

{ SPECIAL ISSUE }

Caregiving



{ A New Role }

By Lambeth Hochwald

Being a caregiver is one of the most important—and loving—things you can do for someone. And, since you're reading this, you're likely one of the millions of Americans who are in this exact role. Navigating this new terrain isn't without its challenges and, while everyone's cancer journey is unique, there are some caregiving tips that universally apply.

Generally speaking, cancer does not move at breakneck speed, and it's important to take some time to process what's happened. While you may be in the "shock and awe" stage with the patient, they are depending on you to be a source of help and comfort.

Talk it out. Once a diagnosis is confirmed, the caregiver can help the patient by discussing decisions that will need to be made quickly, including second opinions, treatment, and where to be treated. And because cancer is rarely simple, many decisions are made with imperfect information. Depending on the cancer, there may be two or more therapy choices with similar chances of success but different side effects. Balancing the risks of a clinical trial in another city against the comforts of treatment at home can be difficult. When faced with challenging decisions, the patient's priorities can help make a complicated medical decision easier. While the patient will want to know what you think about treatment options or next steps, the person with cancer should decide what actions to take. What a person wants most from a caregiver is someone who will listen without offering judgments, easy solutions, or platitudes. Your job is to remain calm and not overwhelmingly anxious. Knowing what they want will maintain forward momentum in the absence of perfect information.

Creating a Caregiver Notebook

Help with research. A good use of this time is to learn about the disease, the range of potential treatment options, and to begin developing a treatment plan. For caregivers, it's worth it to invest a little time helping the patient with their research, and getting up to speed on the vocabulary. This will help break down the social isolation that patients can feel, just by widening the pool of people they can talk to about the absurd minutia of the disease. It won't all be comforting information, but understanding can make it easier to make timely decisions later. The doctor should be able to help guide further education, but doctors have significant schedule constraints and have limited time to spend with patients. To make the most of this time, caregivers can help hone the questions and if needed, request for additional appointments to review the pros and cons of different treatment options. For really big decisions, make sure you talk with the patient a few days beforehand in case questions come up that require a little more research.

Listen and learn. In the doctor's office, a patient is likely to forget a significant portion of what the doctor says. This makes sense considering the fact that cancer is an emotional topic and a lot of life-altering information is presented. This is where you come in. Listen carefully, take notes, or, with the doctor's OK, record the session to help the patient regain the information when you're home and beginning to put together an action plan. A caregiver no-no is pirating the conversation with the doctor. Follow the patient's lead: If you have permission to pursue a dialogue with the doctor, fine. Otherwise, let them make the call. Once the treatment plan has been determined by the medical team, get the plan in writing.

Be realistic about what's ahead. Surgery, chemotherapy, and radiation are very taxing so you never want to minimize what your loved one is going through or may soon experience. Keep in mind that some people experience extreme nausea and fatigue during chemotherapy and radiation, and others will lose their hair. In general, know that the toll chemo takes is cumulative. The patient may feel fine at the outset of treatment but will likely feel worse before they start feeling better.

Watch for hidden symptoms. Once treatment has started, the patient may suffer symptoms or side effects from the cancer or the treatment. However, many symptoms and side effects are silently endured by cancer patients. Here's another entry point for caregivers who may be more likely to notice if the patient is having difficulty with a task or seems especially uncomfortable. Counselors can help ameliorate stress, depression, and other psychological symptoms. Physical and occupational therapy can mitigate pain and infirmity, while dietitians, acupuncturists, and massage therapists can make treatment easier. Social workers can help arrange other needed support services.

Kind gestures help. Small gifts, cards, and flowers can help lift your loved one's spirits. Experts say that it's completely normal for patients to experience days where they feel dejected, lonely, afraid, or depressed. While you don't want to overdo it, consider it your job to offer words of hope and reassurance. In addition, allow the patient some time and space to be alone. Relaxation techniques, such as meditation, light reading, walking, or even a movie, can be helpful. Don't smother or shield your partner from finding his or her own source of strength and inner balance.

Discuss legal issues. If the patient hasn't already, they should take care of important legal affairs such as wills, living wills, and medical power of attorney. Even if the cancer has a high cure rate, it's something we should all do at some point. It's never fun, but it will only get harder as treatment progresses.

Allow the person to feel their feelings. As a caregiver, you want to be sure they feel comfortable expressing exactly how she or he feels. Remember: You don't want them to feel like they have to feel peppy and positive all the time. During chemotherapy or in the waiting room, for example, take your cues from them and give them permission to be whatever they are in the moment—chatty, sad, depleted, or worried.

Take a step back. Conflicts about treatment are often more intense when the cancer recurs or is diagnosed at an advanced stage with expectations of shorter survival, experts say. In these cases, the issue of whether to do more chemotherapy or look into other options rises to the surface more quickly. Caregivers may want the patient to keep pushing and try everything possible to fight the cancer, while the patient believes it's time to stop treatment. Or, a patient may want to pursue alternative treatments, upsetting caregivers who want them to stick to conventional medicine. Regardless of the scenario, it's up to you to step back and, again, allow your loved one to make the choices that are right for him or her.

Call a family meeting. If you're caring for a parent who lives far away from you, speak with family members about how to best manage care. The question: Who will do what? Or more specifically: Who has the time and inclination to do what? And, if the parent can participate, he or she should. It's important for the patient to be involved in the dialogue. Quarterly or monthly follow-up meetings should be planned as well to allow for revisions in the caregiving plan. And meetings should be scheduled before a new stage of treatment. Finally, if outside help is needed, be it a home health aide or hospice care, always be honest with the parent. Ultimately, they should maintain his or her independence and control all the decisions about care.

Organize information. Purchase a binder and a hole-punch. That way you'll have somewhere to place the unending stream of doctor's notes, bills, test results, insurance records, info about support groups, and other cancer-related pieces of paper that will add up—fast.

Ask for help. Doing the laundry and stocking the house with comfort foods, like ginger ale, saltines, and soothing teas are great. But you may also be trying to juggle a job, maintain order in the house, and get the kids to school, and this may be too much. If this is your situation, and you feel like you can't get the basics done, ask for help. Neighbors and friends are usually happy to create a rotating schedule where they pitch in to walk the dog, pick up groceries, or make phone calls. For patients receiving terminal care, respite services for caregivers may be available through a hospice agency.

Set up a survivorship plan. Thinking of life after cancer may be an afterthought, especially with the laundry list of doctors' appointments, household tasks, and outside work that takes its toll on the patient and caregiver. But the transition from active treatment to being a healthy survivor is just as important, including knowing what follow-up visits, long-term effects, and limitations the patient will have in the years after treatment. Survivorship plans have been developed for a number of diseases to help manage health and other related concerns. A caregiver can help by tracking these from day one and by keeping in touch with the medical team during and after treatment.

—Erik Ness contributed to this article.



{ Taking Care of Yourself }

By Melissa Knopper

In the chaos and intensity that surrounds a new cancer diagnosis, everyone tends to focus all of their care and concern on the patient. Too often, medical staff and relatives forget to stop and ask the family caregiver how they are doing.

While caregivers tend to brush their own needs aside, experts warn that completely selfless devotion can backfire. A study in the *Journal of the American Medical Association* found that elderly caregivers have a 63 percent higher mortality rate than their peers. And new research highlights the importance of the caregiver's well-being. It turns out, the health and mental outlook of the caregiver can impact a cancer patient's survival and quality of life.

Take a look at some of the typical "side effects" cancer caregivers tend to experience:

Depression. A study in the *Journal of Clinical Oncology* showed women who cared for their husbands who had prostate cancer experienced depression at twice the rate of the cancer patients themselves. Caring for someone full-time can lead to feelings of panic, despair, and isolation. And after the initial crisis of diagnosis, surgery, and chemotherapy or radiation, there's a lingering worry that the cancer could return. Reach out to friends and family, online chat groups, and support organizations to help reduce the feelings of isolation.

If after talking with friends and family or trying exercise and other stress reduction techniques doesn't help, it may be time to see a therapist or talk to a doctor. This may be the first time you have ever felt truly depressed, but there is no shame in asking a professional to help pull you out of it.

Setting Up a Caregiver Team

Insomnia. Getting up in the night to care for a sick person, offer pain medication, or just listen for changes in breathing can wreak havoc on normal sleep patterns. Sometimes this wakeful type of sleep can become a habit and leave caregivers exhausted during the day. Other times, caregivers may find themselves wide awake in the middle of the night, feeling overwhelmed by fears and worries.

To overcome insomnia, sleep experts suggest everything from guided imagery and relaxation techniques to acupuncture and even warm milk, which contains a sleep-inducing compound called tryptophan. Cutting back on late afternoon coffee breaks and boosting your exercise, especially yoga, can also help caregivers sleep better. Sometimes it helps to write down your worries, and release them for the day, before heading to bed. If all else fails, it may be time to talk to the doctor about a non-addictive sleep aid.

Stress/burnout. The constant stress of caregiving can make you more vulnerable to getting sick. Stress can make your back and shoulders tense, and lead to more aches and pains than usual. Experts at the [Family Caregiver Alliance](#) remind us to listen to the airline attendant who says to put on your own oxygen mask before you help someone else. That means taking a look at your stress level as a caregiver and trying to prevent burnout before it hits. Make a list of what triggers your stress right now. Then make another list of steps

you could take to reduce that stress. As former First Lady and caregiver advocate Rosalynn Carter says, you can't be much help to your sick relative if you don't take care of your own needs—both physical and emotional.

Experts who study the art of caregiving offer the following common-sense solutions to help caregivers manage their stress and refuel:

Find meaning. American Cancer Society researcher Youngmee Kim, PhD, calls it "benefit finding." Other researchers label it a "sense of mastery." If you can take your experience with cancer, even as a caregiver rather than a patient, and learn from it, you will have less depression and anxiety. Cancer caregiving can help you find more meaning in your life and focus on the right priorities into the future. How to better develop this sense of mastery? Work on your personal growth. Participate in an art therapy workshop for cancer patients and spouses, buy a new journal and write your way to the answers, talk with a counselor, or lean on your faith.

Others delve into the cancer diagnosis, trying to learn everything possible about the patient's condition. This gives caregivers a sense of control and helps them to be better patient advocates. If you accept your role as caregiver, and approach it like a professional, it can be a very empowering experience.

Reach out. Support from family and friends is key. Everyone knows this, but it's not always easy, especially for caregivers who live in remote rural areas. Advocates at the [Well Spouse Association](#) got around this barrier by sending "round robin"-style letters to caregivers who lived in isolated settings and couldn't make it to a local support group. [Caringbridge.com](#) is another nice resource for family members who are scattered around the country but want to stay close. Otherwise, support groups for cancer patients and caregivers are pretty easy to find through local hospitals and the American Cancer Society. Join one. It makes a huge difference to feel you're not the only one going through something hard.

Take offered help. As the primary caregiver, you may bump into a friend or neighbor who asks, "What can I do to help?" Veteran caregivers offer this suggestion: Always keep a list in your pocket. That way, you can pull it out and sign them up to sit by your relative's bedside so you can get out for a nice walk, attend religious services, take a yoga class, or get a massage. For other shy types, there are websites such as [Lotsa Helping Hands](#) that allow caregivers to set up a system with calendars and online organizing tools so friends and family can jump in and help without even being asked.

If friends or relatives are not available to step in for a few hours, hire someone, or find adult day care. The U.S. Administration on Aging offers a national database of elder care providers, called [Eldercare Locator](#).

Communicate. Most often, when a person is diagnosed with cancer, it's the spouse who takes over the caregiving. American Cancer Society research shows husbands and wives can affect each other in profound ways in this new relationship (as patient and caregiver). And it goes both ways. First, they discovered wives hold themselves up to impossibly high standards as caregivers. They get stressed out, try to do too much, and rarely make time for themselves. The study showed this had a negative effect on the husband's ability to heal. Instead, the husband absorbed these negative feelings and felt guilty about putting his wife through so much.

Meanwhile, the ACS study found male caregivers also affect their wives, but in a different way. A group of women with breast cancer said their husbands would try to ease their worries and fears by minimizing them and offering "quick fix" solutions. While the husband wanted to help, the wives perceived this as an uncaring attitude. Most of the women said they just wanted someone to listen and give them a hug. As a result of this study, the ACS may soon offer a special course for male cancer caregivers that will teach empathic listening and open communication.

With everything they have to do in a day, caregivers often neglect basic health maintenance. Sometimes caregivers get in the habit of putting themselves last. If that's the case for you, try thinking of it a different way—if you can see it as giving a gift to the person you are caring for, it might be easier to make time each day for good nutrition and exercise. Caregiver groups offer the following reminders to help caregivers take better care of their personal health:

- Make sure you add some fruits and vegetables to your diet each day.
- Eat three meals a day, and guard against weight loss.
- Stay hydrated.
- Take a daily multivitamin.
- Shoot for eight hours of sleep per night, when possible.
- Exercise or go for a walk every day, even if only for 10 to 15 minutes. Studies show exercising four times a week helps caregivers sleep better, prevent heart disease and high blood pressure, and stave off depression.
- Line up help so you can keep your regular appointments for dental cleanings, health screenings, and annual check-ups.
- Get a flu shot so you don't get stuck being too sick to be a caregiver or put your loved one in danger of getting sick themselves.
- Make room for humor. Keep in touch with friends who make you laugh; rent a funny movie now and then.
- Keep up with social groups, such as a book club or a softball team. These are important ways to combat stress. Schedule regular times to socialize with friends and family.

As a caregiver, it's common to get so absorbed in your new role that you lose your own identity. Neglecting your personal needs is easy to do, but avoiding this common pitfall is key, both for the patient's well-being and your own. Remember, you are still a person in your own right and it's not shameful to care for yourself before turning back to your caregiver duties. In fact, it's one of the most important ways you can help another person.



{ 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.

Coping with Grief and Relief

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.