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AML: The Basics

A companion to the Acute Myeloid Leukemia: In Detail booklets

Revised **2025**

*Formerly titled The AML Guide:
Information for Patients and Caregivers*

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Contents

Question Guides

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INTRODUCTION

Acute myeloid leukemia (AML) is a type of blood cancer. It is also known as acute myelogenous leukemia, acute myelocytic leukemia, acute myeloblastic leukemia and acute granulocytic leukemia.

AML is the most common acute leukemia affecting adults. Although AML can occur at any age, adults age 60 years and older are more likely to develop the disease than younger people.

Advances in AML research have resulted in new treatments, but much work remains to be done. New therapies are needed to improve remission rates and increase survival. Researchers continue to study and develop new treatments in clinical trials for people with AML.

The more you know about AML, the better you can take care of yourself—your body, your mind and your health. This booklet provides information about the diagnosis and treatment of AML. It also includes brief descriptions of blood and bone marrow as well as definitions of health terms related to AML.

We hope that you will keep this booklet handy and that, should you ever feel alone in confronting problems, you will turn to it for information and guidance to find the support and resources that you need.

We are here to help.

New treatments may have been approved since this booklet was printed. Check www.LLS.org/DrugUpdates or call (800) 955-4572.

WANT MORE INFORMATION?

For more information about AML, you can view, print or order the free LLS booklets *Acute Myeloid Leukemia in Adults: In Detail* and *Acute Myeloid Leukemia in Children and Teens: In Detail* at www.LLS.org/booklets or contact our Information Specialists at (800) 955-4572 for copies.

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

PART 1 ACUTE MYELOID LEUKEMIA

Overview

- Most blood cells are made in the bone marrow, the soft, spongy tissue in the center of bones. They begin as stem cells that go through many changes to develop into healthy red blood cells, white blood cells or platelets.
- Acute myeloid leukemia (AML) is a blood cancer that starts with a mutation (change) in the DNA of a single stem cell in the bone marrow.
- Acute means that the leukemia is severe, and that it usually gets worse quickly if it is not treated.
- AML is diagnosed with blood and bone marrow tests.
- There are many subtypes of AML. Knowing your AML subtype helps doctors determine the best treatment options for you.

About Bone Marrow, Blood and Blood Cells

The general descriptions below may help you understand the information in the rest of this booklet.

Bone marrow is the spongy center located inside the bones where blood cells are made.

Blood cells begin as stem cells in the bone marrow. Stem cells grow and mature into different types of cells: red blood cells, white blood cells and platelets. After the blood cells have matured, they leave the bone marrow and enter the bloodstream.

Red blood cells carry oxygen around the body. When the number of red blood cells is below normal, a condition called anemia usually develops. Anemia may make you feel tired or short of breath. It may make your skin look pale.

White blood cells fight infection in the body. A low white blood cell count may cause repeated infections. There are two major types of white blood cells: lymphocytes and germ-eating cells.

- Lymphocytes are infection-fighting cells. The three types are:
  - B cells
  - T cells
  - NK (natural killer) cells
- Germ-eating cells kill and ingest bacteria and viruses. The two types are:
  - Neutrophils
  - Monocytes

Platelets help stop bleeding by clotting (clumping together) at the site of an injury. Thrombocytopenia is a condition in which there is a lower-than-normal number of platelets in the blood. It may cause easy bruising and excessive bleeding from cuts and wounds.

Plasma is the liquid part of the blood, not including blood cells. Although mostly water, plasma also has some vitamins, minerals, proteins, hormones and other natural chemicals in it.

Normal Blood Cell Count Fast Facts

The ranges of blood cell counts listed below are for adults. They may be a little different from lab to lab and for children and teens.

Red blood cell (RBC) count

- Men: 4.5 to 6 million red cells per microliter of blood
- Women: 4 to 5 million red cells per microliter of blood

Hematocrit (the part of the blood made up of red cells)

- Men: 42% to 50%
- Women: 36% to 45%

Hemoglobin (amount of the red cell pigment that carries oxygen)

- Men: 14 to 17 grams per 100 milliliters of blood
- Women: 12 to 15 grams per 100 milliliters of blood

Platelet count

- 150,000 to 450,000 platelets per microliter of blood

White blood cell (WBC) count

- 4,500 to 11,000 white cells per microliter of blood

Differential (also called diff)

- Measures the amount (percentage) of each of the different types of white blood cells
- Counts the types of white cells (neutrophils, lymphocytes, monocytes, eosinophils and basophils)
    - Normal adult white blood cell count: 60% neutrophils, 30% lymphocytes, 5% monocytes, 4% eosinophils and less than 1% basophils in the blood

About AML

Leukemia is the general term for a number of different types of blood cancer. AML is one of four main types of leukemia. Although AML can occur at any age, adults age 60 years and older are more likely to develop the disease than younger people.

Causes and Risk Factors of AML. AML starts with a change to a single stem cell in the bone marrow. This means:

- A normal stem cell mutates (changes into a leukemia cell, also called an AML cell or blast cell).
- The mutated cell multiplies into many AML cells.
- The AML cells build up in the bone marrow so there is less room for healthy blood cells to develop. As a result, people with AML do not have enough healthy red blood cells, white blood cells and/or platelets.
- Over time, the AML cells spill out of the bone marrow into the bloodstream.

While doctors do not know what causes most cases of AML, certain factors may increase the risk of developing AML. Having a risk factor does not mean that a person will develop the disease. Some people with several risk factors for AML never develop it, while other people with no known risk factors do. You cannot catch AML from someone else.

Risk factors associated with AML include:

- **Age.** The risk of developing AML increases with age.
- **Sex.** Males are more likely than females to develop AML.
- **Contact with dangerous chemicals.** Long-term contact with high levels of certain chemicals (such as benzene) is linked to a greater risk of AML.
- **Smoking.** AML is linked to exposure to tobacco smoke.
- **Prior cancer treatments.** Some types of chemotherapy and radiation therapy may increase a person’s risk of developing AML.
- **Other blood cancers.** People who have had certain blood cancers (such as polycythemia vera, essential thrombocythemia, myelofibrosis or myelodysplastic syndromes) are at greater risk of developing AML.

- **Genetic disorders.** Certain genetic conditions, such as Fanconi anemia, Shwachman syndrome, Diamond-Blackfan Anemia (DBA) syndrome and Down syndrome, increase the risk of AML.
- **Germline predisposition.** Some people are born with certain gene mutations that may increase their risk of developing AML.

Signs and Symptoms

Healthy people often have a sign or a symptom when they get an illness or a disease. A sign is a change in the body that the doctor sees in an exam or test result. A symptom is a change in the body that the patient can see or feel.

Symptoms of AML may include:

- Extreme tiredness
- Weakness
- Shortness of breath during normal physical activities
- Lightheadedness, dizziness or faintness
- Pale-looking skin
- Fever without an obvious cause
- Frequent infections
- Black-and-blue marks for no clear reason
- Prolonged bleeding from minor cuts
- Pinhead-sized red spots under the skin called petechiae
- Loss of appetite
- Unexplained weight loss
- Aches in bones or joints

The symptoms of AML may be like those of other blood disorders or medical conditions. If you have any of these symptoms, speak with your doctor to get a proper diagnosis.

Diagnosis

It is important for patients to receive the correct diagnosis. AML is diagnosed with blood and bone marrow tests.

Here are some questions you may want to ask your healthcare team. See pages 52–57 for a full list of questions.

1. What kind of testing will be done to diagnose my disease and to monitor my treatment?
2. Where will the testing be done?
3. How will I find out my test results?
4. How long does it take to get the results?
5. How often will testing be needed?

Blood Cell Counts. A test called a complete blood count (CBC) is used to count the numbers of red blood cells, white blood cells and platelets in a blood sample. Usually, patients with AML have lower-than-normal numbers of red blood cells and platelets. Patients may have very high white blood cell counts. But these are not healthy white blood cells—they are leukemia cells that cannot help fight infection.

Bone Marrow Tests. AML usually begins in the bone marrow. A diagnosis of AML is confirmed by removing samples of bone marrow and examining them for leukemia cells.

Bone marrow aspiration and bone marrow biopsy are different tests in which two samples of bone marrow (liquid and bone) are removed from the back of the hip bone using special needles. The samples are then sent to the lab for examination. Additional tests will be done on the the blood and bone marrow samples to gather more information about the cells.

How Are Blood and Bone Marrow Tests Done?

Blood Test—A small amount of blood is taken from the patient's arm with a needle. The blood is collected in tubes and sent to a lab.

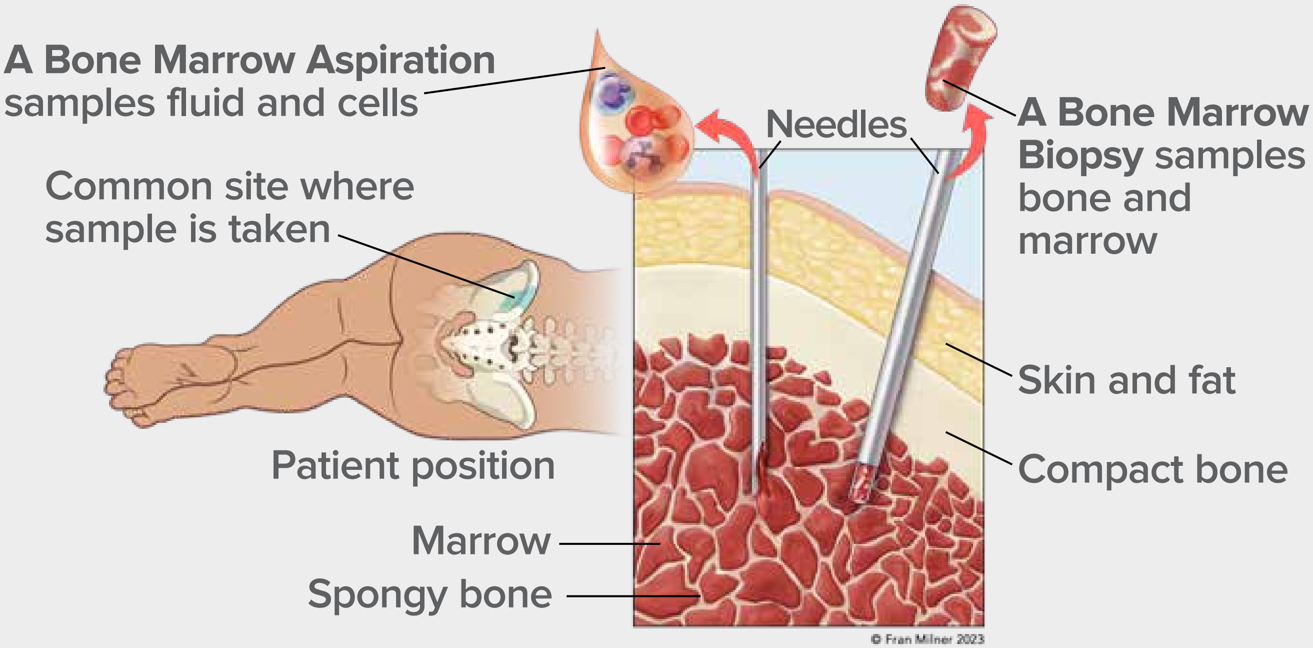
Bone Marrow Aspiration—A sample of fluid with cells is removed from the bone marrow.

Bone Marrow Biopsy—A very small amount of bone filled with bone marrow cells is taken from the body.

Both bone marrow tests are done with special needles. Some patients are awake for the procedure, but some adults and most children are given a drug that makes them sleep. Patients then get medication to numb the skin and the surface of the bone. The samples of cells are usually taken from the patient's hip bone.

Bone marrow tests may be done in the doctor's office or in a hospital. A bone marrow aspiration and biopsy are almost always done at the same visit.

Bone Marrow Aspiration and Biopsy

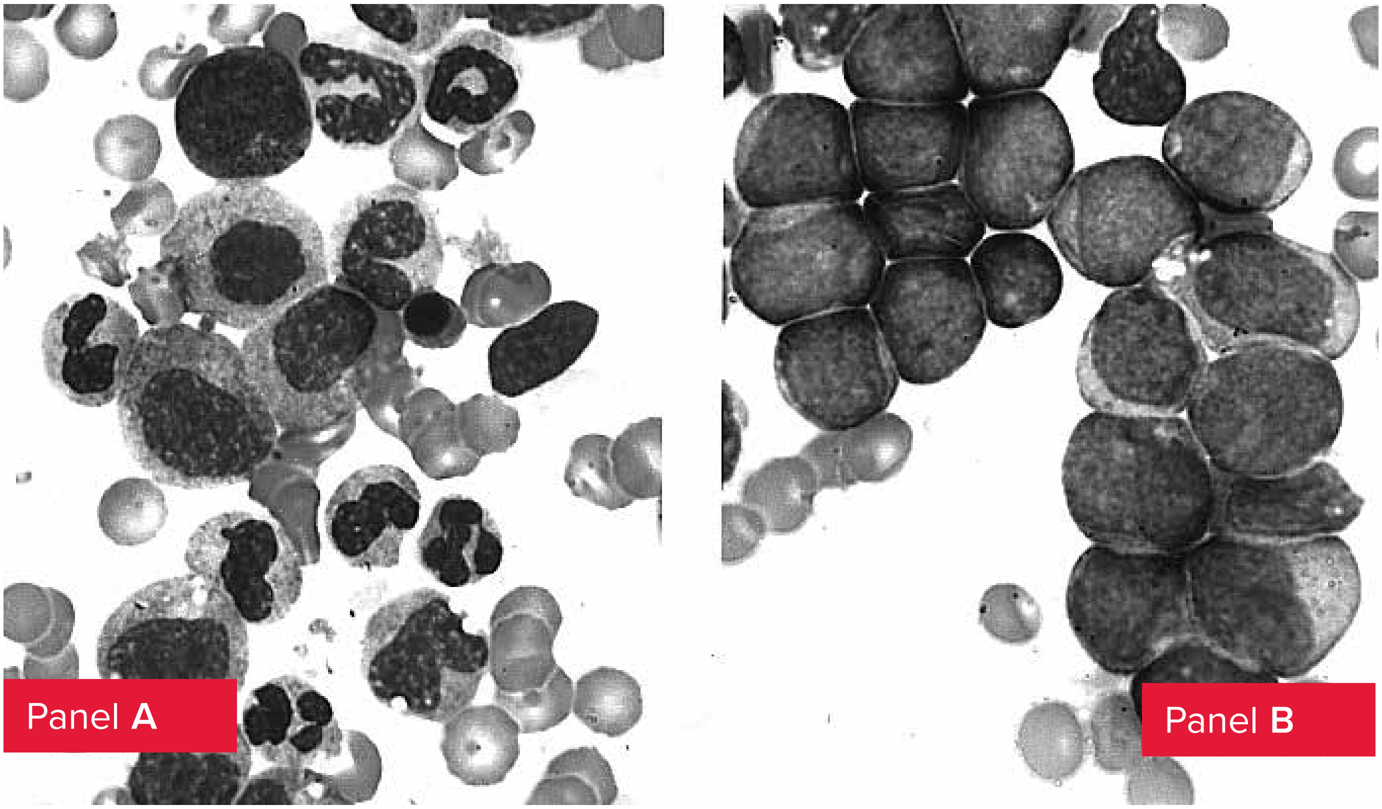


Left: The place on the back of the patient's hip bone where a bone marrow aspiration or biopsy is typically done. **Right:** One needle goes into the bone marrow to get a liquid sample for aspiration (the needle on the left) and the other needle goes inside the bone for a bone marrow biopsy (the needle on the right). The needle for the aspiration is thinner than the one for the biopsy.

Visit www.LLS.org/3D and click on "Bone Marrow Biopsy and Aspiration" to view an interactive 3D image that will help you visualize and better understand the bone marrow aspiration and biopsy procedures.

Cell Examination. At the laboratory, the cells in the blood and bone marrow samples are examined under a microscope. The type of cells and their size and shape are important findings. Another important finding is the percentage of immature blast cells in the bone marrow. Additional tests will be done on the samples to determine the subtype of AML.

Normal Bone Marrow Cells versus AML Blast Cells



The cells in panels A and B are shown much larger than actual size. The cells are also stained with a special dye so that they can be seen more clearly.

Panel A shows different types of normal bone marrow cells seen through a microscope. These normal cells are in various stages of development.

Panel B shows AML blast cells seen through a microscope. These cells have stopped developing.

Biomarker Testing. These laboratory tests use a blood or bone marrow sample to check for changes in the proteins, genes and chromosomes of the cancer cells. Each person's cancer has a unique pattern of biomarkers. Biomarker testing is used to determine the subtype of AML and plan treatment.

Immunophenotyping (Flow Cytometry). This test can diagnose specific types of leukemia based on the proteins on a cell's surface. The sample of cells comes from a blood or bone marrow test. The test can also be used to see if there are any cancer cells remaining in the body after treatment, called measurable residual disease (MRD).

Cytogenetic Analysis (Karyotyping). This test uses a microscope to examine the chromosomes inside the cells. Chromosomes are the part of a cell that contains genetic information. Most human cells have 23 pairs of chromosomes for a total of 46 chromosomes. The chromosomes are a certain size, shape and structure. In some cases of AML, the chromosomes of the leukemia cells have abnormal changes. The results of the cytogenetic analysis test help your doctor identify the AML subtype and plan treatment.

Fluorescence In Situ Hybridization (FISH). This test is used to look at the genes or chromosomes in cells and tissues. Doctors use this test to find changes in chromosomes and genes in the leukemia cells.

Polymerase Chain Reaction (PCR). This is a lab test that finds and measures genetic mutations and chromosome changes that are too small to be seen with other tests or even with a powerful microscope. This test is done on blood or bone marrow samples during treatment or after treatment to see how well treatment is working and test for MRD.

Next-Generation Sequencing. This test looks for mutations in the genes of AML cells. Certain mutations are markers that can help doctors identify a patient's AML subtype and predict how the disease will progress. Next-generation sequencing is also used to test for MRD.

WANT MORE INFORMATION?

You can view, print or order the free LLS booklets *Understanding Lab and Imaging Tests*, *Understanding Genetics* and *Biomarker Testing for Cancer Treatment.* Go to www.LLS.org/booklets or call our Information Specialists at (800) 955-4572 for copies.

Tracking Your AML Tests

These tips may help you save time and learn more about your health:

- Ask your doctor why certain tests are being done and what to expect.
- Discuss test results with your doctor.
- Ask how to get copies of your lab reports. You can ask for copies of your test results from your doctor's office. Many hospitals and treatment centers offer digital patient portals where you can view your medical records online.
    - Keep test reports in a file folder or binder and organize by date.
- Find out if and when follow-up tests are needed.
- Mark upcoming appointments on your calendar.

Subtypes of AML

There are many different subtypes of AML, each caused by different gene or chromosome changes in the leukemia cells. It is important to know your AML subtype because it can affect both your prognosis (the outcome of your AML) and your treatment plan. For example, one subtype of AML, acute promyelocytic leukemia (APL), has a more favorable prognosis and is treated differently than other AML subtypes.

If you are not sure of your AML subtype, ask your doctor. The doctor should tell you your AML subtype and explain how it affects your treatment.

The International Consensus Classification (ICC) has divided AML into different subtypes. For a comprehensive list of the ICC classification of AML subtypes, please see the free LLS publications *Acute Myeloid Leukemia in Adults: In Detail* and *Acute Myeloid Leukemia in Children and Teens: In Detail* at www.LLS.org/booklets, or call our Information Specialists at (800) 955-4572.

Write your AML subtype here: ______________________________

Overview

- People with AML should choose a doctor who specializes in treating AML. This type of doctor is called a hematologist-oncologist.
- Ask questions about your treatment options and do not be afraid to be involved in making decisions about your own care. See the question guides *My First Doctor's Visit* and *Treatment and Follow-Up Care* on pages 52–57.
- Some cancer treatments may affect fertility (the ability to have a child). If you want children in the future, or if you are the parent of a child with AML, talk with the doctor about which treatments may cause problems with fertility and what choices you have.
- The first round of treatment with chemotherapy is called induction. Most patients with AML need to start induction soon after diagnosis.

Finding the Right Doctor

Choose a doctor who specializes in treating leukemia and knows about the most up-to-date treatments. This type of specialist is called a hematologist-oncologist. A hematologist is a doctor who has special training in disorders of the blood. An oncologist is a doctor who has special training in cancer. A hematologist-oncologist has special training in both diagnosing and treating blood cancers.

If your local medical center does not have a hematologist-oncologist, ask your local cancer specialist to consult with a hematologist-oncologist at another medical center. Always check to see if your health insurance covers the services of the doctors (and the hospital associated with them) and the hospital you choose for your treatment.

How to Find a Hematologist-Oncologist

- Ask your primary care doctor for a recommendation.
- Contact your community cancer center.
- Reach out to doctor and/or health plan referral services.
- Call our Information Specialists at (800) 955-4572.
- Use online doctor-finder resources, such as
    - The American Society of Hematology's (ASH) "Find a Hematologist" online at https://www.hematology.org/Patients/FAH.aspx

When you meet with the specialist, ask questions to get a better idea of the doctor's experience and to understand how the office works. Some sample questions are below. See pages 52–57 for a full list of questions.

1. How many patients have you treated with AML?
2. What problems or symptoms should be reported to the nurse or doctor right away?
3. Is there a release form available so my family/caregiver can be given medical information?

Make sure you feel comfortable interacting with the doctor and the rest of the staff. You will be spending a lot of time with the staff at this treatment center.

WANT MORE INFORMATION?

You can view, print or order the free LLS booklet *Choosing a Specialist or Treatment Center* at www.LLS.org/booklets, or contact our Information Specialists at (800) 955-4572 for a copy.

Ask Your Doctor

Talk with the doctor and ask questions about how they plan to treat your AML. This will help you to become actively involved in making decisions about your care.

When you meet with the doctor:

- Ask questions. Below are a few questions to ask. See pages 52–57 for a full list of questions. Visit www.LLS.org/WhatToAsk to find other "What to Ask" healthcare question guides.
    - What are my treatment choices?
    - Are there any clinical trials that I can join?
    - When do you think I should begin treatment?
    - How long will treatment last?
- Take notes. It may be helpful to write down the answers to your questions and review them later.
- Audio record information from the doctor and then listen to the recording later. Ask the doctor and staff if recording is allowed (cell phones have a “record” function; ask someone how to use it).
- Bring a caregiver, friend or family member who can listen to the doctor along with you to take notes and offer support.
- Make sure you understand what the doctor is saying. If you do not understand, ask the doctor to explain it again.

If you need more information or are not sure about your treatment choices, consider getting a second opinion (another opinion) from a different qualified doctor. If you are unsure or feel uncomfortable about how to tell your doctor you are getting a second opinion, call our Information Specialists at (800) 955-4572 to discuss a way that makes you comfortable. You may also want to check with your health insurance plan to be sure that a second opinion is covered.

Treatment Planning

Fertility Concerns. Some cancer treatments can affect fertility (a person's ability to have children in the future). For adults who have AML and may want to have children in the future, and parents of children with AML, it is important to talk with the doctor about whether the cancer treatments could affect fertility.

Here are some questions you may want to ask your healthcare team. See pages 52–57 for a full list of questions.

1. Will this treatment affect my 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?

WANT MORE INFORMATION?

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

Prognostic Factors. Certain factors can affect your prognosis, which is the likely outcome of your disease. Doctors use prognostic factors to help determine your best treatment options and predict how your disease is likely to respond to treatment.

Your prognosis and treatment options may depend on the following factors:

- Your AML subtype
- Your age
- Whether you have received chemotherapy in the past to treat a different cancer
- Whether you have had a prior blood cancer
- Whether you have a high white blood cell count at the time of your AML diagnosis
- How well you respond to induction therapy

About AML Treatments

New treatments may have been approved since this booklet was printed. Check www.LLS.org/DrugUpdates or call (800) 955-4572.

Before you begin treatment, you and your doctor will discuss your treatment options. One option may be a clinical trial. Like all treatment options, clinical trials have possible risks and benefits. It is important to consider all of your treatment options, including clinical trials. For more information on clinical trials, see page 32.

You may receive different drugs from those described in this booklet. This may still be considered proper treatment. Speak with your doctor to find out what treatment is best for you.

Most patients need to start therapy soon after diagnosis. But your doctor may recommend waiting for test results that provide information about your specific subtype of AML before beginning treatment.

Not everyone with AML receives the same type of treatment. Your treatment may include chemotherapy, targeted therapy and/or stem cell transplantion.

Your treatment plan will depend on a number of factors including your AML subtype, age and overall health. Doctors often give the most intensive chemotherapy regimens to people younger than age 60. However, this age limit is just a guideline, and some older patients in good health may also benefit from intensive treatments. For a list of drugs used to treat AML, see *Some Drugs Used to Treat AML* on pages 22–23.

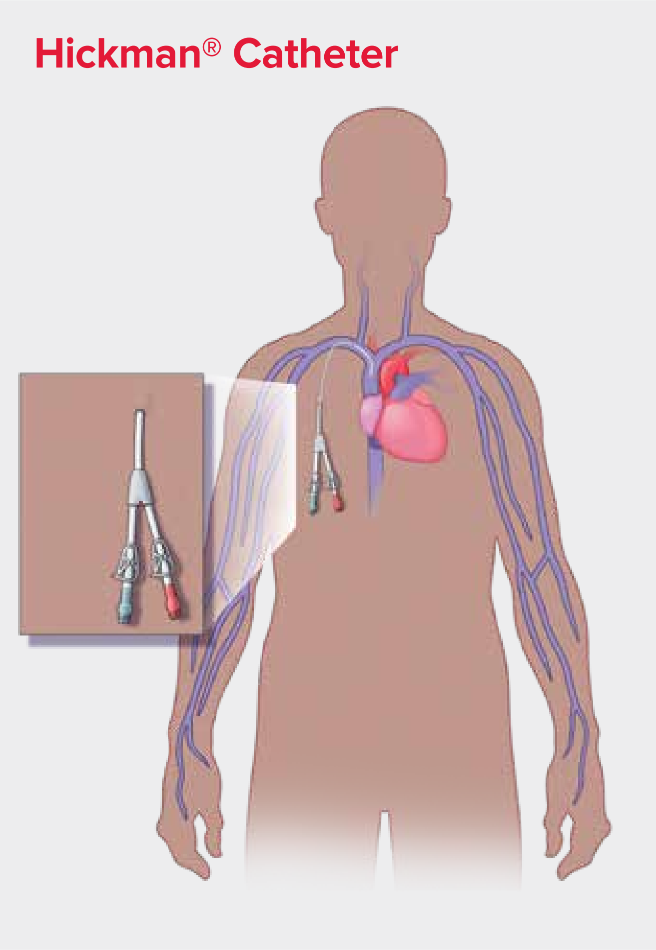
Some drugs are given orally (by mouth). Other drugs are inserted directly into the patient's bloodstream through a central line, a port or a PICC. Central lines, ports and PICCs can also be used to give other medications as well as to infuse liquid nutrition and needed blood cells. These devices can be used in the reverse to take blood samples from the patient. Central lines, ports and PICCs can stay in place for weeks or months. The purpose of these devices is to avoid the constant use of needles and IVs for giving medication and taking necessary samples. Talk to your doctor about the central line, port or PICC that will be used for you.

Central Lines, Ports and PICCs

Central Line (catheter)—A thin tube that is put under the skin and into a large vein in the chest. The central line stays firmly in place. Indwelling catheter is another word for central line.

Port—This is a small device that is used with a central line. The port is placed under the skin of the chest. After the site heals, no dressings are needed and no special home care is required. The doctor or nurse can give medicines or nutrition to the patient or take blood samples from the patient using the port. A needle is simply inserted through the skin into the port. A numbing cream can be put on the skin before the port is used.

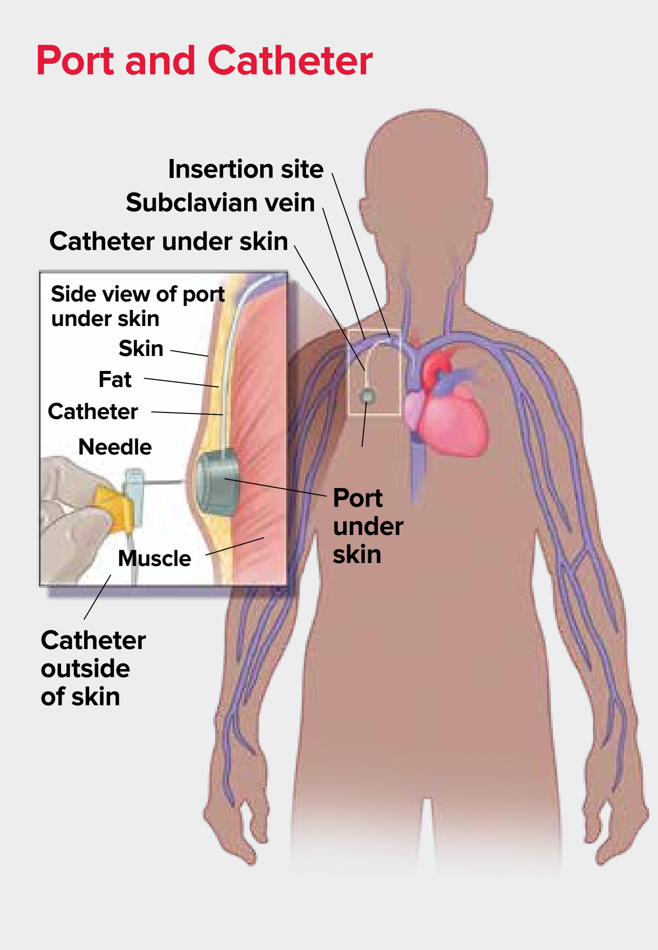
PICC or PIC Line (short for percutaneously inserted central venous catheter)—A PICC or PIC (not shown) is inserted through a vein in the arm.



Hickman® Catheter

Hickman® Catheter: An example of a type of central line.

© Fran Milner 2018



Port and Catheter

Port: A port used with a central line.

Here are some questions you may want to ask your healthcare team. See pages 52–57 for a full list of questions.

1. What is my AML subtype?
2. What are my treatment options, including clinical trials?
3. What is the goal of treatment?
4. What are the benefits and risks of these treatments?
5. Is one treatment recommended over others?

Therapy for Patients Younger Than Age 60 and Fit Patients 60 Years and Older. For this group, the goal of treatment is to increase long-term survival with the possibility of a cure. Treatment is more intensive and may have more serious side effects.

Induction. The first phase of treatment is called induction. The goal of induction is to destroy as many leukemia cells as possible in the blood and bone marrow in order to induce (achieve) a remission. Patients are often in the hospital for 4 to 6 weeks during this first part of treatment.

The most common chemotherapy induction regimen for AML is called the "7 + 3." It includes cytarabine (ara-C; Cytosar-U®) and an anthracycline drug, such as daunorubicin (Cerubidine®) or idarubicin (Idamycin®).

In addition to chemotherapy, patients may receive targeted therapies. Targeted therapy is a type of treatment that uses drugs to targeted specific molecules that cancer cells need to survive. These may include:

- Midostaurin (Rydapt®) or quizartinib (Vanflyta®) for AML with an *FLT3* mutation
- Gemtuzumab ozogamicin (Mylotarg™) for CD33-positive AML

Other drugs may be used as a substitute for the 7+3 regimen including:

- CPX-351 (Vyxeos®)
- High-dose cytarabine with idarubicin or daunorubicin and etoposide (VP-16; VePesid®, Etopophos®)
- High-dose cytarabine with mitoxantrone (Novantrone®)
- Fludarabine (Fludara®) with high-dose cytarabine, idarubicin and a granulocyte colony-stimulating factor (G-CSF)

Some Drugs Used to Treat AML

Below are some of the standard drugs used to treat AML. Some drugs under study in clinical trials for AML are also listed.

Anthracyclines	○ daunorubicin (Cerubidine®) ○ idarubicin (Idamycin®) ○ mitoxantrone (Novantrone®)
Antimetabolites	○ cladribine (Leustatin®) ○ clofarabine (Clolar®) ○ cytarabine (ara-C, Cytosar-U®) ○ fludarabine (Fludara®) ○ methotrexate (Trexall®) ○ thioguanine (Tabloid®)
Anthracycline and Antimetabolite Combination	○ CPX-351 (Vyxeos®)
Topoisomerase Inhibitor	○ etoposide (VP-16, VePesid®, Etopophos®)
Hypomethylating Agents	○ azacitidine (Vidaza®) ○ oral azacitidine (Onureg®) ○ decitabine (Dacogen®)
CD33-Directed Antibody	○ gemtuzumab ozogamicin (Mylotarg™)
FLT3 Inhibitors	○ gilteritinib (Xospata®) ○ midostaurin (Rydapt®) ○ quizartinib (Vanflyta®) ○ sorafenib (Nexavar®)

Some Drugs Used to Treat AML (continued)

IDH1 Inhibitors	○ ivosidenib (Tibsovo®) ○ olutasidenib (Rezlidhia®)
IDH2 Inhibitor	○ enasidenib (Idhifa®)
Hedgehog Pathway Inhibitor	○ glasdegib (Daurismo™)
BCL-2 Inhibitor	○ venetoclax (Venclexta®)
Menin Inhibitor	○ revumenib (Revuforj®)
Retinoid	○ all-trans retinoic acid (ATRA, tretinoin, Vesanoid®)
Antineoplastic Agent	○ arsenic trioxide (ATO, Trisenox®)

Use the lines provided on page 51 to list your treatments.

New treatments may have been approved since this booklet was printed. Check www.LLS.org/DrugUpdates or call (800) 955-4572.

Testing After Induction. At the end of induction, blood and bone marrow tests are done to see how well your treatment is working. The doctor will find out if you are in remission. A remission is achieved when you no longer have signs and symptoms of AML.

If you are not in remission, induction therapy can be repeated, either with the same drugs or with a new chemotherapy regimen.

Even when you have achieved a remission, some leukemia cells that cannot be seen with a microscope may still remain in the body. This is called measurable residual disease (MRD). Patients who achieve remission after initial treatment but have MRD are at increased risk of disease relapse. Testing for MRD can help doctors identify patients who may benefit from further treatment with intensified therapies, such as allogeneic stem cell transplantation.

The tests most commonly used to detect MRD are flow cytometry, polymerase chain reaction (PCR) and next-generation sequencing. These tests typically use samples of bone marrow cells, but in some cases blood samples can be used.

WANT MORE INFORMATION?

You can view, print or order the free LLS fact sheet *Measurable Residual Disease (MRD)* at www.LLS.org/booklets, or contact our Information Specialists at (800) 955-4572 for a copy.

Consolidation. More treatment is usually needed even after an AML patient is in remission because some leukemia cells may remain in the body. These remaining cells have the potential to multiply and cause a relapse. A relapse is a return of the cancer after it has been successfully treated. To prevent a relapse, intensive consolidation therapy is given after the patient recovers from induction therapy.

There are two basic treatment choices for consolidation:

- Additional intensive chemotherapy
- Stem cell transplantation (see page 26)

Patients with favorable risk factors are often given multiple cycles of intensive chemotherapy for consolidation. The number of chemotherapy cycles varies from patient to patient. Patients are often hospitalized during consolidation.

Patients with high-risk AML usually receive more intensive treatments. Their doctor may recommend a clinical trial or stem cell transplantation.

Maintenance. The third phase of treatment is called maintenance. The main objective of maintenance is to deliver a less toxic therapy to prevent relapse after intensive chemotherapy. Maintenance is often given as an extended course of treatment. Not everyone with AML will receive maintenance therapy. Your doctor may recommend maintenance therapy depending on your subtype of AML, your consolidation treatment and your risk of relapse.

For some adult patients, the doctor may prescribe an oral formulation of azacitidine (Onureg®) as maintenance therapy. For patients with a *FLT3* mutation, maintenance therapy such as sorafenib or quizartinib is now commonly used.

Therapy for Patients 60 Years and Older. AML mostly occurs in older adults. At least half of AML patients are older than 60 years when their disease is diagnosed.

For older adults with AML, treatment approaches range from standard intensive induction chemotherapy to less intensive therapies, or the best supportive care. Older patients may be limited to certain treatments because of other medical problems, such as heart disease, kidney or lung disease, or diabetes. The doctor takes these other medical problems into account when deciding which drugs to use and at what dose.

Age alone, however, does not determine treatment options. Physically fit patients in their 70s who have no serious health problems may benefit from intensive treatment often used in patients younger than 60.

For patients who are not candidates for intensive treatment, options include lower-intensity therapies that may relieve symptoms, improve quality of life and potentially extend survival.

Below is a list of some less intensive treatments for AML induction. In the list below, treatments with "azacitidine" refer to azacitidine (Vidaza®)

- Azacitidine ± venetoclax (Venclexta®)
- Decitabine (Dacogen®) ± venetoclax
- Cladribine (Leustatin®), low-dose cytarabine (ara-C, Cytosar-U®) + venetoclax
- Low-dose cytarabine ± venetoclax
- Low-dose cytarabine + glasdegib (Daurismo™)
- Gemtuzumab ozogamicin (Mylotarg™) for AML that is CD33 positive
- Ivosidenib (Tibsovo®) **±** azacitidine for AML with an *IDH1* mutation
- Enasidenib (Idhifa®) ± azacitidine for AML with *IDH2* mutation
- Gilteritinib (Xospata®) ± azacitidine for AML with *FLT3* mutation

Clinical trials are evaluating new and different drugs and drug combinations for older adults, including non-chemotherapy agents that target genetic markers of the leukemia cells. Visit www.LLS.org/CTSC to find out more about clinical trials.

Assessing Treatment Response. For patients treated with a venetoclax containing regimen, the response to therapy is often evaluated early during the first cycle, usually between days 14 and 21. Blood and bone marrow tests are done to check for a remission and to look for measurable residual disease (MRD). A complete remission is achieved when no more than 5 percent of the cells in the bone marrow are blast cells. Testing is usually repeated when there are concerns of relapse or prolonged low blood cell counts.

For patients who are tolerating and responding to treatment, the doctor will generally continue the treatment indefinitely. If there is no response or the cancer progresses, patients may want to consider a clinical trial or treatments for relapsed or refractory disease. Patients may also want to consider only supportive care (see below) to improve quality of life and alleviate discomfort.

Supportive Care. This refers to specialized medical care focused on providing relief from symptoms and the stresses of a serious illness in order to improve quality of life for both patients and families. For patients with AML, supportive care may include transfusions, nontoxic oral medications, growth factors, pain medications and specialized nursing care.

Stem Cell Transplantation. While treatment with chemotherapy alone is appropriate for some patients, others may benefit from stem cell transplantation. Your doctor will talk with you about whether stem cell transplantation is a treatment option for you.

There are two types of stem cell transplantation: one uses replacement stem cells from a donor (allogeneic transplant) and one replaces the patient's stem cells with their own stem cells (autologous transplant). Allogeneic stem cell transplantation is the most common type of stem cell transplant to treat AML.

When doctors are planning treatment, they use a number of factors to determine a patient's need for stem cell transplantation. These factors may include:

- The patient's AML subtype
- If the patient is not doing well with other treatments
- If the expected benefits of a transplant exceed the risks
- If there is a stem cell donor

- Other treatment(s) the patient has received
- The patient's physical ability to have the transplant

Some patients who receive a stem cell transplant can experience serious and life-threatening complications. Stem cell transplantation is not for every patient, but it can be helpful for some.

Allogeneic Stem Cell Transplantation. This treatment uses stem cells from a donor. The stem cells in the donor's blood must be a "match" to the patient. The donor may be a brother or sister (siblings are most often the best match). The donor might also be an unrelated person with stem cells that match the patient's. Stem cells may also come from cord blood (the blood in the umbilical cord after a baby's birth). Allogeneic transplants are done in the hospital. After the patient achieves a remission, the process is as follows:

- Stem cells are collected from a donor.
- The patient is given high-dose chemotherapy and/or radiation therapy.
- The donor stem cells are given to the patient through an intravenous (IV) line or central line.
- The donor stem cells go from the patient's blood to the bone marrow and begin to start a new supply of red blood cells, white blood cells and platelets.

Reduced-Intensity Allogeneic Stem Cell Transplantation. This treatment uses lower doses of chemotherapy than standard allogeneic transplantation. This type of stem cell transplant is for patients who may not be able to withstand the high doses of chemotherapy that are given to patients during a standard, or "regular," allogeneic stem cell transplantation. Some older or sicker patients may be helped by this type of transplant.

WANT MORE INFORMATION?

You can view, print or order the free LLS booklet *Blood and Marrow Stem Cell Transplantation Guide* at www.LLS.org/booklets, or contact our Information Specialists at (800) 955-4572 for a copy.

Acute Promyelocytic Leukemia (APL)

Acute promyelocytic leukemia (APL) is a subtype of AML. It is one of the most curable subtypes of AML if diagnosed early and treated appropriately. APL accounts for approximately 10 percent of all AML cases and occurs primarily in middle-aged adults, although it can occur at any age.

APL treatment differs from other AML treatments described in this booklet. Many people with APL are treated with a drug called all-trans retinoic acid (ATRA, Tretinoin, Vesanoid®) in combination with arsenic trioxide (ATO, Trisenox®). For patients with high-risk disease, ATRA and ATO may be combined with idarubicin or gemtuzumab ozogamicin. Other recommended regimens may include ATRA and ATO with daunorubicin or cytarabine.

WANT MORE INFORMATION?

For more information on APL, you can view, print or order the free LLS booklets *Acute Myeloid Leukemia in Adults: In Detail* and *Acute Myeloid Leukemia in Children and Teens: In Detail* at www.LLS.org/booklets, or contact our Information Specialists at (800) 955-4572 for copies.

AML in Children

AML accounts for only about 20 percent of childhood leukemia cases. Most children who are diagnosed with leukemia have acute lymphoblastic leukemia (ALL).

Because of the intensity of treatment and the risk of serious complications, children with AML should be referred to cancer centers that have doctors who specialize in treating children with AML. These doctors are called pediatric hematologist-oncologists.

The treatment for children with AML often has two phases: induction and consolidation. Children are usually treated with cytarabine and an anthracycline such as daunorubicin. Other chemotherapy drugs may be added such as etoposide or 6-thioguanine.

Unlike adults with AML, children usually receive a treatment called central nervous system (CNS) prophylaxis to prevent leukemia cells from spreading to the central nervous system (the brain and spinal cord). Because standard doses of chemotherapy may not reach leukemia cells in the central nervous system, children receive intrathecal chemotherapy, which means that it is injected directly into the spinal canal. The most common intathecal chemotherapy drugs are cytarabine and methotrexate. If AML cells are found in the central nervous system at the time of diagnosis, more frequent intrathecal treatments may be used.

Consolidation begins once the leukemia is in remission. The goal of consolidation is to kill any remaining leukemia cells that could begin to grow and cause a relapse. Treatment during this phase depends on the subtype of AML and may include:

- Additional intensive chemotherapy
- Allogeneic stem cell transplantation (see page 27)

Just as the treatment of childhood AML requires specialized care, so does the follow-up after treatment. Childhood cancer survivors require close follow-up care because cancer treatments may cause health problems years after treatment has ended. Cancer treatments may damage organs, tissues or bones and may also cause delayed growth and other health problems later in life.

Children who receive intensive chemotherapy with anthracyclines such as daunorubicin are at increased risk of developing heart problems and should receive ongoing heart monitoring.

Treatments directed at the central nervous system, such as intrathecal chemotherapy, may increase the risk of learning difficulties. These learning difficulties may become evident soon after treatment or years later. Common learning difficulties include issues with memory, processing speed and multitasking.

Survivors of childhood AML are also at an increased risk for developing a second cancer later in life. A second cancer may occur months or years after treatment is completed. Patients who have been treated for AML need to be screened regularly for a second cancer.

It is very important to discuss possible long-term and late effects with your child's healthcare team in order to make sure that there is a plan to identify any potential problems as your child grows and treat them as needed.

WANT MORE INFORMATION?

Visit www.LLS.org/booklets to view the free LLS booklets *Acute Myeloid Leukemia in Children and Teens: In Detail* and *Caring for Kids and Adolescents with Blood Cancer* workbook. Or contact our Information Specialists at (800) 955-4572 for copies.

Relapsed and Refractory AML

Some AML patients relapse. A relapse is the return of cancer after it has been in remission. Other patients have refractory AML. Refractory AML is cancer that is not in remission at the end of treatment.

Treatment options for patients with refractory or relapsed AML include:

- **A clinical trial.** Treatment in a clinical trial should be considered first for all patients with relapsed or refractory AML. (See page 32).
- **Re-treatment with the same induction regimen that produced the patient's first remission.** This is an option if relapse occurs 12 months or more after remission.
- **Allogeneic stem cell transplantation.** In fit patients, chemotherapy can be used to induce a remission before stem cell transplantation. This is an option for patients younger than age 60 and patients older than age 60 who are physically fit. See page 27.
- **Targeted therapy.** Some targeted therapies that may be used include:
    - Therapy for AML with *FLT3*-ITD mutation
        - Gilteritinib
        - Azacitidine (Vidaza®) or decitabine (Dacogen®) + sorafenib
        - Quizartinib

    - Therapy for *FLT*-TKD mutation
        - Gliteritinib
    - Therapy for an *IDH1* mutation
        - Ivosidenib
        - Olutasidenib
    - Therapy for an *IDH2* mutation
        - Enasidenib
    - Therapy for CD33-positive AML
        - Gemtuzumab ozogamicin
    - Therapy for AML with lysine methyltransferase 2A gene (*KMT2A*) rearrangement
        - Revumenib
- **Intensive Treatment Options.** Intensive treatments for fit patients, suggested by the NCCN Guidelines, include:
    - Cladribine + cytarabine + granulocyte colony-stimulating factor (G-CSF) ± (mitoxantrone or idarubicin)
    - Cytarabine ± (daunorubicin or idarubicin or mitoxantrone)
    - Fludarabine + cytarabine + G-CSF ± idarubicin ± venetoclax
    - Etoposide + cytarabine ± mitoxantrone
    - Clofarabine ± cytarabine ± idarubicin
    - CLIA (cladribine + idarubicin + cytarabine) + venetoclax
- **Less Intensive Treatment Options.** Less intensive treatments, suggested by the NCCN Guidelines, include:
    - Hypomethylating agents (azacitidine or decitabine)
    - Low-dose cytarabine
    - Venetoclax plus hypomethylating agents (azacitidine or decitabine) or low-dose cytarabine

Note: In the list of treatments above "azacitidine" refers to acitidine (Vidaza®).

About Clinical Trials

There are new treatments under study for AML 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, such as changing the dose of the drug, giving the drug along with another type of treatment, or ordering drugs in new sequences. Different approaches may be more effective in treating the disease.

There are clinical trials for:

- Newly diagnosed patients with AML
- Patients who did not have a good response to treatment (refractory disease)
- Patients whose disease returned (relapsed disease)

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

Here are some questions you may want to ask your healthcare team. See pages 52–57 for a full list of questions.

1. Is a clinical trial a treatment option?
2. How can I find out if insurance covers the cost of the clinical-trial treatment and treatment-related costs, such as testing?
3. Who pays for the travel costs to get to the trial?

Ask your doctor if treatment in a clinical trial may be right for you. For more information, please call **(800) 955-4572** to speak with an LLS Information Specialist who can provide more information about clinical trials. Patients and caregivers can work with **Clinical Trial Nurse Navigators** who will help search for clinical trials and personally assist throughout the entire clinical trial process. Visit www.LLS.org/CTSC for more information.

WANT MORE INFORMATION?

Visit www.LLS.org/booklets to view, print or order the free LLS booklets *Understanding Clinical Trials for Blood Cancers* and *Knowing All Your Treatment Options,* or contact our Information Specialists at (800) 955-4572 for copies.

PART 4 SIDE EFFECTS AND FOLLOW-UP CARE

Overview

- Treatment side effects vary depending on the type of treatment. For example, the side effects of chemotherapy are different from the side effects of targeted therapies.
- Common side effects of treatment for AML may include mouth sores, hair loss, nausea, diarrhea and/or constipation and changes in blood counts.
- Treatment for AML in children may cause educational and learning issues. Parents should talk with their child's doctor if they think their child's learning skills have been affected, so their child can be evaluated.
- Children and adults who have been treated for AML should see their primary care doctor and a cancer specialist regularly for follow-up care.

Side Effects of AML Treatment

The term side effect describes the way that treatment affects healthy cells, and often defines the negative or undesirable effects from a treatment.

Treatment side effects depend on the type of treatment. For example, the side effects of chemotherapy are different than the side effects of targeted therapies. Patients also react to treatments in different ways. Sometimes there are very mild side effects. Other side effects may be uncomfortable and difficult. Usually side effects go away once treatment ends, but some side effects are serious and last a long time. Patients with AML should talk with their doctors about side effects before they begin any type of treatment.

Here are some questions you may want to ask your healthcare team.
See pages 52–57 for a full list of questions.

1. What are the common side effects of 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?

Low Blood Cell Counts. AML and its treatment may affect your blood cell counts:

- Red blood cell counts may fall below normal. This is called anemia. Red blood cell transfusions may be needed to increase red blood cell counts. Transfusions are red blood cells that are provided by a blood donor and given to the patient.
- Patients may have a drop in the number of platelets in their blood. This is called thrombocytopenia. A platelet transfusion may be needed to prevent bleeding if a patient's platelet count is very low.
- A big drop in the number of neutrophils, a type of white blood cell, is called neutropenia. It may lead to an infection. Infections are usually treated with antibiotics. A patient may be given drugs called growth factors such as Neupogen® and Neulasta® to increase white blood cell counts. Growth factors are rarely given to children and only in certain circumstances.

  Infection can be very serious for anyone who has AML. Patients at home should contact a doctor if any signs of infection develop. A fever of 100.4°F or higher (or the onset of chills), may be the only sign of infection in a patient with a very low white blood cell count. Patients with an infection may also have:

    - Coughing
    - Sore throat
    - Pain when urinating
    - Frequent loose bowel movements

  To lower the risk of infection:

    - The patient, visitors and medical staff need to wash their hands often and well.
    - The patient's central line must be kept clean.
    - Patients should take good care of their teeth and gums.

Patients with AML are advised to receive certain vaccinations. For adult patients, these include vaccinations for influenza, pneumococcal pneumonia and shingles. Vaccines for some children with AML may have been delayed during treatment. Your doctor will advise you when to resume your child's vaccination schedule. Current COVID-19 vaccines are also recommended. Talk to your doctor for more information.

Tumor Lysis Syndrome. Patients with AML may be at high risk of developing a condition called tumor lysis syndrome (TLS). This condition occurs when a large number of leukemia cells die within a short period of time, breaking apart and releasing their contents into the blood. This can cause a change in certain blood chemicals that may damage the kidneys and other organs. TLS can be severe during the early phases of treatment, especially for patients who have very high white blood cell counts before starting induction therapy.

If untreated, TLS can lead to heart arrhythmias, seizures, loss of muscle control, acute kidney failure and even death. Patients with leukemia who are at high risk for TLS may be given drugs, such as allopurinol (Zyloprim®) or rasburicase (Elitek®), that prevent or lessen TLS.

Other Treatment Side Effects. Some other common side effects of treatment for AML may include:

- Mouth sores
- Diarrhea
- Hair loss
- Rashes
- Nausea
- Vomiting
- Headache
- Peripheral neuropathy (numbness, tingling or muscle weakness, usually in the hands or feet)

Not all patients have these side effects. Treatments to prevent or manage nausea, vomiting, diarrhea and other side effects can help patients feel more comfortable.

There may be other side effects that are not listed here that you should watch for when taking a specific treatment. Talk to your healthcare team about the possible side effects of your treatment.

WANT MORE INFORMATION?

Visit www.LLS.org/booklets (filter by Side Effect Management) to view, print or order the full *Side Effect Management* series. Or contact our Information Specialists at (800) 955-4572 for copies.

Long-Term and Late Effects

Long-term effects are side effects of treatment that may last for months or years after treatment ends. Fatigue is an example of a long-term side effect. In children, learning skills may be affected.

Late effects are side effects of treatment that may not show up until years after treatment ends. Heart disease is an example of a possible late side effect.

Children who are treated for AML may have:

- Growth problems
- Fertility (ability to have children) problems
- Bone problems
- Heart problems
- Learning problems
- Risk of developing a second cancer

Adults who are treated for AML may have:

- Fertility (ability to have children) problems
- Heart problems
- Risk of developing a second cancer
- Persistent fatigue

Not everyone who is treated for AML develops long-term or late effects. It depends on the patient’s age, overall health and the person’s specific treatment.

Patients should talk with their doctors about any long-term or late effects that they experience. Parents should talk to their child's doctor if they think their child's learning skills may have been affected by the cancer treatment so their child can be evaluated.

Here are some questions you may want to ask your healthcare team. See pages 52–57 for a full list of questions.

1. Who should I work with to ensure lifelong follow up?
2. How do I monitor long-term and late effects of treatment?
3. What types of long-term and late effects should be brought to the doctor's attention?

WANT MORE INFORMATION?

Visit www.LLS.org/booklets to view, print or order the free LLS booklet *A Parent's Guide to School and Childhood Cancer*.

Visit www.LLS.org/SurvivorshipWorkbook to view the free LLS workbook *Navigating Life During and After a Blood Cancer Diagnosis*. There are versions for adults, young adults, and children and adolescents. Each workbook has information about long-term and late effects of blood cancer treatment.

Or contact our Information Specialists at (800) 955-4572 for copies.

Nutrition and Cancer

Eating well is important for blood cancer patients. Proper nutrition plays a key role in keeping the body strong, supporting the immune system and reducing the risk for diseases. Patients who eat well and maintain a healthy weight usually mange treatment and its side effects better. It is also important for patients with weakened immune systems to follow all food safety guidelines to reduce the risk of foodborne illness. Speak to your doctor about food and nutrition and for a referral to an oncology registered dietitian (RD) for specific nutrition advice and guidance.

LLS registered dietitians have expertise in oncology nutrition and provide patients, parents and caregivers with free nutrition consultations by phone. Call (877) 467-1936 or visit www.LLS.org/nutrition to schedule a consult.

WANT MORE INFORMATION?

You can view, print or order the free LLS booklets *Food and Nutrition During Cancer Treatment* and *Nutrition Handbook: Feeding your family from meal planning to mealtime* at www.LLS.org/booklets, or contact our Information Specialists at (800) 955-4572 for copies.

Financial Concerns

Blood cancer patients are living longer, primarily because of the development of new and effective drugs. While this progress is exciting, the financial costs associated with new treatments can become an obstacle to treatment. Paying for healthcare is a major concern for many people who are living with blood cancer. The high cost of cancer can lead to significant financial and emotional stress for both patients and their families.

Even if you have health insurance, cancer can still take a toll on your finances. You may have new expenses such as co-payments or travel for treatment. You may also have less income if you need to take time off from work.

Speak with your healthcare team if you have any concerns about being able to afford your treatment. They may be able to provide information and resources that can help. Health insurance plans may not cover all the costs of cancer care, but there are many resources available to help with prescription drug payment. In addition, several major drug manufacturers currently provide patient assistance or prescription assistance programs. These programs can provide both insured and uninsured patients free or reduced-cost medications.

LLS offers financial assistance programs for eligible patients. You can call an LLS Information Specialist at (800) 955-4572 for more information about our financial assistance programs.

WANT MORE INFORMATION?

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

Follow-Up Care

Medical follow-up is important for every AML patient. Follow-up care helps the doctor see if the disease has recurred or relapsed, and enables the doctor to evaluate the patient for long-term and late effects.

Children and adults who have been treated for AML should see their primary care doctors and their hematologist-oncologists (cancer specialists) regularly for follow-up care. Patients should talk with their doctor about how often to have follow-up visits. You can ask your doctor what tests will be needed and how often you should have these tests.

It is important to get and keep a record of your cancer treatment, including the drugs you received so that your doctor can follow up on specific long-term effects that may be associated with your treatment. See page 51 for a place to list your treatments.

Here are some questions you may want to ask your healthcare team. See pages 52–57 for a full list of questions.

1. Who should I work with to ensure lifelong follow up?
2. Will I continue to see this same healthcare team?

3. What information should be provided to my primary doctor about past treatment and what may be needed in the future?

Follow-up care includes physical exams and blood tests. Sometimes bone marrow tests are also needed. The doctor may advise longer periods of time between follow-up visits. This will happen if you:

- Continue to be free of signs and symptoms of AML
- Do not need medical care for any long-term or late side effects

Survivorship clinics provide services that help cancer patients manage issues related to surviving cancer. A survivorship clinic may help patients deal with physical and emotional changes that may occur after cancer treatment. To find a survivorship clinic and other resources for child and adult survivors, ask your healthcare team if they can refer you to one, or contact our Information Specialists at (800) 955-4572.

Take Care of Yourself

- Keep all doctor and lab appointments.
- Talk with your doctor about how you feel at each visit.
- Ask any questions you may have about side effects.
- People with AML may have more infections. Follow your doctor's advice for preventing infection.
- Eat healthy food each day. It may help to eat four or five small meals instead of three big ones.
- Contact the doctor if you feel tired, have a fever or experience other symptoms.
- Keep a record of your cancer diagnosis, treatment and follow-up care needs. This is often called a survivorship plan. Share this information with any new doctors you see. The plan should include the following information:
  - A list of healthcare providers
  - Diagnosis summary with specifics such as AML subtype and genetic markers.

  - Treatment summary with specifics such as the names, dates and dosages of drugs, transplant information and any treatment side effects.
  - Maintenance treatment, if applicable
  - List of possible late effects
  - Schedule for ongoing monitoring with recommended tests, frequency and coordinating provider
  - Health and wellness recommendations such as nutrition, exercise or other disease information
- Do not smoke. Patients who smoke should get help to quit.
- Get enough rest and exercise. Talk with your doctor about starting an exercise program.
- Keep a healthcare file with copies of lab reports and treatment records.
- Have regular cancer screenings. See your primary care doctor to keep up with other healthcare needs.
- Talk with family and friends about how you feel. When family and friends know about AML and its treatment, they may worry less.
- Seek medical advice if you feel sad or depressed and your mood does not improve over time. For example, if you feel sad or depressed every day for a two-week period, seek help. Depression is an illness. It can and should be treated even when a person is being treated for AML. Treatment for depression has benefits for people living with cancer.

ADDITIONAL RESOURCES

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, visit www.LLS.org/ResourceDirectory to view the directory.

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 a sign language interpreter. Often these services are free.

Information for Veterans. Veterans who were exposed to Agent Orange while serving in Vietnam; to airborne hazards and burn pits while serving in Iraq, Afghanistan and other areas of Southwest Asia; to contaminated water at Camp Lejeune between 1953 and 1987; or to ionizing radiation during service may be able to get help from the United States Department of Veterans Affairs. For more information, please

- Call: the VA (800) 749-8387
- Visit: https://www.va.gov/disability/eligibility/hazardous-materials-exposure/

Information for Firefighters. Firefighters are at an increased risk of developing cancer. There are steps that firefighters can take to reduce the risk. Please visit www.LLS.org/FireFighters for resources and information.

World Trade Center Health Program. People involved in the aftermath of the 9/11 attacks and subsequently diagnosed with a blood cancer may be able to get 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 and those who lived, worked or were in school in that 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

Mental Health. Caring for your mental health has benefits if you are a cancer patient. Seek medical advice if you are struggling. For more information, please:

- Call: The National Institute of Mental Health (NIMH) at (866) 615-6464
- Visit: NIMH at www.nimh.nih.gov

If you or your loved one is experiencing a mental health crisis, call 988 to talk to a trained mental health professional. The 988 Suicide and Crisis Lifeline is free, confidential and always available. For the Crisis Text Line, text HOME to 741741.

Health Terms

Anemia. A condition in which a person has fewer red blood cells than normal.

Antibiotic. A drug used to treat infections caused by bacteria and fungi.

Anthracycline. A type of chemotherapy drug used to treat many types of cancer.

Blast cell. An immature blood cell.

Bone marrow. The spongy material in the center of the bones where blood cells are made.

Bone marrow aspiration. A procedure to remove and examine bone marrow cells to see if they are normal. A liquid sample containing cells is taken from the bone marrow and then the cells are looked at under a microscope.

Bone marrow biopsy. A procedure to remove and examine bone marrow cells to see if they are normal. A very small amount of bone filled with bone marrow cells is taken from the body, and the cells are looked at under a microscope.

Central line. Special tubing the doctor puts into a large vein in the upper chest to prepare a patient for chemotherapy treatment. The central line is used to give chemotherapy drugs, to infuse blood cells and to remove blood samples. Also called an indwelling catheter.

Central nervous system (CNS) prophylaxis. Treatment given to lower the risk of leukemia cells spreading to the central nervous system (brain and spinal cord).

Chemotherapy. Treatment that stops the growth of cancer cells, either by killing the cancer cells or by stopping them from dividing.

Chromosome. The part of the cell that contains genetic information. Chromosomes are made up of genes. Genes give the instructions that tell each cell what to do. Human cells have 23 pairs of chromosomes. The number or shape of chromosomes may not be normal in cancer cells.

Clinical trial. A careful study done by doctors for new drugs or treatments, or studies to find new uses of approved drugs or treatments. The goals of clinical trials for blood cancers are to find cures, and to improve treatment and quality of life.

Consolidation. Treatment given to cancer patients after they achieve a remission following induction therapy. It is used to kill any cancer cells that may be left in the body.

Cytogenetic analysis. The examination of cells in a sample of tissue, blood or bone marrow to look for changes in chromosomes. Changes in certain chromosomes may be a sign of some types of cancer. Cytogenetic analysis may be used to help diagnose cancer and plan treatment.

DNA. The molecules inside cells that carry genetic information and pass it from one generation to the next. DNA stands for deoxyribonucleic acid.

Flow cytometry. See Immunophenotyping.

Granulocyte colony-stimulating factor. A drug that helps the bone marrow make more white blood cells to help prevent infection.

Hematologist-oncologist. A doctor who specializes in the diagnosis and treatment of blood cancers.

Immunophenotyping. A lab test that can measure the number of cells in a sample and determine certain characteristics of cells, such as their size and shape. It can also detect tumor markers on the surface of cells and identify specific types of cells, including AML cells.

Induction. The first treatment given for a disease. The goal of induction is to kill as many cancer cells as possible in order to induce (achieve) a remission.

Intrathecal chemotherapy. Treatment in which chemotherapy drugs are injected into the fluid-filled space that covers the brain and spinal cord. It can be used to treat or to prevent cancer in the central nervous system.

Late effect. A medical problem that does not appear or is not noticed until months or years after treatment ends.

Leukemia. A cancer of the bone marrow and blood.

Long-term effect. A medical problem that is caused by a disease or treatment of a disease and that may continue for months or years.

Marrow. See Bone marrow.

Measurable residual disease (MRD). A very small number of cancer cells that remain in the body during or after treatment and that are difficult to detect. Also called minimal residual disease.

Oncologist. A doctor with special training in diagnosing and treating cancer.

Pathologist. A doctor with special training in identifying disease by studying cells and tissues under a microscope.

PCR. The short name for polymerase chain reaction, a very sensitive lab test that can measure the presence of cancer cell markers in the blood or bone marrow. PCR is used to detect cancer cells remaining after treatment that cannot be detected by other tests or seen with a microscope.

Plasma. The liquid part of the blood.

Platelet. A type of blood cell that helps prevent or stop bleeding.

Prognosis. The likely outcome of a disease; the chance of recovery or recurrence of the disease.

Prophylaxis. Treatment that is given to prevent a disease.

Radiation therapy. Treatment with x-rays or other high-energy rays.

Refractory AML. AML that has not responded to initial treatment. Refractory AML may be AML that is getting worse or staying the same even after treatment.

Relapsed AML. AML that responds to treatment at first, but then returns.

Remission. When signs and symptoms of a disease decrease or disappear, usually following treatment.

Stem cell. A type of cell found in the bone marrow that develops into different types of cells. Blood stem cells can mature into red blood cells, white blood cells and platelets.

Supportive care. Specialized medical care given to provide relief from symptoms and the stresses of a serious illness. The goal is to improve quality of life for both the patient and the family.

Targeted therapy. A type of treatment that uses drugs to target specific genes and proteins that help cancer cells grow and survive, with less harm to normal cells.

White blood cell. A type of blood cell that helps the body fight infection.

MY HEALTHCARE TEAM CONTACT LIST

Use this list to remember names and contact information for members of your healthcare team.

CAREGIVER NAME:

Address: ____________________

Phone number/Fax number: ____________________

Email address: ____________________

Additional information: ____________________

PRIMARY CARE DOCTOR NAME:

Address: ____________________

Phone number/Fax number: ____________________

Email address: ____________________

Additional information: ____________________

PHARMACY NAME:

Address: ____________________

Phone number/Fax number ____________________

Additional information: ____________________

Information Specialists:
Phone: (800) 955-4572
Email: infocenter@LLS.org
Website: www.LLS.org/InformationSpecialists

HEMATOLOGIST-ONCOLOGIST NAME:

Address: ______________________________

Phone number/Fax number: ______________________________

Email address: ______________________________

Website/Portal: ______________________________

Additional information: ______________________________

NURSE/NURSE PRACTITIONER NAME::

Address: ______________________________

Phone number/Fax number: ______________________________

Email address: ______________________________

Additional information: ______________________________

SOCIAL WORKER NAME:

Address: ______________________________

Phone number/Fax number: ______________________________

Email address: ______________________________

Additional information: ______________________________

INSURANCE CASE MANAGER/
CARE COORDINATOR NAME:

Address: ______________________________

Phone number/Fax number: ______________________________

Website or email address: ______________________________

Additional information: ______________________________

PHYSICIAN ASSISTANT NAME:

Address:

Phone number/Fax number:

Email address:

Additional information:

NURSE NAVIGATOR NAME::

Address:

Phone number/Fax number:

Email address:

Additional information:

OTHER:

Address:

Phone number/Fax number:

Email address:

Additional information:

OTHER:

Address:

Phone number/Fax number:

Email address:

Additional information:

MY LIST OF TREATMENTS

Use this space to list your treatments and when you took them.

DATE: ____________________

Treatment: ____________________

DATE: ____________________

Treatment: ____________________

DATE: ____________________

Treatment: ____________________

DATE: ____________________

Treatment: ____________________

DATE: ____________________

Treatment: ____________________

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 them 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 patients may not be old enough or able to make their own decisions. A parent, relative or caregiver may be assisting or making the decisions.)

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 available so my family/caregiver can be given medical information?

Questions for the Nurse

NURSE OR OTHER HEALTHCARE TEAM MEMBER'S NAME:

____

1. How long will 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 they plan to treat your (your loved one's) leukemia. 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 patients may not be old enough or able to make their own decisions. 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 subtype of AML:

____

____

____

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 my subtype?
6. What is the goal of treatment?
7. What are the treatment options?
8. Are there any clinical trials I can 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 back?
3. How are the results 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?
   If the treatment is outpatient:
   - ○ Is it all right to attend work or school during treatment?
   - ○ Will someone be needed to drive me home after treatment?
2. What kind of testing will be done to monitor this disease and treatment? How often will testing be needed? Where is the testing done?
3. How will we know if the treatment is effective? What options are available if the treatment is not effective?

4 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 or ability to do a job/go to school?
2. What kind of financial and social support services are available to me and my family?
3. How can I (we) find out if insurance will cover the costs of the treatment or the study treatment?
4. Who is the best person to speak to about bills and insurance coverage?
5. If I (we) do not have insurance coverage, how can the healthcare team help get the treatment needed? Is there someone I can speak to for assistance?
6. 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?
7. How can I (we) find out if insurance covers 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 lifelong 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 my primary doctor about my treatment?

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

NOTES

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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, and optimism. Finding 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**

LEUKEMIA &
LYMPHOMA
SOCIETY®

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

The Leukemia & Lymphoma Society Mail Center
1201 15th Street N.W., Suite 410, Washington, D.C. 20005

The mission of The Leukemia & Lymphoma Society (LLS) is to cure blood cancer and improve the quality of life of all patients and their families. Find out more at www.LLS.org.

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