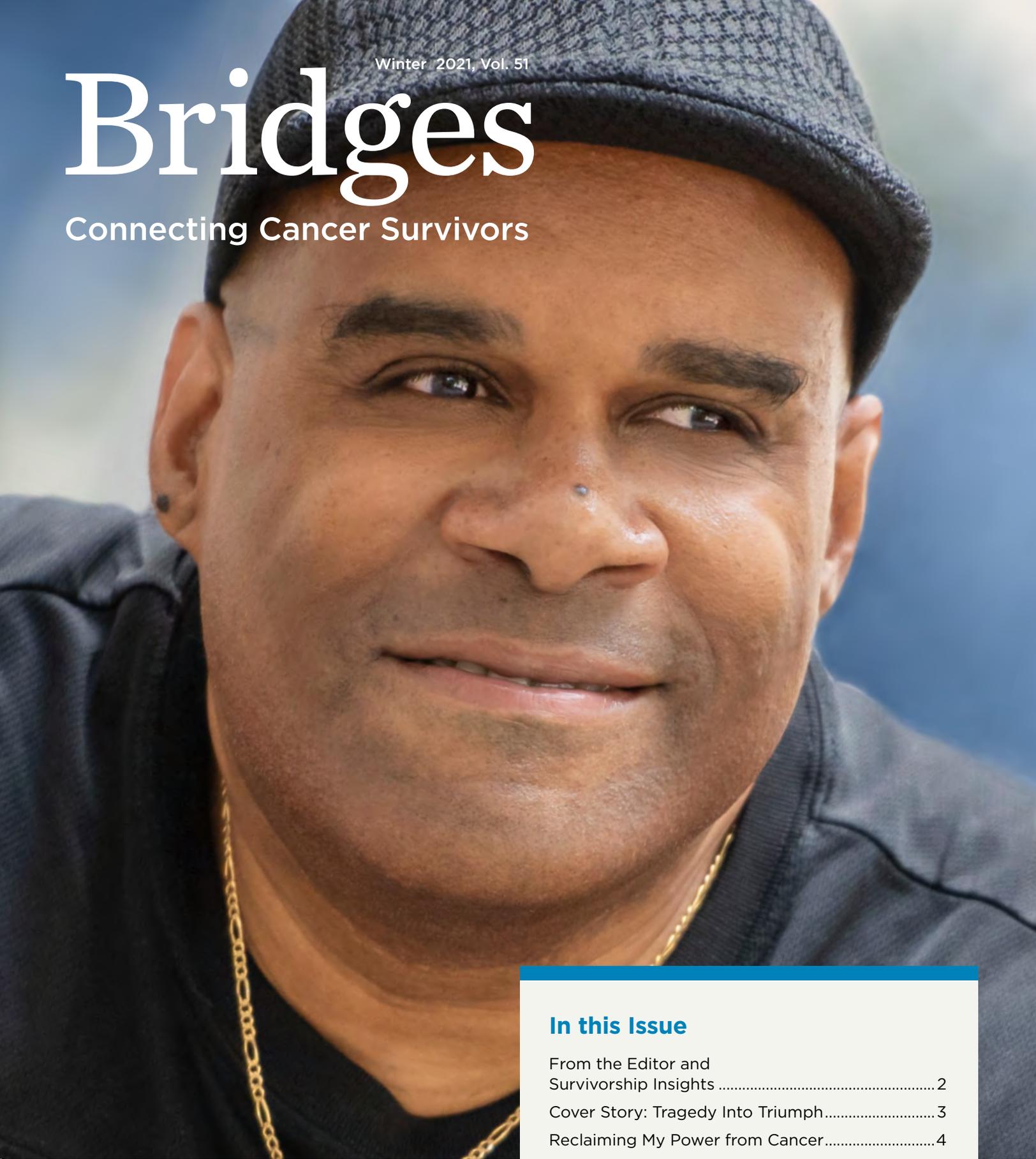


Winter 2021, Vol. 51

Bridges

Connecting Cancer Survivors



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Memorial Sloan Kettering
Cancer Center

From the Editor

By Eileen F. Gould



The holidays are usually a time of reflection and also a time of gratitude, especially after this past year of COVID-19.

As both a patient at MSK and as the Patient Editor of *Bridges*, I continue to be amazed by the institution's ability to stay open for business and continue to provide excellent care during a worldwide pandemic. I want to thank everyone at MSK for their dedication to making sure patients get superb care during very difficult and unprecedented times.

Bridges recently published its 50th issue. Even during these recent difficult months, the need to build connections among cancer survivors continued as the writers shared their inspiring stories. It has been a collaborative effort thanks to many people, and for that I am very grateful.

It has been a privilege to be the Patient Editor for the past 12 years and to see the newsletter grow and expand. I want to thank everyone who made each issue of *Bridges* come to fruition — even during the pandemic. We are looking forward to publishing many more stories of hope and survival in *The World of Cancer*.

As we enter into 2021 and the new normal, we hope the New Year will bring peace and health to all of our readers.

If you would like to share your story or receive an email copy of *Bridges*, please visit www.mskcc.org/bridges

Survivorship Insights: Survivorship and COVID-19

“COVID-19 requires the restructuring of our daily lives. The effect treatment had on my immune system necessitated avoiding crowds, people with colds — basically, situations where I could get sick that would pose little threat otherwise. Acting similarly today is not overly difficult due to past experiences.

Your health is your wealth; invest wisely. Small sacrifices today may lead to larger rewards tomorrow. Limiting our exposure to people, places, and things during COVID-19 is an investment in our future. We've been through/are going through too much to lose sight of the larger picture.”

— Tom Co.

“Dealing with chemotherapy, radiation, a complicated surgery, and a long and difficult recovery taught me patience, resilience, and toughness. I looked at life long-term rather than as a day-to-day journey. I am dealing with the COVID-19 crisis in the same way.”

— Donald

“

Cancer ravaged me in 1997. Not knowing what was happening, I was frightened beyond words. I learned to trust my MSKCC doctors by asking questions. Now? The Internet is full of information — factual and anecdotal — so, do a deep research dive about your personal care to become your own advocate.”

— Steven

“

Life lessons from cancer are key to COVID-19 survival. The rapidity of daily changes, the need for isolation, and the courage to verbalize strong scientific beliefs all were experienced during cancer and COVID-19.”

— Nancy

■ *Continued on page 8*



■ Cover Story

Tragedy into Triumph

By Russell Smith

Russell Smith, a Senior Billing Representative with Montefiore Medical Center, lives in the Bronx area of New York City. He lives alone and enjoys exercising, sketching art, and reading books in his spare time.

In May 2016, I was diagnosed with stage II prostate cancer, and it nearly destroyed my life.

After several months of pain and suffering, I had a prostatectomy. For the next few days, I sat in my apartment in a daze. Then one morning, I opened my window and a gust of wind swept across my face: It felt like pure bliss. For the first time in my life, I started to appreciate the feel of the wind. I took a closer look at the trees, and they were filled with the most beautiful green leaves. I listened closely to the chirping of birds; it almost seemed as if they were singing to me. I know in the past that I saw trees and heard the birds, but this time, I could feel their energy. My entire soul was now completely open, like I had experienced a rebirth. It was a feeling that I will never forget: I became aware of my inner being and divine spirit.

Although surgery cleared me of the cancer, the mental scars are still present. Talking to a therapist helped me to process my feelings about having prostate cancer and its impact on my life. Our sessions were emotional and intense, but I usually left her office feeling fulfilled and burden free. We are all equipped with a healing energy, but it takes discipline to learn how to use it. The secret for me has been learning how to meditate and focus on my breathing, the beating of my heart, and the clearing of my mind. Meditation has been a major key in connecting with my inner being and rediscovering my true self.

I still attend appointments with my oncologist and urologist so they can continue monitoring my progress. Twenty to thirty percent of men who have been treated for prostate cancer might experience recurrence, which is why I still live in constant fear of the cancer coming back and returning me to a time in my life that I would never want to repeat. But in the meantime, my focus is on staying healthy through

exercise, healthy eating, and positive thinking. My new outlook on life is on time well spent and not wasted.

A couple of years ago, I saw one of my co-workers in the park. He assured me of how well I was looking and described me as a walking testimony. I thanked him. He began to cry, explaining that his wife had just been diagnosed with cancer. I hugged him in reassurance and began to cry with him. Earlier, when I was fighting for strength every day and trying to get back to my life by eating healthy and exercising, I had never thought that I could have an impact on someone else's life. I thanked God for allowing me to be a vessel of hope for somebody else, which confirmed why I am still alive.

My suffering, my survival, and my testimony can impact other lives: That is now my goal.

Reclaiming My Power from Cancer

By: Tarlise (Tarlle) Townsend



Tarlle is working towards a PhD in public health. Her research focuses on socioeconomic and racial/ethnic disparities in health with an emphasis on the opioid crisis. In addition to spending time outdoors, she enjoys doing crossword puzzles, knitting poorly, learning new languages, and — more than anything — good conversation. Tarlle, age 28, learned her melanoma had progressed to stage IV in May 2019, over four years after receiving the original stage III diagnosis.

Lately, I haven't been sleeping as well as I'd like. At bedtime I'll be feeling bright, buoyed by the moments of joy from the day, but the choppiness of sleep suggests something darker is lurking. I'll have dreams that my treatment in a clinical trial for stage IV melanoma isn't working. I'll wake up abruptly, heart pounding. This is my first clue that there's something I'm not dealing with.

My doctors have been hopeful about this treatment, and so am I. But the thing I've noticed about hope is that because it is by definition tied to a desire — to not have cancer, to live! — it creates space for fear. Fear that my hope is misguided, that the cancer will win and I will lose. And it is fear that is permeating my sleep, itching at my subconscious despite my best efforts to stay bright.

How do we have hope without fear? I don't have the answer, but I know that suppressing the fear does not work for me. Admonitions to “just stay positive” to banish from my mind all thoughts that treatment might not work for me gives cancer and its associated anxieties a Voldemort-like quality. By not speaking it, not shining a light on it, I can't acknowledge the reality that what I am going through is difficult; I can't have compassion for myself in that struggle. Instead, I add to the internal upheaval by fighting with my fears, telling them to “Get lost!” and I'm left feeling alienated from others, trying to maintain a “strong” and “positive” persona — sometimes as much for their benefit as for mine.

Amid all of this, the fear festers.

So, I'm trying something different. What if “beating cancer” meant rejecting its stranglehold on our life and mental-emotional well-being? What if “winning” meant living well amid and despite cancer, regardless of what lies ahead?

Instead of only thinking positive thoughts, I'm allowing the scary ones in too.

I'm empathizing with myself; this is hard and this is painful, and I'm looking that fear right in the eye. But I'm turning my attention to living well today. How, given the constraints of cancer, can I pack today chock-full of meaning and joy? I've started making what I call “meaning lists”: lists of what gave this past day or week meaning and my plan for making the coming one meaningful too. Some things that make it onto every list: time with loved ones; acts of kindness; personal growth; time in nature.

I've noticed that these meaning lists have led me to revise my regular, work-centric to-do lists. Yes, working toward my PhD in public health is meaningful. Definitely. But so is an impromptu conversation with a stranger, writing someone an out-of-the-blue thank you note, and listening to an audiobook that shifts my mindset. One of the most powerful experiences from this year: a mother-daughter trip to Madagascar for several weeks of hiking and scuba diving.

Do I still hope the treatment works? You bet I do. What a gift it would be to not have melanoma! But, by focusing on living well regardless of the outcome, I take some of the power back from cancer.

And you know what's funny about this? By not trying so hard to stay positive, I end up feeling, well, more positive.



I Feel Like a Butterfly

By Ann Colander

Every night I wrap up in my favorite cocoon a sky-blue wool blanket
Warm, cozy comfortable as a newborn baby in mommie's womb
All my troubles, stresses are being laid to rest, it's called bedtime
Drifting off to sleep a feeling of peace starting to invade my soul
I know this moment was surely coming, meant to be, just as I am
I hear and love the soft flutterings of my heartbeats as I settle down
I'm not afraid, as my body relaxes into mindlessness
Freedom to soar above and beyond, roaming the stratosphere
As my eyes are closing I took a final glance out my bedroom window
A sudden thought flashed through my subconscious a new view, an idea
I've never given it much thought before about this God-given gift, wow
The ability to rest at will when your very existence needs replenishing
When you're healthy, it comes so easily just another routine event
When you're not, only then do you begin to realize this isn't so simple
It's a more complex, difficult thing you've taken for granted each night

I'm bursting out, liberated of the heavy burdens that have been binding me
It is so wonderful, glorious freedom the beautiful, the splendor
I can see forever over the horizon the majesties displayed below
There's blinding sunshine, a cloudless sky, all the colors of the rainbow
Arching across fields of flowers I'm a kid again laughing, running, racing
The wind blowing through my hair, jumping, feet lifting off the ground
Arms spread chasing butterflies trying so hard to see if I could fly too

I want so very much to hover above each plant and taste the sweetened
Nectar of honeysuckles, sweet peas, roses as I flitter from leaf to stem
Feel its soothing caress sliding down my throat, I'm queen of my world
Embracing this existence that only comes to me in my sweet dreams
It's all so marvelous, takes my breathe away, I believe I'm unstoppable
I can conquer anything, overcome any challenges, ills or troubles
Life is terrific as I sail and glide in my innocence over all adversity

In this realm there is no cancer, COVID-19, pain, aches, ghosts, masks
Shadows, no endless tears, ravaged bodies, hair loss, radiation, chemo
Scans, ventilators, operations, sleepless night, sucking of blood
Nausea, raw despair, hopelessness, anger, lost appetite, doctors, nurses
In this sphere I only know the glorious vibrancy of life, a carefreeness
A place where I was whole again as all God's children are meant to be
As the night fades into morn, stars dim, losing their shiny twinkle

The reality of the world that truly exists encroaches my consciousness
Insight diminishing, stirring, becoming more aware of my surroundings
Emerging from a deep restorative sleep, I feel the grind starting again
Awaking to a brand-new day by the grace of God, giving thanks, grateful
For no matter how hard I find what awaits me along the road ahead

I've celebrated three score ten and more against all odds, a boon
Committed to living my best blessed life, every day, one step at a time
Hope reigning supreme, faith my guiding light
Who can ask for anything more than being able each night to
Dream the impossible dream and "float like a butterfly" (Ali)

Ann Colander has been deep in reflection on the world. She believes a change has come because of the pandemic and that things will never again be the same. She relies on prayers and hope for the future as both comfort and companion. Ann shares some inspiration: "As the good book says, 'This too shall pass.' God bless."

Ask the Professional:

Shifting Needs and Priorities in Survivorship

By Natalie Santos, LCSW



Natalie Santos is a licensed clinical social worker with special training in oncology. She received her master's degree in social work from New York University in 2009 and immediately joined MSKCC's social work department. She has extensive experience working in survivorship programs and is currently on the social work team at MSK Basking Ridge.

Why do I sometimes feel sad and overwhelmed now that I am *finished* with my cancer treatment?

It is important to remember that yes, while it's wonderful that you no longer have to be treated for cancer, you still have just gone through something scary, life-threatening, and significant.

We have often heard people say that they got through their cancer treatments and dealt with it relatively

well, and that it wasn't until AFTER they were finished with treatment that the magnitude of what had just happened hit them. It is OK to let yourself feel whatever emotions you are having after your treatment for cancer, and while your sadness may be difficult for others to understand, it does not mean that you are wrong for feeling it.

How can I convey to my family/friends that I don't feel like the same person as a result of my diagnosis?

A diagnosis of cancer will affect most people in SOME way. Many people express that after this diagnosis they have a new outlook on life or a shift in their priorities. This is OK, and quite often survivors experience it as positive. It may be hard for family and friends to understand that you may feel differently about certain things or react in ways you may not have in the past. Plenty of survivors have expressed that after having gone through cancer, many things that used to rate as important or difficult, now seem somewhat trivial. It is a shift in perspective survivors may feel and often spills over into one's personal relationships. You may find it's helpful to communicate these changes to your friends and family when you feel ready.

Is it normal that my needs have changed after treatment?

Cancer is a life-changing experience that in many ways may not be realized until many months or years after

diagnosis or end of treatment. It is important to understand the new health reality you are living in. Your physical and emotional needs are no longer the same as a result of this new reality. The first step is figuring out how your own needs have changed. Perhaps you need more time alone or more time for physical activity. It is OK and normative to experience these shifts in your needs, and it is OK and important to communicate those new needs to the closest people in your life. Sometimes these needs include having to say "no" to things we normally would do.

Why does saying "no" feel so difficult?

Saying "no" may not feel natural to some people and more natural to others. However, for everyone, it certainly takes an understanding of how you are different now following the diagnosis. It is important to reflect on your new needs, both physical and emotional, and understand that to fulfill those needs may require saying "no." For example, perhaps you decline hosting your annual Thanksgiving dinner, or maybe right now you can't be the "go-to person" for supporting your friends. It is normal and OK to give yourself the time and space you need. Prioritizing and adjusting to these new needs and this new health reality is paramount.

Ask the Survivor:

Changes in Survivorship

By Teresa Levitch



Teresa is a survivor of both Hodgkin lymphoma and breast cancer. She is a writer and cancer advocate.

What changes to your lifestyle did you experience in survivorship?

I implemented tiny steps to change my approach to the tasks that were overwhelming for me. Hosting large family gatherings became impossible as a survivor. That was something hard to give up. Why? It wasn't the shopping or cooking and cleaning that gave me pleasure. It was about the closeness and connected feelings of loved ones.

If I gave up work, could I still find that feeling? Small gatherings were the solution.

Meeting at a restaurant or going for a picnic with individuals allowed me to connect even more than hosting parties of the past. This solution gave me time and energy to relax and enjoy my company on a one-to-one basis.

I developed an awareness of how my body is feeling, which isn't always in sync with my mind. My mind keeps saying, "I should do this or that," but my body says, "Not today."

How do you approach feelings of guilt and shame around changes you experienced in survivorship?

When I am in pain or tired, I take the time to slow down now without feeling guilty. I acknowledge the reason. This is a part of my survivorship, which reminds me I am grateful to have the opportunity. I think of those I sat next to while getting chemo who didn't survive. They would trade places with me in a heartbeat, even with all the survivorship issues. Sometimes things have to get done and I need to push myself — dirty floors need to be cleaned. Part of my survivorship means it is important that I add in a resting time of as part of any task.

Were you able to communicate your changed needs to family and friends? What adjustments did you make?

I felt the need to explain why I had to rest more often or couldn't rush through a task.

It worried me I would be viewed as lazy.

I give examples of other visible medical conditions to understand my pain and fatigue. We expect fatigue as part of pregnancy. Having a broken bone limits the ability to hurry. Asking for help with many physical injuries or visible medical conditions was easy. Survivorship issues aren't any different; they are just invisible. Instead of a visible cast around my leg, it is invisible neuropathy. The limitations of both are similar. Would I ask for help if I wore a cast? Yes. So why should neuropathy be different? When pregnant I often said, "No, I am too tired" without embarrassment. My cancer fatigue was just as real. Now, I use those types of examples to communicate the "why" of what I do.

Because of treatments and surgery, it is difficult for me to lift my arms above my head. Putting dishes from the dishwasher to the cabinet is hard work; I need a break. So, the dishes sit on the counter until I can get them away. It seems silly that I would not just put the dishes away as one task. I explained there is a physical reason why that doesn't happen to my husband. Now he puts things away that go up top, and I put things away that go below the counter.

I continue embracing the gift of life after cancer and all the limitations of survivorship. I have survived CANCER!

Survivorship Insights: Survivorship and COVID-19

“

I am an essential automobile dealer and a stage IV terminal cancer patient. I believe controlling your environment and taking precautions can keep COVID at bay. I wore a mask, cleaned my work area, and kept a social distance between fellow employees and customers alike.

Facing each day with a healthy concern but a positive attitude has brought me this far, and I won't stop now.”

— James

“

I have always struggled from the isolation of being alone during and after childhood cancer 50 years ago. COVID is a reminder and a teacher of the fullness and beauty in being alone and having more moments each day to feel. It has also reminded me of the deep grace provided by caregivers — many of whom I remember fondly even now from a 4-year-old's thanks.

Be open to the awesomeness and impermanence of life. No one is better or worse — as cancer and COVID show. Some lives last longer or are shorter, as they both show as well. And some lives are richer, probing, compassionate, and deeper in part because of the challenges and openings that cancer and COVID present.”

— Tom Cr.

“

Having faced the enormity of a cancer diagnosis and the shocking reminder of one's mortality, I was prepared to take the COVID-19 threat seriously and asked myself what I could do positively for me. Another huge inventory was in order: **What stays? What goes? Am I living authentically, really?** During the COVID crisis, I am creating space for new life to pour in, just like in the cancer experience. Except this time, I am much more awake and aware of what's happening and how I respond. Bottom line in both cases: I want to live!”

— Dianne

“

During my year of cancer in 2017, my husband and I faced everything together. Our motto was “One day at a time, one step at a time, side by side.” We have reminded ourselves of this during the COVID-19 quarantine. In fact, a month into the quarantine, we realized we were self-isolating INSIDE our house. We devised a list of all the things we could do together, and we make sure that we do at least one of those things in the week. In fact, some have become regular practices.”

— Karen

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Produced by the

Department of

Marketing & Communications

Bridges is a publication of the

Cancer Survivorship Program at MSK.

HEALTH SCREENINGS

Even during the COVID-19 pandemic, it's important to maintain your normal cancer screening schedule, vaccinations, and other preventive care. Talk to your care team today to review your screening plan and make an appointment. MSK continues to provide a safe environment for you and your loved ones. Your treatments and routine screenings are essential, and our team is here for you and always will be.

Interested in sharing your story or receiving an email copy?

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