

The AML Guide: Information for Patients and Caregivers



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

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



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

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

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

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This LLS Guide about AML is for information only. LLS does not give medical advice or provide medical services.

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

INTRODUCTION

Acute myeloid leukemia (AML) is a type of blood cancer. Another name for acute myeloid leukemia is “acute myelogenous 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 the treatment of AML have resulted in improved remission rates. The number of patients with AML who have gone into remission or have been cured increases each year.

- About 21,450 people in the United States were expected to be diagnosed with AML in 2019.
- About 53,491 people in the United States are living with or are in remission from AML as of 2015.

WANT MORE INFORMATION?



You can view, print or order the free LLS booklet *Acute Myeloid Leukemia* at www.LLS.org/booklets, or contact our Information Specialists for a copy.

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

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PART 1 ACUTE MYELOID LEUKEMIA

Overview of This Section

- Blood cells begin as stem cells, which develop 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 leave the bone marrow and enter the bloodstream.
- Acute myeloid leukemia (AML) starts with a change or a series of changes to a single cell in the bone marrow.

- A patient may have many tests to diagnosis AML, including blood and bone marrow tests.
- There are many subtypes of AML. As doctors learn more, treatment is being improved to better target each subtype.

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.

Platelets help stop bleeding by clumping together (**clotting**) at the site of an injury.

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:

- Lymphocytes are infection-fighting cells:
 1. B cells
 2. T cells
 3. NK (natural killer) cells
- Germ-eating cells kill and ingest bacteria:
 4. Neutrophils
 5. Monocytes

Plasma is the liquid part of the blood. 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 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
- The types of white cells counted are neutrophils, lymphocytes, monocytes, eosinophils and basophils.
- Adults usually have about 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 blood cancer that begins in the bone marrow. A person can get AML at any age, but older people are more likely than younger adults or children to develop AML.

Causes and Risk Factors of AML. AML starts with a change or changes to a single cell in the bone marrow. Doctors do not know what causes most cases of AML. There is no way to prevent AML. You cannot catch AML from someone else.

While the cause of AML is unknown, certain factors may increase the risk of developing AML. Most people who have these conditions or exposures do not get AML:

- Age. The risk of developing AML increases with age.
- Gender. Men are more likely than women 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.

Signs and Symptoms. Many of the signs and symptoms of AML are the same as symptoms caused by other illnesses. Most people with the signs and symptoms of AML do not have AML but may have another disease or condition.

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.

A person who has AML may have

- Tiredness and no energy
- 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

Diagnosis

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

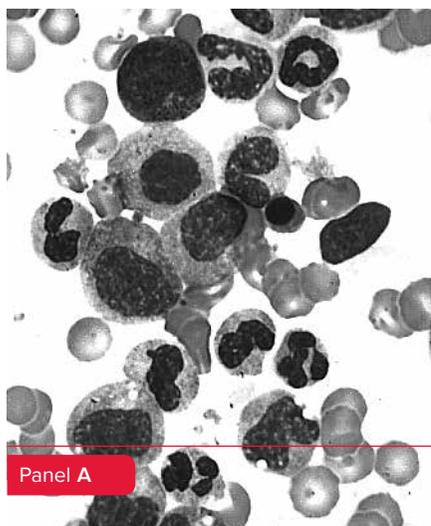
Here are some questions you may want to ask your healthcare team. See pages 43-48 for a full list of questions.

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

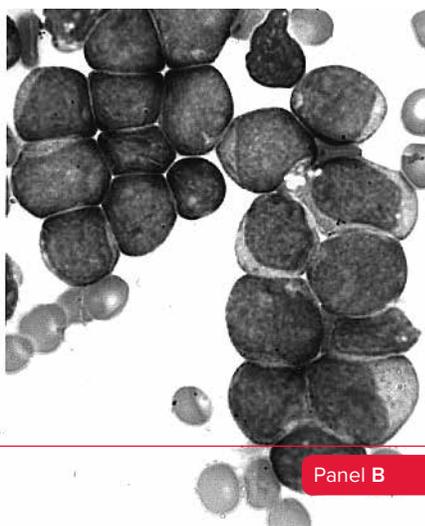
Blood Cell Counts. The doctor orders a test called a **CBC** (complete blood count). This test shows the numbers of red blood cells, white blood cells and platelets in a person's blood. Usually, patients with AML have lower-than-normal numbers of red blood cells and platelets in their blood. Patients may have higher-than-normal or lower-than-normal white blood cell counts.

Blood Cell Examination. The blood cells are stained (dyed) and looked at through a microscope. This test is called a **blood smear**. A person with AML usually has leukemic blast cells in the blood. Blast cells are immature (young) cells that do not function like normal mature cells. Normally, there are no blast cells in a healthy person's blood.

Normal Marrow Cells and 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 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.

Bone Marrow Tests. Bone marrow tests are done to confirm the diagnosis and to help make treatment decisions. Two tests, called **bone marrow aspiration** and **bone marrow biopsy**, take a close look at the AML cells. The tests also determine the percentage of blast cells in the bone marrow. Usually, a diagnosis of AML can be confirmed when 20 percent or more cells in the bone marrow are blast cells.

The doctor uses information from these tests to help decide

- The type of drug therapy a patient needs
- How long treatment will last

The type and length of treatment may also depend on the patient's age and other factors.

How Are the 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.

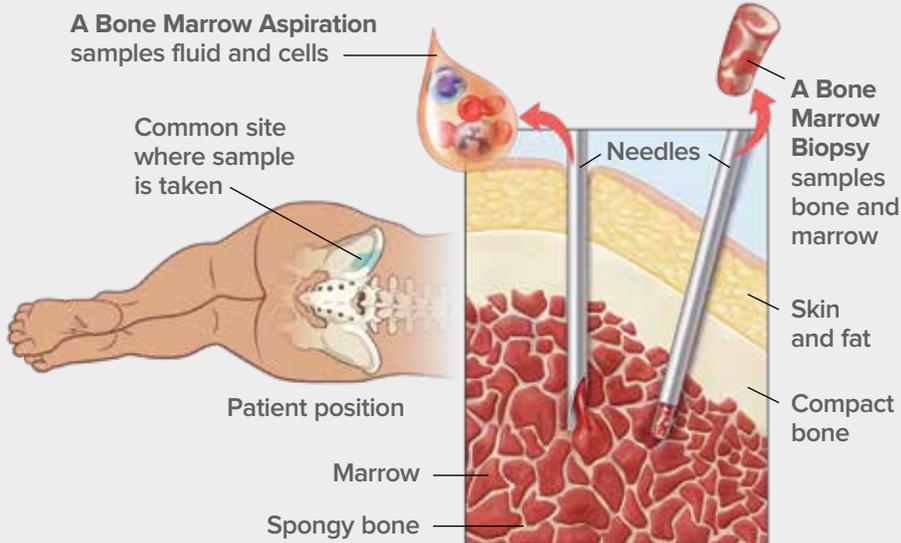
Bone Marrow Aspiration — The removal of a sample of fluid with cells from the bone marrow.

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

Both bone marrow tests are done with a special needle. Some patients are awake for the procedure. They get medication first to numb the part of the body that will be used to take the sample of cells. Some patients are given a drug that makes them sleep during this procedure. The sample of cells is usually taken from the patient's hip bone.

Blood and 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 pelvic bone where a bone marrow aspiration or biopsy is done. **Right:** Where one needle goes into bone marrow to get a liquid sample for aspiration and the other needle goes inside the bone for a bone biopsy. The needles are different sizes.

Immunophenotyping (Flow Cytometry). The proteins on leukemia cells often differ from those of normal cells. Flow cytometry is used to identify specific types of leukemia and lymphoma cells based on the types of proteins on the cell surface. The test can also be used to see if there are any cancer cells remaining in the body after treatment (minimal residual disease).

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 this test help your doctor plan your treatment.

Molecular Testing. Molecular tests are very sensitive DNA tests that check for specific gene mutations in the AML cells. Many genes will be tested. The genes that involve cancer may include genes called *FLT3*, *NPM1*, *CEBPA*, *KIT*, *IDH1* and *IDH2*. Results of molecular testing may be used for treatment planning.

PCR (Polymerase Chain Reaction). This is a test that finds and measures genetic mutation 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 residual disease (MRD), which is 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 for and keep copies of lab reports in a file folder or binder.
 - Organize test reports in order 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 booklet *Understanding Lab and Imaging Tests* at www.LLS.org/booklets, or contact our Information Specialists for a copy.

Subtypes of AML

AML is classified into subtypes that are based on lab test results. Knowing your AML subtype helps your doctor plan treatment. The World Health Organization (WHO) classification is the main system used to classify AML into subtypes. The AML subtypes in this system include

- AML with recurrent genetic abnormalities, which include
 - Acute promyelocytic leukemia (APL). See information about APL treatment on page 21
 - Acute megakaryoblastic leukemia (AMKL) with a translocation between chromosomes 1 and 22. See *Translocation in Health Terms* on page 36.
- AML with myelodysplasia-related changes
- AML related to previous chemotherapy or radiation
- AML not otherwise categorized (does not fall into the above categories)
- Myeloid sarcoma
- Myeloid proliferations related to Down syndrome
- Blastic plasmacytoid dendritic cell neoplasm (BPDCN)
- Acute leukemias of ambiguous lineage
- Myeloid neoplasms with germline predisposition without a preexisting disorder or organ dysfunction
- Myeloid neoplasms with germline predisposition and preexisting platelet disorders
- Myeloid neoplasms with germline predisposition and other organ dysfunction

The word “germline” refers to genetic tendencies that are passed on from parents to children through what are called germ cells, the reproductive cells.

For a more comprehensive version of the WHO classification system, please see the free LLS booklet *Acute Myeloid Leukemia* at www.LLS.org/booklets, or call an Information Specialist.

Overview of This Section

- 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 titled *My First Doctor's Visit* and *Treatment and Follow-Up Care* on pages 43-48.
- Adults with AML who may want to have children, and parents of children who have been diagnosed with AML, should ask about future fertility (ability to have a child). Find out what treatment may cause problems with fertility and what choices you have that may lessen the risk of becoming infertile (unable to have children).
- The first round of treatment with chemotherapy is called **induction therapy**. Most patients with AML need to start induction chemotherapy right away. Induction therapy is usually done 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, and an oncologist is a doctor who has special training in cancer. A hematologist-oncologist specializes in blood cancers. Your local cancer specialist may work with a hematologist-oncologist. Always check to see if the doctor's affiliated hospital or your chosen hospital is covered under your health insurance plan.

How to Find a Leukemia Specialist

- 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/>
 - 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. See pages 43-48 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 this 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, or contact our Information Specialists for a copy.

Ask Your Doctor

Talk with the doctor and ask questions about how he or she plans 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. See pages 43-48 at the end of this Guide for a full list of questions. Visit www.LLS.org/WhatToAsk to find other 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 okay (cell phones have a “record” function; ask someone how to use it if you aren't sure).
- 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 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.

Before-Treatment Considerations

Adults who have leukemia and may want to have children in the future, and parents of children who have been diagnosed with leukemia, should ask the doctor about ways to lessen the risk of infertility (inability to have children) that may be caused by treatment.

Here are some questions you may want to ask your healthcare team. See pages 43-48 for a full list of questions.

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 any decisions?

WANT MORE INFORMATION?



You can view, print or order the free LLS fact sheet *Fertility Facts* at www.LLS.org/booklets, or contact our Information Specialists for a copy.

Treatment Planning

A patient has two options for treatment: standard care or taking part in a clinical trial. It is important to talk to your healthcare team about your best treatment option. A clinical trial may be a good treatment choice for you. Clinical trials are explained beginning on page 26.

The goal of treatment for AML is to cure the disease.

- Patients with acute promyelocytic leukemia (APL) have higher cure rates overall compared with adults who have other AML subtypes.
- Some adults with other subtypes of AML may be cured or have long periods of remission.

Some factors that may affect the outcome of your AML treatment are

- Your subtype of AML
- Chromosome abnormalities and/or gene mutations
- Your age and general health
- Your medical history, including whether you
 - Were treated with chemotherapy before, for another type of cancer
 - Whether you had a prior blood cancer such as myelodysplastic syndrome (MDS) or a myeloproliferative neoplasm (MPN)
- Whether leukemia cells have spread to the area around the brain and the spine (called **central nervous system involvement**)
- High white blood cell count
- Disease that has not responded to treatment, called **refractory disease**
- Disease that has come back after treatment, called **relapsed disease**



Write down your AML subtype here: _____

Fertility Concerns. Some cancer treatments can limit a person's ability to have a baby. Talk to your doctor for information that may help lessen the risk of becoming unable to have children (infertile). See *Before-Treatment Considerations* on page 13.

About AML Treatments

Treatment for patients who have AML (or relapsed AML) may include

- Chemotherapy and other drugs
- Stem cell transplantation
- New approaches under study (in clinical trials)

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

A patient 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 43-48 for a full list of questions.

1. What is the subtype of my AML?
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?

Treatment Related to Chromosome and Gene Changes. Your bone marrow will be examined to see if there are changes to your chromosomes and genes. This information helps your doctor assess risk and it is an important part of treatment planning. About 60 percent of people with AML have abnormal chromosomes. There are treatments available to target specific genetic mutations. Talk to your doctor about additional tests that may need to be done to figure out the best treatment plan for you.

Induction Therapy. Induction therapy is the first phase of treatment. Typically, patients are given large doses of chemotherapy to kill the leukemia cells in the blood and bone marrow. Most AML patients need to start induction chemotherapy right away. Patients are often in the hospital for 4 to 6 weeks during this first part of treatment.

The goal of induction therapy is a complete remission. A complete remission is achieved when all three of these conditions have been met:

1. There are less than 5 percent blast cells in the bone marrow
2. Red blood cell, white blood cell and platelet counts have returned to normal or close-to-normal levels
3. There are no signs or symptoms of AML

Chemotherapy and Other Drugs. Chemotherapy and some other types of drugs kill or damage cancer cells. Several types of drugs are used to kill AML cells. Each drug type works in a different way. Combining the drugs can make the treatment work better.

The most common induction regimen for AML includes a combination of **cytarabine** and an anthracycline drug such as **daunorubicin** or **idarubicin**. Other drugs may be added or substituted for higher-risk patients. For a list of drugs used to treat AML, see page 18.

Some drugs are given by mouth (orally). Other drugs are inserted directly into the patient's body 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 nutrition and blood cells. These devices can be used in the reverse to take blood samples out of 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.

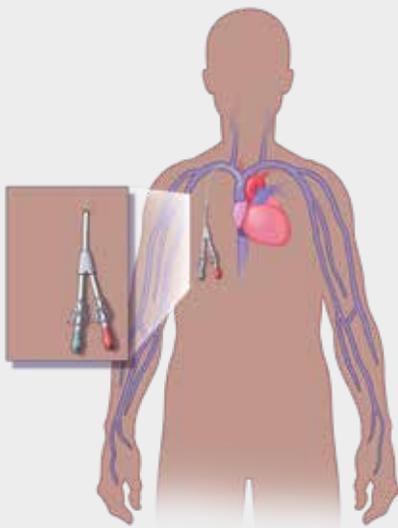
Central Lines, Ports and PICCs

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.

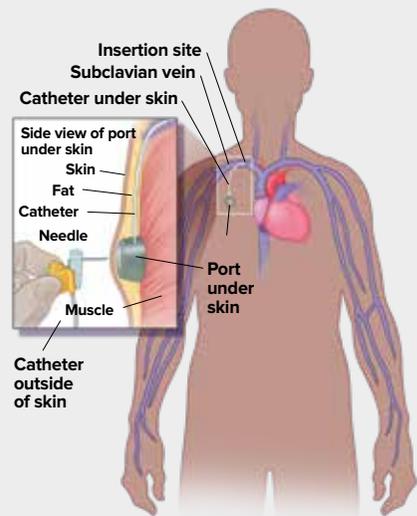
PICC or PIC Line (short for “percutaneously inserted central venous catheter”) — A PICC or PIC (not shown) is inserted through a vein in the arm.

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.

Anthracyclines (Antitumor Antibiotics)	<ul style="list-style-type: none"> ○ daunorubicin (Cerubidine®) ○ doxorubicin (Adriamycin®) ○ idarubicin (Idamycin®) ○ mitoxantrone (Novantrone®)
Antimetabolites	<ul style="list-style-type: none"> ○ cladribine (2-CdA; Leustatin®) ○ clofarabine (Clolar®) ○ cytarabine (cytosine arabinoside, ara-C; Cytosar-U®) ○ fludarabine (Fludara®) ○ methotrexate ○ 6-mercaptopurine (Purinethol®) ○ 6-thioguanine (Thioguanine Tabloid®)
Anthracycline and Antimetabolite Combination	<ul style="list-style-type: none"> ○ liposomal combination of daunorubicin and cytarabine (Vyxeos®)
Topoisomerase Inhibitors	<ul style="list-style-type: none"> ○ etoposide (VP-16; VePesid®, Etopophos®) ○ topotecan (Hycamtin®)
DNA-Damaging (Alkylating) Agents	<ul style="list-style-type: none"> ○ cyclophosphamide (Cytoxan®) ○ carboplatin (Paraplatin®) ○ temozolomide (Temodar®)
Cell-Maturing Agents	<ul style="list-style-type: none"> ○ all-trans retinoic acid (ATRA, tretinoin; Vesanoïd®) ○ arsenic trioxide (Trisenox®)
Hypomethylating Agents	<ul style="list-style-type: none"> ○ azacitidine (Vidaza®) ○ decitabine (Dacogen®)
Immunomodulator	<ul style="list-style-type: none"> ○ lenalidomide (Revlimid®)
Histone deacetylase inhibitors	<ul style="list-style-type: none"> ○ pracinostat ○ panobinostat (Farydak®) ○ vorinostat (Zolinza®)
Antibody Conjugate	<ul style="list-style-type: none"> ○ gemtuzumab ozogamicin (Mylotarg®)
FLT3 Inhibitors	<ul style="list-style-type: none"> ○ sorafenib (Nexavar®) ○ midostaurin (Rydapt®) ○ gilteritinib (Xospata®) ○ quizartinib (AC-220)
IDH1 Inhibitor	<ul style="list-style-type: none"> ○ ivosidenib (Tibsovo®)
IDH2 Inhibitor	<ul style="list-style-type: none"> ○ enasidenib (Idhifa®)
Hedgehog Inhibitor	<ul style="list-style-type: none"> ○ glasdegib (Daurismo™)
BCL-2 Inhibitor	<ul style="list-style-type: none"> ○ venetoclax (Venclexta®)

Information about side effects of treatment begins on page 27.

Use the lines provided on page 49 to list your treatments and when you took them.

Postremission Therapy (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.

The term **minimal residual disease (MRD)** refers to the leukemia cells that may still be present in the body during or after treatment, but cannot be found by common blood or bone marrow tests. More treatment is usually needed to destroy these remaining leukemia cells. Without additional therapy, the leukemia is likely to relapse within months. This part of AML treatment is called **postremission therapy**. Postremission means after remission.

There are two basic treatment choices for postremission therapy:

- Intensive chemotherapy
- Stem cell transplantation (See pages 19-21)

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

Patients with high-risk AML are rarely cured with chemotherapy alone. The treatment options that may be offered to these patients are allogeneic stem cell transplantation (see below for definition) and/or participation in a clinical trial.

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. Information about different types of stem cell transplantation follows.

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 his or her own stem cells (**autologous transplant**).

Stem cell transplantation allows doctors to give higher doses of chemotherapy than can typically be given. High-dose chemotherapy can severely damage

the stem cells in the bone marrow and result in anemia, serious infections and uncontrolled bleeding. Stem cell transplantation replaces the stem cells destroyed by the high-dose chemotherapy.

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 individual's disease
- 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

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 to kill the AML cells in the body.
- 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 marrow and begin to start a new supply of red blood cells, white blood cells and platelets.

Reduced-Intensity Allogeneic Stem Cell Transplant (also called a **nonmyeloablative 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.

Autologous Stem Cell Transplantation. An autologous transplant uses the patient's own stem cells, rather than a donor's. For AML patients, autologous transplant is done less frequently than allogeneic transplant.

After the patient achieves a remission during induction therapy, the process for autologous stem cell transplantation is as follows:

- Bone marrow that contains stem cells is removed from the patient.
- The patient's own stem cells are then frozen and stored.
- After the stem cells are collected from the patient, the patient receives high doses of chemotherapy.
- The patient's stored stem cells undergo a process called "purging" to try to eliminate all cancer cells (although there is a risk of returning some leukemia cells to the patient).
- The patient's treated stem cells are infused back into the patient's body.

Autologous transplantation is sometimes used for patients who do not have a matched donor. Autologous transplants are usually easier for patients to tolerate than allogeneic transplants. This is because patients receive their own stem cells (which are specially prepared for the transplant), so the risk of some complications is lower. The high doses of chemotherapy to the patient, however, can cause major side effects.

WANT MORE INFORMATION?



You can view, print or order the free LLS booklets *Blood and Marrow Stem Cell Transplantation* and *Cord Blood Stem Cell Transplantation Facts* at www.LLS.org/booklets, or contact our Information Specialists for copies.

Acute Promyelocytic Leukemia (APL) Treatment

Acute promyelocytic leukemia (APL) is a subtype of acute myeloid leukemia (AML). It is the most curable subtype of AML. APL comprises approximately 10 percent of all AML cases and occurs primarily in middle-aged adults.

APL treatment differs from the other AML treatments described in this booklet. For more information about acute promyelocytic leukemia, please see the free fact sheet *Acute Promyelocytic Leukemia Facts* at www.LLS.org/booklets.

Relapsed and Refractory AML

Some patients with AML **relapse**, which is when a patient achieves remission but then the AML cancer cells return. Other patients have **refractory** AML, which is when AML cells in the bone marrow do not respond to treatment and patients do not achieve remission.

Treatment options for patients with refractory or relapsed AML include:

- **A clinical trial.** Information about clinical trials begins on page 26.
- **Enasidenib (Idhifa®)**—This drug is FDA-approved for the treatment of adult patients with relapsed or refractory AML who have an *IDH2* mutation, as detected by an FDA-approved test. Enasidenib is an oral medication taken once a day.
- **Ivosidenib (Tibsovo®)**—This drug is FDA-approved for adult patients with relapsed or refractory AML who have an *IDH1* mutation, as detected by an FDA-approved test. This medication is taken orally once a day.
- **Gilteritinib (Xospata®)**—This drug is taken by mouth once a day. It is FDA-approved for the treatment of adult patients who have relapsed or refractory AML with an *FLT3* mutation, as detected by an FDA-approved test.
- **Palliative Care**—This term refers to specialized medical care focused on providing 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. With a palliative approach, less toxic treatments are administered to keep the disease under control for as long as possible. The emphasis is on improving the patient’s quality of life. Palliative care is also referred to as “supportive care.”
- **Intensive chemotherapy and targeted therapy**—These treatments are used for patients younger than 60 (and patients older than 60 who are physically fit) to induce a remission in order to prepare patients for an allogeneic stem cell transplant.
- **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.

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.

Aggressive treatments:

- Cladribine, cytarabine and granulocyte colony-stimulating factor (G-CSF), with or without mitoxantrone or idarubicin

- High-dose cytarabine, with or without an anthracycline
- Fludarabine, cytarabine and G-CSF, with or without idarubicin
- Etoposide and cytarabine, with or without mitoxantrone
- Clofarabine with or without cytarabine and G-CSF, with or without idarubicin

Less aggressive treatments:

- Low-dose cytarabine
- Hypomethylating agents (5-azacitidine or decitabine)

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 postremission (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** in combination with other agents such as **etoposide** or **thioguanine**. (See *Some Drugs Used to Treat AML* on page 18).

Unlike adults with AML, children usually receive a treatment called **central nervous system (CNS) prophylaxis** 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 kill the leukemia cells in the central nervous system and to reduce the chance that the leukemia will come back.

Postremission therapy begins once the leukemia is in remission. The goal of postremission 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:

- Combination chemotherapy
- High-dose chemotherapy followed by an allogeneic stem cell transplantation. For more information on stem cell transplantation, see pages 19-21.

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 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 watch for any potential problems as the child grows, and treat them as needed.

WANT MORE INFORMATION?



Visit www.LLS.org/booklets to view the free LLS booklet *Learning & Living with Cancer: Advocating for Your Child's Educational Needs* for information about planning for your child's entry or return to school following diagnosis and treatment.

AML Treatment in Older Adults

AML is more common in older patients. At least half of AML patients are older than 65 years when their disease is diagnosed.

Today, remissions are possible for some older people with AML, including those who have other serious health problems. But the treatment results in adults are not as positive as treatment results in children, because AML in older people is more resistant to treatment than AML in young people. This is a challenge, and it is clear that new and better treatments are needed for older adults with AML.

For older adults with AML, treatment options include clinical trials, intensive or less-intensive chemotherapies and supportive therapy. 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 therapy with a hypomethylating drug such as **5-azacitidine (Vidaza®)** or **decitabine (Dacogen®)**, or **low-dose cytarabine**.

Additional options that been approved for AML treatment in older patients are listed below.

- **Glasdegib (Daurismo™)**, in combination with low-dose cytarabine, is FDA-approved for the treatment of newly-diagnosed AML in adult patients age 75 years and older, or for those who have comorbidities that do not allow use of intensive induction chemotherapy.
- **Venetoclax (Venclexta®)**, in combination with azacitidine, decitabine or low-dose cytarabine, is FDA-approved for the treatment of newly-diagnosed AML in adults who are age 75 years or older, and for those who have comorbidities that do not allow use of intensive induction chemotherapy.
- **Ivosidenib (Tibsovo®)** is FDA-approved for adult patients with newly diagnosed AML with an *IDH1* mutation (as detected by an FDA-approved test), who are age 75 years or older, or for those who have comorbidities that do not allow use of intensive induction chemotherapy.
- The FDA granted “breakthrough therapy designation” for the oral HDAC inhibitor called **pracinostat**, in combination with azacitidine, for patients with newly diagnosed AML who are older than 75 and who are not candidates for intensive chemotherapy.

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.

About Clinical Trials

New treatments are under study for patients of all ages who have AML. New treatments are tested 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 or giving the drug along with another type of treatment. Some clinical trials combine drugs for AML in new sequences or dosages.

There are clinical trials for

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

A carefully conducted clinical trial may provide the best available therapy for patients with AML.

Here are some questions you may want to ask your healthcare team. See pages 43-48 for a full list of questions.

1. Is a clinical trial a treatment option?
2. How can I find out if my (our) health 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, and help search for a clinical trial for you. When appropriate, personalized clinical trial navigation by trained nurses is also available through the Clinical Trial Support Center. Visit www.LLS.org/CTSC for more information.

WANT MORE INFORMATION?



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

Overview of This Section

- Treatment side effects vary, depending on the type of treatment.
- Common side effects of treatment for AML may include mouth sores, nausea, diarrhea and/or constipation, and changes in blood counts.
- Parents should talk to the doctor if they think their child's learning skills may have been affected by leukemia or its treatment. The child's learning skills should be evaluated by another professional.
- Patients 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.

The aim of treatment for AML is to kill the AML cells. But treatment for AML also affects healthy cells in the body. Treatment side effects depend on the type of treatment. Patients react to treatments in different ways. Sometimes there are very mild side effects. Other side effects may be uncomfortable and difficult. Some side effects are serious and last a long time. Many side effects go away once treatment ends. 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 43-48 for a full list of questions.

1. What side effects should be reported to the team right away?
2. What are the common side effects of this treatment?
3. How long will the side effects last?
4. How can potential side effects be prevented or managed?

Common Treatment Side Effects. AML treatment may affect your blood cell counts and may cause anemia, bleeding, or infection:

- Red blood cell counts may decrease to lower-than-normal and cause 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.

- Platelets may also drop in number in a patient's blood. A platelet transfusion may be needed to prevent bleeding if the patient's platelet count is very low.
- White blood cells may decrease by a large number and lead to an infection. Infections are usually treated with antibiotics.

Infection could be very serious for anyone who has AML. Patients at home should contact a doctor if any signs of infection develop. A fever of 101°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

Growth factors are sometimes given to increase white blood cells. G-CSF (**Neupogen®** and **Neulasta®**) and GM-CSF (**Leukine®**) are drugs that increase the number of white blood cells. Growth factors are used only in special circumstances and routine use of these drugs is not recommended.

To lower the risk of infection

- The patient, the patient's 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.

The doctor may talk about the "absolute neutrophil count" or "ANC." This is the number of neutrophils (a type of white blood cell) that a person has circulating in his or her bloodstream. Neutrophils fight off infection.

Other Treatment Side Effects. Chemotherapy affects the parts of the body where new cells form quickly. This includes the inside of the mouth and bowel, and the skin and hair. The side effects listed here are common during chemotherapy:

- Mouth sores
- Diarrhea
- Hair loss
- Rashes
- Nausea

- Vomiting
- Headache
- Numbness, tingling or muscle weakness, usually in the hands or feet (called **peripheral neuropathy**)

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

Chemotherapy may cause the amount of uric acid to increase in the blood of some AML patients. Some patients also have a buildup of uric acid from the disease itself. Uric acid is a chemical made in the body, but a high level of uric acid can cause kidney stones.

Patients with high uric acid levels may be given:

- A drug called **allopurinol (Aloprim[®], Zyloprim[®])** by mouth
- A drug called **rasburicase (Elitek[®])** by intravenous injection (IV)

Some side effects last a long time (long-term side effects), or they may not occur right away (late side effects). Information about long-term and late effects of treatment begins below.

WANT MORE INFORMATION?



You can view, print or order the free LLS series *Side Effect Management* at www.LLS.org/booklets, 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.

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.

Here are some questions you may want to ask your healthcare team. See pages 43-48 for a full list of questions.

1. Who should I work with to ensure life-long follow up?
2. How can I be monitored for long-term and late effects of treatment?
3. What types of long-term and late effects should be brought to the healthcare team's attention?

Children who are treated for AML may have

- Growth problems
- Fertility (ability to have children later) problems
- Bone problems
- Heart problems
- Learning problems

Adults who are treated for AML may have

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

Patients should talk with their doctors about

- Any long-term or late effects that may be related to their treatment
- When and by whom a child's learning skills should be checked, to ensure they are not affected

WANT MORE INFORMATION?



You can view, print or order the free LLS fact sheets *Long-Term and Late Effects of Treatment for Childhood Leukemia or Lymphoma Facts* and *Long-Term and Late of Effects of Treatment in Adults Facts* at **www.LLS.org/booklets**.

Or contact our Information Specialists for copies.

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 determine how often you should have these tests. It is important to get and keep a record of your cancer treatment(s), 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 49 for a place to list your treatments.

Here are some questions you may want to ask your healthcare team. See pages 43-48 for a full list of questions.

1. Who should I work with to ensure life-long follow up?
2. Will I continue to see this same healthcare team?
3. What information can 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 of AML
- Does not need medical care for any long-term or late side effects

To find a survivorship clinic (a special clinic for survivors of cancer) and other resources for child and adult survivors, contact our Information Specialists.

Take Care of Yourself

- Keep all appointments with the doctor.
- Discuss how you feel with the doctor at each visit. Ask any questions you may have about side effects.
- Follow the doctor's advice for preventing infection. People with AML may have more infections than other people.
- Eat healthy food each day. It is okay 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 of the booklet lists various resources available to you. Use this information to learn more, to ask questions, and to make the most of your healthcare team.

For Help and Information

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

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

Clinical Trials (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. When appropriate, patients and caregivers can work with Clinical Trial Nurse Navigators who will help find clinical trials and personally assist them throughout the entire clinical trial process. Visit www.LLS.org/CTSC for more information.

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

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

Financial Assistance. LLS offers financial support, including insurance premium and medication co-pay assistance, to eligible individuals with blood cancer. For more information, please

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

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

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

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

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

Community Resources and Networking

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

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

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

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

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

Advocacy. The LLS Office of Public Policy (OPP) enlists volunteers to advocate for policies and laws to speed new treatments and improve access to quality medical care. For more information, please

- Call: (800) 955-4572

- Visit: www.LLS.org/advocacy

Additional Help for Specific Populations

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

Language Services. Let members of your healthcare team know if you need 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

World Trade Center Survivors. 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

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 two-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 and enter “depression” in the search box

Health Terms

Absolute Neutrophil Count (ANC). The number of neutrophils (a type of white cell that fights infection) in a person's body. The lower a person's absolute neutrophil count is, the higher the risk of infection.

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 administer chemotherapy drugs, infuse blood cells and remove blood samples. Also called an indwelling catheter.

Central Nervous System. The brain and the 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 be changed in blood 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 improve treatment and quality of life and to find cures.

Combination chemotherapy or drug therapy. The use of two or more drugs given at the same time to treat AML and other cancers.

Consolidation therapy. See Postremission therapy.

Cytogenetic analysis. The examination of the chromosomes of AML cells. This gives doctors information about how to treat patients. Cell samples can be taken from blood or bone marrow.

Diagnose. To detect a disease from a person's signs, symptoms and test results. Doctors diagnose patients.

FDA. The short name for the US Food and Drug Administration. Part of the FDA's job is to assure the safety and security of drugs, medical devices and the United States food supply.

Flow cytometry. See Immunophenotyping.

Gene. A section of DNA that is passed down from parent to child. Genes contain instructions for individual characteristics such as eye and hair color. They also contain instructions for making specific proteins that determine cell functions. The word "germline" refers to genetic tendencies that are passed on from parents to children through what are called germ cells, the reproductive cells.

Hematologist. A doctor who treats blood cell diseases.

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

Immune system. A network of cells, tissues and organs in the body that help the body fight infections and other diseases.

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

Immunotherapy. A type of treatment that uses substances to stimulate or suppress the immune system to help the body fight cancer and other diseases.

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 residual disease (MRD). The cancer cells present in the body during or after treatment that are difficult to detect.

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

Palliative 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. Palliative care is also called “supportive care.”

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 lab test that can measure the presence of cancer cell markers in the blood or bone marrow. PCR is used to detect remaining cancer cells 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 (by clotting), to help wounds heal.

Postremission therapy. Added treatment given to a cancer patient after a disease is in remission. It is used to kill any cancer cells that may be left in the body. Also called “consolidation therapy” and “intensification therapy.”

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

Refractory. Disease that does not respond to initial treatment. Refractory AML may be disease that is getting worse or staying the same, even after treatment.

Relapse or recurrence. When disease comes back after it has been successfully treated.

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

Signs and symptoms. Changes in the body that show the presence of disease. A sign is a change that the doctor sees in an exam or a lab test result. A symptom is a change that a patient can see or feel.

Stem cells. Cells found in the bone marrow that develop into red blood cells, white blood cells and platelets.

Supportive care. See Palliative care.

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: 1-800-955-4572

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:

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: _____

Question Guide: My First Doctor's Visit

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

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

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

Questions for the Doctor

DOCTOR'S NAME: _____

Date of appointment or phone call: _____

1. How many patients have you treated who have this disease?
2. What problems or symptoms should be reported to the nurse or doctor right away?
3. How long does it normally take to receive a return phone call?
4. How can you be contacted when there are questions?
5. How can you be contacted at night? On weekends? On holidays?
6. Who are the other members of the team that I should be aware of?
7. Is there a release form 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 would I (we) have to wait for appointments?
2. What problems or symptoms should be reported to the nurse or doctor right away?
3. How long does it usually take to receive a return phone call?
4. Will there be nurses, social workers and case managers available to help with support needs and quality-of-life concerns?
5. Does your office accept my (our) insurance? Is it considered in-network?

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

Question Guide: Treatment and Follow-Up Care

Talk with the doctor and ask questions about how he or she plans to treat your (your loved one's) 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 the patient may not be old enough or able to make his or her own decision. A parent, relative, or caregiver may be assisting or making the decision.)

DOCTOR'S NAME: _____

Date of appointment or phone call: _____

Write down your diagnosis:

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

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

My List of Treatments

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

DATE: _____

Treatment: _____



Get support. Reach out to our **INFORMATION SPECIALISTS**

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

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



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

(Language interpreters can be requested)



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

**BEATING
CANCER
IS IN
OUR BLOOD.**

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

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