

Bridges

Connecting Cancer Survivors



Normal Life

By Peter Fox

“A branch which has been partner of the tree’s growth since the beginning, and has never ceased to share its life, is a different thing from one that has been grafted in after a severance. As the gardeners say, it is of the same tree but not of the same mind.”

— Marcus Aurelius

Ten years after treatment for Hodgkin lymphoma as a high school senior, I was told I was cured and to go live a normal life. I took it to heart and did my best to live from that moment as if nothing had really transpired at all. I accepted no physical, emotional, or psychological limitations and rarely told the story except to those who encountered scars. I was embarrassed to mention it, like complaining about a skinned knee.

In hindsight, the normal life advice and my response to it were both pretty absurd. I’ve struggled tremendously with alienation, anxiety, and depression from the experience but never sought real help. While I was more health conscious than others and had many false alarms about lumps, infections, etc., I always suspected it was hypochondria and a personal failing. It never occurred to me in the 35 years following radiation treatment that my skinny neck and bony torso signified more than a regrettable, congenital laziness regarding the gym.

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Peter Fox is a contemporary artist whose work has been exhibited throughout the United States and internationally. Diagnosed with Hodgkin lymphoma at age 17, he was treated with mantle radiation and cured. He lives in Queens, New York, with his wife, Cibeles; son, Sam; and their dog, Nikki. When not in his studio, he loves being with family and growing giant sunflowers in his garden and pineapples on the windowsill at home.

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Memorial Sloan Kettering
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Editorial

By Eileen F. Gould

We are proud of Bridges as this is the 40th issue of the newsletter for and about cancer survivors here at MSK. Bridges was started almost ten years ago, and it has been a collaborative effort of several people over the years, including an Advisory Committee composed of patient volunteers, caregivers, doctors, and MSK staff.

I wanted to share with you a note written by one of our Advisory Committee members, Ellen Greenfield, who is a caregiver as well. She was asked by her employer to describe her volunteer work at MSK.

"Since its founding in 1884, Memorial Sloan Kettering Cancer Center in New York City has been one of the nation's premier cancer treatment and research centers. When my husband was diagnosed, it was the place we turned, and we have never regretted that. Every person there with whom we had contact — from parking attendants, technologists, and office staff to the nurses and doctors — treated us with the utmost care, kindness, and respect.

Once his recovery was complete, my focus shifted to giving back to this great hospital. I first began working with Bridges, a quarterly survivorship publication that was started in 2008. Bridges features first-person stories of cancer survivors, caregiver articles, and pieces by MSK professionals. It prints 7,600 copies that are distributed throughout the hospital and is sent to 3,000 email subscribers.

Working with Bridges has been yet another gift that MSK has given me."

Where Are They Now?

By Valerie David

Who could have ever imagined that a newsletter article would be forever life changing? *Bridges* winter 2016 issue featured my article, "The Cycle of Life," about completing a 40-mile bike marathon two months after finishing breast cancer treatment. Sharing my story opened the door to writing and starring in my one-woman play, *The Pink Hulk: One Woman's Journey to Find the Superhero Within*. The play chronicles my much longer autobiographical journey in becoming a two-time cancer survivor (non-Hodgkin lymphoma, 1999, and breast cancer, 2014 through 2015). I wrote openly about how I "hulked out" to beat cancer twice and shared how I channeled my anger into empowerment and humor. In just a few months, my story leapt from the page onto the New York stage. I have been touring with

the show since the play premiered in spring 2016. Since then, it has won multiple awards and been accepted into 17 different theater festivals. The play has been impacting audiences with its universal message of hope and empowerment.

My goal is to inspire not just people with cancer but anyone facing adversity: We all have a superhero inside ourselves — we are stronger than we think — and we can overcome!

Being a cancer survivor and helping others through my play are two of the things I'm most proud of in my life!



ASK THE SURVIVOR:

Patient and Caregiver Volunteer Program

By Mike Philbin

What is the Patient and Caregiver Support Program?

This is a peer-support program that connects current patients and caregivers one-on-one with volunteers who have been through a similar cancer diagnosis. The volunteer understands the challenges and worries of the current patient. The volunteer listens and offers confidential support before, during, and after cancer treatment.

Why did you decide to become a patient volunteer?

When I found out that I had prostate cancer, I was able to speak with three family members and three friends who had been diagnosed with prostate cancer in their 50s, like me. Each helped me understand the various aspects of my treatment and recovery.

But what about people who don't have someone to talk with who has had their type of cancer? Even if they do, that person may not want to talk about certain physical and emotional aspects of their diagnosis and treatment.

How did you apply to MSK's Patient and Caregiver Support Program?

About two years after my surgery I decided that I wanted to help other men as a volunteer in MSK's Patient and Caregiver Support Program. After submitting my application online, I had both a phone interview and a face-to-face interview. I went through eight modules of online training and attended six hours of face-to-face training.

Can you describe what it's like to be a patient volunteer?

One of the things about the patient-to-patient program is that it can be done anonymously. We conduct our conversations over the telephone. I think this anonymity makes it easier for a patient to ask questions that they may not feel comfortable asking someone they know. It is a totally confidential discussion between myself and the patient.



Mike Philbin is an organic chemist and has lived in New Jersey for 29 years. He and his wife, Patty, recently celebrated 24 years of marriage. As a result of his experience as a patient at MSK, Mike became a volunteer in the Patient and Caregiver Support Program in 2016.

I am now one of more than 100 volunteers in the Patient and Caregiver Support Program. When a patient or caregiver calls the coordinator of the program, the coordinator listens to what their concerns are and is then able to match them up with the patient or caregiver volunteer that can best help them.

I have spoken with 14 patients in the 11 months since I joined the program. The conversation always starts off with a very sincere sentiment from the patient thanking me for taking the time to speak with them. There is always a point in the conversation when the patient will ask me, "Do you mind if I ask you some very personal questions?" My reply is always that they can ask me about anything. The only questions I can't answer are those regarding medical advice. Those need to be directed to their clinical team. The best thing that I can hear at the end of our conversation is, "Thank you so much. I feel so much better about moving forward with my treatment."

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Respected and Valued! MSK's Great Employees

By Edward Bell

Ed Bell is a retired business manager of a trade union. He and his wife, Patricia, live in Suffolk County, New York. After battling pancreatic cancer for slightly more than five years, he still enjoys his love of tennis, boating, and fishing.

During an overnight big-game-fishing tournament on August 15, 2012, I fell into a cabinet when a large wave violently shoved the boat sideways. I thought surely I had broken some ribs or worse because of the amount of pain I felt that night and on the slow 65-mile ride back to port.

Upon my return I had x-rays and a sonogram at a local hospital and was assured that there was no damage to my organs and no bone fractures. However, I was cautioned that it may take a very long time to completely heal.

Since I still had much pain near the end of November, my better and smarter half suggested that I visit my urologist because of a history of kidney stones. Of course, like some husbands do,

I finally took my wife's suggestion.

At a visit with my urologist to review a scan he had ordered, I heard the words no patient ever wants to hear: "I have some good news and some bad news." He then said, "I can easily take care of your kidney stone, but you need to see a surgeon about the mass on your pancreas."

A Bit about My Cancer

My diagnosis of cancer occurred in November 2012, and my first surgery, a radical distal pancreatectomy, was done the day after Christmas 2012 at a hospital other than Memorial Sloan Kettering.

Not long after my first surgery, chemotherapy treatments began at

MSK, and following a recurrence of cancer in 2015, all further treatment has been done at MSK. As you can see, November 2017 marks my five-year survivorship of pancreatic cancer, and as a result, I have really gotten to know many MSK employees.

As a former labor leader in the construction industry, I have always had a soft spot in my heart for employees. Wherever I am doing business, I have a terrible habit of prying into the worker-employer relationship. There are businesses that simply don't get my patronage if the employees are not respected and treated fairly.

Of course, I pried into the work lives of nearly everyone I encountered as an inpatient and outpatient during my ongoing treatment at MSK.

When I asked, "How long have you worked with Sloan?" or "What's it like working here?", it pleased me that each and every MSK employee, from porters, greeters, transporters, and aides to nurses and doctors (maybe 150 to 200 in all), indicated, "I love working here."

For the last five years, I have not hesitated to tell others about my journey with hopes that it may be helpful to them or someone they love, should they hear the dreadful message, "You've got cancer."

In addition to receiving the very best lifesaving treatment at MSK, it always gives me great joy to share so many stories, like hearing the heartfelt words of the greeters when entering or leaving the building, receiving the assistance provided when getting on and off the MSK shuttle service, and always for hearing the words, "I love working here."

Surely that's because they have all been respected and valued by their employer and the patients they care for!

To all of you at Memorial Sloan Kettering, thank you from the bottom of my heart!

ASK THE PROFESSIONAL:

Caring for the Caregiver

By Allison Applebaum, PhD

What are the signs of caregiver burden?

Caregiver burden refers to the ways that caregiving can be hard on the caregiver. There are many signs of burden. These include fatigue, irritability, feeling anxious, or generally having trouble doing the many tasks of caregiving. Another sign is caregivers not taking care of themselves. This can mean drinking too much alcohol, not exercising, or not making time for rest. Burden can lead to a weakened immune system. This makes caregivers more likely to get colds or flus, as well as have other medical problems. While not all of these symptoms alone are signs of burden, when they happen together over several weeks or longer, it's usually a sign that burden is present.

What challenges do caregivers face after treatment has finished?

Caregivers are survivors too. They often have many of the same feelings as the person they are caring for, such as fear of the cancer coming back. Survivorship is a time when we see more anxiety and depression in caregivers. They frequently put aside these feelings as their loved ones were diagnosed and getting treatment. When caregivers are able to think about themselves again during survivorship, however, the impact of the entire illness can be felt deeply. For many, this is also a time when roles and responsibilities change. In addition to challenges, caregivers might also go through a period of personal growth. The caregiving experience can have a big impact on one's values, outlook, and priorities.

How important is effective communication between caregivers and patients?

Good communication is the basis for family-centered care. It is necessary for caregivers to understand their loved one's treatment preferences, prognosis, and hopes for the future. For caregivers who also serve as healthcare proxies, it is virtually impossible to honor a patient's wishes if there hasn't been any open discussion beforehand. I encourage all caregivers to talk with their loved ones before every doctor visit, procedure, or treatment and to know the questions they would like to ask. This allows for better conversations with the care team and more chances to plan for the future as a family.



Allison Applebaum is an assistant attending psychologist and Director of the Caregivers Clinic at MSK. The Caregivers Clinic is the first of its kind and provides counseling and support to family members and friends who are taking care of loved ones with cancer. Caregiving can be a very stressful time, and caregivers often face many difficulties in the role.

What resources does MSK have for caregivers?

MSK is doing a phenomenal job in supporting caregivers. Our Caregivers Clinic is the first devoted specifically to supporting caregivers throughout the entire care period. Licensed clinical psychologists see caregivers one-on-one or in groups. If medications are needed, the caregiver can see a psychiatrist. The clinic is part of the Department of Psychiatry and Behavioral Science's Family Care Program. The program also includes the Couple and Family Therapy Clinic, led by Talia Zaider; the Bereavement Clinic, led by Wendy Lichtenthal; and the Child and Family Support Clinic, which is part of the Department of Pediatric Oncology and provides support to families with a child with cancer. Support is also offered through the Department of Social Work and the Caregiver-to-Caregiver Mentoring Program. No MSK caregiver should feel alone or as if they don't have enough support. We are absolutely here to help.



TYA@MSK

Teen and Young Adult Program

By Nina Pickett

A cancer diagnosis in teens and young adults is rare. As patients, they may be treated in either pediatric or adult oncology units based on disease type or local resources and are often “alone” amongst children or older adults with cancer. Their experience is very different than those in other age groups, with individual needs and concerns at different stages in their lives. These often go unsaid and are not met. MSK has responded to help support patients ages 16 through 30 in active treatment in three ways.

TYA@MSK is designed to reach teens and young adults at all of MSK’s locations. Alongside dedicated program managers, a team of physicians, nurses, and others focused on this age group provide input and support. Teens and young adults with cancer may feel isolated and removed from their friends. They talk about being “the only one my age in treatment.” TYA@MSK connects the nearly 2,000 patients between ages 16 and 30 who are treated at MSK each year, no matter what type of cancer they have or where they are being treated. They can meet their peers, ask questions that are otherwise unanswered, and leave their hospital rooms for a space designed with them in mind.

The Lounge is open to both inpatients and outpatients ages 16 through 30. It is located on the 14th floor of the Bobst

Building and may be reached through the Memorial Hospital building as well. The Lounge has many activities and above all is a comfortable place to hang out with friends.

The Lounge Mobile App puts The Lounge in your pocket. On this secure social media platform, users can interact and get information from people they trust. Some patients may choose to just read along, and others may engage in various ways. They can share their personal profiles as well as ask questions and get responses from experts, both other patients and MSK’s staff.

Peer-2-Peer pairs active patients with young adults who have completed treatment. Our volunteers meet with current patients either in person or online. Each volunteer has gone through a similar experience. They once had the same concerns, and their insight can help guide their peers.

TYA@MSK brings focus to the needs of teens and young adults. Giving voice and support to each other helps shape not only their experience but the quality and outcome of their care.

For more information, contact TYA program staff at 212-639-8925 or email tyaprogram@mskcc.org.

NORMAL LIFE

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I didn't make a clear connection between cause and effect until a few years ago, when long-term physical side effects of treatment (stooped posture, dizzy spells) began to impact my life. It was after a scary episode of double vision at the playground with my son — I thought I was having a stroke — that I first searched the words "radiation treatment long-term effects." Google led me to the sudden awareness that there were a whole raft of health issues associated with radiation treatment, and then to Hodgkin survivorship groups, which in turn directed me to the late effects clinic at MSK.



Peter; his wife, Cibeale; their son, Sam; and their dog, Nikki.

I have difficulty thinking of myself as a survivor. We all survive every day, and others face greater obstacles daily than I ever have, regardless of health. Though in denial about the physical side effects of my treatment, I always

knew that my entire adult awareness and engagement with reality was shaped, for better and worse, by my cancer experience. Confrontation with mortality creates its own focus and set of priorities. Mine took place on the cusp of adulthood and thus was foundational.

Pursuing art as a serious career followed from the news that I was cured and had a future to prepare for, something I hadn't allowed myself to expect. I'd drifted until then, directionless, commitment averse, bags packed, waiting to fall. But I didn't fall, and my truth is that the view from the edge is more wondrous, sublime, and beautiful than I can begin to describe. I'm lucky every day. Even if I could erase the rest, I'd never give that back.

MSK Family Care Program

Resources for Families and Friends



The program supports families who face challenges related to cancer across all stages of the disease. We believe that families are a crucial resource in cancer care. Our mission is to identify every distressed family member. We want to make sure that they have the help they need. We offer one-on-one, couples, and family therapy. These services help loved ones address difficulties that come up or are made worse by their experience with cancer.

For more information, call 646-888-0100

MSK Family Care Program

- couple/marital therapy
- family therapy
- support for parents whose children are patients
- support for children when the patient is a parent
- support for individual caregivers and friends
- bereavement support for family members or friends

ASK THE SURVIVOR

■ *Continued from page 3*

What do you get out of being a patient volunteer?

It has made me realize that I really enjoy helping out other people.

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

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.

I'm Still Here Victorious

By Ann Colander

For a long period of time my life was suspended in a void
While I was seeing brief glimpses of my life flashing before me
Cocooned yet protected it was if the gods had decreed my fate
I had no choice but to follow the slippery rocky road until the end
I kept hearing voices in my head asking questions after questions
“Are you all right?” “Are you OK?” My answer is “Yes, yes I am”
I’m alive! I’m breathing. I have beaten the odds by living my best self
I had stepped into the abyss not knowing how all this was to end

I’ve learned to navigate, cope, and accept this is a new me, a rebirth
This may sound strange, but it was the only way for me to move forward
The same fire that was lit and dimmed 11 years ago is burning strong
Helped me endure yesterday and today keeps me warmed and strengthens me
So many memories of the time I have felt the hand of God’s grace
With calmness spreading and serenity ruling by touching my very soul
Sustaining me, keeping me focused on the good and positive things in my life
I have a song in my heart, a tingling along my spine, and a bounce in my step
Your life can change in a moment’s notice but never give up! Stay strong

I can hear it, I can feel, see it, and taste the notes and flavor of the music
The drum beats rhythm, echoing nothing but wellness, the power of hope
The movement of the lyrics, words of comfort and flow, the high and lows
I’m always searching, reaching, trying to find succor, a haven
Maintaining that inner peace, every moment so precious to surviving
I’m blessed every day in so many ways, who could ask for anything more
Surrounded by thoughtful and kind-hearted people has lightened my load
Lifting me up, embraced in those moments of hurt, anger, regret, sadness
I smile, give myself a pep talk. Eating some ice cream and cake makes it easier

I have practiced doing this over time, now it has become second nature
For now safe and secure looking forward to many more tomorrows
Some shadows still lurking but faint, a tiny minute reminder to stay alert
Attached like the tentacles of an octopus in an ever-expanding universe
Forever in the recesses of my mind for now impotent never forgotten
I awake each morning with a prayer, giving thanks, creative ways, ideas
Learning how I can make my day, my joy, and my family and friends’ lives better
A good home-cooked meal is a great and tasty way to start! Blessed!



Ann Colander is an 11-year head and neck cancer survivor, celebrating by living her blessed life to the fullest. She loves cooking, reading, writing poetry, creating art, dancing every Friday night, and lots of laughter, and she always smiles, striving to be positive.

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Cover Bridge Photo
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Produced by the
Department of Communications

Bridges is a publication of the
Cancer Survivorship Center at MSK.

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MSK Blood Donor Room
Schwartz Building Lobby
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