Cancer Health

How to Support a Caregiver

January 16, 2018 By Justin Birckbichler

A cancer diagnosis doesn't simply affect the patient—it affects many in their lives. Since the beginning of ABSOT, I gave voices to my loved ones in the Healthy, But Affected series. My mother and wife (then-fiancee), Mallory, were my two primary caregivers during treatment. Without them, I couldn't have done it. Being a caregiver isn't easy, so here they share some of the things that helped them get through the experience.

Support them at their workplace as they take on a second job as a caregiver.

Mom: "During Justin's treatments, my job was very good to me—never made me feel guilty about going to Virginia for weeks at a time. We had a sub who did a great job and my boss never made me feel bad about missing so much work. The parents of the preschoolers really made me feel good when they would ask about Justin. They all understood why I needed to be away from the preschool and no one ever made me feel bad for not being there."

Mallory: "My school administrators were very supportive. It was never a problem for me to leave early to take Justin to appointments, and they actively wanted to be kept in the loop with Justin's status. If my grade level team noticed I was having a bad day, they would offer to take on some of my extra responsibilities, like recess duty, so I could take a moment to myself to breathe."

Take things off their plate.

Mallory: "Both Justin's and my school organized for meals to be delivered, which was a blessing since Justin is the primary cook around our house, and he didn't always have the stamina to cook. Neighbors chipped in to help with mowing the lawn, shoveling the driveway, and getting groceries for us, so I could focus on helping Justin. Justin's mom would also help take care of him while I took care of the house, or vice versa, and it was extremely helpful to have two people managing the situation."

Mom: "A group of friends organized who would bring food each week to my family in PA. It took a burden off any one person (or my family), and I think it helped people feel like they were doing something to help when there was little else they could do. I appreciated that the house was in good shape when I would come home for a week or a weekend—my family that I left behind at home really stepped up their game and took on the tasks that I generally do."

Ask about their feelings, too.

While my mom said that people would ask her how I was feeling and Mallory said mostly close friends and family members would ask how she was doing, my little sister, Courtney, had a different perspective.

“When Justin was diagnosed, I started to tell people. After sharing, people began to ask me, ‘How’s Justin?’ or ‘How’s your brother doing?’ While it was very nice to ask how he was doing since he was the one doing the real work and the real fight, rarely was I ever asked how I was doing.

“Honestly, I was not okay. I was 16 years old, and my older brother, who was only 25, had cancer. How in any way would I be okay!?

“I was up in Pennsylvania, over three hours away from him, and I didn’t always know what was going on. To make it even harder, since our mom was down in Virginia as his caregiver, I couldn’t even talk to her about it.

“A cancer experience is primarily focused on the patient, and, in my experience, it seems that not as much thought is given to the family member of the cancer patient, especially if they’re not an immediate caregiver. Everyone is nice enough to ask how the cancer patient is doing, but if I counted how many times I was asked how I was doing, I could use one hand. This time was really hard for me, and no one seemed to care to ask about me. While Justin was the one going through it all, he has always been my best buddy and I was being affected by it in a different way.”

Small gifts go a long way.

Mom: “Some of my friends put together a gift basket for me filled with things to do while sitting for hours at chemo or for my long drives to Virginia. Things like books, movies, books on CD, nail polish, lotions, bath bombs, coloring books, colored pencils and snacks. I loved coloring adult coloring books at chemo as it passed the time very quickly. Someone let me borrow their entire DVD collection of Downton Abbey, and that helped fill the time. Another friend gave me a gift certificate for two massages, which really helped me relieve stress.

“While the massages helped provide physical relief, one of the most symbolic and special things I received during Justin’s treatment was an anchor charm for my Pandora charm bracelet from his dad. He said I am the anchor of this family. That meant a lot to me because I felt so torn in so many directions—I knew I wanted to be able to help Justin, but I also knew I was leaving the rest of the family behind to do the things I normally do for them. I had guilt when I was away from them and guilt when I was away from Justin. By Dad giving me the anchor, it made me realize that I was the anchor of the family and was needed everywhere, but I was doing okay by helping everywhere.”

Mallory: “I got a bracelet from Justin’s aunt that said, ‘Courage and strength,’ which helped me find a symbol of strength. Some co-workers got gifts for us to help give us something to do when Justin was having a good day, like a movie night basket. I also enjoyed coloring books, as they helped me to relieve anxiety in a calming way.”

Accept that cancer sucks, and it’s okay to say that to them…

Mom: “One of my good friends once told her after she had a stillborn that she needed to hear people say, ‘This sucks,’ rather than always hearing positive comments. Don’t get me wrong, positive comments are good too, but every now and then, it is okay to be down, and it is okay to hear that ‘this sucks’ because it really does. I have tried to remember that ever since she told me that she needed to hear that sometimes. So tell the patient that it is okay to have down days, and realize yourself that you can’t be positive all the time. But also my dad’s voice is always in my ear, saying, ‘Just tell me what I have to do to take care of this and I will do it,’ so I know I often said that during the course of Justin’s treatment.”

Mallory: “One of Justin’s former co-workers sent me a card that basically said that and it was nice to see that it’s okay to be angry about cancer. A colleague at my school even offered her classroom (which is secluded from the rest of the school) as a place I could come and scream to let out frustration. I never took her up on that offer, but it was nice to know the chance was there. People understood and embraced my feelings and never made me feel bad for saying when things weren’t great.”

…But remember to encourage them to find silver linings where they can.

Mom: “In a weird way it was a blessing because I feel like Justin and I got closer during that time and I also got to know my daughter-in-law much more than most mothers-in-law ever get to know their son’s wife. And she still even seems to like me after spending all those months together!”

Mallory: “I really got to know my mother-in-law better, and now we have a deeper connection on a level that not many people do. [Author’s Note: I can attest to this, as they have a constant group text that I am needlessly included in]. Another silver lining was that I was able to find enough strength to pull myself together and let go of my worries and fears during the treatment process.”

While many of my posts are from my perspective as a patient or survivor, it’s equally as important to recognize the efforts and struggles the caregivers face. I’d like to thank Mom, Mallory, and Courtney for sharing their thoughts here, and I hope their words help you support a caregiver you know

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