

## **Karen Kell Hartman, LCSW-R, OSW-C**

We use the term caregiver often in cancer, and what I find is the people often don't know what the caregiver is. When I meet with the family, I often say to the spouse or the adult child, we will call you a caregiver because people think of often as a caregiver is like a professional home health aide. I define a caregiver as any person who's closely involved in the care of a person with cancer. So it can be a friend, it can be a neighbor, it can be a family member.

## **Karen**

And I use the term caregiver to describe that person's role because it is those people who are deeply involved, whether they're day-to-day with the patient or flies in for couple of days at a time or it's just at the phone everyday with the patient, that's a caregiver. It's somebody whose emotional connections are with the person going through cancer.

## **Dr. Bayer**

The role of the caregiver for a patient with multiple myeloma is critical during the induction and when they're first being diagnosed with the disease. And then the role of the caregiver is also very important during the time of the stem cell transplant.

When we are evaluating a patient for the process of the stem cell transplant, we need to evaluate the support system that the patient has. And it is critical that there will be somebody for six to eight weeks after the patient is discharged from the hospital. It is critical that there will be somebody close by to the patient to assist with shopping, to assist with cleaning the house, to assist with taking the patient to and from their doctor's appointments.

## **Scott**

When I was diagnosed with multiple myeloma, there was a shift in roles in our lives where before, I was out there working. Anything had to be done in the house, I had to get it done, taking out the garbage, you know, things of that nature. These were my responsibilities. Once I was diagnosed with multiple myeloma and there were limitations put on me because, in fact, of the myeloma and the damage, the bone damage I had, there was a definite shifting in roles where my wife and, you would hope, my daughters would then take some of the responsibilities, but it's mostly my wife, are taking responsibilities to doing things. So, in certain cases, that was hard.

## **Diane**

The most difficult time for me throughout this entire journey was the moment that it was confirmed that Scott had multiple myeloma. And we were home and I was in the kitchen and our daughter was sitting at the dining room table, our youngest daughter with her tutor, and he got the phone call in his office and he popped his head out of the office and he looked at me and said, "It's multiple myeloma." And at that moment, that was the worst moment of the journey. And I just felt like everything that was holding me to the ground just – was no longer holding me to the ground. I didn't know what was happening. Everything that I knew, I didn't know anymore and all of the control that I have over my life was gone and it was scary.

## **Karen**

Caregivers need a lot of support and they tend to be forgotten, they're almost like the forgotten patient. In this support group that I do, we mix caregivers with patients, and I've tried to pull the caregivers out to give them their own support group. They don't want to leave, they want to be with the patient. But, when caregivers are in that room by themselves they talk differently.

I think it's really important to help caregivers recognize that their role matters. I find myself often saying to caregivers that you really need to take care of yourself as well as taking care of your husband, your daughter,

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your whoever. Because caregivers tend to be selfless, that's kind of why they're caregivers, they tend to focus on the person with cancer and think that person needs preempt their own. There's actually a caregiver's bill of rights out there, somewhere that lists the things that we should do if we're caring for somebody with cancer and one of those things is to be sure to care for oneself, to take time for oneself, to make sure that we are able to get away a little bit or to spend time with friends, which caregivers often have a hard time doing because they feel that the person with cancer is the focus and should always be the focus. So it requires a lot of ongoing support.

## **Diane**

Scott's multiple myeloma support group had amazing support for the spouses as well as the patients. And I became very close with two amazing women in that group and we go out every month, just the three of us. And we really bonded. And I have my friends, I have my family, my girls.

Just like when you're on an airplane, and they say, "When the oxygen masks come down, always take care of yourself first, and then help those around you." It is really important to take care of yourself first because if I do not take care of myself, I can't take care of him.

## **Scott**

If you take control and take ownership of your cancer. You start planning things out. Start seeing how you have to shift your life in order to live your life. And that's what we're doing, we're living. And we're doing it together, the whole family.

## **Karen**

Cancer treatment is mostly outpatient, and all that expectation of what the patient is going to do with medication and with managing side effects happens at home, and that burden all falls on caregivers. And we, the medical community, hands that responsibility to a caregiver without any training. We expect people to go home and know how to do that. So, I think that's a really important piece for all of us to think about: the importance of caregivers, their role in the patients' life, and on the team, helping them get through this.

## **Dr. Bayer**

I do believe that at some point the role of the caregiver changes a little bit because the patient does get their life back. And the role of the caregiver is really more companionship.

## **Scott**

Roles have changed and – but it's – it brought us so much closer than we've ever been before.

## **Diane**

I feel like I am someone who loves someone that has cancer and I'm here to support him and I'm here to be here for him and I'm here to help him navigate this new normal that we didn't really ask for but we now have.