# living well *afte*r cancer

VOL.10 NO.1 / SPRING 2022

## LISTEN UP! Hearing Loss in Cancer Survivors

Key challenges include improving detection and treatment for inner ear side effects following the use of certain cancer drugs and therapies.

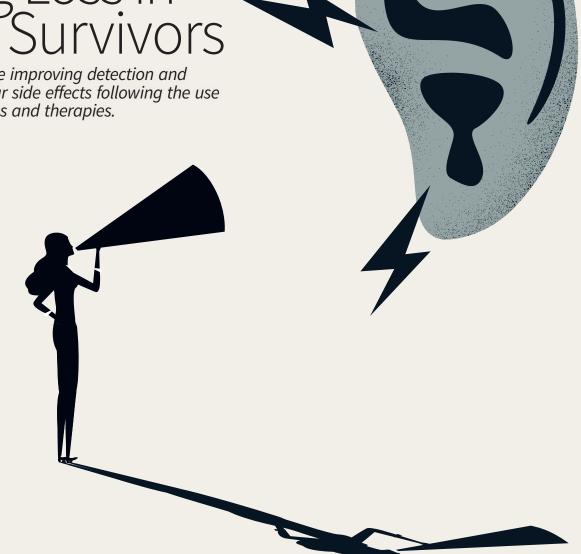
#### Also inside

**Body Image After Breast Cancer** 

20 Years of **Support for Cancer Survivors** 

**Staying Aware** After Surviving a **First Cancer** 

**Goodbye Cancer** Displeasure, Hello Sexual Pleasure



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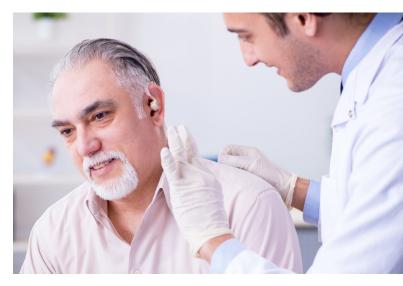
## Listen to This

AFTER A CANCER diagnosis, survivors may want to actively join the conversation about their experience, but challenges could arise if they struggle to physically hear it. Hearing loss is common in those who were diagnosed as adolescents or young adults; however, the problem is not often discussed.

In this issue of *Heal*®, our cover story discusses ototoxicity (hearing loss after cancer treatment), why it happens and what can be done to help these survivors. The individuals featured in our story experience hearing loss due to cancer treatment and discuss how it affects their daily lives. Experts in the field also weigh in about treatment options as well as current gaps and why cancer survivors may experience this problem.

Another great story in this issue concerns the struggle with body image that many breast cancer survivors face after treatment and surgery. Sara Montiel tells us about her decision to undergo a double mastectomy and the long journey toward accepting how her body changed after cancer.

We also have some great insight on the past two decades of support groups for cancer survivors who often experience depression or anxiety after surviving their disease. Today, there are plenty of resources to help them — but what would it have been like 20 years ago? And what may happen 20 years from now?



Also, read about one couple's journey through marriage, parenthood and a patient-caregiver role reversal that led them from feeling angry to adopting a "heck yes" attitude.

As always, we have recipes for some healthy and delicious dishes in this issue. Dip into the warm weather of spring with a few easy appetizers that are full of nutrients and give a healthier

spin on your typical recipes — including a great twist on buffalo wings.

As always, we hope this issue is informative and inspiring to you and your families. Thank you for reading.

#### MIKE HENNESSY JR.

President & CEO



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#### Advice From People Like You

We asked readers, "Did you experience any side effects from cancer or treatment that you weren't made aware of at initial diagnosis?"

Here's what they told us.

Permanent hearing loss.

*- MARSHA* 

- **66** Scalp tenderness/pain and joint pain were unexpected for me. Also, I think it's made my tendons and ligaments more prone to injury. -NANCYM.
- 66 The anxiety of a medical test or procedure never being just a test or procedure. - NANCY D.

Mental health. I was so surprised I went into a depression after treatment was finished. I thought it would have been a happy time but instead everything turned to fear. —ANNE Extreme heartburn that would set in about 48 hours after each chemo. That was probably the worst physical side effect

that I had. — EMILY

Nails turning black and falling off along with neuropathy.

— HOLLY

I've only got three treatments left but foot neuropathy has to be my most noticeable. It's like my feet have been injected with Novocain. Totally numb and dead. — RUSS

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### news & insights

## App May Help Relieve Pyschological Side Effects of Treatment

Those experiencing psychological side effects of cancer can benefit from stress management interventions, although such in-person services are often limited. By COLLEEN MORETTI

**DIGITAL STRESS MANAGEMENT** apps may help cancer survivors who face psychological side effects of the disease such as anxiety, depression and fatigue, according to results of a recent study.

Lise Solberg Nes, senior author on this study and head of the Department of Digital Health Research at Oslo University Hospital in Norway, explained in an interview with *Heal*® that it is important for cancer survivors to have support outlets because of challenges they face that can impact daily life.

"A cancer diagnosis can be life-threatening. This is, needless to say ... stressful. But even with survivorship and a good prognosis for the future, fatigue, pain, uncertainty and worry may be present, and for many cancer survivors, life is changed after cancer. They may look the same to others, but life is forever changed, whether it impacts energy level, ability to work, relationships with friends and family, or their own outlook on life. Many cancer survivors also live with a constant 'hidden' stressor: (the) worry about cancer recurrence," explained Solberg Nes, who is also an adjunct associate professor of psychology at the College of Medicine and Science at Mayo Clinic in Rochester, Minnesota.

She added, "Having someone professional to talk to about challenges that may occur can be of great help. This is why evidence-based psychosocial interventions in support of cancer survivors are so important. The current study shows how a digital stress management program

can provide such support, helping cancer survivors gain knowledge and strategies that may provide and facilitate the use of coping strategies for support at their own preference and convenience."

Previous data have shown cognitivebehavioral stress management interventions have improved psychological well-being in cancer survivors; however, the availability, access and outreach of these in-person interventions are often limited.

"Unfortunately, these types of in-person psychosocial interventions are not always offered or available, and new ways to deliver such support and improve availability and outreach are needed," Solberg Nes explained. "This is why this study is so important; it shows how these highly beneficial psychosocial stress management interventions can be effective also when delivered digitally (for example, in the form of an app-based program), making helpful intervention programs accessible to cancer survivors anytime and anywhere."

Solberg Nes and researchers compared the efficacy of StressProffen, a stress management digital app for cancer survivors (84 patients), to usual care (88 patients). Stress, anxiety, depression, fatigue and health-related quality of life were evaluated at the start of the study, at six months and at 12 months.

Results of the study, published in the journal *Cancer*, demonstrated that over 12 months, survivors who used the app had significantly decreased stress, depression and fatigue, in addition to improved

health-related quality of life compared with those survivors receiving usual care. Solberg Nes said survivors who used the app had an improved ability to regulate thoughts, feelings and behaviors, which was a "very rewarding" finding. She added that there were promising findings at six months as well, demonstrating that survivors using StressProffen had a decrease in anxiety at that point.

"(These results) are definitely significant. This study really shows how effective psychosocial interventions can be delivered through digital formats, providing support to cancer survivors in the form of coping strategies that can in fact help reduce stress, anxiety, depression and self-regulatory fatigue, as well as help improve health-related quality of life, for cancer survivors. Several clinicians and researchers have pointed to the potential of such digital delivery, but this study shows how it can actually be done with (an) effect (that) may even be considered dramatic," she said.

Solberg Nes said these interventions are important to improving a survivor's quality of life, and studies such as this demonstrated the potential of what she calls "blended care," which integrates in-person and remote interventions.

"This study shows how digital stress management interventions such as StressProffen, built on evidence ... have the potential to improve outreach and provide easily available and effective psychosocial support for cancer survivors," she concluded.



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## Cancer Survivors Face 'Alarming' Rise in Chronic Conditions

As life spans increase, so does the risk of health issues that may impact quality of life after a caner diagnosis. By COLLEEN MORETTI

**CHRONIC CONDITIONS IN** adult cancer survivors have increased significantly in the past 20 years, especially in younger (18-44 years old), non-Hispanic Black individuals, according to a recent study.

Dr. Changchuan (Charles) Jiang, lead author of this study and medical oncology fellow at Roswell Park Comprehensive Cancer Center in Buffalo, New York, explained in an interview with *Heal®* that the number of survivors is rapidly growing as cancer treatments continue to improve, so it is important to understand the risk factors and chronic conditions this population might face 10 or 20 years into survivorship.

"I think it's very important for (cancer survivors) to understand that they do have a higher risk of developing more medical conditions. And so we should really be looking at it ... on a populational level ... so we can get a better understanding. So doctors, patients, as well as health care policymakers can really understand what we're facing right now ... and (what) probably (is) going to happen in the next 10 years," he said.

The study, which was published in the journal *Cancer*, evaluated the trends and prevalence of chronic conditions among 30,728 cancer survivors from 2002 to 2018. Additionally, the researchers evaluated trends in multiple chronic conditions, defined as when a person has three or more health conditions.

The results demonstrated an increased prevalence of hypertension (from 35.9% to 40.6%), diabetes (13.4% to 15.3%), kidney disease (4.2% to 5%), liver disease (3.1% to 4.4%) and morbid obesity (5.9% to 9.5%) among cancer survivors. Jiang explained two primary reasons cancer survivors face chronic conditions: They

may have had the condition before a cancer diagnosis or the effects of cancer treatment played a part in the development of the condition.

Many of these chronic conditions can be connected, Jiang added, noting that there is a growing global obesity pandemic, especially in the United States. He said obesity can result in increased risk of hypertension, diabetes and kidney disease, which may be the reason some cancer survivors experience these trends. Additionally, cancer treatment has improved and resulted in patients living longer, giving them more time to develop these conditions.

"Now the treatment is getting much better. So (these) patients really have a chance to survive beyond their cancer and now become a cancer survivor," he said.

It was also observed that cancer survivors with multiple chronic conditions increased significantly from 4.7 million in 2002 to 8.1 million in 2018, and the prevalence increased from 43.7% to 46.6%.

The prevalence of multiple chronic conditions increased more rapidly in young cancer survivors (from 18.4% to 28.4%) and non-Hispanic Black survivors (56.8% to 60.4%) than in those without a history of cancer (1.9% to 2.9% and 19.7% to 21.8%, respectively). Jiang said this is one of the major findings of the study. He explained that this subgroup of survivors tends to have more unhealthy habits that can increase risk of health conditions. They might not have access to great preventive care or care after diagnosis and may have social support and transportation needs, all of which can affect their cancer treatment and survivorship. "(These) patients are the patients

who need the care the most, but they just don't have enough resources," he said.

Jiang advises that "simple things matter" and patients and cancer survivors should do everything they can to modify these chronic conditions to live longer, healthier lives; this includes quitting smoking, exercising more and having a healthy diet.

"I think the key is that it is very alarming to see this rapid increase in ... multiple chronic conditions in the younger population, because we know we're doing such a good job and rapidly treating cancer nowadays compared with 20 years ago; we don't want to lose (these) patients for entirely preventable reasons," Jiang concluded.

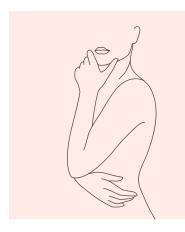
On the other hand, conditions such as ischemic heart disease, chronic obstructive pulmonary disease (COPD) and hepatitis all had significant decreases over the years (from 12.3% to 10.6%; 9.4% to 6.9%; and 5.9% to 4.5%, respectively), according to the study. Jiang attributed these to better treatment options that are available for hepatitis, as well as successful smoking cessation campaigns that have decreased the risk of COPD and heart disease.

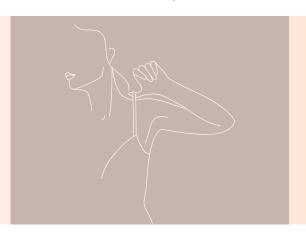
Similar trends were seen in those without a cancer diagnosis (454,505 individuals). However, the decrease in ischemic heart disease and COPD and the increasing trend of liver disease were more prevalent among survivors.

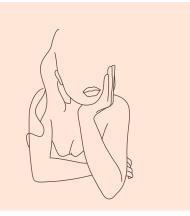


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## Body Image After Breast Cancer

Sara Montiel shares her experience and how time helped her find the confidence she needed for herself and her young daughter. By COLLEEN MORETTI

**BREAST CANCER SURVIVORS** can experience body image issues after treatments and surgeries, which can affect them not only physically but emotionally as well.

Dr. Jennifer A. Ligibel, director of the Leonard P. Zakim Center for Integrative Therapies and Healthy Living and medical oncologist at Dana-Farber Cancer Institute in Boston, said in an interview with Heal® that the journey for patients with breast cancer often can encompass a change in physical appearance. "There are several different aspects of the treatment that we use for breast cancer that can have an impact on women's body image," she said.

Women with breast cancer usually have surgery, Ligibel explained. This can be a less extensive surgery called a lumpectomy (the part of the breast that contains the tumor is removed) or a more extensive surgery called a mastectomy (the whole breast is removed. Other breast cancer treatments like chemotherapy and hormone blocking medications can also cause hair loss and menopausal symptoms. And all these surgeries can negatively impact a woman's body image.

#### **PHYSICAL IMPACT**

Sara Montiel of Miami experienced those body image struggles because of her

treatment for breast cancer. She was 35 when she felt a lump on her breast and went to the doctor. Montiel was told not to worry, because she was young and had no family history of cancer.

After a year, the lump remained. And Montiel discussed it with the doctor at her regular checkup, and although he still did not believe anything was wrong, she was referred for ultrasound. At that point, they realized something was wrong and sent her for a mammogram.

By this time, Montiel was 36. The doctors ordered a biopsy, and she received a diagnosis of breast cancer. "Things happen for a reason, when I think that ... if I had a mammogram one year before, now would be totally different." she said.

Montiel decided to have a double mastectomy because she is a mom and felt she wanted to go through this only once. She was offered reconstruction surgery and decided to go that route as well. She went through chemotherapy and radiation with tissue expanders inside of her chest that would later be replaced with implants. But soon after she received the expanders, she was feeling miserable. She went to the hospital and found out she had an infection. Her doctor tried saving the

expander with antibiotics, and washing it internally, but none of it worked. "It was like a nightmare. I think it was even worse than the chemotherapy treatments," she recalled.

Ultimately one expander was removed, leaving Montiel with one breast filled with an expander and one flat. She was able to manage with a special bra. But after radiation shrank the skin, the surgeon told her they would need to go in a different direction for symmetry. The recommendation was to remove the remaining expander, take tissue from her stomach and put it in place of her breasts. This would have been a major surgery, so Montiel said no.

Her body responded well to chemotherapy and radiation, and she did not experience very many side effects. Ultimately, she decided to go flat and is very happy with her decision.

"I said (to myself) you became, through this journey ... a different person. The things that I was worried about in the beginning — in the end ... it was a totally different story. For me in the end, (it) was: I want to feel healthy, I want to feel happy, I want to enjoy life. Regardless of how I look. Of course, it was not that easy," she said.

#### **PSYCHOLOGICAL IMPACT**

Montiel is not alone in having difficulty accepting changes to her body after surviving breast cancer. Ligibel said many women struggle psychologically with body issues after breast cancer treatment.

"There are definitely relationships between body image and things like anxiety and depression," Ligibel explained. "If people don't feel good about themselves, that can be something that contributes to low mood. And conversely, if people are feeling more depression or anxiety, that can also impact their feelings about themselves. It can at times become a bit of a vicious cycle."

For many women, continuing with life after surviving breast cancer can be a hard journey, and their struggles with body image can be a roadblock. "I think that for many women, the time of transitioning from active therapy into whatever the 'new normal' is, is a very difficult time. Many friends and family members may think that once treatment is done, life should go back to normal. But for many women who have gone through breast cancer treatment, it may take a much longer time to feel better, physically and psychologically," Ligilbel added.

Montiel did not experience much anxiety and depression because during treatment, she was addressing her mental health with self-help classes and meditation, which helped her prepare for what came later. However, it did take her a while to accept her "new normal."

When she chose to go flat, she was not "flat like my daughter," she explained; there were mountains and valleys where her breasts were and it was hard to accept that this was her body. "When you go to the mirror and look at your body, sometimes it's difficult to find that part is not that pretty, you don't have breasts anymore, but you still don't look like your daughter. And you don't have (a) normal body image. So, it took me a while to love me again. The new me," she said.

Montiel luckily had support of her loving husband and daughter through it all, but she was still shy in front of her husband in the beginning. She would try to feel pretty on the outside, wearing nice new clothes



★ MONTIEL and her family enjoying the beach, as she proudly shows off her post-surgery scar.

and pretty bralettes and pajamas to help her confidence. Over time she felt confident on her own.

"It's not that simple. Of course, I was shy. I was afraid how he was going to look at me now. He usually loves that part of my body and now it was not there," she added. "And then I think I started to feel more and more confident. And then one day I was just without clothes (on) in front of him feeling secure and feeling good and confident."

Her husband was not the only one to support her through her journey. Her daughter was also there, and Montiel said it was a bit hard to explain to her what was happening, especially when she started losing her hair.

Ligibel added that women often lose their hair because of chemotherapy, which can be very hard on their self-image, and "it can be a visible reminder to women about their cancer treatment."

Montiel agreed: "I think that throughout treatment, the hair is the most difficult part. And when you are a mom, and you have a daughter to explain (to) that is going to happen, (it) is difficult."

She decided to make a memory for them. Her daughter was almost 4 when Montiel started losing hair, so they started "playing salon." Her daughter cut Montiel's hair a bunch of fun ways and different styles, and in the end her husband shaved it all off — leaving hearts and letters along the way. "We had so much fun that day. ... And she still remembers (it), and I remember with a big smile on my face. So, I think that's the trick for me," she recalled.

#### FINDING CONFIDENCE

Ligibel said a multidisciplinary care team is important for women going through body image struggles. She recommends that women get psychological support for mental health as Montiel did; exercise has been shown to help as well. "I think this is really a place where it may look a little bit different from one place to another, from one cancer center to another, but really making sure that patients aren't just getting their treatment but are also getting care for other aspects of their mental and physical needs through treatment is so important," she said.

Montiel is feeling confident but now is learning to manage the idea of body image with her daughter. Her daughter tells her, "I don't want boobs, because I want to be like you," but then sees other women who do have breasts. She is now struggling because she has an image of her mom and then an image of what a woman's body "should be."

"Now, I figured out I need to manage this for her because I feel confident. I think I need to talk and probably try to find a little bit more guidance to manage this with my daughter," she added. She said cancer allowed her to find herself again, and realized it is what is on the inside that counts and offers that advice to other survivors who might be struggling as she once was.

"Having cancer is a blessing. Because if you have the opportunity to find yourself again, we have the opportunity to learn to love ourselves from the inside. And I think that when we have this love and when this love emerges again, then the outside will glow. Also, it doesn't matter if we lose our hair, doesn't matter if we lose one boob, two boobs, if they are incomplete. If we are glowing from the inside, that is the value," Montiel concluded.



## Hearing Loss in Cancer Survivors

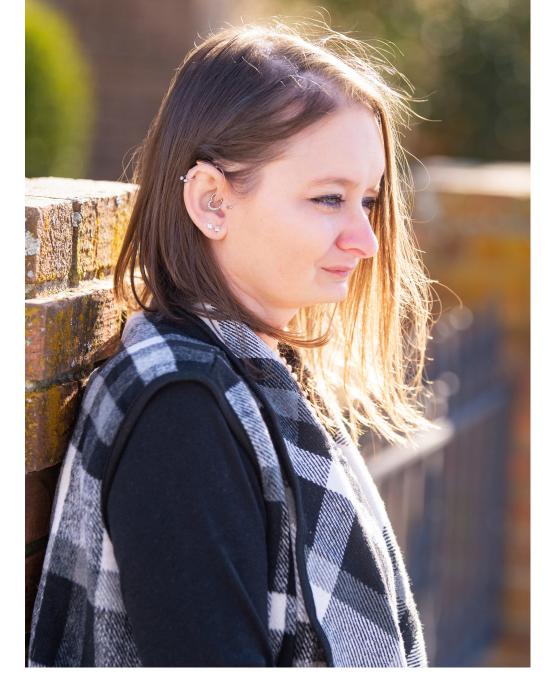
Key challenges include improving detection and response to inner ear side effects following the use of certain cancer drugs and therapies.

By HEATHER STRINGER

rista Bridgmon was 2 years old when her grandfather noticed that the right side of her jaw was enlarged, a symptom marking the beginning of a two-year battle to overcome a cancer of the nerve cells that had spread throughout her body. Bridgmon, now 30, underwent chemotherapy, radiation, surgery and a bone marrow transplant to treat high-risk neuroblastoma (a cancer that starts during very early formation of nerve cells, mostly occurring in infants and young children), but the cisplatin chemotherapy that helped save her life was ototoxic, or damaging to her hearing.

She struggled to hear high-frequency sounds such as "s," "th" and "f." Discerning voices in noisy environments was particularly difficult. She was fitted with hearing aids, but the large, uncomfortable devices were painful and amplified all sounds. Whispering students and shuffling footsteps were sometimes louder than the teacher's voice. She avoided crowds because it was almost impossible to follow conversations in a group, and she became increasingly shy as time went on. >>







"I felt embarrassed and less confident," says Bridgmon, of Arley, Alabama. "I would nod and say, 'yes' even when I didn't know what people were saying." She learned to read lips to compensate, but this strategy did not always work. She still relies on hearing aids when helping her daughter with homework or meeting with her doctors.

#### WHY HEARING LOSS HAPPENS

Bridgmon is not alone in experiencing hearing loss after cancer treatment. Ototoxic platinum-based chemotherapy is commonly used to treat certain childhood cancers, including tumors affecting the brain, nervous system, liver and bones. However, these drugs can cause hearing loss, tinnitus (ringing in the ear) and balance problems. Researchers have found that the platinum accumulates in a part of the cochlea called the stria

vascularis, which regulates the makeup of the fluid that bathes sensory hair cells in the ear. The platinum is eliminated from other organs within days or months after an infusion but can be found in the inner ear years after treatment.

One study, published in *The Lancet*, demonstrated that hearing loss is most common among patients younger than 5 when receiving cisplatin, with 60% in this age group experiencing hearing problems years after treatment. Investigators from Children's Hospital Los Angeles in California analyzed data from more than 1,400 patients in the United States who received cisplatin sometime between birth and age 40. Investigators found that higher daily and cycle doses of the drug — such as regimens used to treat liver cancer, neuroblastoma and central nervous system tumors — increased the risk of hearing loss. Another study suggests that cranial radiation therapy



can also be ototoxic, with 14% of patients reporting hearing loss at least nine years after treatment, according to a study of pediatric patients from St. Jude Children's Research Hospital in Memphis, Tennessee.

Although studies like these are drawing attention to hearing loss and tinnitus among cancer survivors, there are still significant gaps in understanding how to prevent these long-term side effects, or late effects, and how to help patients experiencing them, says Dr. Emily Tonorezos, director of the Office of Cancer Survivorship at the National Cancer Institute in Rockville, Maryland.

"Hearing loss among cancer survivors has been overlooked and understudied," she says. "People do not consider it a serious medical problem, and as a result there are many cancer survivors who struggle to communicate, feel isolated and experience neurocognitive difficulties."

Like Tonorezos, Johnnie Bass, a research audiologist at St. Jude Children's Research Hospital, suspected that hearing loss was affecting cancer survivors more than most clinicians realized. Parents would share that their children were struggling in school, needed speech and language services and were having behavioral issues.

To explore whether hearing loss was linked to neurocognitive function, Bass studied more than 1,500 patients in the St. Jude Lifetime Cohort who had survived childhood cancer five years or longer. Hearing loss in this population was associated with deficits in attention, executive function, processing speed, intelligence and academic function.

"The hearing loss can begin within days or weeks after treatment, and the damage is permanent," Bass explains. "And the hearing problems can worsen over the years as people age." »



Hearing loss affects not only cognitive function among childhood cancer survivors, but also social development. Tonorezos recently interviewed childhood and young adult cancers survivors who were exposed to cranial radiotherapy, platinum chemotherapy or both, and hearing loss was associated with isolation and feelings of exclusion. Many of the survivors had deprioritized or neglected their hearing issues because the problem was a reminder of their cancer history, and they did not want to spend time and energy on hearing loss testing or treatment, says Tonorezos.

#### **IMPROVING ACCESS TO CARE**

As awareness increases about the prevalence of treatmentinduced hearing loss, researchers hope providers will not only prioritize early screening to identify who may be at risk, but also refer patients to specialists who can provide treatment. Before starting potentially ototoxic therapies,

clinicians should explain the potential immediate and long-term effects on the inner ear, says Kathleen Castro, a nurse consultant in the Office of the Associate Director of the Healthcare Delivery Research Program at the National Cancer Institute in Rockville, Maryland.

"If an ototoxic therapy is the best treatment for the cancer, in most cases the decision to move forward is clear," she says. But it is optimal for these patients to receive a baseline audiology test before starting treatment. Subsequent hearing tests can be compared with this baseline, says Castro. "It is so easy to get focused on the moment when facing cancer, but it's also critical to weigh what is at risk with longterm survival," she says. If patients begin to show signs of hearing impairment, reducing the dose of chemotherapy may be a way to decrease risk of further damage, she adds.

To standardize audi-

ology care for pediatric patients receiving ototoxic therapy, a group of international experts gathered to develop guidelines for clinicians. They determined that monitoring hearing and counseling from an audiologist should be considered before each ototoxic chemotherapy cycle. The specific monitoring recommendations for each patient are based on context, including the diagnosis, the drug, the dose and the child's age.

The investigators found compelling data suggesting that, after treatment has been completed, "the screening needs to be tailored to a child's age," says Wendy Landier, one of the study authors. "Very young children should be screened more frequently than older children, but everyone who receives ototoxic therapy needs to be screened even as they move into adulthood," explains Landier, deputy director of the Institute for Cancer Outcomes and Survivorship at the University of Alabama at Birmingham. Children under 6, for example, should be screened for hearing loss every year,



and those from 6 to 12 should be screened every two years. For those 13 and older, screening is recommended every five years, according to the study.

If hearing loss is detected, clinicians can refer patients to an audiologist. "These specialists are underutilized, and they are very knowledgeable about the resources available to address hearing loss," Landier adds.

Raeanna Butcher, 33, of Montclair, New Jersey, benefited from seeing an audiologist but waited several years after cancer treatment because she was skeptical that hearing aids would help. She was diagnosed with pediatric osteosarcoma (a tumor that almost always occur in the bone, commonly near the growth plates of the knee, arms, legs

and pelvis) during her sophomore year of college after her left knee started hurting during volleyball practices. She received two rounds of cisplatin before undergoing surgery to remove the cancer in her knee, and audiogram results during treatment revealed that she was suffering from high-frequency hearing loss. But this problem was overshadowed by more acute consequences of treatment, including six months in a straight leg cast, mouth sores, numbness and tingling in her feet and complications from an intestinal bacterial infection.

During the two years after treatment, these issues resolved but Butcher noticed the hearing loss was persistent. She would frequently ask people to repeat things, »





and felt self-conscious in loud social settings when it was hard to hear. "I knew I was fortunate to have survived and wanted to put cancer behind me, but the hearing loss was always with me," she says.

Butcher finally decided to see an audiologist, who explained that hearing aid technology had improved significantly over the years. He gave her a device programmed to help her hear high-frequency sounds, and for the first time in years she could easily follow conversations at large business events and social gatherings, including her own wedding.

Health insurance coverage for hearing aids for children and adolescents varies by state, and only a few states require insurance companies to cover hearing aids for adults, says Landier.

"Cost is a big problem," says Bass, who found that only 23% of the cancer survivors with severe hearing loss in her study were using a hearing aid or cochlear implant. Butcher paid \$5,000 for her hearing aids; Bridgmon cannot afford new ones because Medicaid stopped covering this expense once she turned 21.

#### HOPE FOR THE FUTURE

Researchers are starting to explore the possibility of preventing ototoxicity by using drugs such as sodium thiosulfate (STS), an antioxidant that binds to harmful molecules produced in cells that have taken up cisplatin. Scientists are working to understand why STS is otoprotective; they suspect the drug prevents free radicals from

damaging the hair cells in the inner ear. It is also possible that STS binds to platinum, which could prevent residual cisplatin from killing cells in the ear.

In one recent study, published in The New England Journal of Medicine, children with localized liver cancer received STS six hours after each infusion of cisplatin.

**«**BUTCHER encourages others on the same journey to be proactive and not ignore the issue of hearing loss due to cancer treatment.

They were half as likely to experience permanent hearing loss as children who did not receive STS, and the drug did not decrease the effectiveness of the chemotherapy. For now, STS is not widely used in cancer institutions, in part because more research is needed to determine whether the drug impacts the effectiveness of chemotherapy, says Dr. Stefanie

Thomas, director of adolescent and young adult oncology at Cleveland Clinic Children's in Ohio. "For now, clinicians are sometimes using STS in children diagnosed with localized cancer, but not yet in metastatic disease," she explains.

In the future, providers may also be able to identify genetic risk factors for ototoxicity. Childhood cancer survivors from the St. Jude Lifetime Cohort who underwent cranial radiation therapy were more likely to have hearing loss and tinnitus if they had a specific gene variation in certain chromosomes, according to a recent study.

Scientists also acknowledge that more research is needed to understand how cisplatin affects hearing and tinnitus in survivors of adult-onset cancer. Eager to study this patient population, Robert Frisina, PhD, director of the Global Center for Hearing & Speech Research at the University of South Florida, joined a multi-institutional team that is following more than 2,000 testicular cancer survivors who received platinumbased therapy. They found that 20% had hearing loss classified as severe to profound and 40% had tinnitus.

These initial findings were based on audiogram testing in which participants pressed a button if they heard a specific tone. The team now plans to expand the testing to evaluate speech processing amid background noise. "I think our findings may surprise some oncologists," says Frisina. "They may not realize that the hearing loss is so severe." He hopes that his work will highlight the consequences of ototoxic treatment, and ultimately help providers to be more attentive to cancer survivors who need audiological support and hearing aids.

Although awareness of this issue is increasing, screening and access to audiologists are not widespread. In the meantime, cancer survivors like Butcher encourage patients to be proactive in addressing hearing loss and tinnitus. "Don't continue to suffer," she says. "I tried to ignore the problem because I didn't want the effects of cancer to be part of my life, but it's wise to educate yourself, talk to an audiologist and see what is available."





## celebration

Help us honor this year's extraordinary healers!

Wednesday, April 27, 2022 6:30 – 8:00 PM PT | 9:30 - 11:00 PM ET

Join CURE® as we come together to recognize and celebrate this year's winner and finalists of the 2022 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, and they deserve to know how much they are appreciated!

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## Partners, Patients, Survivors

Jessica St. Clair and her husband, Dan O'Brien, share their roles of partner and parent, but also patient and caregiver, as their roles were reversed in the blink of an eye.

By COLLEEN MORETTI

JESSICA ST. CLAIR and Dan O'Brien, who met in an improvisational comedy group, have been through a lot together — dating, marriage, work, parenthood and surviving cancer.

St. Clair received a diagnosis of stage 2b breast cancer in 2015. The writer and producer underwent a double mastectomy and six months of chemotherapy and radiation. And she marked her six-year anniversary of being cancer free in September 2021.

For many people, their last day of treatment is a happy one, but on the day of St. Clair's final treatment, O'Brien received a diagnosis of colon cancer.

"So we kind of perfectly pivoted from Jessica's experience as patient to being a caregiver and in my case going from caregiver to being a patient," O'Brien said.

O'Brien, who is a playwright and essayist, had two colon resection surgeries, four months of chemotherapy, liver resection and two more months of chemotherapy. He has been cancer free since the end of 2016.

#### FEELING ANGRY — AND LUCKY

When O'Brien received his diagnosis, he and his wife were angry because instead of celebrating St. Clair's milestone, they were facing a new round of cancer treatments.

"It was a nightmare. And I think ... it's a cliche to say something feels surreal, but there was an unreal quality. ... To have that happen sequentially, on the day

of her final infusion, was shocking, absurd, numbing," O'Brien recalled.

However, they both also felt incredibly lucky. Not only did they have great doctors and successful surgeries, but they had each other and everyone around them.

St. Clair met other women with cancer who were in the last part of their treatment. It was good for her to see that

> other people who had the same experience were able to live a normal life after treatment, she said.

> > "For me, even though it seemed unreal and impossible, knowing that

> > > somebody was living a good life (after treatment) was a real light in the dark," she said. For O'Brien. his beacon of light was his wife, who had already experienced everything he was going through. She was able to coach him through treatments and side effects and help him process his feelings, which made it easier on him, he said.



"I think I had an easier job in some ways than Jessica. ... I tried to be there for her as a loving spouse, trying to help her through what she was going through. But she had just been through something incredibly similar, so I was constantly aware that she was six months further down the road and could tell me. 'Oh, I felt the way that you're feeling today on your fifth round of chemo. That's similar to how I felt. Look at me today, I'm up and about, and I'm living a normal life.' And that was tremendously helpful," O'Brien recalled.

#### **MAKING SENSE OF THE CHAOS**

St. Clair said she didn't realize how difficult it was to be a caregiver until she was one. There is an emotional toll not only on the patient but on the caregiver as well.

"Everybody is thinking about the patient — they're fighting for their lives and they're in a lot of physical pain. But for the caregiver, it's an extreme emotional toll because (they) are usually the one doing

the housework and the cooking and the cleaning and the caregiving of kids. And in addition, you are taking care of another adult person, which is really difficult. And then add to that you are terrified. But you know that if you share how terrified you are with your partner, then that will make them more afraid. ... I had to really keep a lot of that to myself, and that can feel really exhausting," St. Clair said.

O'Brien agreed — when he was the caregiver, he never wanted to burden his wife with how he was feeling. He found comfort in therapy and writing during that time. During her treatment he started writing a book of poems, "Our Cancers," which he finished during his treatment.

"That was a way for me to try to make sense of the chaos of illness, out of the uncertainty of illness, (and) I'm sure there is a self-soothing or self-therapeutic aspect to it. But you know, I remember sharing those poems with Jessica during her treatment as a way to try to overcome what Jessica was talking about, where ... you don't want to burden each other with too much fear or anxiety. But at the same time, you need to try to keep communication open, you need to try to keep intimacy alive, emotional (and) physical intimacy too. ... By revealing our fears, it was easier to also talk about what



we were hoping the outcome would be, and it was a way to keep (our) bond strong," O'Brien said.

#### **SAYING YES TO LIFE**

And not only did they have each other to care for, but they also had their daughter, Bebe, who was not yet 2 years old when St. Clair received her diagnosis and was 3 when O'Brien received his. Since their daughter was so young, they decided to not go into the details with her about their disease.

"There were certainly times, especially with my treatment, where we had to explain that I had a boo-boo after surgery, but we did try to really keep it from her because it seemed like it was just too difficult for her to understand," O'Brien explained. "You never know what kids are absorbing emotionally. And we were aware of that. But we didn't want her to have to try to understand the full implications of what we were going through."

He added that having a child "increased the stakes in a horrible way," because they didn't want to imagine such a young, vulnerable child losing not just one but possibly two parents. It was a "nightmarish scenario," he said.

But Bebe became their motivation. They still had to take care of her, get her to school and arrange for »

#### survivor spotlight

playdates. O'Brien said it made him feel grounded, and he was striving to live for her.

St. Clair explained that their family adopted the motto

"Heck yes, life" during her treatment and said that "any opportunity for joy that we're presented with, we're going to take it." They lived that out and went to Disneyland the day before St. Clair's mastectomy and booked a trip to Ireland after O'Brien's treatment.

"I feel like it's really informed us as parents with Bebe because we really know the secret that life is short and that you should try to enjoy yourself no matter what," she added.

She explained that they are better parents after having gone through this. They feel lucky that

their daughter was so young, and their hearts go out to families with older children who are more aware of what their parents with cancer are going through, St. Clair said.

#### **USING INSPIRATION AND CREATIVITY**

Both St. Clair and O'Brien tapped into their creative side as therapy during their journeys. O'Brien had his writing, and St. Clair started a podcast. She also wrote the last season of her television show, "Playing House,' which aired on the USA Network, with her best friend about the journey through breast cancer.

"It's a great way to tap into the emotions that are underneath it all. I think when you're doing something like art, or dance or even exercise, it's like your conscious

> brain can take a break. And sometimes I think those deep emotions really do need to be experienced," St. Clair said.

O'Brien said they wanted to use their skills to make something meaningful out of their journeys. For them it was expressing themselves through the arts and writing, but for others it may look different.

"I think the question is: What can you do to help people connect to people, create connections, create support? Because that (comes) back to you. In our case, it

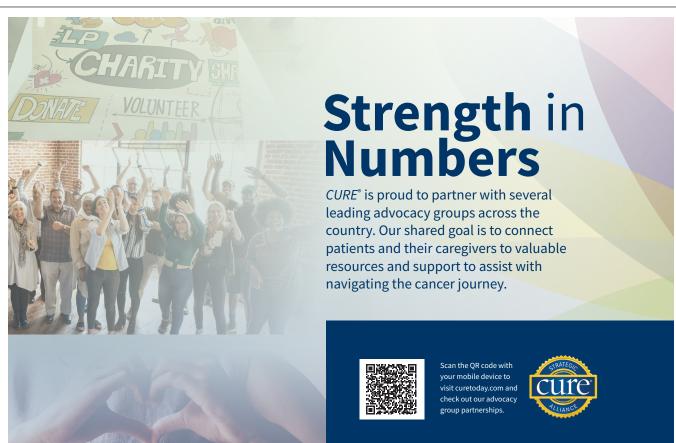
happened to be writing a collection of poetry or Jessica writing an entire season of a TV show about her experience or (her) new podcast. But for anybody else, it could be through teaching, it could be through activism,"

O'Brien concluded.



#### LISTEN IN! SCAN THE QR

**CODE** to hear more about St. Clair and O' Brien's journey with cancer and survivorship.





Increased resources and technological advances are allowing cancer survivors experiencing pyschological side effects to seek help that might not have been available to them 20 years ago. By COLLEEN MORETTI

**CANCER SURVIVORS MAY** experience psychological side effects, such as anxiety and depression. But they have many more resources to turn to for support today, compared with 20 years ago.

Bradley J. Zebrack, professor of social work at the University of Michigan School of Social Work in Ann Arbor, explained in an interview with *Heal*® that at the turn of the century, research into the psychological side effects of cancer was growing more extensive but resources for survivors were lacking. "Twenty years ago, and I'd say that this is still somewhat true today, you have some cancer centers that are well resourced and are doing a fantastic job of providing support services and social workers and psychologists and have staff on site to help people deal with all the fallout of having had cancer," he said. "And then you have other centers that are so under-resourced."

#### **ADVANCEMENTS AND BENEFITS**

As cancer survival rates are continually increasing, so are the rates of side effects for this population. Some of the most common side effects a survivor might experience are psychological, including depression and anxiety.

Survivors today can address these issues with the help of psychologists, therapists and support groups, leading to improvement in quality of life. This can benefit survivors' mental and physical health, relationships with others, ability to work and more, Zebrack explained.

A 1998 study on quality of life in long-term cancer survivors, published in the Journal of the National Cancer *Institute*, found that they experienced negative impacts just as survivors do today. But there were not as many resources for support then.

The advances made in providing support groups have brought greater recognition for cancer survivors, Zebrack said, adding that there is a more open conversation about the impact the disease has on their quality of life. "I think what's different today is a greater recognition of the psychological, the social (and the) spiritual impact of cancer. So, providers, I think, are more willing and able to talk about those topics within the clinical care setting — (compared with) 20 years ago," he said.

Zebrack said the COVID-19 pandemic has allowed for even more innovation in this space because technological changes also have played a role. Two decades ago, the internet was not as advanced as it is today — for instance, there were no Zoom support group meetings, which can be an important resource for cancer survivors now.

He added that in the past, survivors who would benefit from a support group might not have the motivation to leave their house, sit in a room full of strangers and share their story. Today, however, the ability to join a support group using a computer in the comfort of their living room has opened a new world for cancer survivors.

"The ability to provide support to cancer survivors at the time they want it and how they want it is better today," Zebrack said. "For teens and young adults affected by cancer, for example, their ability to find information and support when they need it — like 2 a.m., when they can't sleep or are texting with their friends — is better, given advances in the use of computer technology and the internet to provide resources and support," he said.

#### **THE NEXT 20 YEARS**

Although there have been many improvements in the past 20 years, there is still work to be done in the next 20, Zebrack added. He mentioned that a 2008 report from the Institute of Medicine (now the National Academy of Medicine) on psychosocial care for patients with cancer found that those who would benefit most from supportive »

#### CURE"s 20th anniversary

care — including people with severe mental or physical health disorders, or those in underserved populations — were the least likely to receive and benefit from these advancements.

"Those were the people who are most likely to benefit from the availability of support but were the least likely to

receive those services," he added. "And I think that is still somewhat true today."

In recent years, additional research has shown this gap as well, specifically in cancer survivors who are members of racial and ethnic minority groups, or sex or gender minority populations. For example, according to a 2021 study published in *The Oncologist*, researchers found that Hispanic and Latino cancer survivors experience a more significant and "often disproportionate"

cancer-related burden compared with their non-Hispanic counterparts.

"Quality cancer care is defined as care that is safe, efficient, timely, patient centered, effective and equitable,"

Zebrack explained. "Ongoing disparities in care means we still have a ways to go to achieve equity and thus quality for all."

There has been extensive research over the past 20 years regarding the psychological side effects of cancer and their impact on survivors' quality of life, and resources

needed to overcome these challenges. There likely will be more studies as survival rates increase. It is not just research that has helped these advancements, Zebrack said, but also the survivors who tell their stories.

"I think what is also needed and helpful are the stories that survivors tell themselves; sometimes data is not necessarily the most motivating or stimulating thing to create

change," Zebrack concluded. "We also know that opportunities to tell one's story about living with, through and beyond cancer are powerful mechanisms for physical and emotional recovery and for achieving quality of life after cancer."

I think what is also needed and helpful are the stories that survivors tell themselves; sometimes data is not necessarily the most motivating or stimulating thing to create change. —BRAD J. ZEBRACK



#### **EVENTS THAT EDUCATE AND INSPIRE**

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During his college years, Matt Froestad received the diagnosis not once but twice following self-exams. By COLLEEN MORETTI

SOCIETY

MATT FROESTAD WAS a sophomore in college when he received his first testicular cancer diagnosis. Two years later, as a senior, it happened again.

He was always taught to perform self-exams and seek help if anything felt off, so that is what he did in 2009 when he found a lump on his right testicle. A urologist told him TESY the only way to be certain it was cancer was to remove

the testicle and do a biopsy, so he was scheduled the next morning for surgery. The stage 1a testicular cancer was caught early, and Froestad started a surveillance plan.

"After that first diagnosis it was definitely a shock that I — a relatively healthy, active 20-year-old in college — could get cancer," he recalled in an interview with *Heal*®. He was fortunate enough to not receive chemotherapy or radiation and was able to lead a healthy lifestyle afterward.

"But always in the back of my mind was that I had cancer, and I kept an eye on the other testicle, probably a little closer than I did previously, just knowing that there was a chance that could happen again," Froestad said. In his case, remaining vigilant was the right choice.

#### **UNDERSTANDING CANCER RECURRENCE**

Dr. Shawn Dason, a urologic oncologist at The Ohio State University Comprehensive Cancer Center, Arthur G. James Cancer Hospital in Columbus, explained in an interview with *Heal*® that recurrence in testicular cancer survivors is dependent on the staging of their first cancer and the risk factors. It's important to talk with their oncologist to understand the risk.

Depending on the individual, risk of recurrence could be low as 1% or as high as 50%.

"I think really the first thing is to have that conversation with their oncologist ... to understand what their individualized risk is because it could basically range from very, very limited to very, very likely. And if it is very, very likely, that

could be important (to know) in making (a survivor) want to get any kind of symptom properly addressed if (they) were to have it," he said.

> However, many survivors are still unaware they may be at risk for cancer recurrence, he added. Froestad said, "I didn't know necessarily that it was possible, but it was."

He was a senior in college when he felt some pain and swelling over his left testicle during a self-exam and decided to call his urologist. The doctor gave Froestad a diagnosis

of epididymitis (swelling around a tube at the back of the testicle), prescribed antibiotics and told him he would see him in a month.

After a month the swelling went down but the pain remained, Froestad said. He was scheduled for an ultrasound, during which growth in a mass was identified. His urologist was reluctant at the time to schedule another surgery, so he advised Froestad to get a second opinion near his home in Virginia.

The second doctor reached the same conclusion as earlier: The only way to be certain it was cancer was to remove the testicle. Froestad was scheduled for surgery two weeks later, and found out he again had testicular cancer. Prior to the surgery, he was able to "bank some sperm and get other things in order before going under the knife." »



But always in the back of my mind was that I had cancer, and I kept an eye on the other testicle, probably a little closer than I did previously, just knowing that there was a chance that could happen again. — MATT FROESTAD

"

FROESTAD with his wife, ASHLEY, and their daughter, NOELLE.

#### **STAYING EDUCATED AND AWARE**

Dason recommends that testicular cancer survivors stay educated on recurrence, keeping up with regular follow-ups, screenings and self-exams, as well as remaining vigilant about new symptoms. Unfortunately,

he said, many survivors do not follow up.

"I definitely think there's not enough awareness," Dason said. "And you know the reason I say that is a lot of patients, I find, get lost to follow-up."

He explained that because this patient population is younger, common life activities include moving, getting a new job, continuing education or starting a new relationship. Consequently, fewer patients return for follow-ups and necessary testing after surviving testicular cancer.

"I think it's definitely something that, if we had more awareness that this is something that's curable as long as we find it early enough and treat it appropriately, could make a big benefit in improving outcomes in these patients," he added.

Most commonly, if a testicular cancer survivor receives another cancer diagnosis, it would involve the abdomen, which is harder for individuals to detect, Dason explained. Such discoveries really come from imaging, which is why follow-ups are important, he said. However, some symptoms to watch for include abdominal pain, back pain, gastrointestinal issues, difficulty eating, nausea, vomiting,

constipation and indigestion. "It's so critical that these people who have a previous diagnosis of testicular cancer know about recurrence because we approach cancer of the testicle as curable until it's not," he said.

Froestad, now 32, welcomed his first child this past December. He agrees with Dason and knows that because of his self-exams, he was able to notice something was off and catch the recurrence.

"I would probably just say continue to be proactive," he said. "I will say, yes, having a cancer diagnosis is a blow ... but it's important to remain active ... eating healthy — not to say I'm the healthiest eater either — but remain active to keep that balance and just continuing to have those regular appointments with your

doctor and advocating for your health."

Dason reassures patients that testicular cancer typically has a good outcome, and although recurrence can be hard emotionally and physically, there may be a brighter side.

"The outcome of most patients with testicular cancer is very good, even if you (received a diagnosis of) a recurrence. It's obviously very psychologically taxing and an emotional situation, but we usually have very good treatments that can get you over that," he concluded. "The biggest thing is to have that perspective ... there hopefully will be some light at the end of the tunnel, even (though) for some patients this is a second tunnel in the event of recurrence."



**FROESTAD** 

## community



How my daughter's chemotherapy nurse became her best friend after cancer treatment

A mother describes the lasting good that blossomed for her child, and for her, after cancer. By DEBBIE LEGAULT

MY DAUGHTER ADRIENNE was a typical young woman in her mid-20s when she received a diagnosis of breast cancer. She was establishing her life after finally having found a great job and an equally great apartment that she could afford on her own.

She would go to the lake with friends and float in the water for hours. She attended movie premieres at 12:01 a.m. on opening day and spent far too much money on fancy coffees. She participated in girls night out, where everyone dressed to the nines and headed downtown for an evening of laughter and gossip. She dreamed of traveling to faraway places but, with paying student loans and rent, opted for regularly planned, shorter road trips instead.

And then cancer took her life down a very different path. Adrienne tried very hard to reconnect with her precancer friends after her breast cancer treatment finished, but cancer had changed her in ways that made it impossible to relate to them as she had before her diagnosis.

When you are faced with your own mortality at 27 and can be triggered by simple statements or actions taken by others, it can be healthier to make sure that the people in your life take your experience into consideration when they are interacting with you.

She doesn't harbor any resentment toward her friends who don't understand, because she knows that they can't. It's one of those experiences that you must go through to get it.

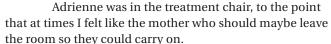
When Adrienne was undergoing chemotherapy, the nurses in the oncology ward were exceptional people, doing all they could to make things easy for Adrienne and me. They included me like an almost equal partner when it came to everything that went on in that room. Considering how helpless I felt, that decision meant more to my mental well-being than they will ever know.

Many of the staff were mothers, like me, and their compassion for me during those five months was like a healing balm that I got to apply as I sat in the chair watching the toxic treatment flow into my child's body.

Other nurses were Adrienne's peers, and I can't imagine what it must have been like for them to have someone their own age sitting in the chemo chairs week after week.

> But they get it, because they have seen it, and one of those younger nurses is now my daughter's best friend.

I don't remember saying this, but I told Adrienne after a few weeks of chemo that I thought she and this nurse were going to become friends. They are a few weeks apart in age, and their conversations were so normal when



They kept in contact after the active phase finished and began to spend more time together. There are no foot-in-mouth moments between them — not because they are consciously avoided but rather because they each instinctively know what is safe and what is not. They both understand that making plans needs to take into consideration the side effects that still plague Adrienne because of the aggressive treatment plan that kept her alive.

If Adrienne is having a rough day, things can change without warning and it's understood by her friend. They laugh at cancer jokes together, something that makes other people squirm in their seats but very much helps when the darkness starts to creep in.

Although it can never achieve balance, this friendship tilts the scales ever so slightly into something good that came out of something horrendous. If it weren't for Adrienne's diagnosis, they likely never would have met. It's a moment of serendipity. And when I am looking for some light, trying to shift my thinking away from despair, knowing this relationship exists brings a smile to my face. Every single time. h



**DEBBIE LEGAULT** 

## When Time Is Precious for Cancer Survivors, Small Blessings Count

One woman talks about appreciating the little things in her daily life after cancer. By JANE BIEHL, PH.D.

**ONE OF THE** things that irritate me most about having chronic cancer is all the medical appointments taking so much precious time.

When I complain, I feel guilty because so many people are much sicker, lying in bed at the hospital, and have more painful treatments than I do. As I try not to complain, I recently realized why it might be so upsetting to me.

I was in the middle of a very strenuous week, not physically but appointment-wise. I had a blood draw, a visit to the hospital for a Retacrit

(epoetin alfa-epbx) shot and a CT scan. I also had an appointment with a special veterinarian an hour away for my aging

> dog. Topping it all off was another appointment for my aging kitty. I joke that I did not plan this well, having all three of us getting old at the same time.

Then I took another look at my calendar. The following week I only had one appointment, the day

before Thanksgiving. What a break. It would have been wonderful to have a week without any appointments, but

this is not a time to be greedy. I only remember one or two weeks in the past three years when I did not have at least one medical appointment. But along with this regimen that all of us with chronic conditions must undergo is a new appreciation for the little things. Other people do not understand, but we cancer survivors do. We celebrate remissions, new treatments and good medical care all the time — the big things. But we also learn that a week with no appointments or only one is also a reason to celebrate. It is the little things that count, and we look for them every single day. In



JANE BIEHL, PH.D.

## Goodbye Cancer Displeasure, Hello Sexual Pleasure

A cancer survivor explains how she was able to intimately reconnect with her spouse after the disease caused their love life to fizzle for many years. By LAURA YEAGER

MY ONCOLOGIST SET me free in July 2021 and then retired. I secretly imagined that she was waiting for me, one of her toughest cases (take my word for it), to reach my 10-year "cancerversary" so that she could leave without guilt.

At the start of 2022, many reminders of 10 years of breast cancer clutter my house. I take inventory and find these cancer artifacts: over a half-dozen prosthetic bras that I never wear, 13 unopened bottles of tamoxifen, years of old calendars with my dozens of cancer appointments marked messily in them, one squishy prosthesis sitting on my bathroom counter and a box of acrylic hats from when I lost all my hair during chemo.

There's also something new in our home, not an object but a development — the most passionate, Hollywoodlike sex I've ever experienced. Finally, I'm over the self-consciousness of my double mastectomy. I don't

care about the scars or the fact that my nipples are gone.

Since my oncologist released me this past summer, I've felt so much better about myself. My husband of almost 25 years and I make love with abandon and with pure enjoyment. I'm not thinking about intercourse anymore — I'm simply doing what



LAURA YEAGER

comes naturally. At almost 59 years of age, I've hit my sexual peak.

I don't think sex would be as good now if I hadn't gone through a tremendous dry spell that lasted a decade consisting of two breast cancers.

But after a recent roll in the hay, I looked in the bathroom mirror and saw that my face was a rosy red. I was flushed with excitement. I was overjoyed.

The next morning, I got on the scale to see that I'd lost a pound. They say good sex burns calories. Here's to a happy, healthy weight loss sparked by good sex.

The physical pleasure that came from our union the other night wasn't even the best part. For the rest of the evening, I felt bonded to my husband in a way I'd never felt before. I enjoyed looking at his face and smiling at him. I found him extra attractive. He was the embodiment of the phrase "happily ever after." Finally, the bad times had calmed down and we were surfing some good ones.

After we came down from our escapade, I asked him, "Where have you been all my life?"He appreciated

I think what also contributed to our excellent sexual experience was that we had both received the COVID-19 booster. We felt a little safer in that department as well.

And it didn't hurt that my hubby had been on vacation from his stressful full-time job as an engineer for almost two weeks.

There are so many things in a marriage marred by cancer that can keep partners from engaging in and enjoying sex. For one thing, you simply don't feel great emotionally; facing death can bring you down. You don't like the way you look. And there's the pain that makes you ache.

But even if you don't have cancer, there are things that can stand in the way. For once, we didn't let the fact that our teenager was in the basement get in the way of making love. Let's just say that the heavens were aligned. Things finally came together, and I'll never be the same. 🖪

#### SHARE YOUR STORY!

Whether you are a patient, survivor, caregiver or health care provider, we want to publish your stories about cancer and the people, places and moments of the experience. They can be funny, poignant or practical. Send stories to editor@curetoday.com, or share on our Facebook page at facebook.com/curemagazine. Submissions should be no more than 600 words and include your name, phone number and email.

## Figuring Out the 'Crazy Game of Life' **AFTER CANCER**

A young survivor explains the importance of creating connections with others who have been through the same experiences. By STEVE RUBIN

I CAME TO terms a while back with the fact that my path in life had changed after cancer. But it took much longer to acknowledge just how much I, as a person, have also changed.

These days, my lifestyle is much more rigid and conservative because of trauma and the understanding of what's at stake if I don't properly care for my body. Although treatment was brutal, for the

lucky ones blessed to resume a life after cancer, most will find it's still pretty strenuous. On the surface there's the damage to our careers, bodies and emotions, but there's also a nagging, constant drain with everything feeling just a little bit harder.

We need support. A lot of support, extending well after treatment. In

addition to my amazing friends and family (whom I legitimately don't think I'd be here without), this year I realized I needed to branch out and

> meet more people like me who are figuring out this crazy game of life after cancer.

Not to say this was a new concept; I'd dabbled with social media and connecting with a few people at the hospital. But it's been a real challenge meeting cancer fighters who are around my age — I was

treated next to infants and teens on the hospital's pediatrics floor, and most people I've met or have been introduced to since are older.

This year I forced myself to make something happen. I asked around and signed up for some online groups.

At first, yes, it was awkward ... not everyone was the right fit. But I kept reminding myself that all it took was one match to build on. Eventually, I started clicking with people. Then, in just a few minutes of swapping stories and talking through challenges, I could already feel the sweet satisfaction of having linked up with my tribe.

It's brought me a lot of inner peace, and I highly recommend making the effort. If you're a cancer fighter with a new world unraveling before you, don't underestimate the need for people in your life with firsthand experience (and who you get along with). You don't have to build your network right away — you may not be ready yet, and we can only take on so much at a time.

Just keep it in mind for when you start to notice that need for a little camaraderie. During your rebuild in life after cancer, this can be your foundation.



## Confronting the Person in the Mirror

It's easy to internalize how others treat you, but often it's a result of their inner struggles, a cancer survivor explains. By JESSICA BOLZ

I HAVE WORN many occupational hats during my 48 years on the planet, from lifeguard to bartender to advertising assistant to dental assistant. I landed in my current state as a water and land fitness trainer about five years ago, and I truly believe it was the universe working the idea of the dynamic exchange of give and take energy from myself to my clients. I felt so purposeful being able to share my knowledge of water and how to utilize it to benefit the body, which can help so many with their comorbidities and limitations. Sharing my story as a four-time cancer survivor who went through nine surgeries, three chemo series

empowering to my population, which consisted of other survivors — people struggling with weight, cardiac issues, diabetes and arthritis. This was more than a position as a trainer. One of my clients called me

and heavy radiation to the chest and abdomen was

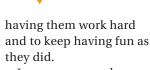
a "minister," saying I inspired people toward change.

JESSICA BOLZ

I realized somewhere around the age of 40 that it is way easier to see others' faults - what they've done to you or how they have caused you to react. It's not as easy, and sometimes near impossible, to look in the mirror and see yourself or even meet yourself for the first time. As I became more engaged in my job, I would look to motivate my clients with fun

themes for my workouts, which had them laughing and singing along as I dressed as Elvis with his sideburns, Princess Leia with her cinnamon bun hair or Wonder Woman complete with her entire Star-Spangled Banner suit (my favorite). I was a stickler about

I went home that night and decided to start a new ritual of looking in the mirror, not to fix my makeup but to see me — the good, the bad and everything in between. —JESSICA BOLZ



I was unprepared — or maybe it was my ego, which I didn't realize was so fragile - for any

critiques that would come my way. I was equally unprepared for how defensive I would get and how I would ruminate afterward. "I worked really hard on that playlist and that costume and those moves. That class was put together perfectly. They just don't know how to work in the pool. They don't listen. They are obnoxious and entitled. They aren't very bright." I had a thousand reasons why it was their fault for not enjoying what I

was doing. The onus was on them, though.

There was a regular client who for years had been coming to the center where I worked. She almost immediately had an issue with me. "Why is your music so loud? No one can hear you." "Why are you getting in the water for exercises? No one can see you." Her hazing was consistent and brutal as she would doggy-paddle around the deep end with one arm, reminding me of Nemo floundering around with his one good flipper. She would join my classes a half-hour after they would start and ferret her way through 20 other clients to find her spot to travel around in her own circle. I began referring to her as



The Bulldog — I felt hatred for this woman. She was embarrassing me. She was rude. She had no respect for me or anyone else in the pool. At times I would shoot back an angry reply to her, having been reminded of my childhood when I felt so many times like a weakling, defeated by my mother's criticisms and disapproval as well as disappointment in me when I didn't meet her expectations. "Everyone else in the pool can hear and see me just fine," I yelled back at her. Undaunted, she rattled on and then would start talking to other clients in the middle of my classes. I wasn"t going to let her get away with this. I was determined to let all my clients know that I was not this passive beta female who would be kicked around. There would have to be rules instituted before my classes so they would know I meant business.

One morning, after yet another exchange with this woman, I met with my supervisor. "You know, I don't think it's right that we have to take abuse from clients. I have no idea why this woman hates me so much and my classes. He turned to me and said flatly, "It's not about you, Jessica." What did that mean? Of course, it was about me. She was complaining directly about me and

to me, and to anyone else who would listen. "Did you ever think that maybe she is unhappy with her life or her own restrictions and you just happen to be the outlet?" "That's not fair," I screamed back at him.

"Take yourself out of the equation," he said, repeating, "It's not about you." I ruminated over that for weeks. I finally decided to speak with the staff psychologist who worked with many of our clients who had weight issues as a symptom of a much deeper problem. Much like I was about to discover, I had symptoms from something way different from my current circumstance. "Jessica, when this woman sees you, you may remind her of someone, she may be triggered by your music and have sensory issues, or it could be your mannerisms," the psychologist explained. Posttraumatic stress rears its head in many ways. I had never thought of that. I was so busy defending myself that I never thought that others had an entire life that caused them to react to things differently. And what about me in those situations? Was I looking at how I was acting? Was I a part of it, or was I able to "take myself out of the equation"? I couldn't say I ever did. In fact, I jumped right into it to defend my honor.

One day after a class I had given, one of my favorite clients came up to me and was recounting how much he enjoyed the class. He laughed because he had seen and heard how I had given a warning to two people in the back who were being too loud and breaking my no talking rule in class. "You are definitely not one I would want to get angry. You don't want to mess with you." For a moment I was elated. This kind of helped with my concern that maybe I was still that young girl who was beaten down emotionally and mentally by a disapproving parent. "You mean you think I'm strong?" I asked sheepishly. "You are like this little petite thing, but when you get in front of that class it's like you are a giant." It made my eyes fill with tears of pride. I went home that night and decided to start a new ritual of looking in the mirror, not to fix my makeup but to see me — the good, the bad and everything in between. It really wasn't fair for me to take the easy road and just constantly play the victim, and this man had reaffirmed I wasn't. I had to take accountability for situations in life too and participate in the human experience. It's a give and take and you play the leading role in the story, always. h



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## heal at home

## **SPRING** Into the New Season With Easy Appetizers!

With the warm weather on the horizon it's time to spice it up in the kitchen – literally with our baked cauliflower wings! RECIPES PROVIDED by RACHEL WONG, RDN, CSO, LDN



#### **Energized Everything Bagel**

#### **INGREDIENTS**

- · 4 ounces whipped cream cheese
- · 1 cup plain Greek yogurt
- 1/2 teaspoon onion powder
- ½ teaspoon garlic powder
- 2 tablespoons everything bagel seasoning, plus extra for topping
- 1 to 2 tablespoons of milk as needed for consistency

Note: Full-fat dairy ingredients may be substituted for reduced fat or fat free

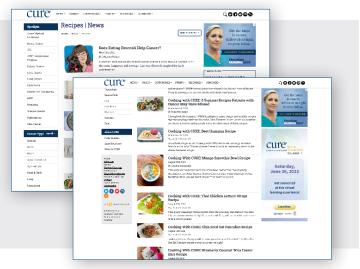
#### **DIRECTIONS**

- 1. Mix all ingredients in a bowl and sprinkle with additional everything bagel seasoning on top. Refrigerate for at least 30 minutes before serving.
- 2. Serve with your favorite chips or vegetables.





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## **Blooming Baked Buffalo Cauliflower Wings**

#### **INGREDIENTS**

- 1 large head of cauliflower (washed, cored and broken into 1.5 to 2 inch florets)
- 34 cup of flour
- · 1 cup of milk or water
- 2 teaspoons garlic powder
- · 1 teaspoon paprika
- ¾ teaspoon salt
- 1/4 teaspoon black pepper
- Cooking spray
- ½ cup hot sauce (Such as Frank's Red Hot)
- 2 tablespoon coconut oil (melted)
- 1 tablespoon honey
- ½ tablespoon lemon juice

#### **DIRECTIONS**

- 1. Preheat oven to 450°F. Grease a baking sheet with cooking spray or line it with parchment paper.
- 2. In a large bowl, whisk flour, milk, garlic powder, paprika, salt and pepper until batter is smooth. Add cauliflower to batter and toss to coat.
- 3. Spread cauliflower onto the prepared baking sheet in a single layer with space between them. Bake in the preheated oven until lightly browned, about 20 to 25 minutes, flipping over halfway through.
- 4. In another small bowl, combine the hot sauce, honey, melted oil and lemon juice until well blended. Brush the buffalo sauce mixture on the cauliflower.
- 5. Return to the oven and bake until they start to brown, about 15 to 20 minutes.
- 6. Serve hot with choice of dressing, celery and carrots, if desired.



## Greek Yogurt Buzzing Blue Cheese Dip – a perfect addition to our wings!

#### **INGREDIENTS**

- ½ to ¾ cup crumbled blue cheese
- 1/3 cup buttermilk (or more for thinner consistency)
- ¾ cup nonfat plain Greek yogurt
- · 1 tablespoon lemon juice
- 1 to 2 teaspoons garlic powder
- · Salt and pepper to taste

#### **DIRECTIONS**

1. Mix all ingredients until well combined but still chunky. Serve and enjoy!







**Moving Mountains for Multiple Myeloma** (MM4MM) is an award-winning collaboration between CURE Media Group and the Multiple Myeloma Research Foundation (MMRF), which raises funds and awareness for myeloma research.

Since its inception in 2016, Moving Mountains for Multiple Myeloma teams have climbed Mount Kilimanjaro, hiked the Grand Canyon, summited Mount Fuji, trekked the Inca Trail to Machu Picchu, reached Everest Base Camp and conquered Iceland's many landscapes. Our team members have raised over \$3.5 million, 100% of which goes directly to the MMRF, which spearheads and funds critical myeloma research. These amazing journeys are captured via blogs, social media posts and video.

After pausing for the global pandemic, we are back with a new schedule of exciting climbs. Patients, caregivers, loved ones with myeloma, and others impacted directly by multiple myeloma will trek through the wilderness of Alaska's Kenai Peninsula, summit Mount Washington and discover the dynamic terrain of Colorado's Backcountry Continental Divide. They will raise funds for multiple myeloma research and demonstrate that the advancements being made in recent years, led by the MMRF, are helping patients live longer with a higher quality of life than ever before.

To learn more and join a MM4MM team visit: **MovingMountainsForMultipleMyeloma.com** 

To learn more about the MMRF, visit TheMMRF.org

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