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Caregivers: A critical link in successful care management

Helen H. Miller, LCSW, ASW

Michelle chose to be a graphic designer and marathon runner, but cancer made her a caregiver. For the past 11 years, Michelle has juggled her career and marathon training with caring for her parents, both of whom had and were successfully treated for cancer—her mother for esophageal cancer and her father for prostate cancer.

Today, as posttreatment survivors, Michelle's parents endure a host of separate, secondary health problems related to their diagnoses and treatments that Michelle must continually address. It's an often grueling role that can wear a person down. Michelle started running in marathons as a way to clear her mind from the cycle of caregiving. "Running is such an integral part of keeping myself balanced in order to be the best caregiver that I can be," she says.

Michelle is just one of nearly 5 million people in the United States who serves as the primary caregiver to a cancer patient or posttreatment survivor.¹ According to a recent study by the National Alliance for Caregiving (NAC) and AARP, caregivers to people with cancer represent about 7% of an estimated 65 million people in the United States who manage a family member's illness on a daily basis¹—a total that has increased from 44 million caregivers over the past 5 years and continues to grow.¹

A shift in cancer care management in recent years has allowed many patients to receive

treatment primarily in outpatient centers rather than in hospitals. Also, more patients receive care in their own home. Today, one or more family members, as opposed to a paid health care professional, provide approximately 80% of home-care services.¹

CAREGIVER ROLE IS DEMANDING AND MULTIFACETED

"Caregivers are an important source of support to the person coping with a cancer diagnosis and can serve many roles," CancerCare Program Division Director Rosalie Canosa, LCSW, notes. "Sometimes that support is very practical, such as scheduling doctor's appointments and driving the patient to and from treatment. Caregiving can also be a very intimate and intense relationship, involving the person emotionally as a confidante and shoulder to cry on." In addition, caregivers are often called on to administer treatments or to help monitor and manage the patient's side effects, making that person a crucial liaison between the patient and the patient's medical team. The caregiver is truly a critical component of the patient's health care team.

But caregiving, while critical for the patient, often takes a toll on the caregiver. The NAC/AARP study found that one in six caregivers (17%) reported that caregiving had a negative effect on their health, and nearly a third (31%) described themselves as "highly stressed" by caregiving.¹ Caregivers often feel that they must single-handedly shoulder the responsibility of caring for a loved one who



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is ill. As a result, they feel tired, isolated, or depressed and experience sadness, anger, or anxiety. Physical problems like hypertension, heart disease, difficulty sleeping, fatigue, and depression have also been linked to caregiving. Caregivers may experience changes in appetite or forget to eat, and may ignore their own physical health concerns.

Many caregivers report having difficulty in finding balance in their daily lives while juggling competing and often conflicting needs, especially in terms of caring for themselves. "Caregivers often express feeling guilty or selfish when attending to their own needs. They have to be encouraged to maintain normal patterns and set reasonable limits," says Canosa.

HELP FOR THE HELPER

You can help your patients' caregivers alleviate some of these issues by directing them toward resources and organizations that provide free assistance to caregivers of people with cancer. CancerCare (www.cancercare.org), The National Alliance for Caregiving (www.caregiving.org), and the American Cancer Society (www.cancer.org), offer free, informative publications that provide caregivers with tips on coping and how to find reliable, local resources. Here are a few to share with your patients and their caregivers.

Time off from work Caregivers who are currently working may be able to take unpaid, job-protected time off from work (up to 12 weeks each year) to provide care for a loved one under the Family and Medical Leave Act (FMLA). They can learn more about the FMLA by contacting the United Way (www.liveunited.org) or Area Agencies on Aging (www.n4a.org).

Discount medications The Partnership for Prescription Assistance (www.pparx.org) and the Patient Advocate Foundation (www.patientadvocate.org) can refer caregivers to more than 475 programs that help patients who qualify receive their medications for free or at a low cost.

Financial assistance Several organizations including CancerCare provide financial

assistance to help cover treatment-related costs like transportation and insurance co-payments. The Cancer Financial Assistance Coalition (www.cancerfac.org) lists financial resources for a variety of cancer diagnoses.

Counseling Many caregivers find the support they need by connecting with other caregivers through support groups, either online or face-to-face. Caregivers who feel they would benefit from support groups can find them through organizations such as CancerCare. Other caregivers may prefer speaking one-on-one with a social worker in an individual counseling session.

Last year, Michelle and her mother received individual counseling from professional oncology social workers at CancerCare after Michelle's uncle died from pancreatic cancer. Her mother found ways to cope with her grief over the loss of her brother and her feelings of survivor's guilt. Michelle found support for dealing with her feelings of grief and the guilt she felt about times she needed to put her own needs in front of her parents'. "Working with a counselor really helped me to learn that it was okay to focus on myself," she says.

The range of a caregiver's responsibilities is wide and often takes a toll on the physical and mental health of the person who is providing the help. That is why your attentiveness not only to your patient's needs but to those of her or his caregiver is critical. Your patient's outcome may very well depend on it.

CancerCare offers free publications about caregiving for a person with cancer, including *Caregiving for Your Loved One with Cancer* and *For Caregivers: Coping with Holidays and Special Occasions*. Call 1-800-813-HOPE (4673) or visit www.cancercare.org to order copies. ■

Helen Miller is CEO of CancerCare.

REFERENCE

1. National Alliance for Caregiving in collaboration with AARP. Caregiving in the U.S. A Focused Look at Those Caring for the 50+. Full Report. 2009. http://assets.aarp.org/rgcenter/il/caregiving_09.pdf. Accessed January 10, 2011.