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The Secret of Caregivers

BY JO CAVALLO

When caregivers feel they have no choice, the challenging role can take its toll.

Although the exact number of cancer caregivers in the United States is unknown, since much of the caregiving responsibility falls to family members, it could be as high as the 1.4 million people diagnosed with cancer this year alone.

For some caregivers, they may be a patient's only option for help, and those thrust into the role by feelings of guilt or obligation may experience reluctance for a variety of reasons, including a strained relationship with the patient, inconvenience, unpreparedness, or unwanted burden. And how well those caregivers fare in the responsibility varies depending on those and other factors, including gender.

Youngmee Kim, PhD, director of family studies research for the American Cancer Society, says when men, either husbands or sons, fulfill a caregiver role that was not expected of them, they experience heightened levels of self-esteem and lower levels of stress. But women, who are often expected to be the family caregivers, usually experience lower levels of self-esteem and higher levels of stress, especially when they're caught in the "sandwich generation" of taking care of their own children while caring for a sick parent.

"Women may be wonderful caregivers but simply because of where they are in their lives, taking care of their children and juggling so many social roles may make them feel more reluctant about their caregiving role," says Kim.

What's more, feeling there's no choice in being a caregiver could also put a caregiver's health at risk. The 2006 survey "Caregivers in Decline: A Close-up Look at the Health Risks of Caring for a Loved One" conducted by Evercare and the National Alliance for Caregiving found that 75 percent of caregivers whose caregiving duties resulted in declining health felt they had no choice in taking on the responsibility of caring for a loved one.

"Feeling you don't have a choice can have a negative impact on the way caregiving affects you," says Gail Hunt, president and CEO of the National Alliance for Caregiving. In fact, the NAC survey found that even despite being in fair, poor, or even worsening health since becoming caregivers, 72 percent of respondents said they had not kept up with regular doctor visits, and even if they did make appointments, 55 percent said they didn't keep them.

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—Youngmee Kim, PhD

Kathryn Marquardt, 51, admits neglecting her own health when she became the caregiver for her mother who was diagnosed with breast cancer several years ago. Although Marquardt kept an appointment for her yearly medical checkup, she didn't follow through with a fecal occult blood test her doctor asked her to take.

"I had all these balls in the air and I couldn't do anything more," says Marquardt, a computer consultant, who at the time was raising two daughters with special needs. "I was feeling good and I thought this will wait, I've got other things to do. I was at the bottom of the list."

Although Marquardt began experiencing weight loss, back pain, and a change in her bowels, she didn't get the symptoms checked out. A year-and-a-half after her mother's diagnosis, Marquardt was diagnosed with colon cancer followed by a breast cancer diagnosis six months later. "Caregivers will just ignore symptoms because we don't have time," says Marquardt.



Ignoring symptoms while caring for her mother, Kathryn Marquardt's colon cancer diagnosis was delayed. Photo by John Valenzuela

Burden of Care

Duration of caregiving responsibilities is also a contributing factor to how well caregivers cope. "Caregivers may feel reluctant because [their duties] drag on and become more involved and more intensive than they ever anticipated," says Laurel Northouse, PhD, RN, co-director of the University of Michigan Comprehensive Cancer Center's Socio-Behavioral Research Program.

Northouse says caregivers move into a higher burden situation where they feel overwhelmed, and worry that taking on this role may be detrimental to other family members. "They may feel reluctant because their own quality of life will start deteriorating because of the high demands of the caregiving situation," she says.

Marilyn Medler began caring for her 57-year-old husband, Wayne, when he was diagnosed with brain lymphoma four years ago. He started exhibiting personality changes, likely because of the cancer and its treatment.

"Wayne was a very kind person but the [cancer and treatment] turned him into a miserable, nasty person," says Marilyn. The treatment left Wayne, who is now in remission, in such an inactive state, Marilyn says, that he spends 22 hours a day in bed with "no desire, motivation, or willingness to do anything." He requires so much hands-on care that Marilyn had to leave her job as a probation officer to take care of Wayne full-time.

She exhausted every inner and outer resource to help Wayne recover, from cajoling him into going out, driving him to psychiatric appointments, and researching brain rehabilitation programs, but he refused every attempt of help. The no-end-in-sight situation exacted such a heavy emotional toll on Marilyn that in March, she decided she could no longer be Wayne's caregiver and asked his family to take over his care.

"There is a lot of pressure in our society for women to be martyred caregivers, and I'm raising the white flag and saying, 'I surrender.' I'm not going to martyr my life anymore," says Marilyn, choking back tears.

Level of Intensity Counts

Experts say the intensive level of care cancer patients often require—even if it's for a short amount of time—can cause emotional strain for caregivers.

"Cancer caregiving happens around the time of diagnosis and treatment and then end of life," says Kim. Treatment may cause side effects, which can happen quickly, she says, and at the end of life, pain may occur. "While the care doesn't last for years, it needs to be very accurate (competent and efficient)."

And with more cancer patients being discharged from hospitals "sooner and sicker," says Northouse, the level of accurate care required once the patient is home can heighten a caregiver's hesitance because he or she doesn't feel competent to carry out high-tech tasks.

"Sometimes caregivers feel unprepared for the situation," says Northouse. "All of a sudden a family member comes home from the hospital with a lot of tubes or procedures and the caregiver has not been prepared or given information on [how to care for the patient]. So they feel incompetent and terrified because they don't want to do harm to the patient."

Finding Relief

Despite the difficulties cancer caregivers often face, Kim says the experience can also be largely positive. "Caring for a loved one makes people realize what the important values are in their lives and prioritize them."

Northouse agrees. "If a caregiver is feeling really reluctant, it may help to talk to other caregivers to see if there's a way to reframe the situation so that the caregiver can get something out of it that hadn't been anticipated, like maybe feeling you're making a contribution."

Caregivers can also seek outside help from home health aides—especially in physically demanding care situations—and negotiating with other family members and friends to take over while the primary caregiver takes regular breaks to get relief. "We encourage caregivers to go outside for a walk because exercise reduces tension, and to take up hobbies so they're doing something other than non-stop caring," says Northouse.

And, perhaps, most importantly, speak up. "Many times we have no idea what

people are dealing with because it's not out in the open. [Oftentimes] people try to either deal with a situation on their own or with limited help, and that can be very difficult," says Northouse. Joining support groups and checking to see whether the local hospital offers supplemental home health care, caregiver training, or other services can help.

Marquardt is now cancer-free, as is her mother, who returned the favor and cared for her daughter following the breast cancer diagnosis. "It has been an action-packed journey for both of us," says Marquardt. "It does sound odd, but I would choose the patient role over the caregiver role anytime."