

The ALL Guide: Information for Patients and Caregivers



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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INTRODUCTION

Acute lymphoblastic leukemia (ALL) is a type of blood cancer. Other names for ALL are “acute lymphocytic leukemia” and “acute lymphoid leukemia.”

ALL is a rare cancer. People of any age can develop ALL, but it affects more children than adults.

This easy-to-understand guide will provide you with basic information about ALL. It also provides information about clinical trials, blood and bone marrow, and questions to ask your healthcare team. Some words in this guide may be new to you. Find definitions in the list of Health Terms beginning on page 38, or call our Information Specialists at (800) 955-4572, with your questions.

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

WANT MORE INFORMATION?



For more information on ALL, go to www.LLS.org/booklets to view, print or order the free LLS booklets *Acute Lymphoblastic Leukemia in Adults* and *Acute Lymphoblastic Leukemia in Children and Teens* or call an LLS Information Specialist at (800) 955-4572 for a copy or to ask other questions.

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

PART 1 ACUTE LYMPHOBLASTIC LEUKEMIA

Overview

- Acute lymphoblastic leukemia (ALL) 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. Stem cells normally develop into healthy red blood cells, white blood cells and platelets. Then they leave the bone marrow and enter the bloodstream.
- ALL starts with a mutation (change) in the DNA of a single stem cell in the bone marrow.
- ALL is diagnosed with blood and bone marrow tests.
- There are many subtypes of ALL. Knowing your ALL subtype helps doctors determine the best treatment options for you.

About Bone Marrow, Blood and Blood Cells

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

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

Blood cells begin as stem cells in the bone marrow. Stem cells grow and mature into different types of cells: red blood cells, white blood cells and platelets. After 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. A low white blood cell count may cause repeated infections and fever. There are two major types of white blood cells:

- Lymphocytes are infection-fighting cells. There are 3 types of lymphocytes:
 - B cells
 - T cells
 - NK (natural killer) cells
- Germ-eating cells kill and ingest bacteria and viruses. There are 2 types of germ-eating cells:
 - Neutrophils
 - Monocytes

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

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

Normal Blood Cell Count Fast Facts

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

Red blood cell (RBC) count

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

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

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

Hemoglobin (a protein in red blood cells 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 blood cells
- Counts the types of white blood 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 ALL

Leukemia is the general term for a number of different types of blood cancer. ALL is one of four main types of leukemia. A person can get ALL at any age, but it is more common in children than adults.

Causes and Risk Factors of ALL. ALL is a type of blood cancer that begins in the bone marrow. ALL starts with a change to a single stem cell in the bone marrow. This means:

- A normal stem cell mutates (changes into a leukemia cell, also called an "ALL cell" or "blast cell")
- The mutated cell multiplies into many ALL cells
- The ALL cells build up in the bone marrow so there is no room for healthy blood cells to develop. As a result, people with ALL do not have enough healthy red blood cells, white blood cells and/or platelets.
- Over time, the ALL cells spill out of the bone marrow into the bloodstream.

ALL develops in early forms of white blood cells called lymphocytes. When ALL starts in early B cells it is called B-cell ALL. When it starts in early T cells, it is called T-cell ALL.

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

Risk factors associated with ALL include:

- **Genetic disorders.** Certain genetic conditions, such as Down Syndrome, Fanconi anemia, Shwachman syndrome, Diamond-Blackfan Anemia (DBA) syndrome and Li-Fraumeni syndrome, increase the risk of ALL.
- **Age.** The highest incidence rates for ALL are seen in children and adolescents younger than 15 years.
- **Sex.** Males are more likely than females to develop ALL.
- **Race/ethnicity.** In the United States, ALL is more common in Hispanics and whites.
- **Prior cancer treatment.** Some types of chemotherapy and radiation therapy may increase a person's risk of developing ALL.

Signs and Symptoms

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.

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

Symptoms of ALL may include:

- Frequent infections
- Fever
- Shortness of breath
- Pale skin
- Extreme tiredness, lack of energy
- Bruising easily
- Pinhead-sized red spots under the skin called **petechiae**
- Prolonged bleeding from minor cuts
- Enlarged lymph nodes
- Aches in legs, arms or hips
- Unexplained weight loss

Diagnosis

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

Here are some questions you may want to ask your healthcare team.

See pages 45-50 for a full list of questions.

1. What kind of testing will be done to diagnose my disease?
2. How long does it take to get the results?
3. How will I get the test 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 number of red blood cells, white blood cells and platelets in a blood sample. People with ALL often have lower-than-normal numbers of red blood cells and platelets. Patients may have higher-than-normal or lower-than-normal white blood cell counts.

Bone Marrow Tests. Leukemia begins in the bone marrow. A diagnosis of ALL is confirmed by removing samples of bone marrow and examining them for leukemia cells. **Bone marrow aspiration** and **bone marrow biopsy** are different tests in which two small samples of bone marrow (liquid and bone) are removed from the back of the hip bone using special needles. The samples are then sent to the lab for examination. Bone marrow tests are done to confirm the diagnosis of ALL and to help make treatment decisions.

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

How Are the 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.

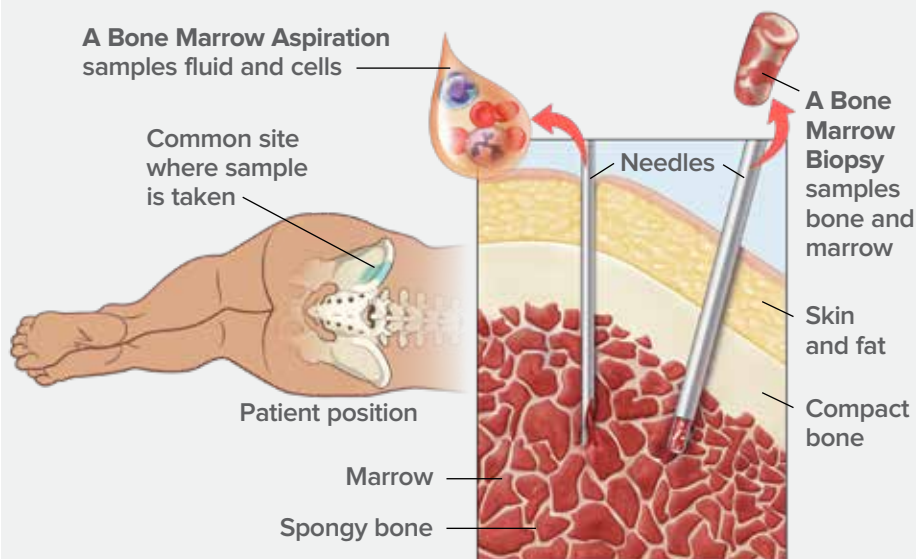
Bone Marrow Aspiration—A sample of fluid with cells is removed from the bone marrow and sent to a lab for testing.

Bone Marrow Biopsy—A very small amount of bone filled with bone marrow cells is taken from the body and sent to a lab for testing.

Both bone marrow tests are done with special needles. Some patients are awake for the procedure, but some adults and most children are given a drug that makes them sleep. Patients then get medication to numb the part of the body that will be used to remove the sample of cells. The sample of cells is usually taken from the back of the patient's hip bone.

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

Bone Marrow Aspiration and Biopsy

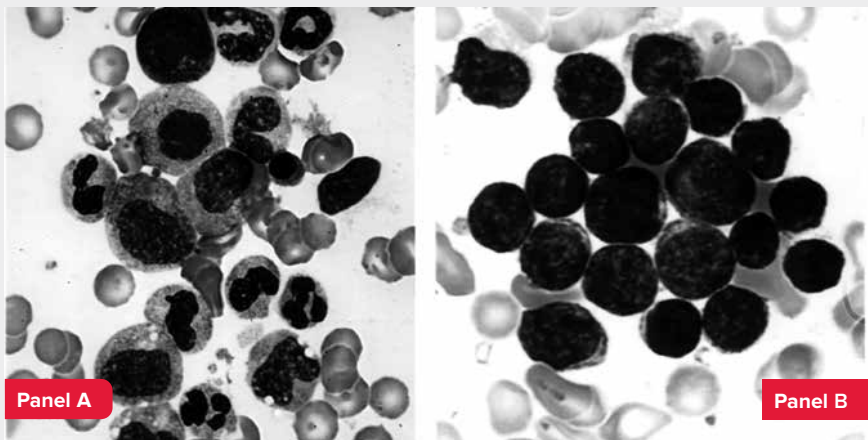


Left: The place on the back of the patient's hip bone where a bone marrow aspiration or biopsy is done. **Right:** One needle goes into the bone marrow to get a liquid sample for aspiration (the needle on the left) and the other needle goes inside the bone for a bone marrow biopsy (the needle on the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

Blood and bone marrow tests may be done during and after treatment. The tests are repeated to see if treatment is working.

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

Acute Lymphoblastic Leukemia (ALL) Cells



Panel A shows a photograph of developing cells in healthy bone marrow. The variation in the appearance of the cells is characteristic of normal bone marrow. **Panel B** shows a photograph of bone marrow cells from a patient with acute lymphoblastic leukemia. An unvaried appearance characterizes the leukemic blast cells.

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

- **Immunophenotyping**—This test is used to identify cells based on the types of proteins on the cell surfaces. It can help determine whether a person has B-cell ALL or T-cell ALL and the subtype of ALL. This test can also be used to see if there are any residual cancer cells remaining in the body after treatment called **measurable residual disease (MRD)**. For more information on MRD, see page 21.
- **Cytogenetic Analysis (Karyotyping)**—Each cell in the body has chromosomes that carry genes. Genes give the instructions that tell each cell what to do. Cytogenetic analysis is used to look for abnormal changes in the chromosomes of leukemia cells. The results of this test help your doctor identify your ALL subtype and plan your treatment.
- **Fluorescence In Situ Hybridization (FISH)**—This test is used to look at the genes or chromosomes in cells and tissues. Doctors use this test to find changes in chromosomes and genes in the leukemia cells.
- **Polymerase Chain Reaction (PCR)**—This test finds and measures some genetic mutations and chromosome changes that are too small to be seen, even with a microscope. PCR is also used to test for MRD.

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

WANT MORE INFORMATION?



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

Subtypes of ALL

There are many different subtypes of ALL, each caused by different genetic abnormalities (gene or chromosome changes) in the leukemia cells. It is important to know your ALL subtype because it can affect both your prognosis (outlook) and your treatment plan. For example, people with the Philadelphia chromosome-positive ALL subtype have tyrosine kinase inhibitors (TKIs), a type of medication, added to their treatment.

If you are not sure of your ALL subtype, ask your doctor what it is and to explain how your ALL subtype affects your treatment.

The World Health Organization (WHO) is the main system used to divide ALL into subtypes. For a comprehensive list of the WHO classification system of ALL subtypes, please see the free LLS booklets *Acute Lymphoblastic Leukemia in Adults* and *Acute Lymphoblastic Leukemia in Children and Teens* at www.LLS.org/booklets, or call an LLS Information Specialist.



Write down your ALL subtype here: _____

Tracking Your ALL 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 at the 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.

PART 2 TREATMENT

Overview

- People with ALL should choose a doctor who specializes in treating ALL. This type of doctor is called a **hematologist-oncologist**.
- Ask questions about your treatment choices and do not be afraid to be involved in making decisions about your own care. See the *Treatment & Follow-Up Care Question Guide* on pages 47-50.
- 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 ALL, talk with the doctor about which treatments may cause problems with fertility and what choices you have.
- The first round of treatment with chemotherapy is called **induction**. Most patients with ALL need to start induction right away. Induction is 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. An oncologist is a doctor who has special training in cancer. A hematologist-oncologist specializes in diagnosing and treating blood cancers. A **pediatric hematologist-oncologist** specializes in diagnosing and treating children with blood cancer.

If your local medical center does not have a hematologist-oncologist, ask your local cancer specialist to consult with a hematologist-oncologist

at another medical center. Always check to see if your health insurance covers the services of the doctors (and the hospitals associated with them), or 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 Society of Hematology's (ASH) "Find a Hematologist" online at <http://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 45-50 for a full list of questions.

1. How many patients have you treated with 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 Specialist or Treatment Center* at www.LLS.org/booklets, or call an LLS Information Specialist at (800) 955-4572 for a copy or to ask other questions.

Ask Your Doctor

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

When you meet with your doctor:

- Ask questions. Below are a few questions to ask. See pages 45-50 at the end of this Guide for a full list of questions. Visit www.LLS.org/WhatToAsk to find other “What to Ask” healthcare question guides.
 - What are my treatment choices?
 - Are there any clinical trials that I can join?
 - When do you think I should begin treatment?
 - How long will treatment last?
- Take notes. It may be helpful to write down the answers to your questions and review them later.
- Audio record information from the doctor and then listen to the recording later. Ask the doctor and staff if recording is allowed (cell phones have a “record” function; ask someone how to use it).
- Bring a caregiver, friend or family member who can listen to the doctor along with you, 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 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 should also check with your insurance to ensure that a second opinion will be covered.

Before-Treatment Considerations

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 can affect fertility.

Here are some questions you may want to ask your healthcare team. See pages 45-50 for a full list of questions.

1. Will this treatment affect my (our) 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 and Cancer* at www.LLS.org/booklets, or call an LLS Information Specialist at (800) 955-4572 for a copy or to ask other questions.

Prognostic Factors. Certain factors can affect a patient's "prognosis," which is the likely outcome of their disease. Doctors use "prognostic factors" to help predict how a patient's disease is likely to respond to treatment.

Prognosis and treatment options may depend on the following factors:

- Patient age
- Number of white blood cells in the blood at the time of diagnosis
- ALL subtype
- Changes in the chromosomes and/or genes in the leukemia cells
- Response to induction (initial treatment)
- Whether leukemia cells are found in the central nervous system (brain and spinal cord)

About ALL Treatments

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

Before you begin treatment, you and your doctor will discuss your treatment options. One option may be a clinical trial. Like all treatment options, clinical trials have possible risks and benefits. It is important to talk to your doctor about all your treatment options.

Not everyone with ALL receives the same type of treatment. Treatment may include:

- Chemotherapy
- Immunotherapy
- Stem cell transplantation
- CAR T-cell therapy

A patient may receive different drugs from those described in this booklet. This may still be considered proper treatment. Speak to 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 45-50 for a full list of questions.

1. What is my ALL 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 there one treatment recommended over others?

Phases of Treatment. Treatment for ALL is usually long-term chemotherapy. Chemotherapy drugs kill or damage cancer cells. Different types of chemotherapy drugs work in different ways to kill leukemia cells so often more than one chemotherapy drug is given.

Treatment for ALL is often divided into 3 phases:

- Induction

- Consolidation
- Maintenance

Children and some young adults with ALL often have additional phases of treatment. For more information, see *ALL Treatment in Children* and *ALL Treatment in Adolescents and Young Adults (AYA)* on page 24.

Consolidation and maintenance treatments are given once the patient has achieved a remission and are called **postremission therapies**. These are described beginning on page 21.

Induction. The first phase of treatment is called **induction**. The goal of induction is to destroy as many leukemia cells as possible in the blood and bone marrow in order to induce (achieve) a remission.

Most ALL patients need to start induction right away. Induction is usually done in the hospital, and patients are often in the hospital for 4 to 6 weeks.

Induction chemotherapy generally uses a combination of drugs that include **vincristine**; an anthracycline (**daunorubicin** or **doxorubicin**); and a corticosteroid (**prednisone** or **dexamethasone**). The doctor may add additional drugs to induction based on a patient's risk group.

For patients with Philadelphia chromosome-positive ALL, a tyrosine kinase inhibitor (TKI) is often also included with the chemotherapy. For more information on Philadelphia chromosome-positive ALL, see page 23.

During induction, patients also receive treatment to prevent ALL from spreading to the central nervous system. This is called **CNS-directed treatment**. For more information, see *Central Nervous System (CNS)-Directed Therapy* on page 20.

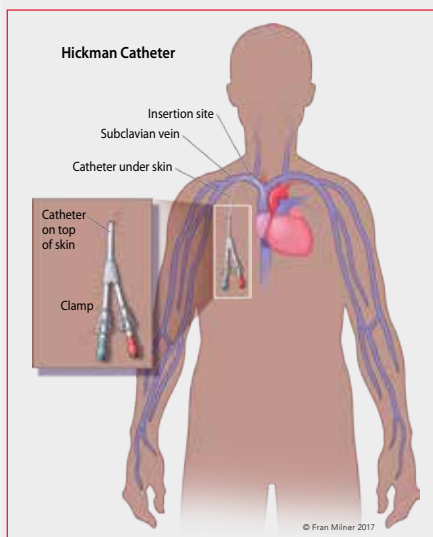
Some drugs are given orally (by mouth). Other drugs are inserted directly into the patient's body through a **central line**, a **port**, or a **PICC**. Central lines, ports, and PICCs can be used to give medications, nutrition and blood cells. These devices can be used in the reverse to take blood samples 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 how drugs will be given.

Central Lines, Ports and PICCs

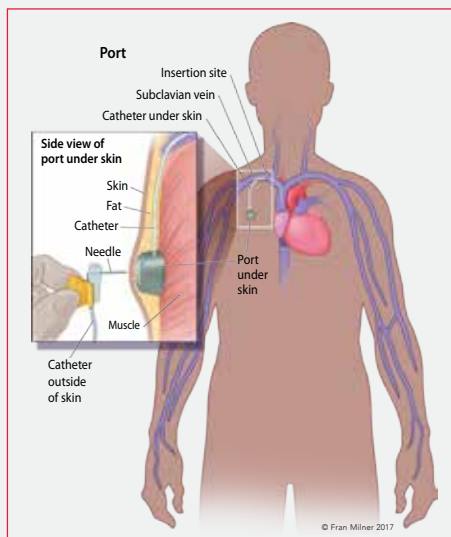
Central Line (catheter)—A thin tube that is put under the skin and into a large vein in the chest. The central line stays firmly in place. “Indwelling catheter” is another word for central line.

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: An example of a type of central line.



Port: A port used with a central line.

Some Drugs Used to Treat ALL

These are some of the standard ALL drugs used. Some drugs under study in ALL clinical trials are also listed.

Drug Types	Drug Names
Antimetabolites	○ 6-mercaptopurine (6-MP, Purinethol®, Purixan®) ○ 6-thioguanine (thioguanine, Tabloid®) ○ cytarabine (cytosine arabinoside, Ara-C, Cytosar-U®) ○ methotrexate (Abitrexate®, Trexall®) ○ nelarabine (Arranon®)
Anthracyclines	○ daunorubicin (Cerubidine®) ○ doxorubicin (Adriamycin®)
Alkylating Agent (DNA-Damaging Drug)	○ cyclophosphamide (Cytoxan®)
Plant Alkaloid	○ vincristine (Oncovin®)
Enzyme Therapies	○ asparaginase Erwinia chrysanthemi (Erwinaze®) ○ calaspargase pegol-mknl (Asparlas®) ○ pegaspargase (PEG-L-asparaginase, Oncaspar®)
Tyrosine Kinase Inhibitors (TKIs)	○ bosutinib (Bosulif®) ○ dasatinib (Sprycel®) ○ imatinib (Gleevec®) ○ nilotinib (Tasigna®) ○ ponatinib (Iclusig®)
Corticosteroids	○ dexamethasone ○ hydrocortisone ○ prednisone

Some Drugs Used to Treat ALL (continued)

Drug Types	Drug Names
Immunotherapies	○ blinatumomab (Blincyto®) ○ brexucabtagene autoleucel (Tecartus®) ○ inotuzumab ozogamicin (Besponsa®) ○ ofatumumab (Kesimpta®) ○ rituximab (Rituxan®) ○ tisagenlecleucel (Kymriah®)
Janus Kinase Inhibitor	○ ruxolitinib (Jakafi®)
Proteasome Inhibitor	○ Bortezomib (Velcade®)

Use the lines provided on page 44 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 or call (800) 955-4572.

Central Nervous System (CNS)-Directed Therapy. ALL can spread to the central nervous system (the brain and spinal cord). A **lumbar puncture** (also called a spinal tap) is used to check the spinal fluid for ALL cells. Even if ALL cells are not found in the spinal fluid, patients are still treated to prevent the spread of leukemia cells to the central nervous system. CNS-directed therapy is typically given to all patients throughout the entire course of ALL therapy, from induction, to consolidation, through maintenance.

Some patients have chemotherapy injected directly into the spinal canal. This is called **intrathecal chemotherapy**. Some patients receive **systemic chemotherapy** in which the drugs are given through a vein.

Other patients may receive radiation therapy to the brain. In most practices, doctors do not routinely use cranial (to the head) radiation except in patients who already have leukemia cells in their central nervous system. In addition, some regimens for T-cell ALL still use cranial radiation, although this is becoming less common. When radiation therapy is used, the chance of long-term side effects is higher.

Visit www.LLS.org/3D and click on "Lumbar Puncture" and "Intrathecal Therapy" to view interactive 3D images that will help you visualize and better understand these procedures.

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

If you are in remission, you will continue on to the next phase of treatment called "consolidation." If you are not in remission, another course of chemotherapy is usually given.

Even if you have achieved a remission, some leukemia cells may still remain in the body that cannot be seen with a microscope. This is called **measurable residual disease (MRD)**. MRD is not found by common blood or bone marrow tests. MRD tests use highly sensitive methods to detect small amounts of cancer cells in the blood or bone marrow.

When a patient tests positive for MRD, it means that residual cancer cells were found. When a patient tests negative for MRD, no residual cancer cells were found. Patients who have achieved a remission after induction but are MRD positive have an increased risk of the disease coming back. Testing for MRD can help doctors identify patients who may need more intense treatments.

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

WANT MORE INFORMATION?



You can view, print or order the free LLS booklet *Measurable Residual Disease* at www.LLS.org/booklets, or call an LLS Information Specialist at (800) 955-4572 for a copy or to ask other questions.

Consolidation. The second phase of treatment is called **consolidation**. Consolidation starts once ALL is in remission. The goal of consolidation is to kill any remaining leukemia cells.

Consolidation treatment is often based on whether the patient is MRD positive after induction. For patients with B-cell ALL who are MRD positive, **Blinatumomab (Blincyto®)** is often the recommended treatment.

For patients who are MRD negative after induction, consolidation is typically combination chemotherapy. Depending on the treatment regimen used, consolidation chemotherapy may use different drugs than those given during induction or some of the same drugs.

As part of consolidation therapy, some patients in remission may receive a stem cell transplantation.

Stem Cell Transplantation. Some people with ALL may benefit from stem cell transplantation. Your doctor will talk to you about whether stem cell transplantation is a treatment option for you.

There are two types of stem cell transplantation, one that uses replacement blood stem cells from a donor (**allogeneic transplant**) and one that 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 ALL.

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

- The patient's ALL subtype
- If the patient is not doing well with other treatments
- If the expected benefits of a transplant exceed the risk
- The patient's age
- The patient's physical ability to have the transplant
- If there is an available stem cell donor

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. Talk to your doctor about whether a stem cell transplant is a possible treatment.

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

- Stem cells are collected from a donor, frozen and stored.
- 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 making a new supply of red blood cells, white blood cells and platelets.

For patients who may not be able to withstand the high doses of chemotherapy that are given to patients during stem cell transplant, there is another type of allogeneic stem cell transplant. **Reduced-intensity allogeneic stem cell transplant** uses lower doses of chemotherapy than a standard allogeneic transplant. Some older or sicker patients may be helped by this treatment.

WANT MORE INFORMATION?



You can view, print or order the free LLS booklet *Blood and Marrow Stem Cell Transplantation* at www.LLS.org/booklets. Or call an LLS Information Specialist at (800) 955-4572 for copies or to ask other questions.

Maintenance. The third phase of treatment is called **maintenance**. It is the final, and longest, stage of treatment. It usually lasts for about 2 years. The goal of maintenance is to prevent relapse. Patients receive lower doses of chemotherapy drugs and, as a result, tend to have less-severe side effects. Most maintenance therapy regimens include **6-mercaptopurine**, **methotrexate**, **vincristine** and corticosteroids.

Philadelphia Chromosome-Positive ALL

About 25 percent of adults with ALL have a subtype called **Philadelphia chromosome-positive ALL** (also known as Ph-positive ALL or Ph+ ALL). The ALL cells of these patients have a genetic abnormality known as the Philadelphia chromosome. A small number of children (2 to 4 out of 100 children) with ALL have Ph-positive ALL.

Patients with Ph-positive ALL are usually treated with a type of targeted therapy called a tyrosine kinase inhibitor (TKI). TKIs are pills taken by mouth. They are generally not used alone to treat ALL. Instead, they

are added to other medications, such as a combination chemotherapy regimen. TKIs used in the treatment of Ph-positive ALL include **bosutinib (Bosulif®)**, **dasatinib (Sprycel®)**, **imatinib (Gleevec®)**, **nilotinib (Tasigna®)** and **ponatinib (Iclusig®)**.

ALL Treatment in Children

ALL is the most common childhood cancer in the United States. Childhood ALL has one of the highest cure rates of all childhood cancers, approaching 90 percent for children younger than age 15.

Children usually receive treatments that are more intense than those given to adults. They also receive treatments for longer periods of time than adults.

Typical treatment for children with ALL involves a multi-drug chemotherapy regimen that is often into five phases: induction, consolidation, interim maintenance, delayed intensification and maintenance. Children with high-risk disease may have additional phases of treatment. In addition, all children are given CNS-directed therapy throughout the entire course of treatment, from induction through maintenance. For more information on CNS-directed therapy, see page 20.

ALL Treatment in Adolescents and Young Adults (AYA)

The term "AYA population" generally refers to older adolescents and young adults age 15 to 39 years. Traditionally, treatment for this group has been similar to adult treatment. However, a number of cancer centers are now using pediatric protocols to treat young adult patients. Researchers have found that young adult patients treated on pediatric protocols have improved rates of survival compared with young adult patients treated on adult ALL regimens.

WANT MORE INFORMATION?



You can view, print or order the free LLS book *Acute Lymphoblastic Leukemia in Children and Teens* and *Caring for Kids and Adolescents with Blood Cancer* workbook at www.LLS.org/booklets. Or call an LLS Information Specialist at (800) 955-4572 for copies or to ask other questions.

Relapsed and Refractory ALL

Some ALL patients **relapse**. A relapse is the return of cancer after it has been in remission. Other patients have **refractory** ALL. Refractory ALL is cancer that does not respond to treatment.

For patients with relapsed or refractory ALL, treatment options may include:

- A clinical trial; see page 26 for more information on clinical trials
- New or different chemotherapy drugs or new combinations of chemotherapy drugs
- For patients with Philadelphia chromosome-positive ALL, a TKI may be given alone or as part of a chemotherapy regimen. If the TKI is part of a chemotherapy regimen, this regimen will usually be different from the one used during initial therapy. For some older patients who cannot tolerate chemotherapy, using a TKI along with a corticosteroid may be an option.
- **Nelarabine (Arranon®)** for patients with T-cell ALL
- **Bortezomib (Velcade®)**+ chemotherapy for patients with T-cell ALL
- **Blinatumomab (Blincyto®)**
- **Inotuzumab ozogamicin (Besponsa®)**
- Allogeneic stem cell transplantation (see page 22)
- CAR T-cell therapy (see below)

Chimeric Antigen Receptor (CAR) T-Cell Therapy. CAR T-cell therapy is a type of treatment that uses a person's own immune cells (T cells) to kill cancer cells. T cells are taken from a patient's blood and sent to a lab. There, the T cells are genetically modified to allow them to identify and attack cancer cells. The T cells are then returned to the patient's blood.

There are two FDA-approved CAR T-cell treatments approved for B-cell ALL:

- **Brexucabtagene autoleucel (Tecartus®)**
- **Tisagenlecleucel (Kymriah®)**

WANT MORE INFORMATION?



You can view, print or order the free LLS booklet *Chimeric Antigen Receptor (CAR) T-Cell Therapy* at www.LLS.org/booklets, or call an LLS Information Specialist at (800) 955-4572 for a copy or to ask other questions.

About Clinical Trials

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

There are clinical trials for:

- Patients newly diagnosed with ALL
- Patients who did not have a good response to treatment (refractory disease)
- Patients whose cancer 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 45-50 for a full list of questions.

1. Is a clinical trial a treatment option?
2. How can I find out if our 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 clinical 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 **LLS Clinical Trial Nurse Navigators** who will help search for clinical trials and personally assist through the entire clinical trial process. 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 call an LLS Information Specialist at (800) 955-4572 for copies or to ask other questions.

Overview

- Treatment side effects vary depending on the type of treatment. For example, the side effects of chemotherapy are different from the side effects of immunotherapies.
- Common side effects of treatment for ALL include low blood cell counts, mouth sores, nausea, diarrhea and hair loss.
- Treatment for ALL in children may cause 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 tested.
- Children and adults who have been treated for ALL should see their primary care doctor and a cancer specialist regularly for follow-up care.

Side Effects of ALL 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 ALL is to kill the leukemia cells. But treatment for ALL 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. Usually, side effects go away once treatment ends. Patients with ALL 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 45-50 for a full list of questions.

1. What are the common side effects of treatment?
2. What side effects should be reported to my 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. ALL and its treatment may cause low blood cell counts.

- Red blood cell counts may fall below normal. Red blood cell transfusions (red blood cells that are provided by a 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. Because platelets work to clot blood, 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 white blood cells may lead to an infection. These 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®** or **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 ALL. Patients at home should contact a doctor if any signs of infection develop. A temperature 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.
- The patient should take good care of their teeth and gums.
- Patients with ALL are advised to receive certain vaccinations for pneumococcal pneumonia and the inactivated ("dead") vaccine for the herpes virus, called Shingrix. For some children with ALL, 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 (TLS). Patients with ALL may be at high risk of developing a condition called **tumor lysis syndrome (TLS)**. This condition occurs when a large number of leukemia cells die within a short period of time, releasing their contents into the blood. This can cause a change in certain blood chemicals that may damage the kidneys and other organs.

TLS can be severe during the early phases of treatment, especially for patients who have very high white blood cell counts before starting induction therapy. If untreated, TLS can lead to heart arrhythmias, seizures, loss of muscle control, acute kidney failure and even death. Patients with leukemia who are at high risk for TLS may be given drugs, such as **allopurinol (Zyloprim®)** or **rasburicase (Elitek®)**, that prevent or lessen TLS.

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

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

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.

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 (filter by Side Effect Management) to view, print or order the full *Side Effect Management* series. Or call an LLS Information Specialist at (800) 955-4572 for copies or to ask other questions.

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 ALL may have:

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

Adults who are treated for ALL may have:

- Fertility problems
- Thyroid problems
- Trouble concentrating
- Persistent fatigue
- Risk of developing a second cancer
- Heart problems

Not everyone who is treated for ALL 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 45-50 for a full list of questions.

1. How can I be monitored for long-term and late effects of treatment?
2. What types of long-term and late effects should be brought to my healthcare team's attention?

WANT MORE INFORMATION?



Visit www.LLS.org/SurvivorshipWorkbook to find workbooks for adults, young adults, and children and adolescents, which contain sections on long-term and late effects.

Visit 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.

Visit www.LLS.org/booklets to view, print or order *Learning & Living with Cancer: Advocating for your child's educational needs*. Or, call an LLS Information Specialist at (800) 955-4572 for a copies or to ask other questions.

Follow-Up Care

Medical follow-up care is important for every ALL patient. Follow-up care helps the doctor see if ALL has relapsed, and evaluate for long-term and late effects.

Children and adults who have been treated for ALL should see their primary care doctors and their hematologist-oncologists (cancer specialists) regularly for follow-up care. Patients should talk with the 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 received them, so that your doctor can follow up on specific long-term and late effects that may be associated with your treatment. See page 44 for a place to list treatments.

Here are some questions you may want to ask your healthcare team. See pages 45-50 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 healthcare team?
3. What information can be provided to my primary care 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 if a patient:

- Continues to be free of signs and symptoms of ALL
- Does not need medical care for any long-term or late 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, talk to your healthcare team, or contact our Information Specialists.

WANT MORE INFORMATION?



For additional information about survivorship, visit www.LLS.org/SurvivorshipWorkbook to reach the children and adolescent, young adult and adult books called *Navigating Life During and After a Blood Cancer Diagnosis*.

Take Care of Yourself

- Keep all appointments with your doctor.
- Talk about how you feel with the doctor at each visit. Ask any questions you may have about side effects.
- People with ALL may have more infections than other people. Follow your doctor's advice for preventing infection.
- Eat healthy foods each day. It may help to eat 4 or 5 small meals instead of 3 big ones.
- Keep a record of your cancer diagnosis, treatment and follow-up care needs. This is often called a "survivorship care plan." Ask your doctor for a written survivorship care plan. Share this information with any new healthcare providers you see. The plan should include the following information:
 - List of all healthcare providers
 - Diagnosis summary with specifics such as subtype and/or genetic markers

- Treatment summary with specifics such as the names, dates, and dosages of drugs, site (on the body) of radiation treatment, surgery and/or transplantation information, response to treatment and side effects
- Maintenance treatment information, if applicable
- List of possible late effects
- Schedule for ongoing monitoring with recommended tests, frequency and coordinating provider
- Health and wellness recommendations such as nutrition, exercise or other disease screenings
- Contact the doctor about tiredness, fever or other symptoms.
- Do not smoke. Patients who smoke should get help to quit.
- Get enough rest and exercise. Talk with your doctor before 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 ALL 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 ALL. 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

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 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 and caregivers of all cancer types. Dietitians can assist with information about healthy eating strategies, side effect management and more. Please visit 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 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 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

Resources for Families. Blood cancer occurs in a small number of children. Families face new challenges, and the child, parents and siblings may all need support. LLS has many materials for families including a caregiver workbook, children's book series, an emotion flipbook, dry erase calendar, coloring books and a coloring app, a school re-entry program, and other resources.

For more information, please:

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

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 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 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 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 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 to find out more.

Connecting with Patients, Caregivers and Community Resources

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 and caregivers reach out and share information. Please visit 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

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 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 to view the directory.

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

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

World Trade Center Health Program. People involved in the aftermath of the 9/11 attacks and subsequently diagnosed with a blood cancer may be able to get help from the World Trade Center (WTC) Health Program. People eligible for help include:

- Responders
- Workers and volunteers who helped with rescue, recovery and cleanup at the WTC-related sites in New York City (NYC)
- Survivors who were in the NYC disaster area and those who lived, worked or were in school in that area
- Responders to the Pentagon and the Shanksville, PA, crashes

For more information, please

- Call: WTC Health Program at (888) 982-4748
- Visit: www.cdc.gov/wtc/faq.html

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, contact a mental health professional. 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

Anemia. A condition in which the number of red blood cells is below normal. Severe anemia can cause a pale complexion, weakness, tiredness and shortness of breath.

Antibiotic. A drug that is used to treat infections caused by bacteria or fungi.

Blast cell. Immature blood cell.

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

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

Central line. Special tubing the doctor puts into a large vein in the upper chest. This prepares a patient for chemotherapy treatment. The central line is used to give the patient chemotherapy drugs and blood cells. Blood samples also can be drawn from it. Also called an **indwelling catheter**.

Central nervous system (CNS)-directed treatment. 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. 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 research study that tests new ways to find, prevent and treat cancer. Clinical trials also help doctors improve quality of life for people with cancer by testing new ways to manage the side effects of cancer and cancer treatments.

Combination chemotherapy or drug therapy. The use of two or more drugs together to treat ALL and other cancers.

Consolidation. Treatment that is given after the cancer is in remission. Consolidation is used to kill any cancer cells that remain in the body.

Corticosteroid. A class of drugs that in high doses can kill leukemia cells.

Cytogenetic analysis. The examination of cells to look for changes in chromosomes. The results may be used to help diagnose disease and plan treatment.

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

Hematologist. A doctor who specializes in treating blood diseases.

Hemoglobin. The part of the red blood cell that carries oxygen throughout the body.

Immune system. Network of cells, tissues, and organs in the body that work together to defend the body against infections.

Immunophenotyping. A lab test that identifies cells based on the types of markers on the surface of the cells. It can be used to diagnose specific types of leukemia or lymphoma cells.

Immunotherapy. A type of treatment that uses the body's immune system to help fight cancer, infection and other diseases.

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

Leukemia. A cancer of the bone marrow and blood.

Lymph node. A bean-shaped organ that is part of the body's immune system. There are hundreds of lymph nodes throughout the body.

Maintenance. Treatment given to patients after induction and consolidation to prevent disease relapse.

Measurable residual disease (MRD). The very small number of cancer cells that remain in the body during or after treatment. MRD can be found only by highly sensitive lab tests.

Oncologist. A doctor who has special training in diagnosing and treating cancer.

Pathologist. A doctor who has special training in identifying diseases by studying cells and tissues under a microscope.

Polymerase chain reaction (PCR). 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.

Platelet. A blood cell fragment that helps prevent or stop bleeding.

Radiation therapy. Treatment with x-rays or other forms of radiation to treat cancer and other diseases.

Refractory cancer. Cancer that does not respond to treatment. Refractory disease may be a disease that is getting worse or staying the same even after treatment.

Relapse. A return of cancer after a period of improvement.

Remission. No signs or symptoms of cancer, usually following treatment.

Stem cell. A cell from which other types of cells develop. In the bone marrow, blood-forming stem cells mature into three major types of cells: red blood cells, white blood cells and platelets.

Targeted therapy. A type of treatment that uses drugs to target specific molecules that help cancer cells grow and survive.

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

MY HEALTHCARE TEAM CONTACT LIST

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

CAREGIVER NAME:

Address: _____

Phone Number/Fax number: _____

Email address: _____

Additional information: _____

PRIMARY CARE DOCTOR NAME:

Address: _____

Phone Number/Fax number: _____

Email address: _____

Additional information: _____

PHARMACY NAME:

Address: _____

Phone number/Fax number: _____

Additional information: _____

Information Specialists:

Phone: (800) 955-4572

Email and Live Chat: 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: _____

DATE: _____

Treatment: _____

DATE: _____

Treatment: _____

DATE: _____

Treatment: _____

QUESTION GUIDE: MY FIRST DOCTOR'S VISIT

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

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

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

Questions for the Doctor

DOCTOR'S NAME: _____

Date of appointment or phone call: _____

1. How many patients have you treated who have my 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 & FOLLOW-UP CARE

Talk with the doctor and ask questions about how they plan to treat your (your loved one's) leukemia. This will help you and your loved one to be actively involved in making decisions about medical care. The following are questions you may want to ask your healthcare team.

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

DOCTOR'S NAME: _____

Date of appointment or phone call: _____

Write down your diagnosis:

Write down your ALL subtype:

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 back?
3. How are the results communicated to me (us)?
4. How often will testing be needed?
5. Where will the testing be done?

Treatment

1. Will this be an in-hospital or an outpatient treatment?
If the treatment is outpatient:
 - Is it 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 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 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 I have side effects later, how can the healthcare team be reached?
6. What information can be provided to my primary doctor about past treatment and what may be needed in the future?

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

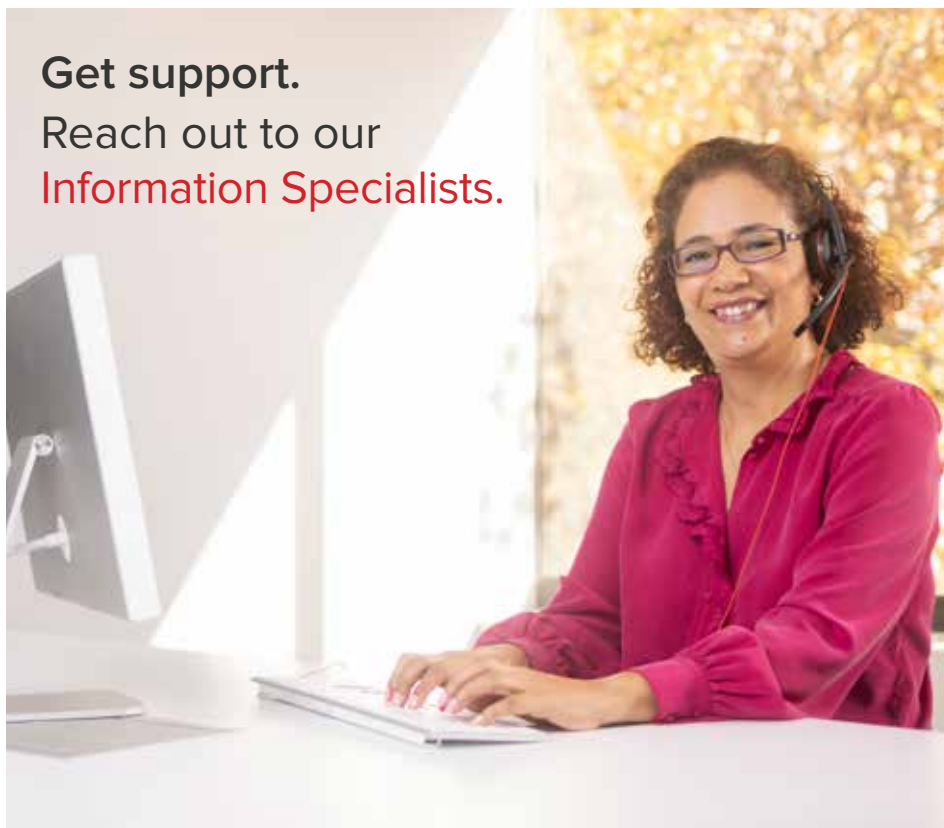
NOTES

This image shows a single sheet of white paper with horizontal ruling lines. The lines are evenly spaced and run across the width of the page. There are no margins, text, or other markings on the paper.

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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-trial 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.