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Bridges

Connecting Cancer Survivors



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Memorial Sloan Kettering
Cancer Center

From the Editor

By Eileen F. Gould



Bridges began as a forum for survivors to talk about their cancer journeys and connect with other survivors and patients going through treatment. As a survivor myself, I have seen the benefits of shared experiences.

I wanted to give others an opportunity to feel empowered by sharing and to inspire hope in people in similar situations. Connections provide us with support, useful information, and a sense of community.

In this issue, members of the MSK community reveal how they found support for themselves. Family, friends, and other important people in our lives are integral to the cancer experience, as are the bonds that we form with those we meet along the way.

At MSK, one outlet is the Patient and Caregiver Peer Support Program. Current patients and caregivers are paired with volunteers who had a similar diagnosis. Michael Tomko describes his experience with the program in this issue.

Connections can also be made through surprising circumstances. In our cover story, Lisa Prati writes about how participating in MSK's Caring Canines program with her dog, Austin, has helped not only her but so many others.

Today more than ever, we have a variety of channels where we can interact and make connections, be it on social media, in chat rooms or moderated group meetings, or through our own networks. We are pleased that *Bridges* is one you have chosen.

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

Survivorship Insights: Connections

Words of advice from others at MSK on how they made connections.

“My husband is a patient at MSK. He has told all our friends. His attitude was very positive as he would explain his disease, which seemed to help those he told. Just knowing that others understand eases the burden.”

— Peggy

“Cancer doesn't have the same stigma it had years ago, when no one wanted to talk about it. Even the word “cancer” was said in a whisper. My advice? Talk about it. I have found my angel of support, a person I met through my mother. She has been my rock. We share similar stories, side effects, anxieties, fears, etc. We are strong for each other, and we speak the same language. Every time I finish a conversation with her, I have a sense of validation of my feelings, thoughts, and concerns. Connections are important.”

— Ed

Charisma after Colon Cancer

By Michael Tomko

Michael Tomko is 48 years old and lives on the Upper West Side with his husband, Tsuyoshi, and their two dogs, Otis and Tobey. He has been a senior interior designer with the internationally acclaimed architecture firm Peter Marino Architect for 14 years. His interests include the decorative arts, collecting art and objects, body training, cycling, and travel.

At 47 years old, after having irregular bowel movements and blood in my stool, I was diagnosed with stage III colon cancer. My journey started with surgery to install a temporary ileostomy bag. After recovering from surgery, I began eight sessions of chemotherapy. These occurred every other week and were administered over 48 hours; I was required to wear a bottle of chemo during that period.

Upon finishing the chemotherapy treatment, I began a regimen of radiation plus chemotherapy pills for another two months. After resting from the treatment, I had a colon resection in March 2019 and finally an ileostomy reversal in June 2019.

Patient and Caregiver Peer Support Program

The Patient and Caregiver Peer Support 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.

Although the recovery for the reversal has been difficult, I'm doing great and on my way to a very manageable digestion system. I worked during the entire process as I felt it was important for my life to be as normal as possible, to not feel sick, and to be myself as much as I could. With the love and support of my husband, family, and friends, I survived a very difficult ordeal.

I have begun to work out with my trainer three times per week. We began concentrating on core work, to tone and strengthen muscles that I had not used in nearly a year. We are now training my entire body, which includes cardiovascular activity, muscle toning, and weight training. This training, combined with proper nutrition, both fuels my body and helps me stay attentive to my digestive system, and it has helped me feel like myself again. All of this while I'm working a full schedule and enjoying leisure time on the weekends in our country home.

On the weekends we focus on long walks or hikes, cooking, exploring new places, meeting new friends, and remembering the people in my life who became even more important during treatment, having supported me through that difficult journey. My life is now a new adventure every day, my mind is much more open to opportunities than ever before, and I never forget that life is worth fighting for at all costs.

I was fortunate to take part in the MSK Patient and Caregiver Peer Support Program at the beginning of my cancer journey.

I was guided through this process by a wonderful volunteer who had been through colon cancer. This selfless person spoke with me every week, and truly, without her I would never have been able to cope. I now want to give that gift back to anyone who needs it. Each week, many people under the age of 50 and over are diagnosed with colorectal cancer; they need help, and we must find a way to help them reach out to the MSK community. And when they do, give them the support they need.



Full Circle

By Lisa Prati

With tears in her eyes, a patient said, “Thank you for putting a smile on my face today.” A nurse commented, “He makes my heart smile.” Another said, “He lights up the room.” It’s these comments and countless others that reaffirm I am in the right place as a volunteer in the MSK Caring Canines Program.

After more than 25 years in the New York Police Department, I was ready to retire and planned on volunteering as a therapy dog team with my golden retriever, Austin. Seeing what an impact therapy dogs had on grieving families at the Family Assistance Center after 9/11 inspired me to get involved somehow with my own dog, who has the perfect personality for the job.

On April 28, 2011, my day started innocently enough, with a day at work and an appointment with my doctor that night. While we were discussing my plans for retirement, my doctor found a lump in my breast, which immediately put the breaks on my plans. After a battery of tests and biopsies, I was sitting in my doctor’s office waiting for my results, and I knew it was a matter of time before cancer would become a reality. I was diagnosed with multifocal invasive ductal carcinoma that had spread to my lymph nodes. With the help and advice of my “survivor sisters,” I prepared myself for a fight.

All the recommendations I received led me to my surgeon, Dr. H, and my oncologist, Dr. T, at Memorial Sloan Kettering. After meeting with these two amazing doctors, I knew I was in the right place.

Their confidence made me confident during this scary time in my life. I had surgery on June 8, the day before my birthday. To me, it was the best birthday present I could receive. My treatment consisted of 16 rounds of chemotherapy, a year of Herceptin, and six weeks of radiation. In September 2012, I was finally finished with all my treatments.

During that time, I joined the Livestrong Program at the YMCA, a 12-week program designed for people with cancer. It helped me regain my strength and confidence, and my personal trainer, and now a good friend, made me stronger mentally and physically. At her urging, I was finally able to shed the baseball hats I had been wearing to hide my baldness. I was ready to start my life again. My dog, Austin, was a tremendous comfort to me during my treatments, so I knew he would be a great comfort to others. I attended training to have my dog certified as a therapy dog and began volunteering at various places on Staten Island.

I always wanted to find a way to thank the kind and compassionate doctors, nurses, and staff at MSK who always made me feel safe and confident in their ability to help me fight this disease.



Lisa Prati is married and splits her time between her home in Staten Island and the Jersey Shore. Now that she is retired from the New York Police Department, Lisa is able to spend more valuable time with family and friends, and volunteering with her dog, Austin. Her favorite pastimes include going to the beach, traveling, reading, and cheering on the Mets. Lisa is eternally grateful for the “clown car” that filled up with family and friends each week for chemo treatments and the enormous support she received from her NYPD family.

The opening of MSK Monmouth provided the perfect opportunity. After going there for my yearly follow-up tests, I inquired about the Caring Canines Program and its expansion to Monmouth. Within a few months, I was able to start volunteering at MSK Monmouth and MSK Basking Ridge. I had come full circle from a patient to a volunteer.

My experiences as an MSK patient who went through surgery, chemotherapy, radiation, and the many side effects that come with it allow me to empathize with patients and their families who are having feelings of anxiety and fear of the unknown. They often have a look of relief when I tell them I am a survivor. Volunteering has also helped me admit that I am a survivor. I was always afraid to say it out loud, and volunteering has made it real. In addition, Austin has become a welcome sight for the MSK family!

Ask the Professional: Obstructive Sleep Apnea

By Miranda Tan, DO



Miranda Tan is a board-certified physician in sleep, pulmonary, critical care, and internal medicine. She is Director of Sleep Medicine and an Assistant Attending Physician in the Pulmonary Service at Memorial Sloan Kettering. The Sleep Medicine section was established in 2019 to address the prevalent sleep disorders in people with cancer and cancer survivors. Its primary mission is to improve quality of life, reduce associated conditions, and research potential associations between sleep and cancer.

What is OSA?

Obstructive sleep apnea (OSA) is a common sleep disorder. It occurs when the muscles of the throat relax and the airway partially or completely collapses repeatedly throughout sleep. The collapse of the airway, or apnea, causes a pause in your breathing and reduces the amount of air entering your lungs, which results in a lack of oxygen. These breathing pauses may cause restless sleep, or you may wake up to stimulate breathing again.

Sleep apnea can have negative long-term health consequences, including high blood pressure, heart attack, stroke, diabetes, and depression.

What are common signs and symptoms of OSA?

Frequent or loud snoring is a common sign of OSA. Tissue in the back of the throat vibrates with a narrow or collapsed airway, which produces the sound of snoring. Daytime sleepiness, chronic fatigue, difficulty concentrating, and memory loss may occur because of disrupted sleep every night. People with OSA may also experience choking or gasping during sleep or wake up frequently with the urge to urinate.

How is OSA diagnosed and treated?

Sleep apnea is diagnosed with an overnight sleep study. The study can be performed at home or in a specialized lab. The study measures several components of sleep. These include your effort to breathe, oxygen level, and heart rate. Treatment for OSA depends on its severity and your medical history. Treatment options include positive airway pressure (PAP) therapy, an oral mandibular device, positional therapy, weight loss, and stimulating the hypoglossal nerve (the nerve that controls the tongue).

PAP therapy is usually the first-line treatment for OSA. There are different forms of PAP therapy, but they all keep the airway open by providing a stream of air through a mask worn while you sleep.

This prevents your airway from closing, so you don't stop breathing or wake up.

How does OSA affect cancer survivors?

OSA may be undiagnosed prior to cancer treatment. It may develop or worsen with weight gain after treatment is completed. OSA can also develop if there is distortion to the muscles in the back of the throat from head and neck radiation. Cancer survivors with OSA may experience constant fatigue and daytime sleepiness, restless sleep, or sleep disturbances throughout the night. Cancer survivors with OSA can improve their sleep quality, energy levels, and mood, as well as live longer, if their apnea is treated.

Connections

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

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

Thoughts on a Tenth Anniversary

By Steve Reynolds

Fall 2018 marked ten years since my diagnosis and treatment for head and neck cancer at MSK. I emerged from the yearlong treatment weakened from the accumulated effects of surgery and cisplatin; 6,600 gamma rays, 30 minutes a day, five days a week; and a year on a Fentanyl patch.

Still, that was better than the year before, when what I thought was a sore throat turned into a biopsy and a diagnosis and surgery and all those trips up First Avenue. I went as aggressively as possible — surgery, chemo, radiation. “Whatever you got, just get rid of it,” I said. I expected loss of some functions, but what I didn’t know was another, hidden kind of loss, for “winning” against cancer is not a binary, live-or-die proposition. To borrow a phrase: “You might win, but you will get hurt.” In my case, in a way I never expected and suspect many of us confront.

At the end of my treatment, I weighed 152 pounds (down from 200), with a feeding tube in my stomach wall. I was anemic, often dehydrated, nausea-prone, and greatly diminished physically and mentally. I felt... provisional. I wondered, How do I know that I’m really going to be here?

This was phase two of the cancer battle, what I now think of as the “cancer flu” — low energy, low expectations. I was living in a tracking window for the next five years and was hyperaware

that at any moment, something could go wrong. When I returned to work, clients I’d known for years couldn’t recognize me. I hardly recognized myself. I trudged along like this, unconscious of any existence but that of being sick. And then one fall day, I was walking through Union Square and realized: Five years since my biopsy... it’s over.

Not long after, I noticed that a gym had opened on the ground floor of a building next to ours. A postcard in the window caught my eye. It was orange and announced Haymakers for Hope, a new cancer charity. I’m not sure why, but the name made me read on. It turned out to be like any other fundraising event, except that instead of walking or running, you sign up for a boxing match. Then it struck me: You’re gonna live. What are you gonna do about it?

I walked into the gym, grabbed the first trainer I saw, and told him, “I want that postcard thing.” I was no longer sick, I decided, so to celebrate, I challenged myself right then to live, not as I was, but newly, as “not sick.” At that point

it had been five-plus years since I’d done anything physical. But my trainer — a Golden Glove boxer, Marine, and absolute great guy — got me through the ensuing six months. Soon I was in the gym by 6:30 AM daily for 200 sit-ups and a two-mile run with hands at my chin. We hit things — big things, little things, things that moved, things that stayed still. I gained weight. And my trainer was with me when I stepped into the ring at Hammerstein Ballroom in New York, the fifth fight on the card. One of the best moments of my life was to donate a chunk of it to my own oncologist at MSK.

We will always be changed by cancer, never be the same as before, but cancer doesn’t own my identity anymore, and I urge anyone who has entered survivor status to plan for what I call the second fight, the fight for who you will be postillness. Pick a physical project to reclaim your sense of self: walk, paint, sing, hike, sail, garden, jump out of a plane. Treatment, of course, comes first, but afterward, be ready to fight cancer again, this time for the life we want, not the one that it leaves us.



Gen X dad Steve Reynolds keeps on punching in Greenwich Village. Between bouts of rage and remorse at aging, he is at work on a memoir about fights, cancerous and otherwise.

Resource Review:

Mindfulness Meditation

By Beth Sandweiss, MA, MSW

Being a cancer survivor requires adjusting to the new circumstances affecting your sense of well-being. For many, a cancer diagnosis brings an awareness of the fragility of life and a desire to live with more presence and meaning. At the same time, new challenges may surface after treatment is complete, including anxiety about the cancer returning and adjusting to changes in your body. Emotions like fear, sadness, and grief that may have been kept at bay during active treatment commonly emerge as you begin to settle back into the routine of your life. You may feel additional strain caused by fatigue or discomfort.

Mindfulness meditation is a powerful healing tool that can help address these challenges, and it is now being offered as a six-week course at MSK. Each hour-and-a-half session includes a mindfulness theme, guided meditation, and instruction on how to weave mindfulness into our daily lives. Between classes, participants can develop their practice by meditating for 20 to 30 minutes each day using the guided meditations available on [MSKCC.org](https://www.mskcc.org).

Mindfulness is a skill that anyone can learn. Like training to run a marathon or learning to play an instrument, it involves practice. Most of us find ourselves regularly lost in thoughts about the future or past, or so distracted by our phones, emails, and to-do lists that we aren't present for the things that matter most to us. The more you are able to pay attention in the moment and accept thoughts and feelings without judgement, the greater your ability will be to respond skillfully to these experiences rather than react to them.

The six-week mindfulness course teaches these principles:

1. Finding an anchor in the here and now

Where you focus your attention can play a powerful role in keeping you in the present moment. Like an anchor keeping a boat from drifting too far away, mindfulness brings you back to the here and now when you get carried away by anxious preoccupation or worry.

Over time, focusing on your breathing and coming back to it when your mind drifts helps develop steadiness, focus, and increased concentration. By learning how to tune into your breath regularly, you are creating a way to help calm yourself when things get difficult.

The class explores a variety of guided meditations that include the sounds of birds or rain, as well as those that concentrate on physical sensations, like feeling your feet on the floor or the chair against your back.

2. Body awareness and gentle movement

Surgery and treatment for cancer often mean that scars, numbness, constriction, and pain are new realities, as is the natural tendency to be hypervigilant about any new changes. In a body scan meditation, you are gently guided to move your attention to different regions of the body. You are asked to explore bodily sensations without trying to change them. This practice can shift your relationship to pain toward a sense of befriending your body.



As a mind-body therapist at MSK's Bendheim Integrative Medicine Center, Beth Sandweiss teaches mindfulness meditation to patients, their families, and healthcare providers. Through her personal meditation practice and her clinical work as a psychotherapist, she has come to value the power of mindfulness to develop greater awareness, wisdom, compassion, and resilience in the face of life's challenges.

3. Kindness

Being present in meditation and in daily life can be difficult when the actual moment includes physical or emotional pain. These moments become easier to bear when you bring a sense of kindness and warmth toward yourself. By practicing self-compassion and loving-kindness, you can allow yourself to be held by the rhythm of your breath and offer yourself words of comfort and encouragement or supportive touch. You can learn to treat yourself with the same kindness that you would offer a close friend and to not feel alone.

Come join the mindfulness meditation classes at MSK, an experience one participant described as an oasis: "Here, I know that the members of the class have struggled with cancer. I am moved by knowing that everyone wishes me well, and we share the insights and discoveries we make through meditation."

Call 646-888-0800 to learn more. To schedule an appointment with an integrative medicine doctor, call 646-888-0845.

My Cancer Story

By Elissa Gold Laster



Elissa Gold Laster lives in Westbury, New York, with her husband, Alan. They have two children and four grandchildren. They love to travel and especially to scuba dive. Elissa was a French teacher in the Plainview–Old Bethpage school district for 35 years.

I divide my life into BC and AC (Before Cancer and After Cancer). I always thought cancer was something that happened to other people. I took care of myself: eating correctly, exercising, and making stress-free life decisions.

It took three months for me to be properly diagnosed with ovarian cancer, stage IIIc. Memorial Sloan Kettering was and is the only hospital of choice. After a 5.5-hour operation, participating in clinical trials, and six recurrences, I am still here enjoying life!

When I awoke one morning and found that my first thought was not about my condition but rather what the new day would bring, I felt I had turned the corner. I always, even as a young child, embraced the newness of the moment. I either have the largest amount of serotonin on the planet or could be the biggest denier. I choose the former.

My surgeon had said that she was told by one of her patients that the significance of what we experience daily should be ultimately and fully appreciated, like something as simple as watching the grass grow.

As simplistic as it sounds, it is heavy in thought. If we have to wait to go on vacation, we lose our time. The moments are our mountaintops. The moments are what count. My humble advice: Clear your life of refuse, don't worry over every little twitch (you can get the common cold in remission), and live in the moment. It's been 13 years since my diagnosis. I am beholden to superior medical care, family support, a little bit of luck, and myself (I give credit where credit is due!). I have a special gratitude for Nick Medley, the greeter at 53rd Street who welcomed me, calmed me, and readied me for my appointments. My magical doctor and the incredible staff deserve mention as well. Special love and appreciation goes to my husband, Alan, without whom I couldn't have rebounded so readily. Caretakers are the guardians of our bodies and souls, and I am married to a divine one who is with me at every step today.

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Interested in sharing your story or receiving an email copy?

Please visit www.mskcc.org/bridges

In my AC life, I scuba dive (more than 1,000 dives), travel, volunteer, substitute teach, and do whatever I want. I also cleaned the slate of people who do not bring me joy, which I think is really important. Surrounding oneself with funny, loving, supportive, caring, and interesting folk is what propels us into our good mind space. It's all up to you to make what you want happen. Bonne chance, à tout le monde!



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