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Bridges

Connecting Cancer Survivors

Pretty Girl Blues

By Jearlean Taylor (co-author Ellen J. Greenfield)

Jearlean Taylor is a Baltimore native with a powerful story to tell. She grew up in a loving family with her two parents, three sisters and two brothers. After being diagnosed with a rare form of cancer at the age of two and a half, her life has been nothing short of a miracle. Jearlean's life has proven to be a journey of unexpected challenges, and "Pretty Girl Blues" is a recollection of her journey.

If there is one thing I have learned in my life, it's that outer prettiness can be misleading but inner strength and beauty endow their owner with a powerful, life-sustaining force.

I was born in Baltimore to a large, happy family. I am a twin and we were the fifth and sixth children. I was only two and a half years old when I was diagnosed with a rare form of cancer (rhabdomyosarcoma) that made my survival beyond the age of three nothing short of a miracle. My whole family thanks MSK for that miracle, which has allowed my life to be a journey of both enormous challenges and unexpected rewards. My childhood included several reconstructive surgeries, lengthy hospital stays, and constant medical evaluations. Starting school was exciting but made difficult by my need to take care of my ostomies, (prosthetic medical devices for the collection of waste). Eventually my parents decided it would be best if I was homeschooled for first grade. After that, though, I was ready to join the rest of my classmates. I give my family a lot of credit for this — they never treated me as anything less than a perfectly normal child who had a couple of extra issues to deal with.

But as I grew older, while others appeared to be living a "normal life," I struggled with self-pity and depression. I found it embarrassing and painful to

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Editorial

By Eileen F. Gould

This past June, in honor of National Cancer Survivors Day, MSK held its annual Survivorship Celebration. Three patient speakers shared their moving personal stories beginning with diagnosis through achieving survivorship status. Shannon Miller, Olympic gold medalist and ovarian cancer survivor, spoke about her experience as a cancer patient, mother, and athlete. Every year, you can sense the celebratory atmosphere among the attendees in the auditorium and the palpable good mood afterward at the reception.

The American Cancer Society reports that as of January 1, 2014, there are nearly 14.5 million people alive in the United States who have been diagnosed with some type of cancer — and that figure is projected to reach 18.9 million by 2024. Improved survival statistics are a result of better early detection, state-of-the-art treatments, and much improved supportive care.

MSK is at the forefront of survivorship care. Physician-in-Chief José Baselga announced at the celebration the establishment of the new Cancer Survivorship Center at MSK (read more below). The Center will provide the gold standard in survivorship care, research, training, and education.

Cancer Survivorship Center at MSK

(From left) Director of Training and Education Charles Sklar, Director of the Cancer Survivorship Center Kevin Oeffinger, and Director of Clinical Programs Mary McCabe

We are excited to share with you the recent announcement regarding the establishment of the Cancer Survivorship Center at MSK. Originally established as the Survivorship Initiative in 2003, our initial goal was to coordinate hospital-wide efforts dedicated to meeting the medical, psychosocial, and general life challenges facing survivors and their families. Looking ahead, we are excited about new opportunities to develop a nationally recognized standard of care for cancer survivors, conducting practice-changing survivorship research and developing the preeminent center for training and education in survivorship.

The *Bridges* newsletter has been such an important element of our patient and institutional community of survivorship for the last several years and will continue to be so for many more to come.

We thank you all for your continued support and look forward to our future as the Cancer Survivorship Center at MSK!

Ask the Professionals:

Managing "Scanxiety"

By Natalie Ishak, LCSW, and Chelsea Chin, LCSW

What is "scanxiety?"

"Scanxiety" is a term often used to describe the feelings people may have when preparing for a follow-up scan or procedure. It can also describe their feelings while they await the results. Many people feel a range of emotions including anxiety, fear, and/or sadness. These feelings can manifest in a variety of ways, both physical and emotional.

I have completed chemotherapy/radiation and am in remission. Why do I continue to feel anxious?

People often experience feelings of depression or anxiety following the end of their treatment. This can be distressing for many people, as they cannot understand why they may be feeling this way. According to well-meaning friends and family, the end of treatment should signify happiness and excitement, which can often be part of what people feel, but it can also be accompanied by feelings of unease or fear. The first thing to stress about these feelings is that they are completely NORMAL!

Cancer is a disease that often takes people by surprise and can completely change their outlook on life. Survivors have shared that a fear of recurrence is something that is always in their head, whether it be in the forefront or somewhere in the back of their mind. It is something they live with each day, even years after treatment has ended. People have even said they worry that every new ache or pain is the cancer coming back. Feeling uncertain about the future is often a side effect of a cancer diagnosis, and these feelings are especially prominent around scan results and follow-up testing. Sometimes one may not even realize they are anxious, but instead experience symptoms like irritability, sadness, or difficulty sleeping. Remember you are not alone in these feelings and there are strategies that can help.

What are some ways I can manage my anxiety around recurrence?

Scanxiety is a common emotional response that can affect your quality of life. Everyone has different ways of coping; you should find strategies that will work best for you. Below are some suggestions that can help reduce feelings of anxiety, irritability, sleeplessness, and depression:

1) Activity

Distraction is a simple way to take your mind away from troubling thoughts. Make an effort to plan activities that you can enjoy independently or with others. Some find pleasure in reading, music, art, sports, games, movies/television, social outings, and perhaps even work.

2) Social Support

Talk with a close family member or friend whom you trust and with whom you can be honest. MSK's Patient-to-Patient Support Program has trained volunteers who can speak with you and share the perspective of having been treated for cancer.

3) Integrative Medicine

Relaxation techniques can activate your body's natural relaxation response. Mindfulness meditation, deep breathing, visual imagery, Reiki

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Ask the Survivor

By Marie Alfano

Marie Alfano lives in Rochelle Park, New Jersey, with her husband, Anthony. She has a daughter, Nikki, and a son-in-law, John. She enjoys writing, reading, gardening, and working on miniature dollhouses.

What do you do as "scan day" approaches to distract yourself from your scanxiety?

It is important to do normal things and think normal thoughts as the day of the scan approaches because it tricks your mind into thinking that everything is OK. Keeping up with normal activities will help keep you focused. When you get right down to those last few days, though, it becomes harder and harder to focus on normal. For example, going to the gym is normal for me and, as an added benefit, it gets rid of all the excess energy I am building up just waiting for the day to finally arrive, so I continue this activity. On the other hand, even though dusting, vacuuming, and doing laundry are also normal for me, they do little to put an end to my fears. Therefore, because there is no added benefit of doing it, it usually falls to the wayside those last few days before the scan. I do have friends, though, who become downright meticulous with the housework in the days leading up to a scan! We each have our own idea of what "normal" is and it's important to do whatever helps you stay calm and relieve stress. For me, the day before the scan I find that my anxiety tends to get the better of me and at this point, retail therapy is my only hope!

What helps you to feel less stressed once you're going through your scan? Do you appreciate music or other distractions?

I am probably one of the very few people who do not listen to music during my scan because I tend to find it a distraction. Being a certified control freak, I find that the only way to control the situation is to totally focus on what is happening. I do like to talk to the technicians before I actually get myself situated and I ask them to talk to me every once in a while during the scan. This gives me reassurance that I am still connected to someone outside of the testing room. When everyone leaves the room and closes that door, a person can start to feel a little cut off from the outside world. It's just you, the machine, and all of your fears. I guess it is at this point that I resign myself to the fact that I really don't have control of anything right then — and so I start to pray. I wonder how many prayers have been said in that room. More importantly, were any of them answered?

Is there something that you wish staff would do or would not do to help alleviate your anxiety? Do you try to read the faces of the technicians for clues about the scan results?

It always helps when staff takes the time to actually talk to us; a conversation between two people is normal. A conversation between two people about normal things is really normal. It's that "normal" thing again! The need to focus on the normal.

As far as reading technicians' faces, while you are lying on that table you twist your neck in ways you never thought you could just to see the technicians through the glass window. In fact, you may discover that you have the ability to read their lips! Your imagination can run wild as you distinctly read their lips as they say, "Oh my, look at that!" Can you possibly get any more paranoid? Of course you can — just when you think your ordeal is over, you hear the technician say those dreaded words: "I'm sorry, we need to take another picture." Another picture! Why?! You try to read their lips to get any further information, but

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The MSK Patient Portal

By Elizabeth Rodriguez, DNP, RN, OCN

Elizabeth Rodriguez, DNP, RN, OCN, is a Nurse Leader in the Outpatient Department. She has worked on the development of the patient portal (MyMSK) from its inception more than ten years ago and has provided significant contributions on the design of the secure messaging system. Dr. Rodriguez completed her doctoral work in 2010; her project resulted in the implementation of the laboratory results display to patients on the patient portal. This was the first "link" between the patient's medical record and the patient portal providing precedence for additional information and greater transparency in the future.

Patient portals such as MyMSK empower patients by giving them the ability to access their clinical information online and increase opportunities to communicate directly with their care team. Patient portals help ensure that patients are well poised to collaborate with their provider and participate in their own care.

Over the years, patient portals have evolved tremendously and now provide increasing transparency of medical record information to patients. Keeping pace, MyMSK provides people with a variety of services and information in regard to their care. For instance, they are able to view, schedule, and modify their appointments, see a number of laboratory results, update their demographic and personal information, and communicate with their care team, all through the portal.

Secure electronic messaging is a safe, convenient way for patients to communicate with their care team and has become a popular service for the nearly 40,000 patients currently registered to MyMSK. In just the last three months, over 20,000 messages have been exchanged between patients and care provider teams on MyMSK! Response times are typically within two business days but are often much quicker. The majority of the correspondence is handled by nurses and office assistants. When necessary, messages are shared with other members of the care team and documented in patients' medical records. As of August 2014, a new feature of the messaging system was introduced that allows for documents to be attached to messages, which will further support the exchange of information between patients and their care team.

Corresponding via an online portal is efficient and effective and gives patients the ability to inquire about easily managed requests such as prescription refills, questions about their treatment, and following up on insurance authorizations. For more complex or urgent issues, including the reporting of symptoms, care providers ask that patients call their physician's office rather than sending a message via MyMSK, as these types of messages require a more timely response.

Another important feature of the MyMSK patient portal is the access it provides to many laboratory results and other outpatient tests. Currently, the portal displays more than 350 outpatient laboratory tests as soon as they are made available within the medical chart. Similarly, results to all radiology exams performed in the outpatient setting display on MyMSK three business days after completion of the test. Educational and other resource documents are available on MyMSK to provide patients with information on the tests performed and how to understand the results.

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Where Are They Now?

Jenny Allen

"Every day I wake up grateful," says Jenny Allen, who contributed "I Got Sick and Then I Got Better" to the Fall 2010 issue of *Bridges*. Since 2005, when Allen was treated for ovarian cancer, she has been in an intimate dialogue with the world about what it means to be a survivor. In 2007, she wrote her one-woman play with the same title because, as she put it, "As a writer, when life hands you material, no matter how difficult, you have to honor it." She took the play on the road, beginning with the New York Theatre Workshop in 2009 and continuing it to Alaska, Florida, Massachusetts, and even Las Vegas, and including performances at Duke University, Adelphi University, and of course, Memorial Sloan Kettering.

"I love doing it. I would do it until the day I die," Allen said. "Although I'm the one who's talking, it's like being in a conversation with the audience. You don't have to have had cancer to relate."

In addition, she serves on the board of the Ovarian Cancer National Alliance and has won a coveted "It's Always Something" Award from Gilda's Club for an outstanding cancer-themed performance.

"There is something about surviving cancer that is kind of joyous," she says, "A gift. It gives you a zest for life."

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or massage therapy, and exercise have proven effective in reducing stress while improving energy and mood. Participation in music and art therapy can also be very helpful.

4) Cognitive Reframing

Thoughts and feelings play an important role in our behavior. Many people feel a significant loss of control when facing cancer and treatment. Cognitive behavioral therapy (CBT) is a technique that allows individuals to control how they view or interpret their experience. It focuses on identifying the situation that triggers a feeling like anxiety, then learning how to replace the unhelpful thought patterns with realistic thought statements. Speak with your social worker and/or the Counseling Center about utilizing CBT to reduce stress and anxiety.

5) Counseling and Psychoeducation

Clinical social workers, psychologists, psychiatrists, and chaplains are trained to provide counseling to those experiencing difficult emotions, such as anxiety and depression, surrounding their cancer experience and recovery. Individual counseling services and educational support group programs are available at MSK through Resources for Life After Cancer, the Social Work department, and the Counseling Center.

Rising Voices

is a fun and lively singing group just for patients and survivors. Open to all MSK patients, Rising Voices is a free, ,supportive activity sponsored by the Integrative Medicine Service.

To join, please contact Anjoli Mammen mammena@mskcc.org or call 646-888-0800.

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 an online community for patients and caregivers. It provides a venue for conversations, support, questions, and companionship.

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

I Am You and You Are Me

By Eliana Weissman

Eliana Weissman is a wife, mother, and attorney who lives in Scarsdale, New York. She cooks and blogs in her free time.

I was in the cancer center the other day for the first time in three months. That place became my second home after diagnosis. I only had two weeks in between chemo cycles, and those weeks were almost entirely consumed with appointments with the doctor and getting blood work, various shots, IV fluids, and blood. I knew this place intimately — the number of seams in the ceiling tiles; the number of squares of rug on the waiting room floor; the areas that were colder or warmer and louder or quieter; and the best bathroom stall that was usually clean, well stocked with toilet paper, and big enough for my wheelchair.

It was hard being in the cancer center after all that had happened. It's the simple things that make a difference: I drove myself there. I walked through the hallways without a wheelchair. I felt strong. Normal. I wasn't *checking in*, I was just checking in. As I sat in the waiting room, I started to look around. There were small groupings of two or three people here, there, and everywhere. You could tell who the patients were, and not because they were bald or had obvious ports in their chest or PICC lines in their arm. They were the ones that were always sitting, the ones that looked utterly exhausted and sometimes even forlorn. I knew that look. I've felt it too. Their loved ones were busily fussing over them or some paper they were reading or chasing after a nurse. I knew what they were doing. I've been there, too. I tried not to eavesdrop; I didn't have to. I could hear the script of their conversations in my head, word for word. *Did you call the doctor? When is your next appointment? What does your lab work look like today? Are you going to get the shot?* It hurt to see other people go through this because I know how much it hurt to go through it.

I saw her sitting there. She was on the couch, looking down. Like a Siamese cat, I wanted to weave in and out around her ankles, jump into her lap, and circle until I found the perfect spot to curl up on. I wanted to nudge my nose under her hand, look into her eyes, and purr, *I am you and you are me. You see, I was here just a handful of months ago. I was in that very same wheelchair. I was the one laying down on the couch because I was too sick to sit up and the wheelchair was too hard to sit on. I was the one who almost fainted three times. I was the one who yelled at the receptionist because they were taking too long to call me and I couldn't wait anymore for fluids. I'm the one who told the lab techs exactly which vein in which arm I wanted them to draw blood from. Can't you see? You will get better. Remission is coming. I am you and you are me and you will be just like me.*

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unfortunately they have lowered their heads.

From your perspective, what is the most important thing survivors can do to help them get through those rough times?

When I was first diagnosed, I had all kinds of fears and anxieties. Everything was new and I had no control over anything. As the years passed I realized that the more that I connected with fellow survivors, the better I felt. I realized that most of us had the same feelings, fears, and anxieties. I am hoping that all of these feelings that I have shared will help someone to understand that what they are going through is normal — and maybe laugh a little in the middle of such a serious situation.

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be considered "different." How could I cope? How would I deal with what life had dealt me? About seven or eight years ago, a mentor suggested that writing a little every day about my life and my feelings could be useful, and was it ever! It finally allowed me to get everything off my chest and confront things I hadn't been able to all these years. I found myself writing and crying, crying and writing, but it really helped me and became the impetus of my internal healing. Last year, I assembled my writing in a memoir that sums up for me the experience of being an attractive woman whose good looks cover a secret world of struggle.

My outward appearance is one of beauty, high fashion, grace, and charm. But for a very long time, my inward existence was one of low self-esteem, shame, insecurity, and complex, chronic medical complications. One of my most bitter regrets was not being able to have children of my own. It took years for me to let go of this impossible dream.

Today I am an author, motivational speaker, fashion model, and owner of a modeling company. I have been a model for more than 16 years (yes, with two ostomy bags!). My outer appearance does not show the physical difficulties that I live with daily. My passion for modeling and my history of cancer led me to open a Christian-centered modeling company in 2006. Our motto declares that "we build, train, and develop from the inside out." In addition, I am founder of Osto Beauties. We are four women who have experienced different life-altering medical conditions, which caused us to be permanently left with ostomies. We have been through rough times and still have challenges; however, we are stepping out of our comfort zone to help others.

I am ever grateful for my faith, family, friends, surgeons, nurses, doctors, and the entire medical team at MSK who gave me the chance to live my life. *I can, I will, and I am living a full and vibrant life.*

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Patient portals have become a valuable healthcare tool and are constantly improving. As they evolve, patients should advocate for the expansion of services and information provided. In fact, many of the changes to MyMSK have been in direct response to feedback received from patients. Going forward, MyMSK may be able to offer proxy access for patients' designated family members and other caregivers as well as access for pediatric patients (as of now, patients must be 18 or older to register). To enroll in MyMSK, please visit My.MSKCC.org. An enrollment ID is required, which can be found at the bottom of your appointment printout or by calling the MyMSK help desk at 1-800-248-0593, Monday through Friday, 9:00 AM to 5:00 PM EST.

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

Patient–to–Patient

We are grateful for the support of our patients and caregivers. If you are a former patient or caregiver of a patient who has completed treatment, please consider becoming a Patient-to-Patient or Caregiver Volunteer.

For more information, contact Maurisha Osi at 212-639-5007 or e-mail patient2patient@mskcc.org.

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