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Easing Side Effects, 20 Years Later

AFTER TREATMENT, EVEN years later, a cancer survivor may experience a side effect called neuropathy. Neuropathy is a condition that causes pain, numbness and tingling in the hands and feet. One cancer survivor even described it as “constant pins and needles.”


In this summer issue of *Heal*®, our cover story dives deeper into what neuropathy is and why it happens. We hear from two cancer survivors who have made adjustments to their everyday life to deal with the pain from neuropathy. As of now, there isn't one definite relief or resolution for neurotherapy; there are medications, but they cause more side effects. And therapy can help for a bit, but as one survivor put it, “No one size fits all.”

However, one expert gives insight into a new therapy that is being evaluated to help ease the pain — scrambler therapy, which uses electrical stimulation to “scramble” the pain signals being sent from the nerves to the brain.

Reflecting on *CURE*®'s 20th anniversary, in this issue of *Heal*® we hear from Gwen Goodman, a cancer survivor of 20 years. When she first completed treatment, there was no plan for survivorship and no one prepared her for the side effects she would later face. She and an expert discuss the

improvements made in cancer survivorship over the past two decades — and what is still lacking.

Cancer survivors also may face anxiety and stress when treatment ends, however mindfulness meditation may help. We talk with clinical health psychologist Erin O'Carroll Bantum about the benefits of mindfulness meditation for cancer survivors. We also provide readers with a step-by-step guide on how to start practicing mindfulness meditation.

And lastly, let's get ready for a hot summer with some cool recipes! Fruits and vegetables provide cancer survivors with tons of nutrients, vitamins and antioxidants and summer is the perfect time to start incorporating more into your meals. In this issue, you'll find three delicious recipes waiting for you. 

MIKE HENNESSY JR.

President & CEO



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overheard on **SOCIAL MEDIA**

Advice From People Like You

We asked readers, **“What is the most challenging part of cancer survivorship?”**

Here’s what they said.

“Fear of relapse.
—*MARIE*”

“The lifelong side effects from treatments that nobody warns you about and few oncologists seem to care (or know) about. —*CHRISTINE*”

“That little voice in the back of your mind that says, ‘What if it comes back?’ —*RYAN*”

Of course, all the usual stuff that has been mentioned. But right now my biggest struggle is feeling comfortable getting back into the dating scene! It might seem trivial in comparison with other struggles, but I think it’s something many of us struggle with. How do I tell someone new that not only did I get through this major health crisis but that I also lost my breasts because of it?! —*AMY*”

“Chemo-brain/brain fog. (It) doesn’t go away after chemo stops. Worrying that one day it will lead to dementia. —*MEL*”

““That ‘survivor’ does not mean the journey ends. You live it the rest of your life.” —*TERESA*”

“Living with side effects of treatment that don’t go away.
—*PAULA*”

“Now that I survived the transplant I’m dealing with chronic graft-versus-host disease. Currently I can’t bend my fingers, my arms are hard as rocks (and) my legs are so stiff I can barely walk. ... I survived cancer because of the transplant but it comes with a ton of other problems. —*RUTHIE*”



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‘Give Yourself Grace’

As a patient moves from treatment to survivorship, the fear of recurrence may overshadow their ability to recognize how much they have endured.

By DARLENE DOBKOWSKI, MA

PATIENTS WITH CANCER are often fearful upon receiving a diagnosis and throughout treatment, but sometimes the fear can carry over into the survivorship portion of a patient’s journey.

“The fear of recurrence is common regardless of what your diagnosis was or what your background is,” Nicole Kulasa, a survivorship nurse navigator at Allegheny Health Network Cancer Institute in Pittsburgh, said in an interview with *Heal*®. “It’s something that is across all different sexes, ages, economic backgrounds, disease sites. Whatever you may have is a common side effect that every cancer survivor encounters at one point in survivorship.”

Kulasa and her colleagues started a survivorship clinic at Allegheny Health Network Cancer Institute in 2020, which included a Survivorship 101 class for patients who had completed therapy. Through this class, patients learn more about resources to help them acclimate

to the “new normal” after cancer treatment and through survivorship. One of the many topics is the fear of recurrence, which Kulasa said is often mentioned by patients.

“(For) patients I’ve talked to, sometimes (the fear of recurrence) can be pretty profound; it almost puts them in a daily panic attack or freezes them from moving on,” Kulasa explained. “Yes, treatment is over, but what if (the cancer) comes back? Worrying about the fear of the unknown instead of focusing on the present day and what’s going on, constantly fearing about what can come in the future, that could be the extreme.”

‘THE NOT-KNOWING PART WAS THE HARDEST PART’

One of the patients from the survivorship clinic who has voiced a similar fear of recurrence is Patty Salerno, who lives in South Fayette Township, Pennsylvania, with her husband, Gary. She received a

diagnosis of stage 1 bile duct cancer in February 2021. Salerno, 62, had worked in several roles for the Pittsburgh Pirates for 31 years, most recently as the senior vice president of community affairs, but she retired in July 2020 because of the COVID-19 pandemic.

Salerno and her husband went to their primary care provider for routine physicals and blood work in February 2021. Results indicated that Salerno had high liver levels of AST (aspartate transaminase) and ALT (alanine aminotransferase). After a few subsequent tests, including an ultrasound, MRI and a liver biopsy, it was confirmed that she had bile duct cancer.

“In all honesty, the not-knowing part was the hardest part,” Salerno said. “Once we had a diagnosis and once we had a treatment plan, then it was ... a little bit easier, but the not knowing part is very scary.”

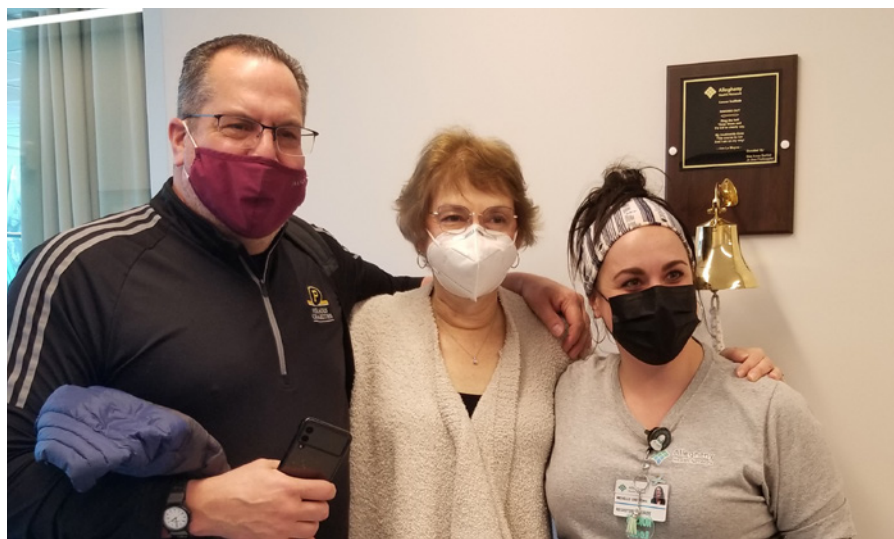
Salerno’s treatment plan included six cycles of chemotherapy, which prepared her for surgery in September 2021 to remove half of her liver. After surgery, Salerno was treated with 27 days of radiation because her margins were so close after surgery and the liver board wanted to play it safe. Treatment concluded after two more cycles of chemotherapy on Feb. 10, 2022. Salerno had scans performed in March, which are “so far, so good,” she said, and she will go back to her oncologist in three months.

“The hardest question to ask my oncologist when I was done with (treatment) was, do you think this (cancer) is going to come back,” Salerno said.

ANXIETY FROM EVERYDAY OCCURRENCES

The fear of cancer recurrence may be triggered by different factors, Kulasa said.

“It could be maybe a new cough,



👉 **PATTY SALERNO (CENTER)**, rung the bell into cancer survivorship when treatment ended with her husband, Gary, and favorite nurse Shelly by her side.

pain, ache or something that triggers (this fear),” she explained. “Is the cancer coming back? Or (patients) could be doing their normal daily activities, going in the grocery store, they’re looking over at *People* magazine and they see the local celebrity, a famous person with cancer. It’s external things that can trigger that fear. Sometimes that fear can affect their lives, impacting their relationships, how they’re talking to people or their daily activities. It can make them not active.”

This fear of recurrence may also stem from the unknown after a patient undergoes cancer treatment.

“When you’re going through treatment, it’s like a full-time job,” Salerno said.

“When we walk into the cancer institute, it may sound odd to you, but we feel very safe when we walk in there because people know us and you’re getting checked, whether it’s every week or every other week, and you’re getting all your blood work done. Now when you’re kind of out on your own again, it’s like, wow, what do I do now?”

Salerno said she asked her oncologists whether they think her cancer will come back, especially since her cancer treatment was labeled as curative. After a discussion about potential recurrence, it was agreed upon by Salerno and her care team that they can be “cautiously optimistic” that the cancer may not return.

“I can’t just jump into the pool of being cancer free, so I’m gradually stepping into the water,” Salerno said.

Salerno added that she now feels anxious with every doctor’s appointment she attends even if it’s not directly related to her bile duct cancer. For example, she recently went for a colonoscopy and the care team noted that she had a fast heart rate. Salerno credits that to the fear of wondering what doctors will find and what will happen next as a result of any doctor’s appointment. Salerno said that one thing she learned from Kulasa’s survivorship class is that there are some things that she can control and things she cannot.

“I can control getting all my screenings.

“The hardest question to ask my oncologist when I was done with treatment was ‘Do you think this cancer is going to come back?’

— PATTY SALERNO

That I can do,” Salerno said. “Trying to be as healthy as I can, trying to move, trying to eat well and have a good attitude, those are things I could control. But there are things that I can’t control. I can’t necessarily control what’s going on inside of me.”

Although it’s difficult for Salerno to fully accept that she is cancer free for now, she said she’s surrounded by a wonderful support system including Gary, her family and friends, all of whom try to keep her in the moment and allow her to be grateful for the good in her life.

SURROUNDING ONESELF WITH SUPPORTIVE PEOPLE

A strong support system, whether it is a patient’s family, friends or support groups through cancer centers, can help patients conquer or potentially reduce their fear of recurrence.


“Some people will say, ‘I’ve carried on with my life, but sometimes that fear will trigger (and) it will come up at some point.’ It can be very scary for patients,” Kulasa said. “Sometimes, it’s hard for (patients) to express themselves if they talk to family members who (say), ‘We got through cancer treatment together. It’s over, (we’re) looking forward to a happy, healthy future.’ Bringing up that fear to their loved ones can sometimes feel like a reminder or may scare their loved ones about what could happen. That’s why our support groups are so good. These survivors can get together and they can have that commonality: ‘I’m going through this too, I feel like I’m in a safe spot where I can express that without feeling like I might be making someone nervous, or I’m making them fearful.’ ”

Talking with others who underwent a similar journey can bring a sense of comfort.

“I have a very, very close friend who has metastatic breast cancer,” Salerno said. “Being able to talk with someone who has gone through or is going through the same thing that you have, it’s a different conversation. That’s some of the feedback that I gave back to Nicole (Kulasa) about survivorship. We like talking to one another because we know what it feels like to have a port. We know what it feels like to have radiation. I know that we all know what that fear is. I think trying to connect with people who are also survivors is important. I haven’t quite gotten there yet, but I think that’s going to be important.”

Kulasa suggested other ways patients and their families can alleviate the fear of recurrence or make it less of a focus on their lives. These include keeping up with screening appointments, reporting any symptoms that may be concerning, journaling and taking care of oneself by eating right, exercising and reducing stress.

Most importantly, Kulasa advises patients to recognize what they went through no matter how they may view their cancer journey.

“The most important thing is for people to realize that cancer does have an effect on your life and your loved ones’ life,” Kulasa said. “Maybe you caught (the cancer) super early, you had a very brief treatment and then you’re in recovery, or you went through a very long and treacherous treatment. Either way, cancer can have a huge impact on your life. Give yourself grace in knowing that what your body’s been through and how strong and resilient you and your family are.” 

Cancer Survivors Need a Ride

Unreliable public transportation or limited access to a working vehicle may lead to delays in important follow-up care for cancer survivors. By COLLEEN MORETTI



CANCER SURVIVORS MAY experience delays in important care due to transportation barriers, which may lead to bigger problems, according to study results.

“We know that cancer survivors are much sicker and have more financial issues compared (with) a patient without a history of cancer. But it’s very important for them to access the health care they need,” Dr. Charles Jiang, lead author on the study, said in an interview with *Heal*®. “And transportation barriers turned out to be one of the key factors contributing to a health disparity in the cancer survivor community.”

Jiang, a medical oncology fellow at Roswell Park Comprehensive Cancer Center in Buffalo, New York, explained that cancer survivors may experience other comorbidities and be at risk for health concerns such as heart disease or a secondary cancer. And it is important for them to keep up with care and doctor’s appointments.

However, this can be difficult for some cancer survivors because of a lack of transportation (not having a car available or not being able to drive) or unreliable public transportation. These barriers can cause them to continuously miss important appointments and

follow-ups, which can create a bigger problem.

“Because (cancer survivors) have a lot of issues and tend to be sicker and weaker, they need more help to get them from home to the clinic. Because once they’ve missed their doctors visit, just simply because they cannot get a bus on time or because there’s nobody to

“Once they’ve missed their doctors visit just because they cannot get a bus on time or because there’s nobody to drop them off, they don’t get the care they need and end up in the emergency (department) for something bigger.”

— DR. CHARLES JIANG ”

drop them off, they don’t get the care they need and end up in the emergency (department) for something bigger,” Jiang explained.

Jiang and colleagues reviewed collected information from 11,856 adult cancer survivors and 136,609 adults without a history of cancer. The results,

which were published in *JAMA Oncology*, demonstrated that cancer survivors were more likely to have experienced delays in health care due to transportation barriers in the preceding 12 months, compared with those without a history of cancer (3.1% versus 1.8%).

Additional results demonstrated that younger cancer survivors (18 to 40 years old) reported more transportation barriers than their peers without cancer. Jiang noted that this is a group that needs a lot of support. They are most likely still working and providing for themselves, as well as raising a family — so for them to receive care without delay is vital, he said.

“(These cancer survivors) need a lot of support and they’re sicker — we have a lot of studies already showing that,” he explained. “But here we’re suggesting that this group of cancer survivors, in addition to having the most financial toxicity and (possibly having difficulty paying) their medical bill, they can’t even find a way to the clinic. And it’s very important, because to (understand) their health care, they need to see their doctor first.”

In an adjusted analysis, cancer survivors who were younger, poorer, uninsured or publicly insured, unmarried or had self-reported physical functioning

limitations were more likely to experience transportation barriers.

“This is suggesting it should be a collaboration or at least a discussion involving all of the stakeholders, not only the patient and doctor,” he said. “We really need more help from the social workers and more importantly we need help from the insurance companies. They have to realize that if they (aren’t) providing the transportation coverage or a convenient transportation option for all these patients, we’re going to see them in the emergency (department) and they’re going to have really negative health outcomes at the end of the road.”

One in 6 cancer survivors with public insurance such as Medicaid reported experiencing transportation barriers, which according to Jiang, was quite surprising.

“Medicaid, which is one of the most common (types of) public insurance

that our cancer survivors are carrying, actually mandates a method of transportation. So Medicaid patients should not have this issue because they are already covered,” he explained. “This is basically telling us either they’re not getting the resources that are there, they don’t know they are there or that what they are providing might not be accommodating to their needs.”

These are not the only gaps in this space, Jiang said. The survey only asked survivors if they had a delay in health care, not whether they had to forgo it all together, which some may have done. They are often asked to make appointments ahead of time, but they may not know if they are going to have accessible transportation. Or cancer survivors counting on taking a bus to an appointment may arrive late if the bus is delayed. This may cause some to have to reschedule an appointment.

Of note, this was an observational

study, meaning Jiang and colleagues looked at past survey results and created their own conclusion.

Jiang suggests that cancer survivors who are experiencing these barriers and delays should talk with their doctors and social workers to see what resources may be available.

“I think it’s just really an understudied issue,” Jiang concluded. “My study is probably one of the few studies in this field, and I think we just need to keep working on this.” [h](#)

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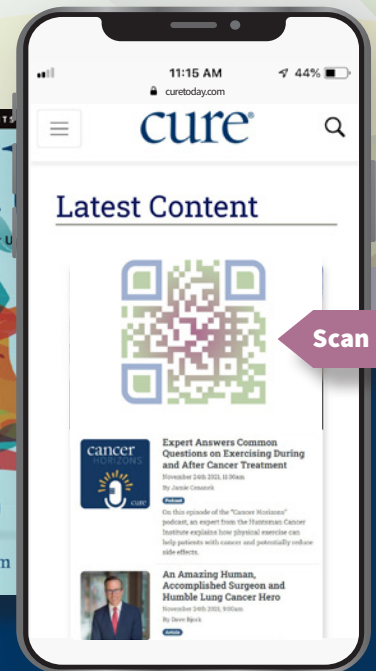
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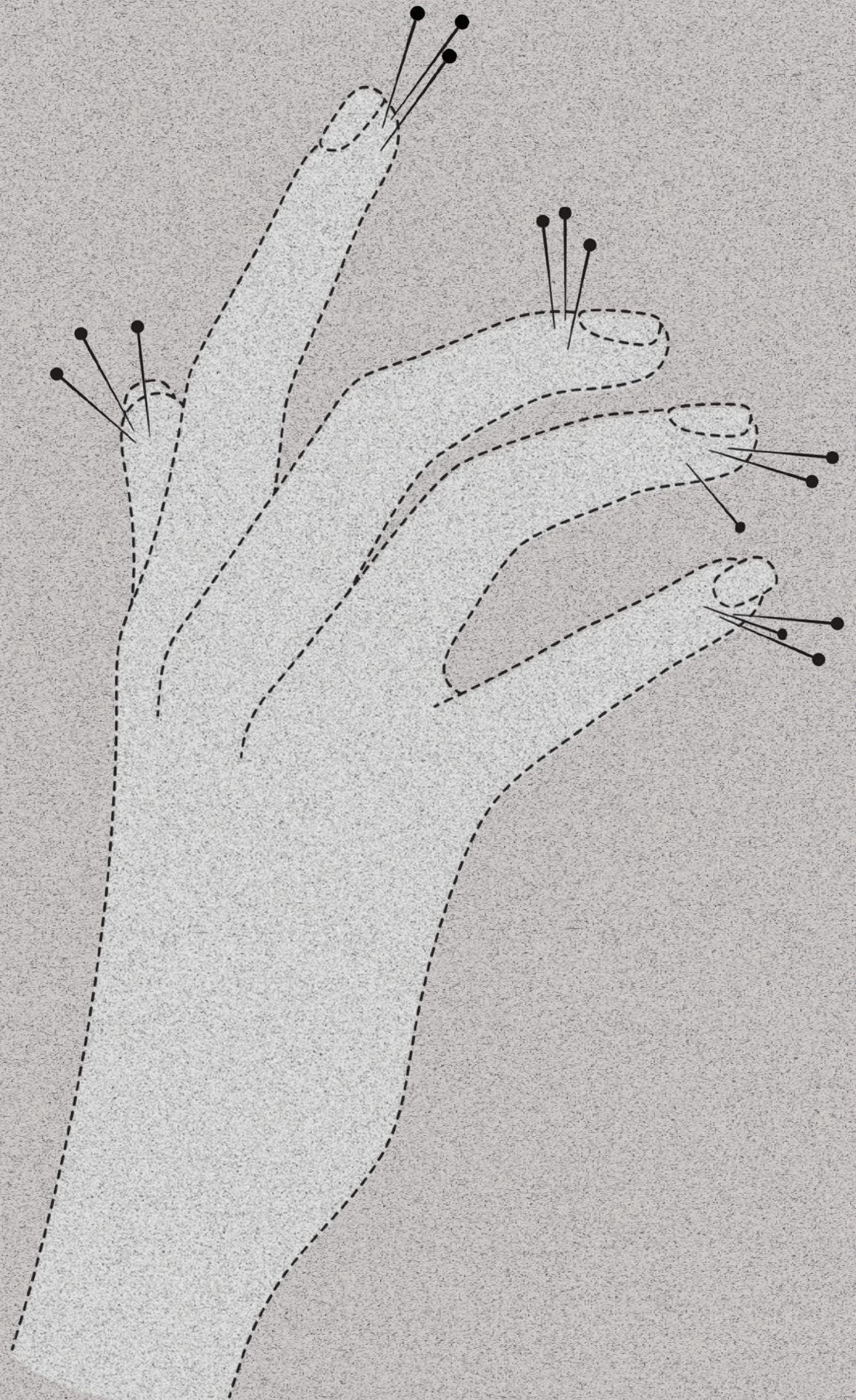
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The INVISIBLE Side Effect

Although there is little relief available to cancer survivors experiencing neuropathy, hope may be on the horizon.

By LINDSAY MODGLIN

Megan McKinney-Dyson was shocked when she received a diagnosis of stage 3b colon cancer in 2021. She was just 42 years old and the mother of two young boys. After undergoing surgery and six months of chemotherapy, she is now cancer-free.

However, the treatment left her with neuropathy, which, according to the American Cancer Society, is a condition that causes pain, numbness and tingling in the hands and feet.

Although her doctor warned her that neuropathy was a potential side effect of her treatment, she wasn't fully prepared for long-term pain and discomfort. "Neuropathy is the biggest thing that I still have to this day," McKinney-Dyson says. "It's like constant pins and needles. It's very painful."

She tried medication, but it didn't provide the relief she was seeking. In addition, "I didn't like the side effects of the medicine because it made me really tired," she says. So McKinney-Dyson turned to alternative treatments such as occupational and physical therapy. »



MEGAN MCKINNEY-DYSON has had to change the way she does daily tasks due to pain caused by neuropathy.

The gap in survivorship research means that patients such as McKinney-Dyson often have difficulty getting the care they need after finishing treatment. “The growing numbers of cancer survivors are outstripping the capacity of cancer care systems to keep pace with demand,” Dr. Aisha Ahmed, an oncologist at Arizona Oncology in Tucson, says.

“Primary care physicians may not be adequately prepared to care for these survivors due to perceived knowledge gaps about the individualized needs, risks and surveillance plans for cancer survivors,” Ahmed says. This is especially true for patients who are living with long-term side effects of their treatment.

WHY NEUROPATHY HAPPENS

Cancer treatment often involves powerful drugs that can damage the nerves, resulting in chemotherapy-induced peripheral neuropathy (CIPN). Although any type of cancer treatment can cause neuropathy, some drugs are more likely to cause the condition.

“Certain types of chemotherapy drugs are neurotoxic,” says Dr. Kord Kober, an associate professor of physiological

nursing at the University of California, San Francisco.

“Unfortunately, two of the most common types of neurotoxic chemotherapies, platinum and taxane compounds, are used to treat some of the most common cancers — breast, gastrointestinal, lung, gynecologic.”

The condition can develop during treatment and persist long after treatment has ended. “Due to the lack of prospective longitudinal studies that have evaluated the onset and persistence of CIPN, we do not know the recovery rates for CIPN,” Kober says.

For McKinney-Dyson, the neuropathy affects the way she uses her hands and feet. “For the longest time I couldn’t explain (the sensation),” she says. She describes it as “the worst feeling you’ve ever felt, for something you can’t feel,” meaning that she experiences the sensation of pain even though no physical stimuli are causing it.

McKinney-Dyson, who is an elementary school teacher, has had to adjust the way she does her job. Tying shoes, zipping jackets, buttoning clothes and even writing can be extremely painful. “I have to take more frequent breaks when I’m writing,” she says. Typing is



JESSICA UNDERWOOD

also difficult, and she often relies on her husband's help with many daily tasks.

CIPN is a relatively new field of study, and there is still much unknown about the condition. Kober works to increase awareness and understanding of CIPN to improve patient outcomes. Results of a study he co-authored and is published in the *Journal of Pain and Symptom Management*, which focused on paclitaxel-induced peripheral neuropathy in cancer survivors, found that patients treated with paclitaxel chemotherapy had more problems with balance, the function of their upper extremities and more severe symptoms than patients who

were not treated with the drug.

Results of the study also showed

that those treated with paclitaxel had reduced quality of life scores in both physical and psychological domains. Another study published in the *Journal of Pain and Symptom Management* found that body mass index may be a modifiable risk factor for the severity of chemotherapy-induced neuropathy. Research results show that survivors with a higher body mass index had more severe symptoms of neuropathy. This finding is significant because it suggests there may be ways to mitigate the severity of the condition with lifestyle and diet changes.

YEARS LATER

Mark Kantrowitz, a survivor of stage 3 testicular seminoma and author of "Tumor Humor: Cancer Jokes and Anecdotes," has CIPN, even though it has been nearly two decades since his treatment ended.

After performing a self-exam at home in 2003 at the age of 36, Kantrowitz found a lump on his testicle. His

doctor scheduled an ultrasound for two weeks later, and the results confirmed that the mass was cancerous. Kantrowitz began treatment immediately. He underwent orchiectomy surgery to remove his testicles and three cycles of chemotherapy and was treated with a combination of bleomycin, etoposide and cisplatin. He credits his research skills for helping him understand his diagnosis and treatment options throughout the process.

Aside from his long-term CIPN, Kantrowitz experienced many rare side effects and complications, including

chemo-induced pancreatitis and gallstones, high-pitch hearing loss, Raynaud's phenomenon (decreased blood flow in the fingers) and diabetes.

The neuropathy has caused him to experience numbness and tingling in his hands and feet, as well as muscle weakness. His symptoms are very noticeable when he walks, and he uses a cane to get around. "In my case, it mostly affected my feet, though occasionally it would affect the first three fingers on each hand," he says.

"It's like wearing a pair of gloves on my feet,"

Kantrowitz says of the sensation. "At the same time, »

For the longest time I couldn't explain (the sensation). It's the worst feeling you've ever felt, for something you can't feel.

—MEGAN MCKINNEY-DYSON



As a school teacher, **MCKINNEY-DYSON** has had to adjust the way she does her job due to neuropathy. Simply writing can be extremely painful and she has to take frequent breaks.



It's like wearing a pair of gloves on my feet. At the same time there is a burning sensation, sometimes really severe.

— MARK KANTROWITZ

« Although neuropathy impacts KANTROWITZ's daily life and there is nothing to help, he would not have done anything differently during treatment.

there is a burning and tingling sensation, sometimes really severe.” He describes the feeling as being similar to when the foot falls asleep and then begins to wake up. “Multiply that by 10 and that’s the sensation of neuropathy I experience,” he says.

According to research published by the American Society of Clinical Oncology (ASCO), the effects of CIPN can last for years. Of 986 respondents to a 2020 ASCO survey, 77% reported current symptoms of CIPN, with the average respondent being more than three years post treatment.

LEARNING TO COPE

McKinney-Dyson and Kantrowitz discovered ways to cope with their CIPN. McKinney-Dyson has made changes to her lifestyle and the way she completes everyday tasks. Although she didn’t do well with the medication, six weeks of occupational and physical therapy helped her gain back some of the function she’d lost.

“For patients with cancer who are experiencing CIPN following treatment, there are some prescription medications that can be used to improve symptoms. One of them is duloxetine,” Ahmed says. According to Kober, duloxetine is the only proven treatment for CIPN, but there are limited benefits to taking the medication.

Gabriela Miller, an oncology physiotherapist and owner of ACE Cancer Rehab in Mission, Kansas, works with cancer survivors before, during and after chemotherapy to help them manage treatment side effects such as neuropathy. She recommends patients with CIPN start by working with a physical therapist experienced in cancer-related side effects to help them regain function and strength as soon as possible.

“CIPN is a very real and common side effect following chemotherapy that can have a huge impact on patients’ quality of life,” Miller says. “People who experience neuropathy have decreased sensation and circulation in their feet, which puts them at risk for falling or sustaining

a soft tissue injury. If the foot is injured, they run the risk of not feeling the injury, which can potentially make the wound worse.”

The effect that CIPN has on a patient’s life can be profound, with many risks and dangers that are often overlooked. “Another danger is increased risk of falling since the balance and sensation are impaired. We also see decreased muscle strength in the muscles of the toes, which further increases fall risk,” Miller says.

Miller suggests patients with cancer consult with an oncology physical therapist as early as possible — even before treatment starts. “This way, we can detect and manage symptoms of neuropathy and educate the person on what to look for and how to improve their sensation and balance,” she says. She emphasizes that exercises to improve circulation and sensation, as well as balance training, are important components of therapy. Learning how to manage symptoms and risks prevent falls or other injuries associated with this neuropathy.

Kantrowitz, who did not take medication for his CIPN symptoms, found that there is no one-size-fits-all solution. Although he also has issues with daily tasks such as typing, he relies on proofreading software and spelling algorithms to help him. When asked what lifestyle changes have helped alleviate his symptoms, Kantrowitz says, “Nothing really helps.”

Despite that, having a positive attitude and high pain tolerance have boosted him through some of the darkest days. “I’ve learned that I can work through the pain,” he says. “I have a constant burning sensation in my feet 24/7.” He frequently uses distraction techniques to take his mind off the discomfort. He’s learned that his mind is a powerful tool for overcoming many obstacles, including neuropathy. “If I don’t focus on it, I can ignore it,” he says.

Kantrowitz and McKinney-Dyson both agree that the lifesaving treatment was worth the side effects.

“In my cancer joke book, ‘Tumor Humor,’ I joke that it’s better to be alive with side effects than dead without,” Kantrowitz says. “I still would have had the same treatment. There really isn’t anything I could have done differently.”

There is much to learn about CIPN and scientists are working hard to find new ways to prevent and treat the side effect. Ahmed and Kober are hopeful that new medications and treatments will be developed to help those with this debilitating condition. Several ongoing clinical trials are testing new and advanced therapies.

“In terms of pharmacology, there are numerous clinical trials under way to evaluate for drug therapeutics to prevent and treat CIPN,” Kober says. Scrambler therapy is

one of the pain management techniques being studied. It uses electrical stimulation to “scramble” the pain signals being sent from the nerves to the brain. Although the study is still in the early phase, Ahmed is optimistic about the treatment’s potential.

“Scrambler therapy is an emerging treatment approach that appears to benefit some affected patients with CIPN,” she says. “Small studies have suggested that scrambler therapy can reduce chemotherapy-induced neuropathy symptoms, even if symptoms have been present for more than one year.”

It’s a small ray of hope and something that patients such as McKinney-Dyson and Kantrowitz can hold on to. Kantrowitz recommends other survivors speak to their doctor about any side effects they may be experiencing, even years after treatment has ended. [h](#)



» **KANTROWITZ** says he had to learn different distraction mechanisms to get through the pain caused by neuropathy.

I'M A SURVIVOR ... *What Now?*



Although much has changed in the past two decades, more needs to be done to prepare cancer survivors for what happens after their treatments end. *By COLLEEN MORETTI*



GWEN GOODMAN

GWEN GOODMAN IS a survivor of stage 4 Hodgkin lymphoma. She was shocked when, years after her treatment, she wasn't taken seriously at the doctors when complaining about symptoms she was experiencing. She had never been told she might have long-term side effects after her treatment was finished.

"All of a sudden when you're cured it's like, 'OK, you're good.' ... I felt like nobody was listening to me anymore," she said in an interview with *Heal*®.

NO ONE'S TALKING OR LISTENING

Goodman, was 22 when she received her Hodgkin lymphoma diagnosis. Then 13 years after she had finished her cancer treatment at the age of 35 she started noticing side effects. She began to experience

neuropathy, a common side effect in cancer survivors that can cause weakness, numbness and pain from nerve damage, usually in the hands and feet. It once became so painful she went to the emergency department where a doctor told her: "You don't have neuropathy; you don't have diabetes." She left crying.

"It's frustrating because you are looked at as a pill seeker or a hypochondriac. But being in that situation at such a very young age, every little bump, every little everything is scary, and you have to find a doctor who really listens to you," she said.

Today, more research is available and physicians are more knowledgeable about what happens after someone has survived cancer.

"I think what we didn't know (20 years ago) is the extent and prevalence of long-term and late effects in the growing population of cancer survivors — and how to prevent and mitigate those," Julia Rowland,

senior strategic adviser for Smith Center for Healing and the Arts in Washington, D.C., said in an interview with *Heal*[®].

In 1996, the National Cancer Institute created the Office of Cancer Survivorship with Rowland joining in 1999 as its first full-time director. She said the focus on cancer survivorship was just beginning.

"I think people were beginning to recognize (cancer survivorship) in a growing fashion that just because treatments are over, it doesn't mean the experience was over," she said.

But there were challenges that remained and some cancer survivors, such as Goodman, experienced this struggle and lack of understanding. There was still a lack of focus on late-term effects and consequences of cancer treatment, as Rowland said. And often patients weren't told about the post-treatment side effects they might experience. All that was really done was scheduling follow-up visits to make sure the cancer didn't come back, Rowland explained.

"We weren't even beginning to talk to anybody about what happens next," Rowland said. "So we allowed people to finish their treatment and it was kind of a pat on the back and a 'Good luck, have a good life.' ... People were kind of pushed out the door and many of them felt abandoned."

THE POWER OF ADVOCACY

Goodman remembers feeling this way. She felt alone and that no one was listening to her.

"Yes, absolutely I had to advocate for myself," she recalled.

She is not the only patient who has had to advocate for themselves after cancer in the past 20 years. The good news is that survivors are starting to advocate for patients and other survivors. Goodman's mother is going through her second journey with breast cancer, and an advocate came in and talked to her about what they went through. It was the kind of connection Goodman would have benefited from 20 years ago.

"I think that's good for somebody to know somebody else has gone through it. That's an awesome program some (care facilities) have," she said.

Rowland agreed and reflected on "the power of advocates" who have spoken up and "pounded" on the doors of oncologists and Congress, demanding to

receive what patients and survivors need.

"These are real lives that are affected and there's nothing that is more compelling than listening to people tell their stories," Rowland added. "And I think that will continue to be the way that we see changes, people talking about that lived experience and how we can

make this better."

That is all Goodman wants: someone to listen and make a change. However, she still sees roadblocks.

A WAYS TO GO

As her mother goes through her cancer journey, Goodman sees a lack of preparation for when treatment is complete.

"My mom, she's going through her second battle with breast cancer, and she's

had a double mastectomy. And I've not seen anything for the future to help her," she explained. "Once (cancer treatment) is over there needs to be something that prepares them, and I just don't see it right now."


Goodman would like to see a program that brings doctors and cancer survivors together so the experts can understand what survivors are going through after treatment and better prepare their patients in active treatment. She hopes people aren't pushed out the door anymore, as she was and as Rowland also described.

"There is a lot more support (now), but it just needs to be talked about before they need that support. That's my goal — to not have everybody pushed out the door like, 'OK you're good, you're cured,'" she said.

Rowland agrees that although the work for cancer survivorship has been significant and beneficial over the past 20 years, more must be done. Areas she said still need to be addressed include psychological well-being, health promotion, financial toxicity and the effects on caregivers.

As there are a growing number of cancer survivors, there are a growing number of issues they encounter, and it is important that over the next 20 years those are focused on, Rowland said.

"The biggest testament to our war against cancer ... is the growing number of survivors," she explained. "We're finding cancer earlier, we're treating it more effectively, we're supporting people to live longer. And that's what on Wall Street they call a 'high-end problem.'"

"It's great there are more survivors, but it's a challenge because they are in the system and we need to be taking better care of them," Rowland concluded. 

“All of a sudden when you're cured it's like, 'OK, you're good.' ... I felt like nobody was listening to me anymore.”

—GWEN GOODMAN



Survivors May Be the *Best Advocates*

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The best advocate for a patient with cancer is someone who knows exactly what they're going through, noted a multiple myeloma survivor. By COLLEEN MORETTI



⚡ BRYON DAILY

BRYON DAILY CONSIDERS

himself fortunate because he did not have many financial issues during his treatment journey and he made an excellent recovery. But, he knows many people don't have the same experience, which is why he has become an advocate for patients with cancer.

Daily received a diagnosis of multiple myeloma in 2018 after he

fractured his finger during a basketball game and it didn't heal for weeks. Daily underwent several months of chemotherapy that led to an autologous bone marrow transplant. Today he still takes some therapeutic medications, which are covered by insurance.

"I consider myself to be very fortunate because it wasn't a catastrophe financially for me," he said.

Additionally, he healed well in remission thanks to taking care of his body and staying active, which he encourages patients and survivors to do.

"I think that was a testament to just making sure that as you get older, you stay active," he added. "Be aware of your body. (When it's) in pain, don't hesitate to go to the doctor and get it checked out. I'm a big believer in self-advocating."

Daily uses his belief in self-advocacy in his current role as the Community Outreach Manager for the Leukemia & Lymphoma Society. In his role, he advises other patients to advocate for themselves — especially those who may not be as fortunate.


He helps guide patients through financial hardships and leads them to resources through his organization and others. He realizes his journey may have been different because he had his wife, along with his three grown children supporting him.

"For me, the personal journey was sort of an existential experience. As you get older and start reflecting back on things you've done, on what could have led up to this, you start thinking about mortality and look around at other people and start comparing it. ... You look at life through a different lens — (we) all have our own experience," he explained.

Daily feels his experience can help others and believes that sometimes the best advocate for a patient is someone who knows exactly what they're going through.

"It can be scary for some people; they don't know what to expect, they don't understand how they respond to various drugs. I mean they might not have the kind of support that I had. ... I feel that I can contribute my story, my experience, to help other people," he said.

A cancer survivor may feel healthy and ready to move on with their life, but they often remember what they have gone through and how hard it was. Daily said survivors can help others who are in the middle of their cancer journey by providing hope or just being a friend who understands.

"I would recommend (that cancer survivors) find an organization where they can volunteer," Daily concluded. "It doesn't even have to be related to your disease, it just has to be somewhere you can give back. It's really kind of a selfish activity because it makes you feel good that you were able to do this, but it also helps other people." 

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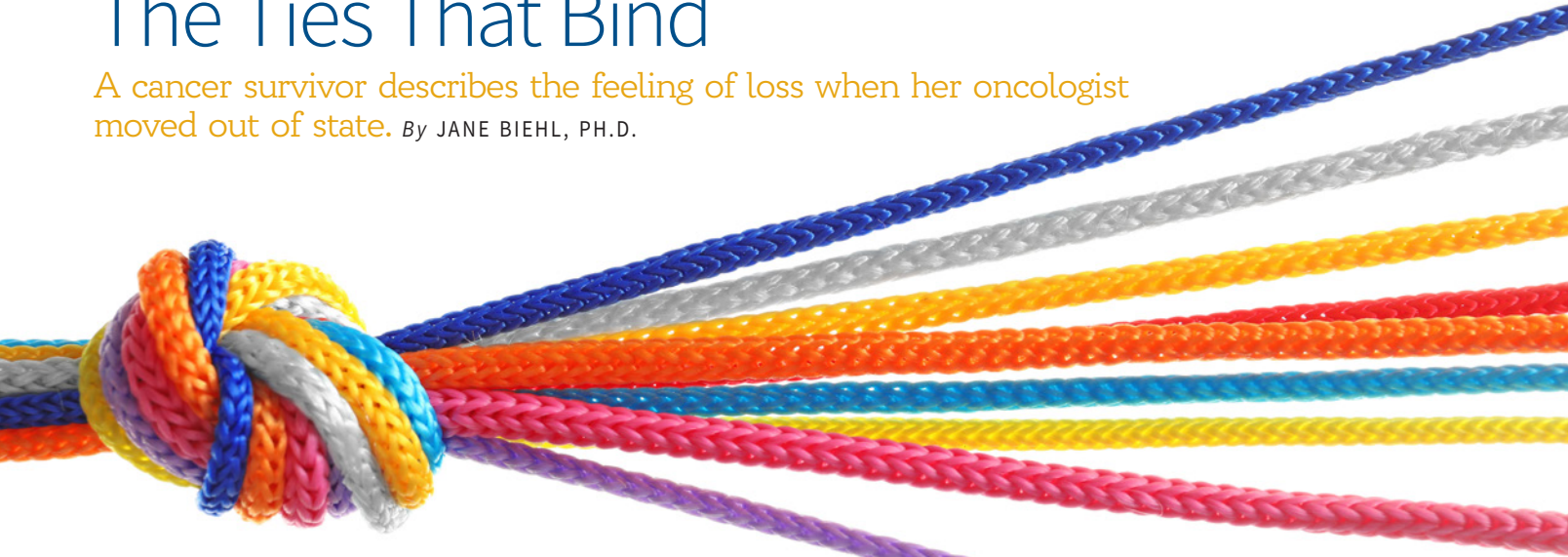
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The Ties That Bind

A cancer survivor describes the feeling of loss when her oncologist moved out of state. By JANE BIEHL, PH.D.



THE RELATIONSHIP BETWEEN an oncologist and patient is different from any other partnership, even with another doctor. As patients, when we begin this journey we are the most vulnerable we have ever felt in our lives. We are reeling from receiving a diagnosis of a disease that may be fatal.

We depend on our oncologist for treatment plans very different from those of a surgeon performing routine surgery or a family doctor prescribing antibiotics. We accept treatments that make us sicker, including surgery, chemotherapy and radiation and intravenous medications.

We feel as though we are on a roller coaster. We rejoice with the doctor when we beat cancer, whether for the short or long term. We commiserate with the doctor if it comes back or gets worse. We run to our

oncologist when there is a new problem because we are scared. They are the most important person in our lives because our living longer depends on them.

They see our vulnerabilities and frequently see our tears. We are fortunate to have many others on our team — the oncology nurses are angels to us. But the oncologist is our quarterback. They become our mentor, our friend and our beacon in the lighthouse in this unique partnership.

I was fortunate to have Dr. Shruti Trehan as my oncologist for more than 11 years. She was all of the above to me. I saw her every month and we learned a lot about each other. We shared a love of writing and she talked to me about spirituality several times.

When my beloved service dog passed away, she immediately called to tell me the dog was watching over me. She had shared with me a few months before that she had dreamed my 17-year-old dog did not have long on this earth. I was astounded when I thought of her hundreds of patients and how

she dreamed about my canine partner.

I asked her one time how she handles it when patients die. She told me that she gathers her faith and spirituality to help the next one.

I told many people that I wanted to be like her when I grow up! Other doctors in the medical community shared with me that she is not only a great doctor but a wonderful person.

When she reluctantly told me that she was leaving her practice to move to a warmer climate, I felt the room spin. I had lost a doctor, a confidante, a friend and a lifesaver. I am convinced I wouldn't have lived this long with incurable cancer if I had not had her.

I summoned up the strength to tell her she needed to do what was best for her. And she does need this — she and her husband wanted to start a new life and she said now was the time.

Of course, she had my back as always. She referred me to the Cleveland Clinic an hour away with another wonderful physician who specializes in myelodysplastic syndromes. She said it was time for me to do this anyway since the variants are getting worse. But I no longer have her to call, answer questions and watch over me.

I think all of us feel abandoned somewhat when we have to replace our oncologist, whether due to a move or change of circumstances, and other cancer survivors have expressed these same emotions to me. But a piece of Dr. Trehan will always be with me. She was with me during the darkest of times and the happiest of times. She will spiritually always be with me even though she is many miles away.

Godspeed, Dr. Trehan ... you will save many more lives in your next phase of life and will always be remembered by those you have helped before. **h**



JANE BIEHL, PH.D.

Now That I'm **CANCER FREE**, Should I Be Doing More?

One cancer survivor's disease has been under control for a few years now, and in his moments of free time, he starts to feel guilty for lacking the drive to take on more.

By STEVE RUBIN

I HAD ALWAYS been a type-A personality with a clear plan of how to spend my time chasing life goals.

But when I was 30 years old, I was engaged to the woman I loved, building a successful executive search career in New York City, hitting my prime — and I received a diagnosis of osteosarcoma, a rare and aggressive bone cancer. Next came treatment, surgeries and multiple recurrences after a few attempted returns to work. The tumor started in my right femur and spread to both lungs multiple times, as well as my left hip, ultimately leading to my oncologist informing me that I had a less than 10% survival rate.

I spent the next few years frantically researching out-of-the-box healing methods and educating myself on holistic health. Thanks to luck and fierce discipline and commitment, I was able to turn my situation around and defy the odds.

It's been almost three years of clear scans and I continue to prioritize my health while coping with arthritis and all the trauma you might imagine after five-plus years of living in constant survival mode. Although I never take my incredible fortune of still being alive for granted, being isolated on medical leave has been difficult. In my mid-30s and no longer working on a day-to-day basis, I feel ungrounded at times, especially compared with my peers.

When catching up with friends and family, I sometimes find myself feeling defensive as I tell them about the latest news on my end, mainly because there's not that much. I keep up with my regimens and routines and do everything I can to give myself the best chance of continued clear scans. Back when

I was bald from chemotherapy and receiving treatment at the hospital, my relationships had a different vibe: my condition was better understood, unquestioned. Now

during the occasional pocket of free time, I find myself plagued with guilt for not having the courage or drive to take on more in life.

I shared these feelings with a therapist, checking in to see if maybe I was holding myself back. Was I just being cowardly?

She calmed me down by comparing my circumstances to someone rehabilitating on crutches after an accident. You wouldn't ask them to run a marathon right away; it takes time to build back stamina and strength, and she reminded me how much I've been through with my cancer.

It felt nice to be validated. Being alone at home for years, I've lost that sense of objectivity. I have been working through my issues, trying to reach a place where I feel comfortable taking on more, but at my own pace. After multiple recurrences, I'm extremely cautious about pushing my nervous system too hard. Fighting cancer teaches you that *you're* the one who deals with the consequences — not the well-intentioned doctor, colleague or friend.

There always will be pressure from society to stay productive, to have goals and achievements readily available to share. But for now I am comforted by the reminder that everything I'm doing is not only acceptable, it's actually really important for my body, mind and spirit to recover and rebuild.

When the moment feels right, I'll make the proper adjustments, just as I have every step of the way so far — taking it one day at a time. **H**



STEVE RUBIN

Being the 'Patient' Patient

Taking it one moment at a time helps one survivor tackle anxiety at follow-up appointments during survivorship. By BONNIE ANNIS

IN THE PARKING lot outside the cancer treatment center, I took a deep breath. In just a few minutes I'd be meeting with the survivorship team. This was the

sixth year since I received my breast cancer diagnosis. The annual visits had become almost routine.

Inside the facility, it felt as though a heavy weight pressed down on my shoulders. As I looked around, my eyes found men and women in various stages of their own cancer journeys. I felt so out of place. I wasn't wearing a wrap on my head; I had a full head of hair. I wasn't hooked up to oxygen or wearing an embedded port. For all intents and purposes, I was healthy and I looked normal. Other than the fact that I was here and I had no breasts, no one would ever know I had breast cancer.

I rode the elevator to the third floor, found a seat in the waiting room and began the routine wait. I was a "patient" patient. I'd brought a book to read. I was prepared for the inevitable wait.

After 30 minutes, I was called back to the exam room. Vitals were taken by a competent nurse and then the doctor tapped lightly on the door. When she came in, I was greeted with a robust smile and a hearty handshake. "How are you doing?" she asked, and I could tell by her exuberance that she was truly interested in my answer.

I told her how I was feeling, both physically and emotionally. When she asked if I was having any problems, I shrugged my shoulders and said, "The only thing I think is bothersome is the fact that I have a hard time sleeping." I knew it was going to open a can of worms even before I said it, but **»**



BONNIE ANNIS

“ I was a ‘patient’ patient but I was also a thriving survivor. I plan to live my life and live it well until next year’s appointment, then the routine will start all over again. —**BONNIE ANNIS** ”

I said it anyway. After a little digging, the doctor surmised I was dealing with past fears associated with pain from surgery — the uncomfortable feelings from remembering how I felt had transferred into my nighttime routine. She said I associated my bed with the memory of my initial diagnosis and surgery, but she assured me she could help. She offered a sleeping pill to help temporarily but I declined. I preferred natural options, I explained. She smiled and said she completely understood. She shared several herbal options, and I was thankful.

When she was satisfied that I was otherwise doing OK, she said goodbye and her staff ushered me toward the lab for blood work.

The lab visit was uncomplicated. I was in and out quickly and was told to head over to the oncology department. As soon as my labs came back, they would send them over to the doctor, who would review them with me.

Once again, I sat and waited. This time, the wait was much longer. I was surprised to find so many people waiting to see the oncologist on a Tuesday. Usually Mondays and Fridays were the busiest days. I pulled out my book and tried to focus but kept reading the same line over and over again as I listened to snippets of conversations from those around me.

The woman next to me was in the final stages of cancer. In a wheelchair, she huddled underneath a blanket as her husband tended to her needs. My heart went out to her and I felt guilty. She was so ill and I was not.

More than an hour later, I was called for my appointment. Walking down the hall with the nurse, I tried to smile as she made small talk. I hadn’t realized how nervous I’d been until that moment. Either the lab work would be good or it would be bad. There was no middle ground and I was concerned, although I hoped for no recurrence the possibility was still there.

In the exam room, I was told the wait could be long. A nurse explained the doctor was running behind due to unforeseen circumstances. Once again, I was the “patient” patient. I smiled and said, “No problem, I completely understand.” And I did.

Another 30 minutes passed before I heard a slight rap on the door. “Come in,” I said as I sat up in the exam chair expecting to see my doctor. Instead, a nurse practitioner stood before me. She explained the office was packed and it would be at least another hour before the doctor could see me. Asking permission to take my case for the day, the nurse practitioner waited for my answer. I nodded in agreement — after all, I was the “patient” patient.

She sat attentively on a stool in front of a laptop. She asked, “How are things going for you?” I told her, “Everything is going well.” She smiled and made some notations in my online chart.

Paper in hand, the nurse practitioner rolled her chair close to me. *Brace for impact*, I thought, *she’s about to give me the results of the lab work*. I was taken aback when she

put her hand on my arm and said in a jovial tone, “Relax! Everything is good! Your tests came back great.”

Never once did she say, “You’re in remission,” or “You’re cancer free,” or “There’s no evidence of disease,” although I would have liked to have heard those words. I have never heard them since the surgery to remove the tumor.

She handed me a copy of a comparative chart for my last three blood draws. I could clearly see a reduction in the numbers for my tumor markers. The reality of that fact felt good.

When she completed the physical exam, she asked if I was OK with not seeing the doctor. I assured her I was, thanked her for her time and walked toward the exit.

When I exited the building, I exhaled. I didn’t realize it, but I’d been holding my breath. An invisible weight lifted, and I thought, “Another year down, and I’m still alive.”

I was determined to look forward. I didn’t want to turn around and look at the cancer treatment center. I’d just received good news, and nothing was going to rob me of that blessing.

There was no need to announce it to the world. There was no need for a survivorship party. But if I’d had the opportunity, I would have walked back into the building and issued a pep talk to all the men and women who were waiting to see the doctor. I would have told them that there is hope and, although we’re all battle worn and weary, we’re all survivors. Whether it’s for the next second, the next minute or the next decade, we survive because we choose to do so.

No red circles marked upcoming appointments on my calendar. I was free, free to be me, the me I’ve always been, the same person I was before, during and now after cancer. I was a “patient” patient but I was also a thriving survivor. I plan to live my life and live it well until next year’s appointment and then the routine will start all over again. ■

THE WAITING GAME:

One mother is haunted by the fact that her daughter's cancer could return and uproot their lives again. *BY DEBBIE LEGAULT*

WE'VE BEEN ASKED to wait a lot in the past two years. Wait to celebrate or to say goodbye. Wait to enter a store or a restaurant. Wait to travel to see loved ones or just to have fun. Wait to see the dentist or the optometrist. Wait to hold that new grandbaby for the first time.

For most of us, it has been an up-and-down rollercoaster of waiting and hoping for the best.

I would happily live the rest of my life experiencing this type of waiting if it meant I would never have to wait to hear the results of tests for recurrence of my daughter's cancer ever again.

When my daughter received her diagnosis of breast cancer at age 27, I had an idea what her next year would look like, but the reality was much worse than I could have anticipated. Now I know what life would be like for her if it came back.

It's a special kind of purgatory, the days or weeks waiting for results when she goes for screening. Because her cancer was regional and not metastatic, she went into treatment with a good chance that her cancer would respond, and the medical team threw everything they had at it.

After three surgeries, months of chemotherapy and targeted hormonal therapy, and six weeks of radiation, grateful is a totally inadequate word to describe how I feel about her walking away with no evidence of disease (NED). But

that is today. She is NED, only for *today*. Every year for the rest of her life they will run tests to see if today has become a woeful tomorrow.

The scariest thing about my daughter's cancer is that if it comes back, she might not be lucky enough to find the lump like she did the first time — it may have recurred else-

where. The initial lump was close to the surface of her breast rather than hiding somewhere deeper where it would be more difficult to distinguish from normal breast tissue. She found it relatively easily while doing a shower exam.

The symptoms of metastatic breast cancer are not always different than those of early-stage breast cancer, which is what she had. And sometimes there are no symptoms at all. At the end of treatment, when I asked her medical oncologist about what she should look for going forward, he just said, "She'll know because it will be different." I looked at him and said, "Well, that's pretty disheartening." And he had to agree.

My daughter has annual MRIs to check for local recurrence, but as of now there is no test to see if it has traveled to another area of her body. So she has to wait for symptoms that tell them what to test for. That means that every ache, every itch, every odd thing that happens could be her body telling her that the



DEBBIE LEGAULT




woeful tomorrow has come. She can go weeks at a time with cancer swept into the corner of the room, time when she forgets just a little bit and lives her life. But unlike a lot of us who can joke about a headache meaning a brain tumor, in her case it might actually be one.

We don't tell that joke anymore, by the way.

There are many things about my daughter's cancer experience that I hate. The helplessness. The fear. The unfairness of it all. But I think the thing I hate the most is the waiting game that we will be living for the rest of our lives.

I practice radical acceptance, which means I have accepted that this is the future but it doesn't mean that I have to make friends with it. And since practice makes perfect, when we're waiting for test results I have to work at it just a little bit harder and repeat this mantra a lot more forcefully:

"She doesn't have cancer today. And that makes it a wonderful world." 

Too Close to Home

A pancreatic cancer survivor explains why hearing the news that someone else has cancer makes it difficult for him to engage in the conversation. *By WILLIAM RAMSHAW*

PUSHING ASIDE HIS menu, my friend grabbed his phone from the table and said, “It’s my wife. I need to take this.”



WILLIAM RAMSHAW

Hearing only half the conversation, I could tell something awful had happened.

Before hanging up he said, “Love you, sweetie! We’ll talk more later.”

My friend (I’m calling him Tim) and I had just sat down for lunch, something we have done every month for years. He is the kind of friend every cancer survivor longs to have.

After I received my diagnosis of pancreatic cancer nine years ago, Tim walked with me through some sunless valleys, never once failing to come alongside me and offer much-needed encouragement. Always understanding, he endured my stories about my journey. Although I tried not to burden him with too many details about the vulgarities of cancer, I’m sure I crossed the “too much information” line far too often.

As he placed his phone back on the table, he had a distant look in

his eyes. One of those “I’m here but not here” looks.

Tim and I have always been candid with each other, holding nothing back. So I asked, “What’s going on?”

Shaking his head, he said, “Our next-door neighbor Amy just was told she has stage 4 lung cancer. It has spread to her spine and brain.”

I said the only thing I could: “I’m sorry.”

Having been through the cancer gauntlet myself, I sometimes fail to remember how terrifying getting cancer news can be, even news about a friend.

For most people, until they are told they would be joining the cancer club they likely had little idea what all of it meant. Previously, each day as the light peeped through their bedroom window, their alarm clock roused them out of their slumber. Knowing they had to get to work, they rolled out of bed, brushed their teeth and maybe shaved, let the shower warm up, jumped in, soaped down, rinsed off, then jumped out, dried off, got dressed and ate something before darting out the door. Just another day among the thousands before it, they thought.

Then things changed. A nurse calls from their doctor’s office saying, “Can you give us a call? It’s urgent.” Maybe it is to review their recent labs results? The C-word is not on their minds. Soon it will be all they can think about.

All too quickly they find themselves sitting in another

doctor’s office they had walked or driven by countless times. They previously had wondered what “oncology clinic” meant. One time they Googled it and found out it was code for cancer. Like most people, they probably put it out of their minds. They never considered they would soon be there, sitting in a waiting room and tapping their foot, glancing at the time, wondering when they would be called back to an exam room to find out how bad it was — hoping something can be done, anything.

What Tim and I talked about over lunch is a blur. I could tell his neighbor’s cancer news had crushed him much like an earthquake flattens buildings.

Later that evening I thought about our lunch and wondered why we didn’t talk more about his neighbor or how Tim was feeling. I suppose I couldn’t face it any more than Tim could. It seems devastating news such as this always takes our words away.

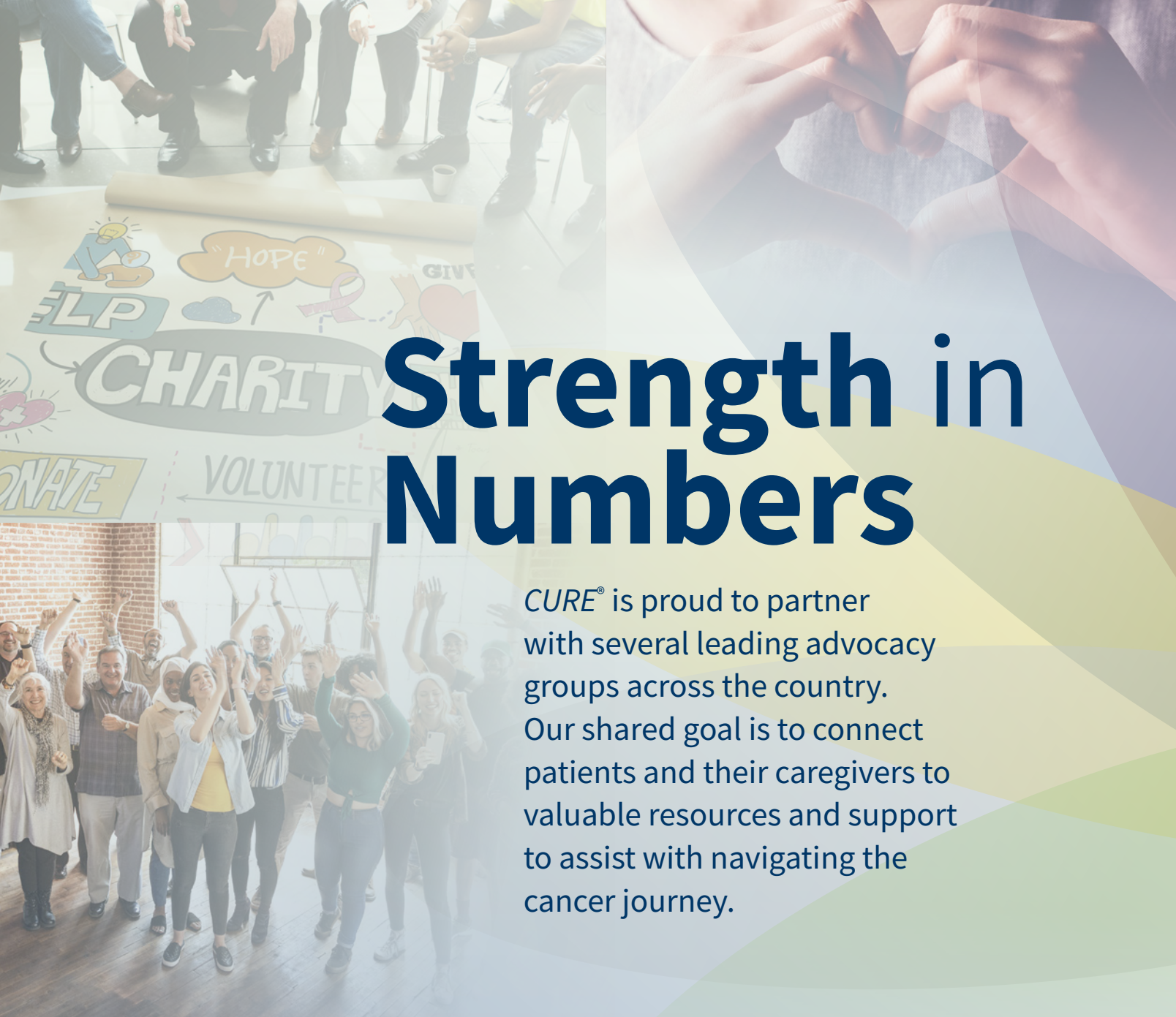
In between bites of food, I had found myself flashing back to my own cancer news as though it happened last week.

I underwent a brutal surgery to extract my pancreatic tumor, followed by weeks of radiation and then months of chemotherapy. Nothing I care to remember.

I suppose this is why we didn’t talk more about Tim’s neighbor’s news. This all seemed too close to home, my home. **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](https://www.facebook.com/curemagazine). Submissions should be no more than 600 words and include your name, phone number and email.



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Keep Calm and Meditate

How mindfulness meditation can help ease stress and anxiety in cancer survivors, and where to start. By COLLEEN MORETTI

MANY CANCER SURVIVORS may think the stress and anxiety are cured along with the disease, but that is not always the case. Stress, anxiety and pain can remain after cancer treatment has ended but practicing daily meditation may help.

Meditation is a mind-body complementary therapy that research has shown improves mood and sleep, in addition

to helping with anxiety and pain. These are side effects that cancer survivors commonly encounter as a result of their disease and treatment. So how can meditation help and how to start?

Erin O'Carroll Bantum, a clinical health psychologist at the University of Hawaii Cancer Center spoke with *Heal*® about meditation.

WHAT IS MEDITATION AND HOW CAN IT HELP?

There are many different types of meditation, Bantum explained, but she primarily focuses on mindfulness meditation for cancer survivors.

Mindfulness meditation allows someone to notice their racing thoughts and sensations in their body, and

A Step-By-Step Guide to START MEDITATING

Bantum explained that meditation can be overwhelming at first. When sitting down and trying not to think of anything, often everything then comes to mind. But if a cancer survivor would like to try meditation, she recommends following these steps:



1

Find a quiet space without distractions to practice.

2

Sit in a comfortable position that allows you to be alert but also relaxed and upright.

3

Rest your arms on your legs or on the arms of a chair — somewhere they are comfortable.

4

Lightly close your eyes.

5

Breathe in through your nose, expanding your belly with air and releasing through your nose. Perhaps let a few long inhales out through your mouth, as well.

6

Finally, be with the thoughts that come to mind but do not attach to them. Focus on breathing and try to simply notice whatever is the feeling you experience, in the moment.

oftentimes, in simply noticing, the body and mind can calm. Bantum described mindfulness meditation as “paying attention to what is,” noticing experiences and being with them but not attaching to them.

As previously mentioned, research has demonstrated that mindfulness meditation can improve things such as pain, how pain is perceived, anxiety and stress. And current research is evaluating if it also can improve neuropathy — a common side effect in cancer survivors.

“I like to think of it as more of an umbrella intervention,” she explained. “There are going to be specific side or late effects that we will want to impact (with meditation) that are bothersome to people. But the general practice is to really look at our overall experience. ... As we do that and extend that into our everyday life, it becomes relevant in interactions with others (and) it can improve

our function and social interactions.”

Bantum added that many cancer survivors who come to her looking for a new approach to ease what they are going through often feel isolated. They may feel lost after treatment is over and that others don’t understand what they are going through. Meditation has been shown to improve mood, so this might be helpful for cancer survivors who are feeling this way, Bantum explained.

“I think building those habits in general ... such as mindfulness meditation ... having those things we can consistently do for our physical and mental health, I think that stability is really grounding when the experience of cancer can be so ungrounding,” she said.

TIPS FOR MEDITATING

Bantum noted that it is important to make a commitment to meditation — she

said the best way to reap the benefits is to practice every day. It is not a long process, she said. A good start would be five to 10 minutes then working up to 20 minutes of mindfulness meditation, either first thing in the morning or right before bed.

“I think sometimes if we expect something unreasonable, in terms of how much time we actually have to devote, we can feel overwhelmed and then we might not practice at all,” she added. “Try to suspend any judgment about the experience for a while. Give yourself a few weeks if you can, and even if it feels like it’s going nowhere, see how it really feels to continue the practice. The best way to know what to keep including in your life is to really feel it out yourself, especially if you can sit through some natural discomfort to see what’s underneath.” **h**

new

Clinical Trial CORNER



Responding to the needs of our readers, we are proud to announce the launch of the new Clinical Trial Corner resource on curetoday.com. There you'll find the latest news on clinical trial availability and enrollments.

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Cool Recipes for a Hot Summer

Check out these nutrient-packed sauces and dips that complement many dishes with their refreshing bursts of flavor. RECIPES by RACHEL WONG, RD, CSO, LD

Fruits and vegetables are rich in antioxidants, vitamins, minerals and fiber, and they offer many protective health benefits to cancer survivors. Summer is a great time of year to find fruits and vegetables in their prime, making recipes even more delicious and nutritious.



Cool Off Chimichurri

Originating in South America, chimichurri typically is used on grilled meat but adds a flavor punch to salads, roasted vegetables, potatoes, rice and sandwiches.

Recipe adapted from feastingathome.com and Bon Appetit

Recipe yields approximately 2 cups.

INGREDIENTS

1 shallot or ¼ cup red onion, finely chopped
1 Fresno chile or red jalapeño, finely chopped (optional)
3 to 4 garlic cloves, thinly sliced
½ cup chopped cilantro
2 tbsp. chopped oregano
¼ to ½ cup chopped flat leaf parsley
2 tbsp. red wine vinegar
3 tbsp. freshly squeezed lime juice
1 tsp. salt plus more for taste
1 tsp. fresh ground pepper
¾ cup extra-virgin olive oil plus more for desired consistency

DIRECTIONS

1. Place shallot (or onion), chile (or jalapeño) and garlic in food processor and chop.
2. Add cilantro, oregano and parsley. Pulse again until mixed in well.
3. Transfer mixture to a medium bowl and add vinegar, lime juice, salt, pepper and ½ cup of the olive oil. Stir. Add in more salt and olive oil until desired consistency and taste.
4. Let mixture sit at least 10 minutes before serving. Chimichurri will keep up to 4 days in a sealed jar in the refrigerator.



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Take It Easy Tahini Dressing

This dressing with Mediterranean flair is great on salads, sandwiches, falafel pita, roasted vegetables and so much more.

Recipe adapted from themediterraneandish.com

INGREDIENTS

- 1 to 2 garlic cloves (peeled and minced or crushed)
- ½ tsp. salt
- ¾ cup tahini paste
- ½ cup freshly squeezed lemon or lime juice
- 1 medium bunch of chopped cilantro or parsley, stems removed
- ¼ cup cold water (more if needed)

DIRECTIONS

1. Add all ingredients except the water to a food processor and blend.
2. Add a little bit of the water at a time and blend until the dressing reaches the desired consistency.
3. Transfer dressing to a serving bowl and enjoy!



Midsummer Mango Guacamole

Guacamole is always a favorite dip for chips, but try it on top of salads and burrito bowls.

Recipe adapted from foodandwine.com

INGREDIENTS

- 1 tbsp. extra-virgin olive oil
- 1 shallot, finely chopped
- 2 dried chipotle chiles, finely crushed, stems discarded
- 1½ cups cherry tomatoes, halved
- ½ cup of finely chopped white onion
- Kosher salt to taste
- 2 diced medium avocados, pitted and skins removed
- 1 serrano chile, minced
- 3 tbsp. fresh lime juice
- ½ cup diced mango
- 1 cup finely chopped cilantro

DIRECTIONS

1. Heat olive oil in a medium skillet. Over medium heat, sauté shallot, crushed chipotle chiles and half of the tomatoes until softened, about 5 minutes. Season with salt. Place aside and allow to cool completely.
2. In a medium bowl, mix together avocados, onion, serrano chile, lime juice and remaining tomatoes. Add the cooled shallot mixture and fold in diced mango and chopped cilantro. Add salt to taste. Serve immediately.



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Step into your strength



The landscape of MPN blood cancers is shifting, with emerging treatments and evolving perceptions that are bringing newfound hope to patients, caregivers, and clinicians. Sole 2 Soul for MPN is an innovative collaboration between Canadian MPN Research Foundation, the MPN Research Foundation, and Cure Media Group and is dedicated to supporting and uplifting the MPN blood cancer community in both Canada and the USA. We empower those who are closely impacted by MPN blood cancers to challenge their inner adventurer while raising funds to fuel change for those who are facing a debilitating incurable blood cancer.

Waterton Lakes National Park August 3-7, 2022

The inaugural trek of Sole 2 Soul for MPN will take place with teams across Canada and the United States trekking through Waterton Lakes National Park in Canada which borders Montana's Glacier National Park. Team members are currently raising funds to fuel research and to amplify the voices of those living with an incurable blood cancer. These life-changing experiences offer participants an opportunity to redefine what's possible during a MPN diagnosis while joining a welcoming team that challenges their personal preconceived limits and widens their circle of support.

For more information
and to get involved,
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