

After Caregiving

BY MARC SILVER

How do you adjust to life after caregiving? If the future looks bright for the family member who's battled cancer, caregivers may sail effortlessly into the post-caregiving period. Yet many caregivers suffer from what could be called "post-caregiver letdown." Like soldiers haunted by wartime experiences, they may have a hard time reclaiming their old identity and leaving the role of caregiver behind.

Mental health experts have identified steps to take, both during and after the months of caregiving, to ease the transition.

During the Caregiving Months

Caregivers know only too well how hard it is to find time to focus on themselves during the often intense months when a loved one is battling cancer. They face more demands on their time than ever before. According to one survey, a third of cancer caregivers spend 40 hours a week meeting the needs of the relative with cancer. They go along on doctor's visits, pick up prescriptions, battle insurance companies, and give injections. Then there's the load of household chores to pick up.

In this extraordinarily busy time, several strategies can be a boon to the caregiver, with both an immediate payoff and a long-term benefit.

Don't be so quick to quit your job. Caregivers who give up a job for the duration of the cancer treatment may find it difficult to land a new position, especially if they're older. Taking a leave of absence or scaling back on hours, if need be, may be a better tactic. Under the Family and Medical Leave Act, you may be eligible for up to 12 weeks of unpaid leave for an immediate family member, allowing you to return to your job once caregiving duties are over.

If you choose to continue working, your job can also be a balm during the months of caregiving—a place where you know what you're doing. As long as the patient is faring well during the treatment, there's no reason you can't head to the office (although you do need to be prepared for unexpected absences).

Don't be afraid to face grim facts. If there is little hope for recovery or remission, the caregiver needs to strike a balance between denial and despair. An overwhelmed caregiver might avoid spending time with the patient. A caregiver who pretends that death is not imminent is likely to avoid meaningful interactions.

In this difficult circumstance, it's perfectly natural to ask questions about yourself: "Will I be OK? What is life going to be like without her?" There may also be practical concerns: "Can I pay the bills? Will I be able to keep the house?" Thinking about such matters does not make you a disloyal caregiver. Talking about these issues with a therapist or a friend can be helpful.

When Caregiving Ends

Your role as a caregiver will inevitably come to an end. Some caregivers feel as if an important part of their life has vanished. Even if the patient is doing well, the caregiver may have a hard time adjusting to the new reality: Instead of being dependent on the caregiver, the patient is independent again. This change is particularly hard if the patient is your child, regardless of their age.

A former caregiver may find that their mental health is suffering. In the American Cancer Society's National Quality of Life Survey for Caregivers, participants were asked about psychological distress. Caregivers reported levels higher than in the general population—even when the family member with cancer was doing well. The explanation: A newfound anxiety about recurrence is embedded in both the survivor and the caregiver's psyche.

If the patient has died, guilt can weigh on caregivers. Maybe the caregiver feels he or she didn't do enough. Or perhaps the caregiver is relieved that the family member is no longer suffering and that the difficult role of cancer caregiver is over. Such emotions can lead to a feeling of guilt. Caregivers who do resume old activities may feel disloyal to the patient's memory.

Here are some general points to keep in mind about difficulties adjusting to life after caregiving:

Time helps. The passing of weeks and months may not heal all wounds but will help with the caregiver's return to normalcy.

Don't minimize your caregiving work. Caregivers may feel frustrated that they didn't or couldn't do enough. In fact, a caregiver's physical presence and emotional support are invaluable. Understanding that you had an important role to play as a caregiver, and that you did it well, is a way of coming to terms with the sacrifices you may have made. You also need to tell yourself that even the best caregiver isn't perfect—in every case, there are times when a caregiver was not able to meet all the patient's needs.

Seek help if necessary. When guilt or grief leads to feelings of depression or hopelessness that are overwhelming, that's cause to seek the counsel of a mental health professional who's worked with cancer caregivers before. In less extreme circumstances, attending a support group for caregivers or confiding in a friend can be helpful. In fact, by sharing such feelings during the months of caregiving, you may be able to avoid a meltdown after caregiving is over.

Look for new challenges. One way to fill the gap in your life after caregiving ends is to tackle a new project. Some caregivers find fulfillment by launching a long-delayed home renovation. Others embrace volunteerism. A former caregiver

might imagine never wanting to utter the word *cancer* again, but plunging into cancer activism can bring fulfillment by putting the caregiving experience to good use.

Reflect on what you've been through. For caregivers as well as survivors, the encounter with cancer can lead to a stage of life referred to as “the new normal”—a deeper appreciation for life and, perhaps, a shifting of priorities. In one study of breast cancer couples, both partners reported personal growth after the suffering caused by cancer.

Friends and family members may urge survivors and caregivers to look toward the future, not the past. But thinking about what you've been through is the only way to take stock, figure out what's meaningful in life, and act upon that hard-won knowledge. Self-reflection is a potent weapon in the efforts to vanquish post-caregiver letdown.