

Each New Day

Ideas for coping with blood cancers



Revised 2020

Acknowledgements

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Introduction

Each year, about 1.7 million people are told they have some form of cancer.¹

Like others with cancer, you have questions to ask and decisions to make.

You have been diagnosed with a serious illness. But your life continues to have meaning and purpose. This diagnosis does not define your life.

It may help to know that many people with cancer

- Survive
- Live many years of good-quality life
- Continue to (or learn to) live their lives to the fullest

It's true that hearing the words, "You have cancer," may not sink in for a while.

You may be in a state of shock, or you may feel as if your whole life has changed in an instant. At first, dealing with cancer may seem scarier than anything you have ever had to face. You may wish for your "old" life, and the days before you learned you had cancer.

You may feel worried about

- Your treatment and side effects
- Your family's well-being
- Money
- Employment—your career or professional standing
- Death
- The unknown

Some people with cancer say they wish they had received more information right from the start.

To better understand your treatment and support options, you have the right to access and be given information, to ask questions and to make your voice heard. Taking an active role in choosing a healthcare provider and making other treatment decisions could have a positive effect on your health and quality of life.

Remember that you are not alone. Help and support are available.

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

Feedback. Visit www.LLS.org/PublicationFeedback to give suggestions about this booklet.

¹Howlander N, Noone AM, Krapcho M, eds. *SEER Cancer Statistics Review, 1975-2016*. Bethesda, MD: National Cancer Institute; 2018. https://seer.cancer.gov/csr/1975_2016/. Based on November 2018 SEER data submission, posted to the SEER website, April 2019.

How to Use *Each New Day*

Each New Day can help you identify what you need to know and do to cope with your diagnosis, treatment and recovery. Together with the programs and services offered by LLS, this booklet will help you gather, understand and organize the information you need to

- Communicate with family, friends and employers
- Deal with your feelings
- Make decisions about treatment and financial matters
- Find social and emotional support

You can use this booklet in different ways. You may

- Read the sections in order. Or you can go straight to the information you think is most important.
- Use the worksheet *Feelings and Thoughts* on pages 36 and 37—you can print extra copies at www.LLS.org/JournalPage.
- Share this booklet with others. The section *Suggestions for Family and Friends* begins on page 29. Also, you can call an Information Specialist or visit www.LLS.org/Caregiver to find information for caregivers.

Many people find that knowing the questions to ask about their treatment helps them feel less overwhelmed. *Each New Day* includes suggested questions to ask your healthcare providers (see Question Guides starting on page 38). Visit www.LLS.org/WhatToAsk to find additional suggested questions.

Throughout this booklet there are messages from other people whose lives have been touched by blood cancer. We hope these messages from the cancer journeys of other people, along with the information in *Each New Day*, provide you with comfort and help.

Life has changed, but come what may,
I'm moving forward each new day!
From family, friends or things divine,
The strength I seek, is strength I'll find.

Do I Tell Anyone I Have Cancer?

Some people with cancer ask, "Should I tell anyone I have cancer?" This decision is personal. However, there are benefits to sharing this information with others. It may help you to know how other people with cancer feel about sharing this information with friends, family and/or employers.

People with cancer may tell their

- Husband/wife/partner
- Children, parents, brothers, sisters
- Children's teachers
- Good friends
- Friends from their place of worship
- Employer and/or co-workers

Some people tell others they have cancer because:

- It is too big and scary to deal with alone.
- It allows other people to give support.
- It gives family and good friends a chance to say how they feel.

Some people do not tell others they have cancer because:

- They are not ready to talk about it.
- They are afraid that other people will be scared.
- They think other people may not want to be around them.
- Saying the words out loud makes the cancer more “real.”
- They don’t want others to feel sorry for them or change how they treat them.

Family and Friends. Many people find that it is best to be honest with family and friends. Then, family and friends have the opportunity to offer their support.

Sometimes another person’s initial reaction to your diagnosis may be overwhelming for you and for them. They may not know what to say, may say the wrong thing or ask a lot of questions. They will take their cues from you. It may be helpful to let them know when you are ready to share. Most people do want to be supportive.

You may want to identify a family member or friend who can become your “press secretary.” This person can be the individual who will get the latest information out to others so that you can focus on your treatment and recovery.

Many organizations, including LLS, provide web-based communities where you can share information and receive support without being overwhelmed by questions and phone calls. Group emails to family and friends are also helpful and efficient. Visit www.LLS.org/community to reach the LLS Community.

You may have relatives or friends who can’t handle it. It happens. But you meet a lot of people on your journey, and they seem to be the strong ones. And other patients understand what you are going through.

Children. Many people with cancer want to hide their illness from the children in their lives because they are concerned it may scare or worry them. Children often sense that something is wrong. They may worry more by not knowing. They may feel that they are to blame. And not telling them the truth means they will miss the chance to talk to you about how they feel. Demystify cancer for the children in your life. Explain that cancer is not contagious and allow children to feel comfortable asking questions and sharing their feelings.

Your healthcare team may be able to give you advice on talking with family, friends and children. You can also contact our Information Specialists.

Knowing someone is listening to what they say can help children feel connected to the family, rather than alone.

Use words and ideas that are right for the child's age. Provide your child with information at a level that matches his or her ability to understand. This is an opportunity to educate your child about any fears or misunderstandings he or she may have about cancer. Use your child's questions as a guide to what he or she wants to know. Don't be overly concerned about giving too much information. Children, like adults, stop listening when they've heard enough. Encourage your child to talk about fears and concerns. You may need to give your child the same information more than once.

You may want someone else to do the talking. There may be times when you feel that it would be best for your child to talk with someone other than you. Each family has different needs. Your healthcare team can help you decide if someone else should talk with your child or children.

Ask children for their help. Younger children can make you get-well cards or bring you a book. Older children can read to you or do extra chores. A child of any age can keep you company, go for a walk with you or provide a smile or hug. Children want to help make you feel better, and letting them help can do just that.

Remind children you love them. Above all, tell children how much you love them. Even if you are grouchy or tired, you still love them and always will. Remind them that you are proud of them. Assure them that it's not their fault that you have cancer. Something as simple as a hug can make both the child and you feel loved.

Employers. Some cancer survivors tell their bosses about their health. Others prefer not to. Some people are afraid of losing their jobs because they have cancer.

Only you can decide what is right for you. It's a good idea to get advice from a professional counselor who understands employment rights for people living with cancer. This is important if you are applying for a new job, too.

Do You Tell Your Boss You Have Cancer?

You might want to because:

- You may need time off for treatments or because you do not feel well.
- You may be able to take family or medical leave. (see below)
- You are applying for a new job.

You might not want to because:

- You are afraid you won't get a raise or promotion.
- You don't want people to feel sorry for you.
- You are afraid of losing your job.

Some employers have free employee assistance programs (EAPs). EAPs help employees deal with personal problems that might affect work and overall well-being. These are private and confidential services (EAP counselors will not tell anyone what you talked about). You can also contact an LLS Information Specialist at (800) 955-4572 for more information.

The Family and Medical Leave Act. Employees who have worked at least 1,250 hours during the 12-month period immediately before the start of the leave may be eligible for family and medical leave.

The Family and Medical Leave Act (FMLA) states that eligible employees in companies with 50 or more employees must give workers up to 12 weeks of time off without pay during any 12-month period. The FMLA can be used by employees who are sick or who need to care for a sick spouse, child or parent.

See “Who Do I Tell and How” on page 9 to help yourself figure out who should know about your illness and figure out how best to tell them.

Job Discrimination. When someone is treated differently because of their health, it is called “job discrimination.” Job discrimination is against the law. There are two federal laws protecting people from losing their jobs because they have cancer.

- **The Federal Rehabilitation Act.** This law helps ensure equal chances for work for people with cancer and other disabilities. Visit www.hhs.gov/ocr or call (800) 368-1019 to contact the Office for Civil Rights for more information.
- **The Americans with Disabilities Act (ADA).** This applies to employers with 15 or more workers. This law says that employers cannot treat an employee differently just because he or she has cancer or another disability, or may need time off to care for a spouse with cancer or another disability. Visit www.ada.gov or call the ADA Information Line at (800) 514-0301 for answers to general questions about the ADA and to order materials.

Get professional advice about what to do if you think you are being treated differently at work. Keep your own record of hours worked and time off for medical appointments or illness. Contact our Information Specialists for more information about job discrimination and resources.

You can view, print or order the free LLS publication *Cancer and Your Finances* at www.LLS.org/booklets or contact our Information Specialists at (800) 955-4572 for a copy.

Cancer is not the end of the life cycle; it’s just another bump in the road. People live fruitful lives with cancer every single day.

Who Do I Tell and How? Some people find it helpful to write down their thoughts. Doing this can help you decide if you will tell anyone about your diagnosis. You may find it useful to make a list of family, friends and professionals you want to talk to. Remember, this is a process. Don't worry if your reasons are not clear or they change.

I do want to tell other people about my diagnosis because

I do not want to tell other people about my diagnosis because

Throughout diagnosis and treatment, you will have many choices to make. They may not be the choices you want to make, but you have the power to choose and to control this part of your life.

Feelings and Thoughts

If you have good ways to deal with hard times from the past, use those same skills to face your illness. You don't have to be positive all the time.

Talking About Your Feelings. People may or may not want to talk about their feelings. Remember, as time goes by, you may change your mind about whether you want to talk about your feelings.

You do not always have to talk. It's okay to say, "I'm not ready to talk right now. Why don't we talk another time?"

Understand that some people are not comfortable talking about feelings.

Ask others, "Is this a good time to talk?" Respect their answers. Some people may not accept that you have cancer. If you can't talk with them, it's important to find someone else you can talk with.

Accept yourself and others. This is a hard time for you, your family and friends. You may resent others who are well. Others may be upset that you have cancer or may be afraid of losing you. There may be arguments.

Take part in a support group. Groups can offer both you and your family strength as well as emotional and social support. Your family member may be interested if you do not feel like participating.

At support groups you can talk with others going through a similar experience. Support groups can help you feel not as alone.

Talk with your doctor. Tell your doctor your fears, your concerns and your symptoms. He or she can help. Bring in a list of questions to ask your doctor and make sure he or she takes enough time to answer them. Bring another person you trust to hear the information.

You may want to write your feelings and thoughts in a journal. Keeping a journal can give you a personal record for looking back on all areas of your life. It can also help you identify goals for the future. Putting your thoughts and feelings into writing can be a way to reduce stress. A sample journal page is included in this booklet on pages 36 and 37 called *Feelings and Thoughts*—you can make copies from this booklet if you want. Or visit www.LLS.org/JournalPage to print additional copies.

Accept that some days may be bad. But expect that others will be better. You may not like the way you feel or look right now. Maybe you don't feel good about anything. Be patient. Everyone is different, so don't compare yourself to others. Don't pressure yourself to feel "up." Remind yourself it's okay to feel sad or angry. But try to focus on your positive feelings.

You may feel better when you

- Accept that your life has changed—but is not over.
- Remember, *you* are not an illness. Your illness is something that happened to you. Remember all the things that you are. For example, you may be a parent, a spouse, a friend, a business person, a musician or a gardener.
- Practice your faith at a house of worship, or connect with your spirituality. Do what gives you strength.
- Plan something you enjoy—a trip to your favorite store, a day with your grandkids.
- Make a list of things that make you feel good. Include activities you can do right now, and plan activities you can do in the future.
- List your passions. What gives you joy? Are you able to do this now, even if a slightly different way?
- Watch your favorite movies.
- Keep a journal.
- Work on craft projects you enjoy, such as knitting, scrapbooking or photography. Distract yourself.
- Volunteer for groups or organizations, if you have the energy.
- Take a class. Pick up a new (or old) hobby. Feel productive.
- Laugh. It changes your brain chemistry, and it is contagious. Cancer may not be funny, but so much of life is.

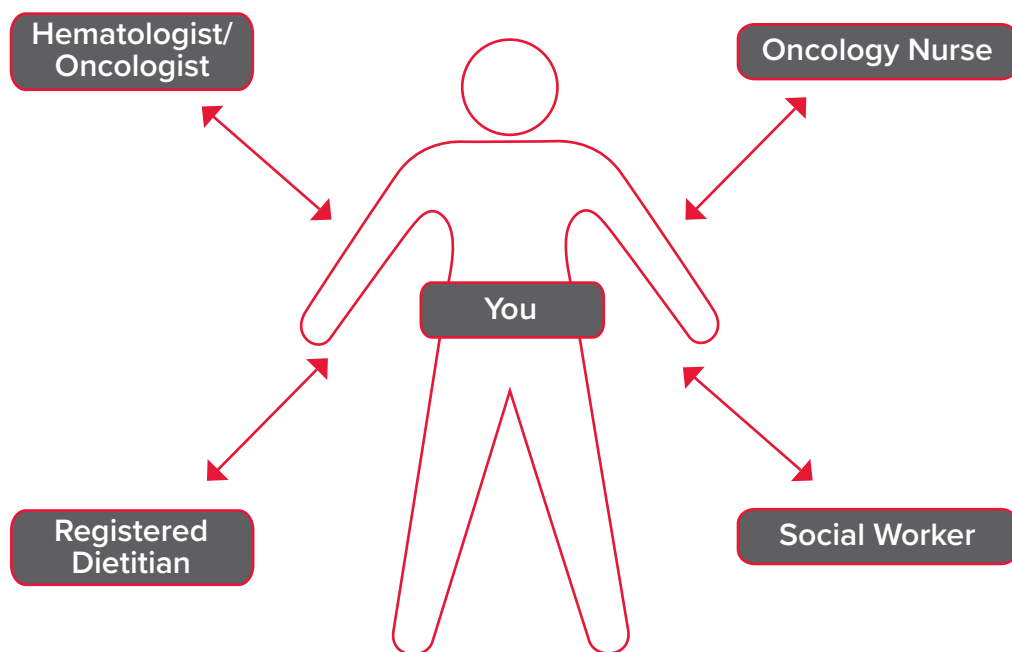
People can get so wrapped up in their disease that they forget who they are—but they are still themselves and need ways to express themselves.

You and Your Doctor

Like many people, you may already have a family doctor or healthcare clinic that you go to for checkups or when you need medical care. Your family doctor or clinic should refer you to a hematologist-oncologist for your cancer evaluation and/or treatment. A hematologist/oncologist is a doctor who treats people with blood cancer.

If your family doctor has not referred you to a hematologist/oncologist, ask for a referral. Or, ask for two referrals and go to one doctor, then to a second doctor to get a second opinion. You can also contact our Information Specialists for help.

You may have a cancer care team. Your care team may include



Preparing for Medical Appointments. You have the right to ask questions and, if you do not understand the information given to you, ask for an explanation from your healthcare team. You deserve respect and for your doctor to look you in the eye when talking or explaining things to you.

Gain as much information as you can about your illness. There are many resources available. The more information I had, the less afraid I felt.

Here are some ways to get the most from your time with the doctor.

Make a list of questions ahead of time. Consider using the questions starting on page 38 to help guide you in preparing for your visit to the doctor's office. Ask your doctor the questions directly or give him or her the list at the start of your visit. You may have questions for your doctor about treatment, fertility (the ability to have a biological child), side effects and clinical trials. Your doctor can answer questions about all of these topics before treatment.

Tell your doctor how much you want to know. Some people want every detail. Others just want the basics. Also, tell your doctor if the amount of information you want has changed.

Take notes. Writing down what your doctor says can help you remember it later. If it is difficult to write while listening to the doctor, take someone with you who can take notes. Because there can be a lot of information provided by the doctor, having the information written down can help.

I would often miss parts of the conversation with the doctor because I was either not feeling well, drifting away or feeling overwhelmed.

Ask for written information about your illness and treatment. You can read it at home and share it with family or friends if you choose.

Ask for copies of your lab test results. It is important to keep a copy of your health records. Many hospitals and clinics offer online patient portals for patients to view their medical records. Ask your healthcare team how to access yours if available.

Ask your doctor to slow down. You can ask your doctor to slow down when talking, or to explain things in another way.

Talk about what symptoms and side effects to expect. Ask about side effects of your medication and treatment, and tell your doctor about any changes in the way you feel or in your activities.

Ask for help. Tell your doctor about anything you need help with, such as paying for medications. Get names, phone numbers and websites.

You have to take charge of your medical treatment. You don't have to do this on your own—find someone to help. If you don't have a friend who can help, ask your nurse for guidance.

Health Calendar. It can be hard to remember how you felt last month, last week, or even yesterday. Keeping a health calendar can help you remember. You can use the same calendar to keep track of your medical appointments and information about side effects. For instance, writing down the time of day your side effects happened and what preceded them can help the doctor establish a pattern (if there is one) and figure out the best way to help you feel better. Many people like to put other events on the same calendar too—birthdays, business meetings, social plans—so that the calendar is not all about cancer, but about life. Write a short note about how you feel along with your activities each day. Share this with your doctor. It can help your doctor manage your treatment and side effects better.

You may want to write things like

- Tired
- Rash
- Lots of energy
- Feel great
- Bad headache
- Walked 1/2 mile
- Lunch with friends
- Cleaned house
- Treatment day—
slept all afternoon
- Morning nausea,
better later

Share the calendar with your doctor at your next appointment. This record will help you and your doctor. By looking it over, you'll see how many good and bad days you're having.

With **LLS Health Manager™** mobile app, you can now use your phone to manage your daily health by tracking side effects, medication, food and hydration, questions for the doctor, grocery lists and more. You can also set up reminders to take medications and to eat and drink water throughout the day. Visit www.LLS.org/HealthManager to learn more and download the app for free.

Sample Health Calendar

		1 Headache	2 Good Energy	3 Walked 1/4 mile	4	5 Walked 1/2 mile
6	7 Slept all afternoon	8 Nauseated on & off	9	10 Lunch with Pam	11 Walked 1/2 mile	12
13 Good energy	14 Tired	15 Walked 1/2 mile	16	17 Cleaned house	18	19
20	21	22	23	24	25	26
27	28	29	30			

You have information that you don't think is very important until you go to the doctor and they start asking you all sorts of questions, and it's all there in your journal. You can also look back and see how far you've come.

Getting a Second Opinion. Some people want to see another doctor for a second opinion. This can help them understand their illness and decide what treatment is best.

You may want to let your doctor know you're getting another opinion. You can say you would like another review of your case so you can make the best decisions about your care. Don't worry about insulting your current doctor when you get a second opinion. A second opinion is reasonable and is your right.

Be sure to check whether your health insurance plan will pay for a second opinion. To find a doctor who can give you a second opinion, you can ask your insurance company. You can also contact an LLS Information Specialist.

Second Opinion Checklists. When you make your appointment, your medical records will need to be sent to the second doctor. Ask how to set that up.

The second opinion may be different from the first. Ask both doctors to explain the reasons for their opinions. You may then want to get a third opinion to help you decide what to do. Check with your insurance about whether a third opinion could be covered. Or you may want to talk with your healthcare team about what to do next.

You should not feel bad about getting a second opinion or changing doctors. Your illness is an important event in your life, and you should feel comfortable about the choices you make in dealing with it. Good doctors understand this.

Changing Doctors. It is your right to change doctors. People may want to change doctors for many reasons. Maybe their doctor isn't as friendly as they would like. Perhaps they have trouble understanding the doctor. Maybe the office is not easy to get to.

It may be hard for you to find a doctor that you trust. It's okay to interview doctors, review their credentials and decide whether you like their bedside manner. You should believe in your doctor and feel comfortable.

You have every right to change doctors. No doctor can promise you a cure. But there are many good doctors. If you want to change doctors, it is okay to tell your current doctor. You do not have to give a reason if you do not want to. It is enough to say you are doing what is best for you.

Steps to Take When Changing Doctors.

- Talk to your insurance company, friends, other healthcare providers, family members or support group members to get recommendations for a new doctor.
- Call the new office and find out if your healthcare coverage is accepted. Ask if the doctor is seeing new patients.
- Schedule a consultation visit (if your healthcare coverage is accepted and the doctor is seeing new patients).
- Arrange to have your records sent to the new doctor.
- Check with the new doctor's office before your consultation visit to make sure your records have arrived.

For suggested questions, use the healthcare question guide *My First Doctor's Visit* on page 38.

There are many types of blood cancer. Ask the hematologist/oncologist if he or she has experience in treating blood cancers or, more specifically, if he or she is knowledgeable about treating your subtype. Each patient's treatment is different.

Your treatment plan may include

- Chemotherapy
- Drug therapy
- Immunotherapy
- Radiation therapy
- Stem cell transplant
- Surgery
- All of the above or a combination of the above
- No treatment at all right now (watch and wait)

Clinical Trials

A clinical trial is a research study led by doctors. There are new treatments under study for blood cancer patients of all ages. New treatments are studied in clinical trials. Clinical trials are also used to study new uses for approved drugs or treatments. For example, changing the amount of a drug or giving a drug along with another type of treatment might be more effective. Some clinical trials combine drugs in new sequences or dosages. Clinical trials aim at improving treatments and quality of life and to increase survival for patients.

There are clinical trials for

- Newly diagnosed patients
- Patients who do not get a good response to treatment
- Patients who relapse after treatment
- Patients who continue treatment after remission (maintenance)

A carefully conducted clinical trial may provide the best available therapy.

With each year that passes, there are more studies and the hope for a cure.

Better treatments for blood cancers depend on clinical trials. To learn more about how new treatments are developed and about clinical trials, speak to your doctor or contact our Information Specialists.

LLS Information Specialists, available at (800) 955-4572, offer guidance on how patients can work with their doctors to determine if a specific clinical trial is an appropriate treatment option. LLS offers help for patients and caregivers in understanding, identifying and accessing clinical trials. When appropriate, patients and caregivers can work with Clinical Trial Nurse Navigators who will help find clinical trials and personally assist them throughout the entire clinical trial process. Visit the LLS Clinical Trial Support Center at www.LLS.org/CTSC for more information.

You can view, print or order the free LLS publications *Knowing All Your Treatment Options* and *Understanding Clinical Trials for Blood Cancers* at www.LLS.org/booklets, or contact our Information Specialists for copies.

Treatment

You will find the healthcare question guide *Treatment and Follow-Up Care* on page 40. You may want to have this with you when you speak to your healthcare provider.

You can print additional copies of this and other question guides at www.LLS.org/WhatToAsk, or request that copies be sent to you by contacting our Information Specialists at (800) 955-4572.

Disease and Treatment Side Effects. The goal of treatment is to harm or kill cancer cells and stop them from spreading. Sometimes treatment also harms good cells. This can cause side effects.

Side effects are different for each person. You can talk about possible side effects of treatment with your healthcare team. This can help you plan for any side effects.

For example, your healthcare team may have told you that your treatment could make you lose your hair. Some people decide to buy a wig or a scarf before treatment begins. Your family or loved ones can support and help you.

Some of the most common side effects include problems with your stomach. These are called “gastrointestinal” or “GI” problems. GI problems can include

- Upset stomach/feeling that you will throw up (vomit)
- Diarrhea
- Having a bowel movement less than three times a week (constipation)
- Throwing up

Other side effects can include

- Rashes and other skin problems
- Mouth sores
- Losing your hair
- Changes in your mood
- Feeling very tired
- Problems having sex (more information about couples begins on page 24)
- Changes to a woman’s period

You may also feel sad. It is important that you speak with your healthcare team about your feelings. If your mood does not improve over time—for example, if you are feeling depressed most of every day for two or more weeks—your doctor may be able to help or refer you to another doctor who can.

Depression is an illness that should be treated, even when a person is undergoing treatment for cancer. In fact, treatment for depression has proven benefits for people living with cancer. For more information about depression and cancer, contact our Information Specialists at (800) 955-4572. Or you can contact the National Institute of Mental Health (NIMH), which has several publications about depression that may be helpful. You can get more information online at www.nimh.nih.gov—enter “depression” in the search box at the top of the webpage. Or call NIMH toll free at (866) 615-6464.

You should tell your doctor about any side effects you have. Most side effects go away when treatment is over. However, some side effects can last after treatment ends. Talking with your doctor about side effects can help you learn how to deal with them. Your doctor might prescribe medicine or suggest other ways to help ease side effects.

Complementary Therapies. Many people use complementary therapies to

- Help deal with symptoms of their disease
- Help cope with side effects of treatment
- Have a sense of control over their health

Integrative medicine (IM) is now offered at many cancer centers. Integrative medicine uses complementary therapies that have been found to be safe and helpful. Complementary therapy is used with standard cancer care such as chemotherapy, radiation therapy and immunotherapy. Examples are support groups, acupuncture, meditation, yoga, touch therapy (called Reiki) and music therapy. Some complementary therapies have been shown to help with nausea, vomiting or fatigue. To date, there is no scientific proof that any complementary therapies will slow cancer growth.

Talk with your healthcare team about any complementary therapies you are using or thinking about using as many have not been studied. These therapies may be neither safe nor effective. Your doctor can give you more information.

You can view, print or order the free LLS publications *Understanding Lab and Imaging Tests, Integrative Medicine & Complementary Therapies Facts* as well as the information in our *Side-Effect Management* series at www.LLS.org/booklets, or contact our Information Specialists for copies.

Healthcare Coverage

Having health insurance is very important for people with cancer. Yet many do not have enough coverage.

Helpful Tips About Healthcare Coverage

- Do not let your coverage end (lapse) when you change jobs (See COBRA, below).
- Talk to your human resources department or a financial counselor before making any changes to your health insurance plan.
- If you lose, leave, or change your job, you may be able to stay on your company health plan through COBRA (Consolidated Omnibus Budget Reconciliation Act). This is a federal program that allows former employees to keep health coverage for a limited time. COBRA can be costly. This federal law also applies to dependents (spouse or child) in situations such as a spouse who experiences divorce or legal separation from a covered employee, dependents of an employee who becomes Medicare-eligible, and dependents of a deceased employee. Check with your human resources department for information about this program.
- If you need a lot of time off, ask your employer about the Family and Medical Leave Act (FMLA). More information about FMLA is on page 7.
- If you do not have health coverage or if you lose your health coverage, visit [Healthcare.gov](https://www.healthcare.gov), a website hosted by the US Department of Health and Human Services. It provides information about the health insurance options available to you in your geographic area.
- Talk to the financial counselor at the hospital or a social worker to see if you qualify for Medicare and/or Medicaid.
- The Affordable Care Act (ACA) allows children to stay on their parent's health insurance policy until they are 26 years old.
- Contact your state's department of insurance to find out if your state has a "high-risk pool." That is a program that makes health coverage available to people who are considered medically uninsurable.

- Veterans' benefits provide comprehensive healthcare and other benefits for veterans and dependents of active-duty, retired or deceased members of the military. TRICARE® is the healthcare program serving uniformed service members, retirees and their families. Visit www.tricare.mil for information about TRICARE.

You can view, print or order the free LLS publication *Cancer and Your Finances* at www.LLS.org/booklets or contact our Information Specialists for a copy.

Life During and After Treatment

I surrounded myself with a small group of people, I researched the illness very thoroughly and spent a lot of time working on hobbies and reading. That's the way I cope. You need to do what works for you.

You can and should resume as many of the activities you need and want to do as soon as you feel able and your doctor says it's okay. Before you were diagnosed with cancer, you had things you enjoyed. You had responsibilities. You had goals. You may have some new priorities now, but many of your former activities are still an important part of your life.

You may find you have a new or renewed desire to help others. Perhaps you will help other people with cancer. You may also need to let others help you. One way to help others is to take them up on their offers to help you.

Where people with a blood cancer can make new friends

- At support groups for people with cancer
- At a prayer group/church/synagogue/mosque/temple
- In doctors' offices/waiting rooms
- In specialty shops, such as wig stores

When I was diagnosed my doctor said, “Now your choices begin.” I didn’t know what that meant at the time. What it means to me now is: You’re not as limited as you think you might be, and cancer doesn’t define you.

Couples. Having a blood cancer can affect even the most private part of your life. You and your partner may have questions about sex now that you have cancer. Know that intimacy can remain.

Like many couples, you may find comfort in knowing that

- Other signs of love are as important as sex. You may not feel up to having sex. But you can still touch, kiss and hold your partner. These signs of love are very important to both of you. Intimacy maintains your connection.
- Cancer is not contagious. Your partner cannot catch cancer from you.
- Ask the healthcare team if it is safe for you to engage in sexual activity and inquire whether any extra precautions need to be taken.
- If you continue to have sex during treatment, be sure to take steps to protect against pregnancy and sexually transmitted diseases (STDs).
- Sometimes treatment lowers a patient’s desire to have sex. Side effects may make it hard to be interested in sex. Problems with sex related to treatment are usually short-term.
- Your partner may be afraid that sex will hurt you. Talking with your partner can help you both understand what is okay to do right now.
- There are people you can talk to. A counselor, priest, rabbi or your doctor can help you and your partner discuss your fears and wishes.

You can view, print or order the free LLS publication *Sexuality and Intimacy* at www.LLS.org/booklets or contact our Information Specialists for a copy.

Family. Living with cancer means change for everyone. The support of your family is very important. Some roles may need to change for a while, especially during your treatment. For example:

- Your spouse or partner may need to do extra chores
- Older children may need to do laundry or help clean the home
- Younger children may need to help with chores
- A grandparent may need to help take care of children

Discuss what needs to be done. Make a chart. Assign tasks. Who does what best?

When we let people support us, we are giving them a gift.
We are helping them to feel connected and useful.

Giving everyone jobs to do can help your family and friends feel better. Still, having too many jobs can affect the physical and emotional health of family members. So you will need to find balance.

Here are some ideas:

- Keep a list of people who offer to help. Call them when a need arises. Remember, they want to help.
- Keep a list of chores that you can use help with—no matter how small. Then when someone says, “What can I do to help?” you will have an answer.
- Accept help from friends or community members to shop, cook, clean, cut the grass, rake the leaves, shovel the snow, fold the laundry, pick up the dry cleaning or walk the dog.
- Let your house be messy—even a little.
- Have simpler meals.
- Spend less time driving the kids around and spend more time together at home.
- Hire help if you can.

Remember you are not alone. There are people who will help you deal with things on a daily basis.

It is important for you to stay involved in family activities and do chores when you can. On the days you are feeling very well, you may want to make a special dinner or work on an item on your to-do list.

Sometimes it seems like cancer is the only thing going on. Remember to make time for family. Take day trips. Play games together. Watch TV or movies together. These times can lift your spirits and give everyone a break.

Helping Children Cope. It is hard for children to have one or both parents away from home during treatment. It can be just as hard to see a parent having trouble getting around at home. Children may be sad or angry that they cannot spend time with you. You may notice changes in their behavior. They may be afraid of losing you.

Children need the support and guidance of a loving adult. Consider asking your spouse, a relative or family friend to help during the times when you need to be away from home or when you do not feel well enough to cope.

You may also want to arrange for your children to talk with a school counselor or social worker. Family counseling or support groups may be helpful as well. You can also stay in touch with your child's teacher to share information that will help.

Living Alone. When there is no one else in your home to provide encouragement, treatment can be a difficult time. It isn't easy, but the truth is that whether we live with a partner or family or live alone, many times we all have to find our own motivation for getting out of bed in the morning.

Before your diagnosis, your life consisted of pleasures and chores. As soon as you can, resume as many of your normal activities as possible.

Some people view their life after cancer as an opportunity to reassess what is important to them. One woman who had been treated for leukemia began helping out at her local senior citizens center. Today, she supervises the kitchen staff and organizes special trips.

I meet so many people and feel so involved with life now. I'm busy and happy, and best of all, I don't have too much time to worry about myself.

By helping others, people often find that they also help themselves. Many volunteer. Others become members of community groups or finally get around to exploring a lifelong interest they had not made time for before.

After Treatment

Cancer has completely changed my outlook on life. It's a wake-up call—a chance to really live and enjoy your life. Find something you enjoy and don't postpone doing it.

No one forgets that he, she or a loved one once had cancer. People are afraid and find it difficult to relax. After remission, the worry can go on, and you may be concerned that your cancer will return, which can cause undue stress. This is especially true when you

- Feel symptoms, even those of a common cold
- Need follow-up visits
- Return to the doctor's office or hospital—places that may cause frightening memories
- Reach a 5- or 10-year anniversary of being diagnosed or being in remission

Seek counseling or support groups. These may be beneficial to you.

Sometimes we focus so much on the cancer and the treatment that we don't look ahead enough to the life after treatment. Take it as it comes. It's the little things that are so precious—like sitting on the deck and taking in the beauty.

Cancer survivors say they are sometimes afraid, but they feel less afraid when they focus on things other than their illness.

They also share a peace that few other people know. Survivors can often enjoy the many ordinary moments that most people ignore. Patients often say that different things are important to them now. Others say they feel able to handle anything life brings.

At first, it may seem hard to face each new day, to welcome or to enjoy it. A time will come when cancer is not the central part of your day—when you don't think about it as often as you once did. Hours of not thinking about cancer can turn into days without thinking about cancer. A sign of normality returning can be as simple as when arguments between family members begin again.

After treatment ends, it might be helpful to ask yourself

- Did I laugh today? How often? When? With whom?
- Do I want to be asked, "How do you feel?" by my loved ones? How often? Not at all?

Some of the things I felt were important before cancer are not so important now. I like to spend more time with my family, and I'm more spiritual. I try to be a better person in helping others when I have the chance.

Ask your doctor for written guidelines about future follow-ups, which may include screening tests for long-term and late effects. Visit www.cancer.net/patient/survivorship to reach information about survivorship from The American Society of Clinical Oncology (ASCO).

You can view, print or order the free LLS publication *Long-Term and Late Effects of Treatment in Adults* at www.LLS.org/booklets or contact our Information Specialists for a copy.

Suggestions for Family and Friends

The news that my wife had cancer confirmed my belief that life is unpredictable, so we should enjoy and live life to the fullest.

If you are the spouse or partner of a person who has cancer, it may be hard to think of yourself right now. You are trying to meet the needs of your loved one. But you need to meet your own needs as well. Taking care of yourself will make it easier for you to care for your loved one. For example, make sure you eat well and get enough rest. That will give you the energy to help do chores and errands for your loved one. You may find yourself feeling very sad or angry. Talking with a counselor or support group can help you work through your feelings.

How to Help

Whatever happens, I will be by your side through this journey.

Family and friends don't always know what to say or how to act. For friends and family, here are some helpful tips:

Be patient. Waiting for your loved one to talk about his or her cancer can be frustrating. Still, it is important to let him or her decide when to talk. Your loved

one may also be directing a lot of anger at you. LLS can connect you with families of patients with a similar diagnosis and treatment as a means of support.

Don't offer false cheer. Don't insist that "everything will be all right." Right now, everything is not all right. Saying so may make your loved one feel as though he or she cannot share his or her true feelings. Instead, it is okay to let him or her be sad. Share some of your own feelings. Knowing you also feel sad or afraid may help your loved one be honest about feelings.

Offer specific ways to help. Most people want to help loved ones with cancer. Yet few people really know what to do or how to act. Be yourself. Think about ways you can help. Tell your friend or family member you would like to help. Then offer specific suggestions.

You may want to say:

- "I'd like to make some meals. Would that be all right? What are some family favorites?"
- "Can I drive you to any doctor appointments or take you on other errands this week?"
- "I'm going to the store this afternoon. How about I call you back in an hour and you give me a list of things I can pick up for you?"
- "If you'd like to rest tomorrow, why don't I take the kids to a movie and out for pizza?"
- "Why don't your kids car-pool with mine this week? That will give you some extra time to rest."
- "There was a sale on laundry detergent at the store. I got some extra for you. Why don't I do some laundry for you?"
- "It's going to be a beautiful day today. How about if I pack some sandwiches and we go to the park for a little while?"
- "There are some new movies available. If it's all right, I'd like to watch one together. You pick."

For even more ways to help, you can

- Donate blood
- Help the caregiver, not just the patient

Remember that your loved one may not be ready for your suggestions. Patients' energy levels may be good one day and low the next day.

Also, call an Information Specialist or visit www.LLS.org/FamilyWorkbook to find information for caregivers.

Many of us like to be supportive—it makes us feel good to be useful. Yet, support isn't always easy to accept. Anyone may have a problem accepting help some or all of the time.

Resources and Information

LLS offers free information and services to patients and families affected by blood cancers. This section lists various resources available to you. Use this information to learn more, to ask questions, and to make the most of the knowledge and skills of the members of your healthcare team.

For Help and Information

Consult With an Information Specialist. Information Specialists are master's level oncology social workers, nurses and health educators. They offer up-to-date disease and treatment information. Language services are available. For more information, please

- Call: (800) 955-4572 (Monday through Friday, 9 am to 9 pm ET)
- Email: infocenter@LLS.org
- Live chat: www.LLS.org/InformationSpecialists
- Visit: www.LLS.org/InformationSpecialists

Clinical Trials Support Center (CTSC). Research is ongoing to develop new treatment options for patients. LLS offers help for patients and caregivers in understanding, identifying and accessing clinical trials. When appropriate, patients and caregivers can work with Clinical Trial Nurse Navigators who will help find clinical trials and personally assist them throughout the entire clinical trial process. Please visit www.LLS.org/CTSC for more information.

Free Information Booklets. LLS offers free education and support booklets that can be either read online or ordered. Please visit www.LLS.org/booklets for more information.

Telephone/Web Education Programs. LLS offers free telephone/Web and video education programs for patients, caregivers and healthcare professionals. Please visit www.LLS.org/programs for more information.

Financial Assistance. LLS offers financial assistance to individuals with blood cancer. Please visit www.LLS.org/finances for more information.

Co-Pay Assistance Program. LLS offers insurance premium and medication co-pay assistance for eligible patients. For more information, please

- Call: (877) 557-2672
- Visit: www.LLS.org/copay

LLS Health Manager™ App. This free mobile app helps you manage your health by tracking side effects, medication, food and hydration, questions for your doctor, and more. Export the information you've tracked in a calendar format and share it with your doctor. You can also set up reminders to take medications, hydrate, and eat. Please visit www.LLS.org/HealthManager to download for free.

One-on-One Nutrition Consultations. Access free one-on-one nutrition consultations with a registered dietitian who has experience in oncology nutrition. Dietitians assist callers with information about healthy eating strategies, side effect management, and survivorship nutrition. They also provide additional nutrition resources. Please visit www.LLS.org/nutrition to schedule a consultation or for more information.

Podcast. *The Bloodline with LLS* is here to remind you that after a diagnosis comes hope. Listen in as patients, caregivers, advocates, doctors and other healthcare professionals discuss diagnosis, treatment options, quality-of-life concerns, treatment side effects, doctor-patient communication and other important survivorship topics. Please visit www.LLS.org/TheBloodline for more information and to subscribe.

Suggested Reading. LLS provides a list of selected books recommended for patients, caregivers, children and teens. Please visit www.LLS.org/SuggestedReading to find out more.

School Reentry. *The Trish Greene Back to School Program for Children With Cancer* is a program designed to increase communication among healthcare professionals, school personnel, parents and patients to assure children with cancer a smooth transition back to school. For more information, visit www.LLS.org/BackToSchool.

Continuing Education. LLS offers free continuing education programs for healthcare professionals including *Staying Connected: Facilitating the Learning Experience During and After Cancer Treatment*. Please visit www.LLS.org/ProfessionalEd for more information.

Community Resources and Networking

LLS Community. The one-stop virtual meeting place for talking with other patients and receiving the latest blood cancer resources and information. Share your experiences with other patients and caregivers and get personalized support from trained LLS staff. Please visit www.LLS.org/community to join.

Weekly Online Chats. Moderated online chats can provide support and help cancer patients to reach out and share information. Please visit www.LLS.org/chat to join.

LLS Chapters. LLS offers community support and services in the United States and Canada including the Patti Robinson Kaufmann First Connection Program (a peer-to-peer support program), in-person support groups, and other great resources. For more information about these programs or to contact your chapter, please

- Call: (800) 955-4572
- Visit: www.LLS.org/ChapterFind

Other Helpful Organizations. LLS offers an extensive list of resources for patients and families. There are resources that provide help with financial assistance, counseling, transportation, patient care and other needs. For more information, please visit www.LLS.org/ResourceDirectory to obtain our directory.

Advocacy. The LLS Office of Public Policy (OPP) engages volunteers in advocating for policies and laws that encourage the development of new treatments and improve access to quality medical care. For more information, please

- Call: (800) 955-4572
- Visit: www.LLS.org/advocacy

Additional Help for Specific Populations

Información en español (LLS information in Spanish). Please visit www.LLS.org/espanol for more information.

Language Services. Let members of your healthcare team know if you need a language interpreter or other assistance, such as a sign language interpreter. Often, these services are free.

World Trade Center (WTC) Survivors. People involved in the aftermath of the 9/11 attacks and subsequently diagnosed with a blood cancer may be eligible for help from the World Trade Center (WTC) Health Program. People eligible for help include

- Responders
- Workers and volunteers who helped with rescue, recovery and cleanup at the WTC-related sites in New York City (NYC)
- Survivors who were in the NYC disaster area, lived, worked or were in school in the area
- Responders to the Pentagon and the Shanksville, PA, crashes

For more information, please

- Call: WTC Health Program at (888) 982-4748
- Visit: www.cdc.gov/wtc/faq.html

People Suffering from Depression. Treating depression has benefits for cancer patients. Seek medical advice if your mood does not improve over time—for example, if you feel depressed every day for a 2-week period. For more information, please

- Call: The National Institute of Mental Health (NIMH) at (866) 615-6464
- Visit: NIMH at www.nimh.nih.gov. Enter “depression” in the search box

Feelings and Thoughts

Date _____

How I feel today in body and mind

I laughed today when

What I did today

I am thankful for

My hopes and fears

My plans

Other thoughts

Question Guide: My First Doctor's Visit

Asking questions will help you take an active role in managing your (or your loved one's) care. If you do not understand any part of the information your healthcare provider gives you, ask him or her to explain it in another way. The following are questions you may want to ask your healthcare team.

When you meet with the doctor, nurse and healthcare team, ask a few questions to get a better idea of the doctor's experience and to understand how the office works.

(Note: The use of "I (we)" and "me (us)" in lists of questions is used for situations in which the patient may not be old enough or able to make his or her own decision. A parent, relative, or caregiver may be assisting or making the decision.)

Questions for the Doctor

DOCTOR'S NAME: _____

Date of appointment or phone call: _____

1. How many patients have you treated who have this disease?
2. What problems or symptoms should be reported to the nurse or doctor right away?
3. How long does it normally take to receive a return phone call?
4. How can you be contacted when there are questions?
5. How can you be contacted at night? On weekends? On holidays?
6. Who are the other members of the team that I should be aware of?
7. Is there a release form to sign so my family/caregiver can be given medical information?

Questions for the Nurse

NURSE OR OTHER HEALTHCARE TEAM MEMBER'S NAME:

1. How long would I (we) have to wait for appointments?
2. What problems or symptoms should be reported to the nurse or doctor right away?
3. How long does it usually take to receive a return phone call?
4. Will there be nurses, social workers and case managers available to help with support needs and quality-of-life concerns?
5. Does your office accept my (our) insurance? Is it considered in-network?

To print copies of other question guides, go to www.LLS.org/WhatToAsk or call (800) 955-4572.

Question Guide: Treatment and Follow-Up Care

Talk with the doctor and ask questions about how he or she plans to treat your (your loved one's) type of blood cancer. This will help you and your loved one to be actively involved in making decisions about medical care. The following are questions you may want to ask your healthcare team.

(Note: The use of "I (we)" and "me (us)" in lists of questions is used for situations in which the patient may not be old enough or able to make his or her own decision. A parent, relative, or caregiver may be assisting or making the decision.)

DOCTOR'S NAME: _____

Date of appointment or phone call: _____

Write down your diagnosis:

Write down your stage (or subtype):

Before Treatment Begins

1. Will this treatment affect the ability to have a child in the future?
2. If yes, are there other treatment options available?
3. What are the options for preserving fertility?
4. How much time do I (we) have to make decisions?
5. What is the stage or subtype?
6. What is the goal of treatment?
7. What are the treatment options?
8. Are there any clinical trials I could join?
9. When do you think treatment should begin?
10. How long will treatment last?
11. What are the benefits and risks of these treatments?
12. Is there one treatment recommended over the others?
13. How can potential side effects be prevented or managed?

Testing

1. What kind of testing will be done to monitor the disease and treatment?
2. How long does it take to get the results?
3. How will the results be communicated to me (us)?
4. How often will testing be needed?
5. Where will the testing be done?

Treatment

1. Will this be an in-hospital or an outpatient treatment?
 - 1a. Is it alright to attend work or school during treatment?
 - 1b. Will someone be needed to drive me home after treatment?
2. How will we know if the treatment is effective?
3. What kind of testing will be done to monitor this disease and treatment?
How often will testing be needed? Where is the testing done?
4. What options are available if the treatment is not effective?
5. What is the likely outcome of the disease (prognosis)?

Side Effects

1. What are the common side effects for this treatment?
2. What side effects should be reported to the healthcare team right away?
3. How long will the side effects last?
4. How can potential side effects be prevented or managed?
5. How should I report side effects (phone call, at the office visit, etc)?

Social/Financial Concerns

1. Are there any side effects that will affect appearance?
2. Are there any side effects that will affect ability to do a job/go to school?
3. What kind of financial and social support services are available to me and my family?
4. How can I (we) find out if insurance will cover the costs of the treatment or the study (clinical trial) treatment?
5. Who is the best person to speak to about bills and insurance coverage?
6. If I (we) do not have insurance coverage, how can the healthcare team help? Is there someone I (we) can speak to for assistance?
7. If I (we) get in a study treatment (clinical trial), will I (we) be responsible for paying treatment-related costs, such as tests, travel or for clinical-trial drugs?
8. How can I (we) find out if insurance will cover the cost of the clinical trial treatment and treatment-related costs such as testing?

Follow-Up Care and Long-Term and Late Effects

1. Who should I (we) work with to ensure life-long follow up?
2. Will I (we) continue to see this healthcare team?
3. How can I (we) be monitored for long-term and late effects of treatment?
4. What types of long-term and late effects should be brought to the healthcare team's attention?
5. If there are side effects later, how can the healthcare team be reached?
6. What information can be provided to a primary doctor about this treatment?

To print copies of other question guides, go to www.LLS.org/WhatToAsk or call (800) 955-4572.



Get support.
Reach out to our

INFORMATION SPECIALISTS

The Leukemia & Lymphoma Society team consists of master's level oncology social workers, nurses and health educators who are available by phone Monday through Friday, 9 a.m. to 9 p.m. (ET).

- Get one-on-one personalized support and information about blood cancers
- Know the questions to ask your doctor
- Discuss financial resources
- Receive individual clinical-trial searches

Contact us at

800-955-4572 or

www.LLS.org/

InformationSpecialists

(Language interpreters can be requested)





For more information, please contact our Information Specialists
800.955.4572 (Language interpreters available upon request).

**BEATING
CANCER
IS IN
OUR BLOOD.®**

National Office 3 International Drive, Suite 200, Rye Brook, NY 10573

The mission of The Leukemia & Lymphoma Society (LLS) is to cure leukemia, lymphoma, Hodgkin's disease and myeloma, and improve the quality of life of patients and their families. Find out more at www.LLS.org.