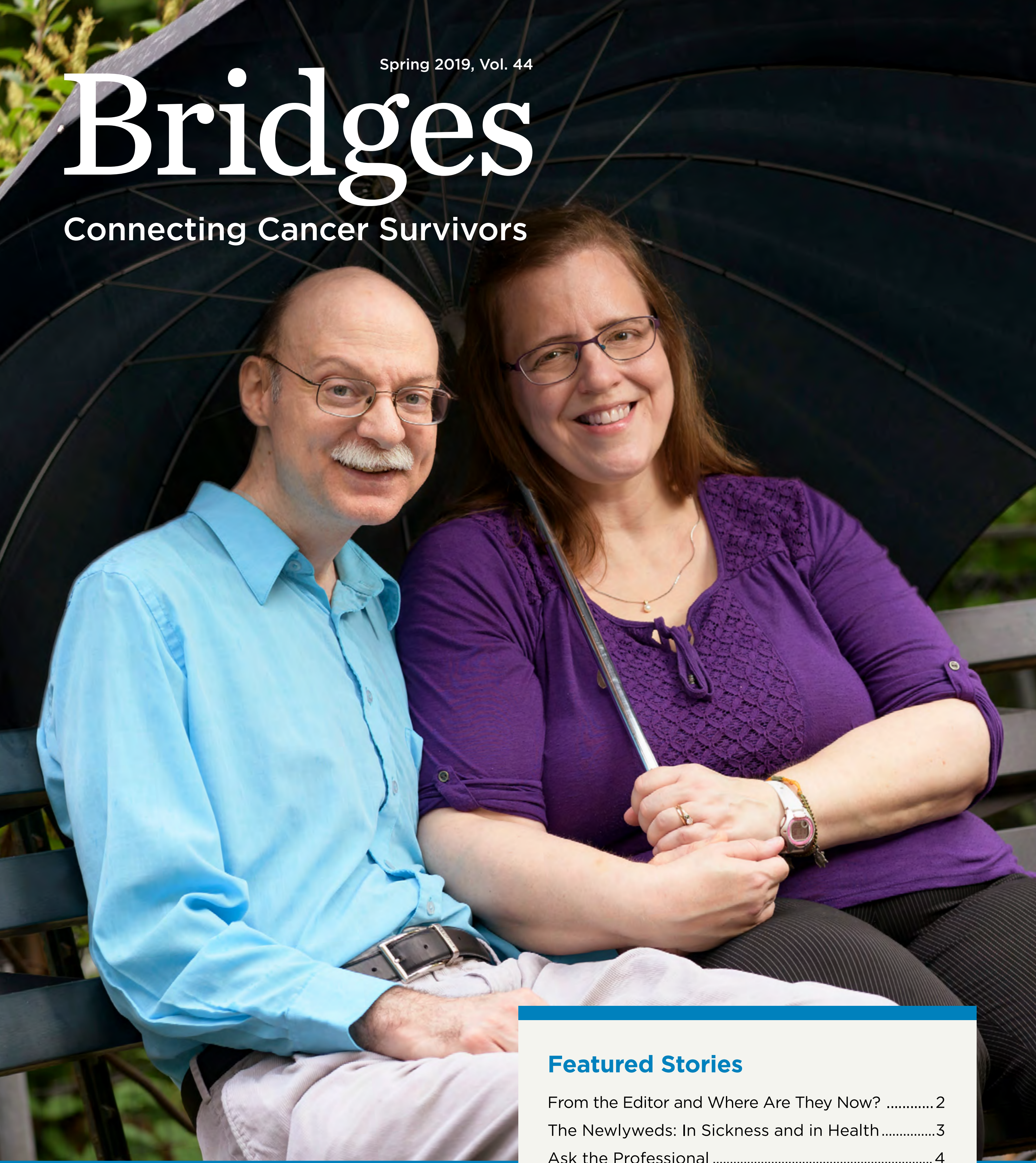
Spring 2019, Vol. 44

Bridges

Connecting Cancer Survivors



Featured Stories

Memorial Sloan Kettering
Cancer Center

From the Editor

By Eileen F. Gould

Recently, I read some interesting articles about why birthdays are so significant for people with cancer and survivors.

I never understand people who dread birthdays or don't like to discuss their age. When someone groans about their birthday, I tell them, "It beats the alternative." Birthdays are a gift of time when you have faced your own mortality, in my case since the ripe age of 21. I am happy for each additional year. I make sure that I celebrate it in some memorable fashion with family and friends. I can recite my various decade celebrations, from fly-fishing in Colorado for my 40th to a party when I turned 60 that included a mentalist. Birthdays take on a new meaning in the *world of cancer*. Some people who have had stem cell or bone marrow transplants even consider the date of the transplant as their new birthday and celebrate it annually.

Cancer survivors are grateful for each additional year. I certainly never expected to reach 50. Then I made it to 60 a few years ago, and now my goal is to reach 70, even while undergoing treatment for my fourth cancer diagnosis. Thankfully, I have no doubt that I will achieve my goal due to the amazing advances in cancer care. I am already thinking about what birthday celebration I will have — perhaps a trip to the Austrian Alps to see where *The Sound of Music* was filmed. I will be sure to keep you posted.

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

Where Are They Now?

By Steve Scalici

Just when I thought I was out of the woods regarding health problems, having survived cancer for more than 20 years, I suffered a minor heart attack, requiring triple-bypass surgery on my 60th birthday. All that following the day my daughter had just graduated from the New York City Police Department Academy in a ceremony at Madison Square Garden. And I thought my lymph node dissection in the summer of 1997 was painful; try having your chest cracked open.

That was two years ago, and it began my thoughts to retirement. My 40-year engineering career was capped off by my pedestrian design work on the new Second Avenue subway and at the reopening of the World Trade Center transit hub.

Life's next chapter is, happily, following a simple American Dream formula with my wife: We've guided our kids' careers through college and now into productive professions, one a police officer, the other a visual merchandising supervisor for Baccarat, a multinational crystal production company. I am a huge movie buff, love golf, and am now *slowly* reading through the morning newspapers, followed by my morning walk to fight inertia.

Cover Story

The Newlyweds: In Sickness and in Health

By Nancy Sibio

Nancy Sibio and her husband, Scott, recently came across Bridges and found it helpful, so Nancy decided to share their story, in the hope that it could encourage others. The Sibios live with their pet parakeet, Pebbles, in Hamilton, New Jersey. Scott works as a library assistant, and Nancy works in an office part time.

> Being newlyweds colored our whole experience. We were young and driven by an intense desire to have a life together.

Eight months after our wedding (in October 1991), my husband, Scott, got brain cancer (pineal germinoma). He was treated according to the intense chemotherapy protocol of a research study at Memorial Sloan Kettering. The cancer went away only to recur in a brain ventricle six months after treatment. Again, he was treated according to an MSK protocol, including chemotherapy, radiation, and a stem cell harvest and rescue. The cancer went into remission, and Scott is still cancer free today. I have been Scott's caregiver through all these years.

Our challenges along life's journey have not been typical for others of our age group. Scott has several lingering physical problems. These include permanent double vision, sinus problems, occasional labyrinthitis, shortness of breath, heart palpitations, osteoporosis, osteonecrosis of the hips, short-term memory problems, and the need for hearing aids. Scott needs to nap a lot. Recently, Scott got pulmonary emboli, which were considered unrelated to the cancer. Both of us have emotional needs that are also not typical of our age. We found it interesting to see an article in this publication in which someone mentioned the effect of the time in life when the cancer occurs. Definitely this is true. Being newlyweds colored our whole experience.

We were young and driven by an intense desire to have a life together. Scott says, "Persistence is highly underrated." As a cancer patient friend of ours shared with us, it doesn't really matter what you are using as motivation, but the important thing is that you show up for your treatments. She also said that the motivation may change as the treatment progresses. We agree with what has been said by others in *Bridges*, that we had to share the life challenge of the cancer. We needed to talk about everything. The experience profoundly affected both of us, and we both made large sacrifices for survival. One of the internal struggles for myself, as the caregiver, has been to strongly correct others (providers, insurance representatives, pharmacists, etc.) when mistakes have been made. Having to be unyielding conflicts with my need for emotional support.

Today, we are close and want to be around each other as much as possible. We even want to be in the same area of the house. The iPhone has been one of the greatest inventions for us. When we are apart, we not only message each other but we use a tracking app so that we know where the other is as much as possible. We also can get overwhelmed by life. We have had to deal with people who cannot cope with our story and have avoided us, although given time, they sometimes adjust. People have judged our lives and think that the cancer should not still be affecting us. We have no children or intense careers. Regardless, we are still happily married.

Ask the Professional:

Living with an Ostomy

By Vashti Livingston, MS, RN, CWOCN, DAPWCA

Vashti Livingston is a board-certified wound, ostomy, and continence specialist. She has worked in the Ambulatory Division at MSK for 13 and a half years. She co-facilitates two support groups for people with bladder cancer and lectures on ostomy management in the United States and at international conferences. She was on the Wound, Ostomy and Continence Nurses Society's task force for putting together "Clinical Guideline: Management of the Adult Patient with a Fecal or Urinary Ostomy."

What is an ostomy?

An ostomy is an artificial opening that surgeons make in the abdomen. Every year, thousands of people have an ostomy. It may be needed to repair an injury or remove a tumor, and can be lifesaving. This surgical procedure involves removing diseased parts of the gastrointestinal or urinary systems. The new opening allows waste materials (like urine or feces) to be transported out of the body. An ostomy may be temporary to allow for healing or permanent as part of a cancer care plan.

What are some common ostomy concerns?

When people are told that they will need an ostomy as part of their surgery, they are often very overwhelmed initially and have many questions. "Will I look normal?" "Will people be able to tell I am wearing a pouch?" "How can I conceal an ostomy pouch?" "What do I wear? Do I have to change my wardrobe?" "Is it going to smell?" "Will I ever be able to swim again?" "Will I be able to go to the gym? What are safe exercises to do with an ostomy?" "Will I be able to travel? What do I do at the airport? Will I be able to go abroad?"

Discussing these concerns is a very important part of your visits with a doctor before the procedure. For a planned ostomy, surgeons will have you see a WOC nurse (wound, ostomy, continence) like me. This specialist will go over your concerns and help teach you about the ostomy.

When I meet with patients beforehand, I ask what their specific concerns are about having an ostomy. I then share with them the resources that are available, such as special bands, underwear, and concealment garments for swimming, the gym, or even active contact sports. We arrange for patient-to-patient contact, telephone buddies, disease-specific support groups, online support groups (which are great for people who don't live near MSK), local support groups, and ostomy associations. We help them identify who and what their resources are for living with an ostomy.

How is an ostomy pouch selected?

Selections are made based on body type, frame, and preference. These supplies are covered by insurance. They can be obtained from major distributors. A prescription from a doctor is required once a year for insurance. A person may opt for a smaller, low-profile pouch.

What products are helpful for people who have an ostomy?

You do not have to change your clothing, however covers or bands can conceal the pouch as needed. Ostomy Secrets (www.ostomysecrets.com), Stealth Belt (www.stealthbelt.com), and Stoma Tuck (StomaTuck.com) are products designed by people who themselves have had an ostomy. I encourage my patients to speak to people at these companies, since they can best recommend samples. All the manufacturers of ostomy products will provide samples when requested. In some cases, they've helped people with financial difficulties or insurance problems obtain supplies.

The pouches are designed for swimming, but people with oilier skin may need more reinforcement. A WOC nurse can make suggestions on ostomy barrier extenders, which help waterproof the pouching system. I have patients who swim, snorkel, scuba dive, or take a bath.

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Family Is My Inspiration

By Donald Marra, Sr.

> It was going to be a tough road, but with the support of my family, I knew I could do it.

Don Marra is a retired high school teacher and assistant superintendent of schools. He is married to Gena, a retired middle school teacher. They have two children and three grandchildren. They live in Dobbs Ferry, New York. Don enjoys golf, gardening, and walking.

It started innocently enough, with hiccups after dinner. When the hiccups appeared more frequently, I became somewhat concerned. A few weeks later, I could not keep food down after eating. I became very worried.

I had a colonoscopy scheduled, so I asked my gastroenterologist to perform an endoscopy at the same time. I will never forget his words prior to the exam: “I am sure it is nothing to worry about.”

After awakening from the anesthesia, I wondered why my wife, Gena, had not come into the recovery room as she usually does. After an extended period of time waiting, my doctor and Gena approached my bed. I was told that a tumor, most likely malignant, was found where the esophagus meets the stomach.

My life turned upside down in seconds. What do I do? How can this have happened? Why me? Thankfully, Gena took over. She immediately called Memorial Sloan Kettering Cancer Center and made an appointment to meet a cardiothoracic surgeon. Gena and our two grown children, Katie and Don, Jr., accompanied me to the appointment. The surgeon was knowledgeable and reassuring. It was going to be a tough road, but with the support of my family, I knew I could do it. I had to.

My beautiful first grandchild, Michael, was born just a few weeks before my diagnosis. I desperately wanted to be part of his life. During chemotherapy, radiation, and surgery, Michael was my inspiration. I remember lying flat during a PET scan, wondering how I could stay still for such a long time. During my most difficult moments, I visually pictured Michael right above me, and he helped me get through the scan.

Chemotherapy and radiation at the same time was difficult, and I felt extremely weak. I did not want to leave the house, but a good friend dragged me to the golf course where we regularly played. Even though I was barely able to play three holes, it was another incentive to fight this disease and get my life back.

About six weeks after my treatment ended, I had an esophagectomy at Memorial Sloan Kettering in Manhattan. Despite a session in the Intensive Care Unit, a lengthy stay in the hospital, and six weeks on a feeding tube at home, I survived the experience and am living my life while still going through periodic scans and checkups. It is filled with enjoying time with Gena and my family, volunteering, running a one-man consulting business, playing golf, gardening, taking walks at the waterfront, and following the Yankees, Giants, and Knicks.

Spending time with my grandchildren is a very enjoyable activity. I so enjoy playing with Michael, Layla, and Joseph. Fortunately, they live close by so I can see them often.

I was always active in my church, but now I am a daily Mass attendee and a lector for three Masses a week. I have become much more spiritual since my cancer diagnosis. I firmly believe that God has looked after me during this difficult time.

Playing golf, following my professional sports teams, taking walks in our beautiful waterfront park remain my passions. Since my cancer episode, I don’t worry as much about my golf score, and I notice and appreciate the beauty of the Hudson River much more. Without Gena and our children, my friends, and Memorial Sloan Kettering, I never would have survived this most difficult chapter of my life.

Ask the Survivor:

Ostomy

By Elisa de la Roche

Elisa de la Roche is an actress, singer, dancer, and writer. She has been featured in various television series, off-Broadway productions, and films. She has written and performed three one-woman shows and published a book and several journal articles. With a doctorate in theater from New York University, she has taught at many schools and universities, as well as artist-in-residency programs.

Initially, what were your anxieties about having an ostomy?

Three years ago I was diagnosed with bladder cancer. The urologist casually told me it would be simple, that they would take out my bladder and put a bag on my stomach. I looked at my son. I told him to give me the pillow because I thought my life was over. I was anxious about my surgery: neobladder or ostomy? I looked at the Bladder Cancer Advocacy Network website and saw videos of people who had had cystectomies. I was amazed to see women who had an ostomy, were wearing regular clothing, and seemed to lead normal lives. Would I be able to swim, bike, hike, and dance? I was worried about the bag showing, and smelling, and leaking, and how often I would have to empty it. And as an actress, I was worried about others seeing it, knowing about it, and how long I could be on stage before having to empty it.

How are you coping with any residual anxiety?

Although the surgery was difficult, the following morning I was walking around, and in three months, I was in the pool again. I learned how to change the appliance and use the overnight bag, which allows me to drink as much as I want and never have to get up during the night! I bought elastic underwear at Macy's, and now I look as sleek as if there was no appliance at all.

Almost every month I attend the Bladder Cancer Support Group at Memorial Sloan Kettering. It feels good coming here, since everyone in the group has lost their bladder. It's our new normal. The members of the group gave me great advice on practical problems, like methods for changing the appliance and avoiding leaks. As I became seasoned, I could share my experiences and offer advice to new members.

What has been your experience telling others that you have an ostomy? What is a good strategy for disclosure?

Talking about my ostomy to people outside the support group is sometimes more challenging, and often I choose not to disclose it at all. Like with all sensitive matters, I can choose to keep quiet, speak about it, or educate others about it. And with each new person I get to decide which of the three options to use.

Have you accepted your new body image, and do you have any concerns, especially as a woman?

There is an adjustment to having an ostomy, both physical and psychological. At first I hated it and didn't want to look at the stoma. I take a shallow bath each time I change the appliance and let the skin air and heal. I became used to my new body, and now, I tenderly clean and rub around the stoma. It's the new me.

It's not easy for women to age in our society. We often feel invisible and undervalued. Having an ostomy can make us feel less attractive and more vulnerable to criticism and neglect. Keeping quiet and feeling bad about myself was not a good option for me. I kept a journal about my experiences during my illness. I started making a theater piece from it, and the following year, it became a one-woman show. It was like radical disclosure — everyone who came to the show now knows I have an ostomy!

I still have moments of discomfort and displeasure, but for the most part, I try to remember that the ostomy bag is my artificial bladder. I feel healthy now and have no evidence of cancer. And for that I am forever grateful.

What It Means to Be a Cancer Survivor

By Thomas Coccia

> Being a cancer survivor is like carrying a backpack you can never remove. You may never be able to take it off, but you can learn how to lessen the weight of that backpack.

Thomas Coccia just turned 61 years old. His entire professional career has been in the health insurance field, and he started his own insurance business five years ago. His interest is in helping his customers get access to the type of medical providers who helped save his life all those years ago. He sometimes jokes that "while I was not smart enough to go to medical school, I ended up consulting and selling health insurance instead."

I came to Memorial Sloan Kettering Cancer Center in January 1975. I was 17, a high school cross-country runner in fantastic shape. When I was diagnosed with a soft tissue tumor called rhabdomyosarcoma, I was still in great shape. At that time I did not know my toughest race was just beginning, and I certainly did not know how it would forever change my life.

It took several decades for me to feel comfortable using the term "cancer survivor." Social media did not exist in the 1970s. My illness was not discussed outside of my immediate family and a few close friends. The word "cancer" was never spoken, at least not in front of me. My situation was described as my "illness" or "being sick." "Survivor" was not a term I used to describe myself after four surgeries, six weeks of radiation, and two years of chemo treatments. I never thought of myself as anything but being finished.

I passed through my 20s and 30s, putting my illness behind me, or so I thought. I never discussed my past illness or that I had been sick with anyone outside of the chosen few, for fear of being discriminated against by present and future employers, insurance companies, and people in general.

I was in my mid-40s when I started to notice a societal change. People began talking about their cancer, and the fortunate ones were referring to themselves as "cancer survivors," as if they were in an unofficial club of sorts. Could these club members be so bold as to admit out loud that they survived their illness? I had an understanding with my cancer that I would not claim victory over it and, in return, my cancer would stay away. My fear was that if I talked about it, the cancer would come back.

I was around 44 years old when I had a conversation with close friends who did not know about my medical history. Weeks after that conversation, I was still cancer free. My admission that I had survived cancer did not cause it to return. From that time on, I gradually became more comfortable talking about my past cancer diagnosis in appropriate situations.

Being a cancer survivor does not just pertain to the physical aspect of surviving. Surviving emotionally is equally important. Most people do not get that tap on the shoulder reminding us of just how mortal we are, how fragile life is, and how we may straddle a fine line of being healthy one day and sick the next. I felt at times that I was running from my past, hoping to put it far behind me. I came to realize that no matter how hard I ran mentally, I could never outrun myself. Having had cancer makes up a part of who I am today.

Being a cancer survivor is like carrying a backpack you can never remove. You may never be able to take it off, but you can learn how to lessen the weight of that backpack. Every cancer survivor carries different things in their backpack. For me, I initially carried the fear that my cancer would return. As each year went by, that particular weight grew lighter until it was replaced by the thought that someday I may have to battle a new type of cancer. I think having had cancer once, it never totally leaves your mind that it could happen again, as opposed to thinking it could never happen to you in the first place. Again, our backpacks are our reminders of that tap on the shoulder.

■ *Continued on page 8*

Continued from page 4, Ask the Professional

Are people with an ostomy able to be active and travel?

We initially encourage walking and discuss working up to exercise equipment and gym classes after a surgeon's approval. Right after surgery, we do caution against heavy lifting, to prevent hernias, but with safe, targeted core exercises, people do return to the gym, running, biking, and so on.

There are TSA travel cards for people who have had an ostomy (www.ostomy.org). We suggest having extra supplies in a carry-on bag at airports.

The expectation is that part of being a cancer survivor is being able to live with an ostomy and return to work and activities of daily living, be with friends and family, and focus on quality of life.

Continued from page 7, What It Means to Be a Cancer Survivor

I realize being a cancer survivor does not just mean you finished your treatments. Being a survivor is a lifetime journey, with a responsibility to those who underwent treatment before us. We must earn our second chance every day with an appreciation for the generations of patient pioneers who came before us, through whom today's breakthroughs in treatment options are being made and, as a result, survival rates increasing.

My name is Tom Coccia, and I belong to a club called Cancer Survivors. There, I said it.

Patient Editor
Eileen F. Gould

Managing Editor
Alexandria Woodside

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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: **mskcc.org/livingbeyondcancer**.

Interested in sharing your story?

Please visit
www.mskcc.org/bridges

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