



Interview Transcript: Jennifer

Jennifer has a background in marketing and sales and is currently a partner at Sklar, Wilton and Associates. She is married and has two children.

Type of Cancer: Acute Myelogenous Leukemia

Age at Diagnosis: 38

Year of Diagnosis: 2003

Treatment: Chemotherapy and Bone Marrow Transplant

Date of Interview: June 2009

I'm Jennifer Smith. I am 43 years old and I'm a survivor from acute myelogenous leukemia. I've been a survivor for 5 years. I was diagnosed in the fall of 2003 so my journey then began. I went into the hospital for a month and did what's called an induction round and that's the first round of chemotherapy. I then went through 3 consolidation rounds, which are like mini versions of the same kind of chemotherapy, followed by bone marrow transplant in March of 2004. I was one of the lucky ones in that my brother—my younger brother Patrick—was a perfect match and his stem cells then grafted onto mine, and here I am today.

Coping

My strategy was definitely a daytoday one. My role was to get better and to do what I needed to do to do that. In some ways the treatment was very clear. There's one key way to treat the type of cancer that I had. That makes things easier in some ways because it's almost like you're getting into a little roller coaster car and you just have to stay in it and hold on and ride the thing.

When I was sick, the doctors told me that I couldn't even think about working at the same time. And they were right. My treatment really was 24/7, every single day. Altogether I spent 75 nights in the hospital in that 7month period. I did nothing but focus on getting better at that time and so by 11 months, I felt like I had my life back. I definitely felt like I could do most of the activities that I was doing before.

Sharing the News

I went from having a BlackBerry filled with appointments for work that were literally back to back to practically chucking that thing away and focusing on nothing but getting better. My life was to change so dramatically that I needed to make sure that people knew. It was important to me to tell people myself. I felt that if I was to tell them myself, face to face, and they could see that I'm OK with this, I can do this. And almost help them through it because I'd had my period of being shocked and of grieving through it. I needed them to have that with me so that they would also feel comfortable talking about it with me. Some people, when they hear somebody else has cancer, they don't know what to say to them so I wanted to help them

through that and make that an easier experience.

Talking to My Kids

We also found it really important to involve our kids in the whole thing. At the time—they were 5 and 7 at the time when I was diagnosed and we wanted them to be a part of the whole experience and part of the care. And so we told them about it, we sat them down; they were quite young. We said, “We have leukemia, I have leukemia, and here’s what to expect.” Mathew said, “Oh, I’m so glad to hear you don’t have cancer.” And that’s when I had to explain, “Actually, leukemia is a form of cancer. It’s a blood cancer,” and so on. And you can help them with what’s their role in the whole care. So we talked to them about their role: to help me to laugh, because laughing is so great for the immune system. And by doing that, we found out that they’re actually really funny. But after you speak with them about what to expect and that I would be away for a while in the hospital, they’d think about it. And then Matt said, “Is it going to be sunny tomorrow?” So kids do what they’re supposed to do and their world revolves around them. And so we found that being very open with them and keeping them involved was very helpful.

The Difficult Part

I think the thing that was harder than I anticipated—I was anticipating leukemia and I was anticipating fighting that disease; I wasn’t anticipating all of the things that go along with it. When you’re in chemotherapy for leukemia, because they’re taking your—they’re trying to kill your blood, basically—you have no neutrophils, so zero immune system. And so they tell you that you will get sick but they really mean it. You get severe fevers and reactions to everything. And that part is not very fun. And related to ‘no immune system’ there are other complications. I remember getting parvovirus, which then made it so I couldn’t even walk. I got a blood clot so I couldn’t walk again on my legs. So there were all these side effects that I remember saying, “Oh come on.” I can handle the leukemia but I’m sick of the fevers, the colds, the blood clots, all of these extra things that come with the package, having no immune system.

The Unexpected

There’s a lot of things that you don’t expect. I knew that losing hair would be hard and so in the end it was probably less hard than I thought it was going to be because I knew it was going to happen. Postbonemarrow transplant there are things that happen that you don’t expect. There was a drug I was taking called cyclosporine that actually made me have hair on my face. That was not something I would care to repeat. But one of the things I found is that if you actually waxed the hair on your face it hurt like anything but it worked and it didn’t come back. So I would focus on what I call ‘control the controllables.’ I can control that. I can control a wig. I can control makeup. The rest of it—don’t worry about it.

Be Your Own Advocate

If I’m talking to somebody who has been recently diagnosed or even somebody who just isn’t feeling well, I would say to them, “Listen to your body, don’t give up. Continue to chase it down. If something is not right, you are right.” And it’s because I did that I’m alive today. Because acute leukemia travels very quickly. Once I was diagnosed I was told I’d be transferred to the oncology department and have a hematologist see me the next day. And once I left the emergency department all of that stopped. And it turns out I was in an administrative queue somewhere and my appointment wasn’t going to be for 2 weeks. So you can sit back at home and wait those 2 weeks or you can continue to call, speak to people that you know in the

healthcare system, get that appointment. And, that's what I did and that's why I'm here today.

A Simple Thing

I think some advice I would have for anybody that's in the hospital for a long time is when they do have visitors come, have them come in 2s or 3s. That made a big difference for me because you could then be a part of a conversation rather than having to feel the pressure if you're really tired to hold up an entire end of it. And so you could discuss what's going on and have fun but in smaller groups. I found it tended to be a little more jovial and easier for everybody.

Bonus Time

There were many positive things that came out, for me, of this experience. To me, it's allowed me to even more understand the importance of family and friends and to live life every day. Life is a gift. I'm now on bonus time. I had the type of cancer that a lot of people don't make it from and don't survive. I did. So what can I do to not only live life and enjoy it every day but to give back and to help others and to make a difference?