

Understanding Lymphoma and Chronic Lymphocytic Leukemia/ Small Lymphocytic Lymphoma (CLL/SLL)



Part 6 — Caregivers

Chapter 21: Caring for Someone with Lymphoma

What Is a Caregiver?

A caregiver is someone who is helping a loved one with lymphoma through their treatment. If you are taking care of your partner, a family member or a friend who has lymphoma, you are a caregiver. While it may feel natural, being a caregiver is often demanding and can be a full-time and hard job. Caregiving can mean many things, including helping with daily activities (practical care), overseeing healthcare routines (medical care) and providing emotional support (emotional care).

- **Practical care:** assisting in daily chores, like running errands, cleaning, meal prepping or childcare. You may also be asked to manage financial and insurance matters, keep track of important documents or be a direct contact for any pressing non-medical issues. Some individuals may not want to burden you but would genuinely appreciate what you would do.
- **Medical care:** going to medical appointments, sorting through treatment options, and making sure medications are taken correctly. You may also assist in managing side effects or special diets according to the doctor's instructions.
- **Emotional care:** offering emotional or spiritual support to the person with lymphoma. This includes listening to your loved one and helping them cope with their feelings throughout the course of treatment. The single most important thing to do is to show up and just be present.

Helping Your Loved One

As a caregiver for your loved one diagnosed with lymphoma, the dynamics of your relationship may change. Caregiving often implies a change in roles, like taking care of your parent as an adult, or caring for your spouse or friend who has always been healthy. In this new role, parents may be uncomfortable with receiving help from their adult children, or a patient may only accept help from a spouse. It is very common for caregivers to feel overwhelmed in the beginning, particularly if they lack experience. Many caregivers say that they learn more as they go through their loved one's cancer treatment. There are many ways you can help a loved one with lymphoma, as follows:

- **Be prepared** — Talk with the healthcare team so that you know what to expect throughout the treatment, how to manage symptoms and when to ask for help.
- **Listen** — Each person asks for help in different ways (some require more comfort; others are more action-oriented). It is important that you understand what your loved one wants.
- **Avoid “cheerleading”** — Do not disregard negative feelings (such as sadness, anger, or worry). Be alert to signs of depression (hopelessness, prolonged crying, or persistent inability to enjoy things) and seek expert help from a mental health professional if needed.
- **Organize help** — If an abundance of help is available, find ways to organize and coordinate help amongst those who are willing, so that anyone offering help can be of the greatest value for a specific need at appropriate times.
- **Offer transportation** — This is important for all, including older people with decreased mobility or limited resources. Making sure your loved one gets to the appointment or simply going along for the ride can be very helpful. Patients may not be able to drive after chemotherapy and supportive care medications.
- **Take notes** — If you go into the appointments, write down notes with the doctor's plan, medications, potential side effects, phone numbers and other relevant information. Keep this information in a place that is easy to find in case there are questions (your computer, cell phone or even a spiral notebook).

Long Distance Support

It is possible to support a loved one with lymphoma from afar. This is called long distance caregiving and applies if you are taking care of a loved one who lives an hour or more away. Long distance caregivers can assist with practical issues, which include helping with finances, arranging for in-home medical care and assistance with daily tasks, clarifying insurance coverages and issues with property, and providing emotional support. While this can occur remotely, long distance caregiving can sometimes require in-person visits. Below are simple actions you can take to support a loved one with lymphoma from afar:

- Build a contact network close to your loved one. This includes members of the healthcare team, social workers, or local relatives, friends or neighbors whom you can call during a crisis or just to check in.
- Share a complete list of your contact information (email, home, work, and cell phone numbers) with the healthcare team, local relatives, friends or neighbors. Ask them to update you as frequently as possible.
- Use remote technologies (like Skype, FaceTime, Zoom) that can bring in others to communicate directly with your loved one and provide emotional support
- Explore the local availability of paid or volunteer support, adult day care centers or meal delivery services.
- Plan your visits. Be familiar with the hospital's most recent visitor policy and ask for visitor information packets or lists. Check with the primary caregiver (if there is one) to learn ahead of time what your loved one needs.
- When traveling, check with transportation companies (bus or airlines) for special deals for caregivers. Time your flights or drives so that you have time to rest.

You can also go online to browse for local resources for your loved one. Helpful links include the Family Caregiver Alliance (visit <https://www.caregiver.org/connecting-caregivers/services-by-state/>). The American Red Cross may offer training opportunities on caregiving (visit <https://www.redcross.org/take-a-class>).

Chapter 22: Talking to Children, Teenagers and Siblings

How to Talk to Children and Teenagers?

Explaining cancer to children and teens is difficult, but it is very important that they do not feel left out of what is happening. There are no “right” or “wrong” ways to have this conversation, but you can follow the suggestions below:

- Do not keep it a secret. Children and teens can tell when something is wrong and may think things are worse or even blame themselves.
- Do not make false promises or feed unrealistic expectations. This can raise trust issues with you and other adults, projecting later into adult life.
- Explain that the treatment may cause visible side effects like decreased energy and hair loss.
- Be patient and ready to explain things as many times as needed. Children and teens may have a hard time processing this information, and repeating the same question can be a way for them to ask for reassurance.
- Keep their routines as stable as possible. This can provide reassurance in times of stress.

It is also important to let their teachers know what is going on. They will be alert for any signs of distress and changes in school performance, which may indicate that the child/teen is feeling anxious and overwhelmed. This may also manifest with physical symptoms (like headaches and stomachaches), sleep disturbances or irritability. If the behavioral changes persist, seek help from a qualified mental health professional.

You can also find resources online for teens dealing with a cancer diagnosis in their family (visit cancer.gov/publications/patient-education).

Impact on Siblings

A pediatric lymphoma diagnosis will also affect any siblings. Here are some practical tips to help siblings cope during this demanding time:

- Explain the situation and let them know what to expect during treatment. Keep them up to date and as involved as possible (e.g. include them in hospital visits).
- Set aside some daily time to check in and see how they are doing, even if just for a few minutes. It is important that siblings feel that they are heard.
- Keep their routines as stable as possible (school and extracurricular activities) and have friends and/or neighbors help if they can.
- Be alert for any signs of emotional distress, anxiety or depression, and seek the help of a trained mental health professional if needed.
- You can also find resources online for siblings of children with cancer (visit cancer.gov/publications/patient-education).

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Chapter 23: Support During Treatment

Depending on the diagnosis, treatment options could be given intravenously at a hospital or can be taken by mouth. Before starting treatment, the doctor will discuss the risks, benefits, and side effects associated with the different treatment choices. It is important to share questions and concerns with the doctor to decide which option is best. This is also time to clarify any caregiver assistance you may need before, during and after undergoing treatment.

For pediatric patients, speak with the health care team about providing age-appropriate information on treatment to help aid their expectations.

Oral Therapies and Adherence

Today there are many drugs for the treatment of lymphoma that can be taken by mouth, either in liquid or tablet/capsule form. Oral agents can be very effective at suppressing cancer cell growth and at maintaining long-term remission (disappearance of signs and symptoms). Adherence, which refers to a patient's ability to consistently take all medication as prescribed, may be a challenge for some patients.

Caregivers can help their loved ones adhere to oral therapies by using diaries and medication dispensers that record when the pill container was opened. Online reminders and apps for smartphones and devices can also be useful. Lymphoma Research Foundation's (LRF's) award-winning Focus On Lymphoma mobile app provides patients and caregivers with comprehensive content based on their lymphoma subtype and tools to help manage the diagnosis and treatments, including a medication manager and side effects tracker.

CAR T-Cell Therapy

Chimeric antigen receptor (CAR) T-cell therapy requires a significant amount of support from a caregiver, including around-the-clock care and monitoring for side effects. Your loved one should identify suitable primary

and alternative caregivers prior to undergoing CAR T-cell therapy. The healthcare team overseeing the treatment should then help select the person most qualified for the role. Overall, the caregiver for the duration of CAR T-cell therapy should:

- Be at least 18 years of age, in good health, able to provide hands-on care, and available around the clock for a designated time frame.
- Not be hired.
- Understand and recognize symptoms of serious side effects like cytokine release syndrome (flu- like symptoms, fever, low blood pressure, body aches) and neurotoxicity (anxiety, delirium, dizziness, headache, insomnia, difficulty speaking, tremors)
- Be able to measure the patient's oral temperature and identify signs of neurologic impairment.
- Communicate with the health care team when needed.
- Transport or accompany the patient to emergency and scheduled appointments.
- Administer oral and potentially intravenous medications as instructed.
- Prepare meals and keep housing clean.

The chosen caregiver(s) must be aware of housing requirements prior to the start of CAR T-cell therapy. Patients must stay close to the center for at least 4 weeks after the treatment, to be monitored for side effects and treated, if needed. Your loved one's healthcare team will provide necessary guidance throughout all stages of treatment.

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Chapter 24: Self-Care

Being a caregiver can be demanding and requires emotional and physical endurance, particularly if you have other responsibilities (such as work or raising children). Caregivers often disregard their own well-being and have a hard time focusing on other matters. Over time, this can lead to “burnout” - a condition marked by irritability, fatigue, sleep disturbances, weight fluctuation, feelings of helplessness or hopelessness, and social isolation. As a caregiver, it is important that you practice self-care regularly to reset your physical and emotional well-being. Adopting routines of self-care throughout the process will help you recharge your batteries and give you the strength you need to carry on. This will make the experience less stressful for you and help you be a better caregiver.

Ways to Take Care of Yourself

Self-care will help you stay physically and emotionally healthy. To achieve that, consider the following suggestions:

Watch your health. Stay up-to-date with your own medical appointments and take any medications as prescribed.

Table 24.1. Tips for Self-Care

Exercise	<ul style="list-style-type: none">■ Stay active with short periods of daily exercise (30 minutes of power walking, jogging, biking)■ Take the stairs instead of the elevator.■ Park farther away than usual.■ Exercise at health facilities or with trainers.
Eat well	<ul style="list-style-type: none">■ Include fruits and vegetables in your meal.■ Maintain a balanced diet
Sleep	<ul style="list-style-type: none">■ Try to get 7 hours of sleep per night.■ Take naps when possible.
Rest	<ul style="list-style-type: none">■ Resting will help you reduce stress.■ Try meditation, deep breathing, and stretching.
Know your limits	<ul style="list-style-type: none">■ It is OK to say no if you do not have time or energy to complete a given task.
Take breaks	<ul style="list-style-type: none">■ Maintain hobbies and keep up with friends.■ Do not neglect your personal life.
Get support	<ul style="list-style-type: none">■ Open up to friends and family.■ Join a support group for caregivers (lymphoma.org/resources/supportservices/lsn).■ Find assistance online with Cancer Care (cancer.org) and Cancer Support Community (cancersupportcommunity.org).
Be alert for signs of burnout	<ul style="list-style-type: none">■ Signs include irritability, fatigue, sleep disturbances, weight fluctuation, feelings of helplessness or hopelessness, and social isolation.■ Seek help from a trained mental health professional if you feel it is too much to handle.

You can also find resources online that address the needs of friends and family members giving care to a person with cancer (visit cancer.gov/publications/patient-education).

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Chapter 25: Workplace and Financial Future

Keeping Track of Your Documents

It can be helpful to keep all important documents and paperwork in one place. This will make things easier to find when you need them and will save your valuable time. Important documents that you should keep include:

- Medical and insurance records
- Pensions and social security records
- Bank statements
- Wills
- Power of attorney
- Health care proxy
- Administer oral and potentially intravenous medications as instructed
- Prepare meals and keep housing clean

Knowing Your Rights

Review your loved one's insurance policies to understand what treatments are covered. There are government programs called entitlements that provide aid to people with cancer. Your hospital or community social worker can help you get in touch with the governmental agencies that regulate these aid programs. If you have been working for more than a year in a company with 50 or more employees, you may be eligible for an unpaid leave under the Family and Medical Leave Act (FMLA). Smaller companies may also let you use sick days and vacations for caregiving purposes. Check with the human resources department to find out whether this applies to you.

Finding Financial Resources

If your loved one expects to run into financial difficulties, reaching out to the people involved and working out payment plans early on can be helpful. This applies to hospital bills, creditors, landlords, utilities and

mortgage companies. Resources for cancer patients requiring financial help include:

- Medicine Assistance Tool (call 571-350-8643 or visit medicineassistancetool.org).
- LRF Helpline (call 800-500-9976 or visit <https://lymphoma.org/resources/supportservices/>)
- CancerCare (call 800-813-4673 or visit cancercare.org)
- Patient Advocate Foundation (call 800-532-5274 or visit patientadvocate.org)
- Social Security Administration (call 800-772-1213 or visit ssa.gov)

Questions to Help Your Loved One with Lymphoma

Doctor's Visits

- What documents do I need for the consultations?
- What are the goals of treatment?
- Is there anything we need to do to prepare for treatment?
- How long will the treatment take?
- Can I stay during the treatments?
- Do you have any written information about this treatment?
- What are the side effects of this treatment?
- Are there any ways to help manage side effects?
- How do we know if a side effect is severe enough to call you?
- Are there any other treatment options?
- Are there any clinical trials we should be aware of?
- How should we file insurance claims?
- What is the best way to let you know when we have questions about treatment?

PATIENT TIP

Helping Your Loved One at Home

It can be difficult to know how to open the lines of communication with your loved one. They also may not be ready to talk when you are. It's important to offer emotional support by allowing opportunities for communication and demonstrating a willingness to listen.

While asking your loved one how they feel may provide an opportunity for them to express their emotions, it may not always feel natural. Questions about practical issues such as how their last appointment went or when the next appointment will be could provide a safer context in which to delve further into more emotional topics.

Provide eye contact to demonstrate your warmth and attention. Ask additional questions to invite your loved one to continue to have an opportunity to talk. You could also paraphrase (repeat) what has been said to confirm you understand what your loved one is saying. If it's not the right time for a discussion, let them know you are available to support them when they are ready for a conversation.

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**Lymphoma Research Foundation
(LRF) Helpline and Clinical Trials
Information Service**

CONTACT THE LRF HELPLINE

Trained staff are available to answer questions and provide support to patients, caregivers and healthcare professionals in any language.

Our support services include:

- Information on lymphoma, treatment options, side effect management and current research findings
- Financial assistance for eligible patients and referrals for additional financial, legal and insurance help
- Clinical trial searches based on patient's diagnosis and treatment history
- Support through LRF's Lymphoma Support Network, a national one-to one volunteer patient peer program

Monday through Friday
9:30 am – 7:30 pm Eastern Standard Time (EST)
Toll-Free (800) 500-9976
or email helpline@lymphoma.org

