

1 INTRODUCTION TO CAREGIVING

Visit www.LLS.org/CaregiverWorkbook to access all chapters and worksheets.

Am I a Caregiver? If you are consistently caring for a person who has a serious illness, you are a caregiver. If you're helping someone with his or her daily needs, such as making food, balancing the checkbook, bathing or dressing, or going to the doctor's office or the grocery store, you are a caregiver. You may be a son or a daughter, a husband or a wife, a parent, an in-law, a neighbor or a friend. You may live together, next door, across the state or across the country. The person may only need support occasionally, or he or she may not be able to manage alone. The relationships between caregivers and persons receiving care vary. Throughout this workbook the person receiving care is referred to as a "loved one" or "patient." These terms may not accurately reflect the relationship between yourself and the person you are caring for.

If you're providing regular assistance, you are a caregiver.

You may not think of yourself as a caregiver. You may just see it as taking care of someone you love or lending a helping hand, but what you are doing is extremely important. Helping a loved one with cancer can be challenging. Caregiving can be a full-time, nonstop job that wears on you physically and emotionally. But, there are many things you can do to make caring for your loved one easier.

This workbook is filled with information, tips and activities to help you through the challenges of being a caregiver.

What Does Caregiving Look Like? Caregivers provide important ongoing care for the patient. The job of a caregiver falls into three basic categories: medical, emotional and practical. There are different levels of caregiving depending on your loved one's age, diagnosis, treatment plan and overall health. Your loved one may only need help from time to time to allow him or her to focus on healing after treatment. Or, your loved one may need constant care. The kind of support needed will be different for each person and may also change over time.

Caregiving often starts gradually with tasks such as driving to medical appointments, shopping for groceries and housecleaning. As treatment progresses, your loved one may need more and more help leading up to round-the-clock care, which may feel overwhelming for you. Your tasks may grow to include feeding, bathing, supervising medications, arranging medical care and managing financial and legal affairs. There may be a time where you have to cope with an emergency situation, such as making a trip to the emergency room or having to contend with severe weather conditions. However, caregiving is not always linear. If treatment is successful, your loved one may become well enough to start taking on daily tasks again.



Use **Worksheet 1: Emergency Room (ER) Plan** and **Worksheet 2: Weather Emergency Plan** to prepare for an emergency situation.

Here are just a few examples of caregiver tasks. Depending on what your loved one needs, you can help by

- Going grocery shopping and preparing meals
- Assisting with personal hygiene and changing clothes
- Assisting with using the bathroom
- Cleaning
- Doing laundry

- Keeping track of finances
- Driving your loved one to appointments and treatments
- Providing emotional support
- Reminding him or her to take medication and adhere to the treatment plan
- Communicating with members of the healthcare team
- Taking notes during medical appointments
- Communicating with other friends and family members.

Caregiving Strategies. Use the following suggestions so you don't feel overwhelmed and can be at your best to help your loved one:

- Acknowledge that an adult has the right to make decisions about his or her life. Respect that right unless your loved one is no longer capable of making decisions or could put himself/herself or others in danger through his or her behavior.
- Whenever possible, offer choices. Making choices is a basic freedom, so provide choices for your loved one when possible. Choices enable us to express ourselves. As your loved one's options become more limited due to health changes, financial constraints or social losses, you may have to work harder to provide choices.
- Do only those things your loved one can't do. If your loved one is still capable of performing certain activities, such as paying bills or cooking meals, encourage him or her to do so. Helping your loved one maintain a feeling of independence will make him or her feel better about being in a care-receiving situation.
- Be prepared to do what you promise to do. Many care recipients find it emotionally difficult to depend on others, and many worry about being a burden. With all these mixed feelings, your loved one needs to be able to rely on you. Do what you promise. Remember that your loved one needs you, even if he or she doesn't say so.
- Take care of yourself. Caregivers often exhaust themselves by trying to handle caregiving responsibilities on top of normal daily routines. Providing care for a loved one while holding down a job, and perhaps taking care of a family, can lead to exhaustion. If you become exhausted, you're more likely to make bad decisions or to take your frustrations out on your loved one. Take time to sleep and to do things you enjoy. It is important to take time for yourself so that you can be there for the long haul. Ask your loved one's healthcare team to suggest local resources, such as adult day care services that can give you some relief from responsibilities that may feel overwhelming.
- Give yourself a break. At some point in your role as a caregiver, you may start to feel resentment toward your caregiving responsibilities or even your loved one, especially if you are a long-term caregiver. These thoughts may be followed by feelings of guilt. Caregiving is a difficult job so don't beat yourself up over these normal and common feelings.
- Remember that your family is your first resource. There can be deep emotional currents when a loved one becomes ill. Some family members will want to do everything, while others will do very little unless they're asked. Yet, spouses, brothers and sisters, children and other relatives and friends can do a lot to ease your caregiving burden. Don't be afraid to reach out to them for help.

“You just need to get friends together and say, ‘Listen, can you help drive my husband here?’ Don't be afraid to say, ‘I need help.’ A lot of people just take it upon themselves. It eats you up and you can get sick yourself from it and be a mess.”

—Donna, caregiver and wife of Pete, acute promyelocytic leukemia (APL) survivor

Excerpt from November 2017 “Processing Our New Plan: Pete and Donna's Story” podcast episode on *The Bloodline with LLS* (www.LLS.org/TheBloodline)



Search for More Helpful Organizations

Many organizations help with cancer-related issues such as financial assistance, support and counseling, assistance with transportation, etc. Don't be afraid to reach out to these organizations for support.

To explore specific organizations by need, visit www.LLS.org/ResourceDirectory or call

The Leukemia & Lymphoma Society (LLS) to speak to an Information Specialist at **(800) 955-4572**.

