

Bridges

Connecting Cancer Survivors



Sing Out, Louise: Crooning the Melody for Happy Stress-Fighting

By Phyllis Fine

At a concert in New Orleans, I heard familiar words come from the stage, sung by jazz great Kermit Ruffins:

“I see trees of green, red roses too, I see them bloom, for me and you. And I think to myself, what a wonderful world.”

I’m reminded of the original, iconic singer of the tune, the legendary Louis Armstrong — his gentle rasp accentuates the message to be grateful for the present.

I’ve taken “What a Wonderful World” to heart as I struggle to balance my anxieties about my health. The dilemma: how to ground myself after my treatment for endometrial cancer ended in August 2013? Let’s just say, I wasn’t completely a stranger to the wonders of modern medicine (hello, Xanax!). But I’d also been trying out non-chemical antidepressants and tranquilizers, from yoga to making music.

Last year I started ukulele lessons, thinking the small, slightly goofy-sounding instrument would be easy to learn. Um, not so much: As an adult who can’t formally read music, I’m still struggling to play chords and sing at the same time.

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Phyllis Fine is a writer and editor who lives in Brooklyn, New York, with her husband.

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Memorial Sloan Kettering
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Editorial

By Eileen F. Gould

This past June, MSK held its annual Survivorship Celebration. More than 500 survivors and their families and friends came together to celebrate with awe-inspiring speakers, food, and conversation. It is always amazing to see so many cancer survivors in one room as MSK honors their strength, courage, and resilience.

I had the delightful experience of meeting two previous *Bridges* cover story authors. They came to the *Bridges* resource table to introduce themselves and it was wonderful to actually meet them

in person. One of the writers told me that she had not been back to MSK in 30 years and drove all the way from Baltimore just to attend the evening. It was gratifying to realize that sharing her story in our newsletter was the catalyst to returning to the institution that saved her life so long ago.

Bridges continues to be a forum for patients and caregivers to connect with each other and to share their stories of hope and survival in the World of Cancer. We welcome stories from patients and caregivers at bridges@mskcc.org.

RESOURCE REVIEW: Rising Voices

By Lauren Robinson, MSHC

On a summery Tuesday evening, a lively crowd gathers in the welcoming lobby of MSK's Bendheim Integrative Medicine Center. Conversations soon turn into a gentle harmonic humming, as the choral director sits down to play the piano. As if on cue, the group breaks into the song and the lobby swells with the warm, comforting sounds of music.

The quality and enthusiasm in these collective voices would have you believe this was a rehearsal for professionals. However, everyone in this talented group is a cancer survivor and a member of Rising Voices, a supportive singing chorus open to all MSK patients, survivors, and caregivers. Rising

Voices offers a lively creative outlet for cancer survivors looking for an interactive, unique, and expressive support team.

"I am so glad I decided to participate in this wonderful survivorship resource. Rising Voices is an opportunity to come together with others and make music," says one member. "Our director is terrific. She has a unique talent in her ability to bring together singers of all different levels of ability."

Since its beginnings, Rising Voices has been under the care of Sue Ribaud, an MSK volunteer for six years. "As a director, I knew I needed to find a repertoire that would please singers with a wide range of abilities and tastes in music," says Sue. "The songs had to have at least one of my criteria: uplifting, fun, beautiful, heartfelt, and nostalgic."

Sponsored by MSK's Integrative Medicine Service and The Society

of MSK, members meet twice per month in the evenings from September through June. Auditions or professional musical experience are not required to join; interested members need only a love of music and a willingness to try. Rising Voices is also a free supportive resource. In June 2015, Rising Voices participated in its first group performance in the Patient Recreation Center, and participants look forward to performing more next year.

Rising Voices is MSK's chapter of Something to Sing About, a global network of choirs dedicated to supporting cancer survivors. Founded in September 2012, Something to Sing About now numbers 250 members worldwide, ranging in age from 8 to 84 years.

Becoming a part of Rising Voices provides an outlet for emotional expression and a chance to build camaraderie with fellow survivors.

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Ask the Survivor

By Carolynn Murphy

Carolynn Murphy is a gardener, environmentalist, and dog walker living in Park Slope, Brooklyn. She has been in a satisfying committed relationship for more than a year and has been breast cancer free since her mastectomy in 2013.

How did you know you were ready to start dating again after your mastectomy?

I didn't really plan it or feel in control of it but I met someone I liked and started dating him. That's when I knew I was ready. That was about six months after my mastectomy and about two months after the reconstructive surgery.

When did you tell your partner that you had cancer and a mastectomy?

I became open with this person about the mastectomy as soon as I knew I could feel emotionally and physically safe with him. Being vulnerable and still going through the process of breast reconstruction, it felt like disclosure was an important act of self-care. I felt it was my responsibility to both of us to be open about the situation so he knew what he was signing up for and I could have a better chance of getting the support I needed.

What did you say to your partner once you decided you would disclose your health issues?

I was very straightforward. I figured I'd learn a lot about him by the way he reacted. I told him my timeline: when I was diagnosed, when I had the mastectomy, the reconstructive surgery, that I still had to wait four months before the nipple could be physically constructed and then another four months before I would get the pigmentation completed. This last part felt important to say because I wasn't ready yet to reveal my breast if we were to become physically intimate and I wanted him to know why. Incidentally, I did find these great bras that allowed me to reveal one breast while keeping the other one covered during sex. They were great because they allowed me to feel very comfortable moving around

during sex. I even made a joke out of the bra...I called it my pirate patch! We got a lot of laughs out of it.

Some survivors are hesitant to start dating again after cancer or a mastectomy because they feel like "damaged goods" and are afraid of rejection. What would you say about that?

I admit that I have occasionally felt like "damaged goods," but those feelings pass and so far haven't kept me from putting myself out there to date.

I was 44 years old when I was diagnosed with breast cancer and I went through a spiritual transformation prior to the mastectomy. I knew on some level that in order to have a good physical and emotional recovery from the surgery, I couldn't afford to view myself as a victim. It took some time, but once I achieved acceptance of my situation I knew I had to view my decision to have the mastectomy from a position of choice. Looking at it that way allowed me to begin to view my situation as something I get to do so that I can be of greater service to other women.

If I choose to, I can see the mastectomy/reconstruction as something that makes my body, my life history, and my character more rather than less interesting. Apparently others can see me that way, too. I met someone and have been in a relationship with him for the past year.

What are some of the positive changes that have come out of your cancer experience that you feel you bring to a relationship?

I feel now that I am more real with myself, my life, and others. I have a more solid "me" as a result of the cancer because I was able to transform suffering into some

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Cancer Dismissed

By Erin Chack

Erin Chack is a survivor of Hodgkin's lymphoma and a senior editor at BuzzFeed.com. She currently lives in Astoria, Queens, where she has an unhealthy relationship with Greek food.

I don't expect anyone who hasn't had cancer to understand this, but there's something sad about being discharged from your hospital. It's kind of like visiting your old high school after graduation and realizing your locker now belongs to a stranger, your teacher has a new favorite student, your seat at lunch has been claimed by some pimply freshman. That's how I feel whenever I find myself on the Upper East Side walking past Memorial Sloan Kettering. Such important and profound things happened to me in that building, but now someone else is sitting in my infusion chair.

Back in March 2014, I had my very last appointment as a patient of MSK. I ended treatment for Hodgkin's lymphoma in 2009 but was still required to stop in once a year so technicians behind glass could scan my insides and make sure everything was how they left it. It sounds crazy, but I looked forward to those appointments. I would wear short sleeves on purpose so after my blood was drawn other patients in the waiting room would know from my Coban wrap that I was still one of them and not just a caretaker or a very lost tourist. I felt proud to be fighting alongside them, even if my own personal battle was over.

But during my last appointment I already started to feel the hospital slip away from me. Standing in the elevator, I forgot which floor to press. I hardly recognized the receptionists who I once upon a time knew by name. And when a nurse I had never seen before called me for bloodwork, I was surprised to feel a small pre-cancer fear of needles rising in the back of my throat.

I wanted to slow everything down. I wanted to hold onto the hospital before it was just another blurry memory of a very weird time in my life. But then I blinked. I was shaking hands with my oncologist, joking that I hoped to never see him again. I blinked again. I was walking down 1st Avenue toward the F train with my back to MSK, a tight scroll of discharge papers in my fist, a diploma that I didn't feel I earned.

It's irrational, but I worry that without my yearly appointments at MSK I might trick myself into thinking that I was never really sick, that it was all a weird, too-real dream. My hair is shoulder length now. The backs of my hands are unscarred. The hospital was my last physical reminder that I'm not making it all up.

About a month ago I was visiting friends in Boston only a few T stops away from where an on-campus doctor first uttered the word "cancer" in front of me. I was about to leave a party when a friend pulled me aside and handed me a tiny box. "Sorry if this is weird," she said. "But I saw it and thought of you."

I lifted a silver necklace from the box. Hanging from the chain was a token with the words "CANCER SUCKS" stamped into the metal.

I guess as time goes on, we learn to make new connections to our past.

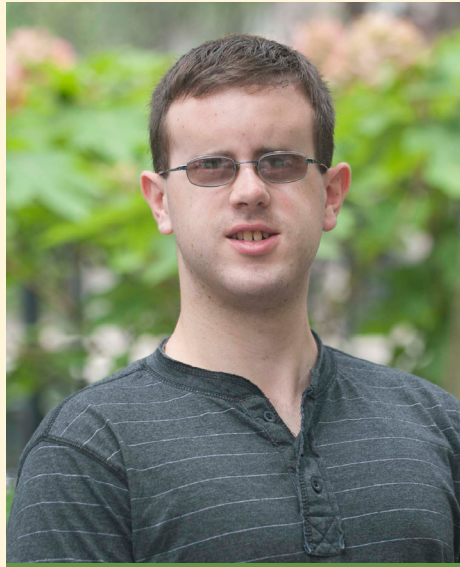
Facing Cancer by Keeping Your Eye on the Ball

By Matt Reed (co-author Ellen J. Greenfield)

For as long as I can remember, soccer has been one of the most important things in my life. I began playing when I was 4 years old and from that point on could almost always be found with a ball at my feet. In fact, I absolutely believe that my competitiveness was one of my greatest assets during my cancer treatment and recovery.

I have battled cancer on two separate occasions, but I don't consider myself different from everyone else. I was too young to recall my first bout with retinoblastoma when I was less than a year old, but my experience with osteosarcoma will forever live with me. I was 14, and naturally I was out on the soccer field. I was jumping up to head the ball, before being pushed from behind. I landed on my face but continued to play. After a few days, my family noticed my left eye was abnormally swollen. That led me to Memorial Sloan Kettering. I went through around nine months of chemotherapy and had surgery to remove a tumor from behind my left eye. I have numerous metal plates and screws in my head, lost my sense of smell completely, and am legally blind in my left eye, but I consider myself lucky. I can still play soccer and I plan to train in order to try out for a semi-professional team in the next year or so.

It's true that everyone knows someone that has had cancer.



Matt Reed is a college student from New Providence, New Jersey, and an aspiring sportswriter and broadcaster.

In my case, both my grandfathers and my father's mother lost their respective battles. They are my heroes. In my experience at MSK, I met some of the most amazing people in my young life. The nurses, doctors, and even members of the Big Apple Circus who visited the pediatric unit twice a week while I was there somehow made it seem like everything was going to be okay, even when there were plenty of times that I was in serious doubt that could possibly be true. Obviously the experience of living through cancer is difficult for anyone who goes through it, but even though

I was old enough to understand what was happening, I was more focused on getting back onto the soccer field and seeing my friends. I can't overstate how utterly blessed I am to be here today. I had the pleasure of sharing rooms with several children in the unit who were fighting even tougher battles than I was.

Some people spend years in the hospital, and unfortunately some never get out. Today, I live every day to the fullest, or at least I attempt to. I am in college, pursuing a major in sportswriting and broadcasting. I hope someday to start my own major sports site and work for a broadcasting station like ESPN or New York's WFAN. In the meantime, I have created my own soccer website that follows the New York Football Club, a Major League Soccer team that made its debut in 2015. I get to attend all of the home games and some of the away matches as a member of the working media, which I realize is a great opportunity.

Like any other experience, sometimes events aren't easily comprehended until well after the fact. One of my favorite quotes comes from former North Carolina basketball coach Jimmy Valvano. He said, "Cancer can take away all of my physical abilities. It cannot touch my mind, it cannot touch my heart, and it cannot touch my soul." I will forever live my life in that belief.



Living with an Ostomy

By Perry Duryea III

Perry Duryea III is president of Perry Duryea & Son, a three-generation seafood business headquartered in Montauk, New York. Mr. Duryea, a graduate of Colgate University and Columbia University School of Business, was diagnosed with colorectal cancer in 2007 and treated at MSK. He presently does extensive counseling for cancer patients and supervises a cancer support group in his hometown.

Adapting to life with an ostomy is physical, psychological, and personal — but at least it is life.

I remember so clearly my pre-surgical consultation some seven years ago with Dr. G from the colorectal surgery department at MSK. Following my abdominoperineal resection, I was told that I would be fitted with an ostomy, and it would be permanent. I replied, “You have the wrong guy. I am in the seafood business. I throw around boxes of fish all day, love to swim and play golf — I can’t function with this.” Dr. G calmly answered that I would get used to it, that some professional athletes have one, and that it would become a part of my daily life. Meanwhile, my mind was racing. What would I look like, what would my wife think, how could it have come to this?

Well, the years have passed and my “appliance” is in fact part of my existence, and I can still swim and still move fish boxes and still have sexual encounters with my loving wife. Sure, even now I look down at my abdomen and wonder about the stoma protruding from my skin, or the closed-end pouch that hangs like a stocking from the mantle. But the procedure that redirected my insides and the process of changing my pouch and seal mean that I can go on with my life, in a productive and affirmative fashion.

I have changed my pouch in a duck blind while hunting and in a restaurant parking lot. I once gave an address at a cancer gathering on Long Island several years ago, and when I turned sideways, I said to

the group, “Can you see a bulge at my midsection?” Not one person said yes. The two rules I follow are don’t leave home without one in my pocket, and don’t lie on my tummy at night. But short of that, I am doing fine.

Have there been accidents? Yes. But the few times it has happened, as I am cleaning myself off I reflect that I am lucky, that I have access to ostomy supplies, that I have so much more flexibility than someone who wanted to have the process reversed, and that I am leading the active life that MSK provided for me. Am I normal in the sense of the standard human configuration? No, and I never will be. But this is the new normal, and I am living well.

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kind of service and gratitude. I also know now that I am strong enough to get through the hard times that life puts in our path. I tend to not sweat the small stuff so much anymore, and I tend not to engage in needless drama (my own or others’).

MSK’s Resources for Life After Cancer offers a twice-yearly support group on dating and disclosure. Whether you are male or female, older or younger, outgoing or shy, sharing your cancer experience can present a challenge. When, how, and whether to disclose your history is the focus of this educational group workshop. You must register to attend. To register and for more information, please call 646-888-8106 or email rlac@mskcc.org.



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“For some, our singing together has offered a break from life’s difficulties, and that in itself has been worthwhile for them,” describes Mrs. Ribaud. “One of our singers said that singing with Rising Voices has also created a much-needed boost to move on from a stubborn place in her life. Simply by starting to sing with us, she soon started taking voice

lessons, looking up music that really spoke to her, and going to concerts and music workshops. I’d like to think Rising Voices helped her begin looking toward her future.”

For more information and to join Rising Voices, please call the Integrative Medicine Service at 646-888-0800.

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Straight singing was easier: no props needed, and a callback to the days of my childhood, when teachers insisted everyone do some warbling. So last September I was excited to join Rising Voices, Memorial Sloan Kettering’s cancer survivors’ chorus, which I’d first learned about while attending an MSK support group.

It’s a typical session, and chorus founder Sue Ribaud is teasing the group. “We haven’t spoken Zulu all night,” she says, referring to the fact that she’s taught us a few African songs, like one of my favorites, “Woyaya,” which chronicles a walk that “will be muddy and rough/But we’ll get there/Heaven knows how we will get there/But we know we will.”

We balance new songs with many more familiar ones — rock classics

like “Stand by Me” and standards like “Danny Boy.” They’re all tunes that “people can learn to sing really quickly,” and are upbeat and soothing, according to Sue.

There’s no pressure to sound perfect, though we’re usually challenged to sing at least one song as a round. And sometimes Sue will ask, “Do you want to try the higher or lower part here?”

I always say no. Though I do have a low voice, I choose to avoid what’s usually the alto’s fate: having to sing the harmony. That’s especially jarring on a familiar tune. Who wants to sing what feels like “I’m dreaming of an off-white Christmas”?

We’re not practicing for a performance, however, but singing “as a celebration of survival,” as another chorus member

Rising Voices

is a fun and lively singing group just for patients and survivors. Open to all MSK patients, Rising Voices is a free, supportive activity sponsored by the Integrative Medicine Service.

To join, please contact Anjoli Mammen at mammena@mskcc.org or call 646-888-0800.

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.

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

points out. “We are not trained voices; we are earnest seekers of celebration via the music.”

Belting out the melody, strong and true — especially on familiar songs like “Over the Rainbow” and Christmas carols in season (though Sue is careful to specify that, sorry, she draws the line at “Rudolph the Red-Nosed Reindeer”) — helps me relax and focus on what’s happening now: I’m feeling good and healthy.

The group is bound together not just by a common medical condition, but by the much-happier fellowship of music-making. Sometimes a member will come in late because she’s just finished chemotherapy. Most of us know exactly where she’s been, and what that’s like. But we just smile at her and make room in the circle.

I'm Leaving in the Woods; I'm Taking From the Woods

By Audrey Weiss Degutz

I'm leaving in the woods *all my fears*, because the woods can accept my fears
and love my fears

I'm leaving in the woods all my doubts, because the woods can accept my
doubts with open arms, and love my doubts, and hold my doubts

I'm leaving in the woods all my regrets, because the woods can hold my
regrets and love my regrets

I'm leaving in the woods all my pain, because the woods can hold my pain,
every bit of my pain, and love my pain

I'm taking from the woods *my gentle spirit*

I'm taking from the woods *patience*

I'm taking from the woods *beauty*

I'm taking from the woods *grace*

I'm taking from the woods *miracles*

I'm taking from the woods *wisdom*

I'm taking from the woods *acceptance*

I'm taking from the woods *sustenance*

I'm taking from the woods *health*

I'm taking from the woods working together in harmony with everyone
and *everything*

I'm taking from the woods *grandeur*

Thank you.



Audrey Weiss Degutz is an occupational therapist who works with children who have special needs. She lives with her husband, Alan, and two teenage daughters and enjoys playing her clarinet and guitar for children and the elderly. Audrey finds peace, joy, and renewal being in nature. She has been treated for ovarian cancer.

Audrey wrote this poem just before leaving the woods, after a three-day hike on the Appalachian Trail in Connecticut in June 2015.

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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.

Patient and Caregiver Volunteer Program

The Patient and Caregiver Volunteer Program connects current patients and caregivers to volunteers who have experienced a similar diagnosis or circumstance related to cancer. If you are a former patient or caregiver of someone who has completed treatment, please consider becoming a Patient or Caregiver Volunteer.

For more information, contact
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