

Metastatic Breast Cancer

Special Issue
FOR
Caregivers

What Your Loved One Wants (and Doesn't Want) From a Caregiver

BY ERIN ROWLEY

When someone you care about is diagnosed with metastatic breast cancer, caregiving becomes a long-term responsibility. Every person has unique needs. But experts say there are a few things nearly everyone wants, or doesn't want, from a caregiver.

We hope you will use this article as a starting point to talk to the person you're caring for about how they feel, what they want, and how to keep your relationship strong as you go through this together.

Want: To Be Heard

Having a caregiver who wants to take charge when their loved one just wants them to listen is a common complaint among women being cared for by male partners, says **Matthew Loscalzo, LCSW**, an oncology social worker and executive director of the department of supportive care medicine at City of Hope, in Duarte, California.

Kathy Townsend, 47, from Helotes, Texas, was diagnosed with metastatic breast cancer about a year ago. Her husband Richard is her main caregiver.

"My husband's first instinct is to try to fix whatever is wrong," Kathy says. "Sometimes I just need a shoulder to cry on or just have someone listen and let me vent. I'm learning to let my husband know when I need him to do something and when I need him to just give me comfort."

When your loved one complains about pain or depression, your first instinct may be to run to the store for medicine, or to say "You should plan an outing with friends. That will make you feel better." But the person you're caring for may want you to stay there with them or for you to say something like

"I'm sorry you're having a rough day. Can you tell me more about why you're feeling down?"

The first statement shows you're listening and that you care. And the second question shows curiosity.

"It's best to be curious and to listen," Mr. Loscalzo says. "I don't think any two things make people feel more heard and more understood."

Open communication throughout the course of the disease is important because needs can change, says **Jennifer Bires, LICSW, OSW-C**, an oncology social worker at the George Washington University (GW) Cancer Center, in Washington, DC.

"Someone may feel one way when they're first diagnosed, and they may feel another way 6 months into their illness, or a year, or 5 years down the line," Ms. Bires says. "Communication may look different at a different point in treatment or disease progression."

Want: To Maintain Healthy Relationships

Spouses, parents, children, siblings and other loved ones provide different types of care to each other throughout their lives. But you may not have experienced the depth of caregiving that a metastatic breast cancer diagnosis can bring, until now. With it, you may feel a shift in the roles between you and the person you're caring for.

If you're caring for an adult child, it may feel natural to slip back into the parenting role. But remember that just because this is *your* child, doesn't mean she is still *a* child. To her, relying heavily on you may feel like a giant step backward.



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If you're an adult child caring for a parent with breast cancer, you may feel good about helping after everything your parent has done for you. But your parent may no longer feel like the authority figure they once were. Or, they may feel guilty about taking up your time.

"I struggle with the idea that my son may feel like he cannot move on with his own life because he is worried about us," says Kathy.

These issues can create power struggles, says **Shara B. Sosa, LCSW, OSW-C**, an oncology therapist at Life With Cancer, in Fairfax, Virginia. Cancer takes away a sense of control, she says. Add to that the feeling that someone is taking away their power, and that can create tension in relationships.

"After a while I realized that I needed my husband to step back and allow me to take control of my diagnosis. I wanted to do my own research and find my own way around learning about my disease and how to cope," Kathy says. "This was important to me, so I could feel like I had control."

Ms. Sosa suggests continually asking your loved one, "How can I best help you?"

"That question really helps people living with cancer feel in control of their own lives," she says.

If you're caring for a spouse or significant other, you may struggle to keep your romantic relationship strong. Ms. Bires says intimacy is important to many couples, but you may feel uncomfortable talking about it. You may fear hurting your partner, and the person being cared for may feel unattractive or unsure of what their body can handle.

There are many other ways to be intimate without intercourse if it's not an option or a desire of both partners, Ms. Bires says. She encourages partnered caregivers to seek out more information from healthcare providers. They can help you kick off a conversation.

"Getting tips on how to talk and how to decide on activities that both people feel comfortable with can be really important," she says.

Mr. Loscalzo says it's common for a man to react to stressful situations, like caregiving, by withdrawing emotionally and socially. That can make his partner feel alone, angry and critical, leading a man to withdraw further. If this sounds like your situation, Mr. Loscalzo recommends you consider seeing a counselor together, to help you get on the same page.

"Couples who overly focus on the bad aspects of any kind of serious situation do less well than couples who are in balance, who can talk, and have multiple good cries, and tell jokes, and go out and do things together," Mr. Loscalzo says.

Kathy and her husband agreed to celebrate with a couples' outing each time she had a scan showing the cancer was stable.

"It is very easy to allow cancer to infect every part of your lives as a couple," she says. "Learning to put cancer away and just be together has become a vital part of our relationship."

Don't Want: For End-of-Life Plans to Replace Life Plans

"I think that initially [after a metastatic breast cancer diagnosis] caregivers tend to think 'OK this is it. We've been given a death sentence,'" Ms. Sosa says. Loved ones may rush into "end-of-life" activities, like preparing or changing wills, or fixing up the house in case they need to sell it. It's important to think about these sorts of practical concerns, but it's also important to be sensitive. Watching people plan for life without her can be very traumatic for your loved one.

"It's this panic-driven decision-making that I think is so hard for the person living with cancer, because they're just trying to digest what has happened," Ms. Sosa says, adding, "The worst thing that you can do is stop making plans with someone living with advanced cancer, because then they think you are done with them."

They may not feel comfortable making long-term plans, says Ms. Sosa, but suggesting enjoyable activities for you to do together in the near future — a day, a week, or a month away — may help people with metastatic breast cancer continue to feel hopeful and supported.

"My husband's first instinct is to try to fix whatever is wrong. Sometimes I just need a shoulder to cry on or just have someone listen and let me vent."

Kathy and Richard Townsend



Don't Want: To Be a Burden

After being diagnosed with a serious illness, most women's greatest concern is not for themselves but for their family, Mr. Loscalzo says. They don't want to cause a drastic change to their loved ones' lives, or to need to rely on family, especially if they are used to caring for everyone else.

"I love my husband. He is my best friend. I don't want to be a burden to him or steal away his happiness," Kathy says. "That will only put more strain on our relationship."

If your loved one can't work, or medical bills are piling up, she may worry about being a financial burden or taking up too much of your family's time and energy. She may worry about losing her independence. It's important to ask about specific concerns, and to talk about them, Mr. Loscalzo says.

Instead of asking "Is there anything you can't do, that you need me to do?" Ms. Sosa suggests you ask, "Is there anything you want help with?"

The second question highlights your desire to help, rather than the other person's limitations. Don't assume the person you're caring for doesn't want or isn't able to do something; ask first.

"[Your loved one] wants to know that they are still an active, contributing member of the family," Mr. Loscalzo says. "I don't think there's anything I've heard more often in the 35 years I've been doing this work more than that. That cuts across cultures. That cuts across age groups. It is pretty consistent." 🐾

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A MOTHER'S LOVE:

A Q&A With Kate Dennin

BY ERIN ROWLEY



Kate Dennin and Maureen Smith

Fifteen years ago, at age 30, **Maureen Smith** was diagnosed with metastatic breast cancer. Her mother, **Kate Dennin**, of Havertown, Pennsylvania, became Maureen's caregiver. Maureen and Kate had trouble finding information for young women with breast cancer. But then they found Living Beyond Breast Cancer, and our many resources for young women. Maureen and Kate began volunteering extensively for LBBC, taking part in our conferences, gala, a photo shoot and other programs.

Maureen passed away in 2015. Kate honors her memory with the volunteer work she continues to do for LBBC. She was recognized this year with LBBC's Caregiver Award (see page 3).

Kate sat down with LBBC's writer and content coordinator **Erin Rowley** to talk about her experience as a caregiver for a loved one with metastatic breast cancer.

Erin

What did you find most challenging about being a caregiver?

Kate

I guess what is most challenging about being a caregiver is the frustration you feel when all you can do is freshen the pillows or bring a cool drink. You can't always take away the discomfort. You can't always take away the heartache. When it's your child and you're the mom, it's your job to make everything better. Mommy kisses it and makes it better. This was beyond the minor boo-boos that you kissed and made better. Cancer's not a boo-boo.

Being a mother of a breast cancer survivor — because she was a survivor for 14 years — it puts you in a very perplexing place. In the beginning you think, 'It should have been me.' And then you have to get beyond that and just be a mom. And being a mom, to me, has always meant being a caregiver.

Erin

What advice do you have for caregivers?

Kate

After you have found the right medical team, the first thing to do is buy the patient a nice journal book and a good pen, and let them write down what they're feeling in the middle of the night or what questions they have for the next time they go to the doctor. Let them have a section that's not so private, so that you can review the questions and know when you go to the doctor with them next that those questions get answered.

And you can listen [to the answers]. Because often, they don't hear the words. ... I think that's what happens, especially in the early stages of any kind of catastrophic illness, is the person who is ill sits there and knows that the doctor's lips are moving, but they have no idea what the doctor is saying. I feel like they need another person there with them who can listen and write things down so that that evening, when the patient is thinking 'What happened today?' she can go back and read through what was said.

The other thing you can do is make a calendar. There are calendar websites [lbbc.lotsahelpinghands.com, for example] that you can send out to friends and family so they can sign up for meals. They can say 'On Tuesday, I'm going to make lasagna and I'll bring salad and I'll drop it off.' Someone else may sign up on the calendar to take the kids to the movies, or do laundry. The person with the illness can look at the calendar and see 'I don't have to worry about dinner tonight,' or 'I don't have to pick up the kids from school today.' Everyone says, 'What can I do for you?' But the person with the illness doesn't know what that person is able to do. This way with this calendar, you can set it up and people can sign up and say 'This is what I'm going to do.'

Erin

Is there anything else you would like caregivers to know?

Kate

As a caregiver, you have to allow people to take care of you as well. That isn't always easy, because you're supposed to be the one taking care. But sometimes you need to step back and allow others to take care of you. ... The caregivers need to be kind to themselves, too. 🍌

