



Camping with Chemo

By Nella Libman



Nella was diagnosed with pancreatic cancer in October 2003. She was treated with surgery, radiation, and chemotherapy. She is very thankful to be alive five years post-treatment.

It was the beginning of June, and I was in the fifth month of a very severe program of chemotherapy for pancreatic cancer. I wore the bottle containing the chemo drugs 24 hours a day for six weeks. After a few weeks off, I would start a new round. I was scheduled to go through three rounds on this protocol.

The bottle was attached to a port under my skin. Every Monday, I had to go to the hospital to get the bottle refilled. The medication left me fatigued and nauseated, and my feet were in constant pain. Between my Monday appointments, I spent most of the time home alone, resting for the next round.

For the past ten years, the beginning of June had meant a weekend camping with friends at the beautiful Indian Head campground in Bloomsburg, Pennsylvania. There, people from all over the country, many of us Russian, would gather to enjoy friendships and hear wonderful, self-composed acoustic Russian songs. When the festival was first held 12 years ago, about 30 people attended. Every year since, it has

grown and grown, until now, it draws 2,000 people or more. In the beginning, it was very informal. People would call each other to make plans. Now there's a Web site, and it's much easier to get information.

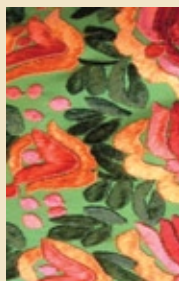
The festival is like a Russian Woodstock, with more than 500 tents crowded with people. They range in age from tiny babies to 90-year-olds. Everyone brings food and we barbecue chicken and sausages. We sit and eat with children and dogs playing around us.

That year, when my friends made their reservations a few months before the festival, I could not even think about going. I was far too weak from the chemo.

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



Memorial Sloan-Kettering
Cancer Center

We are already publishing our third issue of *Bridges*. The stories keep coming in and all of the patient-writers have had such individual, compelling stories to share with their fellow cancer survivors.

We continue to be amazed by the different types of stories written by patients of all age groups and different diagnoses.

Some talk about their fears and the ways they have learned to cope by pursuing their dreams, even during arduous treatment, whether those dreams have entailed competing in athletic events or taking up a new hobby. Other patients write about the effect of their diagnoses on their families and social lives and how they have managed during the upheaval in the family dynamics.

Our fellow survivors continue the path of trying to locate the “silver lining in the clouds” as we connect to one another.

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



Eileen F. Gould, Patient Editor

Ask an Expert



Amy was diagnosed with Hodgkin’s disease in 1987, at age 13, and became the first adolescent with the disease to have an autologous bone marrow transplant at MSKCC. She has been cancer-free since 1989.

In this section, cancer survivors answer questions about survivorship.

A | This is a great question. The short answer is that there is no universal “right time” to disclose your cancer history. Every relationship is different. The key to remember, however, is that you are divulging something precious so you want it to be received as something precious.

Before you share this information, it is important to take a step back and think about what your survivorship means to you. Do you view it as just one aspect of who you are, or is survivorship a more defining and dominant part of your self-image?

Once you’ve determined the role of survivorship in your life, contemplate the part you would like it to play in the life of your partner. Think about the questions he or she may have, what you believe he or she is entitled to know, and the amount of detail you are comfortable divulging — about your past treatment as well as its long-term effects. Remember, if this is a relationship with legs, those potential long-term effects (infertility, relapse, or a secondary

cancer) become as much your partner’s issues as your own.

Though disclosure is not something that must be set aside for a candlelit dinner or a long walk in the park, try to give some thought to the setting. For instance, I would not recommend telling your partner while you are standing on a speeding subway about to get off at the next stop! Remember, this is precious information.

Similarly, timing deserves some thought. When I met the man who ultimately became my husband, I didn’t want to divulge too much too soon and have him think I was planning our bridal registry, but I also didn’t want to wait too long and risk being heartbroken if it all proved too overwhelming and he left. I waited until I felt there was a level of comfort, trust, and respect. I was touched by his interest and appreciation of how meaningful survivorship was to me, yet he was simultaneously able to look beyond the disease and not let it define me, or us.

I am confident that you too will be met with gratitude, respect, and admiration.

Q

I’m a cancer survivor, and I’d like to start dating again. But I’m a little nervous about how and when to

raise the issue of my cancer history. Any tips?

Weaving Whole Cloth

Jane Mather is the Director of Chaplaincy Services for MSKCC. She has been a board-certified chaplain for 13 years and is the mother of six sons; her experience with complex and integrated spiritual themes has been both personal and professional. She is dedicated to supporting patients, families, and staff who struggle with cancer and its impact on their lives.

Q How can spirituality be woven into my cancer journey?

A From across the room it looks like an old Dutch painting, but as I draw closer, I see that the image has actually been delicately woven with silk threads from a palette as rich and subtle as any I've seen on canvas. Like this antique tapestry, our lives are woven with threads — of family, work, culture, nature, and so on — creating the appearance of a single image. The intersection and coherence — the intricacy — of the weaving is as essential to the design of our lives as it is to the tapestry image.

When individuals are diagnosed with cancer, most often the fabric of their lives is torn and these delicate threads unravel. Even when the outcome of treatment is that the disease has been banished from the body, the changes involved are so profound (and subtle) that loose ends remain, robbing us of a sense of wholeness. Restoring that sense of wholeness may require some gentle reweaving.

Healing, health, and wholeness come from a single root and all involve more than “cure.” The threads of physical (bodily) health are interwoven with the mind and the spirit. Spirituality — defined loosely as how humans make, define, and relate to what provides ultimate meaning in their lives — affects the mind, body, and spirit and can aid in the process of reconstruction and reweaving. As the third element in the mind, body, spirit triad, spirituality

may or may not be tied to an individual's religious belief system or practice but has often been shaped by it.

While members of the clinical team are trained to fashion the loose ends created by diagnosis, treatment, and survivorship back into beautiful, recognizable images, chaplains focus on the ways that human beings make meaning in their lives. Whether or not religion is important to you, chaplains can help you explore and access the rich spiritual resources inherent in your own life tapestry.

Cancer treatment causes many losses, many of which are temporary. Just as hair often grows back in new (and better) ways, so can spiritual views and practices grow back — often with stronger, more beautiful threads for the whole cloth that creates the images in the tapestries of our lives.



■ *Continued from page 1*

A week before the camping trip, my friend Alex called. "Please come. We want you to be with us, as always," he said.

I was greatly tempted, but I knew it would be risky. Was I well enough for the three-hour drive? Was I really up to a weekend of sleeping in a tent among so many people?

"I'd love to," I told him, "but I don't have a ticket."

Alex persisted. "Do not worry about it. We'll find one for you. Please go with us."

I couldn't resist. I said yes.

Those three days were completely wonderful. The drive was far easier than

I'd expected. On the way, I was busy anticipating all the fun we would have. My friends and I were so glad to see each other. We talked, laughed, and listened to wonderful old and new songs.

My chemo bottle was attached to the belt under my loose shirt, and most of my friends knew nothing about it. I didn't want to tell them for fear they'd worry about me and that would ruin their good time.

During the weekend, some of them would complain about things in their life. One was having trouble with her daughter. Another had gone through a divorce. From my point of view, these things seemed so meaningless. I had a life-or-death illness, but I did not complain. I was so happy to be there, I almost forgot about my medical condition.

I was grateful and touched that my friends made it possible for me to enjoy this wonderful time. Camping with chemo turned out to be the best medicine for me.

When I came back home, I felt much better. The next Monday, my doctor was surprised by how much better I looked and felt. A month later, my chemo was finished, and I was on my own.

I started doing some things for myself and my health. I joined a yoga class and a hiking club. I got on a healthy diet with mostly organic foods.

And, of course, I continue to go camping with friends. I've been back to that annual festival five times since then, and I hope to go back to many, many more.

You Just Never Know

By Susan Sloan

Susan worked at the New York Times for 30 years. She married at age 63, and she and her husband are fighting her cancer recurrence together. Her philosophy: Keep laughing.



I came to MSKCC in desperation when I'd gone from stage 3 to stage 4 metastatic melanoma. Prior to that I'd been at another hospital in a clinical trial that was both discontinued and, more importantly, not working . . . for me, at least. I'd read all the available literature and knew that my odds were dismal, but I still wanted to be at MSKCC and avail myself to the best and the brightest.

I was very fortunate to be under the care of a doctor who always listened to what I had to say and respected my wishes. He initially offered me a particular protocol, but I rejected it because it, too, was a trial, and I'd just been involved with one that had failed. Instead, I began my chemo treatments with temozolomide.

After six months the drug had miraculously reduced my tumor by 60 percent. In fact, the visit on which I found that out happened to be my birthday. What a special gift. Then it seemed to stop

working, so my doctor put me on a nightly pill form of the same drug, now called Temodar. It did wonders, and six months later I was cancer-free.

I'm now included in a study to figure out why my body and the bodies of several other stage 4 melanoma patients responded as they did to those particular drugs. They certainly don't work for everyone. In fact, very few people survive stage 4 melanoma. A dear friend had stage 4 and was being treated elsewhere, ineffectively. I made it clear that he could not expect the results I had, but he came to MSKCC just the same. He didn't make it, but told me that he felt very safe and cared for during his final months.

I passed my five-year wellness mark and so my doctor and I said goodbye. Then a few months later I noticed brown spots between my big and second toe. Melanoma!

I had a deep excision and a skin graft to try and save the toe, but months

after that the spots reappeared. I didn't hesitate to have my big toe removed. Fortunately, the cancer had not spread, so I'm once again well . . . though I've been granted checkups and CT scans again, which I'm happy for.

During all this commotion I also got married — I was 63 at the time. Yikes. In writing my story, I want to share my

belief that everything in life is just a matter of luck. I never sneer at anyone else's beliefs, but I really think we have very little control over what happens to us once we've received a cancer diagnosis.

Through my cancer journey, I retained my sense of humor (after my initial horror, fear, and sadness); I always kept informed and demanded to know

the facts and my odds, and my doctor respected what I wanted; and I truly ended up at the best place possible for anyone dealing with cancer . . . of any type and at any level.



The One to Get

Joe is a two-time testicular cancer survivor. He resides in Dix Hills, New York, with his wife Lori and their daughters, Jessica and Leah.



the other aches and pains I was feeling. However, it persisted and I finally told my wife who pushed me to see a doctor.

My first sonogram with my local radiologist was like a dream. Well, more like a nightmare — I was terrified.

After spending several hours there the doctor came in and said, "You will need further medical treatment immediately."

It was the first time I heard the phrase "testicular cancer." I thought to myself, "Testicular cancer? Is there even such a thing?"

That night I called my parents. My mother insisted I go to Sloan-Kettering. Two days later I had an appointment with my new doctor. It was also the first of many times I would hear, "If you're going to get cancer, this is the one to get." Somehow it didn't make me feel any better.

Soon after, I had the offending testicle removed, went for radiation treatments, and was sent on my way down the road

of recovery . . . or so I thought. For the next three years life went on pretty much the same as it had before. Cancer was out of my mind and life was good.

By July 2001 that annoying dull ache was back. Only this time it was on the other side. I thought to myself, "This can't be happening. They told me the chances of getting it again in the other testicle are slim to none!" There are roughly 7,500 new cases of testicular cancer each year in the US, and only about 3 percent of those men will get it twice. That's only about 225 men. I was one of them.

Fast-forward seven years. I am now 41, in good health, and in the best shape of my life. My wife, two beautiful daughters, and I are enjoying a good life in the home we worked so hard on. I still see the great people at Sloan-Kettering, but only once a year now. My story is not unique or special to anyone but myself. Cancer has changed my life both in bad ways and in good, but I am no longer afraid of cancer. Like everything else in life, you need to face your challenges head on. As they told me from day one, "If you're going to get cancer, this is the one to get."

It was October 1998. I was 31 at the time. My wife and I were in the middle of a major renovation to our home. I was working on the house nonstop while at the same time putting in 13 hours a day at work. Every muscle in my body ached, and I was always tired.

When I first felt the dull ache in my groin I just thought it was related to all



Pushing Back

By John Linakis

John was raised in New York City by Greek-immigrant parents in a one-bedroom apartment with three older sisters and an uncle. He has been married for more than 35 years to his best friend. He enjoys reading, writing, walking, the sea, and being with family and friends as often as possible.



Wham!! Suddenly, it was as if a steel door hit me in the face.

I was sitting in my office after my staff had gone home, clearing my desk to leave it orderly for the following day — a ritual to clear my head and to give myself a fresh start for a busy tomorrow and an extended business trip abroad within weeks. Then the phone rang at a time when it could easily have been Lynn, my wife, to tell me that she left dinner for me and to wish me luck at my bimonthly poker night. Instead, it was my urologist calling with the results of a biopsy taken the prior week, about which I had completely forgotten.

“It’s cancer; Gleason 9 score.” Perhaps he said more, but these were the only words I heard, and they numbed me immediately. “What does that mean?” I asked. “It’s aggressive,” he replied. The rest of the conversation somehow evaporated before reaching me. I was left breathless. Had all the air in the room been sucked out? Had my fate been sealed by the big slamming door?

I lay the phone on the cradle and stared without focus at a framed photograph of my family: silence all around, except for the sounds of the arriving cleaning people. Was it really about me? A mistake? How could it be *me* when there is absolutely no history of cancer in my family? I exercised regularly, followed a near-vegetarian diet, and quite frankly, took pride in my physical well-being.

But the ferocious words hung over my head. All I could think of was my random victimization and the loss of all future plans.

My drive home was filled with mental chatter: *What does it mean? How do I tell my wife and daughters? How long do I have to live? What do I do next?*

Lynn was out for the evening, expecting that I would also be out on game night. Fearing a few hours alone, I went and sat with seven of my closest friends without revealing my personal agony as they bantered and joked.

After all, I couldn’t tell *them* before telling Lynn when she got home later. Besides, I would undoubtedly sob. So the cards were indeed dealt, and the games proceeded. I witnessed them in slow motion. Two thoughts played in my mind: Am I the only one here tonight who realizes how lucky *they* are to continue with all the plans we had shared over the years? And, oddly, do I now have an *advantage* by appreciating the importance of changing my life ... as if it would end soon?

Needless to say, after days of tears and phone calls, I threw myself into attack mode. Internet searches yielded (perhaps) too much information; some scary and some hopeful. My prognosis was unsettling and resulted in a prostatectomy, nine weeks of radiation, and then two years of hormone therapy. After about three years of no detectable sign of PSA, however, another call from the same urologist came during a casual vacation dinner to tell me that my quarterly blood test showed a rise in my PSA level. *Panic:* Was this it? With my doctor’s agreement, I sought and found a genitourinary oncologist at MSKCC recommended to me as “*the* No. 1 doctor” in our area. (I soon discovered that no one knows a No. 2 doctor!)

It’s been more than five years since reading a terrifying Web site suggesting that I had a life expectancy of three to five years. Of course, I still necessarily make frequent visits to monitor my rising (and falling) PSA levels and certainly suffer emotional pangs as I anxiously await the results of periodic tests. But since the time of my operation and radiation treatment, I noticed that I was still alive ... and doing more things than ever during my early retirement.

Given the apparent severity of my cancer stage, I decided to retire three years ago to enjoy the retirement for which I had worked all my life. I didn’t want to be cheated of that! Somewhere along the way, however, came the epiphany: My cancer was a blessing in disguise. Indeed, a door *opens!*

Long walks and conversations with my wife and two daughters, wise beyond their years, gave rise to greater intimacy. With their understanding and support, I realized that between those worrisome medical appointments, there were many opportunities to exploit an unbridled freedom. I don't think it's my age (66) or modest wealth that gives me permission to say and do (almost) anything I want. It's truly the notion that there are doors of different weight that confront us all and that can shut us off and prevent us from moving forward unless we push

back. In fact, recent test results indicate metastases to some of my lymph nodes and lower spine. Still, I know I can push my door open ... and keep it open ... so long as I engage in positive, forward action: painting, writing, biking, hiking, moviegoing, reading, attending lectures, meeting old friends, schmoozing perfect strangers, and volunteering at Corporate Angel Network, which provides free flights to cancer patients in need of transportation to treatment centers.

Indeed, I've learned that I can help others open a few doors, too, even as I hear mine wobbling on its squeaky hinges.



Movie Review: Crazy Sexy Cancer

Crazy Sexy Cancer is the acclaimed autobiographical documentary film by Kris Carr, an actress, author, and filmmaker, who on Valentine's Day 2003 found out that she had cancer. Diagnosed with epithelioid hemangioendothelioma, a rare and supposedly incurable cancer, Carr takes us on a spirited yet heartfelt ride that captures wonderfully her personal journey in search of a cure, hope, and new possibilities.

Carr's documentary begins with the sobering and shocking news of her diagnosis. Like many cancer survivors, she experiences an immediate period of disbelief and then wrestles with what this deflating information means. Oscillating between intimate video footage of herself and her parents as they travel from consultation to consultation in search of the best specialist and treatment plan, we're reminded of how exhausting this search can be.

Told by her oncologist that her disease is at stage 4, Carr faces the frightening realization that "there is no stage 5." Determined to gain control of a situation

in which she has already lost a great deal of it, Carr begins an extraordinary journey, exploring the realms of alternative and complementary therapies, macrobiotics, spirituality, family, and sisterhood.

One of the key elements of the film is our introduction to the stories of four remarkable female cancer survivors. As she continues to search for answers, Carr understands that she can benefit enormously from the wisdom of others who are braving similar paths. She follows them at social gatherings and medical appointments, recording their experiences and thoughts. Candid and heartbreaking, funny and insightful, the stories of these women leave an indelible impact on Carr as she continues along her own journey of self-discovery.

The documentary film ends on a high note. Carr, who prior to her diagnosis was single, finds love and gets married. Though told by many that her rare disease would get the best of her, four years later it is stable. In *Crazy Sexy Cancer*, we get the rare opportunity to follow a remarkable young woman, who

though dealt an awful hand, discovered that cancer was pushing her to live a fuller, richer life. Describing her own journey as a "story about looking for a cure and finding your life," Carr inspires hope in so many survivors.



Kris Carr's cancer survival guidebook

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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