomfortable. Once I shaved my head, I felt a lot better — somewhat empowered. It was something I could take control of. I like to think I have a good-looking scalp, and once I got a bit of a tan (on) it, I got really comfortable with it. Now (my hair is) back, thick and curly. When the weather is humid, it's crazy. I'm alive and well, so I can live with that. ***— PAUL***"

"After losing my hair, it was traumatic and also humbling. (I) was always complaining about my thin, straight-ass hair. Now I have a new appreciation for it. My hair (is) slowly growing back in. It's wavy, frizzy and gray, not sure if (it's) permanent? No idea what the end result will be, but don't care. I will work around it and cherish it. ***— LIZ***"

"It was very hard for me to deal with the fact that it was all (going to) fall out. It used to be hip length and super thick. Now six years later, it's almost waist length, semi curly and super thin. Pretty upsetting, but sometimes I feel almost vain for being so upset about the hair when there (were) other more important things. I guess you could say the relationship is complicated. ***— STEPH***"

» *We want to know what you think about CURE®. Address your comments to* **editor@curetoday.com**. *If you prefer that your comment not be published, please indicate.*

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Clinical Trial Corner

First Patients Dosed With Novel Inhibitor in Trial on Relapsed or Refractory AML Subset
February 11th 2023
Researchers conducting a phase 2 trial recently dosed the first patients with a novel menin inhibitor for the treatment of patients with NPM1-mutant relapsed or refractory acute myeloid leukemia.

Novel Drug to Be Studied in Ovarian Cancer
February 10th 2023
After promising phase 1 results, ART0380 will be studied in a randomized phase 2 trial for patients with platinum-resistant ovarian cancer.

Direct-to-Bladder Immunotherapy Drug to Be Studied in Bladder Cancer
February 1st 2023
The first patient was dosed with lerapolturev in a phase 1/2 clinical trial evaluating the drug in patients with bladder cancer and other solid tumors.

Trial to Investigate If Novel Drug Combo Can Boost Outcomes in Lung Cancer
January 31st 2023
A phase 3 trial will test datopotamab deruxtecan in combination with Keytruda with or without chemotherapy for certain patients with metastatic non-small cell lung cancer.

First Patient Injected With Novel Radiotherapy in Phase 2b Trial for Brain Cancer
January 28th 2023
The treatment previously demonstrated significantly improved overall survival for patients with recurrent glioblastoma in a phase 1 study.

Latest News
'Drawing on the Other Side' Amidst Cancer
Oral Mucositis Drug Is Under Review by the FDA
Here We Go Again: Waiting for Results After Another Cancer Scare
Life Lessons of a Young Cancer Widow
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ANSWERING *the Call*

BCAN
Bladder Cancer Advocacy Network

Bladder cancer survivors face a bevy of challenges post-treatment, but an immediately available service strives to ease the burden.

By MIRANDA LANKAS, M.A.

SURVIVORS OF BLADDER CANCER face myriad issues, with treatment for bladder cancer being among the most expensive. Many patients face body image distress and shame adjusting to life with a urostomy (a procedure that redirects urine into an external bag as opposed to the bladder), changes to their sex life and a more invasive screening procedure that heightens scan anxiety.

For patients recently diagnosed with bladder cancer or going through active treatment, there are plenty of options to help them manage their disease or finances. But the resources survivors and caregivers would benefit from are largely psychological and involve social support, which doctors and advocacy networks are not always equipped to provide.

> “I think having this social work network can help patients and their loved ones that are helping them find the services that they need. They’re out there, but not if you don’t know what they are.” *—STEPHANIE CHISOLM*

The Bladder Cancer Advocacy Network (BCAN) is changing that. Their recently launched call center gives bladder cancer survivors, their caregivers or those who have lost a loved one to bladder cancer the opportunity to call and be connected to a trained social worker who can either counsel the individual then and there or connect them with local resources.

BCAN has always catered to the needs of patients with bladder cancer and has tried to help survivors and their support systems as well, but they now have greater resources to address the latter group.

Stephanie Chisolm, director of education and advocacy at BCAN, described the benefits of including members of a patient’s support system as well as survivors.

“Most (patients with) bladder cancer tend to be on the older side,” Chisolm explained. “It may well be that some of those caregivers are adult children, who may or may not live nearby, which can be a big concern. I think this is another pivot point that can help support somebody whose parents might be living in Florida, but they live in Chicago. They can find out about the resources that can help their parent in Florida or find out the things that can help them as caregivers for the family... (Being a caregiver) does present its own challenges, in the sense of having to take time off from work to get a parent to treatment or to help with the regular maintenance that that parent needs. Because they’re not well, those are things that are very significant. And I think having this social work network can help patients and their loved ones that are helping them find the services that they need. They’re out there, but not if you don’t know what they are.”

BCAN also plans to use the data collected from the call center to inform future events that will cater more directly to the needs of callers. “Why did people call? If we’re seeing that a lot of patients are calling because they’re in distress, (that can be addressed.)” said Chisolm.

The call center is currently active and operates on Eastern Time, but individuals in other time zones who may call at other hours can leave a message and receive a follow-up call at any time. h

The INVISIBLE Side Effect *of* Visible Survivorship

How do survivors of head and neck cancer cope with drastic changes to one of the most visibly identifiable body parts — the head?

By MIRANDA LANKAS, M.A.

MANY CANCER SURVIVORS display outward signs of their disease history; people lose hair, gain scars and ostomy bags, or even experience the full or partial loss of a body part. Some survivors embrace the physical changes in their lives wholeheartedly, with tattoos or photo shoots commemorating their new normal. However, coping with external changes can be a unique challenge for head and neck cancer survivors, whose facial changes include not only disfigurement but challenges with eating, talking and socializing in general.

Head and neck cancer refers to a group of diagnoses where cancer forms in the face, mouth (including the lips, tongue and jawbone), throat, voice box and salivary glands: highly sensitive and critical areas. Survivors often face challenges speaking, chewing, swallowing and smiling, as well as changes to the skin and control over facial muscles, making this a diagnosis nearly impossible to disguise.

Changes to a person's face and their ability to eat and speak will significantly affect their ability to socialize, which poses a clear risk to mental health as well as the ability to return to previous activities. Stacey Maurer, an assistant professor and clinical psychologist in behavioral medicine in the Department of Psychiatry and Behavioral Sciences at the Medical University of South Carolina in Charleston, has been working with head and neck cancer survivors on the psychological impacts of their treatment.

"The head and neck are parts of the body that you can't hide. So if you've had a lot of changes to them, it's immediately obvious to the people around you; it changes people's relationships, how they communicate with people, even day-to-day social interactions. All of that can change really quickly after head and neck cancer treatment, leading to more distress after the treatments."

Head and neck cancer makes up nearly 4% of all cancers in the United States, according to the National Cancer Institute, and one-fourth of survivors develop clinically significant body image distress. Body image distress has been well studied in breast cancer survivors, but effective treatments for that population have not translated to head and neck cancer survivors because of the vastly different circumstances the two groups face.

Dr. Evan Graboyes, a head and neck cancer surgeon at the Medical University of South Carolina and director of Survivorship and Cancer Outcomes Research at the MUSC Hollings Cancer Center, has examined the effectiveness of applying cognitive behavioral therapy techniques (a specific type of therapy intended to change a patient's thought patterns and behaviors) to patients affected by body image distress specific to head and neck cancer survivors.

"If we can help patients adapt their thoughts and improve their coping skills, but can't actually help them look better or swallow better, is that going to be enough?" Graboyes asked in an interview with *Heal*®. "Our thought is yes. It would seem crazy, in fact, that you could somehow remove half of someone's tongue and their jawbone and replace it with a transplant from some other part of their body, and then just expect them to be fine in their new life without helping them learn new skills to adapt to that."

Graboyes and Maurer collaborated on a brief tele-cognitive behavioral therapy method of counseling survivors. In their pilot study, BRIGHT, they saw success in treating the unique concerns of this patient population, and are currently working on a larger-scale study that will hopefully expand post-treatment therapy options for head and neck cancer survivors.

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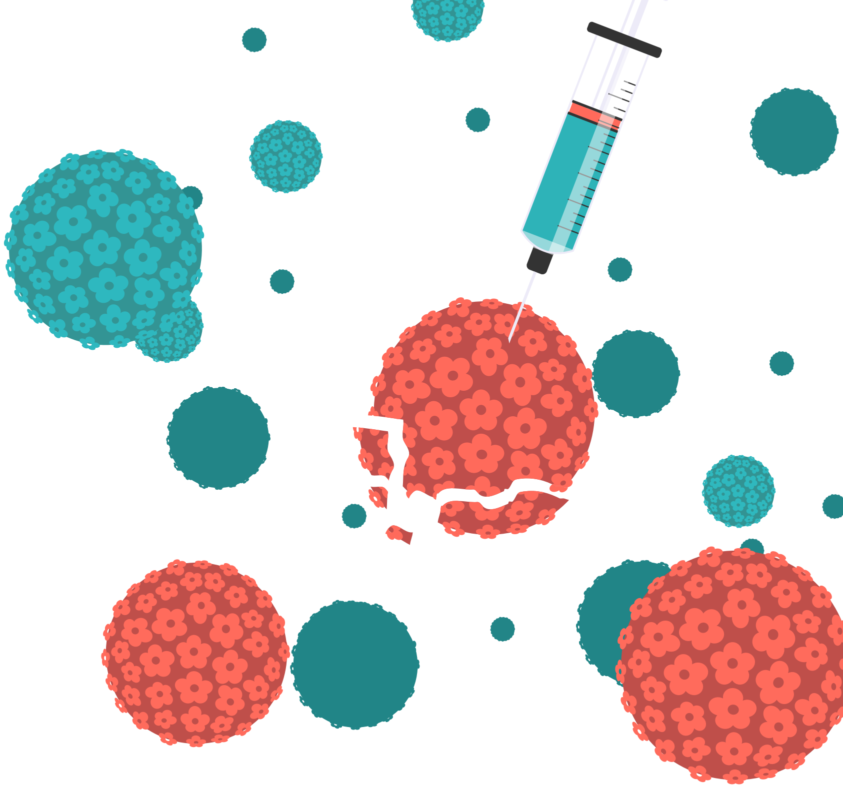
HPV vaccinations



WHY *Risk It?*

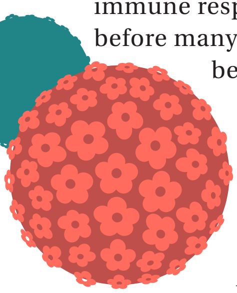
Vaccines have been a hot-button issue for several years now, but are survivors putting their health at risk by avoiding the HPV vaccine?

By MIRANDA LANKAS, M.A.

HPV IS THE most common sexually transmitted infection. According to the Centers for Disease Control and Prevention, 2 in 5 people will be infected between the ages of 15 and 59. Although many infected people will be either asymptomatic or only develop skin symptoms, HPV causes 37,300 cancers per year — despite the fact a vaccine to prevent HPV has been readily available for years.

Almost all cervical cancer is caused by HPV; genital cancers and cancer in the back of the throat and tonsils may also be caused by some strains of the virus. There is no way of knowing whether any one case of HPV will quietly go away on its own or linger and develop into a cancer. However, two specific strains of the virus (type 16 and type 18) have the greatest risk of developing into cervical cancer, and the vaccine can prevent infection with these two strains.

The best time to get vaccinated against HPV is at 11 or 12 years, as children in this age range display the greatest immune response to the vaccine. Vaccination at this age, before many children become sexually active, is also beneficial. Individuals are still recommended to get the HPV vaccine through the age of 26 if they have not been vaccinated earlier.



However, cancer survivors up to the 26-year-old cutoff are sometimes reluctant to receive the HPV vaccination, despite its benefit of preventing cervical cancer.

Brooke Cherven, an assistant professor of pediatric oncology at Emory University School of Medicine in Atlanta, has been examining the safety and efficacy of the HPV vaccine in cancer survivors, but also has been asking patients who decline what their reasons are for doing so. "We looked at all reasons that participants had (given) or that families had given and realized that about 70% of the reasons were related to vaccine-related concerns," she said.

Vaccine-related concerns include safety concerns, vaccine hesitancy, external influences, health beliefs and decisional processes, vaccine-related information deficits and disinterest.

Of note, there was a higher rate of vaccine-related refusal in younger survivors whose parents were making their medical decisions (76%) than in older patients who were likely deciding on their own (60%).

Cherven suggests that health care providers could boost HPV-vaccination rates in the childhood cancer survivor population by giving patients and caregivers evidence-based encouragement tailored to their specific situation as survivors, as opposed to passing on information for the general population.

"The HPV vaccine is recommended [for] all cancer survivors to prevent future cancer," Cherven said. However, she explained survivors who had been treated with "sustained immunosuppression are at the greatest increased risk for HPV persistence and complications."

"Genital HPV has been described as a significant late complication in a cohort of [patients who received] allogenic stem cell transplant, with one-third of long-term survivors displaying HPV-related disease. The patients at particular risk were those with associated chronic graft-versus-host disease requiring prolonged systemic immunosuppressive therapy."

All these risk factors for HPV-related disease are specific to childhood cancer survivors, but many survivors or caregivers may be unaware of this unique risk. If the information gap persists, survivors may easily age out of the HPV-vaccine effectiveness age range and open themselves up to the risk of a new cancer diagnosis.

"We're really focused on helping survivors stay healthy, and interventions that can improve their health and quality of life in the future. And the HPV vaccine is a safe, effective, well-established intervention to prevent future cancers," Cherven emphasized. h

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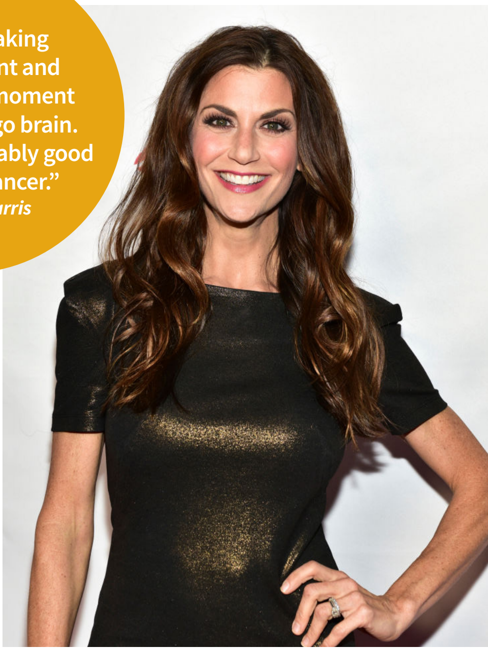
> “(Yoga) is making me stay present and focused in the moment with my go-go-go brain. Okay, this is probably good for me after cancer.”
> ***Samantha Harris***



Exercise à la *Seconde*

After years of working out to look good on-screen, recovering from breast cancer surgeries pushed TV host **Samantha Harris** to move her relationship with fitness to second position.

By MIRANDA LANKAS, M.A.

HARRIS: RODIN ECKENROTH/FILMMAGIC VIA GETTY IMAGES; YOGA (TOP): FLASH CONCEPT / STOCK.ADOBE.COM; YOGA (BOTTOM): NADIA_SNOPEK / STOCK.ADOBE.COM

SAMANTHA HARRIS HAS hosted “Dancing With the Stars,” worked on “Entertainment Tonight” and starred in a Broadway production. She has been on the cover of magazines dedicated to fitness — her body is part of her brand. So her decision to undergo a double mastectomy and subsequent reconstructive surgery in the face of a breast cancer diagnosis was not made lightly.

“I was the fit and healthy one among my friends and family,” Harris said in an interview with *Heal*®, “the one who they made fun of because I ate cheese-less pizzas and tons … of skinless, boneless chicken breasts and egg whites. And then I had this diagnosis, which was shocking.”

Though the toll on Harris’s physical health was obvious during treatment, she talked about how difficult the recovery period was, because she had identified as an active person and was now barred from exercise.

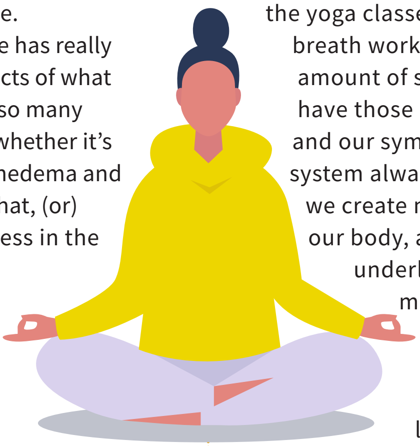
“The biggest challenge I had was the recovery period after surgeries because my reconstructive surgeon had a plan of action where I had to stay in bed for three weeks after each surgery, … only getting up for 20 minutes every two hours. For someone who’s very active and likes to be on the go — I think I woke up from surgery and said, ‘When can I start exercising again?’ — I had a lot of range-of-motion challenges.”

When Harris was cleared to exercise again, her mindset was different.

“My workout routine before cancer was because I wanted to look good in a dress; it was all extrinsic. I was hosting ‘Dancing with the Stars’ standing next to these gorgeous, muscular dancers, and I just wanted to look like them. That’s how I got into yoga, because I loved the arm definition. Then I learned, ‘Oh, this is making me stay present and focused in the moment with my go-go-go brain. OK, this is probably good for me after cancer.’”

Exercising is now also part of a preventive plan to prevent lymphedema, a blockage in the lymphatic system. Harris found herself at risk for the condition when 11 of her lymph nodes were removed due to metastatic disease.

“The biggest challenge has really been the downward effects of what happens after you have so many lymph nodes removed, whether it’s the lifetime risk of lymphedema and being really mindful of that, (or) achiness and the heaviness in the arm from time to time.”



Harris finds using exercise to mitigate the risk of lymphedema gives her a sense of control as well as peace of mind after the tumultuous experience of treatment. “Having to integrate other wonderful tools that have become my go-tos for when I’m getting that heaviness… — that might signal early stages of lymphedema — (can also be challenging). …So having a regular exercise schedule and being physically active on a daily basis, maintaining a healthy weight helps keep lymphedema at bay because we know obesity can exacerbate it.”

Now Harris has turned her new attitude toward fitness into a health counseling group and an ambassadorship for YogaWorks Pink, a yoga program dedicated to patients with breast cancer and their caregivers. She emphasized the meditative benefits yoga provides her with and why she feels breath work and any possible stress reduction is vital to survivorship:

“(YogaWorks Pink) also has not just the yoga classes, but meditation and breath work classes to reduce our amount of stress. … When we have those high levels of cortisol and our sympathetic nervous system always going all the time, we create more inflammation in our body, and we know that’s an underlying cause of so many diseases.”

The changes Harris made in survivorship have been long lasting, as she continues to connect with other breast cancer survivors and furthers her yoga practice — often simultaneously as she encourages others to try her coping mechanism. “For me, guided meditation (and) guided breath work (were) what got me over that hump, and still to this day is what I practice.”

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Your insights can change the future of cancer support

Did your cancer experience include the social support you needed?	Did you experience problems accessing care?	Did caregiving impact your quality of life?

Participate in Important Research

The Cancer Experience Registry (CER) survey from Cancer Support Community (CSC) uncovers the emotional, physical, practical, and financial impact of cancer to help patients and caregivers get the support they need. Through the CER survey, we reach those impacted by cancer so their voices can be part of this important research and so that together, we can:

Influence healthcare policies

Enhance cancer care

Improve support services

CancerSupportCommunity.org/Registry

CANCER SUPPORT
COMMUNITY™
CANCER EXPERIENCE REGISTRY

How it Works

1

Start the survey by selecting patient or caregiver

2

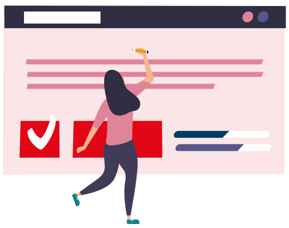
Answer questions about your cancer experience

3

Start and stop when you like by using the unique link emailed to you

4

Be invited to take part in follow-up surveys or other research and programs applicable to you



The survey takes about 35 minutes to complete.

Use the QR code to take the survey

Frequently Asked Questions

What is the Cancer Experience Registry?
The Cancer Experience Registry (CER) is an online research survey that helps enhance cancer care, improve health care policies, and ensure support services better reflect the needs of people affected by cancer.

Who can take the survey? The CER is open to any adult who has been diagnosed with cancer at any point in their life or has been a family or informal caregiver to someone with cancer. Participants must live in the United States, a U.S. territory, or Canada and be able to read and understand English.

What about my privacy? The survey is an Institutional Review Board (IRB) approved research study, which means that the confidentiality, rights and welfare of participants are protected.

Is there a cost to take part? No, there is no cost to take part in this research.

What is the benefit to taking part? By generously giving your time for this important research, your contributions help deliver better outcomes for those impacted by cancer, now and in the future.

What happens when I've finished the survey?
Once you complete the survey, you become part of a registry of patients and caregivers with the opportunity to complete follow-up surveys that track changes over time, or additional surveys that ask about emerging topics in cancer care.

Help change the future of cancer support by taking the CER survey

MANAGING CHEMOTHERAPY-INDUCED Hair Loss

Many survivors see significant hair changes during treatment, leaving a difficult reminder when they look in the mirror.

By JULIE SCOTT, DNP, ANP-BC

Chemotherapy-induced alopecia, or hair loss, is a common side effect of many chemotherapy treatments for cancer. Chemotherapy works by targeting rapidly dividing cells, such as cancer cells. However, hair follicles also divide rapidly and are therefore affected by the treatment. As a result, hair loss can occur anywhere hair grows — on the scalp, face and body. Not everyone who receives chemo will experience hair loss, but for those who do, it can be distressing.

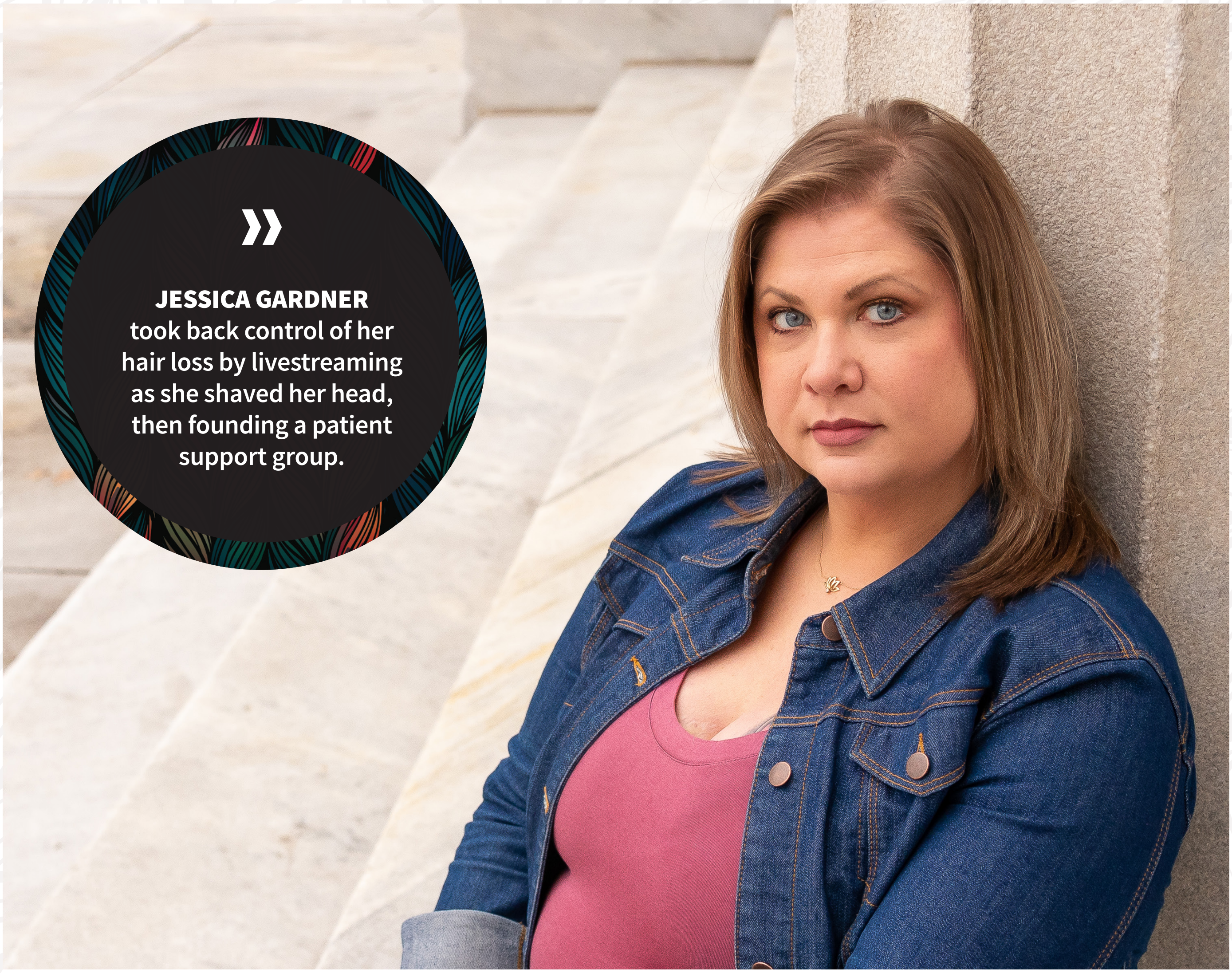
For many people, hair is an important aspect of self-expression and identity, and losing it can be emotionally difficult. As she recalls her experience with chemotherapy for breast cancer, Lauren Thorse remembers that when she was told she would need chemotherapy, “my first thought was that my hair is gonna go.” As someone who reports struggling for years with self-confidence, Thorse, of Naperville, Illinois, found the impending hair loss upsetting. Having always had long blond hair, seeing it fall out in clumps and finding it around the house led her to decide to shave it. With the support of her father, and her mother and sister via FaceTime, her husband shaved her hair off.

After finally coming to terms with losing her hair, she then had to wrap her head around the fact that “it’s going to take years to get back to where it was.” »

CUTTLEFISH84/ STOCK.ADOBE.COM

LAUREN THORSE says a year after completing treatments she still “mourns” her long, pre-treatment hair.

ARIELLE GALLIONE



JESSICA GARDNER took back control of her hair loss by livestreaming as she shaved her head, then founding a patient support group.

Cancer survivor Jessica Gardner of Youngstown, Pennsylvania, also took matters into her own hands when she began losing her hair from chemotherapy. After being diagnosed with breast cancer while 33 weeks pregnant and undergoing a bilateral mastectomy not long after having a cesarean section, she felt that she wanted to have control over something — and that was her hair loss. While livestreaming the shaving of her head, she felt as if she was getting some of her power and control back.

Once their hair was gone, both Thorse and Gardner felt frustrated over the lack of resources that were available to women their age, in their early 30s, with young children. They found that many of the resources were for older women and didn't quite meet them where they were in life. Thorse recalls, "I felt like the wigs I was directed to were more for older women."

Because Gardner found local support groups difficult to connect with, she created the group Cancer Is a Mother on Facebook. She found that this was a way to do something positive with her cancer diagnosis. "It was something I needed to do personally to feel better about cancer and where I was as a survivor."

Hair loss can be gradual or sudden, and it can begin within a few weeks of starting chemotherapy treatment. Some patients may experience thinning of the hair, whereas others may experience complete baldness. In some cases, hair may only thin or fall out in certain areas, creating patchy hair loss. This is most often temporary, and the hair will grow back once chemotherapy treatment is completed. However, in rare cases, some patients may experience long-term or permanent hair loss. The risk of either of those is generally low, but it can depend on the type and dose of chemotherapy used. Certain chemotherapies, such as taxanes, are associated with a higher risk of long-term or permanent hair loss.

Now that a full year has gone by since completing chemotherapy, Thorse states that although her hair is growing, she doesn't look like she used to. "Every now and then I do mourn for myself if I do see a picture. It's been a year, but I still have a long way to go."

Chemotherapy isn't the only cancer treatment that can affect hair. Hormone therapy for cancer treatment can target hormones that help cancer cells grow, such as estrogen and progesterone. It can be used to block the production of these hormones, or block the receptors that respond to them, or lower their levels. This changes the balance of hormones in the body and causes hair thinning. This also causes hair follicles to shrink, leading to thinner, weaker hair.

CCM PHOTOGRAPHY

Lisa Opalweski, of Fond du Lac, Wisconsin, has experienced hair loss multiple times during her cancer journey. Initially diagnosed with breast cancer in 2012, she notes, “Yes, I knew I was going to lose my hair; yes, I was going to run around bald for a while. I knew it was going to come back.” After being diagnosed with metastatic cancer in 2019, she has been treated with hormonal therapy and targeted therapy. “I used to have extremely thick, curly hair. Now I have baby thin hair.”

> I used to have extremely thick, curly hair. Now I have baby thin hair.
>
> **—*LISA OPALEWSKI***

Wigs and hairpieces can be used as a temporary solution for hair loss. Many cancer centers and support groups have resources for obtaining wigs or hairpieces at little or no cost. However, there are now ways to help manage hair loss through scalp cooling. Cooling the scalp during chemotherapy treatment decreases blood flow to the scalp and reduces the amount of chemotherapy drugs reaching the hair follicles. By reducing the amount of chemotherapy that reaches the hair follicles, patients experience less hair loss.

According to the results of one study led by Dr. Julie Nangia, a breast oncologist and an assistant professor of medicine at the Lester and Sue Smith Breast Center and Dan L Duncan Comprehensive Cancer Center at Baylor College of Medicine in Houston, women receiving chemotherapy for early-stage breast cancer were enrolled in a study to evaluate the effectiveness of scalp cooling on hair loss. Of those who underwent scalp cooling, 50.5% had some preservation of their hair after four cycles of chemotherapy. In those who did not use scalp cooling, no one experienced hair preservation.

There are currently a couple of ways to cool the scalp. One way is through the use of cold caps, which uses tight-fitting caps placed on the head to cool the scalp during chemotherapy infusion. The caps are stored in a special freezer and must be changed throughout the infusion to keep the scalp at a sufficiently cold temperature. In order to successfully use the caps, a patient will need to have help to change the caps at the instructed intervals during treatment.

Another method of scalp cooling is through a device that circulates coolant through the cap to keep the scalp at a consistently cool temperature. The hat is placed once at the beginning of treatment and the coolant will continue to keep the temperature consistent. According to Dr. Nangia, cooling the scalp starts 30 minutes before chemotherapy and the cap continues to be worn until 30 to 90 minutes after chemotherapy has been completed. It is also important to practice good hair care with scalp cooling therapy. This can include using a gentle shampoo, avoiding heat styling tools, and being gentle when combing or brushing the hair.

Dr. Nangia notes that the biggest barrier to scalp cooling is the cost. If insurance does not cover the therapy, out-of-pocket costs can be over $2,000. She states that the National Comprehensive Cancer Network, which provides guidelines for cancer treatment and supportive care, has added scalp cooling to these guidelines as a method to be considered for those who may experience chemotherapy-induced alopecia. With this recommendation from the network, Dr. Nangia hopes that insurance companies will start covering the cost of this therapy so more patients can benefit.

The rate of hair regrowth can vary for each patient, but typically hair starts to regrow within a few weeks to a few months after completing chemotherapy treatment. Regrowth may be slow at first, but it should become more rapid over time. It can take several months to a year for hair to fully regrow and regain its previous texture and color. In some cases, hair may not fully regrow or may regrow with a different texture or color.

Chemo curls, also known as “chemo waves,” is a term used to describe the changes in hair texture that some patients experience after chemotherapy. The term refers to the curls, waves or kinks that can develop in the hair as it regrows. This can be caused by the chemotherapy treatment and the changes in the hair structure. It is not exclusive to scalp hair and can occur on hair all over the body. The new hair growth is usually soft and thin at first, and it may take several months for the hair to return to its pre-treatment thickness and texture. Some people may experience complete regrowth of their hair, whereas others may have patchy or thin hair growth. It also might take one to two years for hair to appear as it was before chemotherapy, and this can vary from person to person. Overall, hair growth after chemo is a gradual process, and it can take time for hair to fully recover.

Many members of the health care team are involved during cancer treatment. However, one area that is often overlooked and underutilized during this time is dermatology. Dr. Adam Friedman, professor and chair of dermatology at George Washington University in Washington, D.C., knows what dermatologists can offer patients experiencing hair loss during cancer treatment, but they are not often a part of the cancer experience. »

He suggests prevention of hair loss through scalp cooling may offer the best results if someone is experiencing complete hair loss, but there are other options for those with thinning hair that may be helpful. Applying topical minoxidil to the scalp can keep the hair in a constant state of growth. Friedman notes that it must be used consistently for best results and can be difficult to apply. He cautions against the use of supplements unless they are specifically approved by the health care team. Some supplements, such as biotin, can interfere with some blood tests, and may not be safe for some patients to use. He also notes that the off-label use of Latisse (bimatoprost) can be helpful for regrowth of eyelashes and eyebrows after chemotherapy.

One of the most important things voiced by cancer survivors is that they want hair loss to be a topic that is brought up and discussed, and not glossed over, during visits. Megan Harman, FNP-C, with SSM Health in Lake St. Louis, understands this. She understands that hair loss can be a harsh reality the patient with cancer has to live with. It can be difficult for patients to fully prepare mentally and emotionally for hair loss until it happens. When talking with patients during this time, she often directs them toward various resources and allows them the time to voice their feelings about their situation.

It is notable that much of the research about alopecia focuses on breast cancer survivors in comparison with other cancer survivors. One reason is that breast cancer is the most common cancer among women and the second most common cancer overall, so a large number of patients undergo chemotherapy treatment for breast cancer. Additionally, hair loss is a common and highly visible side effect of chemotherapy treatment, and it can have a significant impact on a person's quality of life. Breast cancer survivors, especially women, tend to be more concerned about hair loss due to chemotherapy as hair loss affects their appearance and self-esteem.

Another reason is that breast cancer research has traditionally been well funded, which has allowed for more research to be conducted on the effects of chemotherapy on hair loss in breast cancer survivors. This has resulted in a greater understanding of the mechanisms behind hair loss and the development of new hair loss prevention and treatment methods specifically tailored for patients with breast cancer.

'Cancer Ghosting' Is an Unfortunate Reality

A survivor ruminates on the painful experience of losing friends after cancer. *By* NATASHA CARLSON

LOSING MY BREASTS was hard, but losing one of my best friends was even harder. And something I've had to come to terms with.

When I began to speak publicly about cancer survivorship, I started by making a list of life lessons that cancer had taught me.

One of the many surprises that cancer had in store for me when I was diagnosed was the fact that I, like so many others, would be cancer "ghosted." I had no idea that this happened at all, much less that it is so common.

This is the phenomenon of friends or family ghosting you or literally disappearing and cutting off all contact after a cancer diagnosis is revealed. In fact, one recent survey found that 65% of respondents reported that they experienced cancer ghosting. This is quite counterintuitive — cancer should be a time when your friends and family band together to form a tight, impenetrable cocoon of support. Why on earth would friends *not* support you in your time of need?

But cancer is funny that way. It has a strange tendency to reveal who your true friends are and, unfortunately, who they are not.

NATASHA CARLSON

In my case, I lost two friends during my cancer journey. They were the very last people I expected to abandon me at my most vulnerable point. One of those people I had considered to be a lifelong friend. We had a solid 22 years of friendship before I was diagnosed.

We had been through good times and bad times together, as is typical with a friendship that spans decades. But after I shared my diagnosis, I was very surprised to find that all contact with me was cut off. No responses to emails, texts or phone calls. Even when I was reaching out because I was confused and hurt, this did not generate any sort of response.

There certainly is the phenomenon of burnout among friends and family members of the person who is living with cancer. This occurs when the need for support becomes so intense in its depth or frequency that the friend/family member needs to take a respite from all things cancer to maintain a degree of emotional self-preservation. This is understandable.

However, this was *not* the situation I found myself in when I was ghosted.

When I shared my diagnosis, it was very early on, and there were a lot of details I didn't yet know, including stage, treatment and prognosis. After that first conversation when I revealed that I had cancer, I heard nothing from this friend for more than a year. They literally had no idea whether I was going to be fine, whether I was going live with cancer or, perhaps, whether I was going to die of cancer.

Honestly, this was one of the most painful parts of the entire cancer experience for me. Losing my breasts was hard. Losing my close friend of 22 years was not something that I had even remotely thought might happen. It was a bitter and painful lesson that I was forced to learn during a particularly vulnerable time in my life.

So why does this happen so frequently to patients with cancer? Well, I certainly have had enough time to ruminate on this thought and come up with all kinds of theories. »

VECTORSANTA / STOCK.ADOBE.COM; ILLUSTRATION BY RAY PELESKO

Maybe they were going through something in their life that made it so that they couldn't be there for me. But then why not reach out once the rough patch for them was over? Shame? Embarrassment? Guilt? Maybe their own mental health was not in the best of shape, and they felt that taking on my crap was too much for them to handle.

I will never truly know why — and that is something I have had to come to terms with. I am still frustrated, hurt and angry that this happened. And because of how it happened, I still have not found closure. It is doubtful that I ever will.

But cancer has some other surprises, too. Sometimes the people who show up for you are the people you least expect. Maybe they hardly know you but heard that you might need some help, so here they are. Cancer introduces you to a whole tribe of supporters, fellow patients with cancer and a community that is like no other.

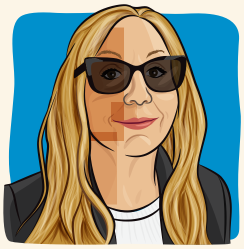
Lesson No. 8 on my list of life lessons that cancer taught me is: Invest your time and emotional bandwidth in people who will show up for you, no matter what. Make new friends. Form a new support network. You do not need the drama of having "friends" who will decide to excuse themselves from your life when things get challenging. If you find that this happens, even though it is *so* painful, let them go. You deserve support from people who will go above and beyond to be there for you and whatever you need.

I'm Grateful for Wigs and Orangutans

How this survivor finds joy in the little things and reconnects with what she loves.

By MARY SANSONE

I'VE BEEN WATCHING a YouTube channel about Borneo orangutans and realized that these animals remind me of myself after cancer.



MARY SANSONE

Every morning I express gratitude to God for being healthy and joyful, along with a long list of other things. I also give thanks for a new animal each day. I am obsessed with elephants, great apes and whales.

I have a coffee-table book on animals nearing extinction. Each day, I turn the page, reflect on the new animal and keep the book open. Lately, I've become addicted to the videos on YouTube's Borneo Orangutan Survival channel. The baby orangutans, with their precious Buddha bellies and disheveled hairdos, are wheelbarrowed out to jungle school. I see myself in these little guys.

First, let's talk hair. After my bone marrow transplant to combat a recurrence of acute myeloid leukemia, I lost all my hair. The alopecia was to be expected. However, the meager regrowth resembled the head of an infant orangutan. Some thin random strands sprouted, growing upward and in odd directions. I told my family to call me "Tang," but it never caught on.

I still have very fine patchy hair that looks like it was hit by static electricity. My scalp is visible. I'm a stunner.

There is an avatar of me next to my blog introduction. Long blond hair falls past my shoulder — a wig.

Whenever I can, I don a baseball cap or scarf to keep my scalp out of the sun. If I am swimming at one of Florida's beaches, I'll go sans head covering. Wearing nothing on my head feels freeing! I would sport my see-through hairstyle all the time, but I personally feel more comfortable in public with a wig.

Since I now work in fine jewelry sales, I want to look approachable. That is, I don't want my customers to have unnecessary concern over my health while they are admiring diamonds and gems.

I work in the fashion and beauty industry. My colleagues dress in designer clothes and apply their makeup with impeccable precision. I decided to invest in a human hair prosthesis. This is considerably more expensive than a synthetic wig. I also knew that I would be wearing this wig for years to come. The silkiness, upkeep and styling are much better than a synthetic wig. It looks natural.

The length is too long. I'll have it cut. I know that once it is cut, it will not grow back, so I want to make sure I know what I want before taking this step.

Like the orphaned orangutans, I also needed to be wheelbarrowed out to jungle school. As a recovering addict and cancer survivor, I had to rely on caregivers — medical professionals and loved ones — to teach me how to thrive in mind, body and spirit. I accepted guidance from many in how to survive in the post-addiction and -cancer relapse world of recovery.

I would cling to my caregivers at first. They provided heaps of love. I was gifted bone marrow from a stranger. My family created a hygienic "nest" for me to sleep and recuperate. They fed me until I got the desire back to eat. Doctors gave me medicine. Treatment gave me coping skills.

I graduated from infant to toddler to teen orangutan and stepped into the next level of my education. I got a wig. I got a job. I got an apartment. I found my passion for life.

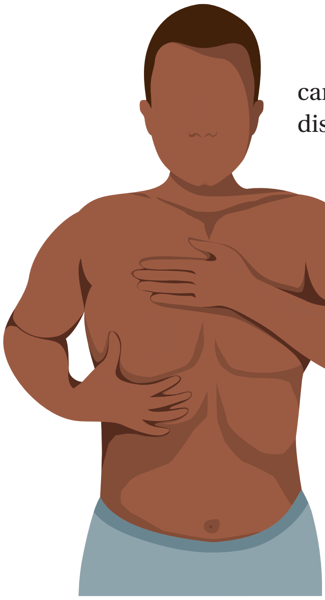
My caregivers taught me how to fend for myself in the wild until I was released.I'm indebted to many people for my current happiness. The wig also helps.

ILLUSTRATION BY RAY PELESKO

How I See Myself — and What I Call Myself — as a Man With Breast Cancer

Why reclaiming titles empowered this survivor.

By KHEVIN BARNES



OVER THE YEARS, I have learned that self-image is an important part of the cancer experience and can change day by day.

KHEVIN BARNES

I've lived on both sides of the cancer fence: first as a caregiver, and now as a survivor.

It's interesting to me that during the four years when I supported my first wife during her struggle with advanced ovarian cancer, I never thought of myself as the "caregiver" in our relationship. This wasn't because I didn't accurately fit that role, as I was at her side every day during that difficult time. But in order to endure the anguish and fear that went along with aiding her in her survival, I somehow found a way to even out the stress that became part of our day-to-day routine. And I managed to do that by seeing myself as part of the cancer experience, rather than just an onlooker.

The stark reality of her terminal stage 4 condition was pushed to the background of our survival strategy, and simply finding a little something good in each day was the centerpiece of our relationship with cancer and with each other. I saw myself as her friend and partner rather than as a caregiver who was keeping her alive by feeding her at home through a food tube. I began to realize that how we see our own role in a cancer partnership is as important as how we see the other person.

After she died, I had a new role in life, and a new title to carry — this time as a widower. I saw that term on a variety of legal papers that I needed to deal with, and I have to say, I never related well to it. It only served to remind me that I had lost something and someone who was very important to me.

Words are powerful. Early on in my performance career as a stage magician, I received an Emmy Award for a television show that I had produced.

I was tagged with that moniker for the rest of my working days. Although I found it useful in the promotions for my programs, it created expectations that were unhelpful in many ways. What seemed to some to be a badge of success, to me became an overrated distraction. I knew that I was simply a modestly successful magician like so many others in my business.

Eighteen years after my wife's death in 1997 at the age of 47, I was diagnosed with my own version of cancer. Male breast cancer is one of the rare diseases that plague unsuspecting guys. The tagline I inherited at that point became "survivor." It's an appropriate description, of course, but that title also carries a lot of vague, emotional nuances that can either be helpful or distracting.

It wasn't long into my survival that I inherited yet another term of endearment that helped me immensely in my relationship with male breast cancer. I became an advocate for the disease as I felt an obligation to share what I knew with the other men who would follow me in the long line of breast cancer survivors.

In my world of male breast cancer, I see men describing themselves as survivors, warriors, patients, conquerors, fighters, advocates, thrivers and more.

So what's in a name? Probably more than we can imagine.

Personally, I have always thought of myself as an adventurer on my expedition through male breast cancer. Like it or not, it's a significant part of my life experience and one that I've learned to accept as I navigate through it.

In these eight years of living with my breast cancer, I've discovered that my self-image can change, even from day to day. So I make it my daily goal to acknowledge how I'm feeling. Today I may be a survivor. Tomorrow I'm an advocate. The only title I don't permit is victim. I like to ask myself, "Who would you like to be today?"

And the truth is, the choice is ours.

OHISHIFTL / STOCK.ADOBE.COM; ILLUSTRATION BY RAY PELESKO

Spring into Salads for Survivors

Spring brings a plethora of refreshing veggies into season, and these salads make the most of their natural flavors and health benefits.

RECIPES *provided by* **THE DANA-FARBER CANCER INSTITUTE IN BOSTON**

Minty Tomato and Watermelon Feta Salad

INGREDIENTS

- 1 (4 to 4 ½ pound) watermelon, preferably seedless
- 3 large ripe green or orange heirloom tomatoes, seeded and cut into 1-inch cubes
- 1 medium sweet onion, such as Vidalia, sliced
- 4 tablespoons chopped fresh mint
- 1 cup (4 ounces) crumbled feta

DIRECTIONS

Yields 10 servings (¾ cup each)

1. Cut off and discard the watermelon rind. Cut the watermelon into 1-inch cubes, removing any seeds as needed.
2. Transfer to serving bowl. Cover and refrigerate until chilled, at least 1 hour and up to 12 hours.
3. Add the tomatoes, onion and mint to the watermelon and toss gently. Add the feta and toss again. Serve immediately.

WATERMELON SALAD: EVGENYB / STOCK.ADOBE.COM; DANDELION SALAD: 13SMILE / STOCK.ADOBE.COM

Waldorf Dandelion Salad

INGREDIENTS

- 2 green apples, cubed with skin
- 1 cup roasted black walnuts
- ½ teaspoon salt
- ½ teaspoon black pepper
- 1 cup red bell pepper, chopped
- ½ cup onion, minced
- ½ cup celery, chopped
- 1 tablespoon yellow mustard
- 2 tablespoons mayonnaise
- 2 cups dandelion greens, washed, wilted and chopped

DIRECTIONS

Yields 10 servings (¾ cup each)

1. Add together all ingredients in a large bowl. Toss well.
2. Chill for 1 hour, then serve.

Carrot and Ginger Salad

INGREDIENTS

- 1 pound carrots, grated
- 3 green onions, thinly sliced
- 1-inch piece of fresh ginger, grated
- 1 teaspoon sesame oil
- 2 teaspoons canola or vegetable oil
- Juice of 2 limes
- 1/2 teaspoon sugar
- Salt and pepper to taste

DIRECTIONS

Yields 2-3 servings

1. Place all ingredients in a serving bowl and stir to thoroughly combine.
2. Serve chilled or at room temperature.

CARROT AND GINGER SALAD: SA SCHA/ STOCK.ADOBE.COM

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Wednesday, April 26, 2023
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Join CURE® as we come together to recognize and celebrate this year's winner and finalists of the 2023 Extraordinary Healer® award for oncology nursing. The annual award recognizes and celebrates oncology nurses who go above and beyond the call of duty regularly to make a difference in the lives of patients with cancer.

The power of recognition and gratitude is tangible during this ceremony, you won't want to miss it!

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