

2 COMMUNICATING AS A CAREGIVER

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

Communicating With the Patient. Communication is key when it comes to caring for a cancer patient. You and your loved one will need to be open and honest with each other from the start. Remember that you are both on the same team and hope for the best outcome. At some point, you will likely have disagreements and maybe even fight, but make it a priority to keep the lines of communication open and set boundaries and expectations early on to make things easier.

What to Say and What Not to Say. If you're not sure what to say to someone who has cancer, you are not alone. Sometimes the simplest expressions of concern are the most meaningful. And, sometimes, just listening is the best thing you can do.

Make sure you speak from the heart. For instance, you might say something like:

- "I don't know what to say, but I want you to know I care."
- "I'm here for you when and if you need me."
- "Let me know how I can help."

While it's usually a good idea to be encouraging, it's also important not to tell people with cancer to "always stay positive." Saying this may seem to discount your loved one's legitimate fears, concerns or sad feelings. It's also tempting to say that you know how your loved one feels. While you do understand that they are going through a difficult time, no one can know exactly how any one person with cancer feels.

Be careful when bringing up a cancer patient's physical appearance. Cancer may bring with it a lot of physical changes—hair loss, weight loss, weight gain, skin changes, and swelling. Cancer patients may struggle with body image and may be embarrassed or sensitive about the changes to their bodies. You may want to tell your loved one that they look great, but it may not come across as the compliment that you intended. For example, weight loss for cancer patients is often a side effect of cancer and treatment, so a compliment on weight loss may come across as insensitive.

It may not be a good idea to share stories about family members or friends who have had cancer. Every person is different, and these stories may not help, especially if the friend or family member has died. Instead, let your loved one know that you're familiar with cancer because you've been through it with someone else. Then let your loved one take the conversation from there.

Humor can be an important way of dealing with cancer. Let the person with cancer take the lead. It's healthy to find humor in difficult situations. Laughter can be a great way to relieve stress. If your loved one makes a joke about the situation, you can laugh with them. However, you never want to joke unless you know they can handle it and will appreciate the humor.

Respect Your Loved One's Privacy. As the caregiver, you may become your loved one's "gatekeeper" as friends and family members reach out to express concern or ask for updates. Ask your loved one who they plan to tell about the cancer diagnosis and how much they want to share. Some patients prefer to keep their diagnosis private, especially in the beginning. If your loved one does not want people to know, respect their wishes.

Be careful about what information you post on social media. Even if your loved one shares the diagnosis with friends or family, they may not want to share the diagnosis with acquaintances, coworkers or classmates. Even private social media profiles may not be as private as you think. Do not post on social media about your loved one's diagnosis without their approval.

Be Aware of Cognitive Issues. Cancer patients sometimes experience cognitive issues, often referred to as “chemo brain,” as a side effect of treatment. Your loved one may become forgetful, have trouble concentrating or seem confused at times. Be patient and understanding. If your loved one is struggling to remember things, suggest writing a to-do list, setting alarms on a mobile phone, or ask if it's okay for you to remind them to take medication or carry out other tasks.



Use **Worksheet 3: Daily Medication Log** to keep track of the medications the patient takes each day.

TIP:

Caregiving can be a difficult job, so it's natural to want to talk about what you are going through. If your loved one wants to keep the diagnosis private, find someone you can talk to in confidence, such as a member of a caregiver support group or a therapist.

Questions for Caregivers to Ask Their Loved Ones. What will your role as caregiver include? Set some parameters and boundaries early. Try not to make assumptions about what your loved one needs or wants. Find out what works best for both you and your loved one.

Here are some questions you should ask your loved one to establish parameters. Go through the following questions together and record the answers:

Are you okay with the healthcare team sharing your medical information with me?

Yes No Other _____

If your loved one answers “Yes” to this question, they will need to sign paperwork at the treatment center to give the healthcare team permission to communicate with you.

Who will be the main contact person for the healthcare team?

Who will schedule the appointments?

What is a good way to keep the lines of communication open? Can you let me know when you need space or begin to feel overwhelmed?

Are you okay with me sharing updates about your treatment or well-being with other family members and friends? And, if so, in what format—phone, email, caregiver app or webpage, social media? *(Remember to discuss disclosure and how sharing this information may affect your loved one in the future.)*

What do you need or want help with? Check all that apply. (Add additional tasks or parameters, as needed.)

- Going to appointments
- Booking appointments
- Talking to members of the healthcare team
- Remembering medication
- Grocery shopping
- Cooking
- Household chores
- Pet care
- Childcare
- Managing health insurance
- Managing finances
- Hygiene and personal care (bathing, dressing, etc)
- Updating friends and loved ones
- Other _____
- Other _____

Are there tasks you don't need or want help with?

Do you have an advance directive? Where can I find copies of these documents? Do any of them need to be updated? (An advance directive is made up of legal documents that communicate preferences for medical care and end-of-life wishes. See **Advance Directive** on page 14 for more information.)

Keep the conversation ongoing. As treatment progresses, you may need to revisit the parameters you set when you first began providing care for your loved one. Don't assume that something is the right thing to do. Ask if your loved one would like you to take over a responsibility. For example, a patient may generally feel well enough to manage household chores, but may need an extra hand the day after a chemotherapy infusion.



To update or create new parameters, use **Worksheet 4: Questions for Caregivers to Ask Their Loved Ones.**

Remember, cancer may mean the loss of your loved one's independence in many ways. Your loved one may resist your care at times and attempt to maintain their sense of independence and normalcy. Try not to take any resistance personally.

Caregiving Situations and Relationship Changes. Managing your relationship with your loved one may be an unexpected challenge of caregiving. Your relationship with your loved one may change as you transition into your new roles as caregiver and patient, changing your day-to-day life and the dynamics of your relationship. All relationships are different, so the challenges you face may also be different. In the following sections, read about possible challenges, by relationship type. Considering these potential challenges in advance may prepare you for any future issues and allow you to take action now to prevent problems.

Caring for Your Spouse or Significant Other. You and your spouse likely view your relationship as an equal partnership, but a cancer diagnosis may change that dynamic. If your loved one has had to stop working for treatment or is not able to help with daily chores, they may feel guilty for not contributing. If you have young children, extra childcare responsibilities may also fall to you.

Cancer can also make intimacy a challenge. Treatments for cancer can cause changes in sexual desire and function. Some patients feel less attractive or desirable when their physical appearance changes or they are not feeling well. All of these issues can build barriers to intimacy. If you are a caregiver for a romantic partner, know that sex and intimacy may change after a cancer diagnosis. Rethink what intimacy means to you both. Do not be afraid to reach out to the healthcare team for help with physical issues, such as decreased desire, pain with intercourse, vaginal dryness or erectile dysfunction.

Infertility is a side effect of some cancer treatments. If you and your partner hope to have children in the future, talk to members of the healthcare team before treatment begins. You may have options to preserve fertility, such as egg, embryo or sperm banking.

Check with the healthcare team and ask if it is safe for your loved one to engage in sexual activity and inquire whether any extra precautions need to be taken because of treatment or side effects. For example, a patient who is at risk for bleeding issues due to low platelet count may need to refrain from sex until platelet numbers improve. If the patient is receiving radioimmunotherapy treatment, it may be necessary to take precautions to protect their partner from exposure to radiation. (With external beam radiation therapy, people in contact with the patient, such as the caregiver, will not be exposed to any radiation.)

If you continue to have sex during the patient's treatment, be sure to use proper protection. Pregnancy during chemotherapy or radiation may not be safe for either the pregnant person or the child. Always use a form of birth control. Since cancer treatment can compromise the immune system, use condoms to protect against sexually transmitted diseases (STDs).



To learn more, visit www.LLS.org/booklets to view ***Sexuality and Intimacy Facts***.

Caring for a Parent or Grandparent. When you are caring for a parent or grandparent, the role reversal may feel odd at first. For most of your life, they may have filled the caregiver role in your relationship. They may be reluctant to accept care and not want to be a burden.

Your parent or grandparent may struggle with the challenges of aging and losing independence. Try to remember that this role reversal may be uncomfortable for both of you.

If you have a spouse or partner, devoting more of your time to care for your parent or grandparent may leave less time for you to focus on your relationship with your partner. Try to set aside regular time for you and your partner to be alone even if it is only to share a cup of coffee in the morning.

If you have young children yourself, your coparent may need to take on more childcare responsibility while you are looking after your own parent or grandparent, which could lead to feelings of resentment. Reach out to family and friends to help with childcare responsibilities so that they do not all fall to the other parent.

Caring for a Young Adult. If you are a parent caring for an adult child who has a cancer diagnosis, remember that the patient is an adult. You must respect their decisions regarding treatment. Young adult cancer patients often face challenges specific to their age-group, both during and after treatment. See **Young Adults and Cancer** below for more on managing your relationship and ways to support your young adult.

Adolescent and Young Adult Caregivers. As an adolescent or young adult caring for a parent, grandparent or other family member, it is especially important to care for your own mental health and wellbeing. Ask the healthcare team if there are local resources for adolescent and young adults caregivers.

Caring for Multiple Individuals. Some caregivers find themselves providing care for multiple individuals. For example, you may be caring for a parent with a cancer diagnosis and a spouse with chronic illness. Or, you may also be a cancer patient or have other medical needs of your own. Discuss with your loved ones how to divide caregiving responsibilities. These conversations will likely be ongoing. Remember to address your own health and wellness needs too. Explain your situation to members of the healthcare team, such as a social worker. There may be additional resources available to you.

Managing Relationship Issues. Early and ongoing communication is the best way to deal with relationship issues. Be aware of your feelings, the patient's feelings and the feelings of those around you. Address any problems as soon as possible. If you are struggling with relationship issues, keep in mind that you are not alone and that these feelings are normal.

If relationship issues persist, it may help to speak to a family therapist. Ask members of the healthcare team or the patient's health insurance provider for a recommendation.



Use **Worksheet 4: Questions for Caregivers to Ask Their Loved Ones** to help set boundaries and assign responsibilities.

Young Adults and Cancer. If your loved one is a young adult (age 18 to 39 years), they may face challenges specific to their age-group during and after cancer treatment such as:

- First time experiencing a serious illness or medical issue
- Frustration at loss of newfound independence
- Less experience and/or confidence advocating for their own care
- A lack of understanding health insurance plans and/or being uninsured or underinsured
- Attending college or university while going through cancer treatment
- Working during cancer treatment, stopping work during treatment and/or putting career goals on hold
- Dealing with the physical changes that cancer and cancer treatment can cause, such as hair loss, weight gain, weight loss, and scars from port placement or other surgery
- Dating while receiving cancer treatment
- Sexual side effects of treatment, such as vaginal dryness, erectile dysfunction, and/or lack of desire
- Making decisions about fertility preservation and/or coping with infertility
- Parenting young children while going through cancer treatment

- Difficulty relating to peers who may not have experience dealing with a serious illness themselves (or in someone close to them)
- Feelings of isolation, depression and anxiety
 - See ***Taking Care of Your Mental Health and the Mental Health of Others*** on page 9
- Finding it difficult to move forward or feeling “stuck” after cancer treatment ends
- Managing long-term and/or late effects of cancer treatment

Awareness of these potential challenges can help you better support your loved one during and after cancer treatment.



To learn more, visit www.LLS.org/YoungAdults or visit www.LLS.org/booklets to view:

- ***Young Adults and Cancer***
 - ***Fertility and Cancer***
 - ***Sexuality and Intimacy Facts***
 - ***Managing Stress: How Stress Affects You and Ways to Cope***
 - ***Write It Out Journal***
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Parents Caring for a Young Adult. Young adults can be at many different stages of life. They may be going to school or working, living independently or living with parents. They may be single, married, and/or have children of their own. As their parent, you will likely still want to be involved in caring for your young adult. However, you may, or may not, be the first person your young adult comes to for help. They may feel more comfortable asking a partner or friend for help. Either way, be respectful of your young adult’s wishes.

If your young adult does rely on you for caregiving needs, it is important to remember that your child is an adult and keep the following things in mind:

- Providing care for your child may feel natural for you, but if your child had been living independently prior to the diagnosis, being dependent on the care of a parent again may feel frustrating. Keep communication open and ongoing.



Use **Worksheet 4: Questions for Caregivers to Ask Their Loved Ones** to help set boundaries.

- As a legal adult, the young adult will have to sign a waiver granting members of the healthcare team permission to discuss their medical care with you and to allow you access to their medical records.
- Young adults can participate in advance care planning, including creating an advance directive and assigning medical power of attorney.
 - See ***Advance Directive*** on page 14.
- The young adult will need to determine who will be the primary decision maker for their medical care. Some young adults may want to make their own decisions about their ongoing care. Some may turn to a friend or partner for support. Still others may feel more comfortable with their parents overseeing their care. You may need to take a step back and allow them to make decisions. Remind your young adult to tell members of the healthcare team who they want to be the main point of contact.
- If your young adult is married or partnered, be respectful of their relationship with their partner. They may wish for their partner to be included in caregiving duties or even be their primary caregiver.
- Teach the young adult how to advocate for their own care. Even if you remain the primary decision maker for your

young adult's medical care, it is important for all persons to learn how to advocate for themselves.

- Encourage your young adult to communicate openly and honestly with members of the healthcare team and to ask questions. See ***Communicating with Members of the Healthcare Team*** on page 12.
- Provide resources for the young adult to learn more about their medical needs. Tell them to ask members of the healthcare team for written information. Show them how to access their medical records. Inform them of any family history of disease.
- Teach your young adult to take all medications as prescribed. Suggest setting a reminder on a mobile phone or using a pill organizer.
- Make sure your young adult knows the names of all of their medications and how and when to take them, including vitamins and supplements. Remind them to take a list of medications to every appointment.
- Although your young adult can remain on your health insurance plan until 26 years of age, teach them how to navigate health insurance issues such as understanding coverage and filing an appeal. Remind your young adult to take an insurance card to all appointments.
- Be aware that there may be times when young adults will want to talk to members of their healthcare team alone to discuss sensitive matters that they may not wish to discuss in front of a parent, such as sexual activity, alcohol or drug use, or mental health. Give your young adult the space they need to have private discussions with the healthcare team.
- Discuss with your young adult what they are comfortable with you sharing about their diagnosis and with whom. They may not want their cancer diagnosis or treatment discussed with others, even other family members or their own children. Additionally ask for their permission before sharing information about your young adult on social media.

Young Adults After Treatment Ends. After treatment ends you may expect or hope that life for the young adult will go back to how it was before the cancer diagnosis. For many young adults, the end of treatment is not the end of recovery. They will need continued follow-up care. They may still need assistance in certain areas, especially if they are still managing long-term effects such as fatigue. Their needs may also change or be ongoing if they have a chronic blood cancer diagnosis. Discuss with the young adult what you can do or continue doing to support them. Emotional support after treatment can be just as important, if not more so, than other forms of caregiving.

Understand that the young adult may also need or want to make changes to their life. For example, they may not be able to return to school or work right away. Or, they may decide they would like to try a new career or life path. Finding their “new normal” after cancer treatment is not always easy and may take time. Be patient and let the young adult take the lead.

TIP:

Talk to your young adult about sharing their diagnosis on social media. Many people share their lives on social media, but even with a private profile, social media may not be as private as they think. Stress how important it is for your young adult to consider all the implications of sharing a cancer diagnosis on social media. Encourage them to take time to think carefully about what they share. Would it upset them if a potential employer, a date or a casual acquaintance learned about the diagnosis from an internet search?



Resources for Young Adults

There are many resources for young adults with cancer. Share this list of resources with the young adult in your life.

The Leukemia and Lymphoma Society's young adult resources include:

- **Survivorship Workbook for Young Adults:** This workbook can be used to collect all the important information a young adult needs as they move through diagnosis and treatment and into long-term management of a blood cancer or begin post-treatment follow-up care. Visit www.LLS.org/SurvivorshipWorkbook to learn more.
- **Weekly Online Chat for Young Adults:** LLS's live, weekly online chat provides a friendly forum where young adults can share their experiences and chat with other young adults. Each chat is moderated by an oncology social worker. Visit www.LLS.org/chat to learn more.
- **LLS Community:** Join online to connect with other young adults and stay up-to-date on the latest diagnosis and treatment information. Share personal experiences and get personalized support from trained LLS staff. Visit www.LLS.org/community to sign up.
- **The Patti Robinson Kaufmann First Connection® Program:** This is a telephone support program that links young adults with a trained peer volunteer who has experienced a similar situation. Anyone with a blood cancer diagnosis, as well as their caregiver, is eligible to receive a call. Visit www.LLS.org/FirstConnection to learn more.

To find more resources, visit www.LLS.org/YoungAdults or call an LLS Information Specialist at **(800) 955-4572**.

Other young adult cancer organizations include:

- Stupid Cancer: www.stupidcancer.org
Offers CancerCon (a conference for young adult cancer survivors), organizes meet-ups, hosts the "Stupid Cancer Show," and provides additional resources and opportunities for young adults to learn and connect.
- Elephants and Tea: www.elephantsandtea.com
Provides a free quarterly print magazine and online site with stories written by young adult cancer survivors and offers digital programs and events to bring the young adult community together to interact and empower each other.
- Cactus Cancer Society: cactuscancer.org
Provides online support programs, lifestyle information, creative workshops, a writing group and more for young adults.

You can also visit www.LLS.org/ResourceDirectory to browse Other Helpful Organizations by need.

Taking Care of Your Mental Health and the Mental Health of Others.

A cancer diagnosis is difficult to cope with for everyone involved—the patient, the caregiver and other family members. Feelings of anxiety and depression are common. When is it time to seek professional help? If these feelings start to interfere with daily activities, you, other family members, or your loved one may need individual counseling from a medical professional.

Reach out to members of the healthcare team if you, your loved one or some other family member is feeling overwhelmed by the following persistent feelings:

- Ongoing sadness or feelings of hopelessness
- Loss of interest or pleasure in most activities
- Major weight loss or weight gain as well as other changes in appearance that are not connected to treatment
- Agitation or restlessness
- Fatigue or no energy
- Trouble sleeping or sleeping excessively
- Trouble focusing, remembering, or making decisions
- Feeling worthless, guilty or helpless
- Thoughts of death or suicide

Even if you or your loved one does not have symptoms of clinical depression or anxiety, you can still benefit from talking to a mental health professional. They will provide you with tools for identifying your emotions and help you to learn ways to cope with them.

Telling Children About a Loved One's Diagnosis. Talking to children about the cancer diagnosis of someone they love can be intimidating. You may worry about what to say or what not to say. You may even wish to protect children by not telling them about the cancer diagnosis; however, children are very perceptive. Even young children may be able to tell that something is wrong. Children will use their imagination and fill in the gaps of information. Giving your children honest information from the start will lead to feelings of trust, control and involvement.

Make a Plan to Talk to Children. Before talking to children, prepare what you will say in advance. If you are talking to your own children or to your loved one's children, make sure that you and your partner or you and the person with cancer are on the same page about what and how to tell the children. Talk to children in a comfortable space where you will not be interrupted. Remain calm when you are talking to children, but know that it is okay to show them how you feel.

Try to anticipate questions and consider your answers. Answer questions as honestly as possible, keeping in mind age-appropriate details. Encourage the child to ask questions and to come to you with any questions or worries in the future.

You may have to have multiple conversations with young children. Children need time to absorb information and can only take in so much new information at one time. You may want to provide basic information at first and then check in with the child later to answer questions and provide additional information.

If you have more than one child, be aware that your children may respond to a loved one's diagnosis in different ways. Some children may want to spend more time with the person. Others may need time to process the information. Allow for these individual differences.

TIP:

For a referral to a mental health professional, reach out to the members of the healthcare team, visit your own doctor or call your insurance provider for recommendations.

You may also want to check in with the child's teachers, coaches, babysitters or other adults who play a role in the child's life.

Remember, you are not alone when it comes to talking to kids about cancer. Ask for input from members of the healthcare team, school counselor or nurse, or other parents who have gone through a similar situation.

Age-Appropriate Discussion. Keep the discussion age appropriate when you talk to children about cancer. Consider the following guidelines by age:

Baby/Toddler (0 to 3 Years)

- Children this young do not have an understanding of illness or cancer. However, they are aware of changes to routines and the feelings of people around them.
- Children may feel separation anxiety and need physical and verbal reassurance.
- You may notice changes in appetite, sleeping patterns or tantrums in response to the changes in their environment.

Preschool/Kindergarten (4 to 6 Years)

- Children in this age-group may have an understanding of illness but not understand the implications of a serious illness, such as cancer. It may be especially confusing to the child if the person diagnosed with cancer does not look or act sick.
- Reassure the child that no one did anything to cause the cancer, neither the child nor the person with cancer.
- As with younger children, a preschooler or kindergarten child may experience separation anxiety, so reassure the child and give advanced warning either if you or the cancer patient will be away.
- You may see signs of regression in a child's behavior, such as thumb-sucking, bed-wetting or tantrums.
- A child may use play to process the information, play-acting doctor/patient scenarios, for example.
- If the cancer treatment will result in any changes to the child's daily routine, explain it to them ahead of time so that the child knows what to expect. Inform the child's teacher so that they can also understand changes in routine.
- Explain, in advance, any physical changes that the child might notice about the cancer patient, such as hair loss, scars or unfamiliar medical equipment.

Elementary/Middle School (7 to 12 Years)

- Children in this age-group may have a good understanding of serious illness, but not specifically cancer.
- The child may hear things about cancer from school, friends, on the TV or have found information on the internet. Ask the child what they already know about cancer. If you encounter any misunderstandings, correct them using straightforward, clear statements such as “You can’t catch cancer from another person” and “No one did something wrong to cause the cancer diagnosis.”
- Explain that “cancer” is a broad term that covers many different types of cancer. It may be helpful to talk to the child about the specific diagnosis of their loved one.
- Younger children in this age-group may also show signs of regression or separation anxiety.
- If the cancer treatment will result in any changes to the child’s daily routine, explain the changes ahead of time so that the child knows what to expect.
- Explain, in advance, any physical and emotional changes that the child may notice in the loved one as a result of treatment.
- Children in this age-group can be very empathetic and caring. They may want to help their loved one. Suggest they write a letter or make a card for their loved one.
- Children may feel uncomfortable around a person they love who has a cancer diagnosis, or they may feel embarrassed when others outside the family know about the diagnosis.
- Children in this age-group may worry but hide their feelings. Try to check in with the child and keep an eye out for signs of depression, such as ongoing feelings of sadness, loss of interest in activities, trouble focusing, problems sleeping, angry outbursts or issues in school.
- Inform the child’s teacher or coaches of the diagnosis. Reach out to the child’s school counselor or pediatrician for help if you notice troubling changes in mood or behavior.

High School/Teenagers (13 to 18 Years)

- Teenagers most likely have a good understanding of cancer, but you may still need to correct some misunderstandings heard at school, from friends, on TV, or information they found on the internet. It may be helpful to explain the cancer patient’s specific diagnosis instead of just using the word “cancer.”
- Having a loved one with cancer may lead teenagers to think more seriously about death and the meaning of life.
- Older teenagers may want to help with caregiving duties. Allow teens to help, as appropriate, but do not lay too much responsibility on their shoulders.
- Teenagers may show anger or frustration but not be willing to share their feelings as people in this age-group are often looking to gain a sense of independence.
- Teenagers may also act out or engage in risky behaviors, such as drinking, drug use, or sex.
- Watch for the signs of depression listed in ***Taking Care of Your Mental Health and the Mental Health of Others***, on page 9.
- Inform the teenager’s teachers and coaches of the diagnosis. Reach out to the school counselor or the child’s pediatrician for help if you notice troubling changes in mood or behavior. You may also want to tell the parents of the teenager’s close friends about the diagnosis.



For more information on talking to children about cancer, visit:

- Cancer Support Community's Frankly Speaking About Cancer® resources: www.cancersupportcommunity.org (Under "Get Educated & Inspired," go to "Order Education Materials.")
- Cancer.Net: www.cancer.net/coping-with-cancer/talking-with-family-and-friends/how-child-understands-cancer
- Telling Kids About Cancer: www.tellingkidsaboutcancer.com



Children's books that address cancer can also be helpful in your discussions with children. Visit www.LLS.org/SuggestedReading for a list of suggested books.

Bright Spot Network provides support groups, resources and financial assistance to young cancer survivors who are parents of small children. Visit www.brightspotnetwork.org to learn more.

Communicating With Members of the Healthcare Team. The doctors, nurses, social workers and other members of the healthcare team can offer crucial support and encouragement as you help your loved one through cancer treatment. A good working relationship with the members of the healthcare team can make navigating the challenges of cancer treatment easier.

Who Makes Up the Healthcare Team? A number of healthcare professionals will be involved with your loved one's care. Based on your loved one's needs, the team may include

Doctors

- Hematologist-oncologists—doctors who are specially trained to diagnose and treat patients who have blood cancers
- Oncologists—doctors who treat patients who have cancer
- Radiation oncologists—doctors who use radiation therapy to treat patients who have cancer
- Radiologists—doctors who are trained to read and interpret imaging studies, such as a computed tomography (CT) scan or a magnetic resonance imaging (MRI) scan
- Pathologists—doctors who use microscopes and different techniques to study cells and tissues in order to identify diseases
- Hematopathologists—doctor-pathologists who are board certified in both anatomical and clinical pathology and who examine blood, bone marrow and tissue samples
- General surgeons—doctors who perform surgical procedures, such as splenectomies, lymph node biopsies and other tissue biopsies
- Gastroenterologists—doctors who specialize in treating patients who have digestive tract diseases
- Nephrologists—doctors who specialize in treating patients who have kidney diseases
- Cardiologists—doctors who specialize in treating patients who have heart disease
- Psychiatrists—doctors who can prescribe medication to help patients with mental health conditions

TIP:

Ask if the healthcare team will designate a team member as your main contact person. They will then be the best person for you and/or your loved one to approach with your concerns and the important questions that will probably come up between appointments. How should this person be contacted? Find out how to communicate with this person through phone, email or an online patient portal offered by the hospital or treatment center.

Nurses

- Oncology nurses—nurses who specialize in treating people who have cancer
- Nurse practitioners—nurses who have advanced training in diagnosing and treating illness
- Oncology nurse navigators—nurses who specialize in cancer and help patients overcome barriers to care and find resources

Additional Members of the Healthcare Team

- Physician assistants—medical professionals who diagnose illness, develop and manage treatment plans, prescribe medications, and often serve as a patient's principal healthcare provider
- Radiology or lab technicians—professionals who withdraw blood or take images of the patient's body
- Psychologists—professionals who are trained to help patients with emotional and mental health conditions
- Social workers—licensed professionals who are trained to talk with patients and their families about their emotional or practical needs and to find them support services
- Child-life specialists—healthcare professionals who can help children and their families cope with serious illnesses, such as cancer
- Financial counselors—professionals at the hospital or treatment center who can help people with hospital bills and insurance claims as well as work with individuals who are unable to pay their bills
- Registered dietitians—healthcare professionals who specialize in food and nutrition

Make sure you keep track of all the contact information for each member of your loved one's healthcare team. Not all cancer patients will need support from every type of healthcare professional mentioned in these lists. The members who make up the healthcare team will depend on your loved one's needs.



Use **Worksheet 5: Healthcare Team Contact List** to keep up with all important contact information.

At Appointments. Your loved one's appointments are the best times to speak with members of the healthcare team. It's normal to feel nervous and worry that you and/or your loved one will forget to ask an important question during an appointment. Good preparation can improve your comfort levels and can make you feel more satisfied with doctor visits overall.

The following tips will help you to better communicate with members of the healthcare team during your loved one's appointments:

- Write down your questions. Number your concerns in order of importance, asking the most important questions first. Let the doctor know you have a list so that they can set some time aside during the appointment to respond to your questions.
- Take notes. Write down the doctor's answers to your questions. Write down any other important information that you or your loved one needs to remember. Notes can include the names of the members of the healthcare team, dates and times of future appointments, and when and how your loved one should be taking prescribed medicines. You can also ask the doctor if you can record the conversation so you and your loved one can listen to it again later.
- Ask for written information about the patient's diagnosis, treatment plan and lab results. Keep everything in one place. This way, nothing gets lost, and you always know where to find the information. Share this information with all the

TIP:

Today, many treatment centers provide a web-based "patient portal." Ask members of the healthcare team how to access and navigate the patient portal. You may be able to access medical records, schedule appointments, message a provider, make payments and more through the patient portal.

healthcare professionals your loved one sees for any health reason, and encourage the healthcare professionals to talk with each other to ensure the most comprehensive care.

- Encourage your loved one to tell the doctor about any signs, symptoms or side effects.
- Ask the doctor to slow down or explain things in another way if you or your loved one is having trouble either following or understanding information the doctor is giving you.
- Make sure you know who to contact in an after-hours or an emergency situation when you need immediate assistance. Ask what side effects, signs or symptoms require a trip to the emergency room and write them down.
- Ask where you can find credible information online or printed resources pertaining to your loved one's diagnosis or other needs.



Use the following worksheets to keep track of appointments and prepare for meeting with members of the healthcare team:

- **Worksheet 6a: Appointment Calendar, by Month**
- **Worksheet 6b: Appointment Calendar, by Week**
- **Worksheet 6c: Appointment Details**
- **Worksheet 7: Questions for the Healthcare Team**

Keeping Medical Records. It's important to keep current copies of your loved one's medical information in an easy-to-find location. Take these records with you to any appointment, especially appointments with new doctors who will need to know the details of your loved one's diagnosis and treatment plan. Information that you should take with you includes:

- The patient's medical history
- The family medical history
- A list of current medications, supplements, and vitamins
- Immunization records
- Copies of recent imaging or scans
- Lab values
- A list of all doctors or specialists the patient sees

TIP:

Today, most facilities use electronic medical records (EMRs). These comprise patient history, lab results, treatment plans, imaging studies and other important information. Providers can easily share this data with other providers. Before your loved one visits a new provider or facility, request that EMRs be shared with the new provider before the appointment.



Use the following worksheets to track the patient's important medical information:

- **Worksheet 8: Medical History**
- **Worksheet 9: Immunization Record**

Advance Directive. An "advance directive" details a person's instructions about future medical care in the event that they are no longer able to speak for themselves. Ideally, an advance directive will be in place before a person is confronted with a serious illness or a medical emergency.

An advance directive is made up of the following two legal documents:

- Living will—This document outlines the wishes and details the medical treatment(s) that the person has chosen to be available to them. A living will only becomes active if the person is incapacitated or unable to speak for themselves.
- Medical power of attorney—This document names a person who is authorized to make medical decisions on a patient’s behalf if the patient is unable to do so. This person is sometimes called a “healthcare agent” or “healthcare proxy.”

The original documents should be kept in a place that is safe, but accessible. As the caregiver, you need to know where your loved one’s advance directive documents are located. Ask if you may have copies of these documents too. You should also give copies to the healthcare team.

Note that an advance directive should be reviewed regularly and updated as needed. If your loved one does not have an advance directive, see **Preparing an Advance Directive** on page 16.

If the Healthcare Agent is Someone Other Than You. In many cases, the primary caregiver is also the patient’s healthcare agent. However, this is not always the case. The healthcare agent may not be the same person providing day-to-day care. Your loved one may choose someone else to be their healthcare agent. Making the decision about who to choose as a healthcare agent is difficult. Support your loved one’s choice.

If you are not named as your loved one’s healthcare agent, you need the healthcare agent’s contact information so you can notify them if your loved one becomes unable to make decisions (for example, after a medical emergency or at the end-of-life). Encourage your loved one to discuss their preferences for medical care and end-of-life wishes with the healthcare agent.

Discussing Preferences for Medical Care and End-of-Life Wishes.

As a caregiver, even if you are not your loved one’s healthcare agent, it is important that you know your loved one’s preferences for medical care and end-of-life wishes. It is also equally important to understand your loved one’s values, priorities and beliefs that guide their preferences for medical care and end-of-life wishes. Talking about these matters is important. This conversation will help you, as a caregiver, to understand and be better able to affirm and support your loved one’s choices and to implement the care your loved one wants.

Furthermore, if you have been assigned medical power of attorney by your loved one, you will need to be able to advocate and make decisions on their behalf, even if others disagree.

The first thing you need to know is whether or not your loved one already has an advance directive. If there is one, ask if you can look at it together. Looking over the advance directives together can help guide your conversation. It also gives your loved one the opportunity to update the documents as needed.

If your loved one does not have an advance directive, choose a practical time and place to have a conversation with them. Let your loved one set the pace of the conversation. Use good listening skills but expect some initial resistance. Encourage your loved one to complete an advance directive through a process often referred to as “advance care planning.” See **Preparing an Advance Directive** on page 16.

TIP:

An advance directive can provide peace of mind. All adults can participate in advance care planning. Ideally, an advance directive will be in place before a person is confronted by a serious illness or medical emergency. An advance directive lessens the burden of decision making in a crisis for family members by clearly communicating a person’s wishes for medical care. If your ill loved one does not have an advance directive, you may find it helpful to go through the advance care planning process together. You can both complete an advance directive together.

There are many tools available to help facilitate conversations about end-of-life care.

- The “Go Wish Game™” (<https://codaalliance.org/go-wish/>) is a card game that helps the players prioritize what will matter most to them during end-of-life care and then share those feelings with loved ones. You can purchase the physical cards to play the game, or you can play for free online.
- The Conversation Project’s *Conversation Starter Guide* (<https://theconversationproject.org>) is free and can be downloaded online.

Preparing an Advance Directive. If your loved one does not have an advance directive, encourage them to complete an advance directive through a process often referred to as “advance care planning.”

Advance care planning includes:

- Reflecting on personal values, beliefs and preferences in regards to medical care and quality of life
- Learning about end-of-life considerations and the risk versus benefits of medical interventions
- Discussing wishes and preferences with family members, loved ones, and members of the healthcare team
- Preparing an advance directive which includes
 - A living will
 - A medical power of attorney

Ask members of the healthcare team for the relevant advance directive documents for your state. The requirements for implementing an advance directive differ from state to state. These documents do not have to be created by lawyers.

When participating in advance care planning, many people choose to also complete other aspects of estate planning.

Medical Interventions. Medical interventions that a living will may address include:

- Life support
 - The use of equipment, such as dialysis machines, ventilators, and respirators is called “life support.”
- Cardiopulmonary resuscitation (CPR)
 - Cardiopulmonary resuscitation is an emergency procedure that is used when the heart stops beating or breathing stops. It attempts to restart the heart or breathing. CPR combines chest compressions and artificial ventilation and may include electric shock and medications.
- Intubation
 - Intubation is the placement of a tube that is passed either through the nose or through the mouth to help with breathing. The patient will likely be sedated.
- Artificial nutrition and hydration
 - If a person is unable to eat or drink, they can be provided with nutrition and/or fluids through an intravenous line or a feeding tube.

Living wills may also include instructions for organ and/or tissue donations.

If treatments have been exhausted or no treatment is available for an underlying disease, illness or injury, these medical interventions may prolong life, but they may not lead to a meaningful recovery. Medical interventions also carry risks that can decrease quality of life. For these reasons, some people choose to forgo these medical interventions when the end of life is near. Discuss medical interventions with members of the healthcare team.

At the end of life, pain management and comfort care will always be provided.

An advance directive can always be changed or updated. Even with a living will, a person always has the right to refuse or discontinue treatment, regardless of provisions specified in the living will.



You can find more information and your state's advance directive forms from the National Hospice and Palliative Care Organization at www.caringinfo.org and PREPARE™ For Your Care at <https://prepareforyourcare.org>.

For more information on advance directives and end-of-life considerations and resources to facilitate these conversations, visit www.LLS.org/booklets to view **Advance Care Planning**.

Long-Distance Caregiving. Family members often live in different cities and states. As a result, some caregivers must help their loved ones from afar. This task can be difficult, stressful and time consuming. To sustain long-distance care over time, you need to be sensitive to your own needs, as well as to those of your loved one.

Is Long-Distance Caregiving for You? In some cases, you may not have time to think carefully and plan fully before entering into a long-distance caregiving situation. The complexity of long-distance caregiving can result in a great deal of stress. Not everyone can sustain these extraordinary pressures over the long term.

First, ask yourself the questions below.

	YES	NO
Can I travel on short notice?		
Will my employer be accommodating when I need to travel? Can I take work with me?		
Do I have family or friends near me to care for my children or pets when I am away?		
Do I have the budget to travel?		
Does my loved one have family members and friends nearby to provide a support system for everyday tasks such as transportation to appointments or buying groceries?		
Is there a budget to pay for home healthcare for my loved one?		

If you check “No” for any of the above questions, you may need to reconsider long-distance caregiving. Is there someone who lives close to the patient who may be able to fulfill the role of primary caregiver? Is it possible for you to move and live with the patient, or for the patient to move in and stay with you? Can the patient get their medical care near you? You and your loved one need to explore as many ways as possible to solve the problem.

You should also decide if you can handle the emotional stress of long-distance caregiving. Most caregivers experience feelings of guilt for not being as available to their loved ones as they feel they should be. The long-distance caregiver can also experience feelings of helplessness from not being present and physically able to provide care and comfort.

As you prepare to care for a person with cancer, think about the difficulties involved in long-distance caregiving. Your loved one may not want to move from their home, but you must consider all the alternatives and then determine which one is the best fit for everyone involved, including yourself.

Tips to Make Long-Distance Caregiving Manageable. The following few tips can help you to feel more engaged in the process and better able to manage care—even from many miles away:

Be organized. Keep the patient’s medical records, healthcare team contact information, insurance, advance directive or other legal paperwork in one place. You will need to reference this paperwork often, so it helps if it is all easily available. If you do not have access to this information, the patient will have to sign a waiver at the treatment center to allow you access.



Use the following worksheets to track the patient’s important medical information:

- **Worksheet 8: Medical History**
- **Worksheet 9: Immunization Record**

Get to know members of the healthcare team. Call or email each member of the healthcare team and introduce yourself. Then, as soon as you can, accompany your loved one to some appointments at the beginning of their treatment. This will give you a chance to actually meet each member of the healthcare team. Remember to collect all their appropriate contact information, too.

Remember, your loved one will have to give permission to the hospital or treatment center to allow you to discuss diagnosis and treatment information with members of the healthcare team.

Update emergency contact information with the hospital or treatment center. Make sure that you are listed as the emergency contact person for your loved one and that you have supplied accurate and appropriate contact information. For example, make sure the hospital has your cell phone number if you do not often answer a home number. It may be appropriate to have a local emergency contact person listed, as well. This way, in an emergency, even if it takes you time to travel, someone can be at your loved one’s side.

Travel the right way. When you are going to visit your loved one, make a plan to accomplish everything that needs to be done. Having a plan keeps you focused and less stressed. Talk with the patient before you go and discuss what they need. This is also a good time to set specific goals for your time together.

Travel expenses add up. If you have to fly to visit your loved one, look for flights at less popular times, such as weekdays early in the morning or late at night. These flights can be less expensive. Use multiple websites to compare prices for hotels and flights. Take advantage of customer loyalty plans. See if any of the airlines you will be using or hotels you may frequent offer discounts or have loyalty plans that allow their members to build up points or miles for free or discounted travel.

Build a long-distance support system. Family, friends, neighbors, and community agencies can provide valuable support as you care for your long-distance loved one.

As a long-distance caregiver, you should establish support systems for both your loved one and yourself. If family members are available but live too far away to provide hands-on support, they may be able to help with financial or legal matters that can be managed by phone or mail. If you have teenagers, ask them to get involved. This can be an opportunity to strengthen family bonds and teach your children about empathy and responsibility. Neighbors and friends in your loved one’s community may be willing to provide transportation or help with shopping, household chores and other tasks.

Ask members of the healthcare team about local resources. Communities have various resources and services to help you to care for your loved one if you do not live nearby.

WANT MORE INFORMATION?

For help finding resources, call an LLS Information Specialist at **(800) 955-4572** or contact your local LLS chapter.

Use a caregiver app to coordinate care. A caregiver mobile or web-based app helps you coordinate aspects of your loved one's care by organizing friends and family who want to help. Use these apps to plan meal deliveries, set up rides to treatment, ask for volunteers who are willing to do chores and give updates on your loved one. Friends and family members can also post messages of support. These apps can be set to "private" so that only people you allow can view the information.



Examples of caregiving coordination apps include

- Lotsa Helping Hands: www.lotsahelpinghands.com
 - CaringBridge: www.caringbridge.org
 - MyLifeLine: www.mylifeline.org
-

Set up an emergency plan. If your loved one has an accident or there is some other emergency situation, you'll want to get to them as soon as possible.

If you have an emergency plan in place, you'll have more time to make clear-headed decisions about your work and home arrangements, as well as the time to think through any decisions you may have to make regarding your loved one. That means less stress, less wasted time and fewer mistakes. Try the following suggestions to help you prepare:

- Develop a support system of friends, neighbors and family members who can step in for you, and clearly define everyone's role in your emergency plan.
- Make a list of all the names and contact information for your support system members.
- Set up a "phone tree" to keep the entire emergency support system informed so that you don't have to call every person yourself.
- Make sure that all members of your caregiving support system have the phone number where you can be reached during a crisis.
- Keep a bag packed and ready with toiletries, appropriate clothing, copies of the patient's important information and an extra phone charger.

Explore home health services. Home health services for your loved one may become necessary as treatment or the disease progresses and if your loved one becomes less able to care for themselves. State or local health departments usually have a list of licensed home-care agencies, and members of the healthcare team can suggest those they trust.

The following resources may be available to you:

- Part-time or intermittent skilled nursing care or home health aide care can be discussed with members of the healthcare team; these services are covered by Medicare.
- Physical and occupational therapy are also services covered by Medicare.
- Some community organizations offer emergency care. The hospital social worker or discharge planner may be able to refer you to community organizations that offer these services.
- Respite care can be arranged through your loved one's local area agency on aging or other community services. Respite care gives caregivers a break from caregiving duties. However, respite care services can also help with short-term care needs while you are working out a more permanent solution.

Even during nonemergency situations, caregiving responsibilities are complicated by distance. Connecting with the right people and services is essential to ensuring the best care and comfort for your loved one.

Communicating as a Caregiver Notes
