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VOL.10 NO.3 / FALL 2022

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Overcoming **THE FEAR** of Recurrence



FOR SOME CANCER SURVIVORS, the end of treatment is an exciting time and they are ready to get back to their life. But for many, a dark cloud continues to hang over them, as anxiety about potentially having to go through another cancer diagnosis creeps in. One cancer survivor described this time in survivorship as never feeling like she's out of the woods and hesitating to spend money elsewhere in fear that the cancer may come back.

This common anxiety is called the fear of recurrence and can affect 2 in 3 cancer survivors, according to a recent study. The cover story for this fall issue of *Heal*® digs further into how the fear of recurrence can negatively affect cancer survivors' daily lives. But most importantly, experts offer advice on how to overcome this fear with worry sessions, journaling and more.

As CURE®'s 20th anniversary celebration continues, *Heal*® spoke with two experts about the past 20 years of development in survivorship care plans. Twenty years ago, survivorship care plans were just a piece of paper and not a process, as one expert noted. But today, they are utilized much more, giving survivors a better idea of what to expect during survivorship and what they need to keep up with, such as follow-up appointments. But is more improvement needed in the next 20 years?

Also in this issue, cancer survivor, Karen Reynolds, describes her health transformation and how it has greatly affected her physical, mental and medical health. She always knew she had to make healthier choices after surviving cancer, so she decided to take control during the COVID-19 pandemic. After exercising more frequently and eating a healthier diet, she is proud to have lost 35 pounds and is living an optimum healthy life.

Speaking of healthy choices, it's time to start incorporating fall recipes and vegetables into your diet! This issue of *Heal*® offers three great recipes that include those delicious fall vegetables that are finally back in season. Make sure to try out the pumpkin pudding to satisfy that sweet tooth. [h](#)

MIKE HENNESSY JR.

President & CEO
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overheard on **SOCIAL MEDIA**

Advice From People Like You

We asked readers, **“Have you experienced the fear of recurrence after surviving? What gets you through that anxiety?”**

Here’s what they said.

“Time makes the fear of recurrence easier, but I think educating yourself on your specific cancer helps too. You have to think of it like Pandora’s box. — **KATIE**”

“By staying in this day. Worrying about what may happen will not change tomorrow. — **NANCY**”

“Living life. I have survived stage 4 lung cancer. No, I never smoked. I’ve had it come back in the lungs once and in other places. I’m still here and I’m living my life and I refuse to fear it. If it comes back, well, I will beat it again. — **JULIE**”

“Writing, research and connecting with others at support groups help reduce my anxiety and fear of recurrence. At first diagnosis, I didn’t want to talk about it. Growing up as a male, we were discouraged from discussing our feelings as it was a sign of weakness. But I’ve since learned that sharing can be extremely therapeutic and good for the soul. — **GOGS**”

“Taking things day by day (so hard) and celebrating the wins! Acknowledging anxiety and scanxiety and talking about it. — **AMANDA**”

“Taking things one day at a time and relying on the amazing support I’ve made in the cancer community. It’s hard to vocalize these fears and have them appropriately understood by those in my life who haven’t been there. — **DANIELE**”



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If you prefer that your comment not be published, please indicate.



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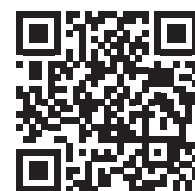
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Advocating for Reproductive Health in Survivorship

Some cancer survivors might not have had the opportunity to preserve fertility prior to cancer treatment, leaving them unable to family plan. *By COLLEEN MORETTI*



CANCER TREATMENT MAY leave some cancer survivors with fertility issues, but patients and survivors who are of reproductive age are consistently reporting fertility-related information as an unmet need. Thus, they are not receiving the care they need for it.

Study results, which were presented at the 2021 American Society of Clinical Oncology Annual Meeting, demonstrated that of 234 cancer survivors, more than half reported that their doctor did not talk about the potential fertility problems they may experience in survivorship. Additionally, one-fifth of survivors were not aware that there was an option to take steps for fertility preservation prior to starting treatment, such as banking sperm or freezing eggs.

“This means survivors are not receiving or cannot recall optimal cancer care,” Julia Stal, lead study author and doctoral candidate in preventive medicine (health behavior research) at the University of Southern California in Los Angeles, said in an interview with *Heal*®. “Rates of fertility counseling are likely to depend on tumor progression and patients’ need for timely treatment. However, a fertility discussion is needed to inform action or manage expectations of preservation among patients.”

Problems with fertility after treatment typically happen because of the tumor location or because of treatment with gonadotoxic treatment

modalities (treatment that temporarily or permanently damages ovaries or testicles), so these discussions should be happening more often.

“These fertility discussions are important to have because the goal is to provide patients with an actionable pathway by which they can make decisions for their reproductive futures,” Stal explained. “The implications of providers not informing patients of possible fertility-related implications after cancer are multifold. Primarily, this may cause patients of reproductive age to be disproportionately affected by their cancer experience. It may also cause patients to lack the needed education to pursue fertility preservation options and ultimately can cause patients to lose their autonomy or their right to make an informed decision regarding their health care and reproductive futures.”

So, what does this mean for cancer survivors who did not have that conversation during treatment and now may be struggling? Stal noted that options to preserve fertility post cancer treatment are limited, which may also affect survivors’ mental health. She highlighted that in prior research, as reproductive concerns increased, so did depressive symptoms among cancer survivors at reproductive age, and roughly half of young adults have reported moderate to high reproductive concerns.

In another study, which included young adult breast cancer survivors, more than half reported that their family plans were not completed at the time of diagnosis and about 65% would have liked to have been counseled on fertility. “Because family planning is informed by comprehensive fertility discussions and planned for through fertility preservation, without adequate fertility counseling, young adults are likely to lack knowledge surrounding their reproductive potential and are unlikely to family plan,” she said. “Targeted reproductive health care is needed to mitigate these concerns.”

For cancer survivors who did not have this discussion and did not family plan prior to starting treatment, Stal recommends establishing care with a clinician who has expertise in oncofertility.

“I encourage survivors to advocate for themselves and ensure their needs are being met. Fertility-related unmet needs are one of the most frequently endorsed unmet needs among survivors of reproductive age and targeted, individualized health care is needed to mitigate these unmet needs,” she concluded. “(They) should connect with a specialist, someone with extensive training in reproductive health — even better if they have training in oncofertility, meaning reproductive health specifically for cancer survivors.” [h](#)

Awareness of Risk for Heart Disease May Mitigate Underdiagnosis in Childhood Cancer Survivors

It is important for cancer survivors to know their risk of developing heart disease, even years after treatment has ended, as they may be underdiagnosed or undertreated for them. By COLLEEN MORETTI

BECAUSE OF PREVIOUSLY received cancer treatment, childhood cancer survivors may be at a higher risk of developing heart disease. However, the risks posed, such as high cholesterol, hypertension, high blood pressure and more, are often underdiagnosed and undertreated, according to a recent study.

The study, which was published in the *Journal of the American Heart Association*, included 571 cancer survivors and 345 age-matched individuals without a history of cancer. The results concluded that survivors were more likely to have a preexisting heart disease risk factor than those without a history of cancer. Dr. Eric Chow, lead study author and pediatric oncologist at Fred Hutchinson Cancer Center in Seattle, told *Heal*® that this is because treatments, such as radiation and anthracycline chemotherapy, increase the probability of developing these risk factors.

Rates of underdiagnosing these risk factors were similar among both groups (27.1% for survivors and 26.1% for those without a history of cancer), but cancer survivors were more likely to be undertreated for these risk factors (21% compared with 13.9%, respectively). The most underdiagnosed and undertreated risk factors included hypertension (18.9%) and dyslipidemia (16.3%).

Chow explained that underdiagnosing is not uncommon, especially in a younger adult population. “We tend to think of these conditions more as problems that affect older adults. So if there is someone in their 20s or 30s with higher blood pressure, as a provider ... they notice it, but it doesn’t strike them



as it probably would for someone in their 50s or 60s,” he said.

Another challenge childhood cancer survivors may face when it comes to diagnosis and treating these risks is that they may not know they are at risk because they don’t remember the treatment they received, as they were so young, Chow explained. Thus, their access — and their physician’s access — to the treatment information may be limited. In this case, Chow said it is important for current patients with cancer and survivors to advocate for themselves and understand what their risk of developing heart disease may be.

Of note, the study results also demonstrated that survivors who had more “self-efficacy” toward their care — meaning they were more willing or able to manage their own health care — were much less

likely to be undertreated or underdiagnosed. “The ability to take ownership and manage their own health is associated, potentially, with better health outcomes,” Chow said. “But ... we don’t just inherit or are born with self-efficacy; that’s something we learn and (is) an important area to improve on.”

With heart disease as the leading cause of noncancer mortality among this population, staying aware of their risk factors and advocating for their health is important for cancer survivors. “One of the messages of the study is that although they can’t undo the chemotherapy or radiation, if (they) do have high blood pressure (or other risk factors), addressing those — at least we think — will reduce the risk of heart disease, (which is) at least something that can be actionable at this time,” Chow concluded. [h](#)

GETTING OUT OF THE WOODS

Cognitive therapy, teletherapy, journaling and taking up other daily activities may help cancer survivors overcome their fear of recurrence.

By JEANNETTE MONINGER



SCAN THE QR CODE to learn more about how support groups may help cancer survivors cope with the fear of recurrence.

When Aleah Hockridge was undergoing cancer treatments in spring 2015 for stage 3a breast cancer, the then 31-year-old resident of Santee, California, longed to hear the words “no evidence of disease.” However, when those words finally came 15 months later, Hockridge didn’t breathe a sigh of relief. Instead, she worried — a lot.

“For the first two years, I couldn’t shake the idea of the cancer coming back or spreading,” Hockridge says. “I would mull scenarios like, ‘How will I manage if the cancer comes back? Should my fiancé and I not buy a home so we’re sure to have the funds to pay for more cancer treatments when it comes back?’”

Even hitting the five-year milestone in February 2020 didn’t ease Hockridge’s fears. “I never feel like I’m out of the woods,” she says. “I don’t know if I’ll ever feel like this is behind me.”

WHEN FEAR TAKES OVER

It’d be hard-pressed to find a cancer survivor who hasn’t occasionally pondered their vulnerability to a cancer recurrence or metastasis. Although many individuals eventually move past this worry, some survivors develop what experts call a fear of cancer recurrence (FCR). Their persistent worries, fears and anxiety consume their thoughts, negatively affecting their ability to get on with their lives. This preoccupation about a cancer recurrence makes them hypervigilant to any physical symptoms that hint that the cancer is back or progressing. »



For **ALEAH HOCKRIDGE**, the anxiety that cancer may recur happens every time she faces a big change or life decision.

“Fear of cancer recurrence is more intense and persistent than ‘scanxiety,’ which goes away after a scan. It’s also different from post-traumatic stress disorder, which causes you to relive past events,” says Heather Jim, a clinical psychologist at the Moffitt Cancer Center in Tampa, Florida. “A survivor with fear of cancer recurrence ruminates about future events they have no control over. Even though a recurrence may never happen, they can’t break free from this cycle of worry.”

As many as 2 in 3 cancer survivors have FCR, according to findings from a 2022 study published in the *European Journal of Oncology Nursing*. Despite its pervasiveness and the fact that this fear has certainly plagued some survivors, it wasn’t until the early 2000s that experts recognized FCR as one of the biggest unmet needs among cancer survivors. That’s when a panel of psychosocial-oncologists developed a Fear of Cancer Recurrence Inventory (FCRI). This 42-item questionnaire uses a scale of 0 (not significant) to 4 (very significant) to

determine how a person thinks about a cancer recurrence. There’s also the FCRI-Short Form (FCRI-SF), with nine questions. For researchers, the FCRI provides a uniform way to measure FCR among survivors. It also gives clinicians a tool to gauge when a person needs help.


Normal or low levels of FCR can also be helpful, as they may motivate a survivor to get follow-up scans and examinations and make healthy lifestyle changes such as exercising more or changing their diet. It’s those with clinically significant results who worry Sophie Lebel, a clinical psychologist and professor of psychology at the University of Ottawa in Canada. “The more severe the fear — meaning an almost daily preoccupation with cancer recurrence — the greater the negative impact on quality of life,” Lebel explains. “Studies, including my own, show a strong correlation between clinical fear of cancer recurrence and depression, anxiety, distress and post-traumatic stress symptoms (such as) hypervigilance, intrusive thoughts and panic attacks.”

Lebel says she often sees patients who have adopted a what's-the-point attitude. "They're unable to plan a vacation, return to work or buy new clothes for fear that cancer will interfere with their plans."

Anyone on the receiving end of a cancer diagnosis can experience FCR, regardless of gender, race, cancer type, stage or prognosis. But results from a study published in the *Journal of Cancer Survivorship* suggest that the fear and its impact may be greatest among young adult cancer survivors. "Perceiving a greater number of years ahead of them may be interpreted as more opportunity for the cancer to come back or spread and a greater burden to remain cancer free," explains Maurade Gormley, an assistant professor at the University of Connecticut School of Nursing in Mansfield.

Gormley's studies on genomic testing for risk of recurrence among hormone receptor-positive breast cancer survivors found that those with a greater risk of recurrence had higher FCR; however, some still had a disproportionately high level of fear, even when their genomic test results indicated a low risk of recurrence. "Factors such as how the individual perceives their illness and its consequences may be more important than their objective risk of recurrence," she says. "This suggests that patients with cancer may benefit from closer follow-up of their emotional response to diagnostic and prognostic testing, regardless of their individual risk of recurrence."

This need for improved communication is especially crucial when a patient transitions from active treatment to survivorship. "I wasn't prepared for what life would be like when the routine of scans, treatments and doctor visits ended," says Keith Tolley, a resident of Warwick, Massachusetts. Tolley was 61 years old in June 2017 when he was diagnosed with stage 3 melanoma. A year and a half later, the cancer spread to his liver and then to other areas. He underwent surgeries, an immunotherapy clinical trial, radiation therapy and additional immunotherapy

A circular inset image showing a woman with blonde hair tied back, wearing a light blue V-neck shirt and dark pants, sitting in a meditative pose on a sandy beach. She has her eyes closed and a calm expression.


I've found some healthy ways to cope like yoga (and) mindfulness... It's been a lot of trial and error, and I still struggle.

— ALEAH HOCKRIDGE

the source of back pain that she was sure was metastatic bone cancer (it wasn't), she made a new rule. "I track any unusual symptoms in a journal for two weeks and only call my oncologist if the symptoms worsen or don't go away."

OVERCOMING THE FEAR

When thoughts of a cancer recurrence become so intrusive that they affect the ability to function, enjoy life or plan »

A circular inset image showing a man and a woman standing on a beach. The man, who is bald and has a beard, is wearing a light blue t-shirt and has his arm around the woman's shoulder. The woman is also wearing a light blue t-shirt and is smiling at the camera.

➤ ALEAH is grateful to be marrying her fiancé, BRANDON LA FLAIR, but still worries that cancer may come back.

treatments, scans taken in July 2020 showed a complete response to the treatments. After his treatments ended, Tolley found himself occasionally struggling with the loss of security he felt while receiving regular medical care. "It can be a struggle to shake that feeling of vulnerability and fear," he says. "Early on, there were times when I would wake up in the middle of the night, worrying about the cancer coming back."

Sleep problems, fatigue and pain are common issues among individuals with FCR. These symptoms can drive them to see their doctors more often, seeking reassurances that everything is OK. These actions can unnecessarily fuel anxiety and lead to higher health care expenses. After Hockridge had a couple of scans to look for



After **KEITH TOLLEY** finished treatment, he would wake up in the middle of the night worrying that the cancer might come back.

for the future, mental health counseling can help. Studies suggest that clinically significant FCR won't get better over time without treatment, and one of the most effective treatments is cognitive behavioral therapy (CBT).

"(CBT) gives you the tools to change negative thought patterns by breaking down what makes you anxious or scared and finding healthy ways to think about and manage them," says Lynne Wagner, psychologist and professor of social sciences and health policy at Wake Forest University School of Medicine in Winston-Salem, North Carolina, who is conducting research on effective treatments for fear of recurrence.

One way to do this, Wagner says, is by scheduling worry sessions. "You set aside five to 10 minutes every day for three weeks to think about your fears and how you would handle a situation, should it come true," she says. "Push aside any fears that crop up outside the session (or write them down)

until it's worry time. You decide when you're going to worry. The sessions challenge the idea that worrying gives you control over a situation or its outcome. You learn to say, 'Let me focus on what I can control' whenever intrusive thoughts creep in."

Wagner also teaches her patients how to use diaphragmatic breathing exercises at the end of each worry session to help ground them. "Deep breathing, mindfulness and meditation are great tools for coping with fear of cancer recurrence," she says. "In some ways, a worry session is a type of mindfulness. The goal isn't to change a thought but to become more comfortable with it."

Facing his fears head-on is one way Tolley copes. "I analyze a fear to figure out what I'm feeling and why," he explains. "I try to determine (whether) this fear is driven by something I can or cannot control and whether it's based on what is actually true or what I'm imagining to be true."



« When anxiety from the fear of recurrence takes over, **KEITH** finds talking to someone in his support system, like his wife **ESMERALDA TOLLEY**, to be helpful.

patient awareness about FCR. The first step involves educating patients during and after treatments about the signs of clinical FCR and when to seek help. This educational step also includes making sure patients understand their actual risk of recurrence based on their unique diagnosis and what signs to look for. The second step encourages cancer care teams and primary care physicians to use the FCRI to identify those who need help.

However, finding that help may still be a challenge, Lebel admits. “This is still a developing field, so it’s often difficult to find a therapist who has experience helping people overcome this fear,” she says. If your cancer center doesn’t have a social worker or therapist who can help, Lebel recommends looking for a provider who specializes in treating anxiety and depression with CBT and mindfulness techniques. “There’s strong evidence that these interventions help, and you don’t need a lifetime of therapy,” she explains. “Many people see improvements after doing six weeks of once-a-week group sessions, or you can do personal sessions or even teletherapy.”

Hockridge tried teletherapy sessions during the height of the pandemic but decided they weren’t for her. “I’ve found some healthy ways to cope, like yoga, mindfulness and challenging myself to try new things like surfing and kayaking,” she says. “It’s been a lot of trial and error, and I still struggle.”

That struggle intensified this year while Hockridge was planning her fall wedding. “The fear of cancer recurrence comes back anytime I’m faced with big life decisions or changes,” she says. “I’m so grateful that I’m here to marry my soulmate and celebrate with our families. And

yet, I have thoughts like, ‘Should we be spending money on a wedding if we need it to pay for future cancer treatments?’”

Hockridge likens her fear to an invisible boulder hanging perilously from a rope above her head. “I try to pretend it’s not there because when I look up, the rope looks more frayed,” she says. “I fight the urge to look. Instead, I do what I can to cultivate joy, reduce stress and keep my eyes focused on the future. I must choose to believe that the boulder won’t come crashing down.” [h](#)

Tolley also sticks to a commitment he made to himself to never go through this journey alone. “When I can’t shake fear or anxiety, I talk to someone in my support system,” he says. “(Often), just verbalizing the fear to someone else takes away its power.”

Tolley learned some of these strategies through a survivorship program at his cancer center. But many centers, and even cancer specialists, are just now recognizing the importance of talking to cancer survivors about FCR. Psychosocial-oncologists are encouraging a two-pronged approach to raise



From a Piece of Paper to a Process

20 Years of Survivorship Care Plans

The time after treatment can be overwhelming, but great progress in survivorship care plans over the past two decades has provided better guidance for an easier transition. *By COLLEEN MORETTI*



DR. ANNE BLAES

THE NUMBER OF cancer survivors living in the United States has reached over 18 million, according to data from a 2022 study published in *A Cancer Journal for Clinicians*. And because the number of cancer survivors continues to increase — expected to reach 26 million by 2040 — care for this population after treatment has ended must continue to advance as well. In honor of CURE®'s 20th anniversary, *Heal*® spoke with two experts about the importance of survivorship care plans, where they were 20 years ago, where they are now and the gaps that still need to be filled.

Dr. Anne Blaes, medical oncologist and director of cancer survivorship services and translational research at the University of Minnesota in Minneapolis, explained that there are two components to a survivorship care plan. The first being an outline of the diagnosis and treatment a patient received. The second is a follow-up plan, which includes the doctors or specialists patients should continue to see, what lifestyle they will need to maintain to stay healthy, advocacy groups for support and more.



DR. EMILY S. TONOREZOS

“It’s important because most patients can’t recall the treatment they have had,” Blaes said in an interview with *Heal*®. “It is also important because it outlines a plan of what they need to do moving forward and who’s responsible for what.”

Dr. Emily S. Tonorezos, director of the Office of Cancer Survivorship at the National Cancer Institute, agreed and added that the care plan can help survivors better understand what late-term side effects they may be at risk for. “Knowing what side effects they’re at risk for and what long-term surveillance or recommendations might apply to them — those tend to be gaps for the survivor and whoever is seeing that survivor, (which is) usually a primary care provider,” she said in an interview with *Heal*®.

So, it is understood that survivorship care plans are important, and they are utilized much more today for cancer survivors to take advantage of. But, 20 years ago, survivors didn’t have this direction.

THAT WAS THEN

Blaes said that 20 years ago there were no

survivorship care plans at all, and then once the gap was recognized it soon became a “big can of worms.”

“What quickly happened is people ... (put) a piece of paper in the (cancer survivor's) hand, which costs a lot of money and time, without educating them and connecting them with services, which is what was actually going to help them,” she explained.

This happened about 20 years ago, when the Institute of Medicine reported that cancer survivors do not have the same life expectancy as those without a history of cancer. They also reported gaps in primary care and a risk for recurrence and other complications. This launched the idea of care plans, which should have been helpful for these patients, but in the end were just a piece of paper, as Blaes described.

Having care plans then became a part of an accreditation, so the National Accreditation Program for Breast Cancers required a treatment summary care plan. If a site wanted to be accredited by the Commission on Cancer, they would need a care plan. Thus, it became more so a requirement for institutions and organizations to have, rather than a helpful tool for survivors.

“When the survivorship care plan was conceptualized, the idea was that you could create a record of the diagnosis and treatment, give it to the survivors and then that would ensure the survivors had the recommendations for surveillance and long-term follow-up,” Tonorezos added. Furthermore, she explained that looking back at what survivorship care plans were 20 years ago demonstrates how much progress they have made today.

THE PROGRESS

What has happened over the past 20 years is an evolution in survivorship care, Tonorezos said. There has been a better understanding of what survivors need after treatment ends, as well as what needs to be included in their care plan. “There's been a movement from thinking of this survivorship care plan as a document to thinking of it as a process,” she explained. “It's not just a one-time hand-off document with some information. It's about an ongoing process to ensure survivors are getting what they need.”

This includes more work with nurse navigators, dietitians and other care team members to care for all parts of a survivor, Tonorezos said. In addition, Blaes noted that this comes from the new accreditation guidelines from the Commission on Cancer.

The update recommends survivorship care plans include a team of individuals for survivors to follow-up with instead of just one primary care provider. They also recommend institutions to take on projects to enhance the outcomes and care for cancer survivors. “I still think the treatments in the care plan are important, but I would look at it as they're

one piece in recognizing that survivors need a team to stay well,” Blaes said.

TODAY'S PLAN

When discussing the progress survivorship care plans have made over the years, both Blaes and Tonorezos agreed that something survivors are benefiting from today is the advancement in technology. Twenty years ago, cancer survivors did not have access to their health records electronically, and were not able to schedule and have a doctor's visit from the comfort of their home — but today they can.


“We have a growing population of cancer survivors, and the electronic developments ... have changed how their care is delivered,” Tonorezos said. “Of course, the (COVID-19) pandemic had an impact on survivorship care. (There has been a) growing utilization of telehealth and a recognition that there are some circumstances where it is extremely useful, and that survivorship care is probably one of those circumstances. With telehealth, a survivorship specialist (can) see more patients and have a broader geographic reach. That has been the most amazing thing that's happened in the past few years.” Tonorezos added that now having access to personal medical records allows survivors to see lab results, past treatments and provider notes.

Additionally, the survivorship care plans can now outline resources for survivors to seek out on their own, such as advocacy groups. Blaes added that there are now webinars and other online educational services that can provide cancer survivors with a better understanding of what they are going through and what to expect in survivorship. She also said that although there have been great advancements in survivorship care plans, and survivors do have many resources available to them, there are still gaps.

FILLING THE GAPS

“We've realized that just enabling telehealth is not enough to ensure there is equitable access or that (those) who need care are getting it,” Tonorezos said.

Blaes agreed, as she said some of the gaps in survivorship care plans today include having parts of follow-up covered by insurance and individualizing care plans for each person based on their socioeconomic background. “We have a lot of these services now, but there is still a problem getting patients to them or to know they exist, or getting them paid for,” she said.

Blaes said she hopes that in the next 20 years, these gaps can be closed. Tonorezos also remains optimistic. “Every time there's an advancement in oncology, diagnosis or treatment, there needs to be a corresponding movement in survivorship research,” she concluded. “Thankfully, there have been tremendous advances in oncology over the last few decades, so we have many opportunities to continue to improve the lives of survivors.” 

The Journey to a Healthy Lifestyle

One cancer survivor describes how making healthier choices in diet and exercise has improved her quality of life and relationship with others.

By COLLEEN MORETTI

DURING TREATMENT FOR stage 2 breast cancer, which ended seven and a half years ago, Karen Reynolds found it difficult and overwhelming to focus on creating a healthy lifestyle. But now as a cancer survivor, she said she finds it simple, empowering and even more important.

“During my treatment, I was so focused on healing that my experience with getting healthy and nutrition was overwhelming and complicated,” the now 59-year-old said in an interview with *Heal*®.

“Now it has become much simpler.”

THE CAUSE

For many years, Reynolds had struggled with her weight and knew she had to make healthier changes to her lifestyle, but once she received her cancer diagnosis, it was all too much.

About two years ago, amid the COVID-19 pandemic, Reynolds had lost her job and decided it was time to take control of her health. “The world (was) changing in so many unimaginable ways, and I felt like everything was so out of control. I knew the one thing I could control was me,” she recalled.

Reynolds made a promise to herself to come out of the pandemic better than how she went in. She joined a friend in her wellness journey, got herself a health coach and has since lost 35 pounds — understands how to keep it off — and improved her mental, physical and medical health along the way.

Some of the changes she made included prepping healthier meals, making healthier choices at the grocery store, adding more water, protein and vegetables to her diet, and eating less carbs and minimal sugar, essentially transforming her habits and relationship with food. She began walking regularly versus just taking her dog out — now she can do anywhere from 2 to 3 miles a day of walking. And

after she lost the first 15 pounds, she got an indoor bike, adding cycling to her routine, and is now adding resistance as a weekly activity.

Changes like these can benefit other survivors, as well. There have been multiple studies suggesting that walking can improve quality of life in cancer survivors, and eating the right foods may decrease the risk of developing a second cancer. Dr. Ajaz M. Khan, medical oncologist and chair of the Department of Medical Oncology at the Cancer Treatment Centers of America in Chicago, discussed this further in an interview with *Heal*®. “There’s a significant amount of studies that have (demonstrated that) ... leading a healthy lifestyle has shown survival benefit (and) a reduction in recurrence for patients who have already had treatment for their cancer,” he explained.

THE EFFECT

Not only can making a healthy lifestyle change improve a cancer survivor’s physical health, but it can also improve their mental health and quality of life. Khan explained that during treatment and thereafter, cancer survivors experience a distress that can negatively effect their quality of life. However, some recent studies have shown it can improve with a healthy diet and exercise routine.

A few days into making her own healthy choices, Reynolds felt that affect on her quality of life, which motivated her to continue the lifestyle. One aspect of her life that she saw an immediate improvement in was sleep. She had experienced insomnia, as many cancer survivors do, for years after treatment. However, after just a few days of making healthy choices, she was falling asleep easier



and faster, staying asleep through the night and not waking up groggy. She was also able to rid the midday fatigue she had been experiencing.

“Feeling rested led to a better disposition for me,” Reynolds explained. “I was less irritable — my family tells me — which also meant a better relationship with my mother as her caregiver.” She has been caregiving for her 88-year-old mother for a few years now, and with the help of Reynolds’ meal changes, she has lost 20 pounds herself.

However, Khan noted, it is important to stay committed if a cancer survivor wants to see changes as Reynolds did. “Particularly in some of the survivorship studies that have been done in breast, prostate and colon cancer, (we’ve seen) that patients who can walk up to 300 minutes in a week (have) shown significant benefits compared (with) those who can’t,” he said. “So, there is an activity level they must achieve to enjoy a greater quality of life in survivorship.”

COMMITTING TO CHANGE

Although these changes are important to leading a healthy lifestyle after cancer, it can be hard. However, the results it can provide, such as better quality of life and reduced risk of recurrence, should fuel motivation, Khan noted.

“The first thing is acceptance of a new norm, which may not be what it was prior to receiving treatment,” he said. “The second thing is there’s still a heightened awareness of being empowered in terms of preventing their cancer from coming back.”

Reynolds is a testament to that. Once she started feeling better, making healthy choices became easier for her and she stayed motivated. “A few days into making healthy choices and experiencing it consistently, I began to feel differently, which allowed that mindset to stay top of mind,” she explained. “Healthy habits have given me a sense of empowerment. Even routine activity is now second nature (rather than) a chore.”

As Reynolds said, starting the commitment was hard, just going to the grocery store for healthy options was overwhelming. But now getting in and out of the grocery store is a much simpler task, and meal prep is something she finds pleasant and easy — she’s “got it down to a science.”

Khan said that before making the commitment, it is important to talk with a doctor or expert in the field, because there are a lot of facts and myths out there regarding a cancer survivor’s



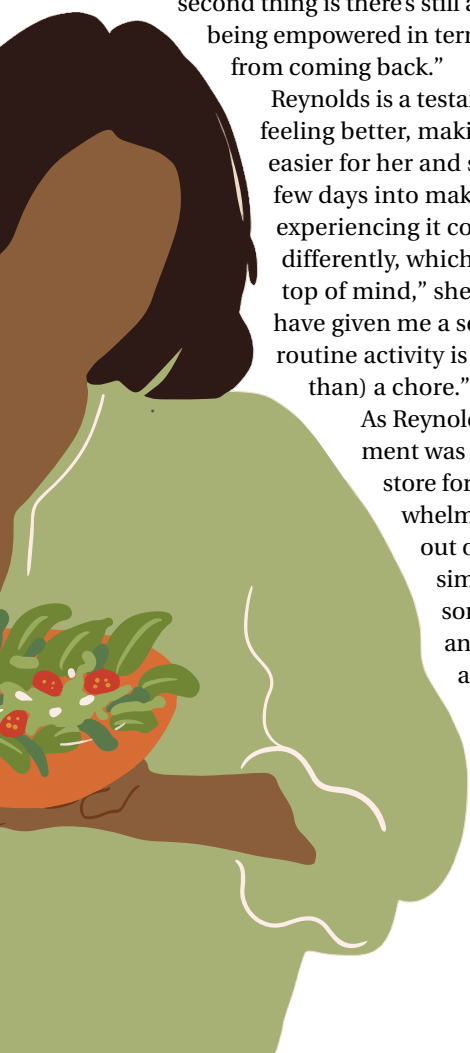
Although it was hard at first, committing to a healthy lifestyle has now become second nature for **KAREN REYNOLDS** during survivorship.

health and wellness. Although it’s a fact that physical activity and healthy eating can reduce risk of recurrence and improve quality of life, some of the myths he encounters with patients include the benefits of antioxidants, alkaline water and mega doses of vitamins. There isn’t enough literature to prove these work, according to Khan. “Those all should be discussed with the provider before engaging with them,” he advised.

Reynolds added that it is not all about losing weight; it is about optimum health and a lifelong transformation impacting all areas of one’s life. “When I think about optimum health, which was the goal for me, I think (about) favorable outcomes, maximizing performance in mind, body, spirit and finances — and all that comes together and impacts how (you experience) the world. Feeling healthy impacts how you show up every day,” she said.

She said a first step a cancer survivor should take is to decide what they want to improve, whether that’s reducing blood pressure, cholesterol, how clothes fit or just feeling all around better. And then find what path will help you accomplish and maintain your goal.

“Be gentle with yourself, because sometimes we get off track or fall short and miss the mark, but just be gentle. It’s a journey, not a race,” Reynolds said. “Getting healthy is liberating, and it’s empowering when you know how to sustain your goals.”



To My Cancer Posse: *Thank You for Everything*

One cancer survivor thanks those who “helped fight the bad guys of cancer with love and support.” By JULIA S. BROKAW

THERE ARE THINGS I am most grateful for as I continue my journey of fighting ovarian cancer. Of course, the excellent care I have received with my doctors, nurses and hospitals has been amazing. In some of the pieces I have had published as a blogger for *CURE*®, I have mentioned a few individuals who have been incredible.



JULIA S. BROKAW

For a while, I have been wanting to take the time to write about a very important topic to me: my posse. This is my attempt to show my appreciation and thanks to a very significant group of friends and loved ones who have been there for me throughout my journey.

My journey began with surgery in February 2013, weeks after I visited my gynecologist for pain I had been experiencing. On a Sunday in January 2013, the day before my appointment with my gynecologist, my husband and I went skiing. When we were done skiing, I could hardly sit, as I was feeling lots of pressure down in my pelvic area. That Monday, my gynecologist told me there was something suspicious happening in my body and she did an internal ultrasound. She felt there was a possibility of cancer.

I walked out of the appointment, and it was a gorgeous snowy day. The snowflakes were huge and beautiful. Of course, the first person I told was my husband via the phone, as he was at work. He was very positive and

supportive, believing we would get through this bump in the road.

As I drove home, my head was full of questions and fear, and I felt numb. I needed to talk to someone. I drove over to a friend's house, and she welcomed me with open arms. We went into her study, and she immediately emailed a friend who was a nurse with many of my questions. I remember staring out the large window, where 20 or 30 red cardinals were gathered in her trees and searching for food. It was such a magnificent sight, with the huge white snowflakes and bright-red color on the birds. It gave me peace. It is funny, the things you remember.

Surgery and chemotherapy came a couple weeks later. My dear friends stopped in to see how I was doing and brought food and flowers. I went to my hairdresser to have my long hair cut for Locks of Love. Then, when my hair started to come out in patches, she came to my house and shaved my head so I didn't have to continue experiencing clumps of hair falling out. She brought me cookies and called me beautiful.

My children lived out of town, but they made trips home to see me regularly. FaceTime became a way to see them every week and on the tough days when I needed to see them. My stepdaughter made many trips from North Carolina and gave me healing stones and crystals, which I placed by my bed. She also used reiki over my body.

My stepchildren have been wonderful. Family dinners



are a regular thing. They live close, and I am so lucky to have them in my life.

Throughout the years, these wonderful people have helped me get through each phase of my journey:

- My husband has been my rock. There are not enough words to celebrate this man. He has been there every moment.
- My immediate family, made up of children, stepchildren, their spouses and grandchildren, have been so loving and helpful.
- My sisters and I have three-way FaceTime calls to catch up, as they live in Louisiana and Utah.
- My best friends are there for me every day, week, month and year. I can call or text them 24/7.
- I have a Friday breakfast every week. These four ladies listen and support me unconditionally, and the restaurant staff is great.
- Adventures on the lake with my friend to celebrate friendship and healing.
- My high school friends and I have reconnected during reunions.
- My neighbors have been so sweet to check in with me.
- Some of my friends have put me on prayer chains.
- Relatives of my children keep in touch through Facebook and cards.
- My nieces and nephews send messages of hope and peace.
- College friends of my children have reached out to me.
- Nurses have become more than friends and are constantly checking up on me — we even do Zumba together!
- My friends who have wine and dinner with me are amazing.
- My nail tech makes my nails gorgeous. I am not only a loyal client but also a dear friend.
- My former secretary and school nurse meet with me each summer to get caught up.
- My dry cleaner's staff always ask how I am doing.

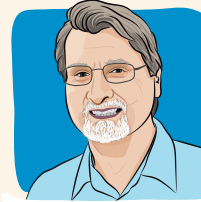
When I look at this list, I know I have missed some of the wonderful people, and for that, I am sorry. These people are my posse. I do not know what I would do without them. My posse may not get on horses like on TV, but they help me fight the bad guys of cancer with love and support. I truly feel blessed that I am so lucky to have the best posse in the world. Thank you, and I love you all. [h](#)

A New Home With Other Cancer Survivors

A survivor reflects on the importance of camaraderie during and after a cancer diagnosis. BY RON COOPER

NATIONAL CANCER SURVIVORS DAY has come and gone, but I like to reflect on the importance of survivorship all year long. I am eight years into my cancer journey, and I feel lucky to be alive and to have so many fellow survivors to tag along with.

Together, we have formed a confidential collective. Ours is a collective of friendship where no topic is off the table. It's a collective of pain where empathy reigns. And it's a collective of unwavering acceptance and wisdom gained through years of sharing, understanding and love.



RON COOPER

Mutual trust binds us. We trust that the innermost details of our cancer world are not shared broadly. Sharing implies discretion, which is a cardinal rule in our collective.

Early on, when the word "cancer" was first uttered to me, I clammed up. I denied this negative turn of events in my health and leaped headlong into my work as a freelance writer. Work was my escape and my salvation. I didn't know there was a world outside the solitary one I had chosen.

FINDING A BRAND-NEW WORLD

When I found the other world via support groups, I was truly amazed that my story would count for something. I was amazed that I would be listened to carefully and patiently and that someone would care. It was a breakthrough moment.

For those patients with cancer who are still hesitant about opening up to others, remember that in our world, strangers can become instant friends, sharing common experiences of pain, anxiety and hope. That first step is always the most difficult to take, but I managed it and have never reversed course.

SHOULD HAVE ACTED SOONER

If I had to do it all over again, I would have acted sooner instead of allowing my denial to take deep root and keep me closed up with my worrisome secret. Yes, it takes courage to walk out into the light, but that decision has changed my life for the better.

I cannot imagine traveling this sometimes-bumpy road without the selfless, generous individuals in my support groups. In addition to my truly remarkable caregiver/wife, they help me find calm amid the chaos in the cancer experience. I've found a collective of shared friendship, pain, wisdom and most importantly, my new home. [h](#)

A Game of Cat and Mouse



A cancer survivor frequently relives that day she received her diagnosis and realized she may need to limit her exposure to other people's cancer journey.

By MICHELE VELEZ

LATELY I HAVE been staying up late at night, getting sucked down the cancer wormhole. It's something that happened a lot when I was in treatment, but not so much in the months after. I guess I was just focused on recovery and healing, which came with more ease for me, because recurrence for my type of cancer is rare.

However, I've noticed I've been worried that one day I'll receive a diagnosis of a different type of cancer — or worse, my kids will receive a diagnosis. I've tried telling myself, "It already happened, so my chances are low," but I honestly don't think that's the case. Cancer is so widespread these days, and stories of individuals being diagnosed more than once are not that uncommon, especially with the amount of cancer connections I have made online.

My husband always likes to point out that because of social media, we hear about so much more, which is true, but it's still hard for me some days. People reach out to me for support and I'm always so glad they do, but occasionally, I find myself feeling very anxious. I worry that cancer will come back and ruin my happiness.

I sometimes feel like it's too good to be true that I could beat cancer, crawl my way out of the darkness and live happily ever after. Sometimes late at night, when everyone is sleeping and I'm completely alone, I start to wonder when something bad will happen again. When something hurts or my recent tingling of the left arm

starts up, my mind instantly goes to cancer.

What if it's a tumor on my spine? What if I find a lump in my breast? What if my son's headaches turn out to be cancer? What if one of my dogs gets cancer? It is always in the back of my mind.

Having this level of anxiety isn't anything unusual for me. I used to worry like this before cancer, but somehow it's different now. Perhaps it's because I have actually been there, or maybe I have some level of post-traumatic stress disorder. I relive the horrible day I received my diagnosis all the time.

A friend of mine who also survived choriocarcinoma has told me that she has to "protect her peace" by eliminating exposure to daily triggers, such as other people's cancer battles. I really thought about that and realized that maybe I need to do the same.

When I think that way, it makes me feel guilty because it feels selfish, but how much can one person take? I just want to find some peace, where cancer isn't constantly stealing from me. I want to be like the people I see around me, living in ignorant bliss and making daily choices without constantly worrying it might tip the scale in cancer's favor.

It reminds me of that movie "Final Destination," where cheating death is impossible. That's what living life after cancer feels like: a constant cat-and-mouse game, where you are trying to outsmart death. [h](#)



MICHELLE VELEZ

Rejoining the Kingdom of the Well After Cancer

After cancer, one survivor's "normal" life has been long forgotten, but how can he get back to life as a person who is well? By WILLIAM RAMSHAW

IN SULEIKA JAOUAD'S gripping best-selling memoir "Between Two Kingdoms: A Memoir of a Life Interrupted," she quotes Susan Sontag from "Illness as a Metaphor."

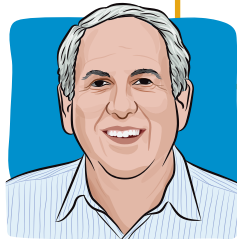
"Everyone who is born holds dual citizenship, in the kingdom of the well and in the kingdom of the sick."

At 22 years old, Jaouad received a diagnosis of acute myeloid leukemia, which can have a poor prognosis. After a battle that lasted for more than four years, which included a harrowing bone marrow transplant, Jaouad wondered whether she would ever rejoin the kingdom of the well. With her seemingly endless treatments finally behind her, she wrote, "I find myself on the threshold between an old familiar state and an unknown future. Cancer no longer lives in my blood, but it lives on in other ways, dominating my identity, my relationships, my work and my thoughts."

I, too, found myself standing at this same threshold. Normal was long forgotten, and I wondered whether I had a tomorrow.

Finding out I had pancreatic cancer, in which only 5 in 100 individuals who receive this sad news live to see five more years, caused me to ask a lot of questions about the life I had been leading and its disconnect from the life I wanted to live. How many hours per week did I need to work? How much money did I need to make? How much professional prestige was enough? These were all good questions — all with sketchy answers.

Many mistake completing our



WILLIAM RAMSHAW

“We are happy to have survived, but we could do without the endless bridge outages and washed-out-roads blocking us from rejoining the kingdom of well. —WILLIAM RAMSHAW”

treatments as a destination, as I did, but it is only the first step in the arduous journey back to the kingdom of the well.

While we were out of town, things changed. Our remaining friends are scared to ask us, "How's it going?" or "How are you feeling?" fearing an answer they don't want to hear. Our mortality reminds them of theirs.

Not only have I lost friends to cancer but I've also lost friends because of my cancer. Honestly, I can't blame them. I remember precancer and how hard it was for me to talk with someone with cancer, fearing not only that I would say something stupid but that I would also find out something I didn't want to know.

After cancer, my calendar is pockmarked with follow-ups, not only with my six-month follow-ups but also with other specialists who treat the many side effects of my cancer. I see a gastroenterologist to monitor my digestive health and an endocrinologist to monitor both my diabetes (thanks to losing a third of my pancreas) and my osteoporosis (thanks to my abdominal radiation).

Like most survivors, every new twinge or bruise raises concerns about my

cancer's return. Every health glitch morphs into a medical emergency. Before cancer, I shrugged off these things. Now alarm bells blare, drowning out life. This has become my new normal, whether I like it or not. I hear similar stories from other survivors. We are happy to have survived, but we could do without the endless bridge outages and washed-out roads blocking us from rejoining the kingdom of the well.

There is a point for many of us, where we feel we have been banished from the kingdom of the well for life. Our treatments seem to have no end. We wonder whether they are our end. But once they are over, we begin our long journey back to the kingdom of the well.

If you want to know more about Jaouad's journey, without reservation, I recommend reading her memoir. Her TED talk "What Almost Dying Taught Me About Living" has been viewed almost 5 million times. If you haven't yet watched it, I would encourage you to. After all, we are all in this together.

Sadly, at this writing, Jaouad has had a relapse — every cancer survivor's worst fear. Happily, she is doing well, having survived a second bone marrow transplant. [h](#)

Trusting the Process

Seeing a friend attend a business meeting made one survivor miss his fast-paced life before cancer, but it also reminded him to trust the process of where he is now.

By STEVE RUBIN



I RECENTLY MET up with a good friend/former client for coffee. He's been a stand-up, loyal friend every step of the way since I received my diagnosis in 2016.

Back then, I worked as an executive recruiter in Manhattan. It was a fast-paced job, with lots of action and good money to be made. But unfortunately, my former life also came with high stress levels. It wasn't great for my health, and after multiple attempts to return to work after treatment, I ended up with recurrences. I can't say for sure what contributed to the cancer coming back, but I'm sure the intensity of each day didn't help my condition.

These days, I'm on disability and medical leave of absence. Fortunately, my health has shown improvement — I treat taking care of myself like a full-time job. However, the days can get lonely, so it was nice to get out on a bright and sunny morning, feel the buzz of New York City and meet up with a familiar face. As always, I enjoyed the conversation; it's nice when a friend can just listen about the current struggles and obstacles of life after cancer without throwing positive spins or aggressive conversation changes in your face. I felt validated and enjoyed hearing about his life; work, kids, vacation plans and all that good stuff.



STEVE RUBIN

My friend had carved out an hour and was meeting a colleague at the same cafe afterward; I even got to meet her when she showed up early. After a quick hello, I excused myself and let them get to business. That's around when it hit me. I had heavy emotions swelling in my gut, heart and throat. *I missed my old life.*

I missed working with cool people in a stimulating environment while providing for my family, contributing value and having clear, defined structure. Of course, that conveniently leaves out the underbelly of frantic emails, fire drills, deadlines, sleep-deprived mornings and all the old triggers that skyrocketed my heart rate on a constant basis — but I was emotional in the moment, not rational.

They say comparison is the thief of joy, and the meeting definitely left me feeling a bit stagnant and empty inside. I've been chipping away at my own life for some time now, trying to decide what I want for a future and working on remembering how to dream again. It hasn't been easy, but ultimately, I'm trying to look at this reaction as a positive sign. Because yes, it sucks feeling unfulfilled, envious and borderline depressed, but I think that's a signal indicating progress I've made this past year.

Going back not too long ago, I don't think I would've been capable of having these feelings, as I was in pure survival mode and living with paralyzing fear and anxiety. The shift from being afraid to trust the universe and venturing out to now wanting and desiring is important. I couldn't even tap into what I wanted a few months ago, and it's something I've been working on actively in therapy, figuring out how to navigate through the confusion, stress and uncertainty that is life after cancer.

The road to recovery hasn't been linear, but I've been committed and have a strong support system. Now it's about being consistent, being patient and trusting the process. It's also about compassion and reminding myself I'm doing OK, even when I'm not always so sure.

A few years ago, doctors ran out of answers and gave me a survival rate of less than 10%, as I had a rare bone cancer. I had to keep moving forward, experimenting with new ideas and techniques, and I was constantly adapting as new information came along. But I stayed diligent in the face of the unknown and miraculously managed to find the light at the end of the tunnel.

I'm just trying to remind myself that I didn't have the road map back when I started then, either, but I got where I needed to go. And I'm hoping that the same applies with finding some form of happiness, comfort and the right fit for Steve 2.0 in a life after cancer. **h**

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With a new season comes a new rotation of vegetables that are at their peak — making it the perfect time to incorporate their nutritional value into meals!

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Roasted Vegetable Quinoa Salad

INGREDIENTS

- 1 cup chopped red onion
- 1 cup chopped carrots
- 1 cup chopped parsnips
- 1 cup chopped butternut squash
- 2 tablespoons extra virgin olive oil
- 1/4 teaspoon pepper
- 1/4 teaspoon salt
- 1/2 cup dry quinoa
- 1 tablespoon apple cider vinegar
- 1/2 teaspoon honey
- 1/2 teaspoon Dijon mustard
- 1 minced garlic clove

DIRECTIONS

1. Preheat the oven to 400 F.
2. Toss all vegetables on a cookie sheet with 1 tablespoon olive oil, 1/4 teaspoon pepper and 1/4 teaspoon salt.
3. Bake for 35 to 40 minutes.
4. While vegetables are roasting, make the quinoa as directed on the package, then set aside.
5. In a separate bowl or jar, prepare the vinaigrette. Whisk (or shake) together remaining oil, vinegar, honey, mustard, garlic, salt and pepper to taste, then set aside.
6. Once the vegetables are fork-tender, toss with cooked quinoa and vinaigrette. This may be served warm or at room temperature.



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Creamy Pumpkin Pudding

INGREDIENTS

- 1 can (16 oz.) pumpkin puree
- 1 package (3 oz.) vanilla or lemon pudding
- 1 cup milk
- 1 teaspoon ground cinnamon
- 1/2 teaspoon ground ginger
- 1/4 teaspoon ground cloves
- Dash of ground nutmeg

DIRECTIONS

1. Combine all ingredients and chill.
2. Add bananas, nuts or coconut flakes if desired.



Creamy Butternut Squash Soup

INGREDIENTS

- 2 medium butternut squash
- Drizzle of olive oil
- Kosher salt and pepper to taste
- 2 cups chicken stock
- 1/2 cup Greek-style yogurt (strained)
- Heavy cream for garnish (optional)
- Chopped chives for garnish (optional)

DIRECTIONS

1. Preheat the oven to 375 F. Cut the butternut squash in half and scrape out the seeds. Brush the cut sides with olive oil and sprinkle with kosher salt and pepper.
2. Place the cut halves of the squash upside down on a rimmed sheet pan and pierce with a knife in a few spots. Roast for 45 minutes, then remove from the oven and let cool.
3. When the squash is cool enough to handle, scoop the soft flesh from the shells.
4. Place the squash in a blender with chicken stock and Greek-style yogurt; puree. Add more or less chicken stock to adjust the finished thickness of your soup. Taste for seasoning and adjust if necessary.
5. Garnish with a drizzle of heavy cream and chopped chives. Serve hot or cold.



SOLE² SOUL for MPN

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,
visit

[curetoday.com/
cure-adventures/
sole2soul](http://curetoday.com/cure-adventures/sole2soul)



To learn more about
Canadian MPN Research
Foundation, visit
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