

FEATURE STORY

For the Caregiver: A New Role

Navigating the challenging territory of caregiving

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 apply to nearly everyone.

Talk it out. Generally speaking, cancer does not move at breakneck speed, and it's important to take some time to process what's happened. Discuss with the patient the decisions that will need to be made quickly, including second opinions, treatment, and where to be treated.

Help with research. Learn about the disease, the range of potential treatment options, and help the patient to understand and follow the treatment plan. The doctor should be able to help guide further education. To make the most out of the short time with the medical team, caregivers can help focus the patient's questions. For really big decisions, talk with the patient a few days beforehand in case questions come up that require a little more research.

Listen and learn. During appointments, listen carefully, take notes, or, with the doctor's OK, record the session. If you have permission to pursue a dialogue with the doctor, fine; otherwise, let the patient lead the conversation. Once the treatment plan has been determined by the medical team, get the plan in writing. Ask questions about any points that are not clear.

Be realistic about what's ahead. Treatment can be very taxing, both emotionally and physically, so you never want to minimize what you or your loved one is going through. Keep in mind that people react differently to different treatments. Some patients will have more nausea or fatigue than others, or a patient may worry about losing their hair more than any other side effect. Also know that the toll chemo takes can be cumulative. The patient may feel fine at the outset of treatment but will likely feel worse before they start feeling better.

Kind gestures help. Small gifts and cards can help lift your loved one's spirits. Experts say it's completely normal for patients to experience days when they feel

dejected, lonely, afraid, or depressed. Allow the patient some time and space to be alone. Don't smother or shield your loved one from finding his or her own source of strength and inner balance.

Discuss legal and financial issues. If the patient hasn't already, they should take care of important 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. Also, consider reviewing financial details, such as bank accounts, tax documents, stocks, bonds, mutual funds, CDs, and contact information for financial advisers.

Allow the person their feelings. As a caregiver, you want to be sure the patient feels comfortable expressing exactly how he or she feels. You don't want them to feel like they have to be peppy and positive all the time.

Take a step back. Conflicts about treatment are often more intense when the cancer recurs or is diagnosed at an advanced stage, experts say. The caregiver 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, allow your loved one to make choices that are right for him or her.

Call a family meeting. Friends and family, regardless of distance, may want to be involved. Organize a family meeting, even by phone, to discuss who will do what. It's important for the patient to be involved in the dialogue. Quarterly or monthly follow-up meetings should be planned to allow for revisions to the caregiving plan. Finally, if outside help is needed, be it a home health aide or hospice care, be honest with the patient. Ultimately, patients should maintain as much independence as possible and control decisions about their care (within reason).

Help the patient set up a survivorship plan. The transition from active treatment to being a healthy survivor is important, including knowing what follow-up visits, long-term effects, and limitations the patient will have in the years after treatment. A number of cancer survivorship plans have been developed (see "[A Post-Treatment Prescription](#)"). A caregiver can help keep up with the plan from day one and keep in touch with the medical team during and after treatment.