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.
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 the most common type of leukemia in children.

Advances in the treatment of ALL have resulted in improved remission rates. The number of patients with ALL who have gone into remission or have been cured increases each year.

- About 5,960 people in the United States were expected to be diagnosed with ALL in 2018.
- About 78,275 people in the United States are living with or are in remission from ALL as of 2014.

WANT MORE INFORMATION?

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

Drugs may have been approved since this book was printed. Check www.LLS.org/DrugUpdates or call (800) 955-4572.
PART 1 Acute Lymphoblastic Leukemia

Overview of This Section

○ Blood cells are made in the bone marrow. They begin as stem cells. Stem cells develop while still in the bone marrow, and they become red blood cells, white blood cells or platelets. Then they leave the marrow and enter the bloodstream.

○ Acute lymphoblastic leukemia (ALL) starts with a change to a single cell in the bone marrow.

○ If you are diagnosed with ALL, choose a doctor who specializes in treating it (a hematologist-oncologist).

○ A patient will have many tests to diagnosis ALL including blood tests, bone marrow tests and imaging (x-rays and scans) tests.

About Marrow, Blood and Blood Cells

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

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

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

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

Red blood cells carry oxygen around the body. When the number of red blood cells is below normal, a condition called anemia usually develops. Anemia may make you feel tired or short of breath. It may make your skin look pale.
White blood cells fight infection in the body. There are two major types of white blood cells:

- Lymphocytes, which are infection-fighting cells:
  - B cells
  - T cells
  - NK cells
- Germ-eating cells:
  - Neutrophils
  - Monocytes

Plasma is the liquid part of the blood. Although mostly water, plasma also has some vitamins, minerals, proteins, hormones and other natural chemicals in it.
Normal Blood Cell Count Fast Facts

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

**Red blood cell (RBC) count**
- Men: 4.5 to 6 million red cells per microliter of blood
- Women: 4 to 5 million red cells per microliter of blood

**Hematocrit (the part of the blood made up of red cells)**
- Men: 42% to 50%
- Women: 36% to 45%

**Hemoglobin (amount of the red cell pigment that carries oxygen)**
- Men: 14 to 17 grams per 100 milliliters of blood
- Women: 12 to 15 grams per 100 milliliters of blood

**Platelet count**
- 150,000 to 450,000 platelets per microliter of blood

**White blood cell (WBC) count**
- 4,500 to 11,000 white cells per microliter of blood

**Differential (also called diff)**
- Shows the part of the blood made up of different types of white cells
- The types of white cells counted are neutrophils, lymphocytes, monocytes, eosinophils and basophils.
- 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 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 under age 20.

Causes of ALL. ALL starts with a change to a single cell in the bone marrow. Doctors do not know what causes most cases of ALL. There is no way to prevent ALL. You can’t catch ALL from someone else.

Signs and Symptoms. 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.

A sign is a change in the body that the doctor sees in an exam or a test result. A symptom is a change in the body that the patient can see or feel.

A person who has ALL may have

- 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 (peh tee’ key uh)
- 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 right diagnosis. ALL is diagnosed with blood and bone marrow tests.

Here are some questions you may want to ask your healthcare team. See pages 44-50 for full list of questions.

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

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?

**Blood Cell Counts.** The doctor orders a test called a CBC (complete blood count). This test shows the numbers of red blood cells, white blood cells and platelets in a person’s blood. Usually, patients with ALL have lower-than-normal red blood cells and platelets.

**Blood Cell Examination.** The cells are stained (dyed) and looked at through a microscope. This test is called a blood smear. A person with ALL usually has too many leukemic blast cells in the blood. Blast cells are immature (young) cells that do not function like normal mature cells. The blood smear sample can also be used for cytogenetic analysis and immunophenotyping, explained below.

- **Cytogenetic analysis** — Each cell in the body has chromosomes that carry genes. Genes give the instructions that tell each cell what to do. The test called **cytogenetic analysis** examines the chromosomes of the ALL blast cells.
- **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 that indicate normal cells have become leukemia cells.
○ PCR — This is a test that 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 residual disease (MRD), which is the small amount of cancer cells left in the body after treatment.

○ Immunophenotyping — This test is used to identify cells based on the types of proteins on the cell surface, to see which of the main subtypes of ALL you have, B-cell ALL or T-cell ALL. Most people have B-cell ALL.

**Bone Marrow Tests.** Other tests will be done to make sure the diagnosis of ALL is correct. Tests called **bone marrow aspiration** and **bone marrow biopsy** are done. These tests take a close look at the ALL cells. They also find out the percentage of ALL cells in the bone marrow.

The doctor uses information from these tests to decide

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

The type and length of treatment may also depend on the patient’s age.

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**How are the Blood and Bone Marrow Tests Done?**

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

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

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

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

Blood and marrow tests may be done in the doctor’s office or in a hospital. A bone marrow aspiration and biopsy are almost always done at the same visit.
Blood and bone marrow tests may be done both during and after treatment. The tests are repeated to see if treatment is working. See Bone Marrow Aspiration and Biopsy, below.

**Bone Marrow Aspiration and Biopsy**

A Bone Marrow Aspiration samples fluid and cells

Common site where sample is taken

Patient position

Marrow

Spongy bone

A Bone Marrow Biopsy samples bone and marrow

Skin and fat

Compact bone

Left: The place on the back of the patient’s pelvic bone where a bone marrow aspiration or biopsy is done. Right: Where the needle goes inside the bone to collect the liquid sample for aspiration and the bone sample for biopsy. The needles are different sizes for each of these tests.

**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 the 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 an ALL specialist. These doctors are called **hematologist-oncologists**.
- 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 44-50.
- Adults with ALL who may want children, and parents of children who have ALL, should ask about future fertility (ability to have a child). Find out what treatment may cause problems with fertility and what choices you have that may lessen the risk of becoming infertile (unable to have children).
- The first round of treatment with chemotherapy is called **induction therapy**. Most patients with ALL need to start induction chemotherapy right away. Induction therapy is done in the hospital.
- Older adolescents and adults younger than 40 should speak to their doctors about treatment with pediatric protocols.

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 both diseases. Your local cancer specialist may work with a leukemia specialist. Always check to see if the doctor’s affiliated hospital or your chosen hospital is covered under your insurance.
How to Find a Leukemia Specialist

- Ask your primary care doctor for a recommendation.
- Contact your community cancer center.
- Reach out to doctor and/or health plan referral services.
- Call an LLS Information Specialist at (800) 955-4572.
- Use online doctor-finder resources, such as
  - The American Medical Association’s (AMA) “DoctorFinder” online at https://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, doctor, nurse and healthcare team, ask questions to get a better idea of the doctor’s experience and to understand how the office works. See pages 44-50 for a full list of questions.

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

Make sure you feel comfortable interacting with the doctor and the rest of the staff. You will be spending a lot of time speaking with this staff and 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 he or she plans to treat your leukemia. This will help you to become actively involved in making decisions about your care.

When you meet with your doctor

- Ask questions. See pages 44-50 at the end of this book for a full list of questions. Find other “What to Ask” healthcare question guides at www.LLS.org/whattoask.
  - What are the treatment choices?
  - Are there any clinical trials that I could 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 on. Ask the doctor and staff if recording is okay (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.

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

Before-Treatment Considerations

Adults who have leukemia and may want to have children in the future, and parents of children who have leukemia, should ask the doctor about ways to lessen the risk of infertility (inability to have children) that may be caused by treatment in their future.
Here are some questions you may want to ask your healthcare team. See pages 44-50 for a full list of questions in this Guidebook.

1. Will this treatment affect the ability to have a child in the future?
2. If yes, are there other treatment options available?
3. What are the options for preserving fertility?
4. How much time do I (we) have to make any decisions?

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

Treatment Planning

A patient has two options for treatment: standard care or taking part in a clinical trial. It is important to talk to the healthcare team about the best treatment option.

There are three stages of treatment for ALL

- Induction therapy
- Consolidation therapy (also called *intensification*)
- Maintenance therapy

Consolidation and maintenance are post-remission therapies. These are described beginning on page 20.

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

- Many children with ALL are cured.
- The number of adults with ALL in remission (no sign of the disease after treatment) has increased.
- The length of remission in adults has improved.

Many children with ALL are treated in clinical trials. Adults with ALL should talk to their doctors about clinical trials. A clinical trial may be a good treatment choice for you or your child. Clinical trials are explained beginning on page 26.
Factors that may affect treatment include

- The subtype of ALL
- The stage and category of the disease
- Disease that has not responded to treatment, called refractory disease
- Disease that has come back after treatment, called relapsed disease
- Patient age
- Other medical problems, such as diabetes, or heart or kidney disease

Some things that may affect the outcome of your ALL treatment are

- The subtype of your ALL
- The results of your lab tests
- Your age and general health
- Your medical history, including whether you were treated before with chemotherapy
- Whether you have
  - A serious infection at the time of diagnosis
  - ALL in your central nervous system
  - ALL that has not responded to treatment or has relapsed

Write down your ALL subtype here: ________________________________

Fertility Concerns. Some cancer treatments can limit a person’s ability to have a baby. Talk to your doctor for information that may help lessen the risk of becoming unable to have children (infertile). See Before-Treatment Considerations on page 12.
About ALL Treatments

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

Treatment for patients with ALL (or relapsed ALL) may include

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

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 44-50 for full list of questions.

1. What is the subtype?
2. What are the 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?

**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 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 of the disease for an extended period of time
Some Induction Therapy Drugs for ALL and How They Are Given

<table>
<thead>
<tr>
<th>Name of Drug</th>
<th>How Administered</th>
</tr>
</thead>
<tbody>
<tr>
<td>Daunorubicin (Cerubidine®) or</td>
<td>IV injection via central line*, port* or PICC*</td>
</tr>
<tr>
<td>doxorubicin (Adriamycin®)</td>
<td></td>
</tr>
<tr>
<td>Asparaginase Erwinia chrysanthemi (Erwinaze®) or</td>
<td>IV injection or by intramuscular (into the muscle) or subcutaneous (under the skin) injection.</td>
</tr>
<tr>
<td>pegaspargase (PEG-L asparaginase; Oncaspar®)</td>
<td></td>
</tr>
<tr>
<td>Vincristine (Oncovin®)</td>
<td>IV via central line, port or PICC</td>
</tr>
<tr>
<td>Dexamethasone or prednisone (corticosteroids)</td>
<td>Oral (by mouth)</td>
</tr>
<tr>
<td>Methotrexate</td>
<td>Injection into the spinal fluid</td>
</tr>
</tbody>
</table>

*See below and page 17 for an explanation of these terms.

Some drugs that are used for ALL induction therapy.

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

The first round of chemotherapy usually does not get rid of all the diseased ALL cells. Most patients will need more rounds of treatment. Usually the same drugs are used for the added rounds.

When there are some leukemia cells remaining in the body that cannot be seen with a microscope, this is called minimal residual disease (MRD). In patients who have achieved remission after initial treatment, 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 precursor acute lymphoblastic leukemia (B-cell precursor ALL) who are in remission but still have MRD. Precursor B-cell is a subtype of ALL.

Some drugs are given by mouth (orally). Other drugs are inserted directly into the patient’s body through a central line, a port, or a PICC. Central lines, ports, and PICCs can 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 the one that will be used for you or your child.

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

<table>
<thead>
<tr>
<th>Drug Types</th>
<th>Drug Names</th>
</tr>
</thead>
<tbody>
<tr>
<td>Antimetabolites</td>
<td>clofarabine (Clolar®), cytarabine (cytosine arabinoside, Ara-C; Cytosar-U®; DepoCyt®, fludarabine (Fludara®), hydroxyurea (Hydrea®), 6-mercaptopurine (Purinethol®, Purixan®), methotrexate (Xatmep®, Abitrexate®, Trexall®), nelarabine (Arranon®), 6-thioguanine (thioguanine; Tabloid®)</td>
</tr>
<tr>
<td>Antitumor Antibiotics</td>
<td>daunorubicin (Cerubidine®), doxorubicin (Adriamycin®), mitoxantrone (Novantrone®), idarubicin (Idamycin®).</td>
</tr>
<tr>
<td>DNA Repair Enzyme Inhibitor</td>
<td>etoposide (VP-16; VePesid®, Etopophos®)</td>
</tr>
<tr>
<td>DNA-Damaging Agents</td>
<td>cyclophosphamide (Cytoxan®), ifosfamide (Ifex®)</td>
</tr>
<tr>
<td>Drugs that Prevent Cells from Dividing</td>
<td>vincristine (Oncovin®) vincristine sulfate liposome (Marqibo®)</td>
</tr>
<tr>
<td>Enzymes that Prevent Cells from Surviving</td>
<td>asparaginase Erwinia chrysanthemi (Erwinaze®), pegasparagase (PEG-L-asparaginase, Oncaspar®, calaspargase pegol-mknl (Asparlas™)</td>
</tr>
<tr>
<td>Tyrosine Kinase Inhibitors (TKIs)</td>
<td>imatinib mesylate (Gleevec®), dasatinib (Sprycel®), nilotinib (Tasigna®), ponatinib (Iclusig®), bosutinib (Bosulif®)</td>
</tr>
<tr>
<td>Corticosteroids</td>
<td>prednisone, methylprednisolone, dexamethasone</td>
</tr>
<tr>
<td>Immunotherapies</td>
<td>alemtuzumab (Campath®) rituximab (Rituxan®), ofatumumab (Arzerra®), blinatumomab (Blincyto®), inotuzumab ozogamicin (Besponsa®), tisagenlecleucel (Kymriah®)</td>
</tr>
</tbody>
</table>

Information about side effects of treatment begins on page 27.
Central Nervous System (CNS) Leukemia

Patients may have ALL cells in the lining of the spinal cord and brain, which comprise the central nervous system (CNS). A spinal tap (also called a lumbar puncture) 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 as a prevention (prophylaxis) against CNS leukemia. Every patient with ALL gets treatment to prevent CNS leukemia.

The spinal cord and brain are hard to reach with chemotherapy that is given through a vein in the arm. To administer chemotherapy to the CNS, the spinal fluid is removed and chemotherapy is injected right into the spinal canal (intrathecal). Drugs such as methotrexate, cytarabine, and corticosteroids (prednisone, dexamethasone) are used.

Radiation therapy may be given to the spine or brain. Sometimes both chemotherapy and radiation therapy are used. In most practices, doctors are not using cranial (to the head) radiation for pediatric patients except in patients who have CNS leukemia or CNS relapse. When radiation therapy is used, the chance of long-term side effects is higher.

Spinal taps are done from time to time throughout treatment. This test checks to see if the ALL cells are being killed.
Post-Remission Therapy

When there is no sign of ALL, this is called remission. Unfortunately, more treatment is usually needed even after an ALL patient is in remission. Some ALL cells may remain. These are not found by common blood or marrow tests. This part of ALL treatment is called post-remission therapy. (Post-remission means after remission.) Chemotherapy is used in post-remission therapy for ALL. Stem cell transplantation may be part of post-remission therapy for some ALL patients. Post-remission therapy consists of consolidation (intensification) therapy and maintenance therapy.

- Consolidation therapy is usually given in cycles for four to six months.
- Maintenance therapy is usually given for about two years for adults and two to three years for children.

For most people, the drugs used during consolidation and maintenance therapy are different from the drugs used during induction therapy.

The doctor considers many things when deciding on a treatment plan. This includes the patient’s ALL subtype, and doses and length of induction. The doctor also notes carefully:

- Did the induction therapy kill the ALL cells?
- Does the patient have changes to the chromosomes of the ALL cells?

Some types of ALL are commonly treated with higher doses of drugs during induction, consolidation and maintenance therapy. These types include T-cell ALL (a subtype of ALL that affects T cells rather than B cells), ALL in infants, and ALL in adults.

An allogeneic stem cell transplant may be a good treatment for some ALL patients. Allogeneic transplants are explained beginning on page 23.
Some Consolidation and Maintenance Therapies

- Vincristine (Oncovin®), by intravenous (IV) infusion
- Prednisone or dexamethasone, by mouth
- 6-mercaptopurine (Purinethol®), by mouth
- Blinatumomab (Blincyto®), by IV infusion
- Inotuzumab ozogamicin (Besponsa®), by IV infusion after premedication
- Methotrexate, by mouth, IV, or injection into the spinal fluid
- Cytarabine (cytosine arabinoside, Ara-C, Cytosar-U®), by IV or injection into the spinal fluid
- Cyclophosphamide, by IV injection
- Asparaginase *Erwinia chrysanthemi* (Erwinaze®) or pegaspargase (PEG-L asparaginase; Oncaspar®), by injection or by intramuscular or subcutaneous injection
- Intrathecal chemotherapy, by spinal tap or device placed under the scalp

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.

**Induction Therapy.** The following are FDA-approved for the treatment of Ph-positive ALL: imatinib mesylate (Gleevec®), dasatinib (Sprycel®), or ponatinib (Iclusig®), which are all given by mouth (orally). Other chemotherapy drugs may be used as well.

**Post-Remission Therapy.** During consolidation and maintenance therapy, Gleevec, Sprycel, or Iclusig is given with other drugs. Usually people with Ph-positive ALL stay on Gleevec, Sprycel, or Iclusig after maintenance chemotherapy is completed.
Relapsed and Refractory ALL

Most children with ALL are cured of the disease. Some patients (children and adults) relapse (when patients achieve remission but ALL cells return). Other patients have refractory ALL (when patients do not achieve remission because ALL cells are still in the marrow after treatment).

Patients with relapsed ALL may be:
- Treated with the same drugs as newly diagnosed patients
- Given different drugs
- Given an allogeneic stem cell transplant if they have a matched donor

Information about allogeneic transplantation begins on page 23.

For patients with refractory ALL:
- Drugs that were not used in the first round of treatment may be given.
- An allogeneic stem cell transplant may also be a part of treatment.

For children with relapsed or refractory ALL:
- The drug clofarabine (Clolar®) is approved by the FDA to treat children (ages 1 to 21) if the usual treatments do not work.
- Treatment with clofarabine followed by an allogeneic transplant may result in a cure.

The FDA has approved these drugs for relapsed and refractory ALL.
- Liposomal vincristine (Marqibo®) is for adult patients with Philadelphia chromosome-negative ALL who have relapsed two or more times. It is also approved for patients whose leukemia has progressed following two or more regimens of therapy.
- Nelarabine (Arranon®) is for patients with relapsed T-cell ALL.
- Blinatumomab (Blincyto®) is given by IV for the treatment of adults and children with B-cell precursor ALL in first or second complete remission, who have minimal residual disease (MRD) of 0.1% or higher on testing. It is also approved for relapsed or refractory B-cell precursor ALL.
- Inotuzumab ozogamicin (Besponsa®) is given by IV for the treatment of adults with relapsed or refractory B-cell precursor ALL.
Tisagenlecleucel (Kymriah®) is a treatment for young patients ages 25 and younger who experience a second or later relapse or who have refractory B-cell ALL. It is the first gene therapy available in the United States.

**Stem Cell Transplantation.** This procedure essentially replaces the patient’s blood with either his or her own treated blood or blood from a donor. The goal of stem cell transplantation is to help the body start a new supply of blood cells. There are two types of stem cell transplantation, one that uses replacement blood from a donor (**allogeneic transplant**) and one that replaces the patient’s blood with his or her own blood (**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 individual’s disease; if the patient is not doing well with other treatments; if the expected benefits of a transplant exceed the risks; if there is a stem cell donor; other treatment(s) received; and physical ability to have the transplant. A stem cell transplant is not for every patient, but it can be helpful for some.

A stem cell transplant is usually not considered for a child unless

- Doctors have determined that the child’s type of ALL is not likely to respond well to chemotherapy
- Chemotherapy has not worked well
- The child’s ALL has returned (relapsed)

Additional information about different kinds of transplants available for some ALL patients is below. Talk to your doctor about whether a stem cell transplant is a possible treatment for you.

**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. The following bullets list the process.
Stem cells are collected from a donor.

The patient is given high-dose chemotherapy and/or radiation therapy to kill the ALL cells in the body.

The donor stem cells are given to the patient through an intravenous (IV) line or central line.

The donor stem cells go from the patient’s blood to the marrow and begin to start a new supply of red blood cells, white blood cells and platelets.

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) is less harsh and 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.

**ALL Treatment in Young Adults**

Older adolescents and adults younger than 40 are often called young adults. 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.
A new type of immunotherapy called **chimeric antigen receptor (CAR) T-cell therapy** uses the patient’s own immune cells to target and eliminate cancerous cells. **Tisagenlecleucel (Kymriah®)** is currently approved for patients ages 25 and younger, and is being studied in the treatment of refractory and relapsed ALL in both children and adults.

Speak to your doctor or call an Information Specialist about the different clinical trials that may be available to you or your child.

### ALL Treatment in Adults

Today, cures are possible for some adults with ALL. These patients include those who may also have other serious health problems. 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 would choose less-toxic drugs, or decrease the dosage and frequency of treatment. New and better treatments for ALL in adults are needed.

A new type of immunotherapy called **chimeric antigen receptor (CAR) T-cell therapy** uses the patient’s own immune cells to target and eliminate cancerous cells. **Tisagenlecleucel (Kymriah®)** is being studied in the treatment of refractory and relapsed ALL in both children and adults.

A number of cancer centers are using pediatric protocols to treat younger adult patients. Speak to your doctor or call an Information Specialist about different clinical trials that may be available to you.

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**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](http://www.LLS.org/booklets), or contact our Information Specialists for a copy.
PART 3  Clinical Trials

About Clinical Trials

There are new treatments under study for patients of all ages with 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 acute lymphoblastic leukemia (ALL) patients
- Patients who did not have a good response to treatment (refractory disease)
- Patients who relapsed after treatment
- Patients who need to continue treatment after remission (maintenance therapy)

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

Here are some questions you may want to ask your healthcare team. See pages 44-50 for a full list of questions.

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

Ask your doctor if treatment in a clinical trial may be right for you. For more information, please call (800) 955-4572 to speak with an LLS Information Specialist who can provide more information about clinical trials and help search for a clinical trial for you. When appropriate, personalized clinical-trial navigation by trained nurses is also available through the Clinical Trial Support Center. Visit www.LLS.org/CTSC for more information..
PART 4  Side Effects and Follow-Up Care

Overview of This Section

Treatment side effects vary depending on the type of treatment (for example, chemotherapy, targeted therapy, radiation, etc).

Some of the common side effects of treatment for ALL may include mouth sores, nausea, diarrhea and/or constipation, changes in blood counts and other side effects.

Parents should talk to the doctor if they think their child’s learning skills may have been affected by leukemia or its treatment. The child’s learning skills should be evaluated.

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 ALL cells. 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 44-50 for full list of questions.

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

ALL treatment may affect your blood cell counts:

- The number of red blood cells may decrease to lower than normal (anemia). Red blood cell transfusions (red blood cells that are donated and given to the patient) may be needed to increase red blood cell counts.
- Patients may also have a drop in the number of platelets in their 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.

Infection could be very serious for anyone who has ALL. Patients at home should contact a doctor if any signs of infection develop. A rise in temperature to 101°F or higher (or the onset of chills) may be the only sign of infection in a patient with a very low white blood cell count. Patients with an infection may also have:

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

Growth factors are sometimes given to increase white blood cells. G-CSF (Neupogen® and Neulasta®) and GM-CSF (Leukine®) are drugs that increase the number of white blood cells. Growth factors are given to children only in certain cases. Scientists are studying which children with ALL are most likely to be helped by treatment with growth factors to prevent infection.
To lower the risk of infection
- Patients, visitors, and the medical staff all need to wash their hands often and well.
- The patient’s central line must be kept clean.
- Patients should take good care of their teeth and gums.

The doctor may talk about the absolute neutrophil count, or ANC. This is the number of neutrophils (a type of white blood cell) a person has in his or her body to fight infection.

**Other Treatment Side Effects.** Chemotherapy affects the parts of the body where new cells form quickly. This includes the inside of the mouth and bowel, and the skin and hair. The side effects listed here are common during chemotherapy:
- Mouth sores
- Diarrhea
- Hair loss
- Rashes
- Nausea
- Headache
- Numbness, tingling or muscle weakness (usually in the hands or feet)
- Vomiting

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

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

Patients with high uric acid levels may be given:
- A drug called **allopurinol** (*Aloprim®, Zyloprim®*) by mouth
- A drug used called **rasburicase** (*Elitek®*), by IV
Some side effects last a long time (long-term) or may not occur right away (late effects). Information about long-term and late effects of treatment begins below.

**WANT MORE INFORMATION?**
You can view, print or order the free LLS booklet *Understanding Side Effects of Blood Therapy* at www.LLS.org/booklets. Or contact our Information Specialists for a copy.

**Long-Term and Late Effects**

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

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

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

**Here are some questions you may want to ask your healthcare team.** See pages 44-50 for full list of questions.

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

Children who are treated for ALL may have:
- Growth problems
- Fertility problems (ability to have children later)
- Bone problems
- Heart problems
- Learning problems
Adults who are treated for ALL may have:

- Fertility problems
- Thyroid problems
- Trouble concentrating
- Persistent fatigue

Patients should talk with their doctors about:

- Any long-term or late effects that may be related to their treatment
- When a child’s learning skills should be checked

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**WANT MORE INFORMATION?**

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

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**Follow-Up Care**

Medical follow-up 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 receive and the time period you receive them, so that your doctor can follow up on specific long-term effects that may be associated with your treatment. See page 50 for a place to list treatments.
Here are some questions you may want to ask your healthcare team. See pages 44-50 for full list of questions.

1. Who should I (we) work with to ensure life-long follow up?
2. Will I (we) 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. As treatment progresses, the doctor may advise longer periods of time between follow-up visits. This will happen if a patient:

- Continues to be free of signs of ALL
- Does not need medical care for any long-term or late effects

To find a survivorship clinic and other resources for child and adult survivors, contact our Information Specialists.

**Take Care of Yourself**

- Keep all appointments with the doctor.
- Discuss how you feel with the doctor at each visit. Ask any questions you may have about side effects.
- 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.
- 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 screening. 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.

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

Resources and Information

LLS offers free information and services for patients and families affected by blood cancers. This section of the booklet lists various resources available to you. Use this information to learn more, to ask questions, and to make the most of your healthcare team.

For Help and Information

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

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

Clinical Trials (Research Studies). New treatments for patients are under way. Patients can learn about clinical trials and how to access them. For more information, please call (800) 955-4572 to speak with an LLS Information Specialist who can help conduct clinical-trial searches. When appropriate, personalized clinical-trial navigation by trained nurses is also available through the Clinical Trial Support Center. Visit www.LLS.org/CTSC for more information.

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.


Co-Pay Assistance Program. LLS offers insurance premium and medication co-pay assistance for certain eligible patients. For more information, please
- Call: (877) 557-2672
- Visit: www.LLS.org/copay

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

Podcast. Listen in as experts and patients guide listeners in understanding diagnosis, treatment, and resources available to blood cancer patients. The Bloodline with LLS is here to remind you that after a diagnosis comes hope. Visit www.LLS.org/TheBloodline for more information and to subscribe.

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

Community Resources and Networking

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

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

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

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

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

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

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

Additional Help for Specific Populations

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

Language Services. Let your doctor know if you need a language interpreter or other helper, such as a sign language interpreter. Often, these services are free.

Children’s Concerns. Parents of a child with ALL 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. For more information, visit www.LLS.org/booklets for the free LLS booklet Coping With Childhood Leukemia and Lymphoma.

The Trish Greene Back to School Program for Children With Cancer. This program helps doctors, nurses, parents and school personnel work together for a smooth return to school for children with cancer. For more information, contact your LLS chapter or call (800) 955-4572.

World Trade Center Survivors. People involved in the aftermath of the 9/11 attacks and subsequently diagnosed with a blood cancer may be able to get help from the World Trade Center (WTC) Health Program. People eligible for help include
○ Responders
○ Workers and volunteers who helped with rescue, recovery and cleanup at the WTC-related sites in New York City (NYC)
○ Survivors who were in the NYC disaster area and those who lived, worked or were in school in that area
○ Responders to the Pentagon and the Shanksville, PA, crashes

For more information, please
○ Call: WTC Health Program at (888) 982-4748
○ Visit: www.cdc.gov/wtc/faq.html

**People Suffering from Depression.** Treating depression has benefits for cancer patients. Seek medical advice if your mood does not improve over time, for example, if you feel depressed every day for a two-week period. For more information, please

○ Call: The National Institute of Mental Health (NIMH) at (866) 615-6464
○ Visit: NIMH at www.nimh.nih.gov and enter “depression” in the search box
Health Terms

**Absolute Neutrophil Count (ANC).** The number of neutrophils (a neutrophil is a type of white blood cell) that a person’s body has to fight infection.

**Anemia.** A decrease in the level of hemoglobin (low red blood cell count) in the blood.

**Antibiotics.** Drugs that are used to treat infections caused by bacteria or fungi. Penicillin is one type of antibiotic.

**Blast cells.** Immature bone marrow cells. About 1 to 5 percent of normal marrow cells are blast cells. In ALL, up to 20 percent of marrow cells may be blast cells.

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

**Bone marrow biopsy.** A procedure to remove and examine marrow cells to see if they are normal. A very small amount of bone filled with 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 directed to the lining of the spinal cord and brain. Used to prevent ALL from going into the CNS where ALL cells often collect.

**Chemotherapy or drug therapy.** Treatment with chemical agents to treat ALL and other cancers.

**Chromosomes.** Any of the 23 pairs of certain basic structures in human cells. Chromosomes are made up of genes. Genes give the instructions that tell each cell what to do. The number or shape of chromosomes may not be normal in cancer cells.
Clinical trials. Careful studies 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 improve treatment and quality of life and to find cures.

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

Consolidation therapy. Added treatment given to a cancer patient after the patient’s disease is in remission. It usually includes chemotherapy drugs not used during induction therapy. Also called intensification therapy.

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

Diagnose. To detect a disease from a person’s signs, symptoms and test results. The doctor diagnoses a patient.

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.

FISH. The short name for fluorescence in situ hybridization, a test to measure the presence in cells of a specific chromosome or gene. This test can be used to plan treatment and to measure the results of treatment.

Hematologist. A doctor who treats blood diseases.

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

Immune system. Network of cells, tissues, and organs in the body that defend it against infection.

Immunophenotyping. A lab test that can be used to identify a specific type of cells such as ALL cells.

Induction therapy. The initial treatment with chemotherapy (or radiation therapy). The aim of induction therapy is to kill a maximum number of cancer cells in order to induce a remission (absence of signs or effects of the disease).
**Intensification therapy.** Another name for consolidation therapy.

**Leukemia.** A cancer of the bone marrow and blood.

**Lymph nodes.** Small bean-shaped organs connected by lymph channels throughout the body forming part of the body’s immune system.

**Maintenance therapy.** Chemotherapy given to patients after induction and consolidation therapy to help destroy the remaining cancer cells. Maintenance therapy is given for about two years.

**Marrow.** The spongy material in the center of bones where blood cells are made (called bone marrow).

**Oncologist.** A doctor who treats patients who have cancer.

**Pathologist.** A doctor who identifies disease by studying cells and tissues under a microscope.

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

**Plasma.** The liquid part of the blood.

**Platelet.** A blood cell that helps prevent or stop bleeding. Platelets cause plugs (“clotting”) to form in the vessels at an injured site.

**Post-remission therapy.** The treatment given to cancer patients after induction therapy. Post-remission therapy may have two parts: consolidation (or intensification) and maintenance.

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

**Refractory.** Disease such as ALL that has not responded to initial treatment. Refractory disease may be a disease that is getting worse or staying the same even after treatment.

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

**Remission.** No sign of the disease and/or a period of time when the disease is not causing any health problems.
**Signs and symptoms.** Changes in the body that show the presence of disease. A sign is a change that the doctor sees in an exam or a lab test result. A symptom is a change that a patient can see or feel.

**Stable disease.** The cancer has not spread to new regions and is not getting better or worse.

**Stem cell.** A type of cell found in bone marrow that matures into different types of cells: 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: 1-800-955-4572

Email: infocenter@LLS.org

Website: www.LLS.org/InformationSpecialists
HEMATOLOGIST-ONCOLOGIST NAME:

Address: __________________________________________________

Phone number/Fax number: ___________________________________

Email address: ____________________________________________

Website/Portal: ____________________________________________

Additional information: ____________________________________

NURSE/NURSE PRACTITIONER NAME:

Phone number/Fax number: ___________________________________

Email address: ____________________________________________

Additional information: ____________________________________

SOCIAL WORKER NAME:

Address: __________________________________________________

Phone number/Fax number: ___________________________________

Email address: ____________________________________________

Additional information: ____________________________________

INSURANCE CASE MANAGER/ CARE COORDINATOR NAME:

Address: __________________________________________________

Phone number/Fax number: ___________________________________

Website or email address: ___________________________________

Additional information: ____________________________________
PHYSICIAN ASSISTANT NAME:

Address: ____________________________________________

Phone number/Fax number: ____________________________

Email Address: ______________________________________

Additional information: ________________________________

NURSE NAVIGATOR NAME:

Address: ____________________________________________

Phone number/Fax number: ____________________________

Email address: ______________________________________

Additional information: ________________________________

OTHER:

Address: ____________________________________________

Phone number/Fax number: ____________________________

Email address: ______________________________________

Additional information: ________________________________

OTHER:

Address: ____________________________________________

Phone number/Fax number: ____________________________

Email address: ______________________________________

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

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

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

**Questions for the Doctor**

**DOCTOR’S NAME:** ______________________________________________________

Date of appointment or phone call: _______________________________________

1. How many patients have you treated who have 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?
Talk with the doctor and ask questions about how he or she plans to treat your (your loved one’s) leukemia. This will help you and your loved one to be actively involved in making decisions about medical care. The following are questions you may want to ask your healthcare team.

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

**DOCTOR’S NAME:** ____________________________________________

Date of appointment or phone call: ______________________________

Write down your diagnosis:

_________________________________________________________________

_________________________________________________________________

_________________________________________________________________

Write down your 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.
My List of Treatments

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

DATE: ______________________________________________________
Treatment: __________________________________________________
___________________________________________________________

DATE: ______________________________________________________
Treatment: __________________________________________________
___________________________________________________________

DATE: ______________________________________________________
Treatment: __________________________________________________
___________________________________________________________

DATE: ______________________________________________________
Treatment: __________________________________________________
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DATE: ______________________________________________________
Treatment: __________________________________________________
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DATE: ______________________________________________________
Treatment: __________________________________________________
___________________________________________________________
Get support. Reach out to our INFORMATION SPECIALISTS

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

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

Contact us at 800-955-4572 or www.LLS.org/informationspecialists (Language interpreters can be requested)
For more information, please contact our Information Specialists 800.955.4572 (Language interpreters available upon request).

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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.