living well *after* cancer

# heal®

VOL.9 NO.3 / SUMMER 2021

# A CHALLENGE TO CHEW ON

*For some cancer survivors, eating and drinking can become difficult, if not impossible, after treatment.*

*Also inside*

Know That You Are Enough

Rampant Drug Misuse Among Young Cancer Survivors

How to Help the Newly Diagnosed

Coping With Infertility

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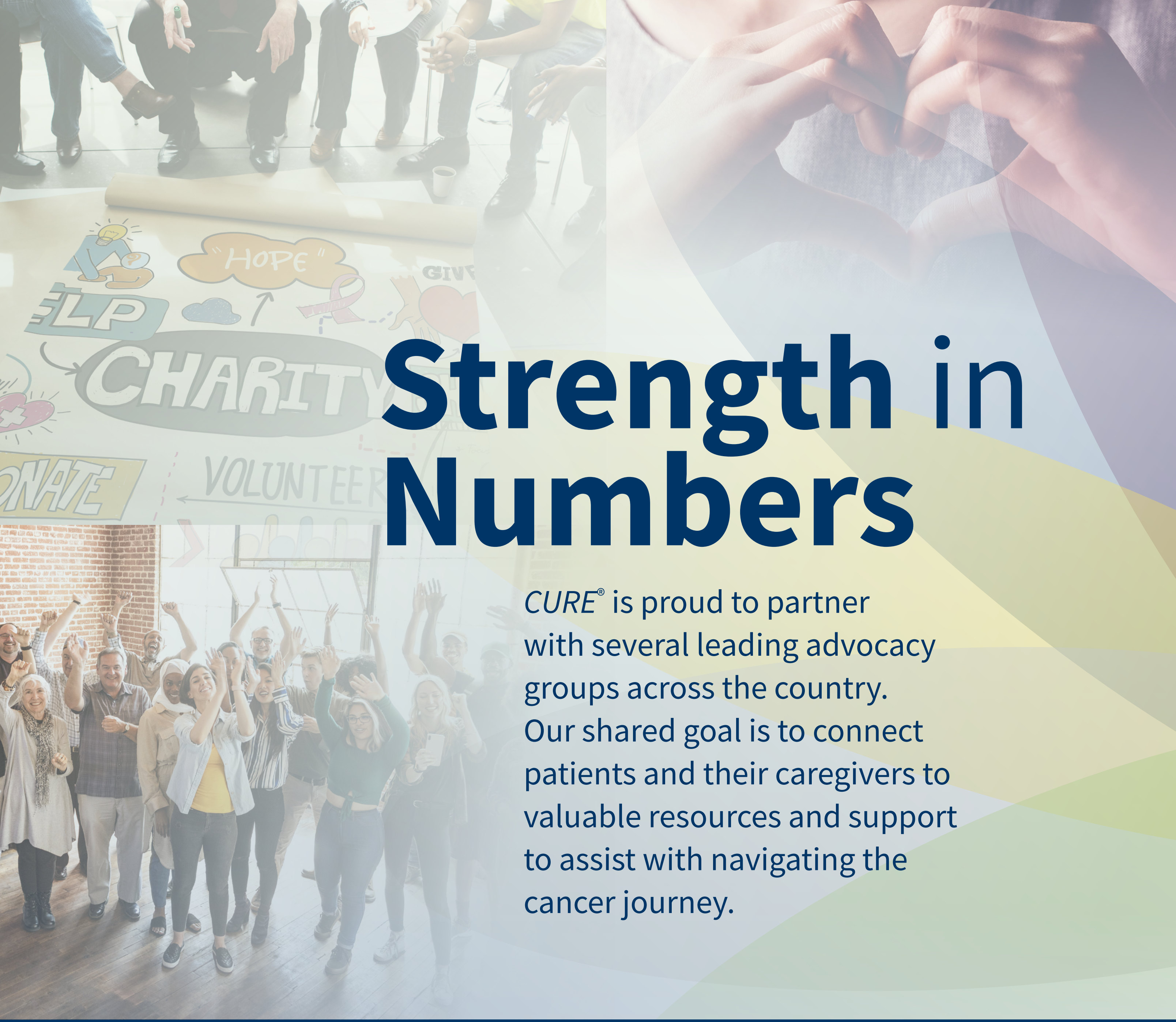

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cure®
ALLIANCE

# heal contents

SUMMER 2021
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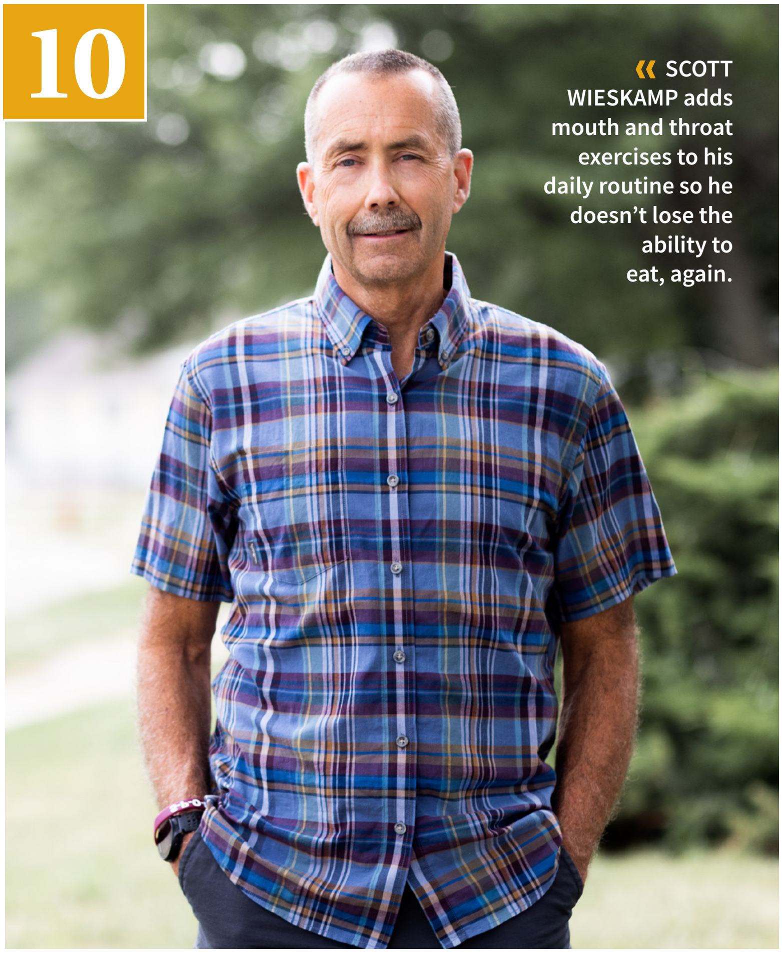
**NEWS & INSIGHTS**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« **SCOTT WIESKAMP** adds mouth and throat exercises to his daily routine so he doesn't lose the ability to eat, again.

## Community Voices

COVER IMAGE: FANTOM_RD / STOCK.ADOBE.COM; NIKKI MOORE; GARDENING: MERFIN / STOCK.ADOBE.COM

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# Eating After Cancer Is Not Always Easy

**AS A SURVIVOR OF ORAL CANCER** caused by the human papillomavirus said in our cover story of *Heal*®, "Our lives revolve around food." And for many survivors of cancer, this can be a burden they experience as a result of treatment-related side effects.

Some cancers, such as head and neck, often require treatment that can affect a person's swallowing, taste and smell. It can be frustrating for survivors to eat after experiencing these side effects, but consuming enough healthy nutrients is vital to returning to a normal way of life.

Also in this issue of *Heal*®, we learn more about the topic from two survivors who experienced it themselves. We also hear from multiple registered dietitians who work specifically in oncology about why these side effects happen and what can be done to work through them.

Also in this issue, we hear from a survivor whose corporate life was turned around when she received a diagnosis of breast cancer. She felt lost after leaving the job she had worked so hard for, but eventually she found her way, wrote it all down in a book and wants everyone to know: You are enough.

Additionally, a survivor of colon cancer shares her story of experiencing infertility after cancer. When she received her diagnosis at the age of 17, she was not concerned about what might happen in the future, but later in life realizing that she would not be able to naturally have a biological child came like "a thief in the night."

Finally, celebrate summer fun in the sun and the return to "normal" — something many of our survivors have felt before — as COVID-19 restrictions life across the country. We have you covered on what to serve. Check out the fresh peach salsa appetizer and a quinoa salad with mango as a side to any of your favorite main dishes. And you know we never forget dessert — this one is filled with fruit and no guilt!

As always, we hope you find this issue both informative and helpful. Thank you for reading.

**MIKE HENNESSY SR.**
*Chairman and Founder*

**TALK TO US!**
**SCAN THE QR CODE** to email correspondence to **editor@curetoday.com** or mail letters to *Heal*®, 2 Clarke Drive, Suite 100, Cranbury, NJ 08512.

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# overheard on SOCIAL MEDIA

## *Advice From People Like You*

We asked readers, **"How has cancer changed your relationship with food?"**

***Here's what they told us.***

> "I went from being mostly vegetarian to eating strictly a plant-based diet. *— BRITT*"

> "I haven't changed much of anything. All food tastes so different now. Meal time for me is more like work. If there is one thing I could change, it would be one more pill to take to replace the food I try to eat. *— ROCKY*"

> "My diet is extremely limited. ... I have regular diarrhea due to surgery to remove part of (my) small bowel that was damaged by radiation. I can no longer tolerate most vegetables and red meat. (I) have to take supplements to augment my diet. Twelve years now and counting. *— ANEETHA*"

> "Made me never take food for granted. During treatment, food and beverages, even water, tasted nasty. Now I relish the flavors. *— BETH*"

> "It changed my appetite! I'm not as hungry as I used to be. Meat tastes funny to me sometimes. *— SHERYL*"

> "I am eating healthy meals now. Started changes prior to cancer, but really stepped it up. *— MARIE*"

> "It hasn't changed much, since I've always eaten pretty healthfully. I have eliminated foods that I must avoid (no more raw bar/sushi, unpasteurized cheese and the like, as they are potentially dangerous for blood cancer). I want to enjoy life, and food is part of it. *— KAREN*"

»» *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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# Surviving Cancer During a Global Pandemic

## Self-coping mechanisms helped survivors of cancer get through their first year after treatment, but many feel more remote-access resources are needed.

By COLLEEN MORETTI

**SURVIVORS OF CANCER WHO** recently finished treatment, especially those over 60, struggled with coping during the COVID-19 pandemic, highlighting the need for the development of a remote-access resource for coping, researchers say.

"We all know that … COVID-19 affected numerous people around the globe, and the World Health Organization acknowledged that those who are the most vulnerable to the negative effects of COVID-19 are those who are older than 60 years of age," said Jacqueline Galica, a nurse scientist and assistant professor at Queen's University in Kingston, Ontario, Canada, during a presentation at the virtual Oncology Nursing Society Congress. "And given that nearly 9 out of 10 cancer diagnoses occur among people who are older than 60 ... this group is an important group to study during the pandemic."

After the first year of treatment, survivors require resources for psychological and informational support, and this is especially true for those over 60, as they might also have other comorbidities. During the COVID-19 pandemic, many resources were limited to these patients. Researchers wanted to see how the population who completed treatment in the past year were coping during the pandemic.

Researchers interviewed 30 participants (56.7% women; mean age, 72 years). According to Galica, questions asked of these participants included:

- **How does the COVID-19 pandemic affect your access to formerly used and/or desired resources/supports?**
- **What coping recourses are you using during the pandemic?**
- **How do these resources help (or not) meet your cancer-related care needs?**
- **What are your reflections on the pandemic? What are your suggestions for suitable resources and delivery methods when traditionally offered resources are limited or unavailable?**

Results showed that survivors initiated coping mechanisms on their own, including acceptance (29 participants; 96.7%), self-distraction (28 participants; 93.3%) and taking action (28 participants; 93.3%). Participants also reported using instrumental (26 participants; 87%) and emotional support strategies (25 participants; 83.3%).

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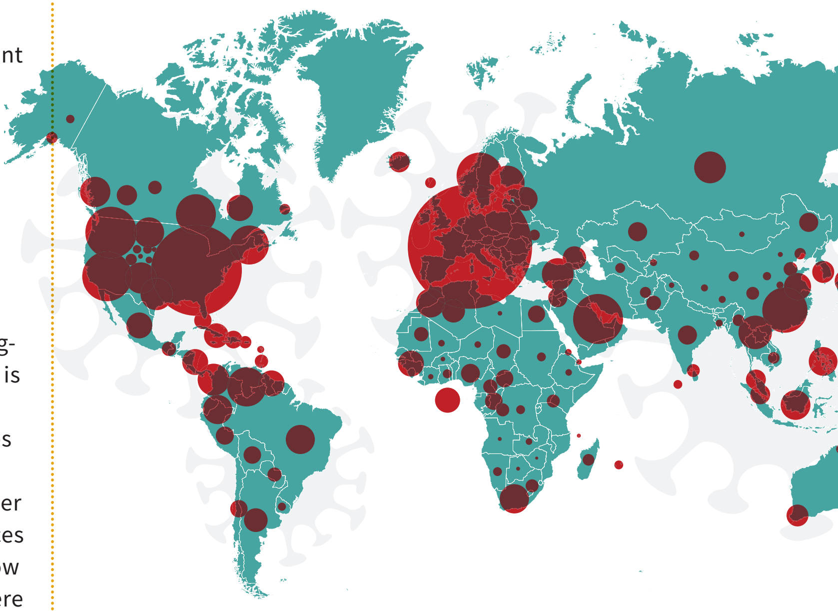

During the analysis, the researchers found interconnected themes in the population, such as drawing on past experiences, redeploying coping strategies and dealing with complications of cancer survivorships in a pandemic.

Drawing on past experiences meant survivors were using coping strategies that they had already known about through previous illnesses or through someone they knew who had an illness, as well as other life experiences, such as work, especially for those who had a background in health. Researchers reported quotes from participants, such as:

- **"I don't find it such a change because the things I'm doing I was doing after I got my cancer diagnosis, anyway, because I wouldn't go near anybody when my immunity was so low, so that's helped."**
- **"I didn't have children I had to worry about shopping for. My parents are deceased. So, really, this pandemic hasn't been that hard for me."**
- **"I have lived in isolation. I had all these supplies that you would use for being isolated. I did it as a routine," from a participant who was a health care professional.** »

The second theme seen was the redeploying of coping strategies. Participants continued their way of life during the pandemic or “even magnified their formerly used strategies during the pandemic,” Galica said. Participants reported taking up new and old activities to help keep them distracted from their concerns. Some participants said:

- **“Absolutely everything is easier post cancer and chemo.”**
- **“I’m using my cleaners more. I was always very particular about that anyway.”**
- **“(Crocheting is) like a therapy to me because it keeps my hands busy. It keeps my mind going. And it keeps my mind off other things because if you sit and you don’t do anything, that’s when you run into trouble, as far as your mind wandering, and you can get yourself really, really worked up.”**

The last theme was dealing with complications of cancer survivorship in a pandemic. “Sometimes survivors observed a dissonance between the coping strategies that were available to them versus those that were familiar. And this made it challenging for them to cope with their cancer-related concerns,” Galica said. This was seen specifically in participants who still experienced side effects that affected their ability to engage in former activities that they enjoyed; some either modified expectations or stopped altogether. Regarding this theme, participants said:

- **“It’s different. … I’ve been going fishing by myself rather than (taking) somebody with me, so it changes the way fishing is. It’s just there’s nobody to talk to or just shoot the breeze with when you’re fishing.”**
- **“Before the pandemic, I would do a lot of activities and exercise because that’s what really helps me with the condition. … While I was exercising, I was doing quite well, but because I’m not going to go to the gym anymore, (it) causes my condition to worsen. So it has had a huge effect on me.”**

Participants had four recommendations for future care. The first was getting enhanced baseline information, meaning having their oncology team help them prepare for self-treatment if there was going to be an interruption in care. Second, participants reported that changes in visitor care were a concern that needed to be addressed. Third, older patients acknowledged the need for technology integration and felt it could be used more or less in certain settings. Lastly, participants valued the use of masks and other personal protection equipment and felt it increased awareness about protecting people even after the pandemic.

The study authors concluded that clinicians can use a strength-based approach for survivors as they draw from their past experiences. Also, there is a need to enhance resources to support coping, specifically using remote methods when patients cannot attend in-person sessions. h

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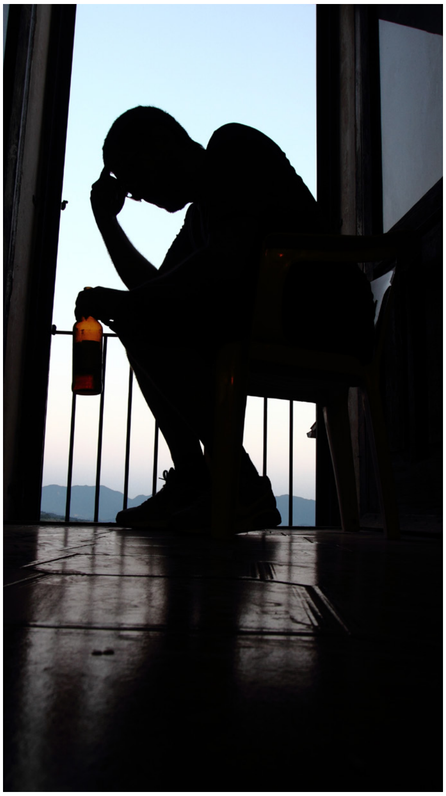
# Drug Misuse in AYAs ‘Underscores Need for Intervention’

Risky, unhealthy habits among adolescent and young adult cancer survivors may be a result of overprescribing from doctors or inefficient pain management. *By* COLLEEN MORETTI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**ADOLESCENT/YOUNG ADULT** (AYAs; ages 12 to 34) survivors of cancer were more likely to use and misuse alcohol and drugs compared with their peers without a history of cancer, according to data from a national survey published in *Cancer*.

AYAs are at a challenging and developmental period in their lives, which often leads to risky and unhealthy habits, the study authors noted. Survivors of AYA cancer can have the risk of cancer-related death increased by using and misusing substances such as drugs and alcohol. Despite this, AYA survivors often continue to partake in unhealthy behaviors.

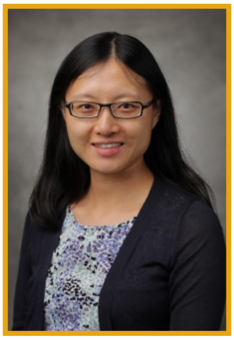
“To better inform interventions to prevent and reduce substance use and substance misuse, there has been a critical need to fully understand the current prevalence and patterns of substance use, misuse and addiction among AYA cancer survivors as compared (with) the general population," said Xu Ji, an assistant professor in the Department of Pediatrics at Emory University School of Medicine and Aflac Cancer and Blood Disorders Center at Children's Healthcare of Atlanta, in an interview with *Heal*®. "Unfortunately, to date, this area has been seriously understudied."

Researchers assessed substance use, misuse (defined by Ji as using a larger amount of a substance than directed by a provider) and disorders in the past year among survivors of AYA cancer. Using a national survey, researchers identified 832 AYA cancer survivors and 140,826 AYAs with no history of cancer. Outcomes assessed included use of tobacco, alcohol, marijuana and illicit drugs, as well as misuse of prescription opioids, substance use disorders (defined by the authors as "past-year abuse or dependence on a substance") and treatment.

In the past year, compared with patients without a cancer history, AYA survivors were 6% more likely to use alcohol, 34% more likely to use illicit drugs and 59% more likely to misuse prescription opioids. In addition, survivors were 77% more likely to have an illicit drug use disorder, 67% more likely to have a marijuana use disorder and 67% more likely to have a prescription drug use disorder.

"We found that the increased rates of substance use and substance use disorders among AYA cancer survivors, as compared (with) their peers without cancer, were largely … explained by their differences in physical and mental health care needs," Ji said. "One of the possible reasons to explain this is (that) there is an increased rate of experiencing physical and mental health problems (in survivors) associated with their cancer diagnoses, treatment and general cancer experience."

When adjusting for health status — specifically depression — there was no difference between survivors and non-survivors in reporting alcohol and drug use, although survivors were 41% more likely to misuse prescription opioids.



**XU JI**

> I think our findings underscore the need for future efforts or interventions to prevent and reduce substance use problems among AYA survivors of cancer. *— XU JI*

"This (percentage of prescription opioid use) is relatively large in terms of magnitude," Ji said. "We think that this finding may at least partially reflect survivors' increased need for opioids to avoid pain or to help address some of their pain problems. In fact, in our data, we found that the vast majority — and more specifically 64% of the AYA survivors — reported that the main reason for misusing prescription opioids was to relieve their physical pain."

Survivors were one to two times more likely to receive treatment for a substance abuse disorder compared with those with no history of cancer (21.5% versus 8%).

"That's actually a relatively good side of the entire story," Ji said. "It's possible that survivors have increased engagement in the health care system because of cancer treatment already. These can provide (patients) more opportunities to identify their substance use problems and also to intervene (with) their substance use problems."

Only 1 in 5 survivors received treatment for a substance abuse disorder.

Ji said that overprescribed opioids and poorly controlled pain may also play roles in increased substance misuse and abuse.

"Under the current and still ongoing pandemic-exacerbated opioid crisis, it's possible that overprescribing of opioids, combined with lack of knowledge and awareness of safer use of prescription opioids, may lead to the increased misuse of opioids among AYA (survivors of) cancer," she said. "On the other hand, because of our (wide) definition of misuse … it's also possible that opioid misuse may reflect poorly controlled pain or badly controlled pain among survivors. Therefore, it's likely that survivors may self-medicate themselves using a larger amount or more frequent or longer duration of prescription opioids than a (doctor would recommend)."

Findings from this study highlight the need for more efforts focused on AYA survivors of cancer, Ji said.

"I think our findings underscore the need for future efforts or interventions to prevent and reduce substance use problems among AYA (survivors of) cancer," Ji noted. "We think that significant efforts are really needed to enhance communication between providers, survivors and caregivers in order to raise young survivors' awareness of their increased risk for adverse health complications compared (with) their peers and also the increased risks associated with their severe substance use behaviors."

Ji noted that teaching survivors coping methods to turn to instead of substance use would help. She added that providers who regularly see AYA survivors of cancer should be assessing substance use among them, referring them to treatment and eventually exploring treatment that does not involve opioids.

# Speaking After Surviving

## Factors such as race, smoking, longer survival time and treatment can increase voice and speech issues in survivors of oropharyngeal cancer.

*By* COLLEEN MORETTI

**SIMULTANEOUS CHEMOTHERAPY** regimens, several modalities of chemotherapy induction, total radiotherapy dose and continued smoking all are factors that can contribute to voice and speech impairments in survivors of oropharyngeal cancer, according to data published in *JAMA Otolaryngology – Head & Neck Surgery.*

Findings from the study also demonstrated that Black and Hispanic survivors of oropharyngeal cancer were more likely to have moderate to severe speech and voice symptoms.

"We postulate that the racial/ethnic differences observed in our study may be owing to low income, lack of health insurance, lack of awareness, differences in the perception of symptoms, behavioral/lifestyle choices, cultural and social differences, and possibly other environmental factors or other comorbidities," the study authors wrote.

Patients with oropharyngeal cancer are often treated with surgery and/or radiotherapy that can affect their oral cavity, pharynx and larynx. As a result, this can affect a patient's voice and speech production. "Voice and speech production are complex physiological functions that are critical for verbal communication and social interaction and an inherent part of a person's individuality and psychological well-being," the study authors noted.

Researchers sought to discover clinical and demographic risk factors that affect voice and speech symptoms through patient-reported outcomes. They analyzed survey responses from 881 survivors of oropharyngeal cancer (median age, 56 years; 15.5% women; 92.4% White; 1.9% Black; 3.8% Hispanic), which were used to calculate scores on speech and voice functionality. Voice and speech scores of 0 to 4 were considered none to mild symptoms, and scores of 5 through 10 were considered moderate to severe.

A total of 113 survivors (12.8%) reported moderate to severe symptoms, and 288 survivors (32.7%) reported none to mild.

Risk factors associated with moderate to severe voice and speech symptoms included increased survival time, increased total radiation dosage, treatment with induction and concurrent chemotherapy, and late and baseline lower cranial neuropathy (functional impariment with deficits in swallowing, speech and voice).

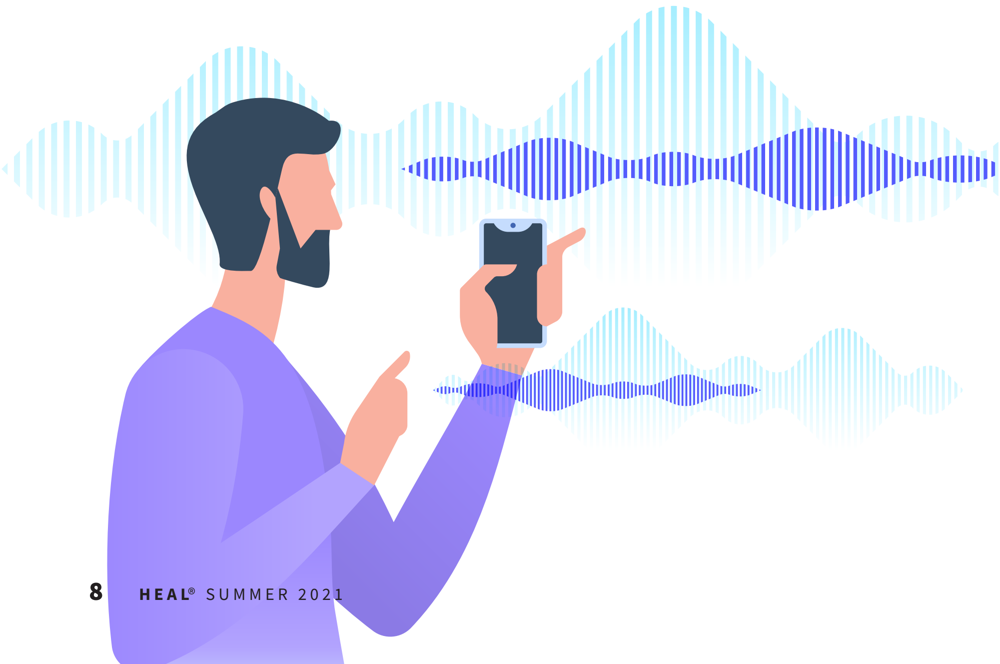
In addition, Black race and Hispanic ethnicity were associated with a higher risk of speech and voice symptoms. Five of 16 survivors (31.2%) who identified as Black and 9 of 33 survivors (27.3%) who identified as Hispanic reported moderate to severe voice and speech symptoms.

Continued smoking was also associated with a higher risk of voice and speech symptoms. The study authors link this connection to the fact that smoking may cause irritation and dry laryngeal mucosa (mucus lining of larynx), which can lead to vocal cord inflammation and irritability.

Those with an increased survival time also had an increased risk of voice and speech symptoms due to the survivor experiencing late toxic effects of cancer treatment as they aged.

Notably, an intensity-modulated radiotherapy split-field regimen was linked with a lower likelihood of moderate to severe speech and voice symptoms.

"Given the ever-growing population of comparatively healthy patients with human papillomavirus-associated (oropharyngeal cancer) who are likely to survive decades after treatment, our therapeutic efforts to preserve function and (quality of life) are important but should not compromise oncological outcomes," the study authors concluded. "In situations in which these goals are competing, they should be prioritized and individual patient preferences and priorities (considered) through a shared decision-making process with the patients and their families."



DZIANIS RAKHUBA / STOCK.ADOBE.COM

# Coping With Infertility Means Coping With Another Loss

A colon cancer survivor recalls how she made peace with being infertile as a result of cancer treatments.

*By* DANIELLE RIPLEY-BURGESS

**MOST OF THE TIME,** if we were going to sit down to chat about my experience with cancer, you'd find me upbeat and optimistic. I'm a fairly positive person, and that comes out when I tell my story. But it's important for me to not sugarcoat the challenging parts. Facing cancer brings both ups and downs. Some of the most joy-filled moments are contrasted with intense, heart-stabbing pains. One of my most searing pains doesn't involve the scars, bathroom emergency stories or treatment side effects that linger today. It involves the reality that, because of cancer, I deal with infertility. This ache follows me every day.

The words flow off my tongue now, as I'm quick to label myself as infertile and explain why I don't have biological children. I can talk about it without crying and even wrote this article with relative ease. But make no mistake: It took me more than 10 years to get here. Nothing feels natural when you're dealing with infertility.

## BECOMING INFERTILE

At first, I wasn't concerned about my situation regarding childbearing. Having received a diagnosis of colon cancer at 17, I knew the treatments could affect my chances of having biological children, but I didn't really care. I had always planned to adopt. Plus, I had other things on my mind. I was just hoping to enroll in my senior year of high school.

I didn't put a lot of thought into what it meant for the doctors to perform an ovarian suspension prior to radiation therapy. Looking back, I can also see how I blocked a lot of fear. Why were common fertility preservation strategies such as freezing eggs not an option for me? There was no time. Doctors couldn't prioritize my ability to create future life and delay treatment with my own life on the line. It was scary stuff, things I didn't want to think about.

For years, being infertile didn't bother me very much. My husband and I considered ourselves fortunate to know I was infertile going into our marriage. We were in no rush for children, and when we were ready, we didn't have to go through years of trying to get pregnant only to face surprising disappointment. Knowing ahead of time saved us a lot of heartbreak. I could count my blessings.

But by the time I hit my mid-20s, when a lot of my friends and family members started getting pregnant, the pain of infertility hit me out of nowhere. The blessings I'd once counted were thrown out the window. Infertility went from something I barely thought about to something that, if I let it, could consume my life. It was like a thief in the night, stealing what I held so dear. Yet the crazy thing was that it stole something that never had a chance at life. This made it even more difficult. As the reality of my being infertile sank in, it led me to a dark place. To feel so powerless over whether you can create a life, while being physiologically built to create and carry life, is devastating.

## ADOPTION DOES NOT TAKE AWAY INFERTILITY PAIN

I wondered, as I imagine most infertile couples considering adoption do, if the pain of infertility would go away once the role of "mother" became a reality. Adoption agencies cautioned us to give ourselves enough time to grieve a biological child. I understood their wisdom once a baby girl gave me the proud title of mom. Although our bundle of joy did indeed bring healing, laughter and light into our world, she didn't take away my infertility pains and the reality that I couldn't bear children as her birth mother did. As I processed this and became real and open about my feelings, adoption became the blessing on the other side of the pain. However, adoption alone didn't take the pain away. Only time spent healing could.

## HEALING TAKES TIME, BUT IT'S POSSIBLE

It's taken me more than a decade to get to the point where I can openly talk about infertility. I started telling my cancer story within months of receiving my diagnosis, but getting to a point where I can talk about what it's like to be infertile has taken a lot of time. I needed to grieve and find nonjudgmental spaces to let my true feelings come out. I needed to give myself permission to feel angry, cheated and hopeless. I needed to skip baby showers, to cry and acknowledge that not having biological children but wanting them is really, really difficult. Even now, some days are easier than others.

All of this work did eventually turn things around for me. Today, I live with optimism and hope. I'm able to count my blessings once again but only because I count the losses, too.

JKLR / STOCK.ADOBE.COM

# A CHALLENGE TO
# CHEW ON

PIXEL-SHOT / STOCK.ADOBE.COM ADAPTED BY GWEN SALAS; WIESKAMP BY NIKKI MOORE

# For some cancer survivors, eating and drinking can become difficult, if not impossible, *after treatment.*

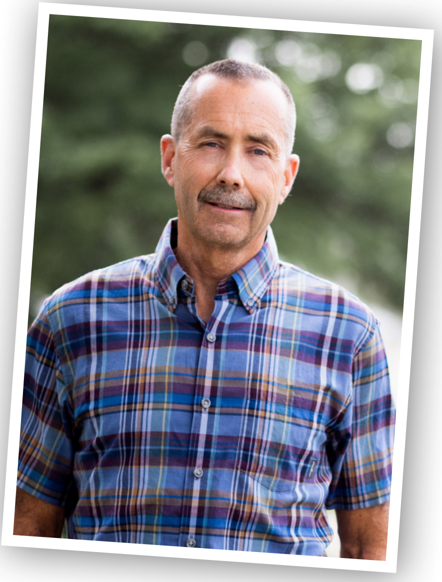
*By* DARA CHADWICK

Exercise has always been part of Scott Wieskamp's life. But after cancer treatment, the longtime runner and marathoner added a new element to his training regimen — exercises to strengthen and maintain his swallowing muscles.

"Every day while I'm driving to work, I open my mouth like I'm yawning to stretch all my facial muscles as much as I can," says Wieskamp, 62, who lives just outside Lincoln, Nebraska. "I take my tongue and put it under the back of my lower teeth and push as hard as I can to exercise my tongue muscles. There's about half a dozen things I do for a few minutes every day."

Four years ago, Wieskamp was treated for oral cancer caused by the human papillomavirus. The aggressive treatment, which included 39 radiation sessions and several doses of the chemotherapy drug cisplatin, knocked out the cancer. But it also left Wieskamp unable to eat, and he lost 15 pounds in a matter of weeks.

"As you get radiation in the neck and throat area, it becomes painful to swallow," he says. "I quit doing all that. I quit eating, quit swallowing — I couldn't even drink."



**SCOTT WIESKAMP** was left unable to eat for weeks because of treatment side effects and had to learn how to swallow again.

Because he was unable to get adequate nutrition, his doctors inserted a feeding tube so Wieskamp wouldn't have to swallow. The tube stayed in place throughout his two months of treatment and for about a month after, he says. »

“I quit eating, quit swallowing. I couldn’t even drink.” — SCOTT WIESKAMP

NIKKI MOORE

Although his nutrition improved, Wieskamp says he was left with another problem: His muscles “forgot” how to swallow.

“I had to go to a speech-language pathologist to help me learn how to swallow again,” he says. “It was scary, painful and frustrating.”

Wieskamp’s swallowing challenges aren’t uncommon. After treatment, survivors of cancer may experience not only difficulty swallowing but also dry mouth and changes in taste, smell, digestion or bowel habits. Any of these changes can make eating and drinking a struggle, which then makes it difficult to get adequate nourishment.

When you’re not getting the nutrients you need, it’s hard for the body to regain strength and rebuild cells, according to Rachel Wong, an oncology dietitian at the Georgetown Lombardi Comprehensive Cancer Center at MedStar Georgetown University Hospital in Washington, D.C.

“Patients can experience delayed healing and recovery caused by poor nutrition post treatment” she says. “A rapid decline in weight from inadequate nutrition often results in both fat and muscle loss, causing significant fatigue and weakness, which can greatly impact one’s ability to accomplish tasks and resume a normal way of living.”

“It can be possible that patients find delayed healing and delayed recovery because of poor nutrition post treatment,” she further explains. “If you’ve lost a lot of weight and you’ve lost muscle, you may sleep a lot during the day.”

Eating challenges can also make it tough for survivors of cancer to enjoy time with family and friends, Wieskamp says. After treatment, he didn’t look forward to social occasions like he used to. “People say, ‘Hey, let’s meet for coffee’ or ‘Let’s have family over and we’ll have a meal,’” he says. “Our lives revolve around food.”

### IMPACTS FROM CANCER TREATMENT

Some types of cancer require treatments that are more likely to affect how people eat and drink. According to Dr. David G. Pfister, medical oncologist and chief of the Head and Neck Oncology Service at Memorial Sloan Kettering Cancer Center in New York City, treatments for cancers of the head and neck pose particular challenges because they can affect swallowing, taste and smell.

For example, surgery in certain areas of the head and neck can disrupt structures used in swallowing, such as the throat and tongue. In addition, oral mucositis — mouth pain, sores and infection — can develop after radiation and chemotherapy. Some survivors experience damage or changes to their salivary glands, which can make the mouth exceptionally dry. This can also predispose them to dental problems.

Jean DiNapoli, 62, of Newburgh, New York, says trying to swallow after completing 30 rounds of radiation for oropharyngeal cancer (a type of cancer found in an area of the throat called the oropharynx) was like "swallowing glass." She also experienced mouth sores and thrush, a yeast infection that develops in the mouth, along with significant dry mouth.

DiNapoli, who is now seven years post treatment, says she lost about 35 pounds immediately following radiation. "I could have gotten a feeding tube, but I really didn't want it," she says. "I didn't want my muscles to atrophy."

Pfister says the decision to place a feeding tube is one that doctors make carefully. "Not that long ago, when significant swelling, pain and weight loss were expected, we would prophylactically put in a feeding tube to get patients over the hump, so to speak," he says. But doctors found that people would soon start taking all their calories through the tube, leading to the exact problem DiNapoli feared — muscle atrophy.

"Your swallowing muscles are like any other muscle. If you don't use it, you lose it," Pfister says, adding that it's critical to make swallowing therapy a routine part of treatment along with good pain control. "We evaluate every patient in an individualized way. (Although) there clearly are settings where we put in a feeding tube, we're more selective."

After her treatment ended, DiNapoli worked with a speech pathologist once a week for a couple of months to regain strength in her tongue muscles and improve her ability to swallow. "I did different exercises, such as swallowing with my tongue between my teeth," she says. "I also had the help of a good nutritionist."

> "Your swallowing muscles are like any other muscle. If you don't use it, you lose it."
>
> —DR. DAVID G. PFISTER

## MANAGING EATING CHALLENGES

Registered dietitian nutritionists trained in mitigating the impact of cancer treatments can help survivors find new ways not only to get nourishment but also to enjoy food again. Annette Goldberg, a senior nutritionist at Dana-Farber Cancer Institute in Boston, says choosing the tools to help individuals bring their symptoms under control can be a bit of a puzzle. It depends on factors such as their overall health prior to treatment, the type of cancer and treatment they had, and the social support system they have.

"Sometimes I'll ask patients if they live alone, and they'll wonder why I'm asking that question," she says. "I want to make sure they have the proper support. If you're not feeling well, you don't want to do anything." That includes cooking, she says.

Maureen Gardner, a clinical oncology nutritionist at Florida Cancer Specialists & Research Institute in Tampa, says survivors who've had cancers in the gastrointestinal (GI) tract or treatment for any cancer in areas near the GI tract — such as prostate, ovarian or uterine cancer — may experience ongoing effects on how food is digested and eliminated. Some survivors may experience weight gain, such as breast cancer survivors who are on long-term hormone therapies or those who have entered menopause. Other people may experience ongoing diarrhea or dumping syndrome — when food moves too quickly from the stomach to the small intestine — after being treated for GI cancers.

Gardner says dietary changes, both in what and how patients eat, can help manage eating challenges after cancer treatment ends. If you have dry mouth, try to:

- **Focus on hydration.** In addition to drinking water, Goldberg recommends keeping your mouth clean and avoiding toothpastes and mouthwashes that are too harsh.
- **Boost saliva production.** Tart foods can stimulate the salivary glands, Goldberg notes. Adding tart lemon juice to water or chewing a strong sugarless mint gum can help.
- **Add soft, moist foods to your diet.** Wong recommends adding extra sauces or broth or even cream to casserole-type dishes or when having drier foods like meat, potatoes and rice.

"Drinking fluids along with your meals can certainly help improve the moisture content in the mouth and make swallowing easier," Wong says. "Just having a glass of water, juice or any type of liquid in between each bite can really help get the food down."

DiNapoli says she drank lots of water to relieve her dry mouth. She also tried different lozenges, mouthwashes and gels. "I still use XyliMelts," she says. "I put (one) in my mouth at night and it slowly dissolves."

Some survivors experience changes in taste and smell that affect the way they experience food. "I lost my sense of taste right after radiation," DiNapoli says. "Everything tasted like paste. But then my sense of taste came back so strong that spicy food was overly spicy. And my sense of smell is stronger." »

**JEAN DiNAPOLI** describes eating after 30 rounds of radiation as "swallowing glass."

"I tell patients that your taste buds and smell will constantly change," Wong says, encouraging people to keep a running list of things that work well and things that don't. "In my experience, a list of what works gives you the motivation to keep trying new things."

If you've had changes in taste and smell that affect how you experience food, try experimenting with seasonings. Adding spices such as basil, pepper or dill can make food more sweet, savory or salty and improve its flavor. Wong also recommends adding different types of sauces, such as ranch, barbecue, or sweet and sour to help bring out the flavor in foods and add some moisture.

If you're experiencing ongoing GI symptoms such as diarrhea, Goldberg recommends talking to your doctor or nutritionist about supplements that might help, such as banana flakes. "It's a product that's made from dehydrated bananas, which contain several soluble fibers including pectin. The soluble fiber absorbs fluid to help firm the stool," she says. "A combination of foods, maybe some supplements and working with your care team can help."

## IMPROVEMENTS WITH TIME

Although eating and drinking can be difficult during active treatment and the weeks immediately after, strengthening exercises and dietary changes can help most people overcome these challenges with time. Addressing issues right from the start can help the healing process, Wong says.

"Getting guidance from a dietitian can impact how patients recover after their treatment," she says, adding that it's important for doctors to talk with patients about challenges they might experience. She also recommends resources such as the American Institute for Cancer Research and the American Cancer Society for advice on managing eating challenges after treatment.

Support groups — both online and in person — can also help. DiNapoli and Wieskamp are members of an organization called Support for People with Oral and Head and Neck Cancer (SPOHNC). Both say SPOHNC has been incredibly helpful as they've healed.

"I would tell most people that I'm 100% normal, but I'm not 100% the same," Wieskamp says. "My brain has had to learn that things that used to taste one way taste a little different today. But I'm only one person. You could probably interview 20 people and they may have 20 different answers." h

ROSE MARIE PHOTOGRAPHY

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to hear more about Jackson's story on *CURE*®'s podcast.

# THE TOUGHEST *RACE* OF HIS LIFE

More than nine hours of surgery to remove a rare form of bone cancer in the his hip and leg forced Colin Jackson to relearn how to do simple tasks. *Months later, he crossed the finish line of a marathon.*

*By* RYAN MCDONALD

**TWELVE HOURS, 32 MINUTES** and 32 seconds. That's how long it took Colin Jackson to cross the finish line of a marathon in Arizona earlier this year.

Jackson, 39, walked the 26.2 miles — equivalent to the length of approximately 95 Empire State Building's stacked on top of each other — because a prosthetic hip and surgically repaired femur prevent him from partaking in his passion of the past several years, running.

On Aug. 9, 2019, Jackson was diagnosed with stage 3 chondrosarcoma, a rare form of bone cancer. The disease usually occurs in the long bones of the arms or legs, shoulder, pelvis or ribs. It makes up approximately 25% to 40% of the 5,000 to 6,000 cases of bone cancers diagnosed each year.

Weeks after receiving his diagnosis, Jackson underwent a nine-and-a-half-hour surgery to remove part of his hip capsule, the top portion of his femur (the thigh bone) and most of the muscles in his buttocks to extract the fast-growing tumor.

"What hit me the toughest was being told that I wouldn't be able to run because of where my cancer was and what was going to have to be removed," he said in an interview with *Heal*®. "My endurance days were coming to an end. That hit me harder than (being) told that I had cancer."

## RUNNING SAVED HIS LIFE

In January 2014, Jackson visited his primary care doctor after having difficulty breathing while doing simple tasks such as walking from the car to his house. He was told that he was morbidly obese and unless he made drastic changes to his lifestyle, he likely would not live to see his next birthday.

After that devastating news, he committed to completing a marathon within the next year. Jackson ran his first marathon in 2015 in Arizona; during his training, he had lost 106 pounds.

"If it wasn't for running, I wouldn't be here today," he said. "I wouldn't even have had a cancer diagnosis because I wouldn't have made it to that point. With running, I've been able to be extremely conditioned. When I say conditioned, I conditioned my mind to overcome the things that I once thought were challenging."

## PREPARING FOR HIS TOUGHEST RACE

When Jackson was training for his first marathon and trying to lose weight, he would set small goals. The plan was to have little victories each week, rather than try to achieve a huge milestone immediately.

"I credit my running and what I got from completing the nine full marathons I had prior to getting diagnosed with cancer to being able to get mentally prepared for ultimately the toughest race of my life, which has been battling chondrosarcoma," he said. "Even though cancer has been a little bit different type of a race, (running gave) me the foundations."

## AN EXTREMELY DIFFICULT GOAL

Marathons had been part of Jackson's life for the past six years. So when he was told he would no longer be able to run, he was absolutely crushed.

However, following the surgery to remove his tumor and replace his hip and femur, Jackson wanted to set an extremely difficult, but not impossible, goal for himself: finishing another marathon.

He set his sights on returning to the same place he completed his first marathon — Arizona.

"I knew that if every day I was putting in work, I would be able to walk the marathon despite how long it might take," he said. "It may have taken me the whole day, (and) I was prepared to go out there and walk the entire day if it meant completing another marathon.

"Before getting diagnosed, my goal was to complete another one. Cancer inconveniently got in the way. But every day when I would … do my physical therapy, or when the world locked down and I was walking outside, I would push farther than I thought I was going to go just to prove to myself, 'Hey, I can do it today, I can do that extra bit.'"

## ACKNOWLEDGE YOUR THOUGHTS

Whether it's positive or negative, Jackson urges others to acknowledge the thoughts that they have during their cancer journey.

In fact, he says it's OK to be scared, want to cry and feel as though you just can't keep going any further. However, he said that it's also OK to be happy and laugh.

"Remind yourself that you've already overcome whatever you've overcome," he said. "Yes, this is extremely challenging. But if you break down other things in (your) life, more than likely there's something that's been a challenge, too, that you thought you couldn't overcome. Use that (experience) to overcome (this challenge)."

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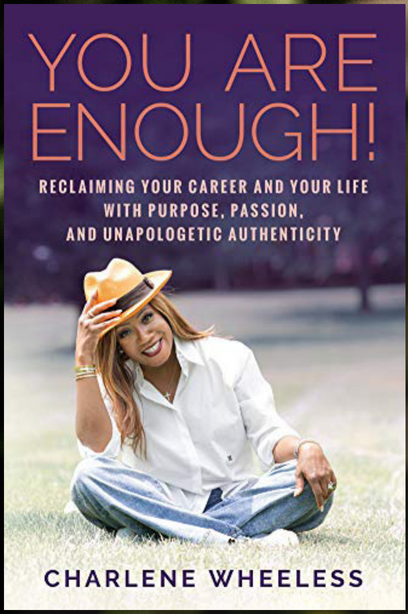


YOU ARE ENOUGH!

RECLAIMING YOUR CAREER AND YOUR LIFE
WITH PURPOSE, PASSION,
AND UNAPOLOGETIC AUTHENTICITY

CHARLENE WHEELESS

**“YOU ARE ENOUGH!”** imparts Wheeless’ lessons learned in business and during her cancer journey. The book is available on Amazon.

# It’s Important to Know: YOU ARE ENOUGH

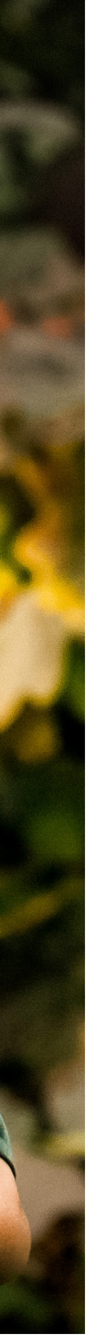
A hard-charging executive felt lost after surviving cancer because she didn’t fit into her old life. But, she says, “**cancer changed my life, so I changed my world.**”

*By* COLLEEN MORETTI

Charlene Wheeless used to describe herself as the “typical type A personality.” That changed, however, after she was found to have breast cancer in February 2017 and had nine surgeries in three years.

When she left her corporate job, she didn’t know what she was going to do but then realized she had a story to tell. She started off writing a blog, which quickly turned into her book “You Are Enough!” Her book tells the story of lessons she has learned through her job, life and cancer journey.

Wheeless talked to *Heal*® about her cancer and survivorship journey and why she felt she *had* to write a book.



### Q: Why did you decide to write this book?

**A:** When I left the corporate world, I didn't know what I wanted to do. And I didn't know what I was going to do. I woke up one day and I thought, "I have an important story to tell and I need to figure out how to tell it." So I started a blog called Just Between Us Girls, and in the blog I talked about the things that (happen) to you post cancer, the way you feel about your body, the people around you, your spouse, how you can become so insecure when that's not something that you're used to being. But when I was looking for resources to help me, I couldn't really find anything, or I found (that) people were doing what I felt was sugarcoating the whole thing. I decided that someone needed to tell an authentic story. Literally, I woke up one day, and I said, "Oh, my gosh, I am being pulled to write a book." … It was a pull to tell the story, warts and all, so that I could perhaps help other people.

… I've been very open with my cancer. (When people found out that after the surgery) I had one and a half (breasts), all these different things, people started reaching out to me. And in many cases, I don't know them, and they'll ask, "I've just received a diagnosis. Can we talk?" And that's been really rewarding, as well. Because of the book, I've been able to tell the story.

I also have the story of what it's like being a Black female executive climbing the corporate ladder. The lessons I learned in doing that, which was really hard, are some of the same lessons I was able to apply to creating my new life as a patient post cancer, if there is such a thing — I think we're kind of always a patient with cancer. But I suddenly understood how important my story was for other people to hear and to learn from, and just maybe their journey would be a little bit easier for them because they read the book. … I wrote it in two months, which people tell me is an incredible amount of time to write a book. I'd never written one, so I didn't know how long it takes. But I guess that's just testament to how strong the pull was to write.

### Q: You say in your introduction you felt you "had" to write a book. Could you explain that a little more?

**A:** I think, both from a cancer perspective and from going through life as a Black female, there's so much to unpack there. When I was younger in my career and I would go to sessions (at conferences), they'd have panels of really accomplished women. I was struggling in a world that was not built for me and I wanted to learn something from these women. And again, everybody kind of sugarcoated it. (They would say), "Oh, I didn't experience blatant bias," and I would walk away actually not feeling motivated and empowered but instead feeling, "What's wrong with me? Why am I having this unique experience?"

And it was the same thing with cancer. It was, "Am I the only one who actually wants to kill herself after surviving breast cancer?" As I started to talk to other people, they gave me (the impression) that they maybe felt the same way but would never talk about it. These are topics that are just verboten — you don't talk about them. I felt really strongly that I'm a fairly fearless person and somebody has to talk about this, right? I decided that person was going to be me, and the best way to do it was to put it in a book so that people could refer back to it. I could tell stories and give people examples and lessons that helped me create the life I have now.

(There is) a woman who used to work for me in London, who I'm still in touch with, who I love dearly. We had dinner in London one night, and she had been going through her own personal things. Afterward she sent me a note and said, "I was reading your blog, and when I started reading it I was crying for you, but when I finished reading it, I was crying for me, because I know how strong you are. And the fact that you were willing to be so vulnerable helped me to feel like I'm OK." I thought, if I can do that for one person, then maybe I can do that for thousands of people. … I believe that legacies are built by the people you touch along the way. I know now that time is finite, and you have an incredible sense of your own mortality when you've gone through something like this. My goal has been to touch as many people with my message as I possibly can.

### Q: What can a reader expect from this book?

**A:** I tell a story about the challenges of climbing that corporate ladder and what happens when you get to the end and ask yourself, "Well, what was it all for?" I managed to blend that with my cancer journey, some of the challenges there and the intersectionality.

As an example, one of the first things I wrote is that it's choice, not chance, that changes your life. I think that applies to work and the situations we can find ourselves in at work. It also applies to dealing with a diagnosis, as well, and dealing with the disease. How you choose to approach that disease can make a really big difference.

I have a chapter about the importance of having a champion at work and being able to advocate for yourself. There's no greater place to advocate for yourself, (no place more) crucial, than in the health care system. In each chapter is a strategy, both for life and for career. When people finish reading the book, they'll realize that it may not be the exact same thing, but my story is their story. It kind of belongs to all of us. If I've done my job, they will walk away feeling empowered, somewhat fearless. (They will know) how to thrive and create the life they want, with purpose and passion and, most importantly, unapologetic authenticity. You don't have to twist yourself into knots to fit someone's ideal of who you are. If I could only deliver one message, it would be "You are enough." So many of us walk around thinking that we don't measure up. I want everybody to know that you are you, and it is enough. »

»

**CHARLENE WHEELESS** didn’t recognize the woman in the mirror after treatment and decided to change her world.

**Q: What are some of the lessons you learned from surviving cancer?**

**A:** There are so many. One of the things that I had to do, and this may sound a little strange, is I had to forgive myself for getting cancer. I think if you’re someone, particularly if you’re a type A personality, you think there’s something you did or didn’t do that caused you to get cancer, (such as) something that affected your immune system. I learned that I just needed to be easier on myself.

I also had to learn that not everybody knows how to have a friend who is sick. You need to give people some grace. I had friends who never came around when I was sick, and there were people I saw all the time. I had to … allow them some grace and some understanding. But, certainly, there’s always room for humanity and compassion, and we should lead with those things.

I also learned, quite frankly, that there are people out there (in the workforce) who will subtly and not so subtly take advantage of your weakened state. My husband, Charlie, said to me when I was getting ready to go back to work — a little bit of tough love here — “I know, you’ve been surrounded by people who have been all about you getting better and wanting to help and do everything they can for you, but when you go back into work, nobody cares that you had cancer and within a couple of weeks, no one’s even going to remember that you had cancer.” And I thought, well, that’s kind of a horrible way to think about things … but I tell you what, he was 100% right. For people who have not had cancer or any kind of a disease who work with people that do, I just beg you to give them some grace and understand that, although they may look normal to you, they could be falling apart inside.

Now when I run into people who have had some kind of a disease or who are suffering from something, I just want to hug them and say, “You are OK. And if you don’t fit into your life that you used to have, you have permission to create another life.” That’s what I learned. I would have never thought that I’d be living the life that I am now. I would have never thought that I would write a book and that I would be on the speaking circuit talking about my life and my experience. But people appreciate and want authenticity, and they want to connect on a really human level, and you have to be willing to do that. There are a lot of people out there who might want to see you fail in the workplace, and, trust me, they’re out there. But there also are so many people who want to help and who want to be your champion, and you just have to let them. But that’s hard because we equate being vulnerable with being weak, right? It’s actually the opposite.

**Q: What was the most challenging part of your cancer journey?**

**A:** It was definitely coming out of it. Coming out of treatment, because I (felt that I) no longer fit into the life I had before. And I didn’t understand the life I was in. I’m such a strong person, I have such a strong sense of identity. And all of that was gone. It was kind of a harrowing experience because I would look in the mirror and I would see this person and I’d stare at her because I didn’t recognize her. I didn’t know who she was. And so it really started a journey of me trying to figure out who I was and how I was going to move forward in the world. One of the toughest parts was realizing that I couldn’t go back to my old life. I couldn’t be that hard-charging executive, type A personality, overachiever, all those things. I had a career as an executive, and I spent 33 years building that career. All of a sudden, it didn’t work anymore. So, I think that was really hard for me. I have two daughters who are now 27 and 25, and they handled it like champs. But I think I did them a big disservice because I think I put on too much of a brave front for them and it took a lot of energy to do that. I didn’t teach them the lesson that sometimes you’re not OK. And it’s all right not to be. You don’t always have to put on a brave face for everyone.

**Q: What advice would you offer someone who has received a diagnosis and may be going through a similar situation?**

**A:** I tell them to not be afraid to reach out and ask for help. I think that’s one of the hardest things to do. We think that it’s a sign of weakness, but I think it’s really a sign of strength to ask people for help when you need it.

The other thing that I would say, which may sound a little strange, is be selfish. Really watch out for what you need and what’s important to you. I have lots of friends who wanted to visit when (I was) going through treatment because I didn’t work during my treatment. A lot of people wanted to visit me, and it was exhausting — I only had so much energy. I realized at some point that they were coming over, they cared about me, but when they came over, I had the responsibility to make sure they knew I was OK. It was more (like) your visitors are there to assuage their feelings as opposed to yours. It’s unintentional, of course, because everybody has good intentions. I just wish that I had been more selfish earlier, reserved my energy and told people, “Feel free to text, send me a note, whatever it is you want to do, an email, but not a visit.” I would tell people to be more selfish because your health is really important, your mental state, you have to manage your energy.

**Q: How has being a survivor changed your life?**

**A:** Wow. I say cancer changed my life, so I had to change my world. And it was realizing that the life I had built for 30-plus years, I no longer fit into it. I found that I just didn’t have the patience for some of the crap that we have to put up with. And I also learned that your time is finite, and you only have so much of it, so we should all think about how we channel that energy, how we use that energy. I’m a big believer in that if something negative happens to you, it’s your responsibility to turn that into a positive for someone else. Through cancer, I found a new voice to tell a really raw and honest and authentic story to help other people. If someone is struggling, and they read something I’ve written, I want them to say, “It’s OK to not be OK. Here was this person who is really strong, and she struggled, so it’s all right if I’m struggling.” I would say that cancer gave me an incredibly strong sense of purpose that I didn’t have before.

**Q: Is there anything else that you think survivors should know, either from your journey or about your book?**

**A:** Regarding the journey, for most of us, you will get through this, and I say most because I’m just being honest. But for most of us, you will get through this no matter how hard it is. Give yourself a break, particularly talking about the career aspect. Again, I’m going to say, “You are enough.” I spent so much time trying to be whatever this company or this leader said I needed to be. I was thinking I’m not enough of this, I’m too much of that, I should be less of this, be more of this. … So much happens that when you look up, you don’t even know who you are anymore. Fitting in is so important in the workplace; unfortunately, it’s like trying to squeeze your size 8 foot into a size 6 stiletto shoe. You’re going to get your foot in that shoe, but at some point it is going to reshape your foot into something you don’t recognize. You don’t have to do that. We don’t have to turn ourselves inside out to be successful. Believe that we are enough, you are enough, every gift you bring to the table — whoever you are, your unique difference — you are enough. That’s what I want people more than anything else to walk away with from the book; believing that, not just saying it, but believing it.

*This interview has been edited for clarity and space.*

# "How Can I Help?"

Survivors should share their knowledge with patients new to the world of cancer, writes one survivor. Here, she shares ways to offer assistance.

*By* BONNIE ANNIS

**I'VE ALWAYS BEEN A** sucker for medical shows on TV. One of the newest shows on primetime TV is "New Amsterdam," the story of a struggling hospital in New York City's Chinatown. A storyline that recently caught my attention had the show's medical director character, Max Goodwin, being given the responsibility of overhauling the facility. As he works diligently to rid the hospital of unnecessary staff and revamp each department, he tries to create a more patient-focused facility and relays his concern to the staff.

**BONNIE ANNIS**

Thinking of ways to accomplish his goal, Goodwin comes up with the catchy tagline, "How can I help?" As he wanders the halls of the hospital, Goodwin approaches one staff member after another with his open-ended question. Their responses vary from mistrust to disbelief until they realize how serious he is. As the hospital begins to adopt this new perspective, viewers begin to focus on the "How can I help?" question as it's repeatedly used in the show.

That question caused me to wonder, "How can we, as survivors, help patients who just received a diagnosis of cancer?" I visited the American Cancer Society's (ACS) website in search of the most-asked questions by those who have received a diagnosis of cancer. I discovered many of the questions were the same ones I'd asked years ago, but others were not included. That's when I realized, as a cancer survivor, it was my responsibility to help, and one of the best ways I could help was to listen and share my knowledge.

According to the ACS website, many people want answers to these questions:

- How common is cancer?
- Who gets cancer?
- What causes cancer?
- What are the risk factors for cancer?
- How is cancer diagnosed?
- How is cancer treated?
- What are the side effects of treatment?

All those questions are important, and the ACS does a great job of addressing those concerns, but what about less common questions posted on social media platforms or overheard in hospital waiting rooms? Those questions are the ones I wanted answers to when I received my diagnosis, and I feel they are likely ones that other people also would ask.

These were some of the questions I had immediately after receiving my diagnosis:

1. What do I do now?
2. How do I tell my family the news?
3. Should I seek a second opinion?
4. Will I need chemotherapy?
5. Will I get sick from treatment?
6. Do I need radiation therapy?
7. How will I pay for procedures my insurance doesn't cover?
8. What if treatments don't work and the cancer spreads?
9. Do I need an advanced directive?
10. Will I survive?

Luckily, I found answers through family and friends who'd already gone through cancer treatment. They were open and honest, willing to help in any way.

A nurse navigator also was helpful. She was assigned to my case by the hospital and assisted me as I experienced each phase of treatment. Knowing what to expect helped lessen my anxiety.

What if, as survivors of cancer, we follow Goodwin's lead and begin asking, "How can I help?" And when someone accepts the offer of assistance, what if we follow through by being willing to help them feel less overwhelmed and less alone?

By offering aid to someone in early stages of treatment or by answering questions they find too insignificant or too embarrassing to ask their medical team, we open the door to feelings of connectedness, compassion and caring. With open arms, we can embrace people who have just received a diagnosis.

It isn't difficult to ask, "How can I help?" But we shouldn't ask if we aren't willing to follow through.

I would have appreciated being asked that question as my journey began. It would have made things a lot easier than having to discover answers on my own through trial and error.

If you have received a diagnosis of cancer, don't be afraid to accept an offer of help. Many of us were once in your shoes. We understand how confusing and frightening being thrust into the world of cancer can be. You don't have to go through it alone. Let us help. Together we can share the burden of this unexpected health challenge. h

ILLUSTRATION BY RAY PALESKO

# Practice Makes Perfect When Helping Others

## There's a fine balance between offering support and guidance and not overwhelming people receiving treatment for cancer.

*By* STEVE RUBIN

**STEVE RUBIN**

**IT'S MUCH EASIER TO** write to the general cancer-fighting community than to support a living, breathing person — especially one you know and love. When friends and family have received a diagnosis of cancer, all I wanted to do was download everything I've learned straight into their brain like Neo in "The Matrix." I've been burned so many times, and the thought of them facing the same kind of misery was almost too much for my nerves.

What was my first instinct? It was to nudge them along the same route I've taken, optimizing all healing factors by every means possible. I wanted to give them the best possible chance of success, of finding an edge.

People have different processes and different comfort levels. My lifestyle overhaul didn't take place overnight — not even close! How could I possibly expect that of someone else?

Also, just because my approach helps me doesn't mean other paths are less effective. It doesn't mean these people are taking the situation less seriously. One friend didn't want to call attention to their disease until they had the facts. Of course, I was expecting the worst and preparing for every possible nightmare. But they wanted to keep it at a yellow alert instead of working themselves up to a CODE RED freak out. And, thankfully, it looks as though everything will (hopefully) be OK. They ended up saving themselves from a lot of unnecessary stress leading up to the scans. Honestly, it was a great teaching moment for me.

Finding a balance between offering support and guidance — especially when you're worried and believe you have serious value to share — while at the same time not overwhelming the person isn't easy. And it may take some practice to get right, but this is an important skill for cancer thrivers to get down. Otherwise, we'll just be wasting all the valuable knowledge, lessons and firsthand experiences we can share with those who need it most.

ILLUSTRATIONS BY RAY PALESKO

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# I Learned That Loss Is Just Change

## A cancer survivor describes her interpretation of a quote about loss by philosopher Marcus Aurelius.

*By* JANE BIEHL, PH.D.

**THE IMPACT OF COVID-19** on our lives has been tremendous. Some of us have had enormous losses and said goodbye to loved ones. Others have lost a job or income. Still others have recovered from COVID-19 but had devastating side effects. All of us have lost the way our lives once were.

**JANE BIEHL, PH.D.**

I recently read a quote by the Stoic philosopher Marcus Aurelius that made me think. "Loss is nothing else but change, and change is Nature's delight." I stopped cold and said to myself, "Wait a minute! How can all the losses we face be a delight? This wise man is wrong!" I then analyzed it further. It's "Nature's" delight, not ours. The loss of a loved one is tremendous and a huge change, whether it is a parent, sibling, child or friend. Our lives without that person are forever different. We miss them, we grieve for them and we regret not being able to see them again. However, we are forced to change.

I saw my mother almost every day and had no idea after her death what I was going to do with the time I used to spend with her. My life slowly expanded to embrace friends and new situations. Perhaps you've lost your job, which is overwhelming, and need to find another path. The loss of a home and its contents in a storm is horrible, but you eventually rebuild.

I think we all fear change. It means facing unknown situations and problems and leaving our comfort zone. Sometimes, it is difficult for me to think back 10 years to when I first received my diagnosis and remember that moment. I knew my life was about to change, but I never dreamed how much. Fortunately or unfortunately, my routine has become one of going for treatments every week (to keep my red and white blood count up) rather than working. I hate it, but I have had to adapt. I have adjusted and made a whole new group of friends, including other cancer survivors and members of the great oncology staff who do so much for us. I have been writing instead of going to work every day; during the pandemic, this was truly a blessing.

With the loss of anything, there is something that replaces it. Marcus Aurelius, who lived during the second century, did not mean that tragedies are "delightful." He meant that these things happen in nature. We all know that one little cell mutating into cancer changes our world forever as we know it. But what he is saying is that any void is replaced by something new. Loss makes us change, nature is a part of it and we need to try to make the most of it.

# Cancer Made Me *Kinder*

A cancer survivor and former military service member used to be short with people, demanding things be done his way and often making others feel bad — that is, until he received his cancer diagnosis. He shares how his experience taught him to be kinder to others.

*By* WILLIAM RAMSHAW

**SITTING IN A TYPICAL BEIGE** waiting room, across from me, was a middle-aged man scanning his phone, not paying attention to anything else around him. Nothing about this seemed out of the ordinary, but the mask he was wearing caught my attention. It had “Spread Kindness” splashed across it in inch-tall gold letters. Of course, it had a big heart in its middle to drive home the point in case the words escaped me.

It once again reminded me of my need to be kinder, gentler and more gracious without prompting.

I smiled at how much I had changed. Years earlier, being a former military guy, I seldom cut myself, or for that matter anyone else, any slack. All too often I had been short with people. I had demanded things be done my way. Sometimes I made someone feel bad when I didn’t have to. Although I have changed, I remain vigilant to make certain I don’t backslide.

What led to my transformation from a hard-nosed, get-it-done guy to a more kindhearted person? I suppose it was receiving a diagnosis of pancreatic cancer, a type of cancer so few survive, it’s considered a death sentence. Spending close to two years needing around-the-clock care humbles a person. Multiple trips to the emergency department and unending weeks in the hospital drove home to me how dependent I am on other people.

But this change didn’t come easily to me. Knowing my life was in the crosshairs, I struggled amid my months of treatments and years of follow-ups to be patient. With so much going on, although people did their best, sometimes things slid sideways. Phone calls were not returned. Lab results were not read. Appointments were not available. I saw many weary, if not burned out, caregivers. And a host of other things tested my patience. This led me to question whether my care was on track. I know I am not alone in having days such as these.

On the flip side, caring for patients with cancer is tough even on the best of days. With our lives in the balance, we can be a wee bit cranky at times. We face far too many unknowns — a pending decision on whether to sign up for a trial, not understanding what is being done to us, asking questions but getting answers filled with medical jargon that don’t make sense. And there is dealing with a doctor who doesn’t get us, or we them. There are too many chances for things to go in the ditch.

Amid this, I realized I needed to be kinder to others. This did not mean lowering my expectations but rather being more understanding when someone flubbed it.

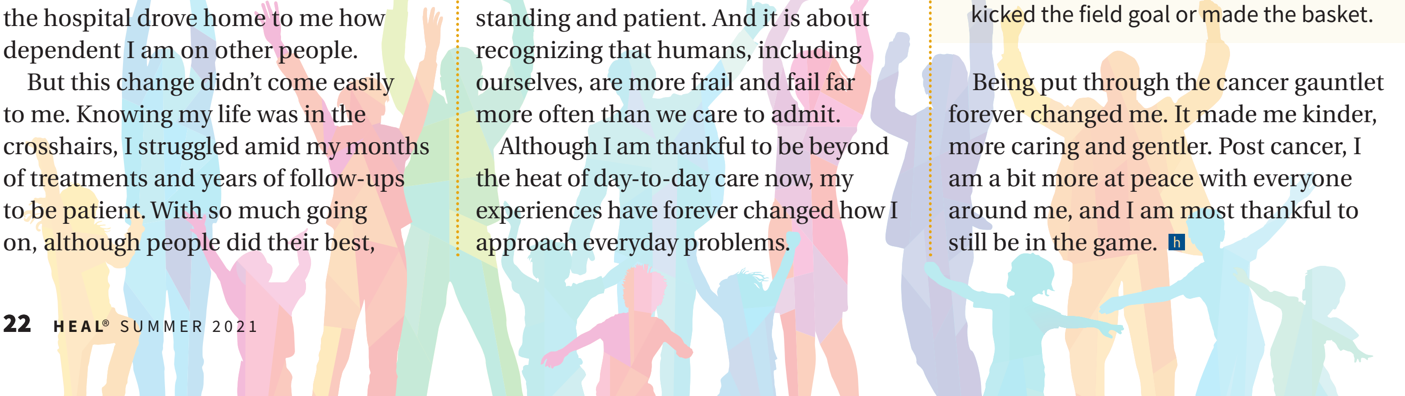
Don’t get me wrong: Being kind is not being weak or letting things fall where they may. Rather, it’s about understanding what it is to be human. It is treating others with respect and dignity. It is about being graceful in the face of adversity. It’s about being understanding and patient. And it is about recognizing that humans, including ourselves, are more frail and fail far more often than we care to admit.

Although I am thankful to be beyond the heat of day-to-day care now, my experiences have forever changed how I approach everyday problems.

***Nowadays, I will:***

- **Look beyond the problem at hand.** How big of a problem is it? Often when something goes wrong and we step back and look at the bigger picture, we realize it’s not the end of the game. Instead, it’s a timeout, a huddle, a picking up of the pieces. It’s getting back in the game.
- **Try to understand someone’s effort**. There is a big difference between someone who is in the game trying to get something done and another person whose heart isn’t in it. Sometimes figuring this out isn’t easy. I try hard to see the effort made, even if it falls short. Rather than demanding more, I cheer them on, letting them know I believe in them.
- **Consider the attitude**. I focus on a person’s attitude rather than the problem at hand. Are they exuding an upbeat spirit and pushing to make things happen when everything seems to be going sideways? Are they in the game and playing at their best or even beyond it? Oftentimes this isn’t easy to figure out, so I err on the side of caution, giving them the benefit of the doubt.
- **Give leeway when I can**. There are many ways to get things done. If someone gets it done, what difference does it make how they did it? What matters is that they got it done. They kicked the field goal or made the basket.

Being put through the cancer gauntlet forever changed me. It made me kinder, more caring and gentler. Post cancer, I am a bit more at peace with everyone around me, and I am most thankful to still be in the game.



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# Caregivers Also May Feel Survivor's Guilt

## Feeling guilty because of a loved one's good outcome is not uncommon for caregivers. A mother describes how she balances guilt and gratitude.

*By* DEBBIE LEGAULT

**WHEN MY DAUGHTER RECEIVED** a diagnosis of breast cancer, I did as much research as I could to find out about types of cancer, stages and the often-scary survival rates. My daughter was very fortunate because, although her cancer was extremely aggressive, she pushed to have the lump looked at even though everyone said she was "too young."

**DEBBIE LEGAULT**

The cancer was caught early and had barely spread to her lymph nodes when the process to kill it began. The powerhouse chemotherapy regimen they chose was exactly what was needed to kill the body-snatching invader trying to take over her body. After 20 weeks of chemotherapy, three surgeries and six weeks of five-days-a-week radiation, she is — as of now — in remission. Although you can never really "unhave" cancer, with the exception of targeted hormonal therapy to help prevent recurrence, she is for the moment walking through life with her cancer diagnosis and treatment behind her.

Along the path I walked as a caregiver, I began to engage with individuals and organizations who were having similar experiences. I would read articles and tweets and see my daughter or me in them and respond based on our experience. As I followed more of these women and they followed me back, more and more of my Twitter feed became filled with their comments about what their lives are like. Most of them are living with metastatic breast cancer.

Recently, one of them spoke about how much her mother was struggling with what was going on with her. I wanted to offer words of support, but my hands hovered over the keyboard, and I couldn't bring them to hit the keys.

Although I know what it's like to have a child experience breast cancer, my daughter's cancer had responded to treatment. I may one day know what it's like to wait for scan results and have it come back with bad news, but for today I get to live in a world where my child's last scans were good ones. I get to look at her in this moment and not look at a calendar to see how much longer she has, to not wonder if she'll make it to another Christmas or birthday.

I can recall us having a discussion early on when she was trying to decide about something. I tearfully said to her, "All I need you to do is live. I don't care how you get there." She did, and the fact that she is still here fills me with gratitude.

But when I read posts from young women or their families who were not so lucky, I am filled with monumental guilt because she survived and others won't. I feel guilty that I get to keep my daughter and others will have to say goodbye.

I am also filled with guilt because I am glad it isn't me who has to contemplate losing my heart. I don't think I could look someone in the eye whose child's treatment did not work and not have them see that, although I am so profoundly sad for them, I am also profoundly grateful that my child's treatment did work.

I'd like to say I wouldn't wish what she went through on my worst enemy, but I'd be lying. Realizing that about myself makes me feel like a bug under someone's shoe. Cancer is simply awful, and when you watch someone who has worked hard, given up much and done all the right things only to be slammed into the ground by cancer and its treatment, there's a lot about your value system that can be rocked.

I even feel guilty when I hit a cancer memory trigger and it stops me in my tracks. I'm not a pessimist by nature, but hearing the news the first time almost ended me because I was so unprepared, and I can't allow that to happen again. So while others in our lives can fully embrace where we are now, I feel guilty when I can't fully share their joy because I have to be mentally prepared for that bad news scan to put her back on the cancer express.

One thing for sure is that the roller coaster I climbed on two years ago is still in motion — it has just moved to a different track. I am not sure I like this one very much, either. I know the ride will stop eventually, and I hope it does long enough for me to reconcile all the stuff I've been carrying along the way. In my daughter's words, it's just a lot.

GOOD STUDIO / STOCK.ADOBE.COM; ILLUSTRATION BY RAY PELESKO

# Brighten Up Your Summer Party

With summer in full swing, it's time to host a get-together. Impress your guests with a fresh summer salsa and a salad with a twist. What about dessert? **Don't worry — this one is guilt-free.**

RECIPES *by* CHRISTINA USHLER, REGISTERED DIETITIAN; USHLER HAS A PRIVATE PRACTICE, WELLNESS BY CHRISTINA.

## Peach Salsa With Jicama Chips

**RECIPE FROM:** *The Integrative Nutrition Cookbook, 2016*

| PREP TIME | COOKING TIME | SERVINGS |
|---|---|---|
| 30 minutes | 0 minutes | 6 to 8 |

**INGREDIENTS**

- 3 peaches
- 2 medium heirloom tomatoes
- 1 medium red onion
- 1 jalapeño
- ¼ cup minced cilantro
- 3 large jicama roots
- juice of 5 limes
- sea salt, to taste

**DIRECTIONS**

1. Wash and pat dry peaches, tomatoes, jalapeño, limes and cilantro.
2. Remove pits from peaches, then chop peaches and tomatoes.
3. Mince onion, jalapeño and cilantro.
4. Combine all ingredients in large bowl and mix well.
5. Transfer to container or glass jar and refrigerate for 15 minutes or longer to allow flavors to combine.
6. When ready to serve, peel and cut jicama root into thin slices, squeeze lime over jicama root and serve with salsa.

## Quinoa Mango Salad

**RECIPE FROM:** *Institute for Integrative Nutrition*

**INGREDIENTS**

- ¼ red onion, diced
- 1 jalapeno (optional)
- 1 lemon, juiced
- 2 limes, juiced
- 3 large mangoes, peeled and cut into cubes
- 3 cups quinoa, cooked and cooled
- 1 bell pepper (any color), diced
- ¾ cup shredded carrots
- 1 avocado, diced
- ½ large cucumber, diced
- 16 ounces (1 can) chickpeas
- 1 large bunch cilantro
- 2 tablespoons olive oil
- 1 tablespoon balsamic vinegar
- Salt and pepper to taste

**DIRECTIONS**

1. Combine onion, jalapeno, lemon juice and lime juice in a large salad bowl.
2. Add remaining ingredients, mix and serve right away. This will keep in the refrigerator up to 7 days.

PHOTOS COURTESY OF LANFORD

# Vegan Blueberry Crisp

## (100% Whole Grain, Dairy Free)

**RECIPE FROM:** *Texanerin Baking Website*

| PREP TIME | COOKING TIME | SERVINGS |
|---|---|---|
| 15 minutes | 30 minutes | 2 to 4 |

### INGREDIENTS

*Topping:*

- ½ cup whole wheat flour
- ¼ cup raw sugar or granulated sugar
- ⅛ teaspoon salt
- 1 teaspoon ground cinnamon
- 3 tablespoons coconut oil or 3½ tablespoons unsalted butter, melted and cooled slightly (use coconut oil for vegan or dairy free)

*Blueberry filling:*

- 2 to 3 tablespoons maple syrup (use 3 tablespoons if your blueberries aren't sweet)
- 1½ teaspoons vanilla extract
- 2 teaspoons cornstarch
- ½ teaspoon ground cinnamon
- pinch of salt
- 3 cups blueberries, rinsed and patted dry

**NOTE:** *This recipe uses refined coconut oil, which has no coconut taste. If you use unrefined coconut oil, the topping may have a mild coconut taste.*

### DIRECTIONS

1. Preheat the oven to 350° F and grease two 4.5-inch or 5-inch mini pie dishes. If you don't have mini pie dishes, use ramekins (about 4).
2. In a medium mixing bowl, stir together all the topping ingredients. Set aside.
3. In another medium mixing bowl, stir together the filling ingredients except the blueberries. When well combined, gently stir in the blueberries and coat in the liquid mixture.
4. Divide the blueberry mixture between the baking dishes. Depending on the size of your dishes, the blueberries may rise well over the top of the dish edge. That is fine — the blueberries will cook down.
5. Distribute the topping evenly over the blueberries.
6. Place the dishes on a baking sheet to catch any spills.
7. Bake for 28 to 32 minutes or until the topping is firm and the blueberries are bubbling.
8. Let cool for 5 to 10 minutes before serving.

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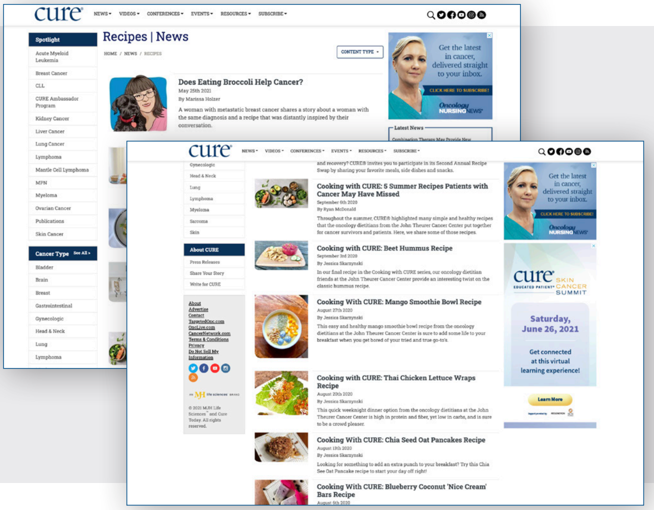

Recipes | News

**Does Eating Broccoli Help Cancer?**
May 25th 2021
By Marissa Holzer
A woman with metastatic breast cancer shares a story about a woman with the same diagnosis and a recipe that was distantly inspired by their conversation.

and recovery? CURE® invites you to participate in its Second Annual Recipe Swap by sharing your favorite meals, side dishes and snacks.

**Cooking with CURE: 5 Summer Recipes Patients with Cancer May Have Missed**
September 6th 2020
By Ryan McDonald
Throughout the summer, CURE® highlighted many simple and healthy recipes that the oncology dietitians from the John Theurer Cancer Center put together for cancer survivors and patients. Here, we share some of those recipes.

**Cooking with CURE: Beet Hummus Recipe**
September 3rd 2020
By Jessica Skarzynski
In our final recipe in the Cooking with CURE series, our oncology dietitian friends at the John Theurer Cancer Center provide an interesting twist on the classic hummus recipe.

**Cooking With CURE: Mango Smoothie Bowl Recipe**
August 27th 2020
By Jessica Skarzynski
This easy and healthy mango smoothie bowl recipe from the oncology dietitians at the John Theurer Cancer Center is sure to add some life to your breakfast when you get bored of your tried and true go-to's.

**Cooking with CURE: Thai Chicken Lettuce Wraps Recipe**
August 20th 2020
By Jessica Skarzynski
This quick weeknight dinner option from the oncology dietitians at the John Theurer Cancer Center is high in protein and fiber, yet low in carbs, and is sure to be a crowd pleaser.

**Cooking With CURE: Chia Seed Oat Pancakes Recipe**
August 13th 2020
By Jessica Skarzynski
Looking for something to add an extra punch to your breakfast? Try this Chia See Oat Pancake recipe to start your day off right!

**Cooking With CURE: Blueberry Coconut 'Nice Cream' Bars Recipe**
August 6th 2020

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# We are helping to move mountains for myeloma patients

**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 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**

## LEARN MORE ABOUT OUR CLIMBS!

### 2021-2022 TREK SCHEDULE

**Alaska Trek**
August 16-21, 2021

**Mount Washington**
Late Summer / Early Fall 2021

**Colorado Trek**
September 9-14, 2021

**Mount Kilimanjaro**
February 19 - March 1, 2022

**Greenland Trek**
Summer 2022

**Sweden Trek**
Summer 2022

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