



My Very Long Journey

By Rosalie Peipert

Rosalie is a wife, mother of two sons and two daughters-in-law, and grandmother of five. She lives in New Jersey now, but considers herself a lifelong New Yorker. She is an avid reader and learns something new every day.

At times, the going has been rough, but I always have a smile on my face when I greet my doctors. It can't be easy to deal with cancer patients all day long. I like to show them that I have a positive attitude and a sense of humor, especially when they seem so serious. When they return my smile, I can see that for a moment, I've brightened their day.

My cancer journey began in 1981. After undergoing surgery for a hysterectomy I was informed that I had a uterine cancer, but that I was cured. It was not recommended that I undergo regular follow-up tests such as chest x-rays or CT scans. Eleven years later, I learned I had breast cancer. During preop testing for bilateral breast cancer, nodules in my lungs were discovered. Six weeks later, I had lung surgery. I had a second bilateral lung recurrence less than three years later. In 2000, I had a fourth recurrence and was reclassified as having a rare uterine cancer with the tongue-twisting name: endometrial stromal sarcoma with LMS sarcomatous cells.

I have the best doctors at MSKCC. My last surgery was very complicated. My surgeon seemed so worried; I patted him on the back and assured him I would come through all right. After all, I had been through two difficult

bilateral lung surgeries and here I was, still going strong.

My family is proud of my attitude. They say I have become their role model. I do believe that if something happens to any of them, they will have the courage, bravery, and the positive attitude that I have worked to show them.

My husband has been at my side every step of the way. This has not been true of everyone. Quite a few people I considered friends backed away because they no longer knew what to say to me. My illness made them uncomfortable. They wanted me to forget about it and move on. At first, I was hurt, but soon I realized that they simply could not cope. It was easier for them to think I was strong and didn't need their support.

I have lived with uterine cancer for more than half of my married life. Self-hypnosis and relaxation tapes have been a tremendous help, teaching me how to relax the muscles that hurt after surgery. The tapes enabled me to ease off my painkillers. When I have stress and feel anxiety, I always go back to them. The voices are soothing, the words are hypnotic, and I can visualize feeling

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If you are interested in submitting your story, please visit www.mskcc.org/bridges



Memorial Sloan-Kettering
Cancer Center

This year, National Cancer Survivorship Day is June 7. According to the National Cancer Institute, there are more than 11 million people in the United States alone living with a diagnosis as compared to three million people back in the early 1970s. Along with improved survival, addressing the needs of cancer survivors and their families has progressed in the last 30 years. Survivor celebrations around the country have grown from small groups to thousands of people getting together to experience their anniversaries together.

As discussed in this issue's "Ask the Expert" section, the healthcare community is working to coordinate follow-up care after cancer treatment and provide patients with a Treatment Summary and Care Plan. Programs and services focused on managing pain, preserving fertility, addressing long-term effects of treatment, and improving mobility and function of cancer survivors are developing across

the country. Furthermore, practical challenges such as medical insurance, employment after cancer treatment, and even dating and disclosure are now being addressed. Resources for the psychosocial repercussions of being a cancer survivor are becoming more available nationally.

The stories of hope and survival in *Bridges* are a testament to the improvements that have been made on behalf of survivors but also reflect the need for continued progress as we move further into the 21st century.



Eileen F. Gould, Patient Editor

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

Ask an Expert



Susan Fischer was diagnosed with breast cancer in 1988 and, again, with an unrelated breast cancer in 1999. She has been treated with surgery, radiation, and chemotherapy. Additionally, Susan has been a volunteer at MSKCC since 1989.

MSKCC is continually striving to improve the quality of patient care. How have patient and family advisors been involved in these efforts, and what impact have they made?

Patient and Family Advisors at MSKCC

During the past two years, MSKCC has made a concerted effort to involve patient and family advisors in a variety of hospital endeavors. Advisors have been serving on the Patient Safety Advisory Council with staff from hospital departments, including physicians, nurses, social workers, patient representatives, pharmacists, patient transport workers, and administrators. The patient and family advisors are providing a new perspective that will, we hope, result in improved quality of patient care... a difficult task given that the quality of patient care is already so high.

One example of an initiative that resulted from a discussion with staff and patient advisors on the Patient Safety Advisory Council is the publication of a new brochure called "It's OK to Ask." This publication, which will be available to MSKCC patients soon, encourages patients to ask questions such as,

"Did you wash your hands?" "What is the medication you're going to give me? What is it for?" and "What will the test you want me to take tell us? What, if anything, should I know about the test before it is given?" In other words, it's OK to ask about anything related to your treatment. The input from patient advisors was crucial to the creation of this booklet.

Other projects that patient and/or family advisors have been working on with MSKCC staff include: the hand-hygiene initiative, visitor policies, patient education, the MSKCC Web site, efforts to improve the transition to palliative care, catheter-care education, advanced-care planning materials, improvements to the communication of do-not-resituate orders, the development of the Rapid Response Team (MSKCC's version of 911), and hospital quality assessment.

Cancer Treatment Summary and Care Plan

By Nancy Houlihan, RN, and Kevin Oeffinger, MD

Nancy Houlihan is the clinical program manager of the Adult Survivorship Program.

Dr. Kevin Oeffinger is a primary care physician and director of MSKCC Adult Long-Term Follow-Up Program.



Q | What is a cancer treatment summary and care plan?

A | A cancer treatment summary and care plan is a two-part document that contains important information about a person's cancer history and recommendations for ongoing health care. The first part, the treatment summary, contains details of the cancer diagnosis and a listing of the various treatments administered. The details of the diagnosis should include the date, type of cancer, location, stage, and pathology or cell type, as well as the names and contact information of the doctors and treatment center(s). Treatment information should include details on the following: any chemotherapy or biotherapy regimen, drugs, or doses; any radiation treatments with the type of radiation, field, and dose; and any surgical procedures. Additional treatment such as a bone marrow or stem cell transplant should be recorded.

The second part, the care plan, outlines the care a person should receive as a result of his or her cancer diagnosis and treatment and should include recommendations for improving health and decreasing risks for other illnesses. The care plan contains information about how often to return for visits,

which testing, such as blood work and scans, will be needed, and what other physicians might be involved.

Prevention and early detection of other illnesses, especially cancer, is important and information about screening tests such as colonoscopy or mammography should also be included. Advice about healthy lifestyle choices such as smoking cessation, regular weight-bearing exercise, and dietary modifications are part of reducing risks after cancer treatment and should be incorporated in the care plan.

Q | Why is having a cancer treatment summary and care plan important?

A | Having a complete record of cancer treatment is crucial information for a patient to provide to his or her other doctors throughout life as there may be times when the effects of the cancer treatment play a part in other illnesses.

Adhering to recommended follow-up care will help detect a cancer recurrence early so that prompt treatment can be provided. Also, knowing what regular testing should be done and which choices might lead to a healthier life can prevent or reduce the risk of other illnesses.

Q | Where do I obtain a treatment summary, and what do I do with it once I have it?

A | Begin by asking your doctor or nurse for one. They have the accurate information about your treatment. You can obtain blank treatment summary forms from the Lance Armstrong Foundation (see the link below). The Web site Oncolink will help you develop a care plan based on general information about your treatment that you may already know (see the link below). Once you have a treatment summary and care plan, make several copies and store them in a safe place for future use. You may want to give a copy to your primary physician for your medical records. Keep the care plan portion handy so that you can easily refer to the visit and testing schedules and recommendations.

Links

LIVESTRONG Care Plan
www.livestrong.org

Oncolife Survivorship Care Plan
www.oncolink.org

relaxed and peaceful. Being productive is important as well. I have dedicated myself to helping others like myself through online support groups. As a long-term survivor, I can offer the benefit of what I've learned. Some patients have limited access to crucial information.

I do research for them, posting articles from medical journals, and I refer them to the sarcoma centers that offer the best treatment. I encourage them to get monitored, which I was not. Even if a cancer is incurable, I hope to help others live with their cancer as a chronic disease.

I have met many of the people I helped at hugfests every year sponsored by the Sarcoma Foundation. We all benefit by knowing we're not alone. It is both a burden and a joy to be the longest-living survivor and the oldest one on the lists with a uterine sarcoma, still around as Stage IV after 17 years.



GIVING BACK

By Bart Frazzitta

As a cancer survivor, Bart finds special meaning in even the small things in life. He spends meaningful time with his wife, Virginia, and with their two daughters, two sons-in-law, and seven grandchildren. He joined Memorial Sloan-Kettering's Patient-to-Patient Volunteer Program in 2002.

When I was diagnosed with Stage III esophageal cancer in 1999, I recall that my first reaction was disbelief. I did not know it was possible to get cancer of the esophagus. At the time of my diagnosis, I traveled frequently for business. I thought my indigestion was a result of late-night dining rather than an early symptom of cancer. When I reflected on what information was available at the time that would have alerted me to my diagnosis sooner, I discovered that there was a lack of educational materials. I decided that was an injustice, and if I were to get an opportunity, I would make people aware that esophageal cancer exists.

My journey through the treatment of this disease included chemotherapy (24 hours a day, five days a week, for six straight weeks), radiation (28 continuous treatments during the same period as my chemo), and then a six-hour surgery in which they took out two-thirds of my esophagus and one-third of my stomach and stretched the remaining part of my stomach up to the remaining part of my esophagus.

In 2002, I joined the MSKCC Patient-to-Patient Volunteer Program. In this program, patients who have completed their cancer treatment at MSKCC come back and walk alongside patients who are beginning their cancer journey. I chose to participate in this program because I believe I can add value to a patient's cancer experience during this anxious time. To date, I have spoken to over 500 patients with esophageal cancer.

In addition to volunteering, I have established a foundation called the Esophageal Cancer Education Foundation (www.fightec.org). The Foundation's Board of Directors includes esophageal cancer patients, caregivers who have lost their loved ones to this disease, and healthcare professionals. These are the goals of the foundation and some of the projects we have implemented so far:

- To educate the public and medical community about esophageal cancer, we have implemented a number of projects, which include the development of radio announcements, pamphlets and videos that can be shown in doctors'

offices and a CD-ROM that is given to patients free of charge.

- The announcements and video are available on the foundation's Web site under the "ECEP Media" tab. I have also co-authored a book with MSKCC medical staff called *100 Questions and Answers about Esophageal Cancer*.
- To walk the journey with patients who have this disease, we have established a patient e-mail network that allows patients to connect and ask other patients questions about quality-of-life issues.
- To support research projects that will lead to an early detection of this disease, our Medical Advisory Committee tracks research opportunities.

I truly believe that without the interventions performed by my MSKCC medical team, I would not be here today. I am so thankful for their efforts. They have made it possible for me to have the opportunity to give back to the cancer community.

YAHTZEE IS THE CURE

By Anthony Saladino

Anthony is a freelance writer who loves comedy and metaphysics. A graduate of the innovative Goddard College, he is also launching a series of poetic prose works that use his personal experiences as a catalyst for social and spiritual commentary (see one of Anthony's drawings at right).



My first response, when I learned I had lymphoma, was that the word sounded almost too pretty to be an aggressive, Stage 4 cancer. But the huge protuberance on my neck was anything but pretty, and after mistaking it for an infection, and then a shaving injury, I was willing to accept any word that more clearly defined my strange and sudden malady. A less than encouraging diagnosis at a West Side hospital (“you might not make it”) led my family on a frenzied search for a way for me to be treated at MSKCC. By none other than Divine Providence, an MSKCC lymphoma specialist called me on the very day I was supposed to receive treatments at the West Side hospital. At MSKCC, I found myself among a team of high-profile experts. My doctor wore jewels that sparkled like talismans against disease. My family and I sensed she had the mind of a genius. Therefore, I agreed to participate in a highly intensive research study, even though the literature cited one of the experimental drugs as possibly causing death.

Before long, I found myself among the many cancer patients being stuck and poked and injected and infused with all sorts of scary-sounding chemicals. “These drugs all sound like Viking warriors,” I chuckled to myself as I lay in the hospital bed staring at the list of scary-sounding names. As in: “I am Zorfan, leader of the rebels of the land of Rituximab! I will lead my people in the uprising against the evil Methotrexate and his army!” The names of the chemicals seemed almost deliberately alienating and unpronounceable, as if science could only provide cures in regions beyond the average person’s comprehension.

My doctor’s nurse offered an anecdote from her personal experience to quell my fear of the fabled side effects of chemotherapy: “When I was a young girl, my parents were driving down this hilly road in San Francisco, and. . . I threw up all over my dress.”

“Yuck!” I said, and suddenly my own fear of vomiting seemed less prominent in my mind, as if the experience was not exclusive to the diseased.

It was difficult for me to accept putting foreign chemicals into my system because I was a bodily purist who’d never smoked, done drugs, or even imbibed seriously with alcohol. It was even more difficult for me to sit still for days on end during my inpatient stays on the 12th floor lymphoma unit. During my time in the hospital, I wondered: Did the American obsession with perfection — perfect bodies, perfect houses, perfect jobs, perfect children — lay us bare to this terrifying assault of cancers? Everywhere I turned, I was reading about or hearing about another case of cancer.

“The disease of modern life is clearly manifesting itself as never before,” I wrote in my *Journal*, a book that had long been privy to my fierce hatred of the soullessness, greed, materialism, careerism, urban addiction, and widespread spiritual decay of modern life. So much of our daily diet, in fact, seemed cancerous to me, from what we eat to what we watch on TV. “Yes,” I thought, “McDonald’s and *American Idol* had combined to create an easy susceptibility to exterior cancers.” MSKCC acknowledged the inner aspect of healing in its innovative Integrative

Medicine Program, which includes yoga, full-body massages, and a recreation center on the 15th floor (where I drew dark and bizarre drawings in a state of creative frenzy). “We’re just starting to be recognized fully as a legitimate accompaniment to more traditional forms of healing,” said a female masseuse as she massaged my more-than-willing feet. Back on the 12th floor, the nurses darted in and out of the rooms, administering all kinds of drugs and tending to the ever-beeping IV pumps (a shrill and maddening sound). With a few skillful presses of buttons, all was quiet again in the house of healing, although this quiet seemed to contain a menacing reminder of all that drugs and medications could not heal.

Occasionally, the nurses allowed human softnesses to escape the rigors of medical training; these were among my favorite moments. “My father bought me Yankee Yahtzee for Christmas,” one nurse sighed, as if her love of the famous baseball team had destined her to receive all kinds of useless Yankee paraphernalia.

“I didn’t know there was a Yankee Yahtzee,” I chuckled.

“There’s a Yankee everything,” the nurse informed me.

In some reality far greater than this one, I pictured us all — patients and our families and nurses and their gift-giving dads and doctors and surgeons alike — playing Yankee Yahtzee with a merry abandonment that at once drew our ailing race together and far exceeded what any drug or hospital could ever do.

A Registered Therapy Dog to Help You Cope

By Carole S. Stein



A resident of Florida, Carole was introduced to Memorial Sloan-Kettering's Long-Term Survivor Program through the Association of Cancer Online Resources. Her therapy dog, Benny Beck, brings joy and comfort to all those around him.

In August 2005, the dreaded cancer struck my husband. For our family, as for most, the world turned upside down. As a caregiver, I viewed one of my “jobs” as finding ways to comfort him through this terrible ordeal.

I have been involved in the sport of dogs for more than 20 years. Before my husband’s illness I had heard about therapy dogs — dogs that are trained to provide affection and comfort to people in hospitals, retirement homes, nursing homes, schools, and stressful situations such as disaster areas.

Therapy dogs come in all sizes and breeds. The most important characteristic of a therapy dog is temperament. A good therapy dog must be friendly, patient, confident, at ease in all situations, and gentle. Therapy dogs must enjoy human contact and be content to be petted and handled, sometimes clumsily.

Basset hounds were my husband’s favorite breed. Through some detective work, I located a registered therapy basset hound in Palm Beach County. The husband of the owner, Cyndi, had recently completed cancer therapy. She was pleased to share her dog, Blossom, with us.

Blossom made her first visit in September 2005. My husband was jubilant. This five-year-old basset hound walked in to our home and stole his heart. He forgot all about

his troubles. Blossom got up on the sofa with my husband, rolled over on her back, and gave him much needed “therapy.” This was the beginning of an unbreakable bond of two families, drawn together by one basset therapy dog and that horrible disease — cancer.

Four months later, we got a Cavalier King Charles Spaniel, Benny Beck. Benny became a therapy dog in training. He and Blossom quickly became friends during our regular visits. Cyndi and my husband, though there were almost 20 years between them, truly enjoyed each other’s company. The dogs were always part of the equation. Cyndi’s husband loved that Benny would jump in his arms and cuddle. My husband was fascinated with Blossom.

Cyndi and I also became good friends. We were two women from different generations, and different parts of the world, drawn together by therapy dogs. We had breakfast together every week. We discussed our issues and of course the dogs. She has walked in my shoes. She understood what I was going through as a caregiver.

Benny Beck, or Lewiswood Ben Casey, which is his registered name (I suppose I knew from the beginning that he would be a healing dog), became therapy dog Cavalier King Charles Spaniel #1217 on October 18, 2007. He is now the Chancellor Charter School’s “Pawz for Reading Dog.” Children of all ages,

from kindergarten through fifth grade, sit and read to him. It is a truly heart-warming experience.

There are several organizations in the US that test and register therapy dogs, including Therapy Dogs, Inc. and the Delta Society. Both of these organizations provide insurance in the event of injury or illness due to contact with a member’s dog. If you are interested in learning more, the following Web sites offer helpful information: www.therapydogs.com and www.deltasociety.org.

MSKCC currently has 11 therapy dogs participating in its Caring Canine Program. The dogs range in size from a three-pound Toy Poodle to a 150-plus pound Bullmastiff. The dogs have seen over 1,100 patients on the 10th and 16th floors of Memorial Hospital since the program’s inception in October 2007. If you would like more information about the MSKCC Caring Canine Program, please contact Von E. Chaney at 212-639-3087.



Survivors Share:



What hobbies or interests did you pick up during or as a consequence of your treatment?

Cooking, blogging, and yoga.

— *Cadence, diagnosed with Hodgkin lymphoma at age 32*

Writing.

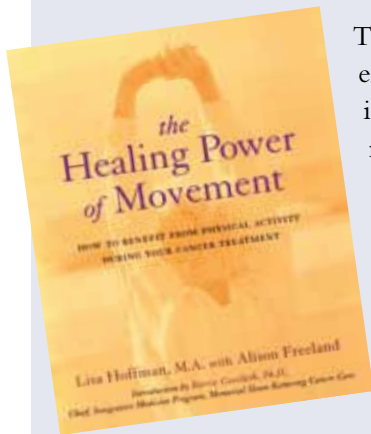
— *Amy, diagnosed with primary squamous vaginal cancer at age 38*

I couldn't concentrate, but I learned how to play Virus Buster on Nintendo's Brain Age. This is ironic as I absolutely hate video games and such. However, I have been hooked ever since.

— *Colette, diagnosed with cervical cancer at age 51*

Resource Review: *The Healing Power of Movement*

By Duane Bailey-Castro



There is a natural tendency for exercise to take a backseat to the initial shock and then subsequent rigorous treatments following a cancer diagnosis. For the patient, finding the mental and physical strength to exercise may seem like a pipe dream. For caregivers, many times their first inclination is to make sure that their loved one does

not exert himself very much. Ample rest during treatment is needed most, goes the logic. *The Healing Power of Movement: How to Benefit from Physical Activity During Cancer Treatment* by Lisa Hoffman with Alison Freeland, however, challenges patients and their caregivers to rethink the revitalizing potency that physical activity has in helping survivors cope and recover during their cancer experience.

The Healing Power of Movement is a short, step-by-step guide written by Hoffman, an exercise physiologist who trains cancer survivors. Physical activity, she argues, can be simple, personalized, and restorative. The product of many years of observation of the unique physical challenges of the survivorship community firsthand and collaboration with medical experts at Memorial Sloan-Kettering and elsewhere, Hoffman's book offers a number of refreshing, low-intensity exercises that improve strength, balance, confidence, and overall quality of life regardless of where one is in his or her

battle against cancer. Understanding the diverse abilities of survivors, Hoffman provides simple and descriptive illustrations of the recommended exercises organized into three levels of movement: bed, chair, and standing exercises. The importance of stretching is also highlighted.

Written in an easy-to-follow style, Hoffman also succeeds at giving an intimate, human face to the challenges of survivorship and fitness by introducing the success stories of some of her clients. The author is a teacher as much as a student. Her clients enriched her both personally and professionally, reminding her that even the simplest of things are to be cherished. "This book," she writes, "came about because of all the brave and funny souls I've worked with during this time, who have taught me that sometimes just putting one foot in front of the other is a major victory."

Based upon her personal experiences as an exercise physiologist as well as clinical research, Hoffman makes a compelling case for the integration of physical activity into one's cancer treatment and recovery plan. Debunking the myths of the past, her book shows that exercise — regardless of one's level of fitness — is an amazing tool of empowerment boosting one's energy, strength, self-confidence, and sense of well-being. "My desire," she concludes, "is that you are inspired by this book to remain active, no matter how impaired you may be from fighting cancer. My desire is that you find a way to choreograph your own dance and to move the parts of you that still work."

Solitary Step

By Deborah Wright

Deborah has been a patient at MSKCC since 2005 and has had three major operations since then. Thanks to the expertise of her surgeons and the incredible staff at Memorial Sloan-Kettering, today she is tumor-free and pursuing her dream of finishing her college education.

I was headed out the door,
when I ran headlong into hopelessness.
I tried maneuvering,
but got tripped up by despair.
Eventually I righted myself,
but not without regret,
for when I looked to see how far I'd gotten
for all my time and trouble spent,
it was rather sobering, this single solitary step.



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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.

If you are interested in submitting your story, please visit www.mskcc.org/bridges.

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 would like to be involved in volunteer efforts at Memorial Sloan-Kettering Cancer Center, please consider becoming a Patient/Family Advisor. We ask that patients be at least one year post treatment.

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



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