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**LEUKEMIA &
LYMPHOMA
SOCIETY®**

fighting blood cancers

Each New Day

Ideas for Coping with Blood Cancers



A Message from Louis J. DeGennaro, PhD

President and CEO of The Leukemia & Lymphoma Society

The Leukemia & Lymphoma Society (LLS) is the world's largest voluntary health organization dedicated to finding cures for blood cancer patients. Our research grants have funded many of today's most promising advances; we are the leading source of free blood cancer information, education and support; and we advocate for blood cancer patients and their families, helping to ensure they have access to quality, affordable and coordinated care.

Since 1954, we have been a driving force behind nearly every treatment breakthrough for blood cancer patients. We have invested more than \$1 billion in research to advance therapies and save lives. Thanks to research and access to better treatments, survival rates for many blood cancer patients have doubled, tripled and even quadrupled.

Yet we are far from done.

Until there is a cure for cancer, we will continue to work hard—to fund new research, to create new patient programs and services, and to share information and resources about blood cancer.

This booklet has information that can help you understand your finances, prepare questions, find answers and resources, and communicate better with members of your healthcare team.

Our vision is that, one day, all people with blood cancers will either be cured or will be able to manage their disease so that they can experience a better quality of life. Today, we hope our expertise, knowledge and resources will make a difference in your journey.



Louis J. DeGennaro, PhD

*President and Chief Executive Officer
The Leukemia & Lymphoma Society*

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Introduction

Each year, about 1.6 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.

A number of 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.

¹Howlader N, Noone AM et al. (eds). SEER Cancer Statistics Review, 1975-2008, National Cancer Institute. Bethesda, MD, www.seer.cancer.gov/csr/1975_2008/, based on November 2010 SEER data submission, posted to the SEER website, 2011.

Please contact **The Leukemia & Lymphoma Society (LLS)** to speak to an **LLS Information Specialist at (800) 955-4572** and to connect with a **Patient Services Manager at your chapter**. You can locate your chapter at www.LLS.org/chapterfind.

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 *Each New Day* in different ways. You may

- Read the sections in any order. Or, you can go straight to the information you think is most important
- Use the work sheet *Feelings and Thoughts* on pages 30 and 31—you can print extra copies at www.LLS.org/firststeps
- Share this booklet with others. The section *Suggestions for Family and Friends* begins on page 27.

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 32). To find additional suggested questions, visit www.LLS.org/whattoask.

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.”*

Here to Help

This booklet will give you suggestions to help you take care of yourself and help you talk to your doctor. We encourage you to take the lead in asking questions and discussing your fears and concerns. These actions will give members of your healthcare team the opportunity to answer your questions, extend emotional support and provide any needed referrals.

A blood cancer diagnosis is often a shock to the patient, family members and friends. Denial, depression, hopelessness and fear are some of the reactions people may have. Keep in mind that

- Many people are better able to cope once they begin treatment and can look forward to recovery
- The outlook for people with blood cancers is continuing to improve. New approaches to therapy are being studied in clinical trials for patients of all ages and at every stage of treatment.

LLS Has Ways to Help. Your treatment may affect your daily life, at least for a time. You may have questions about your treatment and want to have friends, family members or caregivers help you get information.

Making treatment choices, paying for medical care, communicating with healthcare providers, family members and friends—these are some of the stresses that go along with a cancer diagnosis. LLS offers free information and patient services for individuals and families touched by blood cancers.

Speak to an Information Specialist. Information Specialists are master's level oncology professionals. They provide accurate up-to-date disease and treatment information and are available to speak with callers Monday through Friday, 9 a.m. to 6 p.m. ET at (800) 955-4572. You can email infocenter@LLS.org or chat live at www.LLS.org.

Clinical Trials. Our Information Specialists help patients work with their doctors to find out about specific clinical trials. Information Specialists conduct clinical-trial searches for patients, family members and healthcare professionals. You can also use TrialCheck®, an online clinical-trial search service supported by LLS that offers patients and caregivers immediate access to listings of blood cancer clinical trials. Please visit www.LLS.org/clinicaltrials.

Language Services. Free language services are available when you speak with an Information Specialist. Let your doctor know if you want a professional healthcare interpreter who speaks your native language or uses sign language to be present during your visit. Many times, this is a free service.

Información en Español. LLS has a number of resources available in Spanish for patients, caregivers and healthcare professionals. You can read and download these resources online at www.LLS.org/espanol or order printed copies by mail or phone.

Co-Pay Assistance Program. This program offers assistance for financially eligible patients with certain blood cancer diagnoses to help pay for private or public health insurance premiums and/or co-pay costs for prescription medications. Check www.LLS.org/copay or call (877) 557-2672 to speak to a *Co-Pay Assistance Program* specialist for more eligibility information.

Free Materials. LLS publishes many free education and support materials for patients and healthcare professionals. PDF files can be read online or downloaded. Free print versions can be ordered. Visit www.LLS.org/resourcecenter.

Chapter Programs and Services. LLS chapter offices around the United States and Canada offer support and education. Your chapter can arrange for peer-to-peer support through the *Patti Robinson Kaufmann First Connection Program*. The *Patient Financial Aid* program offers a limited amount of financial aid for qualified patients. Find your chapter by calling (800) 955-4572 or by visiting www.LLS.org/chapterfind.

Other Helpful Organizations. Our website, www.LLS.org/resourcedirectory, offers an extensive list of resources for patients and families about financial assistance, counseling, transportation, summer camps and other needs.

Telephone/Web Education Programs. LLS provides a number of free, live telephone and web education programs presented by experts for patients, caregivers and healthcare professionals. For more information, visit www.LLS.org/programs.

School Reentry. *The Trish Greene Back to School Program for Children With Cancer* is designed to increase communication between parents, children, adolescents, young adults, healthcare professionals and school personnel. Informative materials, videos and a wealth of literature are available through LLS chapters to help ensure a smooth transition back to school. For more information, please visit www.LLS.org/backtoschool. For practical guidance on how to support your child, yourself and other family members, see the free LLS publication *Coping With Childhood Leukemia and Lymphoma*.

Suggestions From Other People Living With Cancer

- Get information about choosing a cancer specialist or treatment center.
- Find out about financial matters: What does your insurance cover? What financial assistance is available to you?
- Learn about the most current tests and treatments for your type of blood cancer.
- Keep all appointments with the doctor and talk openly about your fears or concerns or any side effects you experience.
- Talk with family and friends about how you feel and how they can help.
- Contact your doctor if you have fatigue, fever, pain or sleep problems so that any issues can be addressed early on.
- Get medical advice if you have experienced changes in mood, feelings of sadness or depression.

Reach Out. You and your loved ones can reach out for support in several ways:

- LLS offers online blood cancer discussion boards as well as online chats at www.LLS.org/getinfo.
- Local or Internet support groups and blogs can provide forums for support.
- Patients with cancer often become acquainted with one another, and these friendships provide support.

Information for Veterans. Veterans with certain blood cancers who were exposed to Agent Orange while serving in Vietnam may be able to get help from the United States Department of Veterans Affairs. For more information call the Department of Veterans Affairs at (800) 749-8387 or visit www.publichealth.va.gov/exposures/agentorange.

Depression. Treatment for depression has proven benefits for people living with cancer. Depression is an illness that should be treated even when a person is undergoing treatment. Seek medical advice if your mood does not improve over time—for example, if you feel depressed every day for a two-week period. Contact LLS or ask your healthcare team for guidance and referrals to other sources of help, such as counseling services or community programs. For more information you can contact the National Institute of Mental Health (NIMH) at www.nimh.nih.gov and enter “depression” in the search box at the top of the web page, or call the NIMH toll free at (866) 615-6464.

We’d Like to Hear From You. We hope this booklet helps you. Please tell us what you think at www.LLS.org/publicationfeedback. Click on “LLS Disease & Treatment Publications—Survey for Patients, Family and Friends.”

Do I Tell Anyone I Have Cancer?

A number of 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 what 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 discussion boards 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. To reach LLS discussion boards, please visit www.LLS.org/discussionboard.

“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 feel more worry 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 your LLS chapter or our Information Specialists.

“Knowing someone is listening to what they say can help children feel connected, rather than alone in this experience.”

Tips for Talking to Children. 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 children 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 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. Children 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 yourself 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 your LLS chapter or our Information Specialists 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.

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. For more information, contact the Office for Civil Rights at (800) 368-1019 or visit its website, www.hhs.gov/ocr.

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. For answers to general questions about the ADA and to order materials, call the ADA Information Line at (800) 514-0301 or visit its website, www.ada.gov.

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 your LLS chapter for more information about job discrimination and resources in your community. You can also contact our Information Specialists.

Want more information?



You can view, print or order the free LLS publication *Financial Health Matters* at www.LLS.org/resourcecenter or contact our Information Specialists 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.”

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. Or, as time goes by, people may want to change whether they want to talk about their 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 answering 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 at the end of *Each New Day* called Thoughts and Feelings—you can make copies if you want. Or, you can print copies at www.LLS.org/firststeps.

Accept that some days will 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. Still, at times you may want 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 church, synagogue or mosque, 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 in 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 very contagious. Cancer may not be funny, but so much of life is.

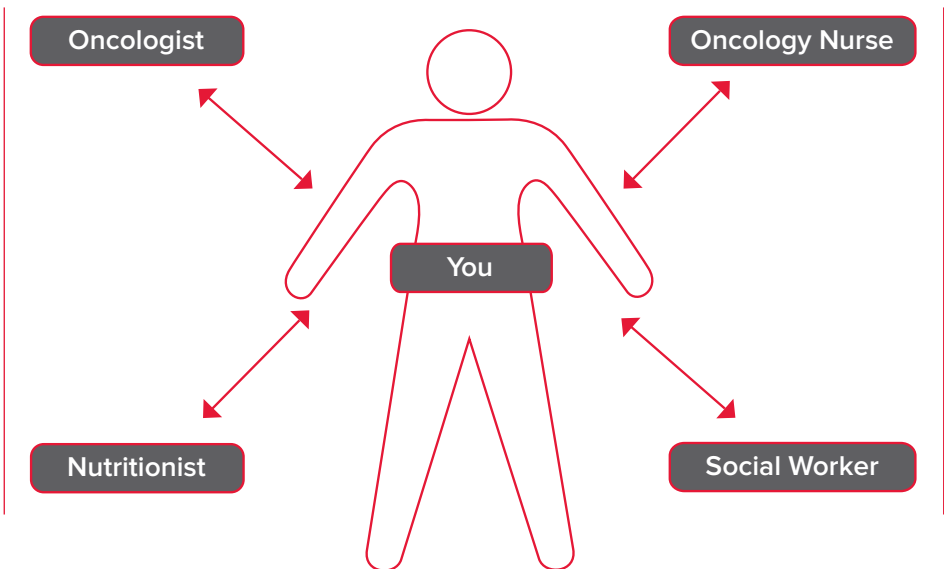
“People can get so wrapped up in their disease that they forget who they are—but they are still themselves and need ways to express this.”

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 may send you to an oncologist for your cancer evaluation and/or treatment. An oncologist is a doctor who treats people with cancer.

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

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 doctors. You deserve respect and the right to have any doctor 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 provided in the inside back pocket folder of this booklet 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 will have questions for your doctor about treatment, side effects and clinical trials. Tell your doctor if you plan to have children one day. Your doctor can tell you about possible steps to take 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 changes.

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. Since 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.

Ask your doctor to slow down. You can ask your doctor to explain things in another way.

Talk about what symptoms and side effects to expect. 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 or last week, 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 make 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
- Felt nauseated this morning, better in afternoon.

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.

Sample Health Calendar

		1 <i>Headache</i>	2 <i>Good Energy</i>	3 <i>Walked 1/4 mile</i>	4	5 <i>Walked 1/2 mile</i>
6	7 <i>Slept all afternoon</i>	8 <i>Nauseated on & off</i>	9	10 <i>Lunch with Pam</i>	11 <i>Walked 1/2 mile</i>	12
13 <i>Good energy</i>	14 <i>Tired</i>	15 <i>Walked 1/2 mile</i>	16	17 <i>Cleaned house</i>	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 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 your LLS chapter or our Information Specialists.

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 than 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. 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 doctor. You do not have to give reasons 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.
- Consider scheduling time to talk with your current doctor about your decision.

There are many types of blood cancer. Ask the oncologist that you decide to go to 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 or other drug therapies
- Immunotherapy
- Radiation therapy
- Surgery
- All of the above
- No treatment at all right now (watch and wait).

Cancer Clinical Trials. A cancer 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 the drug or giving the drug along with another type of treatment might be more effective. Some clinical trials combine drugs in new sequences or dosages. The aims of clinical trials are to improve 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.

“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.

Want 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/resourcecenter or contact our Information Specialists for copies.

Treatment

You will find a healthcare question guide about treatment and clinical trials in the pocket on the inside back cover of this booklet. You may want to have this with you when you speak to your healthcare provider.

You can print additional copies of these 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 because the treatment does not know the difference between good cells and cancer 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, you may have been told 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 23)
- 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 can help.

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 know how to deal with them. Your doctor might prescribe medicine or suggest other ways to help ease side effects.

Complementary and Alternative Therapies. Many people use complementary and alternative (CAM) therapies to

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

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

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

Want more information?



You can view, print or order the free LLS publications *Understanding Drug Therapy and Managing Side Effects*, *Understanding Lab and Imaging Tests* and *Integrative Medicine & Complementary and Alternative Therapies as Part of Blood Cancer Care* at www.LLS.org/resourcecenter or contact our Information Specialists for copies.

Paying for Treatment: Your Healthcare Coverage. Having health insurance is very important for people with cancer. Yet many do not have enough coverage. A patient may be denied coverage for a period of time if his or her cancer is considered a “pre-existing condition.” (That means the condition was already diagnosed before the person enrolled in the plan.)

The Pre-Existing Condition Insurance Plan, created through the Patient Protection and Affordable Care Act, makes health insurance available to people who have difficulty obtaining insurance due to a pre-existing condition. The Act also prohibits denial of insurance coverage for children under the age of 19 with pre-existing conditions. For more information and to find your state’s plan information, visit its website, www.pcip.gov, or call (866) 717-5826.

Helpful Tips About Healthcare Coverage

- Do not let your coverage end when you change jobs.
- Talk to 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. 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 9.
- If you do not have health coverage or if you lose your health coverage, you may be able to join a government program or get other types of assistance.
- Talk to the financial counselor or a social worker to see if you qualify for Medicare and/or Medicaid.
- 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.

Want more information?



You can view, print or order the free LLS publication *Financial Health Matters* at www.LLS.org/resourcecenter 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.

Some people with a blood cancer make new friends

- At support groups for people with cancer
- At a prayer group/church/synagogue/mosque
- 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.

- 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.

Want more information?



You can view, print or order the free LLS publication *Sexuality and Intimacy* at www.LLS.org/resourcecenter 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 clean
- Younger children may need to take on extra 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 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. They may act differently than normal. They may be scared of losing you.

Children need the support and guidance of a loving adult. Consider asking 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 give 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 there is a concern that your cancer will return, which can cause undue stress. This is especially true when you

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

Seek short-term 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. The American Society of Clinical Oncology (ASCO) has information about survivorship. For more information, visit www.cancer.net/patient/survivorship.

Want more information?



You can view, print or order the free LLS publication *Long-term and Late Effects of Treatment in Adults* at www.LLS.org/resourcecenter 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.”

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.

Sometimes the family knows that their loved one has cancer before the patient knows. Then they need to decide

- Whether to tell their loved one
- How to tell him or her
- Which words to use
- How much information to share.

Why to Tell Your Loved One He/She Has Cancer

If you are facing this decision, you may want to consider the following points.

- Most people with a blood cancer agree that they are better off knowing the truth about their illness. They feel they have a right to know about their diagnosis.
- Your loved one can make his or her own treatment decisions.
- He or she can plan for the future, including setting up a will.
- Your loved one can decide how to live his or her life.
- Sharing the information allows people to talk openly about important issues.

Possible Problems With Not Telling the Truth to Your Loved One

- Procedures are needed that are difficult to carry out without the patient knowing why.
- Your loved one may think the condition is worse than it really is if the family seems to be hiding the truth.
- Both patient and caregivers may feel left to cope alone.
- Your loved one may lose faith in the family members who did not tell the truth.
- With increasing survival, families may need to keep their secret for a long time.

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. 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. Everyone wants 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 I pack some sandwiches and we go to the park for a little while?"
- "There are some new movies out on DVD. If it's all right, I'd like to bring one over for us to watch 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.

"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."

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



Questions to Help You Choose a Specialist

Asking questions will help you take an active role in managing your (or your child'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.

Doctor's name _____

Date of appointment or call _____

- 1.** What is your board certification and licensing? Are you a member of any professional societies?

- 2.** How much experience do you have treating patients who have my disease?

- 3.** Is your hospital, university, center or clinic accredited and experienced in treating blood cancers?

- 4.** How long would I usually have to wait for appointments or return of my phone calls?

5. Will there be nurses, social workers and case managers available to help me with support needs and quality-of-life concerns?

6. Do you know of other oncologists who specialize in treating blood cancers? Would you recommend that I speak to any of them?

7. What types of things should I call you about? What types of things should I call my family doctor about?

8. How should I contact you when I have questions?

9. How do I contact you at night? On weekends? On holidays?

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Asking your healthcare provider questions at any phase of your treatment will help you take an active role in managing your (or your child'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.

Doctor's name _____

Date of appointment or call _____

- 1.** What are my (my child's) treatment options? What is the goal of the treatment?

- 2.** What are the FDA-approved treatments, and are there treatments being studied in clinical trials (study treatments), for my (my child's) diagnosis?*

- 3.** What are the benefits and risks of the treatment(s) available to me (my child)? What are the expected side effects?

- 4.** Is there one treatment option (FDA-approved or study treatment) that you recommend over the others? Please explain.

5. If I (my child) enroll(s) in a clinical trial, who will be in charge of my (my child's) treatment?

6. When do you think I (my child) will need to begin treatment?

7. How long will I (my child) be treated and how many treatments will be needed?

8. Will I (my child) need to be hospitalized for all or part of the treatment?

9. What kind of testing will be done to monitor my (my child's) disease and treatment? How often will testing be needed?

10. If I am treated at an out-patient clinic or at the doctor's office, will I be able to drive/get myself home after treatments or will I need someone to assist me?

11. What are the risks if I don't (my child doesn't) get treatment?

12. How will I know if the treatment is effective? What options are available if the treatment is not effective?

13. How do I find out if my insurance will cover the costs of my (my child's) treatment or the study treatment? Who can help answer any medical questions my insurance company or health plan asks?

14. If I do not have insurance coverage, how can the healthcare team help me (my child) get treatment? Is there someone I need to speak to for assistance?

15. If I'm (my child is) getting a study treatment, will I be responsible for paying any treatment-related costs, such as tests, travel or the clinical trial drug(s)?

16. Will the healthcare team continue to check on me (my child) after the treatment is over? If so, for what period of time?

17. I (My child) would like to continue some type of lifelong follow-up care in order to be monitored for long-term and late effects of treatment. Can I (my child) follow up with you?

*For definitions of an FDA-approved treatment and a clinical trial (study treatment), visit www.LLS.org or contact an Information Specialist.

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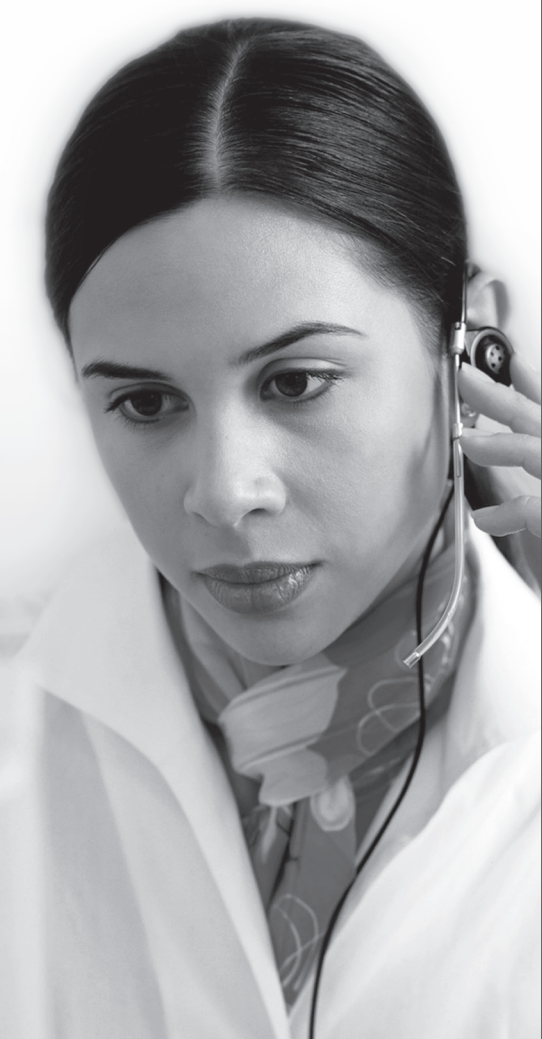
The Leukemia & Lymphoma Society's (LLS) Information Specialists provide patients, families and healthcare professionals with the latest information on leukemia, lymphoma and myeloma.

Our team consists of master's level oncology social workers, nurses and health educators who are available by phone Monday through Friday, 9 am to 9 pm (ET).

Co-Pay Assistance

LLS's Co-Pay Assistance Program helps blood cancer patients cover the costs of private and public health insurance premiums, including Medicare and Medicaid, and co-pay obligations. Support for this program is based on the availability of funds by disease.

For more information, call 877.557.2672 or visit www.LLS.org/copay.



For a complete directory of our patient services programs, contact us at

800.955.4572 or www.LLS.org

(Callers may request a language interpreter.)



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For more information, please contact:

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1311 Mamaroneck Avenue, Suite 310, White Plains, NY 10605

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Our Mission:

Cure leukemia, lymphoma, Hodgkin's disease and myeloma, and improve the quality of life of patients and their families.

LLS is a nonprofit organization that relies on the generosity of individual, foundation and corporate contributions to advance its mission.