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The Shadow Survivors

BY JO CAVALLO

A childhood cancer diagnosis often makes well siblings feel like they're battling the disease too.

Like most high school seniors, Jasmine Brenneman was looking forward to prom, graduating and going off to college. But those plans suddenly seemed in doubt after her younger brother, Josh, now 6, was diagnosed with Ewing's sarcoma in 2004, and much of the responsibility for caring for her three younger sisters fell to her.

"I didn't know what it would mean for me personally and as time went on, it was a hard struggle because I had to finish high school, I was working part-time to get money for school and I was applying for college scholarships," says Jasmine, now 19. "And on top of all that, I had to be there for my younger sisters and take care of them. Sometimes I didn't feel that I did that great a job."

Jasmine admits she's angry at the sense of loss she feels, not just for herself but for Josh too. She lost her senior year in high school and Josh lost his innocence and childhood. "The main thing for me that's so hard is realizing that our lives will never go back to the way they were before. We know all the details of what having cancer means. It's changed us and that's a scary thought," says Jasmine, now a sophomore at Simpson University in California.



The Brenneman family (clockwise from top) Don, Jasmine, Joy, Josh, April, Jubilee, Jordyn and their dog Gladie, in front of Josh's House in the Trees--a 500-square foot tree house the community built for Josh after his diagnosis. Photo by Emily Andrews.

Jasmine is among a growing population of some 18,000 siblings of children diagnosed with cancer each year, according to a group dubbed SuperSibs! by founder Melanie Goldish. The organization raises awareness of the problems these siblings face and provides support services to them and their families. The idea to launch SuperSibs! came when Goldish began noticing behavioral changes in her 4-year-old son Spencer after her other son Travis was diagnosed with acute lymphoblastic leukemia in 1998 when he was 5 years old.

From her observations of Spencer, as well as other families she talked to, siblings of cancer patients can experience feelings of anger and guilt, and their social relationships may suffer. “What we hear many times from siblings is that although on the outside they look fine, on the inside they’re shattered because no one realizes they’re going through the diagnosis too,” says Goldish, who calls these siblings shadow survivors.

Researchers say how well young siblings cope in the aftermath of their brother’s or sister’s cancer diagnosis largely depends on the parents’ reaction to the illness and how well they communicate information about the child’s disease. Joanna H. Fanos, PhD, director of The Sibling Center at California Pacific Medical Center in San Francisco and author of *Sibling Loss*, says that the family typically mobilizes around the sick child. “When a lot of time is being spent on the sick child, and it’s not clear why, the dangerous thing that can happen is that the well siblings think they don’t count, that they’re not as lovable, and resentment builds up.” If the lines of communication stay open, says Dr. Fanos, the well siblings have a better understanding of what’s occurring and the experience isn’t as detrimental.

Larissa Labay, PsyD, a pediatric psychologist at Tomorrows Children’s Institute for Cancer and Blood Disorders at Hackensack University Medical Center in New Jersey, agrees that children who have a good understanding of their sibling’s illness and the challenges they face have been shown in the clinic to handle the family disruption better and can tolerate some of differential parental attention.

Well siblings getting the support they need can also be a predictor of fewer behavioral problems. A recent study in Canada reported that siblings who received more social support had fewer symptoms of depression and anxiety and fewer behavioral problems than siblings without that support. Dr. Labay conducted a separate study with children ages 7 to 16 that measured, among other things, the association between level of empathy and psychological adjustment among siblings. She found that while the level of behavioral problems among siblings with greater empathy didn’t differ significantly from the norm, there was a difference in terms of their social competence.

The reasons, according to Dr. Labay, vary. “A lot of times these kids are pulled out of school or it’s difficult for their families to take them to their activities like they used to. Also, when they are engaged in those activities they’re just not as successful because they may be worried about their brother or sister, or they’re

stressed because their parents haven't been around."

Even for older teenagers like Jasmine, social interactions can become difficult. Her group of friends would attempt to comfort her, but Jasmine says her brother's diagnosis "almost put a barrier between us because they didn't understand." So she wrote about what she was feeling—filling six journals in 2004. "I just needed to get some of the anger, frustration and sadness out."

The age of the well child also seems to play a key role in coping with a sibling's illness. "I think there is a big physical component with cancer, and a lot of the siblings report that seeing the physical changes—such as their brother or sister losing their hair, looking pale and throwing up—was very scary for them, particularly for the younger siblings," says Dr. Labay. Birth order and the closeness of the relationship before diagnosis also impacts how well the sibling adjusts to the illness. "If you're very close to a brother or sister and that person starts to suffer, it has a greater impact on you than if you're really far apart in birth order or if you don't have a lot of contact," says Dr. Labay.

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Regardless of where a sibling fits into the family birth order, it's likely that the experience of witnessing the childhood cancer of a brother or sister will have a permanent impact. Some children, says Dr. Fanos, are so focused on their sick sibling that they may grow up to be more concerned about taking care of the needs of others rather than their own needs. Research is now under way to study the long-term resiliency of these children. Often, the result can be a tremendous drive to succeed. Dr. Fanos interviewed 30 pediatric oncologists and found they all had either early health threats to themselves or experiences with cancer in their family. "Some of them said they had a bad experience when they were in the hospital, and they vowed that no other child would ever have that kind of bad experience."

Although a subset of children will struggle with their sibling's illness and the changes in the family routine, Dr. Labay says the majority of siblings are able to cope well as long as the family responds to their needs. For Jasmine, that meant leaving her home in Oregon to attend college in California. "I was expecting that my mom would be sad because I was leaving, but I saw that she was really happy. She said that in life there are so many changes that can happen and this was a good change."

At the moment, Jasmine Brenneman is just happy to be able to continue her education and isn't thinking too far ahead. "I've learned to appreciate that every moment is a gift."