

# Virtual Mentor

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## Medical humanities

### Surviving (and thriving with) cancer

An interview with Brian Ciccotelli

Brian Ciccotelli was a typical high school senior. He was on the soccer team and a part-time manager of the volleyball team; he went out with friends and had a girlfriend. But his life took a turn when he was diagnosed with early-stage Hodgkin's disease on December 23, 1998. Brian was treated at Yale-New Haven Hospital with a combination of chemotherapy and radiation that lasted for more than six months. Despite his illness, he was able to graduate from Jonathan Law High School in Milford, Connecticut, with the rest of his class in June 1999 and go on a religious mission to California in early 2000. Brian has been in remission for seven years and has shown no signs of relapse.

Recognizing that his is an exceptional story—few indeed recall their experiences with cancer in such a positive light—*Virtual Mentor* sat down with Brian in December 2006 to find out more about his life as a young cancer patient and now as a cancer survivor. Brian kept a journal throughout his time in the cancer clinic and shared some of his stories and views with us.

#### **Q. How did keeping a cancer journal affect your treatment?**

**A.** It didn't. The journal was really just a daily record of what I was doing. I never wrote any deep feelings or secrets in the book. I never vented. I wasn't worried about my disease; I never feared I would die. The book was a way to remember all the things I was able to do with cancer as my excuse. I kept track of how many days I missed school (81) and yet still graduated on time. I also wrote about all the great people I met in the cancer clinic, including doctors, nurses, other kids and the clowns. It wasn't a journal to keep track of eating habits, exercise, pills or anything else to do with my health. Those things periodically made it into the journal, but it was always in passing. For example, "The doctor told me I'm not allowed to eat anything with preservatives, but when I got out of the hospital, I was craving a 99-cent double cheeseburger, so I shot over to McDonald's and got one. With fries. And if he thinks I'm giving up Hawaiian Punch, he can think again." My blatant disregard for doctors' orders was well documented.

I didn't try to hide that I wasn't obeying the doctors. They would reprimand me, saying, "You have to do this-and-this or your health isn't going to improve," or, "It's going to affect your treatment." In the beginning, I listened to almost everything. After the first time they gave me chemo and none of the bad side effects they predicted came about, I only halfway paid attention to them. I figured, even if

something bad happened because I ate a box of Oreos, it wouldn't be as bad as what was supposed to be happening. Cancer interrupted my life; I tried hard not to let it interrupt my lifestyle. I decided to eat and drink and do what I wanted to and accept the consequences. Luckily, the consequences were minimal.

My mother and my grandmother were somewhat supportive of my decision not to follow the doctors' orders. They made sure that I knew the doctor said I couldn't do certain things, but I told them that I didn't care. At first they worried, but when I had no adverse reactions they were cool with it. They said, "It's your health, your body; if you wanna do it, then you do it."

**Q. What was the cancer clinic like?**

**A.** I was older than most of the other kids on the floor because I had just turned 18, but the doctor decided that I should be with them. And it's a good thing; when all my treatments were done and I was in another part of the country and went for follow-ups every six months, I had to be with the adults. And when you walk into the adult ward it feels like you're walking into death. The adults have known so many people who have died from cancer and the atmosphere there is like, "I'm just waiting to die now." But the kids were so alive. The hospital tries to make the children's cancer clinic as much fun as possible. And it makes sense. Since attitude is such a large part of recovery, they try to make your treatments as enjoyable as possible. I had so much fun there. I brought my guitar once; we watched movies; we played games; I met *lots* of people. It was always fun to meet the new kids, scared as can be on their first day, and see the transformation as they began to meet and talk and laugh with others who had the same disease. By the end of the four-hour treatment, they knew everyone in the room and they were having a good time. I wrote about those experiences and kids in the journal, and I love re-reading those stories.

The sad thing is that all of the friends I kept in touch with—all of the people I was friends with—have died. Friends who were so full of life and so much fun to talk to. All of my memories were of the times we were together, when we were having fun. I never had any memories of them suffering at all. So when they died, it was like they were in a car accident. I didn't see it coming at all. Every one of them relapsed; there was a complication or they couldn't get a bone marrow transplant in time; none of them survived. And because we were all in such high spirits when we were at the clinic, I didn't see it coming. I just figured all of us would survive. When they didn't, I took it hard.

**Q. Were you ever scared during the course of your illness?**

**A.** No. Not at any point in my treatment, from the day my friend Tiffany told me I should get the lumps on my shoulder checked to the last day of radiation therapy, was I ever scared. I figured the side effects were inevitable so I just accepted it. I took the attitude that I'd deal with them when they came, but they never did. All of the doctors told me, "This is what's going to happen," and I figured, that was what was going to happen. The doctors, usually four or five of them, told me *everything* to expect. Before I had my biopsy, after my biopsy and before the results, they told me

all of the possibilities. “It *could* be an infection and this is what we do if it’s an infection; it *could* be Hodgkin’s and this is what we do if it’s Hodgkin’s. This is how long it will take and this is what you will have to go through.” And because they went over every single option so clearly before I was diagnosed, when I was going into treatment I knew *exactly* what I was getting into. I was extremely happy that the doctors had told me so much because I knew all of the bad things to expect and I was mentally ready for them. I firmly believed that everything happened for a reason, and I knew that whatever I had to go through, I would learn from it, grow and be a better person because of it. But when none of the side effects happened, it made me feel that much more lucky and that much more blessed. Because everyday I was feeling fine, I knew that I should be throwing up; I should be fatigued; I should be having night sweats; I should be losing weight and losing my hair. Because I knew what *should* have happened, I was able to appreciate my health so much more.

**Q. What made the experience more manageable?**

**A.** Nothing I did made my treatment or recovery more manageable. That fell squarely on my grandmother’s shoulders. I owe my miracle health story to her. She kept me alive and well. If anything, I only hindered my recovery through constant consumption of junk food and doing my best to ignore any part of the doctors’ advice that I didn’t particularly like. My grandmother’s ability to keep me healthy astounds me to this day. She learned about chemotherapy and all of the destruction it was supposed to do to my system (in addition to clearing out the cancer). She also gave me vitamins, other pills (about 25 a day) and food from the health store. I told my doctors that I was taking stuff that my grandma had gotten, but it was never anything that they explicitly recommended. Sometimes the doctors disagreed with what I was taking, but after a while they were okay with everything, especially when they saw that I, a cancer patient, was healthier than they were during flu season. I had to laugh when they came in sniffing and I was clear as a bell. They jokingly asked if my grandma could fix up something for them to take, too.

Anything I needed to do or any treatments I needed my mom *always* came with me. As far as socializing goes, after the first week my friends saw that I wasn’t sickly and they would all come over and hang out. Nobody seemed to avoid me—they were all supportive. The only reaction I didn’t like was when I first got diagnosed and had to go around telling people that I had cancer. I was just kind of *informing* them—I wasn’t telling people I was going to die—which is how a lot of people took it. I knew I was going to be fine; it never occurred to me that I might die from this. Since I was diagnosed on December 23rd, I ended up *killing* two Christmas parties, which I hated doing, because I try to be the life of the party. I didn’t really like the sympathy either—unless it was giving me free stuff.

**Q. Did you have a favorite doctor? Did you develop a relationship with any of the doctors or nurses?**

**A.** Six years later I remember two people. First and foremost is Rachel, the doctor who took care of me the most. Being my doctor she wanted to make me feel better, but she made me feel loved. She was so happy to see me every week, and she always

wanted to hear what I'd been up to. She knew everything. She knew about all of the junk food I ate, the basketball incident—when I came in with a new wound less than an inch away from my porto-cath because I had run into a stray piece of rebar—and the snowboarding escapades. She never told the other doctors (at least as far as I knew). She just made me promise to be more careful next time. She felt like a mom; she cared about me but she was still a friend that I could share secrets with.

The second person I remember is the nurse from recovery. I had surgery three times while I had cancer, and after each one they put me in a room to recover, and the same nurse would come and check up on me and bring me water. I remember her because she was so cute. After my first surgery, I was wearing an Old Navy shirt with a dog on it, and a few weeks later after my next operation, she brought me a little green stuffed dog. Of all the people that must go through there every day, somehow she remembered me and brought me something. That made me so happy, as cheesy as it sounds. I felt so special, and I've never forgotten her.

**Q. What was the rest of your life like at that time? Did your family treat you differently?**

**A.** Even though I wasn't in school, I was in the play and in the fashion show. I still went to track practice. The doctors were supportive of me running track as long as I didn't overdo it. Of course, I overdid it; I ran long distance after all. The only person who had a problem with me running track was the principal, because she said if I was healthy enough to run track I was healthy enough to go to school ... and I couldn't really get out of that one. But just before I went back to school in May I got a freak cold and the nurse told me to go home and finish my treatments. So I was able to stay out of school.

As far as my family, when I was diagnosed they were a little scared and worried, but they tried not to show it because they wanted to be supportive. Once they saw how well I was reacting to the treatment they were completely normal. Really, in my family it seemed like nothing out of the ordinary. It was never, "We have to do this because this could be Brian's last time." And I certainly didn't need any more attention.

**Q. To what degree is your life shaped by the fact you survived cancer? How much do you think about the experience? How has it changed your world view?**

**A.** My general outlook on life has always been optimistic, and I try to make the most out of every opportunity that comes my way. Having *had* Hodgkin's has allowed me to help other people deal with cancer in their lives. As far as being a "cancer survivor," most new people I meet are not aware that I had it. Telling people I had cancer usually evokes sympathy, and I don't deserve that at all. I got to make a wish through the Make-A-Wish Foundation and get treated like royalty—an all-expenses-paid trip to Orlando, no lines at Disney World, Universal Studios, or Sea World, free food at Hard Rock Cafe and any other place you can think of, and general celebrity status at any place I walked into. I was able to sail around Boston Harbor for four days, and explore uninhabited islands (Island of Hope, a weeklong escape for young

cancer survivors), and I got to skip class half my senior year, do less than half the work, still play with my friends and graduate on time. Most people think I'm joking when I say I had cancer, because I say it so easily, and I end up showing my battle wounds (the scars on my shoulder and chest from the surgeries).

As far as cancer reshaping my life or my thoughts, that hasn't really happened. I never gave cancer the respect it deserved. I treated cancer like a cold; I figured it would just go away on its own. I never, not for a moment, even considered the possibility that I might die. I was shocked when they told me I could make a wish: "I thought Make-A-Wish Foundation was only for kids that were dying." "Well, Brian, you did have cancer." "Yeah, but I wasn't *dying*," was my reply. Subconsciously, perhaps, cancer solidified my idea that life is short. I take advantage of every opportunity I come upon, and I try to make the most of each day. No matter what happens to me, I firmly believe that something good comes out of everything.

I have had a lot of experiences that have shaped me into who I am today. I backpacked around Europe, I served a two-year mission for my church, I spent a month in Cambodia and I just spent six months in Mexico. I include cancer as one of the great experiences of my life that afforded me many other new opportunities. I think about it often, only because I have daily reminders. Cancer is so widespread that it has affected almost everyone I know in one way or another, and I am able to encourage and give hope to many people who are so afraid.

My world view hasn't really changed. I've never been one for politics, but if there's a scientist out there who finds a cure for all cancer, I'll vote for him.

**Q. Have you changed your goals or aspirations since your diagnosis and survival?**

A. After I was in remission, someone told me about a list of goals they had made for their life. So I decided to make a list of "Things To Do before I Die." The list is four pages long, and I constantly add to it. It includes everything from "walk on the Great Wall of China" to "write a book somebody will actually read" to "learn conversational Italian." On average, I check off about three or four goals per year. This year I've checked off "go see the Mayan temples in Mexico" and "get scuba-certified." I want to visit all seven continents and every major city in the world. I'm happy to come to Chicago; this is another check on the list.

**Q. Has your respect for cancer increased given the death of your grandmother (2000) and mother (2006) from cancer?**

A. When I left Connecticut, my grandmother was completely healthy. I learned through letters that she was sick and had cancer and then that she had passed away. I wasn't there for any of it; I wasn't there to go through it with her. She wasn't in any pain; she was just tired and in bed all of the time. She didn't go through chemotherapy because the cancer was too far along.

My mom's experience was entirely different. The whole time I was talking to her—even up until the day before I flew home from Mexico to be with her—she kept saying, “Don't worry, don't come home, I'm going to be fine.” And because she kept saying that she was fine, I just backed her up on that and told her, “You're handling it like a champion.” She had to go through a *lot* more than me, and she had a lot of pain and suffering, but she handled it incredibly well. All of the doctors and family members in Connecticut were amazed. She had the same attitude I had. The doctors told her what was going to happen just like they did for me—and all of the nasty side effects actually happened for her—but she just accepted it, and said, “I'm going to take all of the treatments; I'm going to do what they tell me to do; I'm going to be done with it and get on with my life.” And the whole time, this is what she was telling me too. She would say, “It hurts, but it's just for a short time, and then it will all be over, and we'll just get on with life.”

Even though they both died from their cancer, my outlook on cancer hasn't changed. When I got diagnosed, I knew people who had died from the disease. I've just seen *more* people die from cancer. I've always known that cancer *can* kill you, but for me, that just wasn't a consideration. If I get it again in the future, I'm going to treat it the same way I did the first time.

**Q. What is your prognosis, seven years later?**

**A.** The doctors told me that once I finished radiation, I would be “in remission,” which would mean that they thought they got it all. If it hadn't come back after five years of being in remission, I would be cured, and the chances of me getting cancer again would be about the same as everybody else's. They gave me certain guidelines to follow during the five-year interim to decrease my chances of getting it again, but of course I didn't follow them. As far as I was concerned that cancer was gone long ago. I honestly felt like they had gotten rid of it all in the first four treatments of chemo, and the rest was just precautionary.

If by some random chance, I do get cancer again, I'll just go through chemo and be done with it. I'm sure I'll meet some more great people and have some more great experiences.

One week after the doctor told me to stay out of the sun (saying I had a higher risk of skin cancer, which runs in the family), I was at Six Flags all day without a shirt on. My mom called her sister asking, “Why doesn't he wear a shirt? Why doesn't he listen to the doctors?” My aunt replied, “Because he's not worried about getting cancer. He's back to normal.”

My five-year anniversary was just a good excuse to have a party.

**Q. Looking back, is there anything you would change?**

**A.** I would not change a single part of my experience.

*This interview was conducted by Allison Grady, Virtual Mentor editor.*

*Brian Ciccotelli is participating in an internship as the manager of a retail store in Aruba. Prior to that he was studying business management at Brigham Young University in Provo, Utah. He has traveled extensively in Europe, Southeast Asia and the United States. His future plans include becoming a professional photographer and authoring travel books.*

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