

Revising Normal

By Ansley M. Dauenhauer

Ansley is a former elementary teacher and science museum educator and director. Now she is a full-time mom and, in her spare time, author. When she was diagnosed with breast cancer, she and her family lived in Manhattan. They have recently relocated to Midland, Michigan.



I never want to hear that I have “a nicely shaped head” or “you’re lucky because you can be any size you want!” again. After I was diagnosed with breast cancer at the age of 39, I heard those well-meaning comments frequently. Looking on the bright side has limits. I just wanted my hair back, and I had been perfectly happy with my chest size (if not perkiness) pre-diagnosis. After all, I was probably the only woman in Manhattan who dyed my own hair with a kit purchased from the drugstore. Plastic surgery was not on my radar.

But once told “It’s cancer,” my family and I were hurled into all sorts of unexpected territory. Within about a week of the shock of diagnosis, I had a bilateral

mastectomy scheduled, reconstruction planned, and knew chemo was coming.

Sometime during treatment, I was asked what I most wanted. Short of never hearing the words “invasive breast cancer” applied to my body again, I settled on the idea of “being normal.” But, even now, five years later, I don’t really know how to define the concept. What’s “normal” keeps changing on me, and I suspect it will do so for the rest of my (hopefully very long) life.

Right after treatment, I desperately tried to force normal. Even though I didn’t need a bra, I went shopping for one with my kids. The next aisle over, I heard Maddie tell Joseph, “No, that one has underwire. It might shift Mom’s

new boobs around.” I ducked low as everyone else underwear shopping at Kmart looked hard for the lady with the new boobs!

Instead of nipple reconstruction, I chose tattoos to make the white-washed mounds on my chest look more like breasts. Joseph, then four, took one look at the finished product, shook his head in dismay, and announced, “That’s not right. You were supposed to get a butterfly or a leopard. That’s what a tattoo is! You...you just have pink circles.”

While I would rather have my old breasts back, I feel darn lucky to have these pink circles.

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Memorial Sloan-Kettering
Cancer Center



In May, I attended a survivorship research symposium at MSKCC. In his opening remarks, Physician-in-Chief Dr. José Baselga referred to the **science of survivorship**. It was both exciting and enlightening to hear survivorship care as having a scientific basis of knowledge based on facts and principles. I'm pleased that survivorship is now an equal component of patient care and not simply an afterthought.

In June, MSKCC held annual Survivorship Celebrations in Manhattan, Westchester, Long Island, and New Jersey. I attended the event in Manhattan where the speakers shared motivating and inspirational personal stories of traveling through the World of Cancer.

Bridges begins its sixth year of publication with this issue. As the patient editor, I am delighted to continue to bring you stories of hope and inspiration among patients and caregivers as well as all of the latest in survivorship research and information from the clinicians.

We are pleased to include a new column in *Bridges* titled "Where Are They Now?" Our goal is to feature previous writers and bring you up to date on how their lives have progressed and changed.

Eileen F. Gould

Patient Editor

The Black Sequin Dress By Carol J.

The black sequin dress in the window of Reiss Boutique on Columbus spoke to me as I pressed my face against the glass. I dared to imagine what it would feel like to put it on, while fighting concern that the bag I wore constantly was hard to match.

Not long ago, I met with a woman who had the same surgery I underwent, which got me to thinking about that black dress. She told me that the surgery had changed her. While she wore the ostomy bag for just a total of six months, the damage to her sexual identity lasted much longer. Since her surgery, the scars on her stomach had prevented her from feeling sexy. She no longer went out much, and although from my perspective she was a young, beautiful woman in her twenties, she felt that her spark had dimmed.

My response to the black dress in the window, now seven years past, was visceral. My sexual identity was being threatened and I wanted desperately to

protect it. Until then, I had always experienced myself as a sensual being, but the last few years of surgeries had assaulted my body. If the breast cancer surgery hadn't been enough, the chemotherapy that followed had all but destroyed my colon. These operations were like cold water poured on a barely flickering flame. This dress was my doorway back. No one but I would know what was going on under the sequins. The rest of the outfit could be my own secret.

I entered the store and took the dress with me to the dressing area. Then, alone in a dimly lit room surrounded by mirrors, I stood facing myself with the ostomy bag secured to my stomach, since my colon had been declared unfit to serve. I slipped my naked body into the soft, silk lining. I hadn't allowed myself the sensual pleasure of silk since the surgeries.

I felt my skin respond to the smoothness of the material. I stepped into the slinky pumps that waited ready to offer assistance. There I was, still.

Not long after, I wore my new dress to a black tie affair at the W hotel on Lexington in New York City. During the cocktail hour, I remember being photographed many times with my husband. Wearing the short, sexy dress at that time in my recovery took the courage required to rappel down a mountain. I threw myself over the edge that night and prayed that my harness would hold. It was thrilling.

Just recently, I was sitting at my husband's desk and noticed a framed photograph of the two of us taken that evening seven years ago. Of all the photographs we have taken together over the years, he had chosen this one from the night I dared my flame to brighten.





My Father's Gift

By Barbara Plasker

Barbara, a Public Health Educator for the Rockland County Department of Health, lives in New City, New York. The older she gets, the more she appreciates the many gifts that fill her life, especially her kind and loving family and her supportive friends.

Daddy plays killer handball every Sunday at the park on Featherbed Lane or on the Hudson River. He brings me with him.

Sometimes I get into trouble. I spot him at the water fountain, and I give him a playful tap on the behind. It turns out that the man I hit is not Daddy, but he is wearing the same shorts. I fall off the jungle gym and break my wrist. Daddy takes me to the Emergency Room.

Who is this man coming toward me now? He walks with difficulty and needs a shave. As he enters the living room, he looks up. Seeing me, he laughs and cries at the same time. My Daddy's home. He is so happy to be home after six weeks in the hospital. His colon cancer has been replaced by a colostomy. I was 11 years old. He was 40. Nineteen years later he died of heart disease.

In those years he showed me how to live after cancer. He adjusted with a positive attitude. He put himself on a schedule and every other morning took over the bathroom to do what he called his "business."

Colostomy supplies in the marketplace were not suitable for his needs so he designed his own. He was involved with the Colostomy Society of New York and visited patients in the hospital to show them there is life after colostomy.

We adjusted to our new normal and resumed our lives. My parents took salsa lessons at the local continuing education program and then taught what they learned at our synagogue to raise funds. My brothers and I became avid dancers too. The five of us, the Dancing Janneys, did a routine at my brother's bar mitzvah.

At the talent show fund-raiser, Daddy did a lip-syncing routine, playing both the male and female parts. He received a standing ovation.

When I was diagnosed with melanoma three years ago, and part of my left thumb was amputated, I was 67.

I remembered my father and how he lived after his bout with cancer.

I prepared for surgery by focusing on the blessings in my life, not the losses. My spiritual beliefs give me something to rely on.

I do things that feed my soul. I say no to requests that drain my energy and yes to things that energize me. I volunteer to guide others going through transitions. I fill my life with the music and theater I love.

My sense of humor gets me through the tough times. I search my brain for a good nickname for myself. Stubby Bubby tops the list.

I listen to my body. Two years after my amputation, I found a suspicious growth on the remaining portion of my left thumb. A biopsy revealed recurrent melanoma. No other sites were found.

My father's example has been a gift. I have had time to embrace the life I have been given and make the most of it. And maybe I'll have another 19 years before I die.

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Normal is not a bra, soft breasts, or perfect nipple facsimiles.

Normal is when I feel right in my own skin, skin that now sports two globes that poke out below my collarbone, globes that have sometimes, on a crowded subway, caused me to bounce off the wall. Once I grasped that nor-

mal was not static, I also understood that surviving cancer wasn't a magic bullet for change either.

Issues didn't disappear just because I beat cancer, and treatment presented its own challenges. But survival did grant me time with family and friends and the possibility of forging new relationships. And life has reminded

me, time and again, that I have much for which to be grateful, including survival itself.

On occasion, I still chafe at being me, but that disquiet has nothing to do with my chest or thinner hair. It has to do with being human, and cancer cannot take away my humanity.

Ask the Survivor: Stress Reduction

By Maria Quandrino

Maria was born in São Paulo, Brazil. During remission, she moved to New York so she could stay close to her doctors at Memorial Sloan-Kettering. She missed them too much! She married her husband, James, and miraculously had one son and then a set of twin boys. Currently, they are learning to cope as empty nesters with their boys in college.



Q *Easing back into life after cancer treatment can be stressful. What stress reduction methods*

have you employed to stay calm when life becomes chaotic?

A I have been a patient at Memorial Sloan-Kettering Cancer Center for 29 years. I am a survivor of Hodgkin's disease and thyroid cancer, and immediately after both diagnoses I needed to learn how to deal with stress. Once I was in remission, I realized that I had to learn how to live without cancer. As strange it sounds, once the treatment ended and I heard the magical word "remission," I didn't know what to do. I had to continue going

to the hospital, constantly reminding myself that my doctors had become my friends, the nurses my cheerleaders, and the staff of Memorial my family.

Remission is a journey and a state of mind that must be embraced even when anxiety, stress, and fear of a relapse arise every time we go back to the hospital, meet someone sick, or are reminded of a terminal disease . . . and the list of what makes us stressed goes on.

I have tried everything to reduce stress, and I am happy to share what works for me. To relieve stress I meditate, pray, walk, do arts and crafts (watercolor painting, knitting, and crochet), laugh, and talk (a lot) to whoever is willing to listen to me! I try to read books that will make me feel happy, watch com-

edy movies, listen to classical music, go to museums, and play with my dog. Those are some of my stress-relieving activities, but my true secret to dealing with stress is kindness. Trying to help someone who is suffering will change your life for the better. Kindness is contagious and in being kind you feel humble and your stress is reduced. Smiling makes someone else smile; there is no better feeling when you are stressed than a stranger or a friend greeting you with a smile. Do something nice for someone else; we are together on a journey and at the end what matters most is love. Stress will come and go, but kindness and love will stay forever in your heart. Go out there every day and renew your desire to live. Love is good; it cannot only heal and move mountains — love makes stress fade away.

Living with Prostate Cancer By William Houston



Billy lives in northern New Jersey with his wife, Patty. They have two wonderful daughters, Janine and Michele, and were recently blessed with a granddaughter, motivating him to continue battling his prostate cancer.

I was diagnosed with prostate cancer over ten years ago. I was in my prime, working at a job I loved, and only 54 years old. My primary care doctor noticed a rise in my PSA that concerned him, so he referred me to a urologist. A biopsy was done and came back positive with a Gleason score of 7. This was an aggressive cancer, and after much thought

I opted to have radical surgery. There was no spread to the lymph nodes or elsewhere, but I had what is called extracapsular extension, which means that the cancer may have grown outside of the prostate itself.

About seven years later, it became apparent that the cancer had recurred. I had eight weeks of tomotherapy radiation, which did not reduce my PSA at all. A subsequent PET/CT scan showed a nodule on my lung, and surgery was done to remove the upper left lobe. I then found out that the nodule was a

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Ask the Professional: Sexual Health after Cancer Treatment

By John Mulhall, MD, and Jeanne Carter, PhD

Dr. Mulhall is a board-certified urologist and a microsurgeon who specializes in sexual and reproductive medicine and surgery. He is the Director of MSKCC's Male Sexual and Reproductive Medicine Program. Dr. Carter is a clinical psychologist and certified sexual health therapist who provides individual interventions to women with cancer. She heads MSKCC's Female Sexual Medicine and Women's Health Program.

Cancer and its treatments can have an impact on your sexual health, whether you are a man or a woman. These changes can affect people physically and emotionally, decreasing interest in sexual activity as well as self-confidence. MSKCC offers personalized, multidisciplinary support services and therapies for men and women to help them take action and address sexual health issues related to cancer.

Q: What are the benefits of being sexually active?

A: The advantages of being sexually active are physical, psychological, emotional, and relational. Endorphins are released when we are sexually active, and these endorphins can elevate our mood and act as de-stressors. In the context of a relationship, being sexually active can help to maintain a couple's connection.

Q: What is the most common sexual health concern for male cancer patients?

A: The most common problem for men is erectile dysfunction, or ED. ED is the consistent inability to obtain and/or maintain an erection sufficient for satisfactory sexual relations.

Q: Which patients are most at risk for sexual difficulties?

A: Three common treatments for prostate cancer — prostatectomy, radiation

therapy, and hormone therapy — may cause ED. Men with head and neck or lung cancers who have a history of tobacco use are at risk for ED. After a stem cell or bone marrow transplant men have decreased levels of testosterone, which can cause ED and loss of libido.

Q: What are the most common sexual health concerns for female cancer patients?

A: Vaginal dryness, discomfort, and dyspareunia (painful sexual intercourse) after cancer treatment due to menopause or estrogen deprivation are some of the most common concerns. It is also not unusual for women to experience changes in their sexual response, such as loss of libido or difficulties with arousal. Improving vaginal dryness and comfort often improves desire, subjective arousal, and the capacity to reach orgasm.

Q: Which patients are most at risk for sexual difficulties?

A: Women treated for cancer with pelvic surgery may have difficulties when gynecologic structures are affected. Pelvic radiation, given to some patients with cervical, endometrial, bladder, or rectal cancer, can cause changes in the vaginal tissues as well as loss of ovarian function, leading to vaginal dryness, narrowing of the vagina, and pain with intercourse. Certain chemotherapy and hormonal agents may bring on meno-

pausal symptoms such as vaginal dryness. Patients who receive allogeneic stem cell transplantation and develop graft-versus-host disease are at risk for vaginal pain.

Q: How I can bring up a sexual health question with my clinician?

A: Sexual health can be a sensitive topic for many patients. However, it is important that you bring up sexual side effects the same as you would any other health concern.

If you have a particular symptom, the more specific you are with your healthcare provider the better he or she can address the problem. For example, you might say, "I have been experiencing discomfort during intercourse. Is there a way this pain can be relieved?" Or, "My sex drive has really diminished since my treatment. Will this get better?"

Sometimes a very simple intervention can be offered by your treating healthcare provider, and sometimes a referral to a specialist may be needed. Sexual health issues are an important part of your quality of life and are absolutely appropriate to discuss with your provider.

Watch these videos to learn more about sexual health:

www.mskcc.org/malesexualhealthvideo and www.mskcc.org/femalesexualhealthvideo

Resource Review: Cancer Rehabilitation Services

Female Pelvic Health

By Kinnariben Patel, PT, and Lisa M. Ruppert, MD

The pelvic floor refers to a group of muscles that support the organs of the pelvis including the bowel and bladder. Coordinated contraction and relaxation of these muscles is required for bowel and bladder function as well as sexual intercourse. Individuals with neurological, gastrointestinal, urological, and gynecological involvement from cancer and its treatments are at risk for dysfunction of pelvic floor musculature.

Pelvic floor dysfunction may affect urinary and fecal frequency and urgency and result in pain to the low back, sacrum, pelvis, vagina, and perianal regions; incontinence; urinary tract infections; and painful sexual intercourse. These impairments may have an impact on an individual's quality of life, affecting the ability to perform activities of daily living and work-related tasks. Evaluation of pelvic floor dysfunction involves taking a careful history of symptoms as well as oncologic history and treatment. A physical examination is performed to assess sensation in the lower extremities and perianal region, strength of the lower extremities, and sphincter control, as well as physical abnormalities including scarring and edema/lymphedema. Formal evaluation of bowel and bladder patterns may also be conducted.

Treatment of pelvic floor dysfunction includes self-care, medications, physical therapy, and home exercises. Physical therapy to improve coordination of pelvic muscle contraction

and relaxation includes biofeedback, strengthening exercises, and hands-on techniques to improve fascial and scar tissue mobilization. Both physicians and physical therapists play an active role in establishing a management plan and ongoing follow-up to monitor progress and assess for changes in function.

Post-mastectomy Reconstruction Syndrome

By Katarzyna Ibanez, MD

Pain and functional limitations may develop in up to half of breast cancer survivors following treatment with mastectomy and breast reconstruction. Many of the symptoms patients experience after breast cancer surgery result from what is termed post-mastectomy reconstruction syndrome, or PMRS. Commonly encountered problems in women with PMRS include painful spasms of the chest wall, shoulder or arm weakness, swelling, axillary web syndrome (also known as cording), impaired flexibility, and breast tightness. These symptoms can be so severe that they limit the patient's ability to engage in everyday activities and enjoy the normal pleasures of life.

Luckily, there are many rehabilitative interventions that can successfully address these problems. Physical medicine and rehabilitation physicians, or physiatrists, take a comprehensive approach in the evaluation and management of patients with PMRS. The physiatrist obtains a detailed medical and functional history and performs a comprehensive physical examination to identify any underlying problems

with the nerves, muscles, and other body tissues that are responsible for the pain and functional limitations. They may also order laboratory studies and imaging if necessary. Rehabilitative treatments may include medications, injections, or therapy (physical, occupational, or lymphedema). For instance, for patients with long-standing and unremitting chest wall pain and spasms that have not responded to first-line treatments, botulinum toxin injections are often helpful. The mainstay of treatment, however, is highly specialized physical therapy that consists of neuromuscular re-education, advanced myofascial techniques, local lymphedema management, and visceral therapy. The therapist also focuses on improving posture and proprioceptive awareness, muscle strength, balance, as well as joint and tissue flexibility. Every patient is given an individualized home exercise program to address his or her personal goals and target specific underlying functional deficits.

A combination of medical and rehabilitative interventions leads to functional restoration and improved quality of life. If you are suffering from PMRS we strongly encourage you to seek an evaluation with a rehabilitation medicine physician.

To learn more about these services please contact MSKCC's Sillerman Center for Rehabilitation at 646-888-1900. The Center is located at 515 Madison Avenue, 4th Floor, New York, NY 10022 (Entrance on 53rd Street, between Park and Madison Avenues) and is open 8:00 AM to 6:00 PM, Monday through Friday.

Surrendering Pink

By Antoinette Truglio Martin

Antoinette is a patient at MSKCC in Commack. With October fast approaching, she is dreading the onslaught of pink.



OK, I'll say it. I hate pink! I am so done with pink! This is an extremely hard statement for me to admit out loud, and on paper, since pink has forever been my favorite color. Forever! Pink was always my color.

The pink passion started early. My mother always dressed me and my three younger sisters in the same style dresses and coats. We were differentiated by color. Mary had the carefree blues, Diana was in gorgeous greens (the only one of us, with her light eyes and golden hair, who could carry all shades of green), and I in happy pink — from bashful shades to shocking hues. Being that Mary, Diana, and I were all close in age and they seemed to grow at a faster rate than I, my faded clothes passed over them and went to my youngest sister, Barbara, whose color was dubbed peach. Our clothes and selves were easily sorted. We could be quickly identified by our colored pedal pushers and Peter-Pan-collared shirts. As bridesmaids, my sisters wore their colors for a rainbow effect while my little cousin donned my happiest shade of pink. Pink suited me. Light pinks softened my dark eyes and evened my ruddy skin tone. While most girls outgrew their powder pink tendencies, I continued to wear pink, from fluffy headbands to sparkly pink pumps. I preferred pink roses. Conveniently, pink tourmaline marked my birthstone. Soft-spoken pink was not loud like orange or tough like red. Happy, simple pink fit my practical and shy nature best. It was always mine.

Then breast cancer hit. My doctor, nurses, and technicians at MSKCC saw

me through surgery, chemo, and radiation therapy. Their efforts destroyed the stage I cancer and forever placed me in the sisterhood of survivors. This was not exactly a crowd I wanted to be a part of, but since 2007 I have been so glad to have this strong army on my side of the battle.

Pink — the mascot of breast cancer awareness, research, treatment and support — flooded my already pink-themed drawers and closet. During that year, pink crept beyond the clothing and took center stage in my jewelry, accessories, and housewares. I toted a canvas bag with the pink ribbon embroidered on the side and handles, and collected “Fight Like a Girl” and pink sandal promotional pins to give away to colleagues and friends with the message to stay vigilant. I wore pink breast cancer awareness T-shirts and scarves to prove my participation in walks for the cure and donations to fund-raisers. The ongoing research and incredible strides in treatment protocols are made possible by the efforts of the fund-raising machines.

My pink earned a new role. All this pinkness gave visual proof of my membership to the mission. I was proud to be a pink survivor and so happily grateful to have my health and long life ahead.

The bottom fell out in 2012, just ten months shy of my five-year remission date. The menace came back in metastasized form in my bones. Some little cells somehow survived the onslaught five years before and meandered their way to eat my spine. Unbelievable! Now cancer is forever. Currently there

is no cure — just management. I am lucky, though. Thanks to my doctor's insistence on screening, it was caught early, before any real damage occurred. After surgeries and radiation therapy, the ongoing treatment protocol has been minimally intrusive and minimally invasive. I continue to work and take care of my family and home as usual. Play fits in more frequently and there is a dent in an ever-increasing bucket list. I look healthy. I can say, “I'm fine” with conviction. I consider it a chronic condition, not a terminal illness.

Despite the “good attitude,” I do feel betrayed by my own body and angry! Angry! Angry! I am not one to rant over the unfairness of it all or sob through boxes of tissues. (OK, I'll admit to having regular bouts of private pity parties.) I do not intend to allow cancer to rule or ruin my body or my life. I am at war and war is not pretty. Pink has no place in war.

The purging of pink from my wardrobe has begun. I adopted my sisters' blues and greens. Bold purples seeped into my closet. Tough reds gained prominence. The pink ribbon coffee mugs now live deep in the corner of the kitchen cabinet and the pretty pink shoes and handy totes have new homes. I continue to contribute and participate in fundraising events, but forgo the complementary ornaments. The value of the campaigns cannot be overstated. My practical and shy nature reluctantly surrendered its beloved pinks to take on a bold battle stance. The role of pink survivor has morphed into that of stealth warrior.

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metastatic adenocarcinoma of prostatic origin.

Just before that, I knew the time was right to seek treatment at MSKCC, and it was the smartest move I could have made. My oncologist started me on Lupron injections, and since they began almost two years ago, my PSA has remained undetectable.

During the course of treatment, I had to take a great deal of time off from work due to fatigue. Eventually I could no longer put in a full day's work and was forced to go on long-term disability. Not being able to work was a huge slap in the face and I had a hard time accepting it, to the point where I knew I was headed for trouble with depression. I sought help from one of the caring psychiatrists at MSKCC recommended by my oncologist and was put on medication for depression, which quickly pulled me out of my nose-dive. It would not have been as successful had I not coupled the medication with talk therapy. I am now back on an even

keel, looking forward to the future. Having cancer for a long time and knowing that there is the possibility of treatment failure can really get you down. Fortunately, after starting my therapy, my daughter presented my wife and me with a beautiful baby granddaughter. Her birth provided me with renewed energy and commitment to fight this disease by any and all means necessary, and with a focus other than the disease.

I've chosen to help other cancer patients by sharing my experiences on MSKCC Connections – an online community for Memorial Sloan-Kettering patients, survivors, caregivers, and friends to exchange support, information, and inspiration. It's comforting to know that there are others who have similar issues and can relate to what you've been through.

I am a long-term cancer survivor, but surviving is only a beginning, and living a life like everyone else is my focus now. I owe it all to the care I received at MSKCC and thank everyone there involved in my care from the bottom of my heart.

Where Are They Now?: A glimpse at cancer survivors' lives post-treatment



Duane Bailey-Castro

In 2003, Duane was diagnosed with Hodgkin lymphoma and underwent both autologous and allogeneic stem cell transplants. Currently, Duane teaches middle school social studies, enjoys photography, and is working on his second master's degree at Teachers College, Columbia University.



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Resources for Life After Cancer (RLAC)

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

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

PATIENT – TO – PATIENT

We are grateful for the support of our patients and family members. If you are a former patient or family member who has completed treatment please consider becoming a Patient-to-Patient Volunteer.

For more information, contact Jennifer Wang at
patient2patient@mskcc.org.

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.

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