

Understanding Caregiving and Lymphoma



CARING FOR SOMEONE WITH LYMPHOMA

WHO IS A CAREGIVER?

A caregiver is someone who is helping a loved one with lymphoma through his or her treatment. If you are taking care of your partner, a family member or a friend who has lymphoma, you are a caregiver. While caring for your loved one may feel natural, being a caregiver is often demanding and can be a full-time job. Caregiving can mean many things, like helping with daily activities (practical care), overseeing healthcare routines (medical care) or 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.
- **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 him or her 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, so that you are able to provide the best help you can at each phase throughout their diagnosis and therapy.

- **Avoid "cheerleading".** Do not disregard your loved one's 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.** A rush of sudden help upon diagnosis can make the situation harder to manage and create unproductive tension. 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 to you and your loved one at appropriate times.
- **Offer transportation.** This is important for 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.
- **Take notes.** If you go into the appointments, write down notes with the doctor's plan, medications, potential side effects and other relevant information. Keep the doctor's phone number in a place that is easy to find in case you have questions. It is beneficial to keep these in one place such as on your computer or cell phone or even a spiral notebook to keep track of these things and questions that arise.

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 like helping with finances, arranging for in-home medical care, clarifying insurance coverages, 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, or other technologies such as 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 you loved one. Helpful links include the Family Caregiver Alliance (visit <https://www.caregiver.org/connecting-caregivers/services-by-state/?state=alabama> or your state government's website). The American Red Cross may offer training opportunities on caregiving (visit <https://www.redcross.org/take-a-class>).

HOW TO TALK TO CHILDREN/TEENS

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.
- Have an open conversation and encourage them to ask questions if they want to. Be mindful that they might not be ready to talk about it, so make sure they know that it is ok to feel that way and help them find ways to express themselves (like playing, drawing, or writing).
- 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).



PARENTS OF PEDIATRIC LYMPHOMA PATIENTS

CARING FOR A PEDIATRIC LYMPHOMA PATIENT

A diagnosis of pediatric cancer is overwhelming for the child and the caregiver. It is very important that you adopt routines of self-care, because you will need to gather and keep your strength throughout the process (see below *Taking Care of Yourself*). As a parent and caregiver, you can build trust with your child by having calm and honest conversations using some of the tips above (see *How to Talk To Children/Teens*). It is important that you adapt your caregiving approach to your child's age. Young children will generally tend to rely more on physical comfort or being prepared in advance for treatments that cause pain, while older children and teens may need more reassurance on how the disease is going to affect their lives (the way they look, school, daily activities, and friends). You can also consider the following suggestions:

- Your child's healthcare team can help you navigate through important questions like when and how to tell your child, and what you can do to help them cope.
- Let your child know about and help them adjust to visible changes that may happen during treatment (like hair or weight loss). Help them pick a fun cap, scarf or wig ahead of time, or have a registered dietitian prepare a meal plan that keeps your child strong through treatment.
- Explain that their routine is going to change during treatment, and that this may include spending more time in the hospital, being isolated at home and missing school. Help your child adjust to these changes by bringing comfort items to the hospital room, decorating their room at home or preparing education plans with their teachers.
- Provide supportive care to manage side effects and improve your child's quality of life. The healthcare team will let you know how to manage pain, prevent infections and handle other health-related events.
- Keep their network of friends close. Encourage your child to stay in touch with and reach out to friends with remote apps. If allowed by your child and the healthcare team, have friends visit or let your child engage in school activities.
- Use video games, music, movies, or other creative activities (art, massage, or laughter therapy) to keep your child entertained. These distractions are important to help your child relax and focus on something else.
- Be alert to any abrupt and sustained changes in behavior and sleep disturbances, which may signal emotional distress. Seek help from a trained mental health professional to provide strategies to manage stress and be alert for signs of anxiety disorder or depression.

You can also find resources online for parents of children with cancer (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](https://www.cancer.gov/publications/patient-education)).



CAREGIVERS OF PATIENTS UNDERGOING TREATMENT

Depending on your loved one's 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 applicable to the patient's particular situation. Patients and caregivers should share questions and concerns with the doctor so that together they can decide which option is best. This is also time to ask if there is a specific need for caregivers 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 chemotherapeutic drugs and targeted anticancer 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 helping utilize diaries and medication dispensers that record when the pill container was opened, which can be helpful for tracking adherence. 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
- Should not be hired
- Should be able to 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)
- Should be able to measure patient's oral temperature and identify signs of neurologic impairment
- Should be able to communicate with the healthcare team whenever needed
- Transports or accompanies the patient to emergency and scheduled appointments
- Administers oral and potentially intravenous medications as instructed
- Prepares meals and keeps 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.



TAKING CARE OF YOURSELF

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.
- **Exercise.** Stay active with short periods of daily exercise (30 min of power walking, jogging or biking). If not possible, take the stairs instead of the elevator or park farther away than usual.
- **Eat well.** Include fruits and vegetables in your meals and maintain a balanced diet.
- **Sleep.** Try to get 7 hours of sleep per night or take naps when needed.
- **Rest.** Meditation, deep breathing and stretching can help you relax and reduce stress.
- **Know your limits.** It is ok to say no if you do not have time or energy to complete a given task.
- **Take breaks.** Maintaining some hobbies and keeping up with friends is important to help you unwind. Do not neglect your personal life.
- **Get support.** You can open up to friends and family or join a support group for caregivers. You can find assistance online with Cancer Care (visit cancer.org) and Cancer Support Community (visit cancersupportcommunity.org).
- **Keep a journal.** Writing down your experience can be a helpful way to vent your negative thoughts and feelings.
- **Be alert for signs of burnout.** 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).

FINANCIAL AND INSURANCE CONSIDERATIONS

KEEPING TRACK OF 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
- Health care proxy
- Power of attorney

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).
- CancerCare (call 800-813-HOPE [4673 or visit cancer.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?

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 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.



RESOURCES

LYMPHOMA RESEARCH FOUNDATION (LRF)'S HELPLINE AND LYMPHOMA SUPPORT NETWORK

A lymphoma diagnosis often triggers a range of feelings and concerns. In addition, cancer treatment can cause physical discomfort. The LRF Helpline staff members are available to answer your general questions about a lymphoma diagnosis and treatment information, as well as provide individual support and referrals to you and your loved ones. Callers may request the services of a language interpreter. A part of the Helpline is LRF's one-to-one peer support programs, Lymphoma Support Network. This program connects patients and caregivers with volunteers who have experience with lymphomas, similar treatments, or challenges, for mutual emotional support and encouragement. You may find this useful whether you or a loved one is newly diagnosed, in treatment, or in remission.

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MOBILE APP

Focus On Lymphoma is the first mobile application (app) that provides patients and caregivers comprehensive content based on their lymphoma subtype and tools to help manage their lymphoma such as, keep track of medications and blood work, track symptoms, and document treatment side effects. The Focus On Lymphoma mobile app is available for download for iOS and Android devices in the Apple App Store and Google Play. For additional information on the mobile app, visit [FocusOnLymphoma.org](https://www.FocusOnLymphoma.org). To learn more about any of these resources, visit our website at [lymphoma.org](https://www.lymphoma.org), or contact the LRF Helpline at 800-500-9976 or helpline@lymphoma.org.

Resources

LRF offers a wide range of free resources that address treatment options, the latest research advances, and ways to cope with all aspects of lymphoma and CLL/SLL including our award-winning mobile app. LRF also provides many educational activities, including our in-person meetings, podcasts, webinars for people with lymphoma, as well as patient guides and e-Updates that provide the latest disease-specific news and treatment options. To learn more about any of these resources, visit our website at www.lymphoma.org, or contact the LRF Helpline at (800) 500-9976 or helpline@lymphoma.org.

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