

[TRACK 5: SURVIVOR STORIES: MAKING DECISIONS]

Sandra and Jean, Part I

[Sandra]

Like so many in my generation, we live far away from our real families. Our group of friends has become extended family members and so, when Jean needed help, we all pitched in. But, it seemed logical to me - and I guess to the rest of our circle of friends, that I should be the coordinator of our caregiving efforts, so to speak, because I am an oncology nurse and live near Jean.

[Jean]

I visited Sandra just before I was due for a follow-up appointment with my oncologist. I had been feeling really good. My job was settling down. My daughter, Erin, had become a lovely, busy, popular, and happy teenager.

[Jean]

[Pauses] My husband, Hal, and I had had some rough spots in our marriage before I was diagnosed, but we had been able to work things out. I'm so grateful for all of my friends, especially Sandra. She has been so helpful right from the time I was diagnosed. She helped me find a cancer doctor who I really like. Sandra was able to guide Hal and me in figuring out how to talk to our daughter about my cancer. And because she'd known my parents as long as she'd known me, Sandra was, and still is, a communication link between my family back in Nebraska and me.

[Narrator]

Sandra wanted to help Jean stay in touch with her family and friends during her treatment, so she helped her set up a webpage. Jean was able to post notes on it about how she was doing and also to get messages from her family and friends along the way. Also, Sandra set up a group of friends on the site to drive Jean to radiation therapy every day when she was too tired to drive and Hal was working. The Internet, actually made a big the difference for everyone.

[Narrator]

A list of websites that can be used to help keep your family and friends updated can be found in the Cancer Survival Toolbox Resource Booklet. Before you create a webpage, you may want to discuss with your family how much and what types of information you are comfortable sharing with others.

[Sandra]

To help someone who's been such a good friend... it means a lot to me to be able to help Jean. Well, when Hal called me with the news that Jean's cancer had come back, I was stunned, even though I had always known that this was a possibility. But, once we got over that first shock, I started work to "rally the troops" again. At this point, one of my major roles as a caregiver was to help Jean - and Hal too - gather information so they could make decisions about her treatment. Jean asked me to go to her next doctor's appointment with them so that I could be another set of ears. She knew that her state of mind might not let her take in all of the information she needed to hear from her doctor. Of course, I was glad to go with her - honored, really, to know that she trusts me that much. Jean, Hal, Erin, and I had a long talk, and they decided to wait until they

made a treatment decision before telling Jean's parents.

[Jean]

Yes, we knew that there were just so many important decisions that I - well, and Hal and Erin too - would need to make. I really thought then, and still think, that involving my mother and father at that stage of things would have just complicated our decision-making process. Plus, I just didn't want to have to worry about them then. I knew this news would upset them a lot.

[Sandra]

Looking back, it seems like that turned out to be the right decision. It seems like no matter how old we get, our parents will always be parents. At first, it was hard for Jean's parents to see any of us as adults - instead of the teenagers we were when we first became friends. But eventually, Jean's parents came to see, and even admire, I think, the mature way everyone pitched in to help their daughter. We all became sort of like teammates fighting to win - whatever way was best for Jean.

[Sandra]

I think the decisions that had to be made involved a lot more issues than Jean, Hal, or their families ever imagined. Of course, the first decision involved the kind of treatment Jean should have. Very early on, she was leaning toward being in a clinical trial, but Hal wasn't so sure. We spent many hours talking about the "pros" and "cons" - weighing the risks and benefits of all the treatment options Jean's doctors presented to us.

[Jean]

Well, almost every cancer survivor I've met says that, "once you have cancer, you are never the same" - and that sometimes, after cancer, they were stronger, better now, than before they had cancer. I think this is what happened to me. My cancer diagnosis reminded me in no uncertain terms that I'm not going to live forever. I had also decided that I wouldn't let the cancer rule my life. I knew that if I let things get me down, I'd run the risk of spoiling the time I do have.

[Jean]

But knowing that I am mortal - that someday I'll die - pushed me to get my affairs in order and make sure that my family would be okay. First of all, I updated my will. I had a lawyer help me complete what they call an Advance Directive. That's a legal form where I put down on paper what choices I would make if certain situations come up. The Advance Directive will make it possible for Hal and my doctors to follow my wishes even though I may not be able to speak for myself at the time that treatment decisions need to be made. Filling out this form helped us talk through all the complex issues of what I want to happen if my time to die comes sooner rather than later. Hal and I found an accountant to help us work out some financial issues, and ways to make sure that Erin can go to college, even if it's some sort of loan program. We asked a lawyer about viatical settlements - where I would sell my life insurance policy to a company to get my life insurance money now. This doesn't seem necessary at the moment, but we know the option of a viatical settlement is there if we want to consider it later on. Having all of these discussions behind me was a big relief and it let my family and me focus on getting through this. Being clear on what I really want helped my family, Sandra, and the rest of my caregivers by taking a lot of the uncertainty out of the future.

[Sandra] It was important for all of us who were helping Jean to know exactly what she wants. Now, no one has any doubts about what we should do and what we shouldn't do. It was important

to Jean to continue to be involved in her own care and in making decisions. That sort of control would always be important for her - and really, for all of us.