

## [TRACK 9: SURVIVOR STORIES: ADVOCATING FOR THE CAREGIVER]

### Grace

[Narrator]

The next caregiver we'll hear from, Grace, faces a different choice. Listen to how she stands up for herself and her needs without reducing the level of care for her husband, Joe, who has cancer.

[Grace]

We were devastated when my Joe was diagnosed with advanced cancer ten months ago. They tried several therapies but none of them worked. About six weeks ago, we elected to have hospice involved in his care. This is going fairly well, but I have felt pretty stretched with caring for him at home.

[Grace]

On top of this, I recently had to face a personal concern. My only niece, Sharon, was about to get married in New Mexico. Her mother, my sister Terri, was killed in a car accident a decade ago. Since then, Sharon has been like a daughter to me.

[Grace]

Well, my Joe got sicker and there was no way that he would have been able to travel from our home in Florida to New Mexico to attend Sharon's wedding. Our son, Bob, who was part of Sharon's wedding party, even offered to come and stay with Joe so I could go to the wedding. I knew how much he was looking forward to the wedding, so that didn't seem right to me. Also, Bob hasn't seen his dad in six weeks - I don't think he had any idea how much care that Joe needed.

[Grace]

Well, I kept telling myself that taking care of Joe was more important than attending a wedding. But I love Sharon like a daughter and I just felt so sad about not being able to go. That got me to thinking about something my mother had always said. She said, "Where there's a will, there's a way." I thought about whether or not I was being selfish to want to see some happiness in the midst of our sadness. I decided I would find a way to get to that wedding!

[Grace]

So, I decided to talk with the social worker at the hospice. I was afraid she would think I was being silly, but she didn't. She reminded me that hospice had a respite service-where Joe could go into the hospital for a few days so I could get a break.

[Grace]

I finally talked to Joe and he said he knew how important Sharon's wedding was to me, how much I wanted to go, and that he wanted me to go. He said he would go to the respite program while I went to New Mexico.

[Grace]

I had one other problem. I didn't drive much, and the airport is in Miami-almost an hour and a half away. I couldn't afford to take a cab, but I could pay for gas. I called my pastor and asked her if she knew of anyone who could help me. She said she would find some church members to assist me. And she did. One man volunteered to drive me to the airport-and another to bring me back.

[Grace]

Well, I got to Sharon's wedding and it was wonderful. She was a beautiful bride and I'm grateful I was able to be there. I will always hold that memory in my heart.

[Narrator]

Grace honored her own needs and found a way to do something important for herself. She became her own best advocate.

[Narrator]

For most families, the daily caregiving role decreases or even stops once treatment is over and the cancer survivor returns to work or usual activities. For some families, however, the caregiving role ends only when the loved one dies. If you have cared for a loved one throughout the terminal stage of an illness, you know how demanding it can be. After the death, you may feel that there is a big hole in your life-that in addition to missing your loved one, you don't know how to fill your time. You also may feel relief that the heavy demands on you are finished, and this may make you feel guilty. Caregivers often are exhausted from the care they have provided during the last weeks of a loved one's life and they need time to recover physically and emotionally. This is another time when reaching out to friends and helping professionals is important. There are excellent programs for persons experiencing grief. Check with your local hospice, your hospital, your family doctor, or your clergy. They can refer you to a counselor or a support group.