

Bridges

Connecting Cancer Survivors



Keeping It Together as a Caregiver

By Jim Cooper

The roller coaster ride from hell is a widely accepted caregiver analogy, especially for us amateurs thrown headlong into the role without previous experience. My roller coaster exploded from the gate on October 29, 2014, when my wife, Sally, was diagnosed with large B cell brain lymphoma.

The preceding three months had found us in constant anxiety and frustration, not knowing why my wife would stop speaking midway through sentences, call objects by other names, and send text messages that resembled ancient Egyptian hieroglyphics. She had so little motor control over her arms that she looked like she was directing 747s across an airport tarmac. I thought about getting her those orange flashlights just to make her actions appear normal.

I am not a professional caregiver. However, my wife and I raised two kids so that qualifies us for handling certain levels of terror and stress. Still, there are built-in child-rearing breaks; the kids go to school, they finally fall asleep, or they go to parties chaperoned by other responsible adults. Watching a loved one battle cancer does not automatically include stress relief and decompression. It takes a focused effort to keep from losing one's marbles.

Sally survived ten rounds of chemo and a stem cell transplant, thanks to the miraculous doctors, nurses, and staff at Memorial Sloan Kettering, and she is currently 17 months cancer free. Her health is constantly improving. After the treatment phase, however, my health went to hell in a hand basket. Staying on guard 24-7 during the year of diagnosis and treatment took its toll; standing down never entered

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Jim Cooper is a writer living in New Jersey with his wife, Sally. He is currently at work on a book chronicling his caregiver experiences.

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Cancer Center

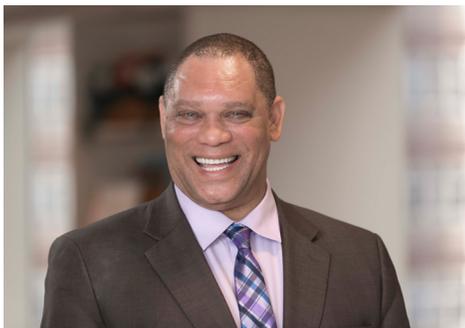
Interested in sharing your story?

Please visit www.mskcc.org/bridges

Where Are They Now?

Nick Medley, in his 17th year as Guest Services Representative Lead at Memorial Sloan Kettering's 53rd Street site, continues to offer friendship, hope, encouragement, and motivation to the many people who enter the building each day.

"It has been a challenging year," Mr. Medley notes, "having lost five family members in two weeks, including my mom, but the work I do helped me through the difficult grieving process. I hear their voices every day, and I feel I am continuing the legacy of healing that they instilled in my heart."



After work, Mr. Medley volunteers at the Moravian Family Center, a social services organization, and he has given two talks through the New Canaan Men's Society on the subject of compassion, care, and support. He is currently working with friends on developing a new outreach project that would establish a phone support group for men needing encouragement in talking about the life challenges they face. "Waking up every day to do the work I do is priceless to me," Mr. Medley says.



Editorial

By Eileen F. Gould

MSK recently held its annual survivorship celebrations at the Manhattan and regional sites. More than 400 people attended the Manhattan event, which is always abuzz with attendees sharing their own stories of hope and survival.

Mira Sorvino, an Academy Award-winning actress, spoke about her experience being a caregiver to several important people in her life. She discussed how important supportive care is to both the patient and caregiver. Two patient speakers also shared their experiences as cancer survivors: one, a current Memorial Sloan Kettering physician-scientist, discussed not sweating the small stuff, and the other, a student at New York University, spoke about her new normal as a cancer survivor.

Mary McCabe, who developed and led MSK's Survivorship Program for more than 13 years, retired last year, and she was honored at this year's celebration. Ms. McCabe leaves behind a legacy that continues to shape how post-treatment care is delivered to cancer survivors. She remains a trailblazer for establishing survivorship care in healthcare settings across the globe. Under her leadership, *Bridges* was established in 2008 and continues to flourish as a newsletter exclusively for and about cancer survivors. I would like to personally thank Ms. McCabe for this wonderful and continued opportunity to be the patient editor for almost ten years.



Mary McCabe and Stacie Corcoran



Celebration Wall



Mary Ellen McEvily, *Bridges* Committee Member

ASK THE PROFESSIONAL:

Women's Sexual Health Program

By Lisania Milli, NP

How common are sexual health problems in female cancer survivors?

Sexual health problems are very common in female cancer survivors. The National Institutes of Health estimates that 40 to 100 percent of cancer survivors will experience some form of sexual difficulty because of their cancer.

What sexual health concerns do women most frequently have after cancer treatment? Do these usually improve over time?

Common sexual health concerns for women after cancer treatment are pain with intercourse, dryness in the vulva (the folds of skin making up the external genitalia) and vagina, and decreased sexual interest or arousal.

Treatment for cancer may include surgery, radiation therapy, chemotherapy, and endocrine therapy. Surgery may cause scarring and may also temporarily affect the nerves in the pelvic area. Radiation therapy targeting the pelvic area can affect tissue quality. Some chemotherapy can cause menopausal symptoms by decreasing hormone levels. These sudden changes can be bothersome. For example, hot flashes and night sweats can disrupt sleep. Some women have found that acupuncture, dietary supplements, and prescription medications can alleviate hot flashes.

The drugs anastrozole (Arimidex®), letrozole (Femara®), exemestane (Aromasin®), and tamoxifen (Novladex®) are used to treat and prevent cancer recurrence. These pills may worsen menopausal symptoms and can also lead to changes in the vagina and vulva.

All of these sexual health concerns have simple strategies that all women can implement to improve tissue quality and enhance sexuality, regardless of a cancer diagnosis. It is important to intervene early so that these symptoms do not get worse over time. If you are experiencing these issues, discuss them with your healthcare team.



Lisania Milli has been working in women's health for more than 25 years in many health-related roles — as an educator, registered nurse, and nurse practitioner. At MSK's Female Sexual Medicine and Women's Health Program, she provides care to people undergoing treatment or who have completed their treatment. She works as part of a team to treat the patient as a whole person, not just someone who has cancer.

What helps with these problems? Are there medically prescribed options to discuss with a provider?

Simple strategies can help with the physical changes caused by surgery, chemotherapy, and radiation therapy. Research has shown that people with cancer need more moisture than the general population. Frequent moisturizing of the vagina and vulva with hydrating over-the-counter products, such as Replens or HyaloGyn, is recommended for help with everyday comfort. For sexual activity, lubrication with products like K-Y or Astroglide is helpful in enhancing sexual touch or allowing penetration to be more comfortable. For some women, dilation is important to massage the vaginal walls and opening. Dilator therapy can help massage the tissue inside the vagina and at the opening of the vagina. Pelvic floor physical therapy is also an excellent resource. If necessary, a doctor can prescribe a localized vaginal estrogen.

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My New Normal

By Corine Mogenis

As a patient advocate, supporter of various cancer charities, and caregiver to family members and friends battling cancer, you would think I would have been ready when I received my cancer diagnosis. I guess it's absolutely true when they say, "You can never be ready." Nothing quite prepares you for that moment in time when you cross that threshold over to cancer patient.

I was diagnosed on October 11, 2016, with papillary thyroid carcinoma. For me, the journey from day one was about survivorship, focusing on what I needed to do each day to get to the end goal: being cancer free! After additional biopsies and testing at Memorial Sloan Kettering, I was told that the cancer had spread into the lymph nodes. My surgery was now going to be much more extensive

and would require radioactive iodine therapy as well. I was a stage IV: A tumor in the thyroid had spread beyond the thyroid and into local tissue, as well as to distant lymph nodes in the neck.

Everyone's journey is different as we go through surgery, treatment, and recovery. I would find my strength deep down in a place inside of me that I didn't know existed.

There was a surplus of strength that I would go to every day when giving myself pep talks through the fear, confusion, or pain. I realized that even with all of the love, support, and kindness of so many incredible

family members and friends, all of the hard work was up to me — physically, spiritually, and emotionally. It's times like this when you are forced to reevaluate your life. Your priorities. Your focus. Then make changes accordingly. I saw how easy it was to let this break me or to take back my control. I had my meltdowns, but then I moved on. I found that releasing and letting go of the bad thoughts and negative feelings as quickly as I could was key in order for me to move forward in a stronger positive way.

As I continue with therapy for the lymphedema I am experiencing in my neck in the aftermath of all of this, I know the journey will change but will never be over. With every follow-up appointment, scan, complication, side effect, or scare I may encounter, I will now be living my new life, my new normal as a cancer survivor. I also know that I have the power to make that life whatever I want it to be. One day at a time, looking forward to the future, staying as healthy as possible, as educated and informed about my cancer as I can — and helping others along the way. Life has changed, and I have changed, but all for the better. Life is what you make it!



Corine Mogenis lives in New Jersey, where she works as a paralegal for a civil litigation law firm. Her passions are writing, remaining active as a patient advocate, volunteering for several nonprofit charities, co-hosting her community TV show, staying connected to her family and friends, and celebrating life with a glass of good wine. She believes that in sharing our stories, we bring awareness and provide support and comfort to others.

ASK THE SURVIVOR:

MSK Nurse and Cancer Survivor

By Nikki Gioia, RN

Do you disclose to your patients that you're a cancer survivor? How do you have this conversation?

If and when appropriate, I sometimes tell them that I am a cancer survivor. However, this is their journey. I never want to make it about me. If the patient needs some words of encouragement and needs hope, I tell them. I believe my story illustrates that people do make it out of this hardship and thrive. It is a difficult conversation to start because I never want to overstep with my patients. I usually listen for a while, then tell them that I understand how they are feeling and what they are going through because I have been in their shoes. Even though my treatment course was not typical, I made it through — I make sure to stress that.

Are you able to connect better with your patients because you're a survivor?

I don't know if it's better — it is just different. I was and forever will be a patient here, since I continue to have long-term follow-up as an adult. I can connect with my patients on their level. I have been on the patient's side of the bed and have had some of the same pains and distress. A majority of the time, it's the uncertainty that I connect with most. There is always a fear that your world will be halted by cancer. As my parents have always told me, and I now tell my patients, "It is what it is and will we get through it together."

Do you think patients are able to connect better with you because you have gone through a similar experience?

I think that patients are able to connect with me because we have both been through it. We understand the pain, the ordeal and stress that another clinician may not be able to appreciate. Something as silly as a shared taste of a certain medication will make a connection. Also, I try my best to never forget the caregivers. I always remember that my parents and brother went through it with me. Their experience and vantage point is



Nikki Gioia is now 26 years old and is a survivor of Hodgkin's lymphoma. She was diagnosed in 2001 at age 10, relapsed twice, and underwent a transplant using her own bone marrow cells. She knew right out of high school that she wanted to be a nurse but not just any nurse, a nurse at Memorial Sloan Kettering Cancer Center.

different, but they were right by my side for every medication and blood draw. I have immense respect and gratitude for caregivers.

Has your experience as a survivor helped you as a clinician or made it more challenging at times?

Being a cancer survivor has helped me as a clinician. Sometimes patients find it hard to express their frustration or pain. I can help put that frustration into words, help them cope, and help medical staff understand what they want or need. Sometimes patients just want a clinician to sit with them or to let them know they are coming back. I have realized that saying "I will be back" is often the best thing I can say to a patient. It is something so little, but it puts them at ease, knowing they are not alone. After my treatment, all I wanted to do was get away from MSK, but now I can't imagine doing anything else. I believe things happen for a reason, and if I didn't go through cancer treatment and the adversity that followed, I would never be doing what I am doing today — paying forward the care that was given to me by my amazing nurses, medical team, and staff.



Life's True Meaning

By Ed Langan

This year marks my 15th anniversary in the care of Memorial Sloan Kettering, whose healthcare professionals have helped me to lead a rewarding and fulfilling life.

Most recently, in 2015, successful surgeries were performed to remove cancer cells from my forehead and ear. Previously, MSK's skilled medical team successfully treated me for throat and prostate cancer.

In the course of these medical events, my wife passed away after being ill for several years in both hospitals and nursing homes. Having developed an affinity for what such residents must endure, shortly thereafter I began volunteering at a local healthcare facility in my hometown of Croton-on-Hudson.

Ed Langan, who is the father of two grown sons and is retired from accounting and sales, lives in Croton-on-Hudson, New York. He spends his time reading, walking, and just enjoying the calming view of boat traffic passing on the Hudson River.

Each day, for approximately the past six years, I have spent time with various residents, but I mostly visit with an individual named Dennis. Diagnosed with multiple sclerosis, he has been a permanent resident at his facility for nearly 14 years. Although Dennis doesn't verbalize, I have been blessed with being able to understand his likes and dislikes from his facial expressions.

Dennis enjoys the interaction with, and acknowledgement by, other residents, many of whom admire him daily. He reciprocates this affection with a ready smile. At his recent birthday celebration, Latin salsa dancers were invited to perform at an event that was thoroughly enjoyed by all of the facility's residents.

In recognition of my work with residents at this facility, in March 2016 I was selected as the New York State Health Facilities Association district and statewide volunteer of the year. That June, the organization honored me at its district and statewide annual convention. Initially, I felt uncomfortable about attending because I knew that I would be asked to deliver a brief acceptance speech, and as a private individual, I had limited experience with public speaking. However, my message of hope, caring, and love for those individuals whose lives

are compromised by myriad disabilities must have struck a chord, for the several hundred audience members present kindly afforded me a standing ovation.

The satisfaction I receive from giving my time to others provides an amazing inner peace. Ultimately, the more I give, the happier I become. I have been fortunate enough to find life's true meaning all around me. Each day brings its own gifts. Just as I am blessed and looked after by God, when I leave Dennis daily he looks at me, smiles, and holds my hand tightly. I tell him God loves him and is looking after him also.

Having successfully overcome recurring cancers, I empathize with those with whom I volunteer, mindful of the uncertainty and enduring challenges that often accompany various debilitating diseases. Being an oncology survivor has enabled me to give hope and understanding to those afflicted with this illness.

It takes only one kind word and, above all, simply being there to offer a smile and an outstretched hand. This provides troubled people with the confidence to know someone sympathizes. I believe that, throughout human history, it ultimately all comes back to caring for each other.

Memorial Sloan Kettering Blood Donor Program

Help MSK patients by donating blood or platelets to the MSK Blood Donor Program. Both general and directed donations are welcome. Please call for hours and more information.

MSK Blood Donor Room

Schwartz Building Lobby
1250 First Avenue
212-639-7648 or 212-639-8177

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my mind. Even with the substantial support system we had in place, I lost focus on caring for my own emotional and physical health. I became openly angry and emotional, especially at work. I was lucky that they were empathetic and didn't kick me out of the door. Through professional counseling, I turned the corner and started to decompress; my roller coaster began decelerating.

Today, I am in a great space, thanks in part to the following caregiving experiences. I hope they benefit you on your journey.

1. Ask for and accept help. Trust me, it makes things easier.
2. Find something to laugh about every day and share it, such as the hospital hallway clock that ran backward. No lie.
3. Take a break every day by doing something not cancer related to distract yourself.
4. Eat a well-balanced diet. It may be tempting, but a box of Twinkies is not dinner.
5. Sleep. Do the best you can.
6. Seek professional help. An experienced perspective can be critical.
7. Stay in touch with friends and family.
8. Talk with other caretakers. There is comfort in shared experiences.
9. Talk to your employer about the Family and Medical Leave Act and work schedules.
10. Spirituality. It doesn't matter if you pray to left-handed penguins from Jersey City, a higher power that provides a sense of peace is essential.
11. When treatments are completed, take time to decompress; weeks, months — whatever it takes.
12. Take the entire experience one day at a time.



DEPARTMENT OF VOLUNTEER RESOURCES

Patient and Caregiver Peer Support Program

**Connect with Someone
Who Understands**

The Patient and Caregiver Peer Support Program connects current MSK patients and caregivers one-on-one with former patients and caregivers. These volunteers can speak with you face-to-face or via telephone, and they are dedicated to supporting you along your journey.

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

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Talking about sexual health can be difficult for cancer survivors. If a member of the healthcare team doesn't ask about these concerns directly, should women approach the topic?

Women need to be their own advocate. If you're having concerns or issues, it's best to bring up the issue soon after diagnosis or when starting treatment. Healthcare providers can offer information or an appropriate referral to address these important topics.

Who should visit a sexual health professional? How can women find support?

Women who need more support or help coping with the changes to their body image or self-esteem should seek out a mental health professional who specializes in treating people with cancer. The American Psychosocial Oncology Society helps people affected by cancer find quality care (www.apos-society.org). To find sexual health counselors, visit the website for the American Association of Sexuality Educators, Counselors, and Therapists (www.aasect.org). Women who need more information on menopause or would like to see a menopausal practitioner can visit the North American Menopause Society (www.menopause.org).

Women can also make an appointment with MSK's Female Sexual Medicine and Women's Health Program by calling 646-888-5076. This program includes a psychologist, sex therapist, and nurse practitioner.

Clear Skies, Clear Scan

Clear skies, lakes, and rivers
Clear scan

Clear head
Clear scan

Clear eyes, nose, and mouth
Clear scan

Clear heart
Clear scan

Clear chest, abdomen, and pelvis
Clear scan

Clear lungs
Clear scan

Clear shoulders, arms, and hands
Clear scan

Clear back
Clear scan

Clear hips, legs, and feet
Clear scan

Clear body
Clear scan

Clear clean emotions
Clear scan

Clear pure intentions
Clear scan

Clear open connection with God
Clear scan

Clear forgiveness for all
Clear scan

Clear gratitude for everything
Clear scan

Clear joy for living
Clear scan



Audrey Weiss Degutz is an occupational therapist who works with children with special needs. She lives with her husband, Alan, and cat, Sneaky, and she has two daughters in college. Audrey enjoys being in touch with her creative side through poetry, art, and music.

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