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Caring for the caregiver

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As more and more of a patient's treatment and care happen at home, rather than at the oncologist's office or hospital, the responsibility for a patient's well-being and adherence to treatment regimens increasingly rests with the family member or loved one who takes on the role of caregiver.

Traditionally, the caregiver provides emotional and practical support to a spouse, family member, or friend in cancer treatment or dealing with the after-effects of cancer treatment. However, many cancer treatments are self-administered and do not require a visit to the patient's health care team; therefore, today's caregivers are often charged with more medical-related tasks such as administering treatment and helping manage side effects, in addition to providing general care each day.

For many caregivers, supporting a loved one going through cancer treatment is a full-time job. According to a recent report from the National Alliance for Caregiving and AARP, caregivers who live with patients spend approximately 39 hours per week providing care.¹ And, much of their efforts go unnoticed. Patients report, perhaps not surprisingly, receiving much more social support than do their caregivers.

One caregiver I recently spoke with admitted that she was "absolutely floored" when the oncology nurse attending to her husband, who was undergoing treatment for advanced-stage colon cancer, asked her a very simple question: "How are you feeling?"

"I didn't know how to respond," the caregiver told me. "Nobody had asked me

how I was feeling in such a long time. It has been all about my husband for years."

Diane, a CancerCare client who sought counseling after her husband, Wayne, received a diagnosis of an aggressive form of prostate cancer in 2003, acknowledges that the support she received from her husband's health care team made an enormous difference in how well she coped with his grueling treatments. After receiving his diagnosis, Wayne underwent radiation, chemotherapy, a prostatectomy, and then whole-brain radiation when doctors discovered a lesion on his brain.

Diane credits her husband's team of oncologists and oncology nurses with helping her to feel supported throughout her husband's ordeal. "The nurses especially spent extra time with me," she says. "Their schedules are so full; I don't know how they do it. But they really do take the time to talk with me and always ask me how I'm doing. It makes a big difference in my ability to get through particularly hard days."

Expecting a patient's health care team, and especially his or her nurses, to have the time and resources to provide the caregiver with the full emotional support he or she may need may be unrealistic. However, many excellent resources are available and can be a great help to caregivers. Nurses can steer them toward these resources to help them cope with the emotional stress of caregiving. For example, Diane found participating in one of CancerCare's free online support groups to be very beneficial. She was able to share her rawest emotions and fears with other caregivers from the

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Helping the caregiver ensures that your patient has the best care available to maximize the best possible outcome.

privacy of her own home, sometimes late at night when the house was finally quiet or she could not sleep. Our online groups can be accessed 24 hours a day, 7 days a week and are moderated by a professional oncology social worker. Participants are required to register first, and access is password-protected, allowing members to communicate in utmost confidentiality. “I always post what’s going on,” Diane says. “It’s nice to know there are people out there who care.”

Caregivers may also receive emotional support through one-on-one counseling, either online or face-to-face, with a social worker who specializes in providing emotional support to caregivers. “Cancer is so all-consuming to a family that it is often the caregivers who can easily neglect their own needs,” says Christine Rubin, a CancerCare social worker who counsels caregivers. “Caregivers often feel a variety of emotions and feelings, ranging from sadness, fear, and anger and then guilt for feeling angry because, after all, they are not the ones with cancer. An important fact to remember is that the caregiver, too, is living with cancer.”

Although researchers have long known that caregiving can have a negative impact on caregivers’ mental health, research shows that caregiving can have serious physical consequences as well. In fact, 17% of caregivers feel that their physical health has worsened as a result of their caregiving responsibilities, which can also have a deleterious effect on your patient’s outcome. Helping the caregiver, then, ensures that your patient has the best care available to maximize the best possible outcome of his or her treatment. Here are some quick tips to share with the patient’s caregiver:

Stay active Build exercise into your daily routine, ideally at least 30 minutes a day. Simply taking the stairs instead of the elevator or parking farther away is beneficial.

Eat healthy meals Maintain a balanced diet that includes fruits, vegetables, and protein. Despite their convenience, avoid fast foods and overly processed foods. Learn to cook simple meals, ahead of time if necessary.

Get some rest Try to sleep 7 to 8 hours a night. Take naps when you need them.

Take care of your own health Stay up-to-date with your own medical checkups, screenings, and medications.

Enjoy some “me time” Take some time out for yourself regularly. Taking even a few minutes during the day to do something you enjoy that is unrelated to your caregiving responsibilities can help you recharge and boost your energy.

To find more helpful information for patients’ caregivers, see CancerCare’s free publications such as *Caregiving for Your Loved One with Cancer* and *For Caregivers: Coping with Holidays and Special Occasions*, which are available on our Web site (www.cancercare.org).

The American Cancer Society (www.cancer.gov) also has excellent resources for caregivers, as does The Family Alliance for Caregiving (www.caregiving.org), which offers additional tips on how caregivers can provide the best care for their loved ones by caring for themselves, too. ■

Helen Miller is CEO of CancerCare.

REFERENCES

1. National Alliance for Caregiving (NAC) in collaboration with AARP. Caregiving in the U.S. Bethesda, MD: National Alliance for Caregiving; Washington, DC: AARP; 2009.



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