Choosing Happy

By Teri Scheinzeit

In the 1960s, the world of cancer was a far cry from what it is today. Treatment was more likely to be experimental and the prognosis was often grim. I was diagnosed with a Wilms’ tumor and considered one of the few lucky ones. I received the right combination of surgery (removal of kidney and spleen), chemotherapy, and radiation. Today, a Wilms’ tumor is 90 percent curable.

Growing up with a cancer diagnosis shaped my life. It’s difficult for me to imagine what my parents must have gone through during my diagnosis and treatment. After all, I was their six-year-old little girl with a large tumor and stage 4 cancer. We lived in upstate New York, but my pediatrician strongly urged my parents to take me to a big city children’s hospital. Wrapped in a blanket, I was rushed via airplane. My uncle Ralph carried me, as my father was too upset.

Growing up, doctors advised my parents to treat me like a normal child. I performed in school plays, danced ballet, took music lessons, and went to summer camp. Yes, I had to wear long-sleeved shirts at the swimming pool (to protect me from the sun) and have check-ups every few months, but I never felt like a sick child. Even today, despite whatever happens, I choose to never feel like a sick adult.

Teri Scheinzeit, a New York City business coach and singer-songwriter, has been cancer free for 55 years. Teri was awarded Best Mentor Coach of the Year from the prestigious Stevie Awards for Women in Business. She’s currently recording her second CD of original songs and writing a business book for women. Despite her medical issues, Teri continues to be upbeat, optimistic, and eager to take on life’s new challenges.
Editorial

By Eileen F. Gould

This spring, at the annual Survivorship Celebrations held throughout the MSK locations, thousands of cancer survivors and healthcare providers will come together to celebrate. Most of those in attendance will have experienced cancer, either firsthand or through a loved one. Many people are forever changed by their travels through the World of Cancer, and the transition into their “new normal.” The phrase often refers to the new state of being after experiencing a dramatic change in one’s life, such as cancer. Going through a cancer diagnosis and treatment often alters much more than physical health and can have a profound impact on daily routines, general outlook, and attitude as well as other important aspects of life. Recognizing and accepting one’s new normal can help individuals cope with their new reality rather than lamenting what could have been.

Sometimes the road ahead after cancer can be difficult to navigate due to the overwhelming number of adjustments and changes, from medical to psychological — all of which affect one’s relationships. Some feel like they have adopted a new cancer identity, but others do not look in their rearview mirrors and are able to just keep moving forward by putting one foot in front of the other. Patients, family members, and caregivers all experience the World of Cancer from a unique perspective and are affected in different ways.

Adjusting to your own new normal is a process that hopefully leads to finding acceptance and comfort.

This issue of Bridges begins the 8th year of publication of the MSK newsletter for and about cancer survivors and their caregivers. We are currently accepting original story submissions from MSK patients and their family members and caregivers. Please submit your stories to bridges@mskcc.org.

Where Are They Now?

Alexandra Capellini

Alexandra Capellini was treated for osteosarcoma from 2002 to 2003 and had her right leg amputated in April 2003 at the age of seven. Twelve years later, she credits MSK for inspiring her to be bold in all that she pursues. She is an avid skier, clarinetist, amputee youth camp counselor, and advocate for young amputees and cancer survivors. Alexandra is enjoying her sophomore year as a public health studies major at Johns Hopkins University and dreams of attending medical school to become a pediatric oncologist. This summer, she looks forward to taking public health classes in Denmark and spending time at home in New York with her sister and parents.
Jennifer Ford, PhD, is a clinical psychologist who specializes in helping children, adolescents and young adult cancer patients and survivors.

Most people look forward to the conclusion of cancer treatment with positive anticipation and hopes of returning to “normal.” For some, however, the completion of active treatment can be a time of ambivalence. People certainly feel celebration and relief, yet they can also feel heightened distress and a renewed sense of vulnerability. In fact, survivors may experience a mix of reactions and emotions. Often those feelings are positive — including new personal strength and stronger relationships with loved ones — but there can also be negative feelings, such as worry and anxiety. Some survivors report feeling anxious or worried because they’re afraid of their cancer returning or of having less frequent visits with their doctor. Other adjustment issues include living with uncertainty, an increased sense of vulnerability, a lowered sense of control, concerns about body image, returning to previous life roles, and hypervigilance to health concerns. Additionally, anxiety and worry can increase as the dates of follow-up appointments approach.

Of course, not all survivors will experience post-treatment anxiety or other negative emotions related to completing treatment, but it is useful to understand the signs and symptoms. Some of the emotional signals include uncontrolled or excessive fear or worry, feelings of dread, trouble concentrating, feeling irritable or on edge, anticipating the worst, watching out for signs of danger, and feeling like your mind has gone blank. Anxiety can also cause physical symptoms such as a pounding heart, trembling or shaking, sweating, dizziness, shortness of breath, muscle tension, headaches, fatigue, and trouble sleeping. Knowing that anxiety can potentially occur long after cancer has been diagnosed is important for survivors and their families to recognize.

So what can you do if you or someone you love experience these upsetting symptoms? It can help to talk to someone, including family members, friends, or mental health professionals. Even the most serious cases of anxiety are treatable — and the earlier treatment begins, the better. The most common ways of helping people with anxiety include individual or group psychotherapy and/or antianxiety medications. Some survivors with anxiety find it helpful to talk to a mental health professional who specializes in treating anxiety and helping people recover from cancer. A therapist can also help with deciding what treatment may be best. For many survivors, a combination of talking to a health professional and taking antianxiety medications works well.

To speak with an expert at Memorial Sloan Kettering who specializes in adjustment after cancer, please call the Counseling Center at 646-888-0200 to set up a consultation appointment.
Steven, a professional engineer in eight states, specializes in planning and design of roadways and transit terminals to ensure smooth operations for motorists and pedestrians. Over the last decade, he has led pedestrian-related design efforts for the new World Trade Center Transportation Hub and for the Long Island Railroad’s entry into Grand Central Terminal, known as the East Side Access project.

As a transportation engineer, I advise architects on how best to design paths that allow large numbers of pedestrians to navigate through complex structures. But when it came to steering a path through my own health crisis, I needed all the help I could get. My wife and my medical team at Memorial Sloan Kettering were the guides that saw me through the convoluted maze that is cancer.

A random game of basketball, a random knee to the groin, and, after some persistent groin pain, a visit to a urologist. I was 40 and married for about 13 years, with two young daughters. Within minutes of feeling around down there, my doctor uttered the dreaded “You have testicular cancer.” Thank God my wife, a registered nurse, was with me to get details, because I heard little else after his initial finding.

So began a six-month whirlwind. Surgery within a week to remove my right testicle, put in a prosthetic, take it out when it wasn’t accepted, my white count rising. But strangely, no chemo was yet administered, even though my cell count continued to rise precipitously. When my health continued to deteriorate, my nurse/wife pleaded with me to go to MSK. It’s a scary thing to see the future, but waiting in a large, noisy visitors’ room, I looked around the room filled with pale patients and realized that I’d soon be traveling their same route. This frightening visage, combined with my youthful intolerance, made me stand up to leave after a seemingly interminable wait.

But by what may possibly have been divine coincidence, a voice called out, “Mr. Scalici, you’re next,” as I was putting on my jacket.

The oncologist proceeded to spend about 45 minutes with me going over details, treatment protocols, and what I could expect over the coming months. So began my journeys between Staten Island and Manhattan, getting dosed with a chemo cocktail for five straight days, then taking two weeks off to recuperate from the drugs’ debilitating effects.

There were the expected hair loss, bloating, loss of appetite, chemo brain, etc. Then, on Thanksgiving eve 1997, my lymph nodes were taken out. After an eight-hour surgery, the lead surgeon told my wife, “He was a mess.” And then things began to turn around.

Free of the cancer, the ensuing years allowed me to reenter my life, only to be challenged by new maladies such as chronic fatigue, loss of some body sensations, extreme skin dryness, and persistent sweating. Testosterone therapy (“the gel”) helped for a bit, but the “new me” took some getting used to. I could boast none of the life epiphanies that some cancer survivors cite. But why not?

Fast-forward to 2002.

Following the 9/11 tragedies, I took a new position that would bring me into lower Manhattan to help in the rebuilding process for the next decade. A couple of years into that work, I slowly began to realize what

Continued to page 7
I was seven in the fall of 1983 when I caught a cold and couldn’t get rid of it. My parents took me to the doctor several times but nothing worked. By December, my leg started to hurt, and eventually became useless. I remember passing out at school, and a few days later hopping in the snow from the car to the lab to have my blood drawn.

The next week was a blur, but the end result was a diagnosis of ALL. I remember learning that my odds of surviving were fifty-fifty (it’s amazing how far we’ve come) and that I’d need years of chemotherapy. Despite the grim news, I was lucky for two reasons: First, my parents chose to bring me to Memorial Sloan Kettering, home of the best doctors and nurses on the planet. And second, I convinced myself that the chemo would cure me, so in my mind, there was always a light at the end of the tunnel. In retrospect it was wishful thinking, but it worked.

My cancer taught me to live for each day, each minute. I would get home from treatment feeling nauseous, but I’d go play with my friends anyway, running in every 30 minutes or so to get sick and then running back outside. At MSK, I asked the inpatient nurses to tape my IV in a way that allowed me to play pool in the playroom — I’d rest the front of the cue between two fingers taped a slight distance apart. Also, after spending so much time in bed or a waiting room, I learned to make the most of when I felt well. I was always on my bike or playing wiffleball or soccer. To this day, I’m happiest many miles into my bike ride, when my legs are tired. I take pictures during each ride; they remind me of where I’ve been, both literally and figuratively.

After radiation and chemo, my cancer was in remission by mid-1984. Following three more years of chemo, my last treatment was in the spring of 1987. It was an exciting time; that summer our family moved to a new house in another state. I made new friends who had little notion of what I had just been through. As the years went by, the chemo, radiation, and sickness slowly went to the back of my brain. We had been told back in 1984 that ten consecutive years of remission meant you were considered to be as good as cured. Year three was 1987. October 1992, year eight-point-five, was when I relapsed.

This time I knew I had cancer before the doctor. What clued me in wasn’t my cold but the pain I felt in my arms. I had volunteered to clear brush from a hiking trail, and I couldn’t lift even small logs — the pain was too intense, too pervasive. It was the same pain I had in my leg nine years earlier.

I was 16 when I started chemo again and 20 when I finished. This time was more difficult physically: two bouts of pneumonia, months in bed, infections, fevers. And it was also more difficult emotionally. I didn’t want to deal with cancer, so I focused on the rest of my life instead. I graduated from high school on time and finished my first two years of college while getting chemo. I finished college with a bachelor's degree in mechanical engineering and upon graduating took a job in another state. Once again, I made my life around people who didn’t know what I had been through.

In the fall of 2002 I met my wife, Tina. At the end of our first date, we discovered that we were both cancer survivors — she had recently survived thyroid cancer. By then, I was ready (and thankful) to meet someone with a similarly unique life experience. When she relapsed in 2011, I was happy to be able to comfort and help her. Thankfully her cancer has been in remission since then, and now we accompany each other to our long-term follow-up appointments.

Today, I’m 38 and still cancer free. It has taken a while, but I’ve gradually allowed myself to learn more of the lessons that cancer has to teach me. I try to live for today, and I thank God each day for both the mundane and the spectacular. I realize how lucky I am, and I consider myself fortunate and thankful for the perspective that cancer has given me.
Paul Garey is the Executive Chef for Memorial Sloan Kettering and is a twenty year veteran of professional kitchens. His experience includes running kitchens in several New York luxury hotels, fine dining restaurants, assisted living facilities and gastro pubs.

We actively engage in a daily mission to promote health and wellness among our patients, staff, and visitors. Promoting health has become a key part of our mission, and that mission can only be achieved through teaching individuals about good eating practices and promoting healthy dietary choices.

All of MSK’s chefs and I are taking the farm-to-table movement to the next level with some exciting changes behind the scenes. With the help of our prime vendors, we plan to develop a program in which local farmers will provide produce for MSK. This ushers in a new era, allowing us to create menus with items that are seasonal and harvested straight from farmers’ fields and delivered at the peak of freshness.

Understanding that individuals are responsible for the choices that impact their health, we would like them to consider our healthy options. With the cafeteria, we are looking to expand our customer base and promote healthful options. We have a new reenergized focus for our Meatless Monday campaign, offering a more diverse, exciting selection of healthy plant-based protein options that focus on seasonality and freshness.

Our main MSK cafeteria has undergone cosmetic improvements, including a new color scheme and enhanced action stations. We have developed a new Soup Station and Frozen Yogurt Station to complement our preexisting offerings — the Seasonal Salad Bar, New York Deli Station, American Grill Station, and Hot Entrée Station. Our Grab & Go program is being upgraded.

We will be introducing a new product line and developing a more contemporary look and style of branded packaging. I believe the MSK cafeteria is a model for cafeterias in other healthcare institutions, setting a high standard of quality when it comes to the wide variety of daily offerings. The Department of Food and Nutrition Services is particularly forward thinking; it is an extension of MSK’s relationship to the broader community. The foods provided are selected to be consistent with the nutrition advice of our Clinical and Wellness Dietitians. We are proud to have been awarded a Healthy Hospital Food Initiative Gold Star by the New York City Department of Health and Mental Hygiene (DOHMH) in recognition of our success in adding a more robust selection of healthier food and beverage options in our cafeteria, as well as our vending machines. Food and Nutrition Services is also working on a Good Choice Program with DOHMH through funding from the US Centers for Disease Control and Prevention. This program will allow us to have a voice in guiding manufacturers to develop products, packaging, portion sizes, and labels that are more in line with today’s health-conscious consumer demands.

Healthy Food and Healthy People

By Paul Garey
Continued from page 1

Back in the 1960s, cancer was hush-hush and often spoken of in veiled terms. For years, I was told I had a “sick kidney,” which the doctors removed. I was not told I had cancer until I was 15 years old — in order to explain why I wasn’t developing breasts or menstruating. Sitting on my parents’ bed, my mother revealed that my sick kidney was cancer, the radiation had destroyed my ovaries, and I would never have children. My mom then went to the kitchen to cook dinner. I went to the bathroom to cry. Nothing more was said.

Everyone’s life has been shaken, tossed around, and compromised in some way. I understand that now. For me, it was cancer. My technique for coping with the fear and anxiety is to own my feelings (thank you, therapy), honor them, and treat myself with kindness.

Fortunately, I’ve always had a loving family, amazing friends, and the ability to express my feelings through music. As a singer-songwriter, I’ve written many songs reflecting a full range of emotions: “Helpless Heart,” “Hold Me Now,” and “Take Time to Wander.”

I also have a wonderful husband, Stuart, my partner for 34 years, and I’ve had great careers. For 20 years, I owned a graphic design firm in New York City. I now work as a business coach, helping entrepreneurs build strong businesses and happy lives. I ask my clients what I consider the important questions: “How can you do more of what you love?” “What can you contribute to the world?” and “What do you want the rest of your life to be about?”

My medical issues now are mostly due to the long-term side effects of radiation. In the past few years, I’ve had four episodes of blocked arteries to my legs, a blood clot in my lung, and a punctured colon during a routine colonoscopy. As one nurse aptly said during my last mammogram, “My, you’ve been busy!”

I’m so grateful and relieved to have found MSK’s Adult Long-Term Follow-Up Program. I’ve always felt my medical history was too complex and doctors never knew what to do with me. My doctors at MSK are wonderful and reassuring. They see patients like me each week with similar histories and issues.

When I was 16, doctors told me I wouldn’t live long. I turned 60 this year and am going strong. My MSK doctor recently told me I could live well into my 90s. Every day, I choose. I can choose to feel resentful, deformed, and inferior or gracefully embrace all that is good in life. I choose the latter.

Life is precious. There’s so much I want to do. I just recorded my second CD of original tunes. The title song? “Choosing Happy.”

Continued from page 4

my salvaged life was extended to accomplish: I would be part of the healing process of a city.

Working directly with world-renowned architect Santiago Calatrava, I used my engineering technical specialties in pedestrian planning to lead building designs in how people would move through the new PATH Transportation Hub — where escalators should be placed, how many doors were needed, how wide corridors should be for smooth travel and commuting. Many take such mundane details for granted; I don’t.

The Hub is opening soon, and I’ll be there to watch the first set of commuters travel through it, thanks in large part to my family and my team at MSK.

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 at 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.

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.
A Favorite Summer Recipe of Chef Paul’s: Tomato, Basil & Chickpea Frittata

PREP TIME: 10 MINS  
TOTAL TIME: 38 MINS  
COOK TIME: 20 MINS  
Yields 6 servings

INGREDIENTS:
• Nonstick spray
• 9 ounces chickpea flour
• 1 ounce rosemary, minced
• 3 1/4 cups water
• 3 tablespoons olive oil
• 2 teaspoons kosher salt
• 1 pint cherry tomatoes, chopped
• Fresh basil, for garnish

PREPARATION:
1. Preheat oven to 450 degrees.
2. Coat 10-inch sauté pan with nonstick spray and heat in oven for at least 5 minutes.
3. In a medium-size bowl, mix chickpea flour, rosemary, water, olive oil, and salt. Pour into hot skillet.
4. Bake in oven for 12 to 14 minutes.
5. Cook for an additional 6 to 8 minutes with oven door ajar.
6. Remove pan from oven when top of frittata is golden brown.
7. Let cool and slice into 6 triangles; top generously with tomatoes.
8. Garnish with basil and serve.