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Dealing With Side Effects and Finding Motivation

SOME MAY THINK that when a cancer survivor finishes treatment, cancer is left behind. However, long-

lasting side effects can have an effect on the daily lives of survivors and their families. After treatments such as chemotherapy and radiation have ended, many cancer survivors may be left with infertility struggles and unable to grow their family.

In this issue of *Heal*[®], we hear from experts about the infertility many cancer survivors face after treatment ends. Unfortunately, many survivors might not have been given an option to preserve fertility — such as banking sperm or freezing eggs — due to a lack of conversation with their oncologist before treatment. One survivor featured

recalls a brief discussion with her oncologist but was so worried about surviving treatment that she did not think about long-lasting side effects. At times she wishes she would have asked more questions about preserving fertility.

Oral side effects of cancer treatment can also affect quality of life. Certain cancer types and treatments may lead to side effects such as dry mouth or increased risk for cavities. In this issue, we talk with an expert about why this happens and what survivors can do to mitigate it.

We also talk with Robert Atteberry, three-time cancer survivor, about how he found motivation during survivorship to compete in Ironman races,

marathons, half marathons, 10K and 5K races. He says he couldn't have done it without family, friends

and his mantra, "Go! Go! Go!"

He advises other cancer

survivors to put their mind to what they want, and never give up.

And we never forget the recipes. In this issue, we are giving you three desserts that are sure to satisfy the sweet tooth, without the unhealthy ingredients.

We hope you find this issue informative and inspirational. Thank you for reading.

MIKE HENNESSY JR.

President & CEO
MJH Life Sciences®



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Advice From People Like You

We asked readers, "Do you experience 'scanxiety' far in advance of cancer scans? What tools do you use to cope?" Here's what they said.

I have had scans every three months for the last three years and it doesn't seem to get easier, but I have asked my oncologist to call me with results. The wait for results is my hardest part. I suffer from severe anxiety on a good day and he knows that, so he has done everything he can to help make it easier on me and I appreciate him so much for that. — STEPHANIE

Before my prostate cancer diagnosis, I never had anxiety. It developed a few years after initial treatment when a few friends had a recurrence. We are about the same age with the same stage cancer, and so far my scans have been clear. But lately, my blood-work has become a bit unstable, so my anxiety is at an all-time high. I try to live in the moment, but it's hard to not think about it. — GOGS

After stage 4 colon cancer, I can tell you it doesn't get easier. Even though a nurse asked me once why I was nervous, it wasn't like it's my first one. Waiting for the results is the worst too! — TERRI

My husband would ask to have his scan within 24 to 48 hours of his appointment to cut down on post-scan anxiety. His oncologist was great about it! - LINDA

I don't have anxiety about getting the scan, it's about the results. Once I know that a radiologist somewhere knows and I don't yet, the clock seems to tick slower. The wait is brutal, especially if it takes longer than normal to hear back. — **VELVET**

We want to know what you think about CURE®. Address your comments to editor@curetoday.com. If you prefer that your comment not be published, please indicate.



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news & insights

Half of Childhood Cancer Survivors Report Moderate Symptom Burden

It is important for childhood cancer survivors to communicate any symptoms experienced during survivorship with their care team before they worsen. By COLLEEN MORETTI

APPROXIMATELY 50% OF childhood cancer survivors experience moderate symptom burden, and some may face higher risk because of treatment or sociodemographic factors, according to recent study results. Findings from this study also demonstrated that different factors — including education level, medical insurance status and type of treatment — were associated with symptom severity.

"This is very important for cancer survivors (and) clinicians to be aware of the symptomatic problem," I-Chan Huang, study author and faculty member in the epidemiology and cancer control department at St. Jude Children's Research Hospital in Memphis, Tennessee, said in an interview with Heal[®]. "The pain, fatigue, sleep, anxiety, depression, the impacts in terms of quality of life are important. (Cancer survivors may) not have the normal physical activity or social interaction as other people."

THE IMPACT ON SURVIVORS

The study, published in the *Journal of Clinical Oncology*, included 3,085 cancer survivors who self-reported on symptoms in cardiac, pulmonary, sensory, motor/movement, nausea, pain, fatigue, memory, anxiety and depression domains. They were then divided into four symptom clusters (groupings of symptoms) as follows:

- Cluster one (52.4%): Patients had low physical, somatic (pain, fatigue and nausea related to psychological symptoms) and psychological symptom burden.
- Cluster two (16.1%): Patients had low physical, moderate somatic and high psychological burden.
- Cluster three (17.6%): Patients had high physical, moderate somatic and low psychological burden.
- Cluster four (13.9%): Patients had high symptom burden in all three domains.

Symptom clusters, rather than individual symptoms, were used because this provides a more accurate representation of what child-hood cancer survivors often experience, Huang explained.

"It's very different compared to the traditional approach," he said. "Basically, we look at the individual symptom — for example, pain, fatigue, sleep disturbance, etc. — but the problem is that all cancer survivors, they have lots of symptoms. Not necessarily everybody

only had one single symptom. If we diagnose the symptom as (groups, this) means different types of a cluster represents different levels of the symptom burden for all childhood cancer survivors."

Huang said the main takeaway from this study is that symptom burden is significant among childhood cancer survivors. In this study, 50% of survivors had at least one moderate symptom burden.

He also highlighted the different risk factors associated with each cluster type. Compared with survivors in cluster one, those in cluster four were more likely to have less than a high school education, no insurance and exposure to corticosteroids (a class of anti-inflammatory drugs). Cancer survivors in cluster three were more likely to have received platinum-based chemotherapy and brain radiation.

"This means various treatment factors, also social demographic factors, (are) associated with different severity of the symptom clusters in our survivor population," Huang explained.

Additionally, cancer survivors in cluster four reported the poorest performance in physical and neurocognitive status and most impaired quality of life compared with survivors in the other clusters.

WHAT DOES THIS MEAN FOR SURVIVORSHIP CARE?

Huang noted that findings from this study may represent a need to shift some of the focus during survivorship care.

"I think that traditionally (in) our survivorship care we focus on the medical effects, for example cardiac, pulmonary, ... the physical health conditions," he said. "I don't think that previous studies really pay attention to the symptom medical problems in our cancer survivors."

It is important for childhood cancer survivors to communicate with their primary care doctor or survivorship specialist about any symptoms they might be experiencing. Their provider can then assess the symptom to possibly mitigate it or put them in touch with a specialist before it becomes a bigger problem, Huang explained.

"(Childhood cancer survivors) need to be aware of their symptomatic problems," he concluded. "(They should) listen to their body. And if they feel something wrong, don't wait until they visit the survivorship clinic or see their primary care doctor. (They) need to communicate and contact their primary care doctor or survivorship clinician as soon as possible.







SLEEP DISORDERS SUCH as insomnia are approximately twice as likely to occur in cancer survivors compared with the general population. However, survivors can take steps to improve quality of sleep, explained Natalie Solomon.

Solomon, a clinical assistant professor in the psychiatry and behavioral sciences department at the Stanford University School of Medicine in California, gave an overview of how survivors can optimize sleep during the 13th Annual Joining FORCEs Against Hereditary Cancer Conference.

'DON'T CHASE SLEEPINESS'

She related sleep effort to a child's finger trap toy requiring the user to put their fingers in each end of the tube.

"The harder you pull, the more stuck you are. ... The way to actually get out of one of those things is to stop trying," Solomon said. "Sleep is a bit like that — the harder we try to force ourselves to sleep, the harder sleep becomes. So one of the keys to falling asleep is to actually stop trying. ... Don't chase sleepiness. Rather, wait for sleepiness to come find you."

In practice, waiting for sleepiness can mean not getting into bed too early, or getting out of bed and doing something else if someone awakens in the middle of the night and has difficulty falling back to sleep. Survivors should wait

until they are sleepy (which is different than being tired) before going to bed, according to Solomon.

"Sleepiness is that feeling of your eyes getting heavy and you feel like if you lay down, it's likely that you would drift off to sleep," she explained.

USE THE BED FOR THE 3 S'S

If someone is in bed struggling to sleep, they may start to feel frustrated or desperate, and when this happens multiple times, they may start to associate the bed with negative feelings — something Solomon called "conditioned arousal."

"Over time, the bed becomes associated with, and can even cue feelings of, frustration, panic or distress," she said. "We really want to protect our relationship with our beds."

To do that, Solomon recommends only using the bed for the three S's: sleep, sickness and sexual activity.

Solomon also recommended implementing a "wind-down time" to transition from daytime to nighttime. This can include taking a shower, reading or watching a relaxing television show.

Cancer survivors can also schedule "worry time," during the day as thoughts can often become more catastrophic at night.

"The recommendation here is actually to give your worries a little bit of your

attention during the day; it could be talking to a friend or provider or journaling," Solomon said. "One of the things I recommend is writing down your top three worries for the day ... when that worry shows up at night, remind yourself that this isn't the best thinking time anyway... thoughts are more catastrophic at night, so think about this tomorrow in the clear light of day."

AVOID THE CLOCK

Whether sleeping or resting, Solomon said that survivors should avoid looking at the clock, as that itself could be very activating.

"I'm sure many of us, myself included, have had the experience of seeing the time, and starting to do some math: how long have I been awake? How long have I been asleep? How long until my alarm goes off?" she said. "We really want to try to protect our curious minds and rather think in terms of 'this window is protected for resting, whether I'm awake or asleep.'"

Even after a difficult night's sleep, survivors should set their alarms for the same time every day.

"Even if you miss some sleep in the short term (perhaps you would have been able to sleep more), it actually keeps the signal for your circadian clock. If your circadian clock is really strong, it makes it more likely that you can get good sleep in the future," Solomon added.



Finding the Right Information

The internet is flooded with information for cancer survivors, and it is vital they recognize the reliable sources from those that are not. By COLLEEN MORETTI



MOST VIDEOS ON YouTube about cancer rehabilitation were of low quality and did not provide sufficient information for cancer survivors, according to a recent study. The research highlights the need for survivors to better understand how to find reliable, personalized sources.

The study, which was published in the *Journal of Cancer Survivorship*, investigated the quality, reliability and accuracy of cancer rehabilitation videos on YouTube. Researchers used the keywords "cancer rehabilitation" and "oncology rehabilitation," and 53 of the first 200 videos met criteria of high quality and reliability — most others were of low quality. Of note, high-quality videos ran longer, had more views and scored higher on reliability.

Heal® spoke with Nicole Reilley
Dosey, network manager of outpatient
therapy services, including oncology
rehab, lymphedema and pelvic health
services, at Allegheny Health Network
in Jefferson Hills, Pennsylvania, about
the challenges cancer survivors face
when searching for beneficial, reliable
resources on the internet.

"There is a variety of information out there covering a lot of different perspectives, from the patient's experiences to professional advice," she said. "When doing my own research, the biggest concern was reliable sources with good content."

It can be challenging for cancer survivors to search YouTube and Google to find a video or article that is reliable, informative and tailored to their needs. Reilley Dosey noted that not every video on the internet is for every cancer survivor, and rehabilitation or exercise therapy is often tailored to specific side effects, treatments or diagnoses.

Prior to researching online, cancer survivors should better understand what they are looking for. If they want exercises to help with lymphedema (swelling, usually of the arms and legs), then that should be the search term — not just "cancer rehabilitation," which can lead anywhere and may not be beneficial.

"We like to make (cancer rehabilitation) individualized," she explained.
"Such as what was the person's level (of exercise) before, where are they in the spectrum of survivorship, what are their goals. So it does become challenging for the patient to determine what direction to go and what resources to look for."

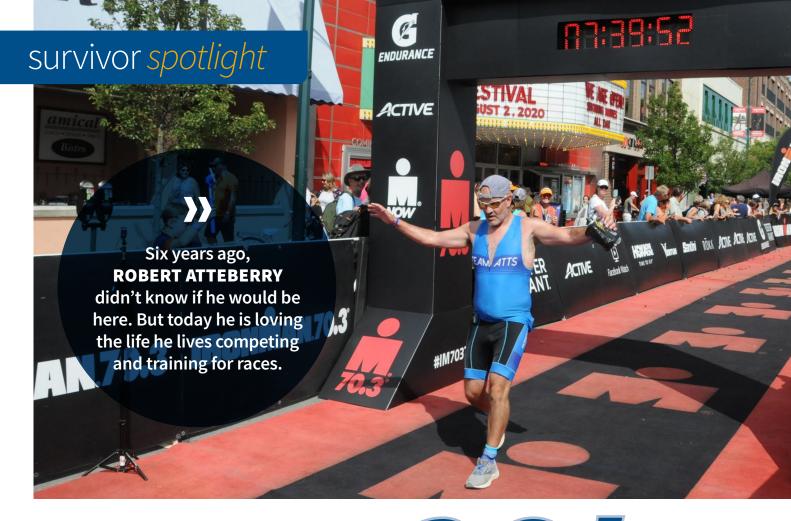
Although not everything online is untrustworthy or dangerous, cancer survivors should be cautious and

understand what is dependable versus what is not. Reilley Dosey highlighted that some of the most reliable information comes from reputable institutions—cancer centers, hospitals, survivorship clinics and advocacy groups. It is also important for survivors to talk with their care team about what rehabilitation they should be doing, so they can better know what to look for in their search—the care team should be able to offer resources as well.

"One of the best resources is your local cancer center, to find out if they offer oncology rehabilitation or oncology exercise programs," she concluded. "When getting started with an exercise program, having a health care professional trained in oncology exercise will help you obtain better outcomes. Support groups are another great resource. There are so many platforms today from in-person to virtual that offer valuable information and programs. Do your research, but don't wait; go out there and start moving."



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GO! GO! GO!

Robert Atteberry never gave up, even after three cancer diagnoses, and has found a motivation and passion for competing in triathlons during survivorship.

By COLLEEN MORETTI

BOUNCING BACK FROM a cancer diagnosis can be difficult during survivorship, but Robert Atteberry, 50, of Clarkston, Michigan, did it three times, and has since competed in multiple marathons and Ironman races.

Atteberry received his first cancer diagnosis in 2012 after turning 40. He was feeling sick and was continuously being treated for sinus infections without getting better. After a visit with a different physician, he received a diagnosis of diffuse large B-cell lymphoma in his sinuses. He finished treatment with chemotherapy, but something still felt off.

"I got out of (treatment) and I didn't feel right," he recalled in an interview with Heal." "I started feeling like I couldn't even go out. I wanted to go out and run; I couldn't do it. And next thing you know, I wasn't walking or talking."

After visits to sleep specialists and psychiatrists, he underwent an MRI, which is when he received his second cancer

diagnosis — brain cancer. The doctor gave him only two years to live. But another doctor at the University of Michigan gave him hope, saying, "I'm going to keep you alive."

After the second treatment, Atteberry started walking and talking again. When he was finally sent home from treatment, he started going out for walks. He hasn't stopped — and has done much more than walking.

During survivorship he has competed in six Ironman races, including five Ironman 70.3 events, which includes a 1.2-mile swim, 56-mile bike race and 13.1-run, and one full Ironman, which includes a 2.4-mile swim, 112-mile bike race and 26.2-mile run. Additionally, he has competed in a few marathons, half marathons and many 10Ks and 5Ks.

These races have become part of a life Atteberry loves — one that six years earlier, during his brain cancer diagnosis, he didn't think he would have. "I have not stopped training.





ATTEBERRY'S
book details more
of his journey
with cancer and
can be purchased
on Amazon.

I have not stopped doing major events," he said. "And I love every single day of my life now."

FINDING PASSION

Atteberry had competed in triathlons before receiving any cancer diagnoses but regained a passion and purpose for them after physical therapy following brain cancer treatment. Because he wasn't walking at his regular pace yet, he began swimming. That started it all, he said. After that, he started walking, running and biking — and didn't stop.

"I never really thought about it. I just did it," he recalled. Training for these races during survivorship was incredibly hard, Atteberry said. But he had help from friends who competed with him; he never felt like he wouldn't make it because he always had someone next to him. That someone next to him was friend of over 25 years, James Collins.

"It's amazing how many friends and family members that help make it OK" he said. "It's just an amazing process. It's awesome. I have an amazing wife that saved me, all the appointments, helping with the pain and never letting me give up. She and our boys mean the world to me."

Also getting him through is his mantra: Go! Go! Go! The phrase came to him during brain cancer treatment; he would say it to himself. Then his physical therapists began encouraging him with it as well. Later, his four children

started saying it and it would appear on team T-shirts at each of his races. It also became the title of his book, "Go! Go! Go! Rise, Fall and Rise Again: The Story of Cancer."

"Go! Go! Go! is what got me through and is what gets me through each and every day," Atteberry explained. It got him through his brain cancer treatment, physical therapy, training for the triathlons and a third cancer diagnosis last year.

During a self-examination, Atteberry felt a lump on his genitals and decided to get it checked. He received his third cancer diagnosis — testicular cancer. He went through six treatments to rid himself of that cancer and extra treatment to make sure it did not spread to his brain. In December 2021, he was told he was in remission.

However, the first two diagnoses didn't stop him and neither would the third. Atteberry continues to train for and compete in triathlons. His most recent events were the Ironman 70.3 Michigan, which he did not fully finish, but he did complete the Detroit International Half Marathon, and is ready for even more in 2023. He said he will never give up competing and that no cancer survivor should give up on themselves either.

"Never give up. Never ever," he concluded. "There's always something. Not everybody has to go out and run, but do something that makes you motivated. It's so important to go, go, go."

Fertility may be affected due to cancer treatment, altering the way survivors move onto their next phase of life parenthood.

By JULIE SCOTT, D.N.P., ANP-BC

bout a week after his wedding in June 2021, 31-year-old Andrew Garcia received a diagnosis of rhabdomyosarcoma (a rare cancer that forms in soft tissue) after what was initially an evaluation of a cut on his hand. After the diagnosis came a whirlwind of discussions about treatments he would need, including surgery, chemotherapy and radiation.

"It felt like life stopped for me," he recalls. "I didn't feel like there was much I could do."

Before treatment started, his oncology team discussed fertility preservation and he was referred to a fertility clinic. "At that time, fertility was the last thing on my mind," Andrew says. "I didn't realize that chemo could make me infertile."

He successfully completed treatment and continues with routine observation to watch for signs of cancer recurrence. Now he and his wife, Cassie, both of Alexandria, Virginia, are trying to pursue the next phase of their lives — parenthood.

"We grieved the beginning of our marriage," Cassie shares. "We didn't get to take a honeymoon yet. The first year he was sick; I was his caregiver, there was work. Ultimately, it has brought us closer together." >>>



After completing treatment for a cancer diagnosis, survivors may feel they have moved beyond one of the most difficult seasons of life. However, for many, the end of treatment marks the start of a new struggle: the path to parenthood. A cancer diagnosis and subsequent treatment can leave long-lasting side effects, making conception a challenge, and for some survivors, an unexpected consequence. Many survivors struggling with fertility feel like cancer has taken one more important thing away from them — a sentiment echoed by the Garcias on their journey to parenthood.

CANCER TREATMENT AND INFERTILITY

Fertility can be affected by many factors including type of treatment received, baseline fertility status, age and other medical conditions. The exact number of people living with infertility due to cancer treatment may never be known but has become more common with cancer cure rates increasing over the years.

Cancer treatments do not universally cause infertility, but many can affect fertility. At the time of diagnosis, a patient may not even be thinking about fertility, or how this health status change could affect the prospect of parenthood. This is especially true in instances of aggressive cancer that requires quickly starting chemotherapy.

Surgery, radiation, chemotherapy and hormonal treatments can lead to infertility for men and women, depending upon their diagnosis. For example, if surgical removal of reproductive organs, such as the ovaries, uterus, cervix or testicles, is required, fertility can be permanently affected. Infertility can also result from radiation treatments provided in the pelvic region.

Additionally, chemotherapy

medications or hormonal treatments may temporarily or permanently stop egg production and induce menopause in women. In men, chemotherapy is known to stop or reduce sperm production.

FERTILITY DISCUSSION

Unfortunately for many, there is no discussion of fertility before treatment starts, and it becomes something else for which those living with cancer, as well as survivors, must advocate for. Experts agree that fertility preservation discussions should be happening from the beginning and continue through treatment and survivorship.

Adriana Sosa, 41, of Castro Valley, California, recalls only a brief discussion about fertility when she received her breast cancer diagnosis in 2015. At the time of her diagnosis, she had a 3-year-old son. "My oncologist was worried because I was so young and had just one child," she says. "He talked about, what were my plans for the future? Did I want more kids?

He was asking questions I didn't know how to answer." She recalls that she was more focused on surviving breast cancer for the sake of her son. "I have to be fine for him. If I can't have kids again, so be it."

Sosa began treatment, which included hormone therapy and surgical removal of her ovaries. Her son is now 12,

and at times she wishes she had asked more questions about how she could have preserved fertility. Her advice to others facing a comparable situation is: "Think out loud. Whatever is in your head, say it. You're the only one who can advocate for yourself."

Dr. Pascale Salem, a medical oncologist at SSM Health St. Joseph Hospital in Lake St. Louis, Missouri, makes a point of having conversations about fertility when discussing treatment options with patients. She recognizes the importance of patients being fully informed about what can happen and wants to do her part to support fertility preservation where possible. "There is a pressure for people to start chemotherapy as quickly as possible," she explains. "But there is time to let fertility preservation take place."

These conversations take place as often as needed for the patient to feel comfortable with the plan and meet directly with experts in this field. She wants patients to have the opportunity to ask questions and have time to seek fertility preservation assistance.

Without adequate conversations between oncologists and their patients, there can be upset and struggles as someone transitions into cancer survivorship and wishes to start a family. Jessica Gorman, an associate professor in the College of Public Health and Human Sciences at Oregon State University in Corvallis, states that many young cancer survivors "are unaware that their cancer treatment was going to affect their fertility. They often state that they weren't well-informed about their fertility options."

Gorman also discussed the impact infertility has on mental health, especially for women, given societal expectations of motherhood. She says cancer survivors have told her that "the idea of not having kids is as hard as, or even harder, than getting the cancer diagnosis. It's a huge loss."

FERTILITY PRESERVATION OPTIONS

Options for fertility preservation and timing for these

interventions can be different for men and women. Depending on the cancer diagnosis, there may not be much time for prioritizing fertility preservation.

Dr. Akanksha Mehta, a urologist at the Emory Winship Cancer Institute in Atlanta, understands that time is pressing in such situations. She works closely with the

> **Emory Reproductive Center** to preserve fertility for cancer survivors.

"When I get a referral, I'll see that patient as soon as possible. I'll either see him in person, in the office or with a telemedicine visit. I like patients to understand how the process works," she says. "Someone needs to continue to follow them even after treatment is done. Many treatments can lower testosterone, and someone needs to follow that as well."

Mehta's patients are men, she adds.

and her approach to fertility preservation includes a recommendation to have one or two sperm deposits frozen for future use. Sperm quality is the best when the sample is collected before starting chemotherapy medications. "Fertility should be a consideration from day one,"

For women, the process is often more complicated and usually requires additional weeks of planning. Egg harvesting from the ovaries may be recommended to help preserve fertility. This is typically done with injections of hormonal ovarian stimulation medications. Hormone levels and the number of egg follicles are monitored with regular ultrasounds. When the follicles reach the appropriate size, a trigger shot is administered, allowing the eggs to be released and harvested a few days later. The eggs can then be fertilized with sperm to form embryos for frozen storage, or they can be frozen without being fertilized.

Previously, egg harvesting could take months, as it needed to be timed with the natural menstrual cycle. With newer medications and procedures, the process now takes two to three weeks. Although the process is quicker, the cost of the procedure and storing the frozen eggs or embryos can be prohibitive for many patients. Everyone's financial responsibility can differ, and it can cost tens of thousands of dollars for fertility preservation.

The price tag associated with fertility treatments has been an issue faced by the Garcias. They both have >>

- ANDREW GARCIA



then pick and choose what

they want to cover. They don't

cover the cost of moving the

14 HEAL® WINTER 2022

ovarian transposition), or even

removal of ovarian tissue to be

frozen and transplanted later



Letting Go of the Victim Mentality

A cancer survivor recently decided to change her outlook to focus on celebrating life every day. By BONNIE ANNIS

VICTIM. THE DICTIONARY defines victim as a person injured or killed because of a crime, accident or other event or action.

That about sums it up. It's how I saw myself — as a victim of cancer. I didn't ask for cancer. I never expected

it. But it came. And when it did, it did a number on me.

You'd think after eight years I'd have let go of the victim mentality, but I hadn't. I didn't even realize I was suffering from that type of thinking until recently.

After a bout of COVID-19 and then several consecu-

tive illnesses, I was sick and tired of feeling sick and tired. I blamed it on postcancer-related fatigue. I struggled daily and my energy level was practically nonexistent. It was difficult to get through each day without making myself do things. Every day was exhausting.

It wasn't living; it was existing. There was no happiness or joy. I wanted to thrive but I didn't know how. How could I when it took every ounce of energy to get through the day?

I'd wake up each morning, thanking God for one more day, but as the day wore on, I wondered why it was so challenging.

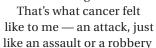
"Why can't I let go and break free?" I asked. That's when I heard a still, small voice speak to my heart: "You've got to let go of the victim mentality."

Although I heard the words clearly in my mind, I was shocked. Had I really been living like a victim? Had I been thinking of myself in that way?

I didn't consider myself a victim not really — but then again, maybe I did.

Eight years gone and you'd think I'd have long since left thoughts of cancer behind, but

> that nagging fear had taken root and wouldn't let me go. Every ache, every pain, every uncontrollable thing my body did made me wonder whether I was going to be under attack again.



or some other violent crime, an unprovoked, unexpected assault on my person. No wonder I'd adopted a victim mentality.

After any kind of attack, whether it be health related or otherwise, the victim has the choice whether to fight to survive or give up. Making that choice is crucial and can greatly impact one's future.

I had to come to the realization that I wanted to live. Not only did I want to live, but I also wanted to live well. I wanted to do the things I enjoyed and have fun. No longer did I want to allow my body, and the way it was feeling, to dictate my choices.

Ironically, our mail that day held the key. Along with a stack of bills was a colorful postcard. On the front in bold colors were the words "Celebrate Life." The card was announcing an upcoming celebration of life ceremony for cancer survivors at our local cancer

treatment center. I'd been invited to participate.

Holding the card in my hands, I turned it back to the front, reading the words over again: "Celebrate Life."

That's when I realized I hadn't celebrated life post cancer. I thought hard about it and made the conscious decision to do something. I had to let go of the victim mentality that had held me prisoner for so long.

Since making the decision to let go, I've felt an indescribable weight lifted from my shoul-

ders. No longer am I carrying around a burden I wasn't supposed to bear. Now, it's like I've been given a new lease on life.

Sure, I still struggle with fear, worry and anxiety — and probably always will. Those are weak spots in my armor, but I know I can choose to move from a victim mentality to a victor mentality with a little effort. It's all about choice.

Although my calendar has more medical appointments on it before the end of the year, there are also some upcoming trips I've planned and I'm looking forward to those. I'm going to visit a local sunflower farm, a state park and a pumpkin farm.

In the past, I stuck close to home, just in case of a health crisis and to avoid the possibility of catching COVID-19 again.

I'm so glad I realized my warped reality. That erroneous way of thinking held me captive. Now, I'm looking for ways to celebrate life. Whether it's something as simple as getting out of bed in the morning and enjoying a steaming cup of coffee or hiking miles of rough terrain in one of our beautiful parks, I look forward to what each new day brings.

Someone once said, "Until further notice, celebrate." What wise words. I think I shall.



BONNIE ANNIS

Control What's Next

One survivor is no longer the "helpless patient," and reminds himself of this to keep in check. By STEVE RUBIN

MYWIFE AND I recently flew across the coast to visit family and friends in California. It's always nice switching up the environment, getting away from our cramped New York City apartment to enjoy fresh scenery and catch up with loved ones.

One aspect that can be challenging for me, however, is losing the sense of control I have back home. For years, I've been on disability/

medical leave. With the help of alternative and

holistic health specialists, I have been healing myself at my apartment after conventional treatment failed to stop my cancer and doctors gave me a less than 10% survival rate.

I'm blessed that my situation has improved, but as my nervous system continues recovering from the trauma, reintegrating back into traditional society has proven ... well, full of lessons. In recent years, I've grown accustomed not only to controlling how I spend my day — diet, activities, spending — but also having people basically yield to what I've needed, me being the cancer patient and all.

Now that my condition has improved and I'm starting to take on more in life, the world seems to be viewing me less as the "helpless cancer patient" and slowly raising its expectations of my contribution level. I don't mean this in an unfair way; I think it's totally natural and warranted, and for the most part this has led to tremendous self-growth. I need to push myself to show up for others more and get out of my own head, stop thinking only about my needs — that kind of thing.

Occasionally I hit my limits. On this trip to California, my wife and I ran into The setbacks are disheartening and, at times, monumentally embarrassing. But they're a necessary part of reaching a more worthwhile destination.

—STEVE RUBIN



STEVE RUBIN

a situation where I dropped the ball. We were out to dinner after a long day with friends and I handled

myself poorly. I was overtired, couldn't find anything on the menu in line with my diet or that I wanted, and felt that everything was overpriced.

Instead of staying flexible and bringing good energy so we could all enjoy a great night together, I grew overwhelmed and experienced dissociation. I basically shut down, checked out and felt detached from my body. My nervous system had blown; I grew irritable, impatient and developed a false narrative in my head that everyone else was terribly inconsiderate for not noticing and responding to my needs. In fairness, that's not at all an accurate representation of what was happening; it's just what I was telling myself. My negative energy was palpable.

Looking back, I'm ashamed of how I handled myself. That's not the person I strive to be. But at the same time, I try to remind myself that I didn't mean to ruin the night or act selfishly (during the dissociation, it felt like I'd become an outside spectator). I just ran into a new situation that knocked me down a setback.

Later that trip, my wife and I were reminiscing through old photos and stumbled upon family holiday pictures from a few years earlier. There I was: bald, bloated and facially deformed from steroids and a year's worth of chemo. It was a shocking sight; I literally don't remember being inside that body. More dissociation, I suppose. Anyway, that moment offered me compassion and reminded me of all I've been up against, and that it's OK to have setbacks — what matters most is getting back on my feet.

Back when doctors passed along such a scary cancer prognosis, there was nobody to turn to for answers to survival. I had to keep researching every single day, experimenting with new ideas and making constant adjustments. It was the scariest experience of my life. Yet, I kept with it and somehow pulled off a miracle.

My recent scan results have come back showing no disease evident.

Aside from the gift of life, this massive accomplishment has instilled in me the confidence to know that I can figure out my way toward leading a healthy, successful life after cancer as well. The setbacks are disheartening, and at times monumentally embarrassing. But they're a necessary part of reaching a more worthwhile destination. I must learn from each growth opportunity and keep plugging along, one day at a time.

Be Kind to Yourself

JANE BIEHL, PH.D.

Why one cancer survivor remembers to not compare her abilities now to those she had before her diagnosis. By JANE BIEHL, PH.D.

ONE OF THE hardest acts for cancer survivors is being kind to themselves. We need to realize how we are impacted by our own thoughts as well as read about the latest information and research about our various cancers.

A phrase that is probably overused these days is "be kind." However, it is an important one. Our world is so full of violence that we have adapted this phrase to remember the importance of kindness. I remember so many times when I have been at my lowest, and a kind word.

at my lowest, and a kind word, a card, a text or even a gift has arrived to cheer me up. I try valiantly to help others with kind gestures, too.

However, what we forget to do is be kind to ourselves. Being a cancer survivor is hard under any circumstances. I never knew how hard until I received my diagnosis. Just this week I lost another tooth, which makes a dozen lost to this vicious disease.

We really do need to take care of ourselves. We must be kind to ourselves. Every one of us has been

> through a lot and that is why we call ourselves survivors, thrivers or whatever phrase you wish.

I personally have a bad tendency to compare my activities before cancer to what I can do now and beat myself up. Does this really make sense? Would

I ever do this to anyone else? The answer is a vehement "no." When I was a counselor, I remember saying to my clients, "Would you ever say the horrible things to someone else you do to yourself?" Terrible thoughts like "I am lazy, I am unmotivated, I am ugly" and on and on. We would not, and we do not deserve that kind of abuse from ourselves.

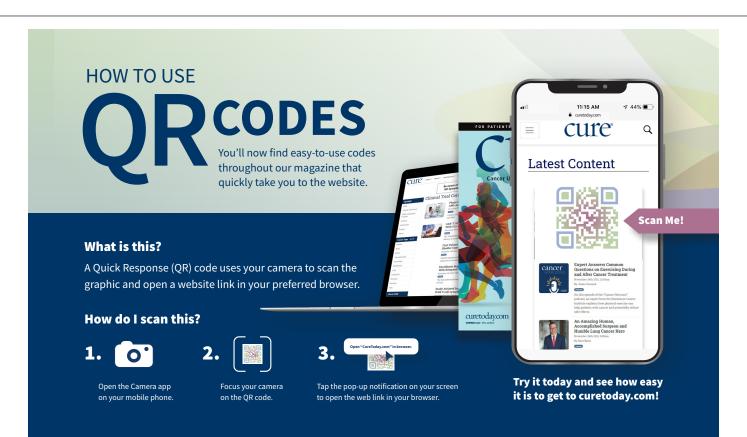
Other people say this better than I do. A dear friend gave me a book titled "A Year of Positive Thinking" by Cyndie Spiegel. There were lots of wonderful quotes, but here are two of my favorites:

"Don't forget to say 'I'm sorry' to yourself as much as you need to. The greatest forgiveness is the forgiveness you show yourself."

"Jack Kornfield says it succinctly.
'If your compassion does not include yourself, it is incomplete.'"

I have several friends who had cancer and some of them are no longer with us. Their inspiration, courage, caring for others and their humor amazed me. They reached out to others by being compassionate to themselves. They did not waste time beating themselves up but extended a hand and kind words to others. We need to love ourselves before we can love others.

Two simple words have a lot of meaning: be kind. ■



Don't Get Run Over by the Cancer Bus

Advice on dealing with fears, worries and uncertainty offered by a cancer survivor. By WILLIAM RAMSHAW

LET'S FACE IT, finishing our cancer treatments is only the first step on a long journey. I wish I could put a happy face on this, but I can't.

Among the many things we cancer survivors face are endless follow-ups

at our clinics, an everpresent reminder of what we've been through. Of course, some of us opt out of these follow-ups due to the gripping anxiety they induce — or worse, we lack insurance to pay for them.

But beyond these constant reminders. many survivors face bouts

of depression and endless days of feeling that although the cancer bus missed us before, it won't next time. Our once-bright futures now seem sullied. Our hopefulness is replaced by dread. We've taken to spying on our body, thinking it is a conniving cheat looking to betray us.

After all we've been through, make no mistake, bouts of depression are real and can be as lethal as what we have survived. Dealing with them is essential. It is easy for some to cast them aside, but others may need to seek help.

When I am feeling like my cancer bus of depression is trying to run me over, I do the following to get out of its way.

Look at it from the outside in

I try to focus on the fact that I have survived pancreatic cancer for almost nine years, when many don't see two and few see five. Sadly, for many of us, simply surviving is like winning the lottery, but we soon forget how lucky we are to have made it.

Perhaps this goes back to the glass half full or half empty analogy. I would portend we can teach ourselves to see our glass as being half full. If a superanalytic person like myself can do it, I would say almost anyone can. It's

> better to be thankful that our glass is not bone dry versus quibble over how full it is. I have found that for every ugly situation I face, there are always other people facing far worse. We need to be thankful for our situation, not wish it was someone else's.



WILLIAM RAMSHAW

Understand that worrying about the future is a fool's game

None of us know our future. Cancer is an indiscriminate killer. But we have an advantage over others in that we have survived it. Cancer is no longer on my list of things that might kill me.

I need to focus on the present and not worry about a future over which I have no control.

Talk it over with a good friend

I am so fortunate to have an awesome friend who, during the past several years, has walked with me through my sunless valleys for months at a time. I am blessed to have him. Simply talking to him, and hearing my words escape my mouth, has helped me realize I am not alone on my journey.

For me, there is nothing more helpful than putting spoken words around what's happening inside my head. It forces me to conceptualize my feelings. Doing this helps me figure out how to handle my primal fear of dying and leaving so much undone. If you don't

have a confidant with whom you can let down your guard and tell them you're scared, find one.

Avoid feeling ashamed

Some people are raised in a family where an admission of needing help is viewed as a grave weakness. The general culture of "buck up, buttercup" is alive and well. Words like "just deal with it" or "tough it out" are said. Shame is something we all face, but for some of us, it stops us from either telling our doctors about what is going on or seeking help for it. Depression is nothing to be ashamed about. Avoid feeling ashamed.

Tell the doctor what is going on

I know my mind can take a twinge in my side and run away with it. I get on the internet and look up all the things that might cause a twinge and, of course, I settle on the worst possible cause. Sometimes a few minutes talking to someone licensed to practice medicine, maybe a test or two, can rule out these worst-case scenarios. But if we don't talk to our doctors, they can't help us.

Seek help

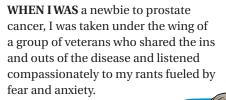
Facing cancer and then surviving it is a feat. However, if you find black clouds lit up with thunder hanging over you without relent, it may be time to seek help. There is no shame in this. The only real shame is in gritting your teeth and gutting it out. Most clinics have trained therapists on staff who specialize in treating cancer-induced depression. If they don't have one on staff, they know who is good in the local community.

There is no need to let your cancer bus of depression run over you.

From Newbie to Advocate

One cancer survivor now finds joy in offering support to others who have fears about their disease and death.

BV RON COOPER



I joined this support group in the late fall of 2014, a few weeks before my prostatectomy, and I learned a lot from men who had been living with the disease for many years. They provided me with information, insight, and, most importantly, confidence that many effective treatments were available for my stage 3 prostate cancer.

I attended these monthly meetings for around eight months and looked forward to seeing these guys and hearing their voices of reassurance and support. When a new member arrived, they were given the floor for most of our hour-long meeting. We took care to listen carefully to this newcomer who sought accurate, scientific information and moral support as he told his unique story.

One new member introduced himself as a three-year prostate cancer survivor who shared his diagnosis and treatment history. He seemed rather matter of fact in relaying all these intimate details to



us, until he reached the part of the story where the doctors had given him just months to live. They had tried every available treatment and, unfortunately, the cancer had spread

> much too far for too long and now he faced the end of life.

"They told me to just go on home," he said. "They said I should get my final affairs together. Thing is, I don't feel that ill. I don't feel like a terminal patient."

He then let out a big sigh and the room was filled with intense silence. All eyes and hearts were directed toward this fellow patient who had tried everything, but now faced a brutal truth. It seemed so impossible that a man who looked to be in the pique of good health could be dying.

RON COOPER

I was thunderstruck by this gentleman whose life would soon be over. I began to see myself in his place in the not-too-distant future, since my disease was stage 3 and worried incessantly that I would move to the final stage of the disease.

I worried that the radiation and hormone treatment therapies that I was then undergoing would prove to be inadequate. I wondered, "Would

I also be told to go home and put my affairs in order?"

Hearing him speak that night caused me to recoil in horror, and I obsessed about the worst-case scenarios of being a cancer patient.

After the meeting, I left feeling distraught and depressed, barely remembering how I even got home. I then decided to drop out of the group so that I would never again be forced to hear another story so grim and devastating as his.

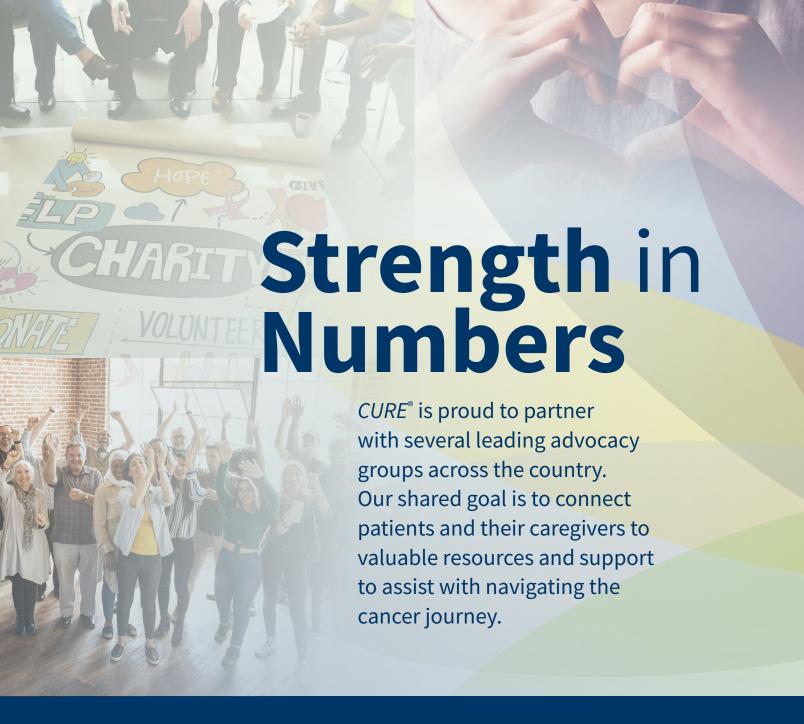
As the years flew by, thankfully my treatments were effective, and I was not told that my days were numbered. I am grateful for my providers and the treatments they chose for me. I know that I could have been that very same man, if my disease had not been caught in time or if my treatments had not hit the mark.

I was humbled by the experience and have since rejoined the group, which was a joyful homecoming.

Now, I am one of those voices of experience, with reassuring words and a compassionate heart, who listens to a man who is freshly diagnosed and talking nonstop about his fears of sickness and death.

I am one who helps and supports the newcomers leaning on veterans.

I am one who finds joy and fulfillment in paying it forward.





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MARESEA KING has since given birth to her second child, whom she was told she would only have a 1% chance of conceiving.

when treatment is finished. Ovarian cryopreservation is still experimental, but may be a treatment choice for those who receive diagnoses during childhood.

Maresa King, 35, of Irvine, California, struggled with infertility during and after treatment for breast cancer. She and her husband decided to go through IVF after understanding the effects chemotherapy would have on her fertility. But because she was on disability, only making 60% of her annual salary, they decided to take out a loan to cover the costs.

However. her treatment and the cancer were so aggressive that the oncologist only gave her one shot at it. They were able to retrieve 12 eggs; however, she was told the quality was "really bad." Three were able to be frozen. After undergoing IVF treatment, during a six-

month break from cancer treatment, two were successful and King was pregnant with twins. Unfortunately, due to pregnancy complications, only one lived.

"After that, the doctor told me, 'You're done. You can't have kids on your own. The possibility of ever having kids on your own is about 1%," she says. "We counted our blessings and understood that was our only shot."

But it was not. With a 1% chance, King was able to conceive naturally. Her pregnancy went well, and she has since given birth — however, one lasting side effect she did experience from chemotherapy was shortness of breath.

"I was very shocked and in disbelief that I was actually pregnant. Then anxiety took over because I didn't believe things would work out and I would go on to have a healthy pregnancy, especially with everything that happened with my first pregnancy. Eventually all I had left to do was have faith and pray that God would allow

me to get through it and bring to this world a healthy baby," King shares.

For some cancer survivors, the path to parenthood may be difficult. There may be multiple options available, though, for those who wish to become parents. In addition to procedures such as IVF, other options can include surrogacy, IVF with donor eggs or adoption.

During this journey, it is important for cancer survivors to be their own advocate. Survivors will need the support of their oncology team not only to treat their disease, but also to live their life beyond cancer while on the path to parenthood. **b**

heal at home

Brush Up on Oral Hygiene

It is important for survivors to maintain healthy oral hygiene because they face increased risk of dental problems. By COLLEEN MORETTI

CANCER SURVIVORS CAN face many side effects from treatment; unfortunately, some are not manageable. However, others, such as dry mouth, can be counteracted by practicing good oral hygiene.

Heal® spoke with Dr. David R. Dean, director of oral medicine at the Fred Hutchinson Cancer Center in Seattle, about risk factors for developing oral problems, effect on quality of life and what cancer survivors can do.

RICKS FACTORS AND SIDE EFFECTS

Developing oral side effects is extremely common in some types of cancer, specifically head and neck cancers. The radiation levels are so intense that damage to salivary glands (which produce saliva that aids digestion, keeps the mouth moist and supports healthy teeth) can result, Dean explained.

Survivors with certain immune-related issues from cancer therapy also can be at risk for oral side effects. This includes those who have had a bone marrow transplant or peripheral blood stem cell transplant and may develop graft versus host disease

(a condition that occurs when donor bone marrow or stem cells attack the recipient), which can also affect the salivary glands. Immunotherapy and chemotherapy also may cause oral side effects in survivorship.

Dean noted that the most common oral side effect cancer survivors experience is dry mouth. This can greatly affect quality of life because survivors can find it hard to talk and socialize. Eating may become difficult as well, so some individuals may lack the nutrition they need.

"The dry mouth issue, which is probably the one that comes up the most often for people, affects quality of life because just in general the mouth is less comfortable — it can make it more challenging to speak, eat and swallow," he explained. Decreased saliva also increases risk for cavities which can lead to pain, increased need for dental work or even loss of teeth. "It's just one more thing on top of every other aspect of survivorship, which can be pretty tough," Dean added.

THE IMPORTANCE

If someone has ended treatment or is undergoing treatment through survivorship, maintaining daily oral hygiene can decrease the likelihood of many of these side effects, Dean said.

His top oral hygiene tip is to keep up with daily brushing and flossing; this will help combat dry mouth, and symptoms that come with it such as tooth decay. Survivors should also have what Dean called a "dental home" — a dentist or clinic they can go to consistently. The dentist should know their cancer and treatment history to personalize treatment for survivors and help them understand risks they face. A dentist can also help to screen for oral cancer, which can be more likely in survivors of certain cancers, and other late effects of cancer therapy, he added.

"Having somebody who knows your mouth well and can provide a general screening to supplement all the things that the medical team is already doing really helps a lot," he said.

Dean added that oral hygiene is an area that can be controlled, which is important for cancer survivors to do to avoid pain or discomfort.

"It's important to try and minimize any pain and suffering related to preventable causes," he said. "It's something where there can be some control. (Cancer survivors) feel like they can actively focus on oral hygiene and that it is likely to make a difference, as opposed to something where it's excessively hard to prevent complication." h

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MOUTHWASH FLUORIDE IS RECOMMENDED

• Survivors should use an antibacterial, alcohol-free fluoride mouthwash — ask the dentist for a recommendation.

• The dentist may recommend a daily fluoride rinse or gel that can be used at home after brushing.

W TO MAINTAIN

Taking care of teeth and gums is always important, and even more so for cancer survivors at higher risk of developing oral and dental problems. Dr. David R. Dean and the Fred Hutchinson Cancer Research Center Survivorship Program suggest the following tips for cancer

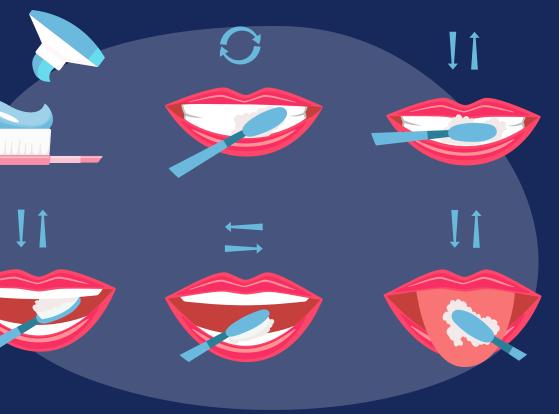
survivors to keep teeth and mouths as healthy as possible.

If cancer survivors notice any signs of infection in the mouth or gums such as redness, tenderness, painful teeth or increased sensitivity — they should notify a dentist immediately.



KEEP UP WITH REGULAR **DENTIST VISITS**

- Survivors should have dental checkups every six months.
- It is important for the dentist to understand their cancer and treatment history so that survivors know what risks they may face.





USE PROPER TECHNIQUE WHEN BRUSHING

- Brushing should be done twice a day using a toothpaste containing fluoride, which will help prevent tooth decay.
- Hold the toothbrush at a slight angle toward the gum while brushing along the gum line.
- Use a gentle touch; brushing too hard may irritate the gums.
- Brush the tongue to remove bacteria, which can cause bad breath.



FLOSSING TO REMOVE BUILDUP

- Brushing alone cannot eliminate bacteria buildup, so gently flossing once or twice a day in between teeth can help remove leftover plaque.
- A small amount of bleeding while flossing is normal. However, if the bleeding increases or gums are red and puffy, this may be a sign of infection; survivors should see a dentist.











Treat yourself without the guilt! Here are three delicious — and most importantly nutritious – desserts to try at home when you are craving something sweet.

RECIPES provided by THE DANA-FARBER CANCER INSTITUTE IN BOSTON



Chocolate Chia Seed Pudding

INGREDIENTS

- 1 ½ cups unsweetened almond milk
- ⅓ cup unsweetened cocoa powder
- 1 tablespoon and 1 teaspoon maple syrup
- ½ teaspoon cinnamon
- 1/8 teaspoon salt
- ½ teaspoon vanilla extract
- 1/3 cup chia seeds

GARNISH (optional)

- 1/4 cup raspberries (fresh or frozen)
- 1 tablespoon fresh mint leaves, chopped
- ½ teaspoon unsweetened shredded coconut, toasted
- 1/2 teaspoon chocolate shavings or cocoa powder

DIRECTIONS (yields 4 servings)

- 1. Add ¼ cup almond milk and cocoa powder in a bowl. Whisk well to combine.
- 2. Add remaining almond milk, maple syrup, cinnamon, salt and vanilla extract. Whisk to combine.
- 3. Stir in chia seeds.
- 4. Cover and place in fridge. Stir after 3 hours. Let chill overnight.
- 5. Garnish with raspberries, mint, toasted coconut, and chocolate shavings.



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or visit us at curetoday.com/recipes for even more healthy and tasty snacks.



Sweet Potato and Dried **Cranberry Cookies**

INGREDIENTS

- 1 medium sweet potato, baked and mashed
- 2 tablespoons ground flax seed
- ¼ cup skim milk (or unsweetened almond milk)
- ¼ cup canola oil
- 1 tablespoon vanilla extract
- ½ cup brown sugar
- · 2 cups whole wheat flour
- ¾ teaspoon cinnamon
- · 1 teaspoon baking soda
- 1/2 teaspoon salt
- · 1 cup rolled oats
- ½ cup almonds, slivered
- ¾ cup dried cranberries

DIRECTIONS (yields 20 cookies)

- 1. Preheat the oven to 450° F.
- 2. Wash sweet potatoes and pierce with a fork. Bake them for about an hour.
- 3. Cool sweet potatoes, then slice in half, scoop flesh into a large bowl and mash.
- 4. Preheat oven to 350° F and lightly grease baking sheets.
- 5. In a large bowl, combine sweet potato puree, ground flax seed, milk, oil, vanilla and brown sugar.
- 6. Sift flour, spices, baking soda, and salt; stir until incorporated.
- 7. Fold in oats, almonds and dried cranberries.
- 8. Scoop onto baking sheet and bake for 12-15 minutes.



Brownies

Black Bean and Walnut

INGREDIENTS

- 1 (15 1/2 ounces) can black beans, rinsed and drained
- ½ cup olive oil
- · 2 large eggs
- 1/4 cup unsweetened cocoa powder
- 1/4 cup agave or maple syrup
- 1 teaspoon vanilla extract
- 1/2 cup mini chocolate chips, divided into 2 portions of 1/4 cup each
- 1/3 cup white whole wheat flour
- ½ teaspoon baking powder
- 1 teaspoon canola, coconut or walnut oil
- ¼ cup chopped walnuts

DIRECTIONS (yields 12 servings)

- 1. Preheat oven to 350° F. Lightly grease 9-by-9-inch square baking pan with oil.
- 2. In a blender, puree black beans in olive oil. Then add eggs, cocoa, agave/maple syrup and vanilla. Melt half of the chocolate chips and add to the blender. Blend until smooth.
- 3. In a small bowl, whisk together the flour and baking powder. Add to the blender and pulse until just incorporated.
- 4. Stir in the remaining chocolate chips and pour into prepared pan. Sprinkle walnuts on top.
- 5. Bake about 20 minutes, until surface looks somewhat matte.
- 6. Let cool at least 15 minutes before cutting and removing from the pan.





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