# Bridges

CONNECTING CANCER SURVIVORS

VOL. 19, WINTER 2013

# Making Life Work — the Rewards

### By Ed Langan

*Ed is retired from sales and has two grown sons. He lives in Croton-on-Hudson, New York, and spends leisure time at a nearby park that sits on the Hudson River and offers complete calm.*

I am blessed by God, who is looking after me. In the summer of 2002, I was diagnosed with throat cancer and treated at Memorial Sloan-Kettering. In the summer of 2003, a "spot" was discovered in the thyroid area. The doctor told me that I could lose my voice as a result of the surgery, but thankfully I didn't and I recovered completely. In August 2010, I was diagnosed with prostate cancer. After completing radiation treatments at MSKCC, I am doing fine today. With the excellent care I've received, I've completed a ten-year anniversary with MSKCC and am leading a full and productive life.

My wife passed away last year after several years of illness and time spent in the hospital and a nursing home. From that experience I came to develop a sense of empathy for what nursing home residents have to deal with. So about four months after my wife's death, I started volunteering in a local nursing home.

I go to the nursing home five days a week in the afternoons, visiting with about seven or eight residents. I spend a great deal of the time with Dennis, a man in his mid-60s with MS. He can't speak or stand up and needs to be tube fed.

I find it rewarding to help make Dennis feel like a human being and not just a body that needs to be physically hoisted from bed to chair and vice versa daily. When he sees me, it takes a few moments for him to acknowledge me. Then he gives me his hand, and I adjust his arm position to make him more comfortable.

I interact with other residents at the nursing home who have their own concerns, but when they see me they always ask, "How is Dennis?" Dennis's sister lives in Boston, so she's not able

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Memorial Sloan-Kettering Cancer Center

## Editorial by Eileen F. Gould

Cancer survivorship used to be just about **quantity** of life but now it is also about **quality** of life. Clinicians here at MSKCC and around the world are focusing their research on ways to improve quality of life throughout the course of care from the time of diagnosis to post-treatment and beyond.

After treatment is finished, cancer survivors can be left physically, emotionally, and even financially spent. Research has shown that many cancer survivors experience at least one "late effect" as a result of their disease or treatment. Some effects are permanent and life altering. Even if cured, cancer survivors often require time to heal and adjust to a new normal.

Survivors can benefit from a comprehensive follow-up care approach that incorporates promotion of healthy habits, early detection of recurrence, and identification and management of treatment-related effects, which can be physical or emotional. For example, some patients experience fatigue, difficulty with sexual intimacy, neuropathy, pain, sleep disturbances, or fear of recurrence. There are therapies and strategies to manage these effects.

The World of Cancer Survivorship continues to develop into its own specialty, and MSKCC is at the forefront of making sure patients and caregivers are offered the best quality of life with a multitude of resources and support as they make the transition from cancer patient to cancer survivor. For many cancer survivors, curing the disease is just the start of their journey.

# Counting My Blessings

### By Barbara Rascati

*Barbara instructs students who are seeking a high school equivalency diploma. She is blessed to have a husband, daughter, and grandchild.*

The 1999 breast cancer surgery I had at a community hospital rendered me a Social Security disability recipient. I cope with an extensive, rare neuropathic pain disorder. This was first diagnosed by a pain specialist trained at Memorial Sloan-Kettering, the only Connecticut doctor with unique background in my two treatment-induced handicaps – the other being the chronic lymphedema he also identified. Both diagnoses were later confirmed at MSKCC's pain clinic.

Due to subsequent biopsies on my affected side, my compromised lymphatics are now pervasive and require constant treatment. I'm categorized as a one-armed worker and teach one day weekly. Although domestic and grooming tasks are challenging, thankfully I am able to ride my bicycle on a good day.

At the same time, I fought two HMO battles for consults regarding my husband's esophageal cancer. Memorial Sloan-Kettering is out of network for us. In 2010, I was diagnosed with a very rare radiation-generated fibrosarcoma. My lesion rested smack-dab in the muscle of my previously treated and pained breast. After local surgeons predicted I was at risk of losing pectoral muscles, three ribs, and a breast/arm combo to amputation followed by years of reconstructive operations, I was ever so MSKCC bound.

I fought my HMO for the privilege of arm/breast-salvaging surgery by my internationally renowned MSKCC sarcoma surgeon. My pain doc informed my insurer that surgeons from only six hospitals worldwide (including MSKCC) had the capability to treat me, especially in light of my preexisting maladies.

I was assisted in my three-month insurance war by representatives from my state's attorney general's office and healthcare advocate agencies. The industry of my MSKCC patient-intake nurse proved invaluable. Miraculously, I was approved for my operation, which was masterfully executed. One muscle and part of a minor one were excised with no loss of function.

Insurance approvals for follow-up MSKCC services now come much easier, and with the help of my sarcoma surgeon, I recently scored a consult with a urologic surgical oncologist regarding a kidney tumor. All ever so worth the four train rides from Connecticut!
I have offered myself as a telephone match volunteer for R.A. Bloch, Imerman Angels, and cancer groups, lending support to the similarly afflicted. I am enrolled in the database of the Sarcoma Alliance to whom my docs submit my medical status reports for research purposes. I'm a proud member, too, of the Connecticut Center for Patient Safety and have facilitated a pain support group. These endeavors, and especially my volunteerism at a hospice, enable me to count my blessings.

# Life Lessons – How My Dog Helped Me Find My Cancer

By Barbara Breivik

*For more than 20 years, Barbara has been a Client Relations Director in law firms. She enjoys gardening and raising Labradors.*

In April of 2010 my yellow Lab, Autumn, had a seizure after receiving too many vaccinations at her annual physical. Fearing that she might have cancer, I researched a new veterinarian and made an appointment for a second opinion. She found the mast cell tumor right away. My first life lesson came while I was busy researching a second medical opinion for my dog, and I felt a lump in my breast almost daily for three weeks before I picked up the phone and called my doctor. I knew it would be bad news, and it was. I'm smarter now.

Autumn had her tumor removed, and I had a mastectomy and 16 lymph nodes removed. While I moved on to four months of chemotherapy, Autumn woke up one morning in October and couldn't walk. My new vet decided she needed an ultrasound to determine where she was bleeding internally, and she arranged for one of her employees to drive us the 70 miles to the specialty hospital. My second life lesson was that Angels appear just when you need them.

Once there, Autumn gave me a look that said it was time to let her go. This kind woman looked at my bald head and said that I was going to be just fine. My cancer was gone. In the minute it took for Autumn to sleep, she took my cancer to heaven with her. I had rescued Autumn and her son, Taylor, from a farm seven years ago, and she had just paid me back.

My third life lesson was, where you go first for treatment really does make a difference. Choosing Memorial Sloan-Kettering Basking Ridge was the best decision I could have made. The doctors and nurses there are wonderful. No matter how overwhelming my treatments seemed, they took the time to listen and show compassion. My faith and sense of humor got me through some tough days.

While I was finishing chemo, Taylor was a very sad dog. He missed Autumn terribly, so I decided I needed some joy and a playmate for him. In December, I brought home Tucker, a two-month-old yellow Lab, and my life has not been the same since. I moved on to 28 days of radiation and six months later to reconstructive surgery. As the puppy grew, he taught me to slow down and live more in the moment. Everything was new to him, and I was just a person fighting cancer.

Surviving cancer proved to be much easier than being a cancer survivor. Dealing with daily fatigue and joint pain can wear you out. I managed to make it more than a year cancer-free before I developed lymphedema in my left arm. This condition is chronic, meaning I would have to deal with it for the rest of my life. That took me a little while to get my head around. Feelings of sadness, grief, anger, worry, and fear almost overwhelmed me. Then I realized I had already beaten cancer, and I could handle this as well.

Once again it was time to summon my "Inner Warrior" and create a battle plan. I am a lefty, so this condition has changed my daily living. No heavy lifting or repetitive yard work, and having to watch for cuts and infections with a large puppy in the house has challenged my creativity. Gardening is my way to relax, and I am not going to give it up. I wear a compression sleeve in the daytime and sleep in a Solaris sleeve at night. Daily massage to move the fluid in my arm is time consuming but necessary. This is my new way of life, and it appears to be working.

Autumn and the doctors at MSKCC gave me my life back. It may be a different way of living, but I'm alive. With family and friends keeping an eye on me, and my faith and sense of humor intact, I can make this work.

# *Ask the Survivor:*
# The Transition from Patient to Caregiver

By Felicia Blum

Q *I survived my cancer, but my spouse just received a diagnosis. How can I prepare myself for the role reversal of being a caregiver rather than a patient?*

A I was diagnosed with rectal cancer in October of 1991. I was 58 years old. Having had two C-sections, a gallbladder removal, and a hysterectomy, surgery was not an unknown factor, but cancer was! No one in my family had ever had it, and I truly knew little about it. I was fortunate to be treated at Memorial Sloan-Kettering. I had surgery, chemo, and radiation. My colon perforated in 1993, and a second time in 1995. As a result, I had a temporary ileostomy. A final surgery for adhesions in 2000 ended my hospital stays. Throughout all my surgeries, my husband was the perfect caregiver. He came to all my appointments, kept notes, reminded me of questions I needed to ask, and calmed me down. Although he isn't fond of hospitals in general, he was the last face I saw as I went into surgery and the first face I saw coming out of it. He was totally supportive during treatment. He was sympathetic, but also encouraged me to put in a few hours at work. He was so right! You need to think of something else! My "bag" didn't bother him in the slightest, nor did my somewhat irregular bathroom habits. For all of this, I am forever grateful.

As a result of my successful recovery at MSKCC, I became a patient-to-patient volunteer in 1997 and find my continued involvement extremely rewarding.

In the fall of 2009, my husband was diagnosed with multiple myeloma, a blood cancer involving the white cells of the bone marrow. It is not curable but it is treatable. Suddenly our roles were reversed, and I became the caregiver! Having no knowledge of myeloma, I did a lot of investigating on the Internet and the MSKCC website. Following bone marrow biopsies and PET scans, he started a strong treatment of chemo. He lost 50 pounds and had no energy or appetite. His kidneys almost failed. He required blood transfusions and massive doses of magnesium. I kept the notes this time, went to all appointments, started files for blood work and chemistry results. I found the warm blanket cabinet in the chemo room, figured out where the apple juice was kept, and put in an order for the daily newspapers, though he slept most of the time during treatment. The winter of 2009/2010 was pretty grim. I tried to entice him with interesting and exotic meals, which weren't too successful with him, but I gained ten pounds! The fall of 2010 was the turnaround: He began to gain weight, and his counts leveled off and started to improve. We were optimistic but still wary! When the oncologist stopped one of his chemos, we were thrilled. The other chemo was in pill form, so the weekly visits to the hospital became monthly. Now I am in charge of managing prescriptions, stacking the weekly pill box, keeping the counts, and being vigilant.

I truly believe that it is harder to be a caregiver than a patient. Waiting and watching is frustrating, whereas being a patient you're "out" a lot of the time. But attitude plays an important part in both roles. I cannot stress this enough. Thinking positively and just "getting on with it" can work – not, sadly in all cases, but it sure worked in ours!

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■ *Continued from page 1*

to visit on a regular basis, and his brother's schedule doesn't permit him to visit as frequently as I can. I provide them with regular updates on how Dennis is doing. Dennis and I leaf through catalogs or sit out on the patio, or I throw a baseball to his good hand. Sometimes, when I speak to Dennis, I tell him I went to Dennis College to understand him and he looks at me and smiles. I know that despite all his disabilities, he knows someone cares, and that is very meaningful to me.

# *Ask the Professional:*
# Head and Neck Cancer Follow-Up Care

**Q** I had chemotherapy and radiation for head and neck cancer. What kind of follow-up should I have as part of my survivorship care?

By Shrujal Baxi, MD

*Dr. Baxi is a medical oncologist with special training in treating and researching tumors of the head and neck.*

**A** Patients treated for head and neck cancer with chemotherapy and radiation together can face real challenges after their treatment is complete. While some of the side effects of treatment will improve with time (e.g., mouth sores, decreased appetite, fatigue), others might be more long-standing and require ongoing attention (e.g., difficulty swallowing dry mouth, difficulty hearing). Survivorship care in head and neck cancer is about addressing these symptoms, and survivors should be communicating these issues with their doctors. Tobacco and alcohol cessation are important aspects of survivorship care both to prevent recurrent and new head and neck cancers, but also for general health overall.

Surveillance is another important aspect of survivorship care. The National Comprehensive Cancer Network (NCCN) and the American Head and Neck Society (AHNS) recommend a schedule of head and neck physical exams. This sometimes includes an evaluation with a camera that is passed through the nose, which should take place regularly after treatment and then less frequently over time. A single PET/CT scan about three months after completion of radiation therapy is generally utilized to assess for any residual disease, but beyond this, routine imaging of the head and neck is not generally recommended. If you have any new signs or symptoms in the head and neck, you should notify your doctors immediately, and they may initiate a more extensive work-up at this time.

All survivors who have received radiation to the head and neck region should have an annual blood test that assesses for thyroid function (i.e., TSH and free T4). Hypothyroidism, or low thyroid function, can occur due to radiation to the thyroid gland. This is a completely treatable condition with supplemental thyroid hormone pills. This blood test can be ordered by any physician, and the disease can be managed by many physicians although you may be asked to see an endocrinologist, who specializes in hormone levels.

Radiation to the oral cavity has significant dental implications. First, radiation to the salivary gland can result in decreased saliva production and dry mouth. In addition, radiation to the jaw can result in weakened bones, and there is concern over demineralization of teeth in the radiation field. Survivors are at an increased risk for cavities, tooth decay, and other dental problems after treatment. As such, many patients will have their problem teeth pulled before the start of treatment. Following treatment, survivors are encouraged to have an aggressive dental hygiene program that should be developed in consultation with a dentist who has experience caring for patients who have received prior radiation. It would likely include a combination of brushing your teeth multiple times a day, using flouride treatments (e.g., trays, high-flouride toothpastes, mouth rinses), rinsing your mouth after meals, and making frequent visits to the dentist for cleaning. Patients who have prosthetic teeth may suffer from chronic dental irritation due to lack of saliva.

Surviving head and neck cancer and the challenges of concurrent chemotherapy and radiation is a major feat. It is important that all aspects of care, including surveillance, monitoring for late effects, and preventing future problems, are addressed in the survivorship phase.

# Textures

### By Ann Colander

*At the age of nine, Ann moved to New York from Virginia. She attended the High School of Art and Design. She is a retired postal office supervisor and also had a catering business. Her friends and family call her the Barbecue Queen. In 2007, she was diagnosed with stage IV oral cancer. After two operations, chemo. radiation, and reconstructive surgery at Memorial Sloan-Kettering, and by the grace of God, she is cancer-free and writing poetry.*

I awoke that morning with no expectations other than to attend an art class at Memorial Sloan-Kettering. I would have a chance to go back in time to my teenage wonder years when I had planned a career in fashion designing and illustrations. I was excited yet reserved to learn a new medium. Along this new path of life that I am traveling on, there are always surprises around the bend and curb of the road when I least expect it. What I found was a pleasant surprise, an inspiration, a release for the soul. Allowing my imagination to roam free, to soar to new highs, to explore and become whatever I wanted it to be.

To some this might sound like a slight exaggeration, a little overkill, but as a cancer survivor you learn to appreciate that every day, every moment, every new experience is precious. The "*Art Expressions*" class is aptly named. It allowed me to find an outlet to relieve some of the frustrations and confinement this disease has imposed on my life. It let me take a deep breath, pain free, with no restrictions, then breathe again. I found myself in a place I never thought I would revisit. I had come full circle back to art, which had been such a big part of my life from third grade through high school.

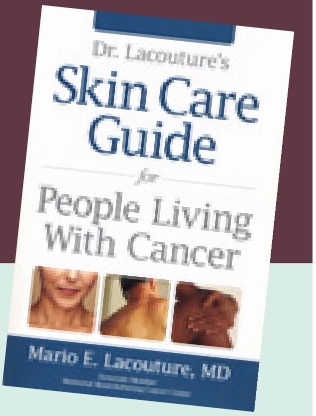
The program ended a month ago, and I've had time to reflect on the feelings and joy I felt during those classes. All I can say is, "Wow, that was just great!" I was a little disappointed in my acrylic paint renderings. The blending of paints to find the right colors, shades rather than hues I wanted, was hard, but life is full of challenges and I've always been a fighter. I improved a little with each weekly session and enjoyed meeting new people and sharing this adventure with them. The time sped by so fast. They say time passes quickly when you are having fun — and this was fun!

Here was a group of strangers who had never met before. Our only bond was that we were all cancer survivors at various stages personally. At this moment we had come together to share an unexpected blessing. I believe God leads us by the hand if we just let Him. Placing a guardian angel over each of us to watch and bring us to salvation when we need it. This was our time to drink at the fountain of life, to refuel and feed our souls. As I glanced up and looked around the room at my fellow participants, I saw people involved in creating something beautiful, inspiring, bright, lively, and colorful.

All our energies were full focus on our canvases, trying to convey with brushes in hand some of what we saw and were feeling. Seeking to find our core, uninhibited, releasing an inner peace previously unbeknownst to us, losing ourselves within the art. No sounds but the strokes and movements of air all attune to creating a picture. Some of us were doing it better than others, but no one was envious of the other. Praise abounded, and there was no room for any of the negativity or ugliness of this disease, only positivity and serenity. We all stepped into another world for a few hours in time, and as the weeks passed by we found a Joy to renew our spirit and hope in our lives. This is what I felt and am looking forward to in my next meeting in the world of *Art Expressions*. THANK YOU to all the volunteers who make the program possible.

# *Resource Review:*
# Dr. Lacouture's Skin Care Guide for People Living with Cancer

By Rebecca Steed, NP



Regardless of what type of cancer treatment a survivor has been through, changes to the skin, nails, and hair may linger after treatments are complete. Difficulties with skin, hair, and nails are important quality-of-life issues and helpful solutions do exist. In his book, *Dr. Lacouture's Skin Care Guide for People Living with Cancer*, Memorial Sloan-Kettering dermatologist Mario Lacouture reviews common dermatologic problems cancer survivors may face and discusses strategies to improve these symptoms, enhance quality of life, and improve appearance.

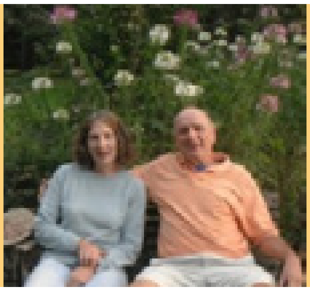
Changes to the skin after surgery, chemotherapy, or radiation are common. Survivors may experience dry skin, scarring, rashes, discoloration, or itching. Nails may be brittle, become dark, or grow slowly. Survivors may experience hair changes such as hair thinning or changes in texture or color. Many survivors are not aware that these difficulties are common and that treatments are available. In his book, Dr. Lacouture describes simple strategies to improve the health of skin, nails, and hair. Additionally, sections such as "Sun and Survivors: Playing it Safe" and "Lymphedema Dos and Don'ts" outline recommendations for protecting yourself against sun exposure and reducing symptoms of lymphedema. Helpful and informative "Question and Answer" sections and "Things to Remember" lists address a wide variety of topics such as vitamins and supplements for skin health, exercise with lymphedema, and specific issues such as those faced by childhood cancer survivors. Additional information is provided for survivors with amputations and graft-versus-host disease.

Dr. Lacouture highlights the importance of consulting with a dermatologist in the management of skin, hair, and nail problems after cancer treatment and updating the treating oncologist with any new recommendations given by the dermatologist. His book is an easy-to-read and informative resource for both survivors and clinicians.

A video summary is available at:
www.mskcc.org/cancer-care/survivorship/skin-hair-and-nail-care-survivors

# My Angel Doesn't Quit

By Paul Sanford



*Paul lives in a small town in central New York with his wife, Dolores. It's paradise. Their daughter, Leslie, lives in Buffalo and son, Chris, lives in Burlington, Vermont. Both were close enough to be instrumental in their mother's fight against cancer.*

My wife Dolores beat stage IV cancer. It's an amazing story of faith, perseverance, courage, teamwork, and her love of gardens. Her cancer hit in February 2000 and her doctor gave her very little chance to live.

The shock was overwhelming, as anyone who hears this news understands. She was 54 years old and had never been sick. My background was in sales and coaching and both would prove to be the right combination of arsenal to help fight this battle together. Dolores was the star and I was the coach.

Immediately we drove to a cancer center near our daughter's home. Here we got the quality of life talk. We said, no, no thanks. We decided that what we needed to do is fight this back home. We found a doctor who would take an aggressive approach. He advised us to get a second opinion, and that's how we arrived at Memorial Sloan-Kettering Cancer Center. The doctors worked together with us to develop an aggressive approach. After a full year of chemo and radiation, Dolores was operated on in November 2001. The surgeon spent eight hours in surgery and did a tremendous job to clear out the cancer. The pain, as the doctor put it, "would have killed most men" but after being released from the hospital my wife would endure more chemo. Then in 2003, the news we were praying for finally came. Dolores was cancer-free. She had checkups four times a year.

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Then they were reduced to two. Life went on as normal for the next nine years, but then a regular check-up confirmed that the cancer had returned. Our approach would be exactly the same, and she beat it again.

It's now 2012 and she is still cancer-free. I believe Dolores beat cancer for many reasons. Great doctors, tremendous faith, teamwork, and the power of prayer from her and our family and friends. Everyone joined the team and fought with her. But one of Dolores's strongest characteristics is her love for life. You can see this not only in her everyday actions but as expressed through her gardens. Dolores has turned her two-acre yard into a paradise of plants and trees. She probably spends six to eight hours a day caring for them, and the work has certainly paid off. So much that her gardens were featured in our local newspaper. So our advice to anyone who is faced with cancer for the first time or the second time or more is, build your team, pick your arsenal, and fight it with the passion, courage, and perseverance that we all have inside us.

## A Poem by Denise Prager

# Young Survivor

*Denise is a 26-year-old colon cancer survivor who is now battling sarcoma. She is an animal lover and a writer, and she is determined to beat this disease!*

Familial polyposis is a genetic form of colon cancer disease.
Take it slow and take time to believe.
It runs in the family at fourteen I showed a sign.
My mom was supportive and assured me I'd be fine.

We go to the doctor and they performed a test.
She wouldn't put me in harm's way and I had the best.
Doctor and hospital for cancer in the United States.
Caring and loving individuals who make no mistakes.

Then I'm scheduled for surgery and go under the knife.
All of this is done to help save my life.
The removal of my colon and a bag on my tummy.
I'm all bandaged up and feel like a mummy.

Now I have to wear this bag for a little while.
Carry a water bottle on me at all times it's my new style.
On a December night I eat a bagel and start to feel pain.
There was nothing I could do but cry and complain.

April comes around and I go in for reversal surgery.
Infection sets in and my house looks like an infirmary.
So the doctor comes in to remove my staples with a clipper.
Then my incision was ripped open like a zipper.

Had a long and deep wound filled with infection.
It took so many bandages to give it protection.
Every day it was packed wet to dry.
At times my mom would look at me and start to cry.

But we both stayed strong to make things better.
My mom is my hero and also my protector.
When the wound finally closed it left a permanent scar.
It reminds me how tough I was and that I am a star.

Even years later I still take it day by day.
And everyday im grateful that im okay.
So listen to the doctors they are good advisors.
Then you take control and become the survivor!

### Resources for Life After Cancer (RLAC)

RLAC welcomes survivors to participate in programs that encourage healing through education and support.

Please see the online calendar at:
**www.mskcc.org/livingbeyondcancer**

### Connections

is an online community for patients and caregivers. It provides a venue for conversations, support, questions, and companionship.

To register, visit:
www.mskcc.org/connections

### Visible Ink™

**A one-on-one Writing Program for MSKCC patients**

Interested patients will work individually with the guidance, encouragement, and support of a professional writer on a topic and project of their choice.

This program is **FREE**. All levels and writing interests welcome.

**For more information or to arrange a writing session, please contact Judith Kelman at 212-535-3985 or kelmanj@mskcc.org.**

Memorial Sloan-Kettering Cancer Center

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