



PROVIDING THE LATEST INFORMATION  
FOR PATIENTS & CAREGIVERS

# The AML Guide: Information for Patients and Caregivers



Revised **2023**

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

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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](http://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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## 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.

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

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### WANT MORE INFORMATION?



You can view, print or order the free, more detailed LLS booklets *Acute Myeloid Leukemia in Adults* and *Acute Myeloid Leukemia in Children and Teens* at [www.LLS.org/booklets](http://www.LLS.org/booklets) or contact our Information Specialists for copies.

**Feedback.** Visit [www.LLS.org/PublicationFeedback](http://www.LLS.org/PublicationFeedback) to give suggestions about this booklet.

### Overview

- Acute myeloid leukemia (AML) is a type of cancer of the blood and bone marrow. "Acute" means that the leukemia is severe, and that it usually gets worse quickly if it is not treated.
- Blood cells begin as stem cells, which develop in the bone marrow inside bones. These stem cells normally develop into healthy red blood cells, white blood cells or platelets.
- AML starts with a mutation (change) in the DNA of a single stem cell in the bone marrow.
- 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 Guide.

**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 they have matured, the red blood cells, white blood cells and platelets 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. There are five types of white blood cells, which are usually categorized into two groups, lymphocytes and germ-eating cells:

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

**Platelets** help stop bleeding by clumping together (**clotting**) 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 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 blood 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 (PLAT C)

- 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)

- Shows the part of the blood made up of different types of white 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.

AML is a type of blood cancer that begins in the bone marrow. A person can get AML at any age, but most people diagnosed with AML are older than age 60.

**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)
- Mutated cells multiply into many cells (also called "AML cells" or "AML blast cells")

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 a test result. A **symptom** is a change in the body that the patient can see or feel.

Symptoms of AML may include:

- 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** (peh tee' key uh)
- Loss of appetite
- Unexplained weight loss
- Aches in bones or joints

Many of the signs and symptoms of AML are also signs and symptoms of other illnesses. Most people with these signs and symptoms do not have AML.

## 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 41-46 for a full list of questions.

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



**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.** Leukemia begins in the bone marrow. A diagnosis of AML is confirmed by removing samples of bone marrow and examining them for leukemia cells. The tests called "bone marrow aspiration" and "bone marrow biopsy" are usually done during the same visit. Two samples of bone marrow (liquid and bone) are removed from the hip bone using special needles. The samples are then sent to the lab for examination. Bone marrow tests are done to confirm the diagnosis and to help make treatment decisions.

**Visit [www.LLS.org/3D](http://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.**

## **How Are Blood and Bone Marrow Tests Done?**

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

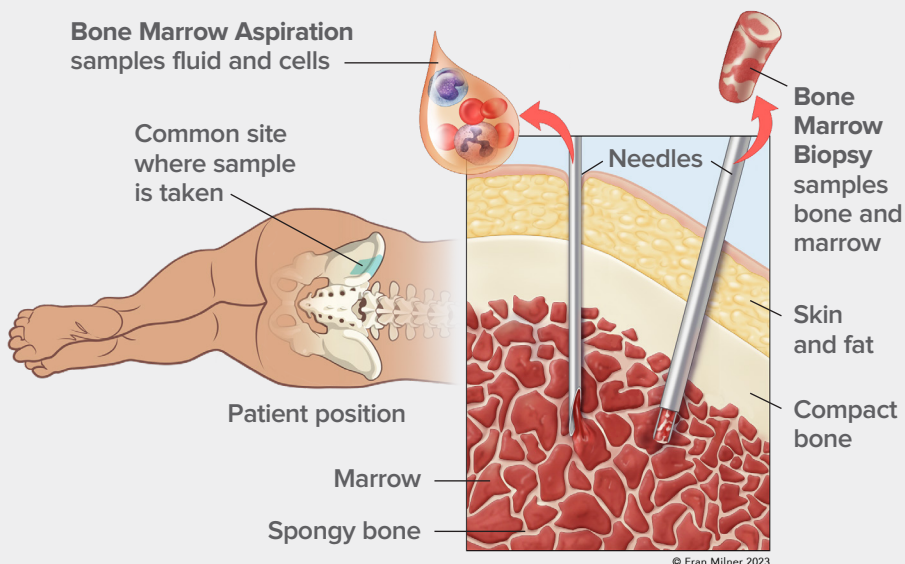
**Bone Marrow Aspiration**—The removal of a sample of fluid with cells from the bone marrow.

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

Each bone marrow test is done with a special needle. The samples are usually taken from the patient's hip bone. Bone marrow tests can be painful for many patients, so adults and teens will often receive medicine to numb the skin and the surface of the bone. They may also have the option to take medicine before the procedure to help them relax. Most children undergoing bone marrow aspiration and biopsy are under sedation or general anesthesia.

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

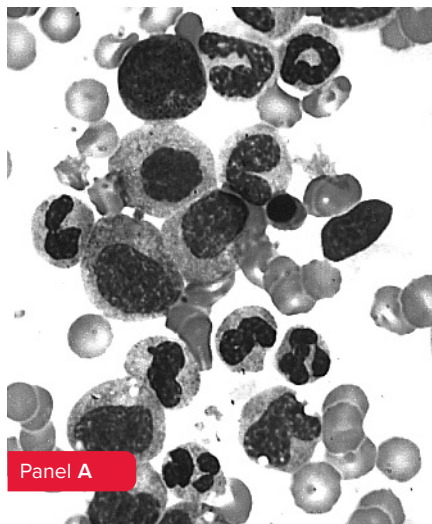
## Bone Marrow Aspiration and Biopsy



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

**Cell Examination.** At the laboratory, the cells in the blood and bone marrow samples will be 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



Panel A



Panel B

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.

**Immunophenotyping (Flow Cytometry).** This test can diagnose specific types of leukemia and lymphoma by detecting certain 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 "**minimal/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. Normal human cells contain 46 chromosomes (22 pairs plus the sex chromosomes, which are different in males and females). 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 your AML subtype and plan your treatment.

**DNA Sequencing.** This test uses blood or bone marrow samples to look 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.

**PCR (Polymerase Chain Reaction).** This is a 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 given during treatment or after the patient is treated, and the results allow doctors to determine the amount of minimal/measurable residual disease (MRD), the small number of cancer cells left in the body after treatment.

## 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 in person at your doctor's office. Many hospitals and treatment centers now 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.

### WANT MORE INFORMATION?



You can view, print or order the free LLS publications *Understanding Lab and Imaging Tests* and *Understanding Genetics*. Go to [www.LLS.org/booklets](http://www.LLS.org/booklets) or contact our Information Specialists for copies.

## Subtypes of AML

There are many different subtypes of AML, each caused by different genetic abnormalities (gene or chromosome changes) in the leukemia cells. It is important to know your AML subtype because it can affect both your prognosis (outlook) and your treatment plan. For example, one subtype, 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 what it is and to explain how your AML subtype affects your treatment.

The World Health Organization (WHO) is the main system used to divide AML into subtypes. For a comprehensive list of the WHO classification system of AML

subtypes, please see the free LLS publications *Acute Myeloid Leukemia in Adults* and *Acute Myeloid Leukemia in Children and Teens* at [www.LLS.org/booklets](http://www.LLS.org/booklets), or call an Information Specialist.



Write your AML subtype here: \_\_\_\_\_

## PART 2 TREATMENT

### 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 *Treatment and Follow-Up Care Question Guide* on pages 43-46.
- 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 therapy**. Most patients with AML need to start induction therapy soon after diagnosis. Induction therapy is usually done while the patient stays in the hospital.

### 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 the cancer specialist you see if they can 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 an LLS Information Specialist at (800) 955-4572.
- Use online doctor-finder resources, such as
  - The American Medical Association's (AMA) "DoctorFinder" online at <https://doctorfinder.ama-assn.org/doctorfinder/home.jsp>
  - 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 41-46 for a full list of questions.

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. 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 speaking with the staff at this treatment center.

### WANT MORE INFORMATION?



You can view, print or order the free LLS booklet *Choosing a Blood Cancer Specialist or Treatment Center* at [www.LLS.org/booklets](http://www.LLS.org/booklets), or contact our Information Specialists for a copy.

## Ask Your Doctor

Talk with the doctor and ask questions about how they plan to treat your leukemia. 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 41-46 at the end of this Guide for a full list of questions. Visit [www.LLS.org/WhatToAsk](http://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 on. 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 another opinion (a “second 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 insurance company to be sure that a second opinion will be 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 leukemia and may want to have children in the future, and parents of children who have leukemia, 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 41-46 in this Guide 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 Facts* at [www.LLS.org/booklets](http://www.LLS.org/booklets), or contact our Information Specialists for a copy.

**Prognostic Factors.** Certain factors can affect a patient's "prognosis," which is the likely outcome of their disease. Doctors use **prognostic factors** to help determine the best treatment options and predict how a patient's 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 leukemia cells have spread to your central nervous system (the area around the brain and spine)
- Whether you have a high white blood cell count at the time of your AML diagnosis
- How well you respond to induction therapy
- Whether your AML has been treated before and relapsed

## About AML Treatments

New treatments may have been approved since this booklet was printed. Check [www.LLS.org/DrugUpdates](http://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 participation in a clinical trial. Like all treatment options, clinical trials have possible risks and benefits. By considering all of your treatment options, including clinical trials, you will be taking an active role in this very important decision-making process.

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 transplantation.

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 page 17.

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

Our Information Specialists can help you plan questions to ask your doctor about treatment.



**Here are some questions you may want to ask your healthcare team.** See pages 41-46 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 Therapy.** 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 includes **cytarabine** and an anthracycline drug, such as **daunorubicin** or **idarubicin**. This is called the “7 + 3” regimen. Other drugs may be added or substituted for higher-risk patients. These may include:

- **Midostaurin (Rydapt®)** 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**
- **High-dose cytarabine** with **mitoxantrone**
- **Fludarabine** with **high-dose cytarabine**, **idarubicin** and a granulocyte colony-stimulating factor (G-CSF)

Some drugs are given by mouth (orally). 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.

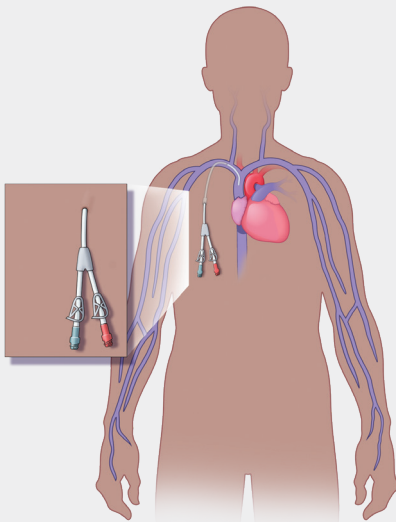
## Central Lines, Ports and PICCs

**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.

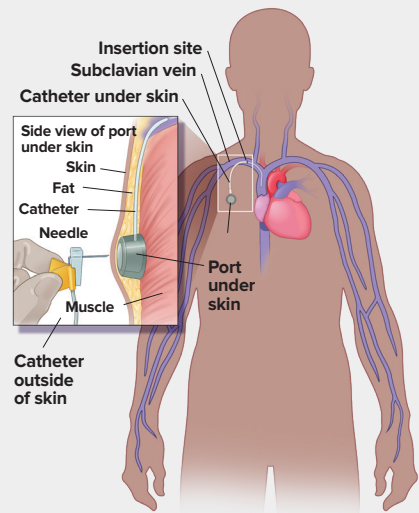
**PICC or PIC Line** (short for “percutaneously inserted central venous catheter”)—A PICC or PIC (not shown) is inserted through a vein in the arm.

### Hickman® Catheter



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

### Port and Catheter



Port: A port used with a central line.

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## 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.

<b>Anthracyclines (antitumor antibiotics)</b>	<ul style="list-style-type: none"> <li><input type="radio"/> daunorubicin (Cerubidine®)</li> <li><input type="radio"/> idarubicin (Idamycin®)</li> <li><input type="radio"/> mitoxantrone (Novantrone®)</li> </ul>
<b>Antimetabolites</b>	<ul style="list-style-type: none"> <li><input type="radio"/> cladribine (2-CdA; Leustatin®)</li> <li><input type="radio"/> clofarabine (Clolar®)</li> <li><input type="radio"/> cytarabine (cytosine arabinoside, ara-C; Cytosar-U®)</li> <li><input type="radio"/> fludarabine (Fludara®)</li> <li><input type="radio"/> methotrexate</li> <li><input type="radio"/> 6-thioguanine (thioguanine; Tabloid®)</li> </ul>
<b>Anthracycline and Antimetabolite Combination</b>	<ul style="list-style-type: none"> <li><input type="radio"/> CPX-351 (Vyxeos®)</li> </ul>
<b>Topoisomerase Inhibitors</b>	<ul style="list-style-type: none"> <li><input type="radio"/> etoposide (VP-16; VePesid®, Etopophos®)</li> </ul>
<b>Cell-Maturing Agents</b>	<ul style="list-style-type: none"> <li><input type="radio"/> all-trans retinoic acid (ATRA, tretinoin; Vesanoid®)</li> <li><input type="radio"/> arsenic trioxide (Trisenox®)</li> </ul>
<b>Hypomethylating Agents</b>	<ul style="list-style-type: none"> <li><input type="radio"/> azacitidine (Vidaza®)</li> <li><input type="radio"/> oral azacitidine (Onureg®)</li> <li><input type="radio"/> decitabine (Dacogen®)</li> <li><input type="radio"/> oral decitabine and cedazuridine (Inqovi®)</li> </ul>
<b>Antibody Conjugate</b>	<ul style="list-style-type: none"> <li><input type="radio"/> gemtuzumab ozogamicin (Mylotarg™)</li> </ul>
<b>FLT3 Inhibitors</b>	<ul style="list-style-type: none"> <li><input type="radio"/> crenolanib</li> <li><input type="radio"/> gilteritinib (Xospata®)</li> <li><input type="radio"/> midostaurin (Rydapt®)</li> <li><input type="radio"/> quizartinib (AC-220)</li> <li><input type="radio"/> sorafenib (Nexavar®)</li> </ul>
<b>IDH1 Inhibitors</b>	<ul style="list-style-type: none"> <li><input type="radio"/> ivosidenib (Tibsovo®)</li> <li><input type="radio"/> Olutasidenib (Rezlidhia™)</li> </ul>
<b>IDH2 Inhibitor</b>	<ul style="list-style-type: none"> <li><input type="radio"/> enasidenib (Idhifa®)</li> </ul>
<b>Hedgehog Inhibitor</b>	<ul style="list-style-type: none"> <li><input type="radio"/> glasdegib (Daurismo™)</li> </ul>
<b>BCL2 Inhibitor</b>	<ul style="list-style-type: none"> <li><input type="radio"/> venetoclax (Venclexta®)</li> </ul>

Use the lines provided on page 40 to list your treatments and when you took them.

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

**Testing After Induction Therapy.** At the end of induction therapy, blood and bone marrow tests are done to see how well your treatment is working. The doctor will see whether 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 **minimal/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 used most commonly to detect MRD are flow cytometry, polymerase chain reaction (PCR) and DNA sequencing. These tests typically use samples of bone marrow cells, but in some cases blood samples can be used.

**See the free LLS fact sheet *Minimal/ Measurable Residual Disease (MRD)* for more information.**

**Consolidation Therapy.** 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 therapy:

- Additional intensive chemotherapy
- Stem cell transplantation (see page 20)

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

Patients with high-risk AML usually receive more aggressive therapy. The treatment options that may be offered to these patients are participation in a clinical trial or stem cell transplantation (see page 20).

**Maintenance.** The third phase of treatment is called “**maintenance.**” The main objective of maintenance therapy 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.

**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.

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.

Lower-intensity treatment strategies for induction as recommended by the NCCN Guidelines include:

- **Venetoclax** and **azacitidine (Vidaza®)**
- **Venetoclax** and **decitabine (Dacogen®)**
- **Venetoclax** and low-dose **cytarabine**
- **Azacitidine**
- **Decitabine**
- Low-dose **cytarabine**
- **Glasdegib** and low-dose **cytarabine**
- **Gemtuzumab ozogamicin** for CD33 positive AML
- **Ivosidenib** for AML with an *IDH1* mutation
- **Ivosidenib** and **azacitidine** for AML with an *IDH1* mutation
- **Enasidenib** for AML with an *IDH2* mutation
- **Enasidenib** and **azacitidine** for AML with *IDH2* mutation
- **Sorafenib** for AML with *FLT3* mutation
- **Azacitidine** or **decitabine** and **sorafenib** for AML with an *FLT3*-ITD mutation
- **Gilteritinib** and **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](http://www.LLS.org/CTSC) to find out more about clinical trials.

**Assessing Treatment Response.** After the completion of induction therapy, blood and bone marrow tests are done to check for a remission and to look for minimal/measurable residual disease. A complete remission is still possible with lower-intensity treatments. A complete remission is achieved when patients no longer have signs and symptoms of AML.

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 transplantation 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.** An allogeneic transplant is a treatment that 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 during induction therapy, the process of allogeneic transplant 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 Transplant** uses lower doses of chemotherapy than a standard allogeneic transplant. 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 "regular" allogeneic stem cell transplant. 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* at [www.LLS.org/booklets](http://www.LLS.org/booklets), or contact our Information Specialists for a copy.

## Acute Promyelocytic Leukemia (APL) Treatment

Acute promyelocytic leukemia (APL) is a subtype of acute myeloid leukemia (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 the other AML treatments described in this booklet. Many people with APL are treated with a drug called **all-trans-retinoic acid (ATRA)** in combination with **arsenic trioxide (Trisenox®)** and in high-risk cases, chemotherapy such as **gemtuzumab ozogamicin (Mylotarg™)** is also added.

#### WANT MORE INFORMATION?



You can view, print or order the free LLS booklet *Acute Promyelocytic Leukemia Facts* at [www.LLS.org/booklets](http://www.LLS.org/booklets), or contact our Information Specialists for a copy.

# AML Treatment 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 pediatric AML. These doctors are called **pediatric hematologist-oncologists**.

The treatment for children with AML usually has two phases: induction therapy and consolidation therapy. Children are usually treated with an induction therapy similar to that used for adults: **cytarabine** and an anthracycline such as **daunorubicin**, **idarubicin** or **mitoxantrone**. Other chemotherapy drugs may be added to the cytarabine plus anthracycline, such as **etoposide** or **6-thioguanine** (see *Some Drugs Used to Treat AML* on page 17).

Unlike adults with AML, children usually receive a treatment called **central nervous system (CNS) prophylaxis** (prevention treatment) during the induction phase of therapy. Because standard doses of chemotherapy may not reach leukemia cells in the central nervous system (brain and spinal cord), children will also get intrathecal chemotherapy, which means that it is injected directly into the spinal canal. It is given to prevent the spread of leukemia cells to the central nervous system. The most common intrathecal chemotherapy drug used in children with AML is **cytarabine**.

If AML cells are found in the central nervous system at the time of diagnosis, a more intensive CNS-directed therapy is used. In these cases, additional drugs are included in the intrathecal chemotherapy, such as **methotrexate** and a corticosteroid.

Consolidation therapy begins once the leukemia is in remission. The goal of consolidation therapy 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 20)

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 **doxorubicin**, **daunorubicin** or **idarubicin** are at increased risk of developing heart problems and should receive ongoing heart monitoring.



The chemotherapy drugs **cytarabine** and high-dose **methotrexate** can increase the risk of health problems that affect the brain and spinal cord after treatment. If the brain is affected, 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](http://www.LLS.org/booklets) to view the free LLS booklet *Acute Myeloid Leukemia in Children and Teens* and *Caring for Kids and Adolescents with Blood Cancer* workbook. Or contact our Information Specialists 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.** Information about clinical trials begins on page 24.
- **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 20.
- **Targeted therapy.** Some targeted therapies that may be used include:
  - **Gilteritinib** for AML with an *FLT3* mutation
  - **Azacitidine (Vidaza®)** or **decitabine (Dacogen®)** plus **sorafenib** for AML with an *FLT3* mutation
  - **Enasidenib** for AML with an *IDH2* mutation
  - **Ivosidenib** for AML with an *IDH1* mutation

- **Olutasidenib** for AML with *IDH1* mutation
- **Gemtuzumab ozogamicin** for CD33-positive AML

Research is ongoing to determine optimal drug combinations, doses and administration schedules. The following combinations are commonly used and are considered “aggressive” and “less-aggressive” treatment regimens for refractory and relapsed AML as recommended by the NCCN Guidelines.

Aggressive treatments:

- **Cladribine, cytarabine** and granulocyte colony-stimulating factor (G-CSF), with or without **mitoxantrone** or **idarubicin**
- High-dose **cytarabine**, with or without **idarubicin, daunorubicin** or **mitoxantrone**
- **Fludarabine, cytarabine** and G-CSF, with or without **idarubicin**
- **Etoposide** and **cytarabine**, with or without **mitoxantrone**
- **Clofarabine** with or without **cytarabine**, with or without **idarubicin**

Less aggressive treatments:

- Hypomethylating agents (**azacitidine** or **decitabine**)
- Low-dose **cytarabine**
- **Venetoclax** plus hypomethylating agents (**azacitidine** or **decitabine**) or low-dose **cytarabine**

## PART 3 CLINICAL TRIALS

### 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 41-46 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](http://www.LLS.org/CTSC) for more information.

### WANT MORE INFORMATION?



Visit [www.LLS.org/booklets](http://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 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 targeted therapies are different from the side effects of chemotherapy.
- Common side effects of treatment for AML may include mouth sores, 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 41-46 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 (red blood cells that are provided by a blood donor and given to the patient) may be needed to increase red blood cell counts.
- 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, (this is called **neutropenia**) may lead to an infection. Infections are usually treated with antibiotics. To help improve white blood cell counts, 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 and pneumococcal pneumonia and the inactivated ("dead") vaccine for the herpes virus, called Shingrix. For some children with AML, their vaccines 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 cancer cells die within a short period of time, releasing their contents into the blood. 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.

As the leukemia cells die, they break apart and release their contents into the blood. This can cause a change in certain blood chemicals that may damage the kidneys and other organs. 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®)**, which 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. You can also call our Information Specialists.

### WANT MORE INFORMATION?



Visit [www.LLS.org/booklets](http://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 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.

**Here are some questions you may want to ask your healthcare team.** See pages 41-46 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](http://www.LLS.org/booklets) to view, print or order these free LLS publications:

- *Learning & Living with Cancer: Advocating for your child's educational needs*
- *Long-Term and Late Effects of Treatment in Adults Facts*

Visit [www.LLS.org/FamilyWorkbook](http://www.LLS.org/FamilyWorkbook) to find additional information about long-term and late effects in children in the chapter, *Beyond Treatment* in the *Caring for Kids* workbook.

Or, contact our Information Specialists for a copy.

## 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 find out 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 and the time period you receive them, so that your doctor can follow up on specific long-term effects that may be associated with your treatment. See page 40 for a place to list your treatments.

**Here are some questions you may want to ask your healthcare team.** See pages 41-46 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 a patient:

- Continues to be free of signs and symptoms of AML
- Does 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.

## Take Care of Yourself

- Keep all appointments with your doctor.
- Discuss how you feel with the doctor at each visit. Ask any questions you may have about side effects.
- People with AML may have more infections than other people. Follow your doctor's advice for preventing infection.
- Eat healthy food each day. It may help to eat 4 or 5 small meals instead of 3 big ones.
- Contact the doctor about tiredness, fever or any other symptoms.
- 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.

## RESOURCES AND INFORMATION

LLS offers free information and services for patients and families affected by blood cancers. This section lists various resources you may find helpful.

### For Help and Information

**Consult with an Information Specialist.** Information Specialists can assist you through cancer treatment, financial and social challenges and give accurate, up-to-date disease, treatment and support information. Our Information Specialists are highly trained oncology social workers and



nurses. Language services are available. For more information, please:

- Call: (800) 955-4572 (Monday through Friday, 9 a.m. to 9 p.m. ET)
- Email and Live chat: [www.LLS.org/InformationSpecialists](http://www.LLS.org/InformationSpecialists)

**Clinical Trials (Research Studies).** Research is ongoing to develop new treatment options for patients. LLS offers help for patients and caregivers in understanding, identifying and accessing clinical trials. Pediatric and adult patients and caregivers can work with our Clinical Trial Nurse Navigators who will help find clinical trials and provide personalized support throughout the entire clinical trial process. Visit [www.LLS.org/CTSC](http://www.LLS.org/CTSC) for more information.

**Nutrition Consultations.** Schedule a free one-on-one nutrition consultation with one of our registered dietitians who have expertise in oncology nutrition. Consultations are available to patients of all cancer types and their caregivers. Dietitians can assist with information about healthy eating strategies, side effect management and more. Please visit [www.LLS.org/nutrition](http://www.LLS.org/nutrition) for more information.

**Free Information Booklets.** LLS offers free education and support booklets for patients, caregivers and healthcare professionals that can either be read online or ordered. Please visit [www.LLS.org/booklets](http://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](http://www.LLS.org/programs) for more information.

**Financial Assistance.** LLS offers financial support to eligible individuals with blood cancer for insurance premiums, co-pays, and non-medical expenses like travel, food, utilities, housing, etc. For more information, please:

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

**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. Visit [www.LLS.org/TheBloodline](http://www.LLS.org/TheBloodline) for more information and to subscribe to access exclusive content, submit ideas and topics, and connect with other listeners.

**3D Models.** LLS offers interactive 3D images to help visualize and better understand blood cell development, intrathecal therapy, leukemia, lymphoma, myeloma, MDS, MPNs and lab and imaging tests. Visit [www.LLS.org/3D](http://www.LLS.org/3D) for more.

## Free Mobile Apps.

- LLS Coloring For Kids™ — Allows children (and adults) to express their creativity and offers activities to help them learn about blood cancer and its treatment. Visit [www.LLS.org/ColoringApp](http://www.LLS.org/ColoringApp) to download for free.
- LLS Health Manager™ — Helps you track side effects, medication, food and hydration, questions for your doctor, and more. Visit [www.LLS.org/HealthManager](http://www.LLS.org/HealthManager) to download for free.

**Suggested Reading.** LLS provides a list of selected books recommended for patients, caregivers, children and teens. Visit [www.LLS.org/SuggestedReading](http://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. Visit [www.LLS.org/community](http://www.LLS.org/community) to join.

**Weekly Online Chats.** Moderated online chats can provide support and help cancer patients and caregivers reach out and share information. Please visit [www.LLS.org/chat](http://www.LLS.org/chat) for more information.

**Local Programs.** 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 region, please:

- Call: (800) 955-4572
- Visit: [www.LLS.org/LocalPrograms](http://www.LLS.org/LocalPrograms)

**Advocacy and Public Policy.** Working closely with dedicated volunteer advocates, LLS's Office of Public Policy elevates the voices of patients to state and federal elected officials, the White House, governors and even courts. Together, we advocate for safe and effective treatments. We pursue policies that would make care more accessible to all patients. And, most of all, we advocate for the hope for a cure. Want to join our work? Visit [www.LLS.org/advocacy](http://www.LLS.org/advocacy) for more information.

**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](http://www.LLS.org/ResourceDirectory) to view the directory.

## Additional Help for Specific Groups

**Información en Español (LLS information in Spanish).** Please visit [www.LLS.org/espanol](http://www.LLS.org/espanol) for more information.

**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 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: [www.publichealth.va.gov/exposures/AgentOrange](http://www.publichealth.va.gov/exposures/AgentOrange)

**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](http://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](http://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](http://www.nimh.nih.gov) and enter “depression” in the search box

## 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.

**Blast cell.** Immature (not developed) bone marrow cell. About 1 to 5 percent of normal bone marrow cells are blast cells. A diagnosis of AML usually requires having at least 20 percent of blasts instead of mature blood cells in the bone marrow or blood.

**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 therapy.** 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 therapy.** The first treatment given for a disease. The goal of induction therapy 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.

**Minimal/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 measurable 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.

**Translocation.** A chromosomal abnormality in which a piece of one chromosome breaks off and attaches to another chromosome. The location of the break may affect nearby genes and lead to medical problems.

## 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 and Live Chat: [www.LLS.org/InformationSpecialists](http://www.LLS.org/InformationSpecialists)

HEMATOLOGIST-ONCOLOGIST NAME:

Address: \_\_\_\_\_

Phone number/Fax number: \_\_\_\_\_

Email address: \_\_\_\_\_

Website/Portal: \_\_\_\_\_

Additional information: \_\_\_\_\_

NURSE/NURSE PRACTITIONER NAME:

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: \_\_\_\_\_

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DATE: \_\_\_\_\_

Treatment: \_\_\_\_\_

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DATE: \_\_\_\_\_

Treatment: \_\_\_\_\_

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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 decision.)

### Questions for the Doctor

DOCTOR'S NAME: \_\_\_\_\_

Date of appointment or phone call: \_\_\_\_\_

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

## Questions for the Nurse

NURSE OR OTHER HEALTHCARE TEAM MEMBER'S NAME:

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

To print copies of other question guides, go to [www.LLS.org/WhatToAsk](http://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:

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Write down your subtype of AML:

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## 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 could join?
9. When do you think treatment should begin?
10. How long will treatment last?
11. What are the benefits and risks of these treatments?
12. Is there one treatment recommended over the others?
13. How can potential side effects be prevented or managed?

## Testing

1. What kind of testing will be done to monitor the disease and treatment?
2. How long does it take to get the results?
3. How 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?
  - Is it alright 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 (clinical trial) 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 the 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 a primary doctor about this treatment?

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







**Get support.**  
Reach out to our  
**Information Specialists.**



The Leukemia & Lymphoma Society® team consists of highly trained oncology social workers and nurses who are available by phone, email and live chat 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-trials searches
- Get connected to resources

Contact us at  
**800.955.4572**  
or **www.LLS.org/**  
**InformationSpecialists**

(Language interpreters  
can be requested.)



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

**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](http://www.LLS.org).