LEUKEMIA & LYMPHOMA SOCIETY®

PROVIDING THE LATEST INFORMATION FOR PATIENTS & CAREGIVERS

The ALL Guide: Information for Patients and Caregivers

Revised **2022**

Support for this publication provided by Autolus Takeda ONCOLOGY

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.**

Inside This Guide

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

INTRODUCTION

Acute lymphoblastic leukemia (ALL) is a type of blood cancer. Other names for ALL are "acute lymphocytic leukemia" and "acute lymphoid leukemia." People of any age can develop ALL.

- About 6,660 people in the United States were expected to be diagnosed with ALL in 2022.
- About 77,711 people in the United States were living with or in remission from ALL as of 2018.

Advances in the treatment of ALL have resulted in improved remission and cure rates. But much work remains to be done. Researchers continue to study and develop new treatments in clinical trials for patients with ALL.

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

Visit www.LLS.org/booklets to view, download or oder all the free LLS publications mentioned in this book.

WANT MORE INFORMATION?

You can view, print or order the free LLS books *Acute Lymphoblastic Leukemia in Adults* and *Acute Lymphoblastic Leukemia in Children and Teens* at www.LLS.org/booklets or contact our Information Specialists for copies.

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

PART 1 ACUTE LYMPHOBLASTIC LEUKEMIA

Overview of This Section

- 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 are made in the bone marrow. They begin as stem cells. Stem cells normally develop into healthy red blood cells, white blood cells or 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.

About Bone Marrow, Blood and Blood Cells

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

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

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

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

White blood cells fight infection in the body. There are two major types of white blood cells:

1. Lymphocytes are infection-fighting cells. There are 3 types of lymphocytes:
   - B cells
   - T cells
   - NK (natural killer) cells
2. 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 blood cell 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

- 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 that is made up of different types of white blood cells
- The types of white blood cells counted are neutrophils, lymphocytes, monocytes, eosinophils and basophils
- In the white blood cell count, adults usually have about 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.

ALL is a type of blood cancer that begins in the bone marrow. A person can get ALL at any age. The overall risk of getting ALL is low for both children and adults. However, ALL remains the most common type of cancer in children younger than age 20.

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

- A normal stem cell mutates (changes into an ALL cell)
- The mutated cell multiplies into many ALL cells

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 Fanconi anemia, Shwachman syndrome, Diamond-Blackfan Anemia (DBA) syndrome, Li-Fraumeni syndrome and Down 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 to develop ALL than females.
- 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:

- Aches in legs, arms or hips
- Black-and-blue marks for no clear reason
- Frequent infections
- Enlarged lymph nodes
- Fever without obvious cause
- Pale-looking skin
- Pinhead-sized red spots under the skin called **petechiae**
- Prolonged bleeding from minor cuts
- Shortness of breath during physical activity
- Tiredness or no energy
- 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 46-51 for 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 low-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. **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 and to help make treatment decisions.

The doctor uses information from these tests to help decide:

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

Visit www.LLS.org/3D and click on "Bone Marrow Biopsy and Aspiration" to view an interactive 3D image which 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 get 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.

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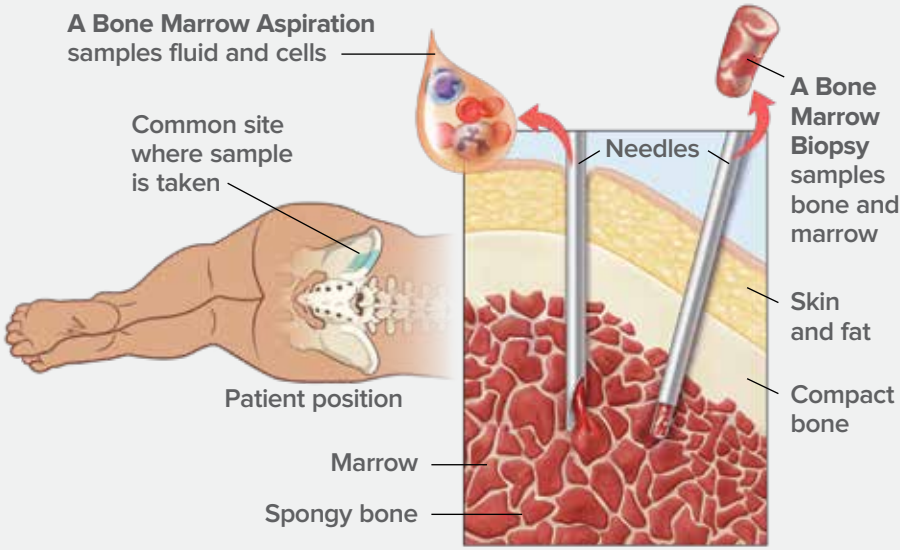
Bone Marrow Aspiration and Biopsy



Left: The place on the back of the patient's hip bone where a bone marrow aspiration or biopsy is done. **Right:** Where the needles go inside the bone to collect the liquid sample for aspiration (the needle on the left) and the bone sample (the needle on the right) for biopsy. The needles are different sizes for each of these tests.

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. The blood cells and bone marrow cells are stained (dyed) and examined under a microscope. A person with ALL usually has too many leukemic blast cells in the blood and bone marrow. Blast cells are immature (young) cells that do not function like normal mature white blood cells. The blood and bone marrow samples can also be used for additional tests, explained below.

- **Immunophenotyping**—This test is used to identify cells based on the types of proteins on the cell surfaces. It can help determine the subtype of ALL, whether it is B-cell ALL or T-cell ALL.
- **Cytogenetic Analysis (Karyotyping)**—Each cell in the body has chromosomes that carry genes. Genes give the instructions that tell each cell what to do. In many cases of ALL, the chromosomes of leukemia cells have abnormal changes that can be seen under the microscope. 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. This allows doctors to determine the amount of minimal/measurable residual disease (MRD), which is the small amount of cancer cells left in the body after treatment.
- **DNA 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.

WANT MORE INFORMATION?

You can view, print or order the free LLS books *Understanding Lab and Imaging Tests* and *Understanding Genetics*. Go to www.LLS.org/booklets or contact our Information Specialists for copies.

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 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.

PART 2 TREATMENT

Overview of This Section

- 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 and Follow-Up Care Question Guides* on pages 48-51.
- 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 therapy**. Most patients with ALL need to start induction chemotherapy right away. Induction therapy 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, and 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 the cancer specialist you see if they can consult with a hematologist-oncologist at another medical center. Always check to see if your health insurance covers the services of the doctors (and the 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 Medical Association's (AMA) "DoctorFinder" online at https://apps.ama-assn.org/doctorfinder/
  - 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 46-51 for a full list of questions.

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

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

WANT MORE INFORMATION?

You can view, print or order the free LLS fact sheet *Choosing a Blood Cancer Specialist or Treatment Center Facts* at www.LLS.org/booklets, or you can contact our Information Specialists for a copy.

Ask Your Doctor

Talk with the doctor and ask questions about how they plan to treat your leukemia. This will help you 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 46-51 at the end of this book 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 treatment should begin?
  - 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 you can record the conversation (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 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 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 could affect fertility.

Here are some questions you may want to ask your healthcare team. See pages 46-51 for a full list of questions in this Guide.

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.

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 therapy (initial treatment)
- Whether leukemia cells are found in the central nervous system (brain and spinal cord)

Write down your ALL subtype here: _____

About ALL Treatments

New treatments may have been approved since this book 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
- Targeted therapy
- Immunotherapy
- Stem cell transplantation
- CAR T-cell therapy

A patient may receive different drugs from those described in this Guide. 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 46-51 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 therapy
- Consolidation therapy
- Maintenance therapy

Children and some young adults with ALL often have additional phases of treatment, and the treatments are given for longer periods of time. For more information, see *ALL Treatment in Children* on page 24 and *ALL Treatment in Older Adolescents and Young Adults (AYA)* on page 25.

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 Therapy. Induction therapy is the first round of treatment with chemotherapy. Most ALL patients need to start induction chemotherapy right away. Induction therapy is usually done in the hospital.

Patients are often in the hospital for four to six weeks.

The goals of induction therapy are to:

- Kill as many ALL cells as possible
- Get blood counts back to normal
- Get rid of all signs and symptoms of ALL for an extended period of time

For patients with Philadelphia chromosome-positive (Ph+ ALL), a tyrosine kinase inhibitor (TKI) is often also included with the chemotherapy. For more information on Ph+ ALL, see page 24.

Some Induction Therapy Drugs for ALL and How They Are Given

Name of Drug	How Administered
Daunorubicin (Cerubidine®) or **doxorubicin (Adriamycin®)**	IV injection via central line*, port* or PICC*
Vincristine (Oncovin®)	IV injection via central line, port or PICC
Dexamethasone or **prednisone** (corticosteroids)	Oral (by mouth)
Pegaspargase (PEG-L asparaginase; Oncaspar®)	IV injection via central line, port or PICC or by intramuscular (into the muscle) injection
Cyclophosphamide (Cytoxan®)	IV injection via central line, port or PICC or oral (by mouth)

*See below and page 18 for an explanation of these terms.

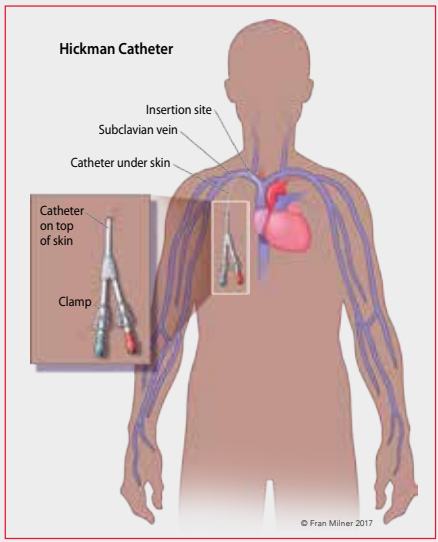
Some drugs are given orally (by mouth). Other drugs are inserted directly into the patient's body through a **central line**, a **port**, or a **PICC**. Central lines, ports, and PICCs can be used to give medications, nutrition and blood cells. These devices can be used in the reverse to take blood samples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

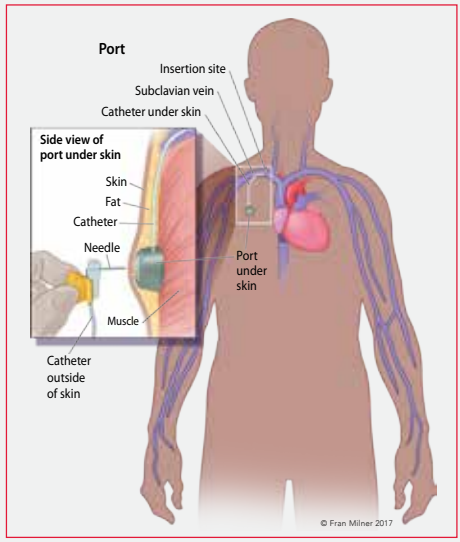
Central Line (catheter) — A thin tube that is put under the skin and into a large vein in the chest. The central line stays firmly in place. "Indwelling catheter" is another word for central line.

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	○ clofarabine (Clolar®) ○ cytarabine (cytosine arabinoside, Ara-C; Cytosar-U®) ○ fludarabine (Fludara®) ○ 6-mercaptopurine (6-MP, Purinethol®, Purixan®) ○ methotrexate (Xatmep®; Abitrexate®, Trexall®) ○ nelarabine (Arranon®) ○ 6-thioguanine (thioguanine; Tabloid®)
Anthracyclines	○ daunorubicin (Cerubidine®) ○ doxorubicin (Adriamycin®) ○ mitoxantrone (Novantrone®)
DNA Repair Enzyme Inhibitor	○ etoposide (VP-16; VePesid®, Etopophos®)
Alkylating Agents (DNA-Damaging Drugs)	○ cyclophosphamide (Cytoxan®)
Drugs That Prevent Cells From Dividing	○ vincristine (Oncovin®) ○ vincristine sulfate liposome (Marqibo®)
Enzymes That Prevent Cells From Surviving	○ asparaginase Erwinia chrysanthemi (Erwinaze®, Rylaze™) ○ calaspargase pegol-mknl (Asparlas™) ○ pegaspargase (PEG-L-asparaginase, Oncaspar®)

Some Drugs Used to Treat ALL (continued)

Drug Types	Drug Names
Tyrosine Kinase Inhibitors (TKIs)	○ bosutinib (Bosulif®) ○ dasatinib (Sprycel®) ○ imatinib (Gleevec®) ○ nilotinib (Tasigna®) ○ ponatinib (Iclusig®)
Corticosteroids	○ dexamethasone ○ hydrocortisone ○ prednisone
Immunotherapies	○ blinatumomab (Blincyto®) ○ brexucabtagene autoleucel (Tecartus®) ○ inotuzumab ozogamicin (Besponsa®) ○ rituximab (Rituxan®) ○ tisagenlecleucel (Kymriah®)
Janus Kinase Inhibitor	○ ruxolitinib (Jakafi®)

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

Use the lines provided on page 45 to list your treatments and when you took them.

Central Nervous System (CNS) Prophylaxis. 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. It can be given to all patients throughout the entire course of ALL therapy, from induction, to consolidation, to the maintenance phase.

The spinal cord and brain are hard to reach with chemotherapy that is given through a vein in the arm. Some patients have chemotherapy injected right 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 spine and brain. In most practices, doctors do not use cranial (to the head) radiation for children except in patients who already have leukemia cells in their central nervous system. 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 which will help you visualize and better understand these procedures.

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

If you are not in remission, another course of chemotherapy is usually given, often using different drugs.

Even when you have achieved a complete remission, some leukemia cells may still remain in the body that cannot be seen with a microscope. This is called **minimal/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.

In patients who achieve a complete remission after induction therapy, the presence of MRD means they have an increased risk of relapse. **Blinatumomab (Blincyto®)** is approved by the U.S. Food and Drug Administration (FDA) to treat adults and children with B-cell ALL who are in remission but still have MRD.

WANT MORE INFORMATION?

You can view, print or order the free LLS booklet *Minimal/ Measurable Residual Disease* at www.LLS.org/booklets, or contact our Information Specialists for a copy.

Postremission Therapy. Postremission therapy refers to ALL treatments given to patients after their disease is in a complete **remission**. Even after a patient with ALL is in remission, more treatment is usually needed because some leukemia cells are likely still in the body. Postremission therapy consists of **consolidation therapy** and **maintenance therapy**.

Consolidation therapy is typically combination chemotherapy. Depending on the treatment regimen used, consolidation therapy may contain different drugs than those used during induction. For others, the drugs used during consolidation are the same as the ones used during induction.

As part of consolidation therapy, some patients in remission may receive an allogeneic stem cell transplant. Allogeneic transplants are explained in the section on *Stem Cell Transplantation* below.

The third phase of treatment is maintenance. The goal of maintenance therapy is to prevent relapse. Patients receive lower doses of chemotherapy drugs and some medications orally (by mouth). Most maintenance therapy regimens include **6-mercaptopurine, methotrexate, vincristine** and corticosteroids.

Some Consolidation and Maintenance Therapies

- Vincristine, by intravenous (IV) infusion
- Prednisone or dexamethasone, by mouth
- 6-mercaptopurine, by mouth
- Methotrexate, by mouth, IV, or injection into the spinal fluid
- Cytarabine, by IV or injection into the spinal fluid
- Cyclophosphamide, by IV injection
- Pegaspargase, by IV or by intramuscular injection
- Central nervous system prophylaxis therapy

Stem Cell Transplantation. This is a procedure in which patients receive healthy stem cells to replace their own stem cells that have been destroyed by cancer or cancer treatments. The goal of stem cell transplant is to help the body start a new supply of blood cells after the patient receives high-dose chemotherapy.

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**).

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 serous 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. 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 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, with or without radiation therapy, to kill the leukemia 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 bone marrow and begin 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** (also called a **nonmyeloablative transplant**) uses lower doses of chemotherapy than a standard allogeneic transplant. Some older or sicker patients may be helped by this treatment. Talk to your doctor about whether stem cell transplant might work for you.

Autologous Stem Cell Transplantation. An autologous transplant uses the patient's own stem cells, but this type of transplant is not commonly used to treat ALL. This is because of the high relapse rate following this type of transplant in patients with ALL. Your doctor will talk with you about whether an autologous transplant is a treatment option for you.

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.

Ph-Positive ALL

About one out of four adults with ALL has a type called **Ph-positive ALL**. A small number of children (2 to 4 out of 100 children) with ALL have Ph-positive ALL. Ph stands for Philadelphia chromosome, a genetic abnormality.

Patients with Ph-positive ALL are usually treated with a type of drug called a tyrosine kinase inhibitor (TKI) combined with chemotherapy. 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+ ALL include **imatinib (Gleevec®)**, **dasatinib (Sprycel®)**, **ponatinib (Iclusig®)**, **bosutinib (Bosulif®)**, and **nilotinib (Tasigna®)**.

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 more intense treatment 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 divided into 5 phases: induction, consolidation, interim maintenance, delayed intensification and maintenance. Children with high-risk disease may have additional phases of treatment.

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 contact our Information Specialists for copies.

ALL Treatment in Older Adolescents and Young Adults (AYA)

The term "AYA population" generally refers to older adolescents and young adults aged 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.

ALL Treatment in Adults

Today, cures are possible for some adults with ALL. But treatment results in adults are not as positive as treatment results in children. ALL in adults is more resistant to treatment than ALL in children. Older adults may have other medical problems, so a doctor may choose less-toxic drugs, or decrease the dosage and frequency of treatment. Older adults may want to consider a clinical trial as a treatment option. See *About Clinical Trials* on page 27 for more information.

WANT MORE INFORMATION?

You can view, print or order the free LLS book *Acute Lymphoblastic Leukemia in Adults* at www.LLS.org/booklets. Or contact our Information Specialists for a copy.

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 27 for more information on clinical trials
- New or different chemotherapy drugs or new combinations of chemotherapy drugs
- For patients with Ph+ ALL, a TKI may be given alone or as part of a chemotherapy regimen. In some cases, the TKI may be combined with a corticosteroid. 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** for patients with T-cell ALL
- **Blinatumomab (Blincyto®)**
- **Inotuzumab ozogamicin (Besponsa®)**
- Allogeneic stem cell transplantation
- CAR T-cell therapy (see below)

Chimeric Antigen Receptor (CAR) T-Cell Therapy. CAR T-cell therapy is a type of treatment in which a patient's T cells, a type of white blood cell, are removed from a patient and changed in the lab so they will attack cancer cells. The programmed T cells are then returned to the patient's body to find and kill cancer cells.

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

- **Brexucabtagene autoleucel (Tecartus®)**, indicated for the treatment of adult patients with relapsed or refractory B-cell ALL
- **Tisagenlecleucel (Kymriah®)**, indicated for the treatment of patients up to 25 years of age with B-cell ALL with relapsed or refractory ALL

WANT MORE INFORMATION?

You can view, print or order the free LLS booklet *Chimeric Antigen Receptor (CAR) T-Cell Therapy Facts* at www.LLS.org/booklets, or contact our Information Specialists for a copy.

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:

- Newly diagnosed ALL patients
- 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 46-51 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 and help search for a clinical trial for you. Clinical trials can be difficult to navigate and figure out, but The Leukemia & Lymphoma Society is here to help. Patients and caregivers can work with **Clinical Trial Nurse Navigators** who will help find potential clinical trials. Visit www.LLS.org/CTSC to learn more about this service.

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. For example, the side effects of chemotherapy are different from the side effects of targeted therapies.
- Common side effects of treatment for ALL include mouth sores, nausea, diarrhea, hair loss, and changes in blood counts.
- 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 the 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 46-51 for 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 (this is called **anemia**). 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 the 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. 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 cancer cells die within a short period of time, releasing their contents into the blood. TLS can be severe during the early phases of treatment, especially for patients who have very high white blood cell counts before starting induction therapy.

TLS happens when leukemia cells die, break apart and release their contents into the blood. This can cause a change in certain blood chemicals that may damage the kidneys and other organs. If untreated, TLS can lead to heart arrhythmias, seizures, loss of muscle control, acute kidney failure and even death. Patients with leukemia who are at high risk for TLS may be given drugs, such as **allopurinol (Zyloprim®)** or **rasburicase (Elitek®)**, which prevent or lessen TLS.

Other Treatment Side Effects. Some other common side effects of treamtent 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 contact our Information Specialists for a copies.

Long-Term and Late Effects

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

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

Children who are treated for ALL may have:

- Growth problems
- Fertility problems (ability to have children later)
- 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

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 46-51 for 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 my healthcare team's attention?

WANT MORE INFORMATION?

You can view print or oder the free LLS book *Learning & Living with Cancer: Advocating for your child's educational needs* at www.LLS.org/booklets.

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.

Or, contact our Information Specialists for copies.

Follow-Up Care

Medical follow-up care is important for every ALL patient. Follow-up care helps the doctor see if disease has recurred or 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 45 for a place to list treatments.

Here are some questions you may want to ask your healthcare team.
See pages 46-51 for 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 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 the doctor.
- Discuss 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 the 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 chemotherapy or other 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 of the booklet lists various resources available to you. Use this information to learn more, to ask questions, and to make themost of your healthcare team.

For Help and Information

Consult with an Information Specialist. Information Specialists are highly trained 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 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. 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.

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.

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. Please visit www.LLS.org/HealthManager to download for free.

Children's Concerns. Parents of a child with leukemia may want to talk to members of their child's healthcare team about how to find enough time for everything, pay for treatment, and best help their children. Visit www.LLS.org/FamilyWorkbook to find additional information.

The Trish Greene Back to School Program for Children With Cancer. This program is designed to increase communication among healthcare professionals, school personnel, parents and patients to assure children with cancer a smooth transition back to school. For more information, visit www.LLS.org/BackToSchool or call (800) 955-4572.

LLS Coloring for Kids™. This free coloring app allows children (and adults) to express their creativity and offers activities to help them learn about blood cancer and its treatment. The app includes blank canvases, general coloring pages and pages from LLS coloring books. This app can be used anywhere and may help pass time in waiting rooms or during treatment. Visit www.LLS.org/ColoringApp to learn more and download.

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), local support groups and other great resources. For more information about these programs or to contact your chapter, please:

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

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

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. It also can remove blood samples. Also called **indwelling catheter**.

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

Chemotherapy. Treatment that stops the growth of cancer cells, either by killing the cancer cells or by stoping 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 careful study done by doctors for new drugs or treatments, or studies done to find new uses of approved drugs or treatments. The goals of clinical trials for blood cancers are to find cures, improve treatments and improve quality of life for patients.

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

Consolidation therapy. Treatment that is given to a cancer patient after the disease is in remission following induction therapy.

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.

Fluorescence in situ hybridization (FISH). A test to study abnormal genes and chromosomes in cells. This test can be used to plan treatment and to measure the results of treatment.

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.

Induction therapy. The first treatment given to treat ALL. The goal of induction therapy 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 therapy. Treatment given to patients after induction and consolidation therapy to prevent disease relapse.

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.

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

Plasma. The liquid part of the blood.

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

Postremission therapy. Treatment given to cancer patients who have achieved a remission after induction therapy. It is used to kill any cancer cells that may remain in the body after initial therapy.

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 or recurrence. A return of cancer after a period of improvement.

Remission. No sign of the disease, usually following treatment.

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

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:

   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 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

LEUKEMIA & LYMPHOMA SOCIETY®

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

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

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

Contact us at
800-955-4572 or
www.LLS.org/informationspecialists
(Language interpreters can be requested)

LEUKEMIA & LYMPHOMA SOCIETY®

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.

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