



I Got Sick Then I Got Better

By Jenny Allen

When everyone knows you have cancer, everyone feels compelled to say something. And no one knows what to say. So everyone tells you how great you look all the time. For a while I got told how great I looked every five minutes. Who can blame people? It's a nice thing to say. It's the first thing you think of to say when you run into someone you know with a terrible disease. I say it myself.

I preferred it to people gripping me and saying, "How are you?" And I think people were telling the truth, more or less, about how I looked. I didn't look great, but I looked okay.

Some people were so vociferous about how great I looked — "YOU LOOK GREAT!" — I felt they were trying to convince both of us that looking great might be a sign that my illness would be transient. The reasoning seemed to be: You simply cannot look this healthy

and be so sick. Maybe you don't have real cancer — maybe you're just cancerish, and it'll pass, like the flu.

Some people offered looking great as a kind of booby prize: "Well, you look great."

Other people seemed taken aback that the cancer hadn't ravaged my appearance. "Oh my God, you look great!" The subtext here was, "You don't look like a cadaver at all" — which is how many people think people with cancer are supposed to look.

Sometimes it wasn't subtext. Sometimes it was right out there in the open. I saw a retired art history professor I knew. "You look great," he said, "and I was dreading seeing you."

Hardly anyone else tried to be refreshingly candid — although I was at my friend's apartment when Rufus Wainwright, the singer, happened to come over one

■ *Continued on page 3*

Jenny Allen was treated for ovarian and endometrial cancer at Memorial Sloan-Kettering in 2005. The following is an excerpt from her one-woman show, "I Got Sick Then I Got Better." The show appeared at New York Theatre Workshop last fall and was directed by James Lapine and Darren Katz. She now performs it at theaters and at cancer conferences around the country. Visit her Web site at www.jennyallenwrites.com.

In this issue

- 2 Editorial & Meet Paul
- 3 Ask the Professional
- 4 Robin and Me
- 5 Resource Review
- 6 This Can't Be Happening to Me
- 7 Ask the Survivor
- 7 Biopsy

If you are interested in
submitting your story,
please visit

www.mskcc.org/bridges



Memorial Sloan-Kettering
Cancer Center



This past June, MSKCC celebrated cancer survivorship with a terrific evening reception featuring two inspiring patient speakers, and keynote speaker Hoda Kotb from NBC's

Today Show. One patient speaker, Duane Bailey-Castro, who has survived three rounds of Hodgkin lymphoma and two stem cell transplants, was about to embark on a three-month trip to Asia that same week, fulfilling a life-long dream to sail on a commercial freighter for the first part of his voyage to Korea. The other patient, Samantha Eisenstein Watson, a survivor of Ewing's sarcoma, started a foundation called The SAMFund for young adult cancer patients, which aids those who are in need of financial support during illness. Both of these young people were awe-inspiring, as they told their stories of survivorship. The guest speaker, Hoda Kotb, spoke about her own experience with breast cancer while she continued to work as a morning television host. She kept the audience laughing with her own trials and tribulations.

More than 400 people attended the event, which in addition to guest speakers also featured highlights of several programs offered by the Integrative Medicine Service as well as dermatology, nutrition, and exercise services and a space just for Young Adults to mingle and meet. It was an outstanding event for patients to come hear fellow survivors speak and to see a room filled with many survivors of all different ages who have survived many different cancer types. Having attended survivorship events around the country for the past 20-plus years, I continue to be amazed by the people I meet along the path of survivorship and the level to which fellow patients are both delighted and grateful to be celebrating with one another year after year.

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



Meet Paul

By Paul Michael Onder

I am a 47-year-old man who has chronic lymphocytic leukemia, a blood cancer. I also have idiopathic thrombocytopenic purpura. I was told about this in 2005 when I was 42 years old. This is when my life started to change for the better.

Let me start with who I am. I am a

loving husband, father of two children: 18-year-old Stephanie and 13-year-old Stephen. My loving wife's name is Anna Marie.

We have been married for 20 years and are still going strong in our relationship. I have three siblings, Peter, Mary, and Michael. My parents were Peter and Dorothy Onder.

I am a professional plumber who received my Master Plumber's License from the state of New Jersey when I was 22 years old. I spent five years prior to that working as a plumber in order to take the test to get a license. I am also the President of my local church.

I believe because of my profession as a plumber, I have absorbed the metals and chemicals that I have used in my trade of installing and repairing plumbing for the last 30 years.

This is when I start to look at where the cancer came from and let it take me back to where I lived as a child and an adult.

I feel this was brought to me from the life I have lived, and my attitude is that this cancer is a battle or test that

I need to win, so I can live the life I was born to live.

I am fighting this battle of cancer with inspiration from my family and my spiritual family. For, as you know, you need every prayer and blessing you can receive as you war with this enemy.

My doctors at Memorial Sloan-Kettering are doing their best to understand and kill this enemy of the body from the inside. I feel that I must stay strong with my hope and the confidence of my faith, that I must stand with my doctors to win this war inside of me. Because my plumbing trade has made me sick, I have to realize I cannot continue to be a hands-on plumber.

I must reinvent myself and find the next chapter of my life so that I have a chance to live out my future. I am not going to let this cancer be a negative in my life. If cancer changes your life from what it was to something different, then I am going to take the negative and make it a positive and renew my life so I can be an inspiration to all of my brothers and sisters who are fighting this same evil: CANCER.



Ask the Professional

Coping with Pre-Visit Anxiety

By Jimmie Holland, MD

A psychiatrist for more than 30 years, Dr. Holland has devoted her career to helping patients, their families, and medical staff as they cope with the psychological burden of cancer and its treatment.

Q I finished cancer treatment over a year ago, but I find myself getting very anxious every time my follow-up appointment approaches. I'm afraid that if I don't maintain a positive attitude that I will make myself sick again. Do you have any suggestions about how I can handle this?

A The anxiety that you experience before follow-up appointments — and it is also true of scans — is something that every person describes, to some extent, particularly in the early period just after completion of cancer treatment. While ending treatment seems like a time for

celebration, we find there is an increase in worry for some because treatment has stopped and the visits to the doctor are less frequent. Some have described it as “it is hard to be on my own without anyone checking me regularly — I get worried about if I am OK.” As time goes by, the anxiety becomes less but one young woman described her anxiety before scans as “PSE,” or “Pre-Scan Psychosis,” which was gone as soon as the scans came back normal.

The second issue you bring up is whether your attitude has to be positive in order to stay cancer-free. This is a myth foisted on cancer patients that makes coping with cancer so much more difficult. We don't ask people

who are ill with a heart attack to “stay positive” and neither do we stay positive all the time when we are healthy. I have called this “the tyranny of positive thinking.” There are no data that support the hypothesis that you should fear to express your usual emotions (even negative ones) after having cancer. It is important to recognize that sometimes you may feel worried or depressed and it is far better to seek help — there are many resources available today to help with coping, from online to groups to one-on-one counseling. Ask your oncologist's office for a referral or call the Memorial Sloan-Kettering Counseling Center at 646-888-0068 for an appointment.

■ *Continued from page 1*
day. “Oh, hello, Jenny,” he said. “Aren't you supposed to be dead?”

People said, “It's so unfair.” Hadn't they heard of genocide, or tsunamis, or Ted Bundy?

People said, “You don't deserve this.” Like there was someone who did.

People said, “There's always someone worse off than you.” How can you make yourself feel better about your own calamity by measuring it against someone else's worse calamity? And what if you're the worse-off person that people are thinking about? “At least it's just a fibroid. At least I'm not Jenny Allen. That would suck.”

People said, “You never get more than you can handle.” That is just not true. People get more than they can handle all the time. That's why people jump out of windows, or become Scientologists.

And the one I hated the most: People said, “Everything happens for a reason.” It seemed to me that many things happen for no reason at all, or more reasons than you can possibly ever tease apart, and anyway, when people say “everything happens for a reason” what they mean is “everything happens for a purpose.” And I'm sorry, but I just don't believe in that kind of divine direction. I think that life is amazing, and precious and a gift, but I don't necessarily think it has a point.

I should say here how generous and loving many people were, what kind things they said and did for me. People called, they wrote, they sent their favorite scarves for my head. A few of my friends even delivered dinners to me and my family, which I know is done all the time in most of the country, but is just not part of Manhattan culture.

I wanted to keep people at arm's length so they wouldn't feel sorry for me; but then, if they didn't ask how I was, or they asked in a way that seemed to minimize my situation — “I meant to call you, somebody told me last summer you were sick” — I'd feel slighted.

There really was no pleasing me.

Robin and Me

By Elizabeth Bonwich

Elizabeth is a native New Yorker, though her heart belongs to her chosen homeland of mid-coast Maine. She holds a BA in biology from Barnard College and has been active in the performing arts. Now 37, she's soldiering on through her fourth unique cancer since age 15.

Where were you on New Year's Eve 1986?

I know where I was, in bed watching Robin Byrd's New Year's special, along with the other pediatric patients in our room at the orthopedic hospital. Byrd, of course, was an "adult entertainer" who had her own show on public-access cable, a new creation in the '80s, and hospital officials had not yet realized that insomnia wasn't all that was keeping us up late. At 14, I was the eldest but the least experienced at the world of illness and hospitalization. I'd landed there thanks to a broken finger and ominous bone scan.

"Has anyone discussed with you the possibility of this being cancer?" the doctor asked, staring down at 14-year-old me in my wheelchair. "No," I said. With that she bolted from the hospital room.

But cancer it was, the first of four separate malignancies over the past 22 years.

This means that, including the relapses, I've had eight "you have cancer" diagnostic moments.

As a teenager I had bone cancer, osteogenic sarcoma. The treatment complications were so severe that the

nine-month protocol took 18 months to complete. That meant missing half my sophomore and my entire junior year of high school. Surgery left me with one less finger and titanium where my knee and lower femur used to be. The near-constant hospitalizations tipped off post-traumatic stress disorder, an ailment commonly found in combat veterans, not high school girls. I lived in constant terror that the cancer would return.

The sarcoma didn't return. Instead I got a brand new form of cancer. Non-Hodgkin lymphoma was the bane of my mid-20s. Relapsing twice, it interfered with my recent entrance into the workforce, my relationships, and my general plans for life.

Cancer three should have been a small thing, a blister on the bottom of my foot — my good foot — but morphed into a multi-year, ulcerated cause célèbre, which destabilized my gait so severely, that I broke my prosthesis twice in two years.

Where was the year off? The opportunity to settle into a career? A marriage? A baby even? It wasn't coming.

Yet, despite the constant health problems I was actually doing okay. I forced myself past my old stage fright

and was singing again, I'd fulfilled a life dream and moved from Manhattan to a small town in coastal Maine, I was in a stable relationship and even taking aerobics classes, when, at 35, the unthinkable happened and I was diagnosed with cancer four: squamous cell carcinoma of the base of tongue. Three years and multiple recurrences later this is my current nightmare.

Cancer as a chronic illness is tedious stuff. We like to think that there is some redemptive power to life-threatening illness. It sounds nice, but it's not really true. It also puts a lot of pressure on the sick person, who is already either falsely glorified — "Oh you're so strong" — or falsely reviled — "You need to get a more positive attitude." I've heard both, sometimes on the same day.

Now I do the medical commute between Maine and New York. As I sit in Manhattan flipping through the channels, I'm glued to the home and garden shows. But sometimes when I can't sleep and wonder if after 20-plus years things will ever get better, I snap past something strangely familiar; Robin Byrd can still be found on cable TV.

Resource Review: MSKCC Outpatient Rehabilitation Center

By Eileen F. Gould

Memorial Sloan-Kettering Cancer Center proudly opened a state-of-the-art Outpatient Rehabilitation Center on May 3, which will expand MSKCC's ability to offer physical and occupational therapy as well as rehabilitation medicine services to cancer patients and survivors. The Center resides on the fourth and fifth floors of 515 Madison (entrance on East 53rd Street between Madison and Park Avenues).

The fourth floor has all of the latest in exercise equipment and custom-built treatment rooms for cancer rehab therapy. There are 15 treatment bays allowing for adequate privacy during hands-on therapy work. In addition, two rooms are specifically designed for the management of lymphedema, which can be a chronic condition. Occupational therapists utilize a specialized kitchen and bathroom with grab bars to practice activities of daily living. In addition, occupational therapy helps people with arm and shoulder problems, works on dexterity and coordination, and treats cognitive dysfunctions — mild and severe.

The exercise machines are situated in the spacious gym area, which resembles a full-service commercial-style gym. There is an area in the center of the gym that simulates a park where the patient can practice stepping on and off curbs and walking on uneven surfaces. Some of the machines offer very advanced therapy and many of them are wheelchair compatible. For example, the Power Tower is a strength-training machine that uses



gravity and one's own bodyweight as resistance, while providing a full-body workout emphasizing core stability and strength. The Cybex machine combines computer technology and highly sophisticated pressure sensors with various computer games, thereby offering a fun and effective way to build lower body strength, coordination, and endurance. Large cushioned mats are available to provide safety and comfort during all exercise and activities. There is a separate exercise room with mirrors and ballet bars, which will be used for group instruction and floor exercise. Physical therapists use this state-of-the-art

space and equipment to help patients decrease pain with activities, improve strength and range of motion, enhance coordination and balance, and improve their ability to walk safely. The center offers additional specialized programs including Women's Health physical therapy, vestibular rehabilitation, trismus treatment, radiation fibrosis and scar management, peripheral neuropathy management, and osteoporosis group education. All programs are specifically designed for cancer patients.

The fifth floor houses the clinical space as well as the offices for three MSKCC physiatrists. There are six exam rooms used to administer assessments and treatments, including muscle/joint injections for pain relief and osteopathic treatment techniques. Two of these exam rooms are fully equipped to provide EMG testing. Physiatrists are the physician of choice for the management of musculoskeletal and neuromuscular pain and dysfunction in cancer survivors. In addition to pain management, physiatrists evaluate the need for specialized prosthetics and orthotics, which enhance a person's ability to function in his environment. Patient Financial Services has staff located in the Center as well, which allows patients to have on-site financial consultations.

A patient van provides convenient transportation to the Outpatient Rehabilitation Center from other MSKCC sites. Discounted parking is also available. To learn more about the Rehabilitation Center, please contact call 646-888-1900.

This Can't Be Happening to Me

By Rosanna Logozzo

Rosanna Logozzo is a 28-year-old survivor of ovarian cancer. She resides in Brooklyn with her husband, Anthony. She is currently a second-grade teacher in Bay Ridge, Brooklyn.



It all began one day while grocery shopping. Something inside of me told me to buy a pregnancy test. I had no pregnancy symptoms but something made me buy a test. You could only imagine my shock when the test came out positive. I couldn't believe I was pregnant! I immediately called my gynecologist and made an appointment. The test there came out positive as well, but my gynecologist thought it was a little strange that I felt fine. After a series of blood tests with my HCG level fluctuating they assumed I just had a miscarriage, until I felt a very slight pain on my left side. I would have normally ignored the pain but since I was sitting in his office I mentioned it. I was immediately sent for a sonogram. From there they saw what they thought were cysts on my ovaries. I was then sent for an emergency CAT scan. I was told to meet my doctor at his office on Monday where I heard the dreadful words . . . "It may be ovarian cancer"! I cannot tell you what I felt at that moment because it was all a blur. I just kept thinking to myself I am 25 years old . . . why is this happening to me??

I went to several doctors trying to find the doctor who I thought would be best for me. Who would be able to

save me from cancer? I finally decided that I wanted to go to Memorial Sloan-Kettering. I was reluctant to go there because that would mean I was a cancer patient. I was having a hard time accepting the fact that I was sick. How could I have cancer when I felt nothing! Going to Sloan-Kettering was a decision I will never regret. I believe they saved my life.

I met with my doctor the day before Thanksgiving. Even though the news he gave me was the worst news of my life, I felt comfortable with him. He told me that my cancer had progressed to Stage 3! All I could think was that I was going to die . . . how could I have Stage 3 ovarian cancer? He spoke to me about the surgery, and without thinking twice I booked my surgery for the following week.

On December 4, my surgeon performed my long and very extensive surgery. He had to remove both ovaries and several lymph nodes. Since my cancer had spread to my lymph nodes I needed chemotherapy. Upon hearing how extensive my chemo treatment would be I immediately broke down and cried. Not because of the struggle I would face but because of having to be out of work until the end of May.

How would I face 20 second graders and tell them their teacher will be gone for another five months? Not being able to work was the hardest thing for me.

On April 20, 2009, my doctor spoke the words I had been longing to hear, "Rosanna, you are in remission!" Tears of joy immediately started to flow! I can finally put this all behind me and live my life.

If it wasn't for my family, friends, and co-workers, I wouldn't have made it. I am happy to say that today I am cancer-free and in remission. Unfortunately, ovarian cancer shows no symptoms. If it wasn't for the gut feeling I had I don't even want to think about where I would be today. Memorial Sloan-Kettering was a blessing to me. The entire staff helped me forget I had cancer. My hospital stay after my surgery was kinda like a hotel visit. That was my first hospital stay ever and I must say it was very comfortable. My time at the clinic while receiving chemo was just as comforting. Thank you for helping me through my horrific year.

Ask the Survivor: Coping with Hair Loss



By *Kate Charap*

Katherine Charap is a native New Yorker who lives with her 17-year-old son, Sam, and her husband, Ross, on the Upper West Side. She loves long walks in the park with her beloved rescue dog, Lulu, and spending time with her family.

I have explored wearing hats, scarves, and even a wig to cope with the loss of the hair on my head, but I am struggling with how difficult it is to have lost my eyebrows and eyelashes. What advice do you have about coping with this change?

In some ways, losing my eyebrows and eyelashes during chemotherapy was more traumatic than losing my hair. I could cover my bald head with a head-scarf or a wig depending on the occasion. But there was no covering up those naked brows and eyelids.

Without eyebrows and lashes, the woman I saw in the mirror just wasn't me. She was a very vulnerable alien from another planet, and she didn't look too happy to be on planet Earth.

So, was I to do?

Summer or winter, I never left the house without my sunglasses. I wear corrective lenses, so I invested in a pair of the most glamorous sunglasses my budget would allow. If you don't need prescription lenses, I would suggest assembling a large collection of inexpensive sunglasses. You can have some fun selecting a different pair to suit your mood. Wearing my chic sunglasses and an attractive headscarf, I often felt more like a movie star traveling incognito than a cancer patient.

I also mastered the fine art of penciling on eyebrows. I wanted them to look as natural as possible. I went to a fancy makeup shop where the sympathetic salesperson was happy to help me choose the right color and teach me how to pencil on brows that looked quite natural. I practiced at home until I was able to create natural-looking brows in no time.

As for lashes, I found that once I had penciled on my brows, my missing lashes were hardly noticeable. But the same friendly saleswoman gave me some tips on how to create the illusion of lashes with an eye pencil. There are also some remarkably natural-looking false eyelashes available if you search around a bit.

For me, the worst part of chemotherapy was feeling that I had no control over what was happening to my body. Losing my eyebrows and eyelashes certainly wasn't the worst problem I faced. But finding solutions to help myself continue looking like myself gave me confidence that I could take control of the big problems as well.

Biopsy *By Deborah Jacobson*

Deborah is an artist living in lower Manhattan. Her passions include painting, jewelry making, and writing, among other creative pursuits.

I was informed, the mammo has changed from six months ago, and now there is a cluster of calcium deposits. This did not look suspicious, but because of my history I was told I should check it out. Stereotactic vacuum-assisted core biopsy. I was lying on a table contorted; one

arm draped over my head and the other at my side, one breast is stuck through a cutout in the table. I am listening to my ipod. Jack Jackson is singing in one ear, and I am listening to instruction in the other ear. I hear: "breathe, don't breathe." Which is it? Do I breathe or don't breathe?

■ *Continued on the back page*

■ *Continued from page 7*

I have one sound coming through the headset, one in the distance telling me what to do, and yet another screaming in my head telling me that I have been through this before, where the result was not so great. This present-day experience and eight years prior felt the same. I was transported back to the time of disease and my husband's demise in the trade center.



Deborah Jacobson's painting was displayed at the 2010 MSKCC Patient Art Fair

In seconds I erased years of my journey striving for health, clearing my body of disease and chemicals, clearing my mind of toxic thought. I was back to square one, thinking about my own mortality and how alone I felt in this experience.

I am on auto pilot; I remove myself from the experience, from my body. It is natural for me and not planned. I need to process this experience, so I correct it with an acupuncture appointment later in the day. I keep thinking how easily I fall into this feeling of helplessness and loss of control. It is so challenging to pull myself out of the pitfall of depression and feeling sorry for myself. I must make a choice, and I ask myself, Do I stay in this depressed state or do I find a place of peace? What I do have is my painting, my creativity, my imagination, where life is calm and beautiful. It is the feeling of the sun warming me in the chill of the day, a trip to the waters edge, looking at a sunset, or seeing the flowers emerge after a difficult winter. The flowers have new beginnings and greet Mother Earth. What appears as delicate and weak emerges year after year. I can do that. I can re-create that by just painting a beautiful blue or a sun-filled yellow. The greens can be a field of plush foliage. The color alone has capability to transform my vision, and already I feel better.

Patient Editor
Eileen F. Gould

Advisory Committee
Duane Bailey-Castro
Joanne Candela, ANP, MPH
Diane Dunst
Jennifer Ford, PhD
Barbara Golby, LCSW
Judith Kelman
Mario Lacouture, MD
Mary McCabe, RN, MA
Meghan Newcomer, MPA
Robin Rawlins-Duell, NP
Mary Sue Rosen
Michael Stubblefield, MD
Clare Thomas

Bridges is available to read online at 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.

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.



Memorial Sloan-Kettering
Cancer Center

Bridges is a publication of the Memorial Sloan-Kettering Cancer Center Survivorship Initiative.

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.