

A Medication Resource for Blood Cancer Patients



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A six-word narrative about living with blood cancer from patients in our LLS Community

Stay strong and keep moving forward. Find the positive in every day. Be your own best patient advocate. Changed my life for the better. Accept, learn and focus on present. Learning to live a different life. Sudden and life changing—be positive. Waiting, worrying, anxiousness/happy I'm alive! Embrace a new normal each day. 5 years, 41 infusions, constant fatigue. Patience, positive attitude, hope and faith. Test to test, I will survive! Treatment, fatigue, treatment, fatigue and survival. Love life, live better every day. I don't look back only forward. So far, so good, live life. Meditation, mindfulness, wellness, faith, nutrition and optimism. Finding the joy while living with uncertainty. Watch, wait, treat, regroup, rest, re-energize. Blessed to be doing so well! Eye opening needed learning and healing. Feel great: uncertain travel plans annoying. Renewed faith, meditation, diet, mindfulness, gratitude. Watchful waiting can be watchful worrying. Scary, expensive, grateful, blessings, hope, faith. Thank god for stem cell transplants! Do not know what to expect. Extraordinarily grateful, I love my life. Diagnosed; frightened; tested; treating; waiting; hoping. I'm more generous, impatient less often. Embrace your treatment day after day. Live today, accept tomorrow, forget yesterday. Strength you never realized you had. Challenging to our hearts and minds. Life is what we make it. Live life in a beautiful way.



Discover what thousands already have at
www.LLS.org/Community

Join our online social network for people who are living with or supporting someone who has a blood cancer. Members will find

- Thousands of patients and caregivers sharing experiences and information, with support from knowledgeable staff
- Accurate and cutting-edge disease updates
- The opportunity to participate in surveys that will help improve care.

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This publication is designed to provide accurate and authoritative information about the subject matter covered. It is distributed as a public service by The Leukemia & Lymphoma Society (LLS), with the understanding that LLS is not engaged in rendering medical or other professional services. LLS carefully reviews content for accuracy and confirms that all diagnostic and therapeutic options are presented in a fair and balanced manner without particular bias to any one option.

Oral Adherence [ad-heer-uh ns]

Taking oral (by mouth) medication as prescribed by your healthcare team

Over the last several years, there have been many changes in how cancer is treated. Many new therapies are now taken by mouth (orally). Oral therapy now plays, and will continue to play, a large role in treating blood cancers. With doctors prescribing oral medications more often, the issue of treatment adherence is important.

Why is treatment adherence important? Taking your medications exactly as prescribed gives you the best chance for a successful treatment outcome and helps keep you safe. If you do not take your medications as prescribed, your treatment may not work as well. Taking medication incorrectly can also be dangerous and increase the risk of side effects and complications. Visit www.LLS.org/booklets to view *Oral Treatment Adherence Facts*.

Tips for Patients

- Before you leave your medical appointment, be sure you understand and have a plan for remembering to take your medications as prescribed. Ask for written instructions and whom you can contact if you have questions. You may also find it helpful to take someone with you to appointments to listen to the medication instructions, too.
- Find activities you do every day at the same time you need to take your medication, such as brushing your teeth or feeding your pets. Use these activities to help remind yourself to take your medications.
- Make taking your medication part of your self-care routine. Taking your medication as prescribed is an important part of self care. Take your medication when you meditate, journal, go for a walk, or do another form of daily self care.
- Set your watch alarm, cell phone alarm, or virtual assistant to remind you when to take your medications.

Tips for Patients (continued)

- Use sticky notes to remind yourself. Place the notes where you will see them, such as on the bathroom mirror or the refrigerator door.
- If you use a pillbox, keep one pill in its original bottle. Then if you forget what a pill is for, you can find the bottle it came from.
- Put your pillbox in a place where it will remind you to take your medications. For example, if you need to take medication 3 times a day with meals, put those medications in a pillbox near where you eat.
- If you are taking other medications that don't fit in the pillbox, such as a patch or nebulizer treatment, place a large and/or colorful button in your pillbox as a reminder. Once you've taken that medication, move the button to the next scheduled dosage.
- If your spouse, partner or someone else living in your home takes medications on the same schedule, take your medications together so you can remind each other.
- Be sure you understand what each medication is for and how to take them correctly and safely. Ask your doctor what side effects you should report and when and who to call if you think your medication is causing a problem.
- Know when you will run out of each medication. Write refill reminders on your calendar. Don't wait until you have only one or two pills left. If your health plan has a mail-order service for refills, it may be easier and less expensive than a pharmacy. You may be able to get a 30- or 90-day supply of many medications. You may also be able to sign up for email, phone or text alerts from your pharmacy to be alerted when a refill is ready.
- Make sure your medications haven't expired. Ask your pharmacist how to safely dispose of expired medications.

How to Use Your Calendar

It helps to have a daily medicine routine. Use this calendar as an easy way for you and your family to manage medications and follow the doctor's instructions.

- The blank calendar days provide space for you and your family to write helpful information, such as
 - Medications taken
 - Reminders to fill your pillbox
 - Doctor appointments
 - Side effects you experience
 - Reminders to refill your prescription
- Use **Your Medication Chart** on pages 30 and 31 to list all prescription and over-the-counter medicines, vitamins, and supplements. Take it with you to every doctor visit, and be sure to update it whenever your medications change. Make sure family members have copies in case of an emergency.
- Use the **Notes** section at the bottom of each month to write questions you may have for your healthcare team or additional information.
- Use the **Important Names and Numbers** section on page 32 and 33 to list contact information about your doctor, healthcare team, pharmacy, caregiver, insurance, and other important people.
- Use the pocket on the inside back cover to hold the medication information provided by your pharmacist.

If you have any questions, please call the LLS Information Specialists Monday through Friday, 9 a.m. to 9 p.m. (ET) at (800) 955-4572.



LLS Health Manager. With the LLS Health Manager™ mobile app, you can use your phone to track side effects, medication, food and hydration. You can set up reminders to take medications, to eat, and to drink water throughout the day. You can also share the information with your doctor to identify patterns and develop strategies to help manage side effects. Visit www.LLS.org/HealthManager to download.

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 individualized clinical-trial searches

Contact us at
800-955-4572 or
**www.LLS.org/
InformationSpecialists**

(Language interpreters can be requested.)

Month 1

Month Name _____

“Hope is being able to see that there is light despite all of the darkness.”

– Desmond TuTu

SUNDAY	MONDAY	TUESDAY

NOTES

REMINDER:

Prepare medications for next week.

WEDNESDAY	THURSDAY	FRIDAY	SATURDAY

DID YOU KNOW?

Medication adherence can get confusing. Ask your healthcare team for a complete medication list to use with this calendar. Remember to organize your pills and store them as required.

Month 2

Month Name _____

“Cancer is a word, not a sentence.”

– John Diamond

SUNDAY	MONDAY	TUESDAY

NOTES

REMINDER:

Prepare medications for next week.

WEDNESDAY	THURSDAY	FRIDAY	SATURDAY

DID YOU KNOW?



There are over 50 oral anticancer medications approved by the United States Food and Drug Administration (FDA). Discuss treatment options with your healthcare team to determine the best treatment(s) for you.

Month 3

Month Name _____

“Courage does not always roar. Sometimes courage is the quiet voice at the end of the day saying, ‘I will try again tomorrow.’”

– Mary Anne Radmacher

SUNDAY	MONDAY	TUESDAY

NOTES

REMINDER:

Prepare medications for next week.

WEDNESDAY	THURSDAY	FRIDAY	SATURDAY

DID YOU KNOW?

Managing side effects is an important part of cancer treatment and improves quality of life. Ask your healthcare team for a referral to palliative (supportive) care for help managing side effects.

Month 4

Month Name _____

“The human spirit is stronger than anything that can happen to it.”

– C.C. Scott

SUNDAY	MONDAY	TUESDAY

NOTES

REMINDER:

Prepare medications for next week.

WEDNESDAY	THURSDAY	FRIDAY	SATURDAY

DID YOU KNOW?

You should always check with your doctor or pharmacist before crushing or splitting any of your medications. Some pills should only be swallowed whole.

Month 5

Month Name _____

“Oh,
my friend,
it’s not what
they take
away from
you that
counts—
it’s what
you do with
what you
have left.”

– Hubert
Humphrey

SUNDAY	MONDAY	TUESDAY

NOTES

REMINDER:

Prepare medications for next week.

WEDNESDAY	THURSDAY	FRIDAY	SATURDAY

DID YOU KNOW?

Anemia (a low red blood cell count) is a common concern for people with blood cancer. Discuss your diet with your healthcare team to ensure you are getting the proper amount of vitamins.

Month 6

Month Name _____

**“Some days
there won’t
be a song in
your heart.
Sing anyway.”**
– Emory Austin

SUNDAY	MONDAY	TUESDAY

NOTES

REMINDER:

Prepare medications for next week.

WEDNESDAY	THURSDAY	FRIDAY	SATURDAY

DID YOU KNOW?

All of your doctors should be told about all of the medications and natural remedies you are taking and using, including prescription and over-the-counter medications, and any herbs and supplements.

Month 7

Month Name _____

“Toughness
is in the soul
and spirit,
not in
muscles.”

— Alex Karras

SUNDAY	MONDAY	TUESDAY

NOTES

REMINDER:

Prepare medications for next week.

WEDNESDAY	THURSDAY	FRIDAY	SATURDAY

DID YOU KNOW?

Remembering all of the information from your doctor's appointment can be difficult. Invite a family member or friend to go along with you to help take notes.

Month 8

Month Name _____

“Every tomorrow has two handles. We can take hold of it by the handle of anxiety, or by the handle of faith.”

— Henry Ward Beecher

SUNDAY	MONDAY	TUESDAY

NOTES

REMINDER:

Prepare medications
for next week.

WEDNESDAY	THURSDAY	FRIDAY	SATURDAY

DID YOU KNOW?

Talk to your doctor about each medicine you take.
Make sure you know what to do if you miss a dose.

Month 9

Month Name _____

“Each day comes bearing its own gifts. Untie the ribbons.”

— Ruth Ann Schabacker

SUNDAY	MONDAY	TUESDAY

NOTES

REMINDER:

Prepare medications
for next week.

WEDNESDAY	THURSDAY	FRIDAY	SATURDAY

DID YOU KNOW?

A family member or friend can help you prepare your medication schedule.

Month 10

Month Name _____

“Hope is the
only thing
stronger
than fear.”

— Author
Unknown

SUNDAY	MONDAY	TUESDAY

NOTES

REMINDER:

Prepare medications
for next week.

WEDNESDAY	THURSDAY	FRIDAY	SATURDAY

DID YOU KNOW?

Open communication with all the members of your healthcare team is important so that you make the best and most appropriate healthcare decisions.

Month 11

Month Name _____

“You never know how strong you are until being strong is the only choice you have.”

— Cayla Mills

SUNDAY	MONDAY	TUESDAY

NOTES

REMINDER:

Prepare medications for next week.

WEDNESDAY	THURSDAY	FRIDAY	SATURDAY

DID YOU KNOW?



Some medications can cause constipation. Discuss your fiber and water intake with your healthcare team.

Month 12

Month Name _____

"Cancer is so limited...
It cannot cripple love.
It cannot shatter hope.
It cannot corrode faith.
It cannot eat away peace.
It cannot destroy confidence.
It cannot kill friendship.
It cannot shut out memories.
It cannot silence courage.
It cannot reduce eternal life.
It cannot quench the Spirit."

— Robert L. Lynn

SUNDAY	MONDAY	TUESDAY

NOTES

REMINDER:

Prepare medications
for next week.

WEDNESDAY	THURSDAY	FRIDAY	SATURDAY

DID YOU KNOW?

Exercise and journaling can improve your physical and emotional health.

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 support including insurance premium and medication co-pay assistance as well as travel and other needs to eligible individuals with blood cancer. For more information, please

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

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.

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), local 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

Language Services. Let members of your healthcare team know if you need translation or interpreting services because English is not your native language, or if you need other assistance, such as the service of a sign language interpreter. Often these services are free.

Information for Veterans. Veterans who were exposed to Agent Orange while serving in Vietnam may be able to get help from the United States Department of Veterans Affairs. Please call the Department of Veterans Affairs at (877) 222-8387 or visit www.publichealth.va.gov/exposures/agentorange for more information.

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

Feedback. Please visit www.LLS.org/PublicationFeedback to give suggestions about this resource.

GET ONE-ON-ONE SUPPORT

The Leukemia & Lymphoma Society's **Information Specialists**, master's level oncology social workers and health educators, can provide information and support and connect you to our **Clinical Trial Support Center** and **Registered Dietitians**.

- Call **800.955.4572** Mon.-Fri. 9 a.m. to 9 p.m. (ET)
- Visit **www.LLS.org/PatientSupport**



LEUKEMIA &
LYMPHOMA
SOCIETY®

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.