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Bridges

Connecting Cancer Survivors



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Memorial Sloan Kettering
Cancer Center

From the Editor

By Eileen F. Gould



As I write this editorial for our winter issue, I like to be mindful of giving thanks. It is important that the entire staff at MSK, who keep this

institution running at full throttle 365 days a year, be recognized all year long but especially at the holidays. We, the editors of *Bridges*, could not produce this newsletter without the collaborative effort of many people here at MSK.

In June, we were excited to celebrate the tenth anniversary of the *Bridges* newsletter, written for and about cancer survivors. Over the past decade, *Bridges* has seen tremendous growth and covered a variety of subjects. Each issue of the electronic subscription now reaches over 4,000 faithful readers.

As always, our readers are most important to us. The *Bridges* editors would like to hear what you think of the newsletter and its content. Is there information specifically for cancer survivors that might be helpful or topics you would like to read about?

Please send us your thoughts at bridges@mskcc.org. We look forward to hearing from you.

If you would like an email copy of *Bridges*, please sign up at www.mskcc.org/bridges to join the mailing list.

Where Are They Now?

By Dianne Sposito

Cancer is the bridge in my song

Though not a songwriter, I deeply appreciate how songs tell a story by way of an introduction, verse, chorus, bridge, and coda. The bridge speaks the loudest to me: a reflective pause with a shift in emotion (key change!), then release and the pronounced resolution of dissonance. Differing melodically from the rest of the song, the bridge ensures that the message gets across.

Cancer is the bridge in my song.

My life before cancer was full of struggle surrounding the acceptance of my artistic nature and creative work. I was deeply

fearful of others' negative opinions, so I really held back and lost so many opportunities. With cancer, the possibility did indeed exist that I could die without creative fulfillment, and frankly, that was unbearable.

"If I live, I'll be creative with my whole heart and soul."

So when given the gift of survival and a second chance at living, I kept my promise: I found my voice and the full creative life I know is mine. I mean to live it. A chance to co-author Theatre for Young Audience plays fell into my lap, and beautiful productions ensued. I parlayed my floral photography



into a line of handmade cards. And I won an award for artistic excellence in playwriting — twice! Now I couldn't be more thrilled to share the wonder and beauty I see with the world.

I don't know the precise moment when my bridge was built; I only know by singing my song that it was.

Nezam's C Journey

By Emily Nikoo



Cancer changes people — patients, caregivers, family, and friends. Reality shifted from when cancer was on the outside to when cancer became our entire world and shaped our future. A battle, from diagnosis through treatment and now in survivorship.

Diagnosis

For my husband, Nez, the battle began with weight loss and extreme fatigue. For me, his wife, Emily, it started with a horrible feeling that something wasn't right. This wasn't the man I'd known and loved for more than 30 years. Always the life of the party (whether dancing or doing impromptu push-ups), Nez became quiet and withdrawn.

The diagnosis stage was the hardest part for me. I was so fearful of the unknown and hated the roller-coaster of uncertainty. When Nez's symptoms worsened, we went to the nearest emergency room, where they discovered brain lesions. That's when the path led to MSK to find answers, simply by calling 800-525-2225.

Diagnosis continued with test after test at MSK, but a biopsy finally gave the key to the puzzle: Nez had brain cancer, primary central nervous system lymphoma (PCNSL). Dr. K laid out the treatment plan based upon years of research and knowledge at MSK.

Treatment

Treatment consisted of a hospital stay every two weeks for chemotherapy, a total of eight rounds plus consolidation. In the hospital, Nez participated in music therapy and stayed active by walking laps around his floor and visiting the Patient Recreation

Center. If he wasn't in the hospital, he was working; it wasn't easy, but he wanted a normal routine.

Luckily, Nez had an amazing team led by the doctors and nurses at MSK, me, our beloved family, and dear friends. I created a set of group texts to communicate with "Nez's Team." This became a lifeline, a circle of support and encouragement that gave Nez strength in tough times.

Survivorship

The first year after treatment was filled with unbelievable superhuman energy and living life to its fullest, including travel and a newfound love of Instagram. After a year, the adrenaline waned, life became more difficult, and managing stress became a priority. Thank goodness, the new perspective gained from facing cancer kicks in during difficult times. Yoga, meditation, and massage are tools we use against the imbalances of everyday life; I depend on journaling as well.

Every two to three months Nez has an MRI scan. There are no sweeter words than Dr. K saying "Your scan is perfect." But the week before, there's a sense of restlessness. "Scanxiety" is very real for both of us. Symptoms seem to appear, and our hearts and

Nez and Emily Nikoo are college sweethearts who met at Purdue University. First and foremost, they love spending time with their two grown children, along with their extended family and friends. They can be found traveling, enjoying the beach, or discovering new restaurants in New York and Philadelphia.

thoughts race until the results are in. Distraction is important at this time, communicating with each other as well as reaching out to MSK's clinical social workers to talk through it all. Open dialog at every step in the journey has been imperative for us.

Nez reached a big PCNSL milestone: his two-year anniversary and he had his port removed. It's a time to celebrate, another step into survivorship, but there's a hesitation. Letting go of the port was like losing a security blanket that had been vital for all those months. As with each scan, anxiety hit us. We just don't know for sure if everything will be OK.

But does anyone really know?

Before cancer we liked to think we did, but after cancer, we know better. All we can do is focus on today, make the most of each moment, find some joy in the life we have right now, and love our loved ones. When the next day comes along, we take a deep breath and take the next step in our journey.

Ask the Professional:

Pain in Cancer Survivors

By Natalie Moryl, MD



Natalie Moryl, MD is an associate attending physician in the Supportive Care Service and a Co-Chair of MSK's Pain and Quality Assurance Committee. The Supportive Care Service helps people with pain and other symptoms related to cancer diagnosis, treatment, and survivorship. Dr. Moryl's research interests are safety and opioid pain management.

My scans are stable. Should I stop taking my pain medications?

Most cancer survivors stop taking pain medications when their treatment is done. Prescription pain medications, however, should not be stopped abruptly. It is better to decrease them gradually. This keeps your pain controlled while avoiding or minimizing withdrawal. Having withdrawal symptoms does not mean you are addicted. It usually means that medications were stopped too quickly.

My pain is decreasing but hasn't stopped yet. If I keep numbing the pain, how will I know if the cancer has come back?

Paying attention to your body is important. You'll want to monitor yourself for signs your cancer may have returned and alert your care team to any treatment side effects or other medical issues unrelated to the cancer. Fortunately, taking pain medications, including opioids, doesn't hide new symptoms. Being on chronic opioid medications may increase your sensitivity to new pain instead of masking it. If a cancer survivor takes pain medications, they will still feel new pain if it occurs.

I've read about overdoses and am worried about my kids. Where do people who overdose on prescription opioids usually get the medication?

Opioid addiction and the number of opioid-related deaths have been on the rise. According to a study, between 2008 and 2011 at least half of people who overdosed on opioid medications got them from friends or relatives who were prescribed the drugs by doctors. Giving prescription medication to someone who wasn't prescribed it is illegal. It is called drug diversion. Prescription medications should be safely stored away to avoid accidental

poisonings and drug diversion. If you have opioid medications that you didn't use, take them to your local controlled substance public disposal location. The Drug Enforcement Administration also allows flushing unused opioids down the toilet.

I think I may be getting addicted to my pain medication. I am really uncomfortable discussing this with my doctors. What can I do?

Although addiction in people with cancer-related pain is rare, it is not impossible. Certain risk factors may contribute to a higher risk of opioid use disorder. These include a previous history of a substance use disorder, age, early exposure to opioids, and anxiety disorder or depression, among others.

If you are concerned about getting addicted or having an addiction relapse, talk to your care team. Your cancer doctors aren't the only ones who can help. Nurses and social workers can help you get the care you need too. You can also ask to talk to a psychiatrist. At MSK, we will support you and help you get treatment for substance abuse either at MSK or with an outside substance abuse professional.

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David Kerr is a 32-year-old retired Marine. He is a six-year survivor of sarcoma and one-year survivor of melanoma. He hangs out in Virginia Beach, Virginia, with his daughter, Lillian, and his girlfriend, Taylor. He is a participant in the Visible Ink program at MSK.

Angel Flights

By David Kerr

This flight was going to be my happy thought for the next three days. I felt light, good, and full of faith, ready for the next obstacles.

I sat on the private plane, awaiting takeoff for the short flight from upstate New York to White Plains. I was scheduled for another round of chemotherapy and too weak to make the trip by car or train.

I listened through my headset as the pilot conducted his preflight checks. The single prop engine hummed and jerked, eager to burst aloft.

The day was perfection. A few puffy clouds dotted the crisp blue sky. The trees wore their fall foliage: reds and yellows splashed with piney greens.

The grass on the runway was brilliant emerald. The scent of decomposing leaves tinged the air.

After a short trip down the runway, we were airborne. The ground fell away as we edged higher, banked left, and then leveled out. We passed through clouds that engulfed us in

darkness and fog. Moisture pocked the windshield, blinding the view. Just as an uncomfortable feeling began to take root, the clouds parted on an azure sky.

The pilot spoke to the tower in White Plains as we flew over the Catskills. They drew long and perpendicular beneath us. I sat quietly, stunned by the natural beauty yet aware of creeping dread inside. I tried not to think about the impending three days of inpatient chemo. I focused instead on the blessing of the moment. My fear slowly yielded to calm, and peace.

The runway suddenly appeared on the horizon. The pilot's voice sounded through my headset: "My wife is a seven-year cancer survivor. You're going to the best doctors in the world. You're going to survive and be around for your little girl. Just listen to your doctors and never take anything for granted. Even if you have a cough that you think is nothing, get it checked out. You and your wife and daughter will be in our prayers."

This flight was going to be my happy thought for the next three days. I felt light, good, and full of faith, ready for the next obstacles.

Weeks later, as I lay at home on the couch, recovering from another round of chemo, a small envelope arrived for me. Inside was a small card with a handwritten message:

"Dear David: My husband, Michael, was your Angel Flight pilot. He told me about you and your family. Enclosed is a medallion I had blessed by my local priest that I have worn around my neck for the last seven years. It's Saint Michael. It will protect you, and I hope that it brings you peace and comfort as it did for me. You and your family will remain in our prayers. Love, Annie."

I placed this medallion on my neck beside the cross my mother had given me years earlier. It has remained there for the past five and a half years. Angels do exist and love conquers all. If I will myself to, I can still travel back to that flight in my memory. It continues to bring me peace, love, and a deep sense of gratitude.

Healthy Eating Made Simple

By Shane Dunne; Timothy Gee, CEC; and Veronica McLymont, PhD, RD, CDN

Veronica McLymont is the Director of Food and Nutrition Services at Memorial Sloan Kettering. Timothy Gee is the MSK Executive Chef, and Shane Dunne is the Project Manager of Sustainability.



MSK Executive Chef, Timothy Gee.

Healthy Eating Made Simple

Hospitals should be models for healthy eating. Food and Nutrition Services at Memorial Sloan Kettering stands by this mission.

To craft our nutrition program, we use the New York City Department of Health and Mental Hygiene's Healthy Hospital Food Initiatives. These criteria have helped us improve the nutritional quality of the food and beverages we offer. We have also signed the Healthy Food in Health Care Pledge. We have agreed to follow sustainable food procurement practices and to reduce

the environmental impact of our food services.

Here are some of the ways MSK is leading in healthcare nutrition.

Patient Meals

MSK's top priority is positive patient outcomes. Our dietitians and nutritionists work closely with patients' care teams. We apply the latest research to meet patients' personal nutrition needs. Regular diets offer a wide variety of fresh fruits and vegetables and plant-based selections, and limit fried foods.

Vending Machines

Sugary drinks contribute to obesity and the chronic diseases that go with weight gain. In vending machines, MSK limits high-sugar drinks to 12 ounces. Machines stock fewer of the high-sugar choices and more water and low-calorie beverages, which are displayed more prominently at eye level. The packaged snacks in machines are grain-based, contain fiber, are 200 calories or less, and have reduced amounts of fat, saturated fat, sugar, and sodium.

Less Meat, Better Meat

Eating just one meatless meal a week lowers the environmental burden from industrial food production. Furthermore, having plant-based foods at least once a week may help improve health. These dishes often reduce the amount of bad fats consumed and lower the risk of certain diseases.

Meatless Mondays at the MSK cafeteria encourage diners to pick a plant-based meal on a regular basis. Some of our more popular dishes have included quinoa-stuffed acorn squash, lentil and sweet potato shepherd's pie, and Beyond Burgers™, which are a pea protein base made with no GMOs, soy, or gluten. Our international theme days — from India to the Caribbean, Morocco to Mongolia — further highlight plant-based options.

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MSK offers red meat entrées only once a week. A cousin to Beyond Burgers, Blended Burgers are another alternative, made of ground turkey and mushrooms. All of the meat and poultry served at MSK is raised without the routine use of antibiotics. The beef is from 100 percent grass-fed cows raised on open pastures. Poultry is raised on an all-vegetarian diet.

Through collaboration with MSK's Sustainability Department and our partnership with Practice Greenhealth, MSK works with other hospitals to increase the availability of meat and poultry raised without the routine use of antibiotics throughout healthcare systems. Practice Greenhealth has included MSK in its Circle of Excellence for leadership in sustainable food services four years in a row.

The Wisestop and FoodWise Programs

When it comes to the benefits of healthy eating, employees get the message too. Wellness fairs, lectures, and cooking demos all contribute to employees' overall nutrition IQ. One of the most visible education strategies is a traffic light-inspired concept. Foods marked with a red dot in the cafeteria are higher in calories, fat, or sodium than those with yellow or green dots. A recent survey showed that more than half of the respondents had noticed the colored dots, which then helped them make buying decisions.

The Wise Choice meal, which is discounted for employees, is another label to look for. These dishes contain less sodium and saturated fat than

other offerings and include vegetables and whole grains. They center around a lean protein, such as fish, poultry, tofu, or legumes.

What's Next?

Food and Nutrition Services plans to increase the use of locally sourced and certified sustainable food and beverages and antibiotic-free meats. We will be converting the Chef's Station to a Mediterranean Station. Menus will be expanded to include organic produce and vegan dishes. Meanwhile, we will continue to reduce the availability of sugary drinks.

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What do I do if I still have chronic pain?

Most cancer survivors have no pain from cancer after finishing treatment. Any persistent pain will require attention long term. Your care team may refer you to a rehabilitation therapist or a mental health or pain specialist. Eventually, your primary care doctor should be able to take over all your medical needs.

Your medical history, personal preferences, and lifestyle play a role in developing a safe pain management plan. Creating healthy habits and minimizing the side effects of medications are equally important. A healthy lifestyle to prevent and reduce pain from sources not related to cancer, such as arthritis or back pain, will be a priority.

Survivorship is about recovery and a return to your everyday activities as much as possible. Cancer treatment and pain management have dramatically improved over the years. Medications, physical therapy, integrative medicine, and interventional approaches allow survivors to have the personal, social, and professional lives they want both during and after cancer treatment.

Visible Ink™

A One-on-One Writing Program for MSK patients

Interested patients will work individually with the guidance, encouragement, and support of a professional writer on a topic and project of their choice. This program is FREE. All levels and writing interests welcome.

For more information or to arrange a writing session, please contact Judith Kelman at 212-535-3985 or kelmanj@mskcc.org.

Patient and Caregiver Volunteer Program

The Patient and Caregiver Volunteer Program connects current patients and caregivers to volunteers who have experienced a similar diagnosis or circumstance related to cancer. If you are a former patient or caregiver of someone who has completed treatment, please consider becoming a Patient or Caregiver Volunteer.

For more information, contact Wendy Bonilla at 212-639-5007 or patient2patient@mskcc.org.

Meatless Black Bean Chili



Chili usually gets its rich, satisfying flavor from meat or salt. This version gets its depth from unsweetened cocoa powder.

Each Monday, the staff of Memorial Hospital's cafeteria packs the menu with healthy vegetarian options as part of the Meatless Mondays program. This veggie chili is one of our favorites. Garnish with fresh corn and cilantro for an extra pop.

Yield: Serves 2

Instructions

1. Combine onion and garlic in a bowl. Let sit for at least 5 minutes.
2. Place all ingredients in a large pot and stir to combine. Cover and bring to a simmer over low heat. Cook for about 20 minutes.

Nutritional Information

Calories: 250 calories
Carbohydrates: 55 g
Fat: 1.5 g
Fiber: 19 g
Protein: 13 g
Saturated Fat: 0 g
Sodium: 590 mg
Sugar: 11 g

Ingredients

1 medium onion, chopped
2 cloves garlic, minced or pressed
1 15-ounce BPA-free can low-sodium black beans, drained and rinsed
1 15-ounce BPA-free can no-salt-added diced tomatoes
1 tablespoon chili powder
1 tablespoon cumin
1 teaspoon unsweetened cocoa powder

Recipes for People with Cancer:

<https://www.mskcc.org/experience/patient-support/nutrition-cancer/recipes>

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Resources for Life After Cancer (RLAC)

RLAC welcomes survivors to participate in programs that encourage healing through education and support.

Please see the online calendar at: www.mskcc.org/livingbeyondcancer

Connections

is MSK's online community for patients and caregivers. It provides a venue for conversations, support, questions, and companionship.

To register, visit: www.mskcc.org/connections

Interested
in sharing
your story?

Please visit
www.mskcc.org/bridges



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