

Not on the First Date

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Surviving acute myeloid leukemia (AML) and undergoing bone marrow transplant as a 19-year-old isn't something most people do. In fact, it is something that only 50% of persons with my diagnosis and at my age do.¹ One of 2 people who go through what I went through do not survive, and that's a fact that weighed heavily on me. After almost 4 years of living through AML, my hair is much thinner, I weigh 60 lb less, and I have an entirely different perspective on life. But despite these changes, I found myself still struggling to acknowledge what it is that is truly different about me.

Yes, my body is different—it is more sensitive to sounds, tastes, and temperatures. But inside, at my core, I am still Jake. My character and sense of humor remain the same. My dreams of making a contribution to the world and my aspirations of becoming a physician are the same.

After finishing treatment, I initially felt uneasy leaving Moores Cancer Center and returning to college to pursue my bachelor's degree. I felt different from my peers; I lived with an undefined fear. What was I so afraid of? I had spoken effortlessly about my experiences in front of lecture halls filled with medical students. I had talked to groups of strangers before in efforts to raise awareness and money for opening more bone marrow donor pools. Yet, the transition from Moores Cancer Center back to school was like traveling through uncharted waters. Nobody tells you how to act or react, or how to carry yourself in the "real world" again; nobody tells you the buzzword answer for why you look different from your driver's license picture or your Facebook pictures.

I was struggling to adjust back into the real world and had no peers my age who understood my circumstances. Most of the other patients I met at Moores Cancer Center were 30 to 40 years my senior; a few were even older. I felt like an island. For young adults such as myself, being able to share experiences is beneficial. Perhaps the gap

I felt needed to be addressed with a network of young patients and social workers.

When I met people, it was hard for me to tell them that I am a cancer survivor or a bone marrow transplant recipient. Would they judge me? Would they pity me? Would they treat me as if I am crippled or incapable? These questions always ran through my mind. I wanted to be perceived as "normal."

The blood and lymph course director at Western University of Health Sciences, where I attend school, invited me to talk to his first-year osteopathic medical students during a lecture, as I had done for the past 3 years. However, now I was in the class, no longer just a guest; I knew the faces that would be staring at me. I initially declined, but I felt torn and conflicted. The night before the lecture I e-mailed him. If the opportunity to speak were still available, I would do it.

Sitting through almost 3 hours of lecture consisting of 4 patient case discussions before I would speak was nerve-racking. Although no one knew it but me, this was my big debut. After a hematologist finished discussing case 4—my case—the course director took the mic and reminded everyone that these cases all reference real patients. My heart was nearly pounding out of my chest with fear, each beat like a drum, and my hands were now dripping with sweat, for I knew what I had to do next.

"In all of the large group lectures, for any system, these are not just cases, but people, and I know case 4," he said. "Everyone in this room knows case 4," he paused. "It's Jake."

Shimmying through the tight seats to make my way down the stairs to the front of the lecture hall, I could feel my heart beginning to race again, not with fear now, but with excitement. A hush had fallen over the room. My classmates' faces showed shock and surprise. After 40 minutes of me sharing my story and some of the experiences I went through, I received a standing ovation. Here were 300 medical students on their feet, applauding me

for giving them insight into something so unique and personal. Dozens of my classmates came down afterward to give me hugs and shake my hand to thank me for sharing with them. It was a feeling I won't soon forget; I felt support and acceptance, but mostly relief. Nobody had judged me or treated me any differently. I was still the guy who wears a broad-brimmed hat and long sleeves outside when it's 95° in the scorching California sun, but now they knew why.

Here at a well-renown medical institution, self-awareness and understanding were furthered. About 3 months after I spoke to my class, I was honored to become the genetics summer scholar. I was introduced to a multitude of physicians, genetic counselors, dietitians, and ancillary staff. It wasn't until I met a wicked-sharp, middle-aged geneticist that I began to grasp what it was that haunted me. We spent a few hours together, talking about the patients she saw, but also about our personal lives. She asked as she was typing on the computer, "What type of doctor do you want to be?"

Without hesitation, my answer was, "A bone marrow transplant doctor."

She whipped her chair around, looked me square in the face. "Why? What is it about bone marrow? You are a first-year medical student—what do you know about bone marrow? I know there is more to this story, so tell me. Do you know someone who had a transplant?"

I froze, my face as hot as embers for what felt like an eternity. What do I say? What do I do? Finally, I thought, the heck with it, and pointed to myself. The most dumbfounded look appeared on her face.

"You?" she paused, clearly shocked. "You had a bone marrow transplant?"

"Yes," I nodded.

The next day, I met with my mentor, an excellent physician with striking white hair and darting blue eyes. She questioned me as to why I am hesitant to share that I am a cancer survivor. It wasn't until my mentor pressed the issue harder that it all began to click and I could finally answer.

"Well, it's not my typical icebreaker," I said with a grin hiding my pain.

She replied, "When I have genetics patients who ask me if they should tell people about their condition, I tell them not on the first date."

Not on the first date.

We delved deeper into my issue with sharing such personal medical history. She asked, "Why did your face turn red when I asked you that? What were you feeling during that time?"

With renewed clarity, I knew my answer. "Fear." That was it.

There was an immense fear in my stomach and an ache in my heart during those 10 seconds with the geneticist the day before. And I finally acknowledged why. It is the fear of judgment, pity, and being treated differently. I explained, "I am afraid to be vulnerable. I don't want people to look at me as less; I don't want to be treated differently, or to be given special treatment."

"Well, did she treat you differently after you told her?" she asked.

That was it. That was when it finally hit home. No. No she didn't, not at all, and no one else that I've confided in has treated me any differently either. I realized that I was running away from the risk of being coddled like I had been during my treatment. It has taken me almost 4 years to see that my concerns weren't warranted. I carried a burden that didn't exist.

We kept talking. "Why did I feel so segregated and isolated from everyone else?" I asked my mentor. People have chronic struggles and hurdles to jump over daily, but most have not lived their lives on the precipice of death as I once did.

"Everyone has something," she said. Although not everyone has had a bone marrow transplant, everyone has some story to tell. This is my story and, finally, I can tell it.

Over the next few days, I found myself being hyper-vigilant with the patients I met. A man with HIV neu-

ropathy and a woman with Pompe disease were incredibly inspiring to me. After spending time with both of these patients, I realized that they do not allow disease to define who they are. The patient with HIV is in constant pain and hasn't been able to "feel the grass under his feet" in 15 years, but that doesn't make him any less of a person. He has feelings, thoughts, and emotions just like I do. The patient with Pompe can't lift her grandkids, but she chooses to make the best of things. Her disease is merely 1 facet of her life and nothing more.

It took me 4 years to have this awakening and to realize that my disease is just part of my life. My patients will not be "the HIV patient" or "the Pompe

patient." I will know they are people with family and friends, with jobs and interests. It has been a bumpy road to travel, but the difficulties I endured and the lessons I've learned will serve me well on my journey as a future osteopathic physician. For those who walk along the path I once did, I hope someone enlightens them, too, with what it means to know, "not on the first date." (doi:10.7556/jaoa.2016.017)

Reference

1. U.S. patient survival report. US Blood Cell Transplant website. http://bloodcell.transplant.hrsa.gov/research/transplant_data/us_tx_data/survival_data/survival.aspx. Accessed July 29, 2015.

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