



Soon, falling flat on my face would be the best evidence that I was surviving and thriving through cancer. In the spring I finished radiation. I planned for the triathlon to be my next adventure. But fate had other plans.

I spent the winter training — tired, sore, cold, and with an afternoon bedtime. A triathlon is a swim, bike, and run all in one race. I'd never done anything like it before. I couldn't stay up late enough for swim practice, and on the weekend I lost swim races against my mother at the Jewish Community Center. I didn't even have a bicycle, much less the balance, energy, and technique I'd need for the grueling athletic endurance test that is triathlon race day. But this was an irresistible challenge for me. Cancer doesn't have finish lines.

I couldn't wait to ride a bicycle again and experience the freedom of movement that cancer so limited. My first ride should have been a lesson in humility. A bike messenger yelled at me for walking, not riding. No sooner did I clip my feet into the pedals than I promptly fell over. Even in New York, a survivor's spirit is no substitute for actually biking. What I needed was more saddle time. My third time out, I was riding fast and furiously, feeling the

wind on my face. Exhilarated, enjoying the sense of freedom and accomplishment, until suddenly I saw a soccer ball. CRASH!

I regained consciousness, afraid and in an ambulance. My head was in a brace strapped to a board. I was busy self-assessing: my hands hurt, my foot hurt, my head hurt. The EMT asked,

"Do you have any medical conditions?" This was a remarkable moment. Do you have any medical conditions?

"Cancer," I said, and, despite the pain, I laughed so hard I nearly choked.

There I was — bloody, broken, five teeth gone, and in need of a new nose — and suddenly, cancer wasn't the most important medical condition I had.

"We're going to cut your clothes off."

"No!" I cried. "Brand new race outfit!"

■ *Continued on page 4*

The Crash

By David Dorfman

Christmas chemo rescheduling put me next to Erica, a ginger-haired, angelic-looking patient about my age. She was more vibrant than the other patients waiting for treatment. When I asked about this, she revealed her secret: a triathlon team.

In this issue

- 2 Editorial & Ask an Expert
- 3 Ask the Professional
- 4 Leading the Way
- 5 Put On a Happy Face



6 Dating with E.D.

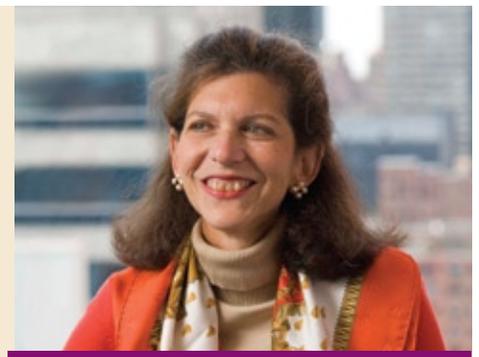


Memorial Sloan-Kettering Cancer Center

The first issue of *Bridges* was officially launched in June 2008. So far the response has been very positive, and MSKCC patients and staff have been incredibly supportive. The thing that I have enjoyed most is the experience of taking an idea and watching it develop from the beginning to the end product. In this case, the end is a wonderfully produced publication that the Bridges Committee is very proud of. This would not have been possible without the hard work and support we have received from MSKCC administration and Medical Graphics, as well as the patients and staff on the Bridges Committee and, most importantly, the survivors who have shared their stories.

Our goal from the beginning was a publication that could actually make a difference in people's lives in the World of Cancer by connecting them to one another. One major lesson learned along the cancer journey is that you never know where life will take you.

I am sure for many of us life has not always been exactly what we predicted. I have tried to find "the silver lining in the clouds" rather than take the "why me approach." This does not mean that it has not been arduous or overwhelming at times, but one has to try and find something good in the difficulties. The wealth of knowledge accumulated, not by choice, but by need, is daunting. We can help each other by



Eileen F. Gould, Patient Editor

sharing what we have learned. Not only is life unpredictable, but so is cancer. The journey will continue as cancer survivors are connected to one another through *Bridges*.

If you are interested in submitting your story or have suggestions for newsletter content, please e-mail bridges@mskcc.org.

Ask an Expert

In this section, cancer survivors answer questions about survivorship.



Linda Horowitz Freedman

is the wife of David Freedman, an amazing survivor of small cell lung cancer, initially diagnosed at MSKCC in May 2000. She is also the mother of two remarkable and strong children, Samantha, 19, and Zach, 16. Together, as a family they experienced firsthand how to live with cancer and manage the "ups and downs" while always recognizing the moment, their good fortune in having each other, and the incredible support they receive from other family members and friends.

Q My wife and I would like to discuss her cancer diagnosis with our children, but we are not sure how to start. What can we say?

A "Honesty is the best policy" may sound quite cliché, but when my husband was diagnosed with small cell lung cancer, we found that with two inquisitive children it was important to be as honest as possible, explain what was happening, and address all their questions to ease their fears. As parents, we wanted to do everything in our power to protect our children from harm's way and keep them safe. So, what makes sense? There is no right or wrong answer. Ultimately, you and your family are the only ones who can decide the best path to take.

Our kids were concerned about what impact the diagnosis would have on their dad and how it would affect them. Depending on his or her age, each child absorbs the information differently. Our son, who was 8 years old at the time, focused on the fact that Dad was not always going to feel up to playing baseball whereas our daughter, who was 11 years old, wanted to know more details. Kids are a lot more knowledgeable than we give them credit for and are very sensitive to changes in their routine and times when there's more stress at home.

Be yourself and be honest.

Thankfully, eight years later, our children are happy and strong individuals prepared to deal with whatever comes their way.



Spotlight on Rehabilitative Medicine

Cancer and cancer treatments can cause complications in some patients. Michael D. Stubblefield, MD, specializes in the evaluation and treatment of neuromuscular, musculoskeletal, and functional complications of surgery, radiation, and chemotherapy.

Q What are the common treatment-related problems that you see in cancer survivors in your rehabilitative medicine practice?

A The most common problems I see are complications of chemotherapy, radiation therapy, and surgery. Many of the most frequently used and effective cancer chemotherapeutics, including paclitaxel, vincristine, and carboplatin, are potentially damaging (neurotoxic) to the nerves and cause neuropathy (nerve sickness). While any patient treated with these medications may develop neuropathy, patients who have preexisting nerve dysfunction are more susceptible. Patients with degenerative changes in the spine, diabetes, or previous exposure to nerve-damaging chemotherapies, for instance, are more likely to end up with pain, weakness, balance difficulties, numbness, and other sensory abnormalities when treated with neurotoxic chemotherapies.

Treating the late effects of radiation has become another major component of my practice. I am now starting to see patients from all over the United States and other countries who have

found out about our interest and early successes in treating what I term the radiation fibrosis syndrome. The main patient groups are survivors of Hodgkin's disease (some treated and cured more than 30 years ago) and head and neck cancer patients. We also see survivors who have been treated with radiation for other cancer types, such as breast cancer, prostate cancer, and sarcoma. Radiation causes DNA damage that results in fibrosis (abnormal protein accumulation) in and around the microscopic blood supply to the tissues in the radiation field. This results in slow and insidious damage to every type of tissue including bone, nerve, muscle, heart, and lung. There is nothing to directly prevent the progression of this damage, and it will continue indefinitely. The major complications I see are damage to the spinal cord, peripheral nerves, and muscles, which may manifest as weakness, spasms, contracture, pain, and difficulties with balance, walking, bowel and bladder function, etc.

Q What help/assistance/interventions can you offer for survivors with these treatment-related problems?

A One of the most important aspects of successfully treating complications of cancer related to treatment is accurate, precise, and specific diagnosis. The exact anatomic and pathophysiologic cause or causes of the pain and their interrelationships should be identified so that treatments can be targeted to yield the most impact with the fewest side effects. A good example of this is a Hodgkin's survivor with shoulder pain. Such a patient is likely to have a combination of nerve dysfunction at many levels including the spinal cord, nerve root, brachial plexus, and peripheral nerves contributing to the pain. The patient is also likely to have a combination of shoulder arthritis, impingement, frozen shoulder, etc. Simply giving an opioid is not likely to be particularly effective, especially on the patient's function. My approach is to identify the major causes of the pain and dysfunction from the disorders described above so that a variety of specific treatments can be instituted simultaneously. The successful rehabilitation of such complicated patients may require a combination of injections, anti-inflammatories, nerve stabilizing agents, opioids, and very specialized physical and/or occupational therapy.

■ *Continued from page 1*
They cut. I passed out again.

After midnight, on morphine following stitches and CT scans, I wanted to go home. I'd had enough of being a patient.

"You're not going anywhere," the nurse said. "Do you even know where you are?"

I read the sheets: "Saint Luke's Roosevelt Hospital." Not my cancer hospital.

"Can you walk?"

Hoping I could, I tightened my stomach muscles, took a deep yoga breath, and slid off the bed. I was in pain, but not

cancer pain. Regular, normal, crashed-my-bicycle pain. My face was sticky and hurt even through the pain killers, but not to the touch. Then I heard, "You can't leave. You don't even have any clothes."

I wrapped myself up mummy-like and told the nurse, "I'm taking your sheet." After all, at 2:00 a.m. on a Saturday night in New York, who's going to notice a slightly bloody guy walking down Broadway with no teeth wearing a sheet?

The triathlon was only a week away. With broken teeth, swollen lips, and a mouthful of stitches, I couldn't use the phone. Instead, I sent a text to my brother. "Big crash."

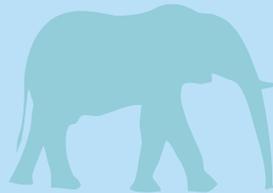
He responded by getting on a plane and competing in the triathlon at my side. My brother was worried, my coach was worried, my team was worried, but I was completely determined and refused to quit. No matter what, I was going to complete this race.

Triathlon day arrived. Swimming was first, and at the sound of the starting gun all the participants dove into the ocean. The sting of the saltwater burned every cut and scrape. My shoulder and knee were banged up, and my face was a mess. But I just kept swimming, biking, and finally running.

Leading the Way

By Gretchen Penn

How do you pick the doctor who will save your life?



I couldn't get this question out of my head, and it led me to search the Internet for advice. Ten days after my first child, Sarah, was born I had a lumpectomy and sentinel node biopsy. After the surgery, I was told that 15 of my lymph nodes were positive. It was 2005. I was 32 years old.

The Internet advice that stuck out was "you have to like your doctor." I recall thinking, "Are you kidding me? I don't need to like them; I just want them to save me! I have a newborn — I don't want to die." My emotional level was near panic, and I cried myself to sleep and slept all day and into the night. It wasn't until my daughter's 2:00 a.m. feeding that I realized that I had wasted all my energy and time on this confusing research when I could have been enjoying my newborn daughter. As she was drinking her bottle, I laughed because I noticed

that she was wearing pajamas with a cute little elephant on them. Upon Sarah's birth, we had received a number of gifts with the elephant theme. The elephant had become a running joke at our house because my husband and I are very active Democrats and the Republican mascot is the elephant.

Early the next day we met with an oncologist at a local hospital. It was the first of two meetings that my husband had set up. When the doctor came in to greet us he was wearing an elephant tie. I took this as a sign, and upon leaving told my husband this would be our doctor. Marc said, "Okay, but let's still keep the second appointment." Jokingly, I asked him if he noticed the doctor's tie, and he laughed and said "yeah." A couple of days later, Marc and I were driving to the newly opened Memorial Sloan-Kettering Cancer Center in



Commack, and I stubbornly said to him, "I have made my decision. This is a waste of time." He said, "Just do this for me." The moment I stepped in the front door, I was taken aback at the beauty of the facility and the professionalism of everyone. Right from the start I was impressed with the oncologist. He was straightforward, and it was as he was going over my information that I noticed on his desk a business card holder that was held together with elephants on each end! I had to interrupt him laughingly to tell him our elephant connection despite our donkey affiliation. He listened

■ *Continued on page 6*

Put On a Happy Face

Two years post-stem cell transplant, Rachel Cappio works in the Dermatology and Plastic Reconstruction Clinic at 53rd Street. She is still planning to pursue her MSW and one day hopes to be working in the Department of Social Work at MSKCC.

“And Rachel, what are you going to be when you grow up?” my friend’s mother asked me around the age of seven.

“A clown,” I answered quite matter-of-factly, “because then I can always make people laugh.”

Although always inspired to shoot for my dreams, my 21-year-old self was a bit more practical than my seven-year-old self while I was in college studying to pursue my master’s degree in social work. Life was rolling along smoothly until one abnormal blood test and three bone marrow biopsies later, I was diagnosed with acute myelogenous leukemia.

I spent the next six months getting chemotherapy, radiation, and a bone marrow transplant. During this time I spent about 11 weeks total as an inpatient at MSKCC’s main hospital; and as much as I tried referring to this period as the time I was able to sublet a studio apartment on the Upper East Side, nothing about this part of my life was easy. So I continued to do what I have always done when my life starts to get rough and channeled my inner clown for support.

I know that, for me, the emotional side of having cancer was just as tough to handle as the physical toll the illness



took on my body. I believe that having someone to make you smile or make your day a little less stressful can sometimes be more important than that morphine drip or anti-nausea medication. I was the patient who would sit in the hallway with a fellow patient’s spouse trying to comfort her after they had gotten into a fight. I was the one who popped my head (and my IV pole) into other rooms asking if anyone wanted to play a board game, color, or just take some time to vent.



You could figure out right away which bald head belonged to me because I was the one using an umbrella straw to drink my CT scan contrast. I did all of these things because knowing I could bring a smile to someone’s face was the ultimate therapy for me.

After graduating from college, I knew that the only way (without my MSW or a desire to be a clinician) to continue to be of some help in the lives of cancer patients would be to work for the very place that saved my life, so I became a session assistant at MSKCC’s 53rd Street Outpatient Pavilion. I’m the one in the blue coat assisting fellow patients (although they don’t usually know I’m also a patient) with anything they may need during the course of their appointment or treatment, and hopefully, alleviating some of the stress they’re feeling being at a cancer hospital. So maybe I’m not exactly on the career path toward becoming a clown (which is probably a good thing considering my juggling skills leave much to be desired), but for now I continue to be thankful not only for my health, but also for the days that I leave work knowing I made at least one person’s day a little bit better.

■ *Continued from page 4*

to my whole story and I realized that I had found the doctor who was going to save my life. If he had the patience to listen to me babble on then we would make a good team. So despite my initial

frustration with the advice from the Internet about “liking” your doctor, it was right.

Today my daughter, Sarah, is a jolly three-year-old; my husband was elected

to the New York Assembly; and we welcomed our son, Samuel, this past April 1. His name was chosen because it means “gift from God,” and that is how we think of each and every day.

Dating *with* E.D.

by John Mohan

John was diagnosed with prostate cancer in 1994. After receiving radiation therapy, his cancer is currently in remission. John has developed a Web site, www.trackyourpsa.com, that allows men to track their PSA levels. He lives in Douglaston, New York.



When I first learned about erectile dysfunction (E.D.) as a possible consequence of being treated for prostate cancer I didn't understand, like most guys, what E.D. meant. Did it mean I would lose my libido? Did it mean I wouldn't be able to experience sexual satisfaction? I thought the answer to both questions was yes, and I was devastated that could happen to me. If so, then it surely meant that I would lose my manhood.

Almost a year after being treated with external beam radiation I was relieved to still have functionality. It wasn't till a few months later that E.D. began to slowly set in. My anxiety increased as I began to lose full sexual function. Another two months later and my manhood was a goner. What woman would want me now? I tried Viagra — no help. I tried a pump — no help. I didn't want an implant — not my style.

I still had a very imaginative libido and could derive some sexual pleasure,

which mitigated my depression. But I couldn't try dating.

How could I explain my problem to a woman I had just met? And when could I ever bring up my deficiency?

It took me two years to ask a woman for a date, thinking that at least we could have a platonic relationship. I didn't tell her about my problem until the fifth date. The relationship only lasted a year because I felt that I couldn't satisfy her sexually, so I stopped trying. When it was over she let me know that she wasn't very pleased about my waiting till the fifth date to tell her about my problem.

It took another two years to try dating again. This time I told the woman on the third date, and she seemed to accept it. Meanwhile, I began to try penile

injections. It didn't work for me at the dosage I was taking and I gave up on them. When this relationship ended for reasons that I think were more about caring than sex, I decided to sit it out another two years. Desperately trying to connect again, I foolishly told one woman about my problem on our first date and she ran for the hills.

Who could blame her? Around this time I began to come to the conclusion that for some women the extent of the sexual relationship is more important than for other women.

Finally, I met someone who was more compatible with me on many levels, and that made all the difference. I even tried penile injections again and found that increasing the dosage did the trick. Now I realize what I should have known long before: that a compatible partner supersedes any E.D. problem you might have. If your partner really cares for you, you both will find a way to develop your sexual relationship whatever your anatomical differences.



Survivors Share: *The Book That Got Me Through*

As a caregiver for my husband, and as a cancer patient myself, Dr. Holland's words put the human face on my fears and helped me marshal my own strengths to go through the "cancer process."

The Human Side of Cancer: Living with Hope, Coping with Uncertainty by Jimmie C. Holland, MD, and Sheldon Lewis

— Jane, diagnosed at age 53 with thyroid cancer. Her husband was diagnosed at age 57 with head and neck cancer.

Both of Lance Armstrong's books — we had the same neurosurgeon!
It's Not About the Bike: My Journey Back to Life by Lance Armstrong and Sally Jenkins

Every Second Counts by Lance Armstrong with Sally Jenkins

— Lindsay, diagnosed with a brain tumor (astrocytoma grade II) at age 21

I was diagnosed in 1978. Looking back, I think I wanted the *why* answered, and I was trying to prepare myself for an uncertain future. These are the books that helped me:

The Bell Jar and Poems by Sylvia Plath
Why Bad Things Happen to Good People by Harold Kushner

You Can Fight for Your Life: Emotional Factors in the Treatment of Cancer by Lawrence LeShan

Illness as Metaphor by Susan Sontag

— Carolyn, a 30-year survivor of Hodgkin's disease (stage IIIS)

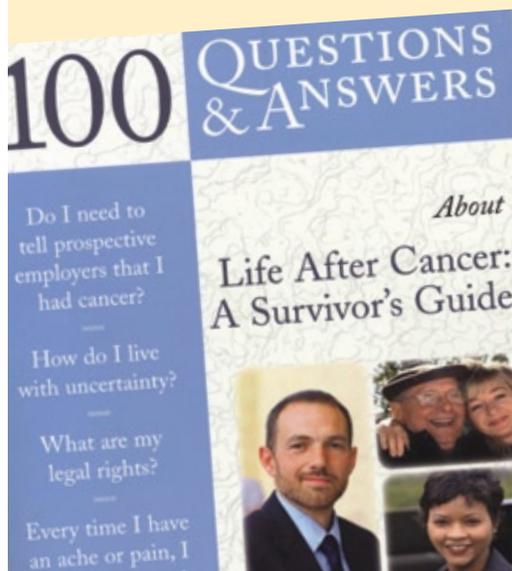
What assuaged my fears and total upset throughout my diagnosis and treatment was the essence of humor and beauty in the chaos. Both of these themes were very much alive in *Crazy Sexy Cancer*, *The Happy Day* books, and the works of both Steve Martin and Tom Robbins. All of these literary pieces helped me laugh, a lot, and through the laughter showed me that how you survive is more important than simply surviving. Life is about the journey, the process — and we might as well enjoy the ride, even when it is chaotic.

Crazy Sexy Cancer by Kris Carr
The Happy Day series

— Jill is a four-year survivor of lung cancer (carcinoid tumor)

Book Review

100 Questions & Answers About Life After Cancer: A Survivor's Guide by Page Tolbert, LCSW, and Penny Damaskos, LCSW, OSWC
Boston: Jones and Bartlett Publishers, 2008.



100 Questions & Answers About Life After Cancer: A Survivor's Guide is a 165-page paperback book written by two experienced and accomplished social workers in the Post-Treatment Resource Program at Memorial Sloan-Kettering Cancer Center. These authors have extensive experience working with cancer survivors and are certainly knowledgeable and experienced enough to author this book.

The book is structured in a straightforward question-and-answer format that is clearly written, easy to understand, and quite engaging. It contains thoughtful answers that address the common experience of survivorship while acknowledging individual differences. The book touches on the following issues: completion of treatment; ways to manage uncertainty; commu-

nication with family and friends; legal, financial, and workplace concerns; special concerns of those diagnosed with cancer as children or as young adults; health management; sex, intimacy, and fertility; growth, change, and spirituality; and cancer as a chronic illness (including specific issues for those individuals with metastases). This book also contains a fairly comprehensive appendix that lists additional resources, including Web sites and other recommended written materials.

100 Questions & Answers About Life After Cancer: A Survivor's Guide covers a wide range of issues relevant to cancer survivors and addresses cross-cutting, universal, and germane topics. This book is truly an excellent resource for cancer survivors, their families, and healthcare professionals.

Dedication

Bridges is dedicated to all of the MSKCC patients who have endured many hours of arduous treatment and difficult challenges, and as a result, have become cancer survivors. The purpose of this newsletter is to offer a forum where patients and their families can share experiences.

Bridges is also dedicated to all of the MSKCC professionals who have worked in the world of cancer. These people have devoted their lives to making it possible for cancer patients to become survivors.

We hope that you and your family will share your stories with us.

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If you are interested in submitting your story, please e-mail bridges@mskcc.org.

If you would like to connect with other survivors through the Post Treatment Resource Program, please see the online calendar at www.mskcc.org/livingbeyondcancer.

We are grateful for the support of our patients and family members. If you have undergone treatment for cancer at Memorial, or are a family member of someone who has, and would like to be involved in volunteer efforts at Memorial Sloan-Kettering Cancer Center, please consider becoming a Patient/Family Advisor.

For more information, call the Department of Volunteer Resources at 212-639-8623.



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