living well *after* cancer

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VOL.9 NO.4 / **FALL 2021**

LOSING SLEEP

Remission should lift the burden of cancer, but the effects that follow treatment may keep many cancer survivors up at night.

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Inside

NEWS & INSIGHTS

TRACY WORRELL is six months into remission and says she just wants her energy back after struggling with sleep.

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COVER IMAGE: ELENA ABRAZHEVICH / STOCK.ADOBE.COM; WORREL BY DEBBIE TROY; GLOBE: DIGILIFE / ADOBESTOCK.COM

chairman's letter

Sleeping After Surviving

GETTING A GOOD NIGHT'S rest after surviving cancer is vital to maintaining a healthy lifestyle, but for some it is not that easy. In this issue of *Heal*®, our cover story discusses the struggles many cancer survivors experience with their sleep. It is a common experience — a study in *Sleep Medicine* reported that more than half of survivors experience high sleep disturbance during the night and 20% report poor quality of sleep.

Both survivors featured in our cover story experience poor quality of sleep due to their cancer treatment. One has been in remission for six months, the other for six years.

Also in this issue is an exciting interview that will make you feel proud to be an American and a cancer survivor. Kevin McDowell, a triathlete who took silver with his team at this summer's Olympics, tells us about his journey surviving Hodgkin lymphoma. He highlights how his mindset went from winning competitions to surviving cancer and how being an athlete helped him through his treatment.

Another great interview in this issue is with a radiation oncologist who saw the other side of treatment. Dr. Curtis Mack, a radiation oncologist at Arizona Oncology, went from treating patients with radiation to receiving it himself after a diagnosis of acute lymphoblastic leukemia. Mack tells us how his journey with cancer has made him more empathetic and how he now can relate to his patients on a different level.

Additionally, you will want to run to the bookstore after our review of "Pretty Girls Don't Get Cancer" — yes, you read that right. Author Patricia Diaz tells the story of receiving a cancer diagnosis as a teenage girl and how it shaped her into the self-care advocate she is today. And, of course, she explains where that title came from.

Finally, you know we never forget the recipes. We have some great treats for your fall football party — and of course they are full of nutrition. One great aspect of our powerful pesto recipe is the versatility of it — enjoy it on pizza and pasta and even mix it with plain Greek yogurt for a great dip! And our roasted chickpeas make a great crunchy, addition to any salad.

MIKE HENNESSY SR.
Chairman and Founder

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overheard on SOCIAL MEDIA

Advice From People Like You

We asked readers, **“Have you experienced cognitive dysfunction as a result of cancer treatment? How do you deal with it?”**

Here’s what they told us.

> “I have learned I have to WRITE EVERYTHING DOWN! *– JANE*”

> “Chemo brain is real. I used to read a couple of books a week. Now, one book can take me months to get through and it has to be non-fiction. I can no longer read novels. Thank goodness for poetry. That’s almost all I read these days. *– VIRGINIA*”

> “YES!!! I make lists and try to write everything down on my calendar. The thing that has helped the most was taking dance lessons! Moving my body and learning something new has made a huge difference. It’s not perfect, but it’s so much better than it was. *– BUFFY*”

> “I am four years in remission for stage 3 (non-Hodgkin lymphoma). I have it really bad and it saddens me because I was so sharp before and an assistant to public figures, managing their days. No way I could do that job now. I’m 66 and I hate when people brush it off to age. I know many 66-year-olds who are rocking and rolling. *– GOLDIE*”

> “Yes, eight years out and still have issues. *– MARCIA*”

> “Everything important has to be written down! I can forget what was discussed in a meeting after walking back to my desk. By far the hardest challenge to deal with when it came to side effects from treatments five years ago. I am happy that, finally, long term chemo brain is more widely acknowledged, as it was even more frustrating to be told it’s just age related! *– DEBBIE*”

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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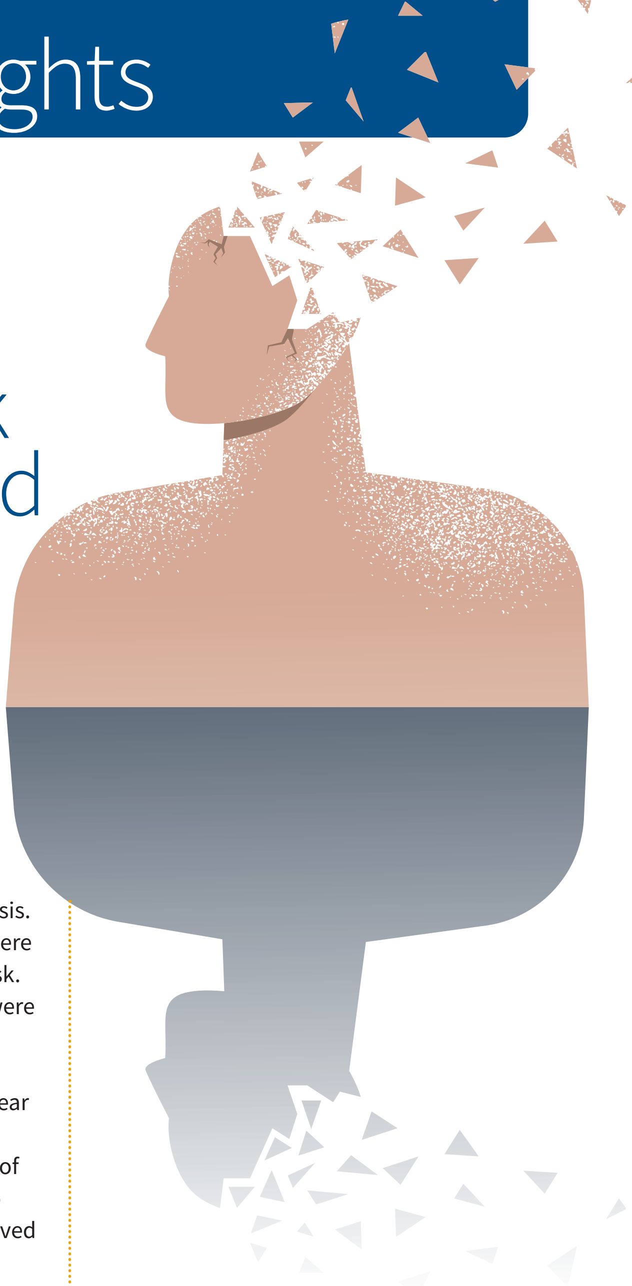
Short-Term Memory Decline May Lead to Risk of Dementia in Childhood Cancer Survivors



Childhood cancer survivors are advised to move more, eat well and stay socially active to reduce risks of frailty and cognitive decline.

By COLLEEN MORETTI

CHILDHOOD CANCER SURVIVORS, who were defined as frail or at significant risk of becoming frail, were more likely to struggle with cognitive skills over a five-year span than those who were comparatively stronger, according to study findings published in the *Journal of Clinical Oncology*. Cognitive skills were defined as visual-motor processing speeds, verbal fluency, memory and attention.

"(These results) indicate to us that we should be focusing on physical activity interventions early on, perhaps even for current patients who are actively in treatment, to try to prevent any of that physiologic decline and maintain their physical function over this entire period instead of waiting until they actually experience that decline and intervening then," lead study author AnnaLynn Williams, a postdoctoral research fellow at St. Jude Children's Research Hospital in Memphis, Tennessee, said in an interview with *Heal*®.

Frailty is often linked with neurocognitive decline in the elderly population, but there has yet to be an association discovered in the 8% of childhood cancer survivors who are or at risk of becoming frail.

To assess if frailty predicted future neurocognitive decline among young adult survivors, Williams and colleagues evaluated 845 childhood cancer survivors who were an average age of 30 years and, on average, 22 years out from diagnosis. At enrollment, 6.1% of participants were frail and 18.2% were considered at risk. The goal was to assess if those who were frail at enrollment would experience greater cognitive decline than their non-frail counterparts during a five-year follow-up.

During the five-year period, 17.6% of survivors moved from being at risk to becoming frail, whereas 11.5% improved their status.

The data demonstrated that survivors who were frail or at risk performed worse on cognitive skills assessments compared with those who were not frail.

At the five-year follow-up, frail or at-risk of fragility survivors experienced a decline in short-term memory recall, a common symptom associated with aging and dementia. "To see this striking decline in short-term recall at such a young age really concerns us and makes us worry that this particular group of survivors is at an increased risk of dementia and/or Alzheimer's (disease) as they continue to age," she added.

Cancer survivors who are frail often appear to be several decades older than they are, added Kirsten Ness, a physical therapist and a member of the Epidemiology and Cancer Control Department at St. Jude Children's Research Hospital. Frailty can prohibit young adult survivors from performing daily tasks, such as crossing the street efficiently, going to the grocery store and engaging in social activities, and later could result in the inability to bathe, dress and cook for themselves, Ness, who was also an author on the study, said.

"If we can prevent conditions like frailty and neurocognitive decline, we'll improve (survivors') ability to return to work or school and have successful careers, have successful family and social lives, and live the life they should have lived had they never been diagnosed with cancer in the first place," Williams mentioned.

Williams, Ness and Kevin Krull, their colleague and fellow study author, stressed that current survivors should maintain their physical activity, eat a

EVERYTHING BAGEL / STOCK.ADOBE.COM

well-balanced diet, and keep socially active to prevent frailty and its effects.

"My standard line is 'Move. Eat in moderation — mostly plants. Don't smoke. And do your crossword puzzles,'" Ness said.

> "My standard line is 'Move. Eat in moderation — mostly plants. Don't smoke. And do your crossword puzzles'." — *KIRSTEN NESS*

It's essential that long-term survivors maintain contact with their physicians and go through recommended screening to identify early chronic conditions that may affect frailty and neurocognitive abilities, Krull added.

Children who have cancer can also follow these approaches, Williams noted. She advised that patients talk with their doctor about what kind of activity they can do during treatment. Moderate exercise, such as yoga, light stretching and walking, is beneficial. Children receiving treatment for cancer might consider reading or playing cards with visitors to prevent cognitive decline, Williams added.

"I think it's important in all groups, but I think it's especially important in survivors of childhood and adolescent cancer, because this is a unique group of survivors who (may) have many decades ahead of them," Williams said. "… (They) may be cured of (their) cancer at age 14, and we want to ensure that (the survivor) makes it all the way to 100 feeling great, living the life the way (they) would have if (they) didn't have cancer." h

'Move More, Sit Less'

Performing the recommended 150 minutes of physical activity per week could lead colorectal cancer survivors to "a healthy and happy life" after treatment.

By COLLEEN MORETTI

BY PARTICIPATING IN LIGHT-INTENSITY physical activity, survivors of colorectal cancer may have improved quality of life, social and physical functioning and feel less fatigued up to two years after treatment, according to study findings published in *Quality of Life Research.*

"It is advisable for colorectal cancer survivors to follow the recommendations to move more and sit less. This will very likely contribute to leading a healthy and happy life after colorectal cancer," Dr. Martijn Bours, from the Department of Epidemiology of Maastricht University in the Netherlands, said in an interview with *Heal*®.

Colorectal cancer treatment often leads to long-term side effects, such as fatigue and bowel problems, which can negatively affect quality of life.

Evidence from previous studies demonstrated that higher levels of light-intensity physical activity are associated with health-related quality of life improvements in colorectal cancer survivors. However, those studies did not assess the long-term benefits. Other study results have shown that colorectal cancer survivors are often physically inactive and spend, on average, about two-thirds of their time sitting or lying down.

Researchers evaluated questionnaire responses from 325 stage 1 to 3 »

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colorectal cancer survivors (67.1% men; average age, 67 years). The questionnaires included information on hours per week spent doing light-intensity physical activity and quality of life. They were administered at six weeks, and six, 12 and 24 months posttreatment. Survivors were also asked to wear activity monitors to objectively measure their sedentary habits. The results demonstrated statistically significant long-term associations between performing more light-intensity physical activity (eight hours per week) and improved quality of life, social and physical functioning and feeling less fatigued.

Median self-reported time spent participating in light-intensity activity at diagnosis was 10.5 hours per week, which decreased at six weeks post-treatment to 7.5 hours but then increased again further after treatment. Most participants said physical activity consisted of light housework. And at diagnosis, 74% of the patient population reported adhering to Dutch physical activity guidelines. At six weeks, the total decreased to 60%, went up at 12 months to 68%, then dropped at 24 months post-treatment to 63%.

Notably, mean fatigue scores decreased, and the mean quality of life and functioning outcome scores increased between the six-week and 24-month period after treatment.

However, this patient population faces challenges to staying active. Performing activities that require moderate to vigorous strength can often be difficult because of past cancer treatment, Bours noted. In addition, he said, age plays a role: Many of these individuals are over 70 years old and often have other health conditions, such as diabetes or rheumatoid arthritis. They can take part in light-intensity physical activity such as slow-paced walking, playing billiards and doing housework, while standing.

Although there are no specific recommendations for light-intensity physical activity, Bours said that these results highlight the positive effect that any kind of physical activity can have on quality of life, daily functioning and fatigue symptoms. He highlighted a previous study that showed similar results from replacing one hour of sedentary time per day with one hour of standing.

“Importantly, a physically active lifestyle includes both increasing physical activity *and* decreasing sedentary behavior,” Bours noted. “Besides having a positive influence on quality of life after colorectal cancer, moving more and sitting less can, for instance, also decrease the risk and impact of several health conditions, such as obesity, diabetes, cardiovascular disease and cancer.”

Getting Better Sleep May Mean Fewer Headaches

Breast cancer survivors saw a reduction in headache burden following a guided program that promoted regular sleep, reduced coffee intake and reduced light and electronic stimulation.

By COLLEEN MORETTI

AFTER SIX WEEKS OF SLEEP behavioral therapy, survivors of breast cancer saw a significant reduction in headache burden that can often be associated with the disease and some of its treatment, according to Dr. Yohannes Woldeamanuel.

The data, which were published in *Cancer*, also showed an improvement in insomnia. Moreover, the results of the sleep behavioral therapy program had lasting positive effects after a year of follow-up.

"(Headache burden is) highly stigmatized," said Woldeamanuel, a physician, research scientist and neurologist at Stanford University School of Medicine. "It's undertreated or even underdiagnosed or misdiagnosed."

Headaches and migraines can be highly debilitating, affecting a survivor's ability to think clearly, be physically active, and increase sensitivity to light and sound, Woldeamanuel, who is also the lead study author, told *Heal*® in an interview. "It is important to address this headache burden in cancer survivors, so as to improve their quality of life and to make them more productive," he mentioned.

Stress or side effects may be reasons for survivors' headaches, according to Woldeamanuel, who works in the division of headache and facial pain and collaborates with the survivorship research program. Insomnia and headaches are directly associated, he noted: "The presence of one leads to the presence of another so it's bidirectional. If we reduce the insomnia, we can also reduce the migraine or headache component."

Treating chronic headache disorders in people affected by cancer is difficult because there is a chance that negative drug-to-drug interactions with chemotherapy or other cancer drugs could occur, and many patients hesitate to add another drug to their regimen, the authors wrote.

Therefore, the authors wanted to examine the efficacy of behavioral interventions that target cancer-related insomnia to, hopefully, alleviate headache burden, reduce insomnia symptoms and improve overall quality of life.

Participants who were actively receiving chemotherapy were randomly assigned to either brief behavioral therapy for cancer-related insomnia (BBT-CI; 73 patients; median age, 52 years) or healthy eating education learning for healthy sleep (HEAL; 66 patients; median age, 49 years). They were evaluated at the start of the trial and then reevaluated at six weeks and six and 12 months.

During the six-week BBT-CI program, participants maintained regular sleep, avoided stimulus before sleep, cut back on coffee several hours before sleep, reduced light and electronic stimulation, and used the bedroom only for sleep and sex.

The authors found that participants who received BBT-CI had significantly fewer headaches over time. Those who received HEAL also saw a reduced headache burden, but it was not significant.

"The message of the research is one, sleep behavioral intervention can reduce the headache burden," Woldeamanuel noted. "(And) two, the type of headache burden that most of these patients face is similar to what is known as a migraine."

The data demonstrated that both groups experienced an immediate effect at week six. The decline in headache burden was sustained in the absence of further treatment in the BBT-CI group but increased at the one-year follow-up for those who received HEAL.

Among 12 patients with migraines, the headache reduction was not significant.

Survivors should get regular sleep, exercise, stay hydrated, and consume healthy and nutritious foods to optimize the nervous system and help prevent headaches, the authors said.

Although this study focused on breast cancer survivors, Woldeamanuel and his team anticipate that sleep behavioral therapy may relieve headache burden across all cancer types. "Since insomnia is a common comorbidity in nearly half of all cancer types, and since insomnia and headache are closely interrelated (and) are bidirectional, a sleep behavioral intervention targeted to insomnia is expected to reduce headache burden in cancer survivors of any type of cancer," he concluded.

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Surviving the Other Side of Cancer

Dr. Curtis Mack can relate to his patients on a level other radiation oncologists might not be able to because he has received a diagnosis, gone through treatment and survived himself.

By COLLEEN MORETTI

DR. CURTIS MACK, a radiation oncologist at Arizona Oncology, switched roles in 2013 after he received a diagnosis of acute lymphoblastic leukemia. Mack had to change his lifestyle after treatment, just as any survivor does. Being a survivor changed his life, and as an oncologist, he knew what his patients were going through and could offer relatable advice and stories of his own journey.

THE OTHER SIDE OF RADIATION

After running a half marathon in June 2013, Mack knew something was off. He had run many races, but this time he was slower, and it was the first time he didn't enjoy it. But he thought he must not have trained well enough. Time went on, and he even went camping at 8,000 feet, but he spent most of his time by the fire because his hands were cold. And during a few runs with friends, he asked to walk, which was out of the ordinary for him. That's when he decided to get a blood test.

The next day, Mack's blood test results showed that he had acute lymphoblastic leukemia.

Although Mack is a radiation oncologist, he didn't know what to expect in all parts of his cancer journey. Through his career, his interactions with patients with leukemia has been minimal, but he knew what to expect when he received total body radiation. But the chemotherapy was all new to him.

"I was a pretty good patient. I didn't complain too much," he said.

A MILLION FRIENDS'

Mack received prednisone, a steroid often used to reduce inflammation during treatment and says he always felt hungry. During Mack's time in the hospital, the chief medical officer and hospital administrators would check in on him. He would tell them he was fine but that there were starving people in there.

Mack would have his first breakfast at 5:30 a.m., a second at 8 a.m., then lunch, then dinner and then another dinner brought by friends. His appetite, however, did not last long. After a stem cell transplant, his nutrition was strictly IV and fluids.

"(I) could not eat if I wanted to and believe me, I did not want to," he recalled.

Mack said "a million friends" helped him through his treatment. He had high points and low points, just like any other patient, but he really appreciated his friends bringing him food and trying to distract him.

"I did some silly calls with the office and office parties and stuff like that just to feel connected," he explained.

Mack was also grateful that people would bring his dogs to visit. His two Weimaraners are always by his side, even while he spoke with *Heal*®, and the younger one has been helping him train for his first race, which occurred recently, since the one in 2013.

TRANSITIONING BACK

Mack thought he would be able to get back to work right away, but he said the doctors laughed at him and told him he would need time to recover and get stronger first. He felt pretty weak after treatment and decided to start exercising, beginning with walking lunges.

He went down and couldn't get up after one lunge.

He tried walking along a (hand) rail. That didn't work either.

He finally followed some instructions from a physical therapist for exercises in a chair that helped.

"So transitioning was basically spending time getting stronger, exercising, walking, so that I could feel ready to go into the clinic," he said. He might have felt ready physically, but mentally he was worried.

"I was scared to death about resuming work. It had been exactly one year … and before, I was reading journals, keeping up on newsletters, seeing patients," he noted.

He said he would think to himself, "I'm going to walk in the clinic, I'm not going (to) know anything, I'm going to be stupid, I'm not going to know how to do anything."

But he proved himself wrong and remembered everything. "Surprisingly, I walked back into the clinic and it was almost like I never left," he said. He added that at the start it wasn't bad; mostly he was just feeling tired.

Mack was able to relate to his patients on a different level after his own treatment. "I was a pretty empathetic guy before. But there's no way you can't be more empathetic," he recalled.

He could relate to patients better and tell them they would get their appetite back since it had happened for him. He said the patients appreciate when he tells them he has been through the same experiences, because they feel he can understand them more.

MACK is seen here during treatment (left). And after his most recent race, with his Weimaraners of course (right).

PHOTOS COURTESY OF MACK

BEING A SURVIVOR

Being a survivor has changed Mack's life. "It's changed my priority somewhat," he said. After he survived cancer, people would ask if he would go back to work, and he'd say "Of course," because he loves his job, working with the patients and doing good for people.

Mack just completed the half marathon he had been training for. He was happy with his time of just under two hours, only 28 minutes slower than when he was running before his diagnosis. He is happy to be back training, of course, with the help of his younger dog, Lexi.

Cancer taught Mack that sometimes life stops, and there might not be time for regular activities. So now he doesn't feel as though he has to read every paragraph of every email he gets, or if something is delivered in six weeks instead of two days — no big deal.

"It's really good to say that I don't sweat the small stuff as much as I used to," he concluded. h

LOSING SLEEP

ELENA ABRAZHEVICH / STOCK.ADOBE.COM

Remission should lift the burden of cancer, but the effects that follow treatment may keep many cancer survivors up at night.

By ANDY POLHAMUS

By the time she received her double mastectomy, Tracy Worrell was thrilled. Finally having the surgery meant that Worrell was now well enough for doctors to remove her breasts and several lymph nodes to prevent a recurrence. It was a landmark step in her journey with stage 4 triple-negative breast cancer that had metastasized to her liver and lymph nodes. Following chemotherapy, she experienced a complete pathological response (disappearance of all cancer signs), and scans showed her liver metastasis had disappeared. And once the breast and lymph node surgery was finished and the radiation therapy was over, Worrell felt she'd been given a gift, since not many patients are in a position to have metastatic lesions resected and be left with no evidence of remaining cancer.

"I was probably the most excited human on Earth to have my double mastectomy," says Worrell, of Mullica Hill, New Jersey. "I just knew it was one more chance to keep me here longer. To give me more time, and that's what I want — more time."

But surviving came with a cost she didn't expect. »

> Even after **WORRELL** finished treatments and felt like she was mentally in a good place, sleep was still hard to come by.

DEBBIE TROY

"It just takes me an extremely long time to fall asleep," Worrell says. "And once I do fall asleep, I wake up a bunch."

In the six months she's been in remission, Worrell often lies awake at night while her husband lies next to her and falls asleep immediately. She's tried listening to relaxing music, taking melatonin, avoiding electronics before bed, reading and even just lying in the dark hoping sleep would come. Still, her problems persisted. She frequently gets out of bed until she feels tired again, which usually takes at least an hour, then gets back in bed and starts the process over again.

"I'm done (with) my treatments and I'm in remission and I feel like mentally I'm in a good place," says Worrell. "Why am I still not sleeping?" she asks herself.

CANCER'S IMPACT

Sleeping problems are common among cancer survivors and can persist for years after a patient enters remission. A study published in the journal *Sleep Medicine* found that more than half of long-term cancer survivors in a national sample reported experiencing "high sleep disturbance," whereas 20% reported having poor quality sleep. By comparison, the Centers for Disease Control and Prevention estimates that in the general population, 26.3% of people 65 years or younger get less than seven hours of sleep each night. What's more, 17% of survivors reported both sleep disturbances and poor sleep quality. One striking aspect of the study was the sheer length of time involved: The patients who participated were all nine years into remission. And four major issues were found to be linked to sleep disturbances in the survivors: emotional distress, physical distress, fear of cancer coming back and economic distress.

"There are 12 million cancer survivors in the United States, approximately. This is a big topic that hits a wide audience — not only the patients, but also their families," says Dr. Erev Tubb, the oncologist who treated Worrell and medical director of the cancer center at Inspira Medical Center Mullica Hill. "It can be a major problem because sleep is very important."

> I knew it was just my brain racing. After chemo I definitely started having more and more sleep issues.
>
> —*TRACY WORRELL*

"I've been in remission for six years now," says Linda Youse, of Hainesport, New Jersey, who received a breast cancer diagnosis in 2013. "And I believe I've been struggling the whole entire time. I can't remember a time when I was having quality sleep since I've had my cancer."

Like Worrell, Youse hoped life would return to normal after a lumpectomy and the resection of several lymph nodes.

"My surprise was that I never got back to normal, and sleeping has been an issue the entire time," she says.

Naming one specific cause of these sleep disturbances can be very difficult, Tubb says, because there are many contributing factors. Frequently, sleep problems begin when a patient initially receives a diagnosis and is struggling with anxiety related not just to the possibility of death but also intensive therapies and major surgery. Worrell, however, understood why she wasn't falling asleep in the weeks following her diagnosis.

"I knew it was just my brain racing," she mentions. "After chemo, I definitely started having more and more sleep issues."

"Sleep is really multifactorial. There are physical aspects, and there are emotional aspects," notes Dr. Ana Maria Lopez, professor and vice chair of medical oncology at Sidney Kimmel Medical College, Thomas Jefferson University in Philadelphia, and chief of cancer services at Sidney Kimmel Cancer Center in Washington Township, New Jersey.

Tubb and Lopez point out that cancer is a psychologically traumatic experience, which plays a role.

"It's a hard diagnosis," Lopez says. "And it can't help but bring up for people the risk of death, risk of disability, of life not quite being the same. Sleep is when people feel comfortable, feel like they can relax, feel like they can be free and rest. If people have gone through something traumatic, it can make it much more difficult to relax and allow the sleep process to happen."

So do medications like steroids, hormone-manipulating medicines and immunotherapies, which can have both short and long-term consequences. Hormonal treatments can cause hot flashes that bother people as they lie in bed »

DEBBIE TROY

> I’ve been in remission six years now. … I can’t remember a time I was having quality sleep since I’ve had my cancer.
>
> — LINDA YOUSE

LINDA YOUSE struggles with sleep as a result of cancer treatments, and often feels she is not alert enough to drive herself for plans she has made.

BARBARA WENTZEL

at night, and chemotherapy and immunotherapy drugs, besides having immediate side effects like nausea, can cause nerve damage, known as neuropathy in the oncology field.

Neuropathy can often manifest itself as feelings of numbness, tingling, weakened grip strength and instability while walking. But it can also compound preexisting sleep problems, like obstructive sleep apnea, Lopez notes.

“Often, the nerve symptoms may be noticed more at bedtime. When a person is quiet, trying to get to sleep, those symptoms become bothersome and impede sleep.” Furthermore, she adds, “neuropathy can be painful.”

Eric Zhou, a staff psychologist at Dana-Farber Cancer Institute in Boston, says that rather than any single cause, patients and survivors of cancer have a “myriad” of things that keep them up at night. And in many people, the trials of cancer diagnosis and treatment may exacerbate preexisting issues.

“They might have historically carried a greater disposition for poor sleep, and the cancer diagnosis and subsequent treatment push them over the edge,” he says.

People who have cancer are also prone to depression, one symptom of which is trouble sleeping, Zhou adds. This can cause a vicious cycle because lack of sleep can contribute to depression.

WHAT CAN HAPPEN?

With these sleep problems come other issues, including fatigue, nausea and long-term effects that not only affect a patient’s quality of life but can also cause serious health conditions. A 2020 study found that poor sleep quality was associated with greater disability and worse overall quality of life in people who survived breast cancer. Survivors can also suffer from a reduced capacity for carrying out basic routine tasks and struggling with fatigue at work.

“The short-term side effects are just not feeling well,” says Tubb. “Then there are other side effects that are more long-term and insidious.”

These include high blood pressure and its associated side effects, like headaches or vision damage. People deprived of sleep can also become emotionally labile, getting into arguments and interpersonal problems because they are more irritable, and their moods are less stable.

Cognitive impairments are another problem. The Harvard Medical School's Division of Sleep Medicine says that a lack of high-quality sleep can cause problems with focusing and paying attention, leading to problems with retaining new information. Poor sleep can also negatively impact mood, Harvard experts say, which can in turn impede learning.

"Sometimes when I want to get out or I have a plan or something, I don't know that I'm alert enough to even be driving," says Youse.

Lopez emphasizes the importance of sleep for general well-being and for recovery from sickness or injuries. "Restorative sleep is very important — important for healing, important for mental health and important for how we think," she says. Recently she saw a patient who had a hard time sleeping the night before.

"As we were talking, it just became very clear that she was not really able to process what we were talking about because she was just so tired. Lack of sleep can impact our healing, our processing of new information and just our overall sense of well-being," she says.

MANAGING SLEEP

There are a few options for survivors with sleep issues, including prescription sleep medications, cognitive behavioral therapy and physical activity. Anyone who feels that their sleep is an important issue in their life should seek a formal evaluation from a sleep center or expert.

More than a quarter of respondents in the *Sleep Medicine* study reported taking sleep aid medications, but these medications are not good long-term solutions and do not necessarily address the underlying problems that keep people from sleeping, and many patients are reluctant to use a pharmaceutical sleep aid.

"I don't think anyone thinks that's a solution," says Lopez.

Furthermore, patients can be reluctant to use sleep aids. Both Worrell and Youse say they would prefer to avoid these drugs.

Although medical cannabis and CBD products are often marketed and used as sleep aids, Lopez and other professionals point out that cannabis products are still a pharmaceutical intervention, and say that working on sleep hygiene or trying to develop healthy sleep habits through therapy is better, especially until researchers more thoroughly explore cannabis and CBD as therapeutic options.

"We want to support studying them," Lopez says.

Although physical activity is generally recommended to all cancer survivors for both general health and sleep, it is important to remember that exercise is generally indicated for improving the quality of a patient's sleep rather than improving the amount of sleep a patient gets at night. Study results released at the 2021 American Society of Clinical Oncology Annual Meeting indicated that yoga and cognitive behavioral therapy were both associated with improved sleep duration and "sleep efficiency" among cancer survivors.

Christina Dieli-Conwright of the Dana-Farber Cancer Institute and an associate professor of medicine at Harvard Medical School points out that cancer treatment can lead people into physical inactivity and poor diet, both of which can be disruptive to sleep.

"From my perspective, it is important to focus on those lifestyle factors that are modifiable, as we would say, in order to help improve sleep," she says.

Dieli-Conwright specializes in studying exercise as a planned, prescribed type of physical activity — as opposed to more general physical activity, which can refer to the act of moving around in general. Some of her work focuses on examining how exercise interventions affect sleep in cancer survivors. In one study, Dieli-Conwright and colleagues prescribed a 16-week program of mixed aerobic- and resistance-based exercises performed three times per week at "moderate to vigorous intensity."

"Not to our surprise, because this aligns well with the literature out there in studies focused on individuals who do not have cancer, we found that exercise quite profoundly impacted and improved sleep quality," Dieli-Conwright says. "Individuals who were previously characterized as poor sleepers … that percentage of individuals was reduced." Various measurements, such as sleep duration and quality, increased, whereas the use of sleep medications decreased, she adds.

For now, Worrell is pinning her hopes on an intervention similar to those described in recent literature. She will soon begin a type of therapy she describes as "cognitive physical therapy," an intervention designed to help with the cognitive effects often called chemo brain that she hopes will also help her get back on a healthy sleeping schedule.

"For me it's part of the compromise of getting to live," she says. "I'm willing to do it because I want to be here." She hopes the therapy will alleviate some of the frustration she's felt over the past few months.

"I'm tired of being tired," she concludes. "I just want my energy back." h

SCAN THE QR CODE to learn more about how yoga may help cancer survivors sleep better.

bookshelf CORNER

“PRETTY GIRLS DON’T GET CANCER” tells the story of Patricia Diaz and what her cancer journey taught her. The book is available on Amazon.

‘Pretty Girls Don’t Get Cancer’

Because of her cancer journey, Patricia Diaz was not new to self-isolation during the COVID-19 pandemic and used the time to finally share her story with everyone and advocate for self-care.

By COLLEEN MORETTI

PATRICIA DIAZ WAS 16 when her first doctor told her not to worry, that "pretty girls don't get cancer," after she complained of symptoms. Four months later she received a diagnosis of stage 4 non-Hodgkin lymphoma.

Diaz was in her hometown of Maracaibo, Venezuela, living the life of any normal high school student, riding bikes and hanging out with friends. Her life changed when she started to get headaches, nausea, nosebleeds and fevers that got worse with time.

"I was in the middle of the storm, so all I could do was just hold on and swim as best as I could," Diaz told *Heal*®. She received radiation and chemotherapy, and after the first treatment, about 85% to 90% of the cancer was gone. Her doctor told her to thank her kidneys because they saved her life.

She decided to share her story in a book titled "Pretty Girls Don't Get Cancer." She named it after what her first doctor said to her. When she was in the hospital receiving treatment for her disease, she thought back to that moment and how much could have been prevented if the doctor hadn't see her as just a pretty girl.

"We all can get cancer, whether we are thin, obese, brown, Black, White, whatever color we are. … So we're all exposed to potentially being victims of cancer," she said.

The book is a raw account of Diaz's journey, told in her own narrative voice to take readers through her life. She talks not only about her cancer journey but also about conflict management, a community coming together and a teenager getting through her changing life. There are moments of drama, cheer, happiness and even some Venezuelan history.

Diaz decided to write her book because she wanted to share her story with the people around her who might not have known the full details of it otherwise. She also wanted to share her "can-do mentality," which she believes was very helpful and played a role in her surviving, as well as keeping her in remission. She noted that everyone has genes, and not every cancer responds to lifestyle choices that are made, but "when you do make the effort some good things can come out of it."

"I very well might come up with an illness tomorrow. I don't know. But at least I'm doing everything I can to prevent that," she noted.

Diaz decided to publish her book while she was self-isolating during the COVID-19 pandemic, although the term "isolation" and what it brought was not new to her. During her cancer she couldn't go out, and if she did, she'd have to wear a mask. She also didn't have internet, so she couldn't have Zoom calls which became popular during the pandemic. While her friends were out partying, she was home bored, but she recalled she learned a lot while she was doing it, even if she didn't notice it at the time.

"Isolation can be beautiful if you make it about projects that need time alone," she mentioned.

In her book and life, Diaz is an advocate for self-care, something she was practicing during her cancer isolation before it had even become a buzzword or a part of anyone's daily routine. As a health-supportive chef and yoga teacher, Diaz believes there is an undervalue in self-care and listening to one's body. She thinks self-care is important for everyone, but cancer survivors specifically should make time for it because of the harsh treatment they have gone through.

In Diaz's book, readers can learn about how she leaned on self-care throughout her personal struggles with cancer.

"Cancer can be really hard and scary, but it also brings many opportunities to learn about life and what's really important. And what (readers) will read through those pages is my journey and how I dealt with my healing at a time when I should have been out partying with my high school friends," Diaz explained.

celebrity SPOTLIGHT


World Triathlon
Tommy Zaferes

Surviving Cancer and Winning Olympic Medals

When he was 18, Kevin McDowell had to change his goal from winning triathlons to surviving cancer.

By COLLEEN MORETTI

» **KEVIN MCDOWELL** believes that his discipline as an athlete helped him through his cancer treatment.

KEVIN MCDOWELL RECENTLY returned from an epic showing at the 2020 Tokyo Olympic Games as a member of the USA Olympic Triathlon Team. His team took home silver in the mixed relay event and individually he finished sixth, the best finish by an American man since triathlon was added to the Olympics in 2000.

But a decade ago, McDowell wasn't worried about competing against 54 other triathletes; he was focused on competing against cancer. At age 18 he received a diagnosis of Hodgkin lymphoma and stopped all training for six months to undergo intense chemotherapy. He didn't think he'd be able to go back to the sport he had loved since he was 10, but decided to stop putting limits on himself and return to triathlon.

McDowell tells *Heal*® about how his mindset changed from a winning athlete to a patient overcoming cancer and how his journey helped him through the Olympic Games.

Q: *HEAL*®: Can you tell us a little bit about your cancer journey?

A: McDowell: I was 18. And it was my final year in the junior category. The year before I had been third in the world, so this was my final year. My goal was to win the junior

PHOTOS COURTESY OF WORLD TRIATHLON

world title that year. Actually that winter (I) was training pretty hard and came out and did my first professional race, just to see how things were (at) the next level to prepare me for when I was racing the best in the world for the junior category.

And I went there and surpassed all expectations, was really excited with where I was at. I went home. My mom's a nurse, and I was excited, telling her how the race went. And she saw — I was wearing a big T-shirt that day — this lump in my neck. And she didn't like how it looked so she took me in the next day. I got scans done, a lot of things done. And the following day my parents broke the news that it was cancer.

So that was a tumor in my neck and then I had a few tumors in my chest as well. And then two days later, after we went in and did a biopsy, we learned it was Hodgkin lymphoma. So that year, instead of working toward my goal of winning junior worlds, it changed to beating cancer. (I) underwent six months of chemotherapy and beat cancer. And now I'm 10 years out and cancer free.

Q: How did your life change from being an athlete to being a patient with cancer?

A: In some ways, I feel like me being an athlete actually helped me (go) through my battle with cancer because (I) was such a goal-oriented person and knew the discipline and how it works to be an athlete. So I kind of changed my mindset from my goal that year to win the junior world title … to beating cancer.

So my goal then was: How do I get the best out of myself to beat cancer? What do I need to do? What did the doctor tell me to do? … I need to be the best at beating cancer. So I kind of changed that mindset. I was pretty disciplined at times, but I also had a pretty good balance. I definitely pushed boundaries at times of what I was doing from an activity standpoint. But I think because I was so healthy going in, and I already had such good habits on eating healthy, sleeping well and all these other little things, I think it helped me get through my treatment a bit better than even some of my doctors might have thought.

Q: How was the transition going back to training and competing after treatment?

A: I came back very quick. And I was surprised at how fast I was improving and getting back to fitness. But it was short-lived. Because what had happened was, I was not fully prepared, like fully healthy yet, to get back into high training. I'd gone through six months of intense chemotherapy; it took a huge toll on my body, more than I even realized at the time. It took me many years to realize exactly what that toll was. So I would come back, and do maybe one race really good. And then my body would break down and then I'd return and then do it again.

And in 2013, two years after any treatment, I almost stepped away completely from the sport and was like, I can't do this anymore. My body kept breaking down. I wasn't right. And so I put a focus on school and took five months away from the sport, and just did a little bit of activity, but nothing that was considered training. And then five months later I was like, "Hey, I actually want to maybe give another go at this triathlon thing. I'm a lot healthier." Because one thing we learned was that through chemotherapy and stuff, it can really mess up all your hormones and everything. My testosterone was zero; everything was really messed up for a bit because I just never let myself heal, like normally, and put on the weight after I finished my chemo. So what I should have done is taken a break, heal, put the weight back on, let my body really regenerate and recover instead of going into this intense elite training. I never allowed my body to recover. In those five months, I definitely allowed my body to recover a bit more. (I) improved a lot from a health standpoint.

I was then returning and doing better, but it was still kind of hit or miss a bit. And then I'd say (between) 2017 (and) 2018 my body came full circle and I hit kind of a little bit of a growth spurt. It's like I finished my puberty at 26. I was back where my weight was, more of a stable situation; my hormones were back in check. And everything had come full circle and balanced (and) I then put on about five kilos (approximately 11 pounds) of muscle mass. I grew half an inch. So it was just kind of like a complete thing. Because I mean, one thing that happened was when I went through my chemo, I was 18. Finishing puberty and growth is big (at that age). So I think that delayed everything quite a bit for me.

Q: Can you compare competing in the Olympics to cancer?

A: In some ways you can intertwine them; in other ways, not. Obviously, one of the big goals, once I got cancer, was to beat cancer. And it was one of those like, "Yeah, I spent six months fighting it and beating it, but then it's five years until you're in full remission and you're considered cured." So that's kind of like you achieve the first goal, but then you're still going and then you get that word — you're still cancer free five years out, and then 10 years out. Those are huge markings to hit. And so that was a pretty big deal hitting that. And then to translate it to the Olympics — it's been a childhood goal of mine. So when I actually qualified and made the team, that was a huge moment, for me. (I was) very excited. And then I was excited to go to the Games. Then it was extra special because I really wanted to go to the Games, but I didn't want just to attend them; I wanted to compete. So then to be able to go there and have performances like I did was just even more special. »

MCDOWELL tells survivors to not set limits on themselves. He didn't and later walked away with an Olympic silver medal.

Q: You had one of the best showings for a male triathlete and won the silver in the mixed relay in the Tokyo Olympics. Can you talk about that feeling? And what kind of message does that send to survivors?

A: I'm still kind of absorbing what I did. I mean, obviously, the goal is always you want to go there and do the best you can. And I didn't quite have the expectations on that in the individual race, so when I got sixth, I was pretty excited about that. I never went in thinking, "Oh, this is a number that I want to get." I want to just focus on the process and then the results will come. And then coming away with the silver with our mixed team relay was especially special as well. And I think there's one thing to take away from it: Don't set limits on yourself.

Throughout that, I definitely, in the early stages, was like, "Oh, should I be running with these people on this individual race? I've never been running with these top guys before." Normally, I'm probably in the 10th to 20th range. And I (said), "No, let's go. This is the Olympic Games. Let's take a risk. Let's roll with it. And don't overthink it."

I had to turn my brain off to not overthink things. And when I did that, I was running in new territory and that's what I think carried me into sixth. And in a situation where at one point, I was definitely still running up in the middle position, which I'd never envisioned at that point. I think one big thing is just not setting limits on yourself within a race and just rolling with it when you have good feelings on stuff. Don't set boundaries. And I think that's what helped me then in the mixed team relay — not be afraid of who I was going against. I mean, in my leg, I was going against one of the best triathletes in history, Jonathan Brownlee. And I wasn't afraid of him on the race course. The old me might have been, but I was like, let's see what we can do. I'm excited to compete against him and give it to him in a way. And I think that mindset helped a lot.

Q: What's one thing you know about yourself now that you didn't know before cancer?

A: I've always been a tough child in the sense of I'm pretty stubborn. And I know what I want and I'll go after it. But I think one thing now that I've learned about myself is I never gave up. And I was just committed into that grind. And I can be pretty gritty. And I can be kind of that relentless in pursuit. Because I mean, there were multiple times where I literally about walked away from the sport, walked away from other

PHOTOS COURTESY OF WORLD TRIATHLON

McDOWELL almost stepped away from the sport he loved because his body kept breaking down. But after time and healing he was ready to compete again.

things. I just didn't think I'd be able to do it. So then to be able to pull it off, and not just pull it off, but having (a good) performance in the Games as well, just showed me, I'm glad I didn't step away from the sport or quit at a certain time. And I think that mindset is kind of what helped carry me through cancer as well. It's looking into the positives and not just the negatives. That whole mindset really helped carry me as well through it all. So I think that's one thing I've learned.

And I think one thing I've learned through all this time, too, is I just am finally finding what I love to do and the passion and just (how) passionate I am, not just about the sport, but also now giving back in the cancer community and getting more involved in everything and that side of things. And I just feel like I have so much more to give. And I'm just touching, tapping into what I've got ahead of me.

Q: You've survived cancer and competed in the Olympics. What's next?

A: I honestly think these Olympic Games just opened my mind to what I am capable of. Now I'm like, "I can truly make it in this sport. And it's not just a fluke that I was selected for the team because it was controversial why I was selected"; some people questioned my selection to the team. But it was nice to be able to go there and show them why I was selected and prove not just to them, but to myself, too. So I'm definitely going to be going for the 2024 Olympics. I'd love to be in a position where I'm going for a medal, but I don't want to stress on outcome because I think that's also what helped me have such a good result in this last one. I'm honestly wanting to just enjoy the ride and the environment. And I'm kind of making things more stable. Because one cool thing for me this year is I made some changes in my coaching and my environment as a whole to where it's more of a home base in Colorado Springs, where my whole family lives, (and) creating a lot more friends. And I'm having a much better balance in my life than just straight-up triathlon. I'm still focused and sometimes you do have to make those hard sacrifices. You're not going out with friends or doing this, but I've had such balance that even if I stepped away from the sport right now, there's not much I'd changed in my life. I mean, sure, I'd have to go and get a real job and do that part, but outside of that, I wouldn't change how I'm living things or where I'm based.

It's pretty cool to see I produced that result with not feeling like I've made too many sacrifices that a lot of athletes actually will make going into the Games.

I want to keep improving myself in the World Triathlon series and play one day beyond, (reach) a podium there. And I think, just keep raising the bar for the men's side of USA Triathlon as well. The women are so highly established, and I think men are just starting to knock on the door more. I think these games have displayed that, between myself and Morgan Pearson and others. I'm excited about that.

And then I think after that I really want to keep getting involved more in the cancer side of things, with charities and events and more, maybe some speaking events and just really becoming a voice and using this platform that I've got to show that there's no limits on things and you can do a lot that you don't even realize that's possible at times. Or you may set limits on yourself, but actually if you open your mind to new opportunities, there's a lot more out there than you even realize. h

LISTEN IN!

SCAN THE QR code to listen to McDowell's story and other inspiring stories from patients and survivors of cancer.

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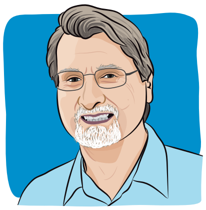
Cancer Remission: Time to *Breathe* Again

A survivor of prostate cancer celebrates the news that his cancer has not spread and describes how remission has made him feel. *By* RON COOPER

HALLELUJAH! I GOT the best news possible this summer: My four-month blood test showed no spread of my aggressive prostate cancer. Remission is such a blessing. Nearly seven years and counting!

This definitely calls for a celebration!

In the past, my wife and I celebrated these small victories over cancer with a steak dinner at my favorite restaurant. But COVID-19 put the kibosh on that for well over a year and we were forced to mark the occasion with drive-through burgers and fries at McDonald's.



RON COOPER

Just keeping things simple, you know?

But hey, a celebration is a celebration on this bumpy road called cancer, and best of all, a welcomed break from the grip of this deadly disease brings me newfound freedom. I am:

- free to breathe more easily,
- free to enjoy life,
- free to pamper myself, and
- free to thank those helping me on my own journey.

So you might wonder: Do I live a charmed existence now? Most definitely not! Am I totally anxiety free? Heck no! Do I worry now and then? An emphatic yes! But the crushing weight of "what-ifs" has been lifted from my soul — for now.

Naturally, any cancer survivor can relate to these nagging what-ifs. Here are some common examples:

- What if the cancer has spread and I need chemo?
- What if treatments leave me so fatigued I can't follow my passions?
- What if the cost of care bankrupts me and my family?
- What if I'm entering the final chapter of my life?

Well, for the time being, with no evidence of disease, I can set aside these troublesome what-ifs and replace them with some tantalizing "how-cans."

- How can I squeeze joy out of every single moment?
- How can I put my anxiety in its place once and for all?
- How can I turn off the cancer-themed tape recorder in my head?
- How can I find a greater purpose?

Skeptics may ask if I have truly turned the corner from what-ifs to how-cans. Well, the proof is in the pudding:

I now rest better and my appetite has improved. I have learned to turn off the news and spend my leisure time watching standup comedy and silly sitcoms.

I now say yes to invitations for outings and visits with loved ones rather than staying home awaiting the next test results (it helps that we're all fully vaccinated in my inner circle).

I now devote my time to helping others, serving as a cancer advocate and paying it forward one phone call or text at a time.

So, friends, while I'll always be a tiny bit on guard for the next wave of bad cancer news, I can exclaim in this

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

Why Cancer Survivors Cannot Always Be Positive

A cancer survivor describes how frustrating it can be to experience toxic positivity.

BY JANE BIEHL, PH.D.

OVERALL, I CONSIDER MYSELF to be a positive person. I try to look on the bright side while constantly fighting a tendency toward the depression I have battled all my life.

That is why I recently was blindsided by some friends whom I have known for over 30 years. I didn't even think I was complaining when I simply stated that I was tired after two years nonstop of going twice a week for bloodwork and shots for my cancer. “Oh, but don't you enjoy the social interaction?” they chirped. “You have a chance to get out with people.” My mouth dropped open, especially since they're all counselors!

I tried to explain that while the staff and nurses were wonderful, it was time-consuming and it took chunks of time from other things for two days each week. I also do not need this social contact since I belong to many organizations, including church, writers club, book club and committees, and have other friends I see frequently. I thought to myself about the scar tissue developing where I get my blood drawn. I am tired of commuting then fighting at the local hospital for a place to park, going through the COVID-19 protocol, going to the infusion floor, and often taking half an hour for shots that take five minutes. This is easy compared with what most cancer survivors go through, but it is also tiring.


JANE BIEHL, PH.D.

I honestly do not think they were being insensitive. My sister recently sent me a great article, “How to Cope When Positivity Turns Toxic,” by Maile Timon.

The author explains that toxic positivity is defined as “the belief that, regardless of how unfortunate or dire a situation, maintaining a positive mindset is paramount.” The article reminds us that feeling bad is part of our evolving emotions in any kind of loss, ranging from a job loss to losing a loved one to receiving a diagnosis of a serious disease. All many people want is validation. When people try to induce positivity they often shame the person despite having good intentions.

I have honestly learned so much on this cancer journey. I used to be one of these people who caused toxic positivity. Now, when friends face a terrible loss of any kind, I simply say, “I am sorry. I am here for anything you need, even if it is to sit with you and hold your hand.”

Being cheerful is a good thing until it is not. I am sure every one of us cancer survivors has our own story about the insensitive comments people have made to us. We need to understand where they are coming from and resolve not to do this to someone else. We of all people know that sometimes, just being there and listening is all other people want or need. And we can do that!

The Game of Cancer

A survivor makes a comparison between cancer and a game. By JULIE S. BROKAW

WHEN WE THINK OF GAMES, we typically do not think of cancer as one. But cancer is a game with all the parts and pieces. The parts of a game include the box, game board, directions, rules, tokens, challenges, penalties, strategies, dice, spinners and other things the competition depends on, with the result of winners and losers. As kids, we play games with family and friends. We continue to play games as adults. We learn strategies to beat other players. Often, we lose while we are learning those strategies. But the next time we roll the right number, we can get our token or marble on the board, and we continue to play the game.


JULIE S. BROKAW

So how does a game relate to cancer? Our bodies are the box the game comes in. How we deal with our cancer is the game we play. The game board is our path that we are expected to follow; collect $200 or go to jail. The tokens are the people who surround us. Sometimes they are family and friends. Others

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WOOSTER / STOCK.ADOBE.COM; ILLUSTRATIONS BY RAY PELESKO

> “The game of cancer is emotionally, socially, physically and financially challenging.” —*JULIE S. BROKAW*

include physicians, nurses, techs and receptionists. The obvious challenge is to get well and fight the cancer that you have with all you have. Your strategies are finding ways to move forward on the board and get through the difficult procedures, medicines and hard discussions. Sometimes we take the chances of a spinner or dice roll. Should I seek another opinion or another hospital? Is one medicine less toxic with fewer side effects? Other times, we follow protocol because of the research out there on the specific cancer we fight.

I have been playing the game of cancer for a long time. Even though I received my ovarian cancer diagnosis in 2013, I knew something was wrong in 2012. I went to my regular physician but she did not find anything wrong with my gallbladder, which is all she checked. I should have gone to another doctor right then, but I waited five months before seeing my gynecologist and then the cancer was found. Hindsight is 20/20. How I wish I had done things differently.

I continue to play the cancer game every day. You are never away from the game board. Sometimes you do get to collect that $200. Other times, the challenge is to get to the next day and remain vigilant in your fight. The game of cancer is emotionally, socially, physically and financially challenging. The mental difficulties, social interactions with others, the changes in your body and paying to try to manage an expensive disease can wreak havoc on you.

Emotionally, the game of cancer can take a toll in your head. You start seeing commercials on television or other media for pharmaceuticals for every disease out there, sometimes for the actual cancer you have. It would be nice to not have the constant reminder or tap on the shoulder that you are fighting for your life. Oh, how I wish I had psoriasis or at least something that was not cancer. Patients with psoriasis: Do not take this comment as a slam against you. I just wish my disease was not cancer.

Socially, the “game” of cancer can be a two-edged sword. For me, I chose not to wear a wig when I lost all my hair from my first chemo. Hats were my choice. I wore all kinds of hats — pretty fun colors, ball caps, wide-brim beach hats and sometimes just a bandanna. Because I was bald, I had all sorts of people come up to me and make supportive comments. “I will pray for you” and “I love your hat,” they said. Their intentions were good, but sometimes it was awkward. My worst comment was from a gentleman who clearly had health issues. One evening, I was in a restaurant wearing a hat. This man came up to me, put his arm around my shoulder and asked, “What kind of cancer do you have?” as he held his fingers to his throat to cover the hole in his trachea from his cancer treatment. He was a bit too close and that was uncomfortable for me. My best comment was from a gal coming out of the grocery store. She was darling, with cute blond hair below her chin, and she said: “I looked just like you a year ago. You are going to be OK! Good luck!”

Physically, if you are fighting cancer, you know what I am talking about. If you have just recently received a cancer diagnosis, then you will know. My body has drastically changed. I have incision scars from surgeries, bad veins and baldness from chemo, burns from radiation and bruises from bloodwork. My body can feel very beat up on some days. However, the incisions are less pronounced, the veins have withstood the chemicals and the radiation burns have healed.

Financially, the game of cancer is expensive. Thank goodness for insurance. My one surgery bill was over $100,000. I did have to pay $6,000 over time. Chemo and radiation costs add up quickly as well.

The emotional, social, physical and financial tolls on you and your family are honestly difficult. But I am here today to say it is all worth it. I try to remain positive and celebrate that my cancer is under control and in remission as of just this past week. I still go out to dinner, meet with family and friends and live my life to the fullest every day. I use the medicines prescribed to alleviate the pains and infections that I fight with treatments. I follow my physician’s suggestions for health and wellness. My scars are just part of my journey. And I do my best to make sure my bills are paid.

I continue to count my blessings every day and celebrate life as I know it. The game of cancer is just that, a game. I want to live my life and strive to be a winner and today, I am doing that! h

Life Is a Blink

A four-time cancer survivor shares the advice her father gave her when she was a young child during her first journey with cancer. *By* JESSICA BOLZ

JESSICA BOLZ

WHEN I WAS A LITTLE GIRL, it was a common ritual to visit Pinelawn Cemetery to see the grave of my dad's mother. I would be curious with anticipation every time we got there, to explore, learn, or guess about the history of the mysterious people who were behind those granite mausoleum stones. After my mother would give my sister and me tasks to do, such as go to the spigot and fill a bucket with water for the flowers we would plant, instead I scurried about and I entered a tunnel into the final resting places for so many, surrounded by squares with names and dates. Some passed on very early in life, some had lived for years and years, and then the names of some were engraved on very small squares.

"Mom, why do some of the people that died have such a small square?" I asked curiously.

My mother replied, "Those people were cremated and their remains were placed in the wall."

"Hmmm," I thought. "That makes so much more sense to me. Why take up space when you're dead? I'll do that when I die, a thousand years from now," my 8-year-old brain was reasoning. Death had yet to become a fearful concept for me. And I realized as I got older that fear in general doesn't paralyze a young mind. As we grow, we learn to become afraid.

I was 11 years old when I found out I had Hodgkin disease. Barely entering middle school, and the word "death" was introduced into my personal life. Carefree days of playing tag, riding bikes, and hanging out in my friends' basements creating fictional stories came to a halt. I was suddenly faced with that word, "fear", devirginizing me from my innocence, where I had been blissfully ensconced for my first 10 years on this planet. And I did not know how to come out of that bubble into the harsh realities that for the most part, only older people have to face. Could I end up a square in Pinelawn? All of those names that I had looked at, that I had read like a delicious book that I could not put down. I had given them all a personality. I had given them a face in my mind. I thought about how they had lived their lives. Did anyone remember them now that they were behind that stone in the wall? I was not ready for the wall or a square yet. I was not even ready to think about what would put me there.

Pushing through a grueling regimen of surgery, which included a staging laparotomy, which doctors said I may not survive, and heavy chemotherapy, I was living in a very different world from the carefree one that seemed just moments before. My mother attempted to keep our life consistent and structured in some ways, so our visits to the cemetery continued. There was a huge expanse of grass that seemed as long as a football field between my grandma's grave and the other crypts across the way, and I liked to run or skip across it and hear the small jet planes from the nearby private airport fly overhead. The buzz of those engines was always calming and resonate with the memory of my grandma to this day.

One day my father took us out to see his mom's grave. She had passed away in 1975 from breast cancer. He always looked so pained when we would go see her stone, and I asked him why one crisp morning as we stood in front of it. He turned to me and said: "She isn't here. It's just a stone." At first, that upset me. But then he explained something to me that I used to strengthen me for the rest of my 35 years of survivorship.

He said, "She left that body, and she is in another place now." I became hopeful! Was he saying life goes on? This is not the end, behind the square?

"Jessica, life is a blink," he went on. "When you close your eyes and then open them, half of your life will have gone by. So hold on to every moment. It's just a blink."

As I traveled on and fought through four cancers, that word became a code word for my father and me. Whenever I felt I could not fight, that it was too much, he would just say "blink," to remind me that what I was experiencing in time would end, and things would get better, but also, to remind me to hold on to each moment and make something of it.

I now have the word inscribed on my left shoulder with lashes on the "K." And when others ask me, "What's blink?" I can impart on them the wise words my father shared with me, which shifted how I looked at my situation and life in general. He was right. We have a choice, but time is always moving. Blink and it is gone. So make it happen in the "now." h

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.

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

Now Everyone Understands What Cancer Is Like

A survivor of pancreatic cancer shares how the COVID-19 pandemic is similar to cancer.

By WILLIAM RAMSHAW

LOOKING BACK OVER THE past year-plus of COVID-19 mania, I think many now understand what cancer is like. There are freaky similarities between COVID-19 and cancer: thinking about your health nonstop, hypervigilance about every unexplained twitch, wearing a mask everywhere and feeling vulnerable to something insidious, something that you can't see but could kill you. Here are five invaluable lessons I have learned.

WILLIAM RAMSHAW

1 It's time to get on with my life. Much like cancer fatigue, I have come to believe COVID-19 fatigue is real. Most of us are ready to get out and start living our lives again. We've spent months locked down, not seeing our close family or best-best friends, not attending weddings and at best only being able to attend someone's memorial service via a sketchy video connection. Much like how cancer shrinks our lives, making them a shadow of their former selves, this pandemic has done the same. Much like when our hideous cancer treatments finally came to an end, with COVID-19 starting to wane, we realize it's time to get on with our lives.

2 There is only so much I can do. Early in the pandemic, we stayed at home for days or sometimes weeks at a time. We bought gallons of disinfectant (OK, a bottle or two as everyone hoarded it) and wiped down everything in our home multiple times to the point of wearing the finish off things. As the pandemic progressed, it became apparent that we needed to get to the store for the essentials, so we bundled our trips into a single, do-it-all trip. We double-masked, washed our hands until they were cracked and bleeding and maintained our distance from others with a 6-foot stick. But after months of this, it became apparent that if we got COVID-19, we got it. To this day I wonder if there was anything I could have done to avoid getting pancreatic cancer. I'll never know. There is only so much we can do.

3 I learned how to flow with it. Early in the pandemic people appeared hesitant to mask up. Now, even with being vaccinated, people seem to be hesitant to drop their masks. A few weeks ago, after the Centers for Disease Control and Prevention relaxed mask guidelines, I was at the supermarket and most people were not wearing masks, so I decided not to wear mine (yes, I am vaccinated). I darted into the produce aisle to pick up a head of lettuce. A masked woman a few feet in front of me whipped her cart around and marched off in the other direction. I felt bad and wanted to say, "Sorry," but it was too late. Similar to COVID-19, early in the cancer process, it is quite difficult to manage all the rules and lifestyle changes but as it goes on, we learn how to flow with it.

4 Telemedicine left me feeling like a widget on the assembly line. During the heat of the pandemic, seeing a doctor face to face became a unicorn event. Telemedicine might have kept us from getting COVID-19, but something was lacking in the flickering video. My pre-COVID-19 doctor appointments left much to be desired, at best a few minutes to unpack my super-complicated medical life. But my COVID-19 Zoom appointments left me empty, craving a personal connection beyond a video one. Telemedicine left us feeling like a widget on the assembly line.

5 I need to connect. Terrified we might get COVID-19, most of us not only socially distanced but much like a telephone call going south, we also hung up on other people. Getting struck with cancer can leave a person feeling alone, wanting an ever-so-brief connection with another human being. Not only have I lost good friends to cancer, but I have also lost them to my cancer. Unable to face their own mortality, that they also had an expiration date, uncertain of what to say to me, they disappeared. They hung up on me. Phone calls unreturned. Texts unanswered. We all need to connect.

COVID-19 and cancer have much in common. We realize it's time to get on with our lives, there is only so much we can do, we learn how to flow with it, telemedicine makes us feel like widgets and we all need to connect.

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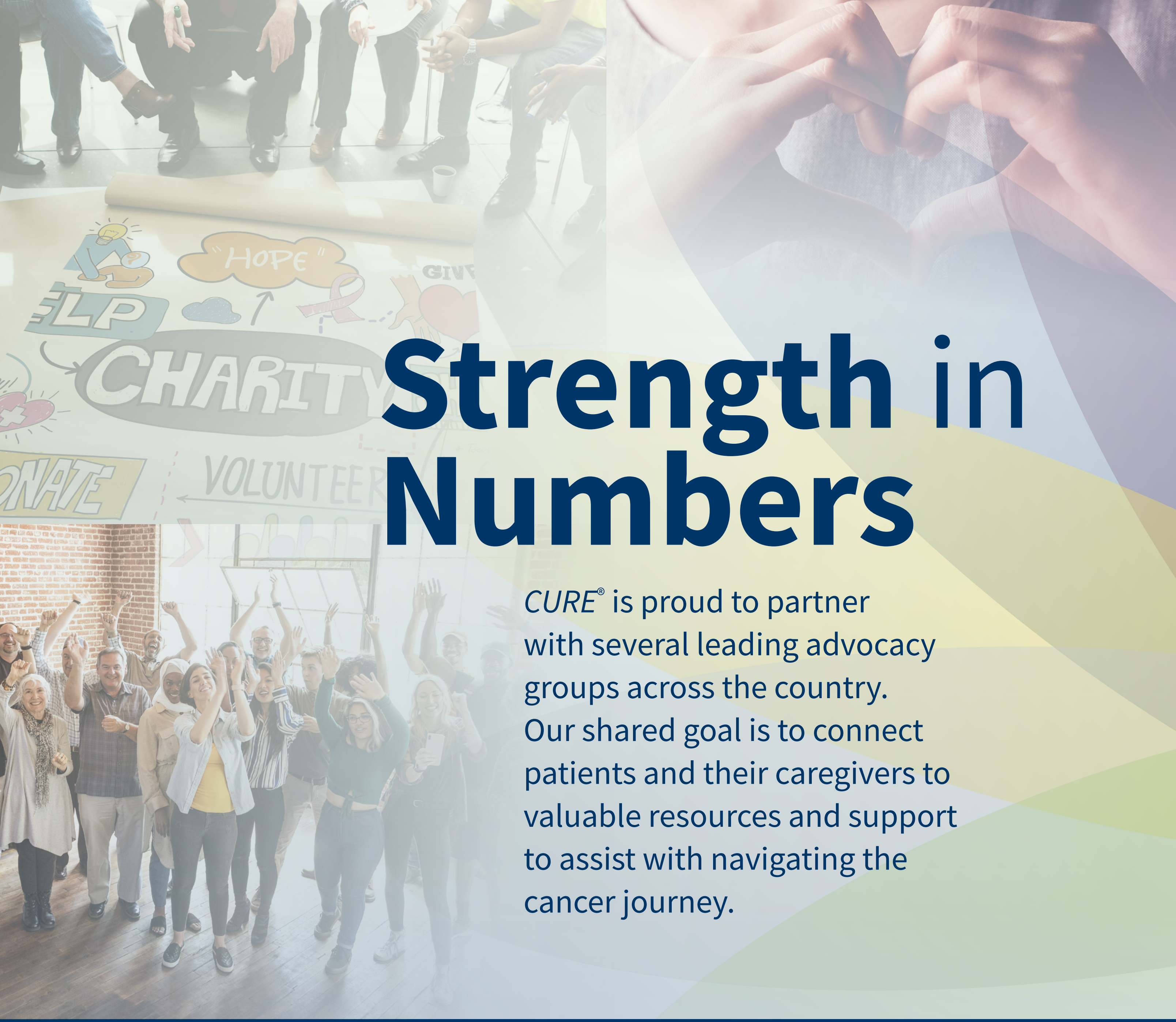
"HOPE"
GIVE
HELP
CHARITY
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Falling Into New Recipes

It's back to the basics with these fall recipes! Pesto can be put on anything and stays fresh for up to six months. The roasted chickpeas are a great salad addition that provides protein. And we never forget about your sweet tooth — or the need for energy — with these peanut butter bites!

RECIPES *by* CAROLINE PRIESKORN, RDN, LDN, AN OUTPATIENT ONCOLOGY DIETITIAN AT THE MEDSTAR WASHINGTON HOSPITAL CENTER IN WASHINGTON, D.C.

Peanut Butter Oat Energy Bites

INGREDIENTS

- 1 cup raw old-fashioned oats
- 1/2 cup ground flaxseed
- 1/3 cup semisweet chocolate chips
- 1/2 cup natural peanut butter
- 1/3 cup pure maple syrup
- 1 tsp vanilla extract

DIRECTIONS

1. Stir all ingredients in a bowl, then form into balls.
2. Refrigerate for 30 minutes then enjoy!
3. Refrigerate to keep fresh.

SCAN THE QR CODE
for recipes and more

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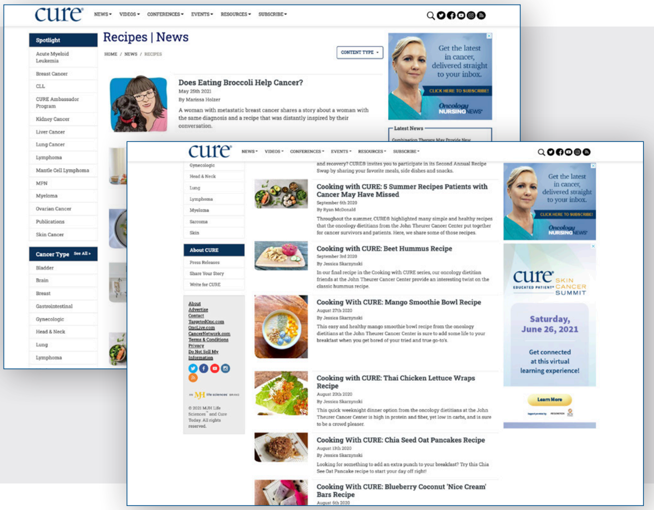
instagram/curetoday



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

PHOTOS COURTESY OF PRIESKORN

Roasted Chickpeas

INGREDIENTS

- 1 can chickpeas
- 1 tablespoon extra virgin olive oil
- 1 teaspoon smoked paprika
- 1/4 teaspoon sea salt
- 2 teaspoons pure maple syrup

DIRECTIONS

1. Preheat oven to 425°.
2. Rinse chickpeas in a colander, pat dry and arrange on a baking sheet lined with parchment paper.
3. Mix olive oil, paprika, salt, and maple syrup and pour over the chickpeas.
4. Roast 20 to 25 minutes or until lightly browned.

Powerful Pesto

INGREDIENTS

- 2 cups packed basil leaves
- 1 cup walnuts
- 2 cloves garlic
- 1/2 cup olive oil
- 1/4 cup low-sodium chicken broth or water
- Salt and pepper to taste

DIRECTIONS

1. Place basil, walnuts, garlic and oil in food processor and begin pureeing.
2. Slowly add 1/3 cup low-sodium chicken broth.
3. Add additional 1/4 cup low-sodium chicken broth if not smooth.
4. Refrigerate for use within a week or freeze for up to six months.

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 Kilimanjaro
February 19 - March 1, 2022

Greenland Trek
Summer 2022

Sweden Trek
Summer 2022

Mount Washington
Date to be announced

Colorado Trek
Date to be announced

endurance.themmrf.org/MM4MM

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