



Breaking the Code of Silence

By Duane Bailey-Castro

A three-time survivor of Hodgkin's lymphoma who has received both autologous and allogeneic stem cell transplants, he blogs about his cancer experience and his thoughts about life at The Journal of a Prizefighter: www.thejournalofaprizefighter.com.

A cancer diagnosis causes great anxiety and fear; and it can create a terrifying sense of helplessness and loneliness. When confronted with such frightening news, it is no surprise that many people prefer to remain silent, keeping the news of their illness limited to their immediate family and perhaps a few trusted friends. The fear of what their diagnosis may mean is too difficult to bear, let alone share with anyone else who is beyond that small and immediate circle.

What I have just described may be but all too familiar to many cancer survivors. Indeed, this was true for me. In the fall of 2003, I went to my general practitioner for a routine checkup after having just returned home from one of the most enjoyable experiences of my life: spending the first year after my college graduation studying and traveling throughout the Mediterranean and the Middle East. To my surprise and to that of my family, this seemingly ordinary checkup turned out to be far from

that. What ensued was a series of consultations, tests, scans, and a biopsy that led eventually to a diagnosis of stage 2A Hodgkin's lymphoma at age 23.

With few exceptions, my parents and I did not tell others about my illness. We had adopted a code of silence. Like any proud, loving parents, mine were devastated by my diagnosis. They had such a difficult time coming to terms with it themselves that it hurt them too much to share. It

was far easier, far less painful to say nothing, and so that's what we did.

I remained silent about my illness for almost two years until the lymphoma returned. A routine PET-CT scan followed by a biopsy had shown that the cancer was back. This time an autologous stem cell transplant was recommended. With no idea what this was, I read a number of guides and booklets, and I surfed the Web, where I found more information

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Memorial Sloan-Kettering
Cancer Center

Welcome to *Bridges*

For the past 30 years, I have found my own path through two cancer diagnoses and helped very close family members and friends navigate the maze of choices and treatment related to cancer treatment. I decided it was time to give back to the World of Cancer after having been fortunate enough to have received the best medical care from coast to coast and locations in between. When considering what type of volunteer work to take on in addition to my regular day job, I reflected on my own cancer experience.

When I was diagnosed with Hodgkin's lymphoma at the ripe age of 21, I fell into the gray area that is neither pediatric nor adult cancer. For a long time, I did not have an

outlet to be able to express what it was like to go through cancer at a young age. When I was able to find a magazine article or saw news reports of others who had been down the same road, I knew I was not alone and found some solace in that shared experience. Life continued on, and at age 42, I received a second cancer diagnosis — breast cancer. By then, there were more ways for people to share their experiences, but I think more can be done.

While medical advances are helping reduce the late effects of cancer treatment, the psychological repercussions of surviving cancer can still be daunting for patients and their families. As my way of giving back, I envisioned a newsletter for cancer patients, survivors, and their families



Eileen F. Gould, Patient Editor

at Memorial Sloan-Kettering Cancer Center to provide an additional source of support and a way to share stories of inspiration, hope, and challenges. Through *Bridges*, my hope is to encourage others to write about topics related to their illness and their journeys.

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

Editorial



Survivors Share: *Quotes, mottos, and mantras used for strength during treatment*

Recently, I think my motto has been “keep moving forward” from the movie *Meet the Robinsons*. I guess only people with kids might be aware of it, but it definitely works for me and the little z's.

— Heather Z.

“It is what it is” and “It's all good” were mine. Because no matter what life hands you, you deal with it and move on. Complaining or worrying will not change anything and will just add to the problem.

— Maureen

Our motto was “One day at a time.”

— Adrienne

There are many written quotes, words, etc., that have given me great strength, but none so effective as the words that have come from my own loved ones.

Sometimes the words are simple — a certain sentence “strikes,” and it sticks because WHO the person is who said it and WHAT that person means to me.

— Diane

My motto was “It's not always what we accomplish in life that matters, it's also the things we overcome.”

— Mary Beth Alpina

While it might not sound particularly uplifting, my personal motto during treatment was “It is what it is.” It helped me to try to stay in the present. To not worry about what might be around the bend because it is what it is and worrying isn't going to change that. I also like the Eleanor Roosevelt quote “You gain strength, courage, and confidence by every experience in which you really stop to look fear in the face. You are able to say to yourself, ‘I have lived through this horror. I can take the next thing that comes along.’ You must do the thing you think you cannot do.”

— Nancy



Ask the Professional: Spotlight on Integrative Medicine

Many cancer survivors are interested in the role of complementary therapies after cancer treatment. Gary Deng, MD, PhD, helps patients understand how such therapies may help manage symptoms related to cancer or its treatment.

Q Which of the therapies offered by MSKCC's Integrative Medicine Service could be beneficial to patients who have recently finished cancer treatment? How do these therapies help?

A Integrative medicine is the incorporation of complementary therapies derived from ancient healing arts into mainstream medical care. These therapies help patients manage stress, reduce symptoms, improve quality of life, and promote a sense of wellness.

For patients who have recently finished cancer treatment, complementary therapies can help them recover from treatment side effects and deal with the anxiety about cancer recurrence. For example, certain chemo drugs cause numbing and tingling of the finger tips and toe tips (called peripheral neuropathy). Our clinical experience shows that acupuncture may help reduce these symptoms in some patients.

After initial treatment for cancer, patients often worry about recurrence, especially right before those every three- (or six-) month follow-ups. Here is when some of the mind-body therapies can be helpful. Meditation, mindfulness techniques, or guided-imagery practices are aimed at developing one's ability to achieve

and maintain inner calmness when confronted with adversity. When practiced regularly, they help people deal with the anxiety, fear, or even the dread of having to face the unknowns.

Q Can long-term cancer survivors who completed treatment many years ago benefit from therapies offered by the Integrative Medicine Service?

A Integrative medicine is especially beneficial to long-term cancer survivors. The diagnosis of cancer may serve as a reminder to some patients about the importance of taking good care of our bodies. Integrative medicine can empower patients to become proactive and engaged in a healthy lifestyle. A proper diet, regular exercise, and stress management not only help prevent diseases, they can also contribute to one's sense of well-being, and to a more fulfilling life.

Some long-term cancer survivors are interested in the use of dietary supplements to help them maintain health. However, the use of certain dietary supplements or herbs can be risky for cancer survivors. For example, supplements promoted to treat menopause symptoms often contain estrogen-like activity derived from plant products (phytoestrogens). Breast cancer patients should not use them. Other supplements may interact with

medications such as blood thinners. We guide patients to avoid risky supplements while making use of those supplements that are safe and potentially beneficial.

Another long-term problem seen in some cancer survivors is post-chemotherapy fatigue. These individuals report having never fully regained the energy level they had prior to treatment. We have conducted a small clinical study showing that acupuncture can reduce this problem, and we are now conducting a larger study to verify those findings. We are actively recruiting patients for the study, so this is something to consider if you have post-chemotherapy fatigue. Patients will receive free acupuncture treatments as part of the study.

For more information about or to make an appointment for the fee-for-service therapies offered by MSKCC's Integrative Medicine Service:

In Manhattan

The Bendheim Integrative
Medicine Center
1429 First Avenue (at 74th Street)
Phone: 212-639-4700

In New Jersey

136 Mountain View Boulevard
Basking Ridge, New Jersey 07920
Phone: 908-542-3000

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about stem cell transplantation (“SCT”), but I still found myself searching for more. Like most people who are newly diagnosed, I was eager to learn about the personal experiences of those who had gone down the road on which I was about to embark. *How did they do? How did they feel during and after the transplant? How did this intense treatment affect their quality of life? And most importantly, Did anyone die?* I had read enough of the medical literature and its jargon. I wanted to hear survivors’ stories. The rest, as they say, is history.

I turned to the Internet – that seemingly boundless universe – for some meaningful human perspective. As I combed search engines for the stories of survivors of Hodgkin’s lymphoma who had been through stem cell transplantation, I came across dozens of personal blogs and Web sites. I was amazed and encouraged. Though I had not yet had the opportunity to talk to an SCT survivor in person, there before me via this amazing virtual world were the stories of people not very different from my own.

I knew that my many questions, hesitations, and fears were in fact by no means unique. I was not alone.



In June 2007, Duane and his family celebrated his graduation from The University of Chicago, where he received a master’s degree, which he accomplished while receiving three months of chemotherapy.

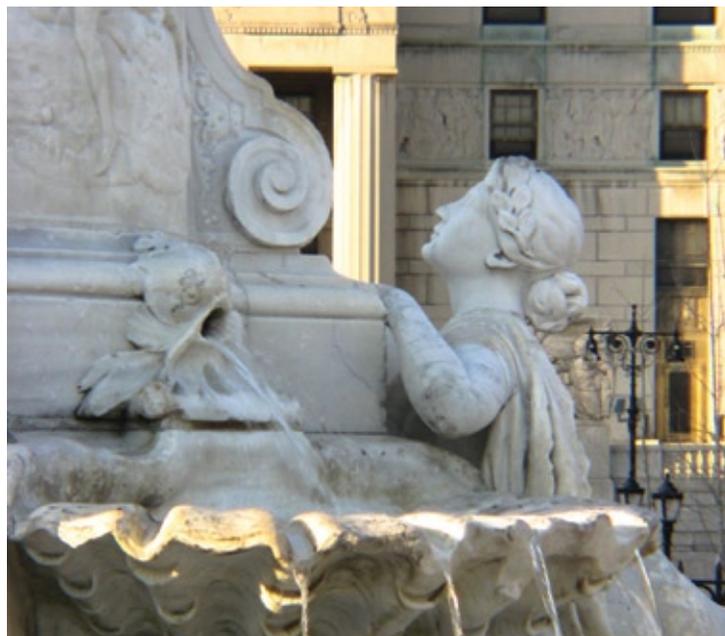
A small number of the brave stories that I read ended tragically, thus helping to put a real human face on the seriousness of what I was about to undertake. After initial success, some survivors found that their disease had returned, and so their battle continued. However, the majority of the stories that I found online ended positively, and therefore, gave me the boost of confidence that I needed so desperately moving forward. It was due in large part to the courage and humility of these SCT survivors (regardless of the outcome of their treatment), who wanted to share their experiences candidly with family, friends, and strangers alike, that I was spurred to break my own silence.

Remarkably, when it would have been so easy for these cancer survivors to retreat under the terrifying weight of their own diagnosis, they chose to do the extraordinary instead. In trying to make some sense of what they were feeling, they looked outward beyond their own immediate concerns helping to humanize the SCT

experience and in the process (whether they expected to or not) educated and inspired so many others. Encouraged by the personal stories of these cancer survivors, in October 2005 as I began intense chemotherapy treatments in preparation for the upcoming autologous stem cell transplant, I created my own blog and have kept it going ever since. It is thanks to these selfless SCT survivors that I began to learn that silence, though safe and easy, carries a price of its own. My parents and I

didn’t understand this in the beginning. Tension, anger, and depression are some of the usual consequences of such insularity. Being able to talk openly about one’s experiences can be healing.

I don’t believe that every cancer survivor must have his innermost thoughts splattered across cyberspace. But whatever the means of communication – a blog, a journal, a support group, sessions with a therapist – self-expression and openness about one’s feelings can make a world of positive difference. When these remarkable SCT survivors decided to share their stories, perhaps they had the spirited words of the enthusiastic Hector from the film *The History Boys* in mind: “Pass the parcel. That’s sometimes all you can do. Take it, feel it and pass it on. Not for me, not for you, but for someone, somewhere, one day. Pass it on, boys. That’s the game I want you to learn. Pass it on.”



Duane picked up photography as a hobby after his allogeneic stem cell transplant. Shown here: A photo he took of the Lorelei Fountain in Joyce Kilmer Park, New York City.

Sharing More Than Blood

By Laura



Hospitalized at 13, my cousin Valérie grew up in and out of the cancer center in Lyon, France, during the 1980s. I had only sporadic contact with her as she remained in isolation due to her low white blood count. In her will, Valérie bequeathed an anthology of poems later published. I surreptitiously “borrowed” the book from my parents — I was a mischievous child — and stored it away in my library. My cousin’s written words allowed me to commemorate her, but otherwise held little significance.

When I was diagnosed with non-Hodgkin’s lymphoma in 2005 at age 22, the hematology ward struck deep within buried memories. I had to be reminded that with an additional 20 years of blood cancer research, my fate was not tied to that of my cousin’s, who had passed away from leukemia during my childhood.

I felt an unrelenting wave of nausea — pre-chemo — when asked for the hundredth time about my family’s history of cancer. “What kind of leukemia did your cousin have?” I never knew. Was it so hard to believe that to my younger self Valérie had been a person first, before a medical condition? I was unnerved that my cousin’s “medical history” defined her again, this time in relationship to mine, and that we both belonged to patient XYZ file. Fighting back the tears, I focused on the physical assault of my treatments.

I have often been asked whether lymphoma is a “genetic” disease. Whatever the answer, it is a burdensome question to bear in your 20s. I felt very overwhelmed post-treatment with a flow of feelings that troubled me incessantly. Over time and with patience (not my strongest suit) I found gradual solace through MSKCC’s post-treatment programs. I am lucky not only to have had access to wonderful cancer survivor networks, but also to a cousin who left behind countless words of wisdom.

I share one of my cousin’s poems hopeful that it can bring to other survivors, as it has to me, a sense of perspective. Twenty years ago, Lance Armstrong had yet to prove that there were cancer comebacks; survivorship programs and the Internet did not exist. My cousin, as a young cancer patient, felt very isolated, left solely to her diary writing. She simply wished that her life would and could improve with time:

Le temps

J’espère bien qu’avec le temps
Je pourrai enfin oublier,
J’espère bien qu’avec le temps
Je pourrai enfin exister.
J’aimerais me sentir normal
Je voudrais ne plus avoir mal,
J’aimerais bien que l’on oublie
Pour une fois ma maladie.
Que l’on m’écoute quand je parle
Que l’on m’écoute quand je dis:
En ce jour-même je suis guérie,
En ce jour-même j’aime la vie
J’aimerais bien qu’avec le temps
A tout jamais s’en aille la peur
Que je trimalle au fond du coeur
Comme une grosse peine, un lourd malheur.
J’aimerais bien qu’avec le temps
Je puisse enfin tout oublier.
J’aimerais bien qu’avec le temps
La peur fasse place à la gaieté.

Time

I do hope that with time
I will finally forget,
I do hope that with time
I shall finally exist.
I wish to feel normal
I wish to no longer feel pain,
I wish for people to forget
For once my disease.
For people to listen when I speak
For people to listen when I say:
From this day on I am cured,
From this day on I love life
I do hope that with time
Forever the fear will disappear
That I carry at the bottom of my heart
As a great sorrow, a heavy burden.
I do hope that with time
I can finally forget.
I do hope that with time
Fear will be replaced with gaiety.

Time never came for my cousin; she died at 20. But with the passing of “time,” many of her private hopes have been granted to me and many other survivors. I cannot imagine a greater tribute to Valérie than to have her poem read and feelings shared with so many other survivors, families, friends, and hospital staff. To me that process is at the core of survivorship.



Laura, Valérie, and Laura’s sister.

Surviving *the* Cure

By Robert J. Dwyer



How bad can it be? That's what I asked myself as I entered the men's locker room to put on a gown for my first of 30 radiation treatments.

After all, my modified neck resection had gone swimmingly (once they removed the Frankenstein monster stitches that ran from my left ear to my Adam's apple). I had benefited greatly from sleep and two weeks off from work and even liked the hospital food! But as I was removing my shirt (carefully, to avoid dislodging my feeding tube), a patient — just back from his treatment — staggered into the locker room and muttered, "I'll kill them if they put me through that one more time." Suddenly I understood that this noninvasive treatment wasn't going to be a piece of cake. How was I going to get through it?

I returned, as I always do, to the three basic questions of life: Who am I? What do I want to be? What does it take to get there? The first two were easy: I am a 57-year-old patient with head and neck cancer (squamous cell carcinoma, with unknown primary) who recently had 42 lymph nodes and associated lymphatic vessels removed from my neck. I wanted

to be cured so that I could have many more years with my family, my friends, and my work. The third was the hard one: How could MSKCC's doctors and staff cure me if I couldn't stand to continue the treatment?

The first two weeks weren't so bad after all. It was disconcerting to be the Patrick McGoochan character in the British TV show *The Prisoner* — strapped virtually naked to a cold table, unable to see or talk, barely able to breathe, alone except for the occasional disembodied voice piped in from outside, the background music, and the sounds of "Creaky," my treatment machine. Creaky's sounds helped me track the progression of my daily treatments — creaks in my right ear meant I was almost done. The only time I threatened not to return was the day I was tortured with Diana Ross music.

But after that it was all downhill. I woke up tired every day and had to take a 3:00 p.m. nap at work before my 5:00 p.m. treatments. I couldn't eat much; my nutrients mostly came

through the feeding tube that my doctors had insisted on (ignoring my protests that I was mentally tough enough to take anything). The bright side — some well-needed weight loss and a "healthy" glow from the radiation — wasn't enough to overcome the desire not to return.

But return I did every day for the remaining four weeks. How? I had figured out three things in my first two weeks:

- **First**, I had to maintain a positive attitude. If I could smile and say hello every day when I checked in, and say thank you to the radiation therapists every day after treatment, I was way ahead of the game. Those simple expressions of gratitude were symbolically important: I was there to be helped, they were there to help me, and I had to acknowledge that.
- **Second**, I had to understand my good fortune. As a New Yorker in the early 21st century, I had the best modern medicine available to me. I was at MSKCC,

and my treating oncologist and radiologist were talented doctors who communicated well and were very personable. I was determined to take advantage of the treatment that others in different times or places did not have available.

- **Finally**, I remembered a trick of my youth when running miles daily for conditioning — it only hurt if you thought about what you were doing. MSKCC needed to treat my body, but my mind didn't have to be there. So every day, while strapped to that bench, I took my mind somewhere else, to happier times and places from the past. I replayed the 1968 Amherst-Williams soccer game, returned to my Hawaiian honeymoon, won a lot of arguments in court, and had nothing but good times. I was able to zone out so successfully that often I did not know that my treatment had ended until I was being unstrapped.

That worked for me. I did all six weeks of radiation and six days of chemo, and I keep returning regularly for all the necessary post-treatment poking, prodding, and sticking. If you face up to something like this in your treatment, try what I did — it can't hurt. And send me a postcard from your visits to the happy times in your past.

Ask an Expert

In this section, cancer survivors answer questions about survivorship.



Our first question is answered by young adult survivor Brian Wickman. Brian was diagnosed with two cancers in 2006: an extraskeletal myxoid chondrosarcoma of the ankle and a papillary carcinoma in his thyroid. After receiving surgery and chemotherapy for both, he is currently in remission. Brian is a participant and volunteer with First Descents, an outdoor adventure program for young adults with cancer (www.firstdescents.org). He lives and works in New York City.

Q I know my loved ones mean well, but sometimes they just do or say absolutely the wrong thing. Why does it make me so angry?

A In my experience, the issue here is one of misplaced expectations. It's important to consider each individual in your support network and to have realistic expectations about the kinds of support you can expect from her or him. For instance, I don't expect my parents to understand every detail of my medical treatment; when I have medical questions, I consult a doctor or nurse. Similarly, it is unfair for me to expect that someone who hasn't experienced cancer will understand (and respond "correctly" to) my

emotional reactions during and after treatment. When I need to talk to someone who understands completely, I turn to a friend from my cancer patient support group. I can always count on my family for unconditional love, but I realize that their ways of showing this may not always be the ways I want to receive it. By clearly identifying what types of support I can expect from a given individual and, furthermore, by asking for what I need from the appropriate person or group, I tend to encounter less frustration. Sometimes this means saying to my loved ones, "I know you are trying to help, but this isn't helping me right now. Instead, I would be so grateful if you could do X for me." In this way, they will have a better idea of what you need and expect, and you will be able to seek help from a more appropriate source.

Web Site Review



The mission of Beyond the Cure is to help childhood cancer survivors integrate the cancer experience into their new life as survivors and successfully handle the challenges that are ahead of them and to celebrate survivorship.

In addition, Beyond the Cure hosts free teleconferences on a variety of issues and concerns relevant to survivors who have completed treatment for childhood cancer. For example, this past April participants had the opportunity to listen to representatives from the Patient Advocate Foundation present information about recognizing and solving potential challenges that survivors of childhood cancer may face when making the transition to their own health insurance. Beyond the Cure is truly an excellent resource for childhood cancer survivors and their families.

Beyond the Cure is a program of the National Children's Cancer Society (NCCS). NCCS is a nonprofit, tax-exempt organization based in St. Louis that is dedicated to improving the quality of life for children with cancer and their families.

The Beyond the Cure Web site, www.beyondthecure.org, offers many resources for patients and their families, which include: an active message board, a list of scholarships for survivors, links to survivorship clinics across the country, and the option to sign up for biweekly e-mail updates on relevant survivorship news.

STAY TUNED

Next issue survivors will share "The Book That Got Me Through."

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.

Patient Editor
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Duane Bailey-Castro

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If you are interested in submitting your story or have a question for the experts and professionals, please e-mail bridges@mskcc.org or call 212-639-3947.

We are grateful for the support of our patients and family members. If you have undergone treatment for cancer at Memorial or are a family member of someone who has, and would like to be involved in volunteer efforts at Memorial Sloan-Kettering Cancer Center, please consider becoming a Patient/Family Advisor.

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



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