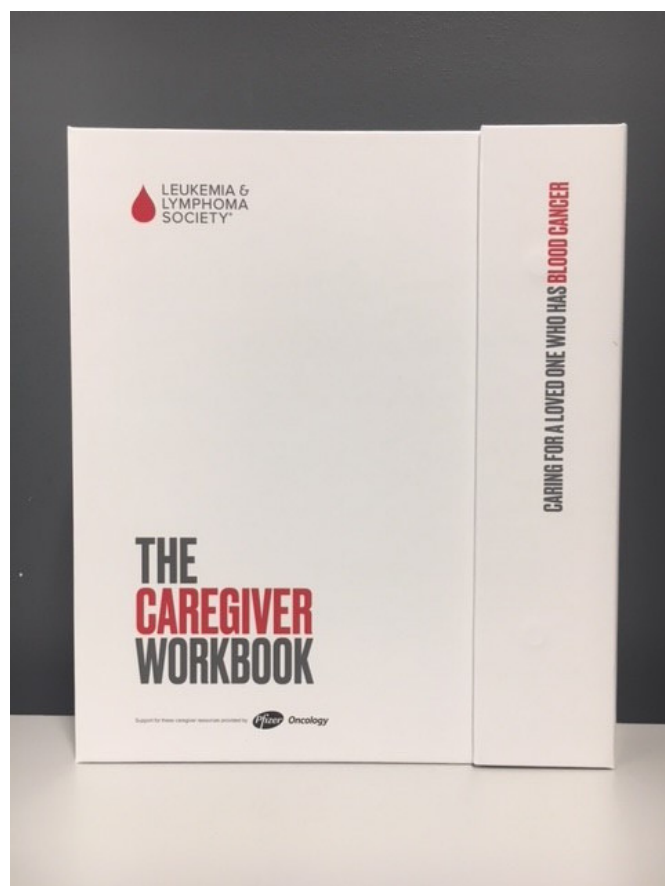


Caregivers may often be overlooked, as the focus is on the patient's care. The Leukemia & Lymphoma Society has created a comprehensive binder to assist caregivers in their role.

**TELL YOUR
PATIENTS'
LOVED ONES
ABOUT THIS
VALUABLE
RESOURCE**



**TO ORDER THE CAREGIVER
WORKBOOK, PLEASE HAVE
CAREGIVERS CALL OUR
INFORMATION SPECIALISTS AT
800.955.4572**

BEATING CANCER IS IN OUR BLOOD.



Examples of chapters included in The Caregiver Workbook:

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 loved one with a serious illness, you are a caregiver. If you're helping your loved one 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, parent, an in-law, a neighbor or a close friend. You may live together, next door, across the state or across the country. Your loved one may only need support occasionally, or your loved one may not be able to manage alone.

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 isn't always easy. Caregiving can be a full-time, nonstop job that wears on you physically and emotionally, but there are many things that you can do to make caring for your loved one easier.

This Workbook is filled with information, tips and activities to help you work through the challenges of helping the cancer patient in your life.

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, this can lead to round-the-clock care, which can feel overwhelming. 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 deal with an emergency situation, such as 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

5 CAREGIVING DURING TREATMENT

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

Preparing the Home. During and after cancer treatment, your loved one may find life at home becomes increasingly challenging. Make changes to the home that will make life easier and safer if your loved one is experiencing mobility issues, peripheral neuropathy, pain or weakness after treatment.

Home Changes Checklist. Check off the changes as you implement them around the home to make it more comfortable and safer for a patient who will be undergoing cancer treatment.

- ☐ Put items in easy-to-reach places. For example, put clothing in baskets or drawers instead of on high shelves or in closets.
- ☐ Lower the patient's bed or get a step stool to make getting into and out of bed easier.
- ☐ Keep stairs and hallways well lit.
- ☐ Get rid of slippery rugs that can slide or bunch up causing a tripping hazard.
- ☐ Add a shower seat and hand-held showerhead to make bathing easier.
- ☐ Use nonslip bath mats, both in and outside the tub/shower. Add a safety bar or hand grips to reduce the risk of falls.
- ☐ Find a raised toilet seat or commode.
- ☐ Use nonbreakable dishes and cups for food.

Depending on your loved one's diagnosis, treatment, and health, you may need professional help to make larger or structural changes to his or her home. For example, if your loved one is wheelchair bound, you will need to add a ramp to the entrance of the home.

Other Things You Can Do to Prepare the Home. Follow these tips to prepare your loved one's home.

- ☐ Stock the pantry, fridge, and freezer with healthy food choices.
- ☐ Move comfortable, easy-to-wear clothing to the front of the closet.
- ☐ Keep throw blankets and extra quilts in an accessible location. Cancer patients can be more susceptible to cold.

Use **Worksheet 10: Grocery List** to begin with a fully stocked pantry.

FACT

Peripheral neuropathy results from damage to the nerves in the arm, legs, hands or feet which can cause numbness, tingling, burning, coldness or weakness in the affected area. It can be a side effect of some cancer treatments. Peripheral neuropathy can also lead to mobility issues.

8 CARING FOR YOURSELF

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

As a caregiver you may neglect to take good care of your own needs because you are so focused on caring for your loved one. This is understandable, but to offer your loved one the best possible care, you need to be healthy and well yourself, both physically and emotionally. In the next few pages, learn strategies for taking better care of yourself while caring for a cancer patient.

Ways to Care Yourself. Caring for someone who is sick and, at the same time, worrying about what the future holds is exhausting and can quickly lead to burnout. Caregiving can often be a full-time job. Often, caregivers will just keep doing what needs to be done and neglect their own well-being or feel guilty if they do take time for themselves.

Use the following strategies to make sure you don't forget to take care of yourself. Even if you only have a few minutes to spare here and there to do these things, it can still make a difference.

- Get some form of exercise like walking or an aerobics class.
- Create a support system. Call friends or family when you need to talk or need help.
- Keep up with a hobby or something you enjoy doing, such as reading, painting or gardening.
- Try to stay connected with friends even if you do have to cut back on your social life.
- Eat well-balanced meals. Caregiving can leave little time, and many people turn to fast food or junk food. Get the nutrition your body needs.
- Have a place where you can go to "escape" and just be by yourself.
- Set priorities each day and make sure the most important tasks get done, but try not to worry about items further down your to-do list.
- Seek proper medical care for yourself as well by seeing your primary care provider (PCP). Follow any directions given by your PCP. For example, take any medications as prescribed.
- Try to cut out smoking and drinking alcohol.
- Try to get a good amount of sleep each night and find time to rest throughout the day.

Accept help from friends and family. Learning to let go and to accept help will lower your anxiety levels and raise your spirits. People want to chip in, but they may not be sure what kinds of help you need. Keep a list of all caregiving tasks. That way, when friends or family offer to help, you can give them specific tasks. Try using a caregiver mobile app to help you coordinate help from family and friends.

"Being a caregiver is stressful. It is a necessary thing... To me, there is a lot of on-the-job training. There are a lot of decisions that you have to make that you wish you didn't have to make; a lot of decisions that you have to make that you are just completely unprepared for, but in order to get through it, you definitely need some down time. You need some 'me' time and don't feel bad about it!"

—Kimberly, caregiver and wife of Elgin, who passed from myeloma

Excerpt from July 2018 *My Plateau* by Caregiver Kimberly's story, written specially for The Advocate with LLS. www.LLS.org/TheAdvocate

Helpful worksheets included in The Caregiver Workbook:

Worksheet 1: Emergency Room (ER) Plan

Worksheet 10: Grocery List

Worksheet 2: Weather Emergency Plan

Worksheet 11: Chore Chart

Worksheet 3: Daily Medication Log

Worksheet 12: Food Intake and Side-Effects Log

Worksheet 4: Questions for Caregivers to Ask Their Loved Ones

Worksheet 13: Meal Planning

Worksheet 5: Healthcare Team Contact List

Worksheet 14: Insurance Call Log

Worksheet 6a: Appointment Calendar, by Month

Worksheet 15: Understanding the Health Insurance Plan

Worksheet 6b: Appointment Calendar, by Week

Worksheet 16: Health Insurance Appeal Tracking Form

Worksheet 6c: Appointment Details

Worksheet 17: Budgeting

Worksheet 7: Questions for the Healthcare Team

Worksheet 18: Financial Assistance Record

Worksheet 8: Medical History

Worksheet 19: Creating a Self-Care Plan

Worksheet 9: Immunization Record



Items included with
The Caregiver Workbook

For questions or to order THE CAREGIVER WORKBOOK, please have caregivers call our Information Specialists at 800.955.4572.

The Caregiver Workbook is available as a PDF on the LLS website at www.LLS.org/CaregiverWorkbook.