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# Navigating the Caregiver Terrain

BY MARC SILVER

I remember how lost and lonely I felt when my wife was diagnosed with breast cancer. I didn't know what to do. I didn't know what to expect. And I didn't want to burden Marsha by telling her how frightened I was. So the two of us would go from doctor's office to doctor's office, where we'd sit, side by side, overwhelmed by the emotions welling up inside and by the barrage of strange new words falling from the doctor's lips. Looking back, I wish just one of those docs had taken me aside and given me the following advice.

**If you feel as if you've been hit by a truck, that's perfectly normal.** That's because cancer is still one of the most frightening words in the medical dictionary. And there might be more bad news ahead as doctors investigate the life-threatening disease that afflicts your wife's breast. Marc Heyison, who co-founded the educational group Men Against Breast Cancer after his mother's diagnosis, is not a medical professional, but he knows how to inspire a downtrodden breast cancer husband, quoting the immortal words of the late Vince Lombardi: "It's not whether you get knocked down, it's whether you get up."

**Feeling scared? That's normal, too.** You might want to share your feelings with your wife (although be sure to add, "But I'll always be there for you"). Or you might decide to keep your feelings from her because she needs to take care of herself instead of worrying that her poor, dear husband is going to melt down. Whether you disclose or conceal, take heart, because ...

**In some ways, the first month is the worst.** Breast cancer has rocked the foundation of your world. In a matter of weeks, your wife must assemble a team of doctors she likes and settle on a treatment plan that makes sense to her. Once she's reached that point, some of the free-floating anxiety you both feel will lessen—only to be replaced by new anxieties, like, "What's chemo like?" But I'll get to that a bit later.

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**Will there be stress on your marriage? You betcha.** A cancer diagnosis can tip a marriage over—even a marriage that seemed fine beforehand. There will certainly be times when you and your wife are out of synch—just as you sometimes were before cancer. But plenty of couples fight the disease hand in hand; some grow closer after their months on the battlefield. And the best way to remain close is to

keep talking and to heed the breast cancer husband's motto: "Shut up and listen."

**Two words: breast specialists.** A generalist may be perfectly capable of caring for your wife, but a specialist offers the knowledge gained from experience and from following the latest research. In my wife's case, a general surgeon recommended a mastectomy. Because the tumor was near the nipple, he felt a lumpectomy would disfigure the breast. We went to a breast specialist for a second opinion. She was confident that a lumpectomy would leave just a small dent. How do you find out how often a doctor treats breast cancer patients? Just ask. And the answer doesn't have to be all the time. Even 50 percent of a practice devoted to breast cancer means a significant amount of time spent treating the disease.

**Don't ask what the doctor would do if the patient were his wife.** A well-meaning male oncologist used the "my wife" construct when he met with Marsha and me. "If this were my wife," he said, "I'd recommend chemotherapy." The problem is that his wife is not my wife. A breast cancer patient must make many choices, and there isn't always a one-cure-fits-all treatment. The doctor has to present a treatment plan that makes sense for your wife, and she has to agree with his recommendation. Oh, and one more thing to remember about the "if it were my wife" line: Even doctors admit they are notoriously bad at taking care of their family's health.

**Doctors aren't mind readers.** Here's what a very genial surgeon told my wife: "I can tell you'll always worry about recurrence, so I'd recommend a bilateral mastectomy." What's wrong with that statement? He'd just met Marsha minutes before, at a time when she was coping with news of a cancerous tumor in each breast. How dare he presume to know what she was thinking! If a doctor makes this sort of remark, the husband is the one who can later ask his wife: "Is that really how you feel?"

**A mastectomy is not a guarantee of a cancer-free future.** Even after a mastectomy, a breast cancer patient runs a small risk of recurrence along the skin or the chest wall, typically in the 5 to 10 percent range—about the same risk of recurrence after a lumpectomy and radiation. The risk of recurrence for mastectomy patients is even higher if the tumor is 5 centimeters or larger, or has spread to four or more lymph nodes, or if the patient has inflammatory breast cancer, an especially aggressive variety.

**Don't be a take-charge guy.** You're not the boss of her. It's not your job to run her medical treatment. You're the caregiver, the support guy, the sounding board. She may ask you what you think, and you can tell her, but she's the one who will decide what to do about her breast cancer.

**Your ears are better than her ears.** In the doctor's office, a breast cancer patient is likely to forget a significant portion of what the doctor tells her. She may misremember information or focus on the negative. By listening carefully and either taking notes or, with the doctor's OK, recording the session, you can help your wife regain the information she lost due to her cancer-induced state of stress.

**Ask for directions.** That's not something guys like to do. But face it: You've most likely never been a caregiver before. So tell your wife that you'd like to do

anything that will make her life easier—trying your luck with the laundry; renting a movie she’s always wanted to see, even if it’s a chick flick, and watching it with her; ordering her favorite take-out meal. But whatever you do, don’t rearrange the kitchen.

**Buy a binder and a hole-punch.** That way you’ll have somewhere to put the unending stream of doctor’s notes and bills and other cancer-related pieces of paper that will come sailing into your life.

**When it comes to chemo, expect the unexpected.** I heard lots of theories—the first infusion is the worst because of the anticipation. No, it gets worse each time. After living through my wife’s six sessions, and talking to many doctors, nurses, and women about the nature of chemo, I can only tell you that you can’t count on anything. Some women sail through with minimal problems. A small number suffer extreme nausea and fatigue and other debilitating side effects. And the majority fall somewhere in the middle. But one rule usually holds true: The toll that the chemo drugs take is cumulative. That is, your wife will most likely feel (and look) worse and worse as time goes by.

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**Losing hair can be more traumatic than losing a breast.** So if your wife is obsessing about her bald head, don’t grow impatient (as I did). Many women have since told me that staring in the mirror at a hairless head during chemotherapy was far more devastating than undergoing a mastectomy. A loose blouse can conceal the loss of a breast, but even the best wig is, in the end, just a helmet of hair.

**Splurge.** Maybe every cancer doc should play that old song, “You Don’t Bring Me Flowers” in their waiting room as a cue for the clueless guy. Even when I had bad news to deliver after a doctor’s phone call, my wife was somehow less depressed if I brought a beautiful bouquet of her favorite blooms. Some men make even grander gestures: One woman told me how her husband gave her a diamond and sapphire tennis bracelet (and matching earrings yet) during her chemo months. Of course, the truth is that it doesn’t matter what kind of gifts you buy (well, definitely not a blender). The point is to show your wife you are thinking of her in a loving and romantic way.

**Don’t be shy about flirting.** Actually, my wife’s oncologist did tell us that intimacy was still possible during chemotherapy, and we’re glad he did. If she’s not in the mood because of surgery, chemotherapy, or radiation side effects, she’ll let you know. But imagine how she’ll feel if you never try—as if breast cancer has stripped her of her sexuality. And you should also remember that sexual intercourse isn’t the only kind of intimate contact in a couple’s life. Sometimes what your wife needs most is a good cuddle, a back rub, a foot massage, and those three little words that are sometimes hard to say, but that will never mean more to her than they do now: I love you.

**The year ahead will not be the year you thought you were going to have.** You’ll

spend time and money on things you hadn't planned. Maybe you won't have a spare afternoon to fix the leaky faucet. Maybe your wife won't be up for a vacation you've been planning. "I always considered that year [of active treatment and recuperation] to be a sacrifice you make in the interest of the rest of your life," says surgeon Sherwin Nuland, author of the award-winning *How We Die*. And when the year is up and you're ready for some semblance of normality, that leaky faucet will still be there, just waiting for you.