



PROVIDING THE LATEST INFORMATION
FOR PATIENTS & CAREGIVERS

Understanding Blood Cancers



Revised **2024**

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, and optimism. Finding joy while living with uncertainty.** Watch, wait, treat, regroup, rest, re-energize. Blessed to be doing so well! **Eye opening needed learning and healing. Feel great: uncertain travel plans annoying. Renewed faith, meditation, diet, mindfulness, gratitude.** Watchful waiting can be watchful worrying. Scary, expensive, grateful, blessings, hope, faith. **Thank god for stem cell transplants! Do not know what to expect. Extraordinarily grateful, I love my life. Diagnosed; frightened; tested; treating; waiting; hoping. I'm more generous, impatient less often. Embrace your treatment day after day. Live today, accept tomorrow, forget yesterday. Strength you never realized you had.** Challenging to our hearts and minds. Life is what we make it. **Live life in a beautiful way.**






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

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

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

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This publication is designed to provide accurate and authoritative information about the subject matter covered. It is distributed as a public service by The Leukemia & Lymphoma Society (LLS), with the understanding that LLS is not engaged in rendering medical or other professional services. LLS carefully reviews content for accuracy and confirms that all diagnostic and therapeutic options are presented in a fair and balanced manner without particular bias to any one option.

Introduction

This booklet provides information for anyone interested in learning more about blood cancers. This may include people diagnosed with a blood cancer, caregivers, family members and friends, or students. This booklet explains the main types of blood cancers, how blood cancer is diagnosed, general methods of treatment, some side effects and how The Leukemia & Lymphoma Society (LLS) can help patients diagnosed with a blood cancer and their caregivers.

For more detailed information on specific types of blood cancer, visit www.LLS.org/booklets to view all of our free guides and disease fact sheets and booklets.

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

Understanding Blood Cancers

What is Blood Cancer?

Leukemia, lymphoma, myeloma, myelodysplastic syndromes (MDS) and myeloproliferative neoplasms (MPNs) are types of cancer that affect the bone marrow, blood cells, lymph nodes and other parts of the lymphatic system. Each of these blood cancers also contains different subtypes.

Blood cancers can be either acute (severe and sudden onset) or chronic (disease progresses slowly).

To better understand blood cancer, let's learn more about normal bone marrow, blood and blood cells.

About Bone Marrow, Blood and Blood Cells

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. Anemia is a condition in which there is a lower-than-normal number of red blood cells in the blood. It may make a person feel tired or short of breath. It may make their skin look pale.

White blood cells fight infection in the body. There are five types of white blood cells, which are categorized into two groups, lymphocytes (B cells, T cells and natural killer [NK] cells) and (neutrophils and monocytes). Neutropenia is a condition in which there is a lower-than-normal number of neutrophils in the blood. It may cause the patient to be at higher risk for infection.

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

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

Normal Blood Cell Counts Fast Facts

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

Red blood cell (RBC) count

- Males: 4.5 to 6 million red cells per microliter of blood
- Females: 4 to 5 million red cells per microliter of blood

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

- Males: 42% to 50%
- Females: 36% to 45%

Hemoglobin (amount of the red blood cell pigment that carries oxygen)

- Males: 14 to 17 grams per 100 milliliters of blood
- Females: 12 to 15 grams per 100 milliliters of blood

Platelet (PLT) count

- 150,000 to 450,000 platelets per microliter of blood

White blood cell (WBC) count

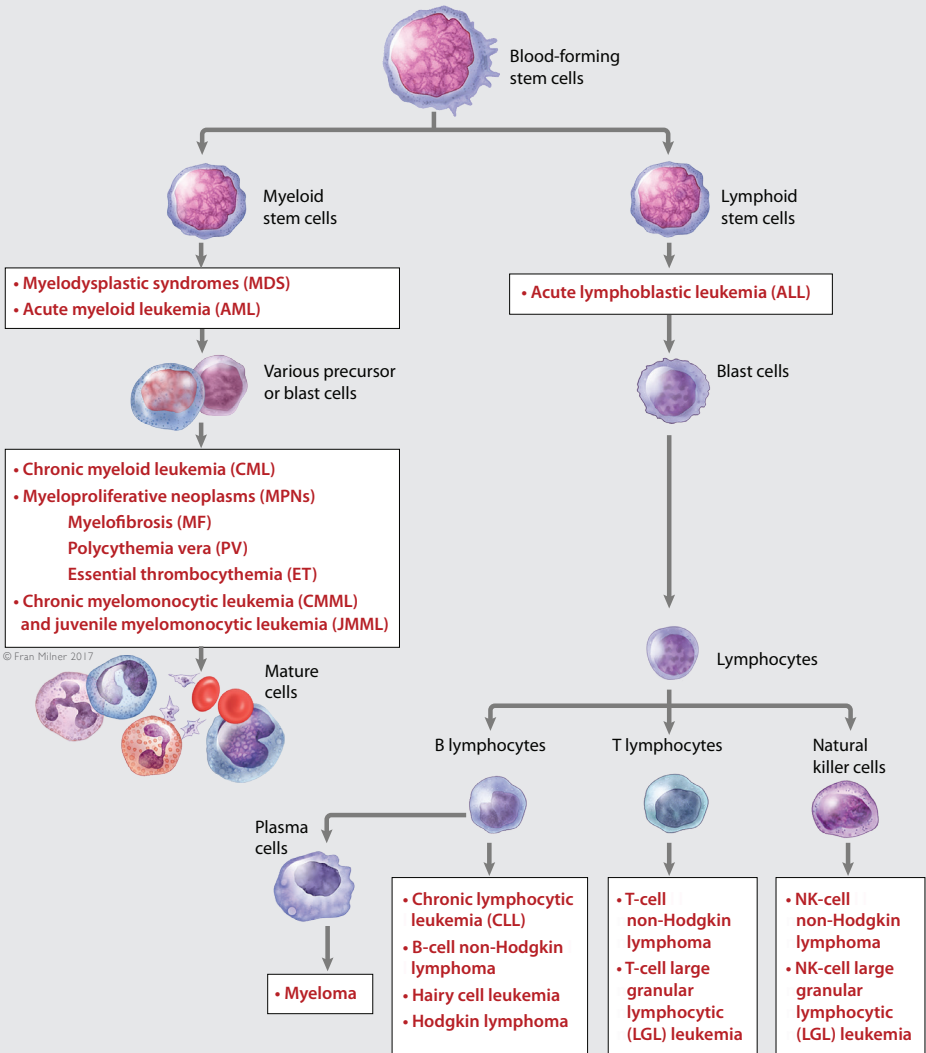
- 4,500 to 11,000 white blood cells per microliter of blood

Differential (also called “diff”)

- Shows the part of the blood made up of different types of white blood cells
- Counts the types of white blood cells (neutrophils, lymphocytes, monocytes, eosinophils and basophils)
 - Normal adult white blood cell count: 60% neutrophils, 30% lymphocytes, 5% monocytes, 4% eosinophils and less than 1% basophils in the blood

Where Do Blood Cancers Develop?

Blood cancers can develop in many different places during normal blood cell formation. The type of blood cancer that results has to do with where normal cell development is blocked. This diagram illustrates the cell type where different blood cancers arise.



Who is At Risk?

Blood cancers affect people of all ages, races and sex. Blood cancers are not contagious. You cannot “catch” blood cancer from someone else. Doctors do not know the causes of most cases of blood cancer.

The term “risk factor” is used to describe something that may increase the chance that a person will develop a blood cancer. For most types of blood cancer, the risk factors and possible causes are not known. For some types of blood cancer, specific risk factors have been found. These include factors related to genetic disorders, autoimmune diseases, exposure to certain chemicals or radiation, and prior cancer treatment. Most people with blood cancer do not have these risk factors, and many people with these risk factors do not get blood cancer.

What Are the Signs and Symptoms of Blood Cancer?

The signs and symptoms of blood cancer depend on the type of blood cancer. Some signs and symptoms of blood cancer are similar to other common and less severe illnesses. Specific tests are needed to make a blood cancer diagnosis.

People with chronic blood cancers may not have any symptoms at the time of diagnosis. They may learn they have blood cancer after a blood test that’s part of a regular checkup.

Any person troubled by signs and/or symptoms, such as lasting low-grade fever, unexplained weight loss, tiredness, night sweats, shortness of breath, or a swollen lymph node, or someone who is generally feeling unwell should see a doctor.

Diagnosis

The tests needed to diagnose blood cancer depend on the patient’s signs, symptoms and other medical history. Some of the types of tests used to diagnose blood cancer include:

- **Blood cell counts**—A test called a “complete blood count (CBC)” is used to count the numbers of red blood cells, white blood cells and platelets in a blood sample.
- **Bone marrow tests**—These tests, called “bone marrow aspiration” and “bone marrow biopsy,” are usually done during the same visit. Two samples of bone marrow (liquid and bone) are removed from the hip

bone using special needles. The samples are then sent to the lab for examination.

- **Lymph node biopsy**—A surgeon uses a special needle to remove either all or part of an enlarged lymph node, a small bean-shaped organ that contains lymphocytes. The cells of the node are examined under a microscope by a doctor.
- **Urine tests**
- **Other blood tests**
- **Imaging tests**, including x-rays, computed tomography (CT) scan, magnetic resonance imaging (MRI) and positron emission tomography (PET) scan

These tests can be repeated after treatment begins to measure how well the treatment is working.

How Are the Blood and Bone Marrow Tests Done?

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

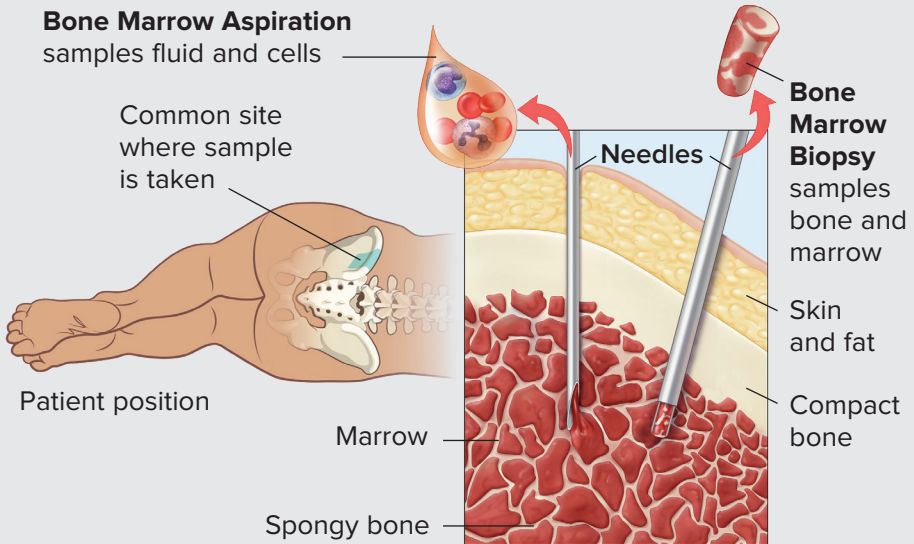
Bone Marrow Aspiration—A sample of fluid with marrow cells is removed from the bone marrow.

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 special needles. Some patients are awake for the procedure. The patient is given medication first to numb the area before samples are taken. Some patients are given a drug that makes them sleep during the procedure. The samples of fluid or cells are usually taken from the patient’s hip bone.

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

Bone Marrow Aspiration and Biopsy



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

Visit www.LLS.org/3D to view an interactive 3D image that will help you visualize and better understand the bone marrow aspiration and biopsy procedure.

Biomarker Tests

Biomarker tests, also called “molecular profiling” or “molecular testing,” use a sample of tissue, blood or other body fluid to check for certain genes, proteins or molecules that may be a sign of a disease, such as cancer. Biomarker testing can also be used to check for certain changes (mutations) in a gene or a chromosome that may increase a person’s risk of developing cancer or other diseases. Biomarker testing may be done to help doctors to diagnose some types of cancer. Doctors may also use the findings to help plan treatment and to find out how well treatment is working. These types of tests may include:

- **Fluorescence in situ hybridization (FISH)**—A test for studying abnormal genes and chromosomes in cells and tissues.
- **Immunophenotyping (flow cytometry)**—A lab test that can measure the number of cells in a sample and determine certain characteristics of cells, such as their size and shape. It can also detect tumor markers on the surface of cells and identify specific types of cells.
- **Karyotyping**—Testing to create an organized profile of a person’s chromosomes. It includes the size, shape and number of chromosomes in a sample of cells.
- **Quantitative polymerase chain reaction (qPCR)**—This is a test that finds cancer cells based on their genetic mutations and chromosome changes. This test can find cancer cells that are present in amounts that are too small to be seen with other tests—even when the blood samples are viewed under a powerful microscope.
- **Next-generation sequencing (NGS)**—This term refers to several different laboratory tests that can quickly examine the exact sequence (order) of the genetic code in DNA. This makes it possible to find genetic changes in a patient’s cancer cells.

For more information, see the free LLS booklets *Understanding Lab and Imaging Tests* and *Understanding Genetics*.

Treatment

Finding the Right Doctor

Patients with blood cancer are treated by specialists. These are doctors called “hematologist-oncologists.” A hematologist is a doctor who has special training in disorders of the blood. An oncologist is a doctor who has special training in cancer. A hematologist-oncologist has special training in both diagnosing and treating blood cancers. Some hematologist-oncologists specialize in specific types of 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 hospital you choose for treatment.

Ways to Find a Blood Cancer Specialist

- Ask your primary care doctor.
- Contact your community cancer center.
- Ask your health insurance provider for a referral.
- Call LLS at **(800) 955-4572** or visit **www.LLS.org/CancerCenters** for a list of cancer centers.
- Visit **www.hematology.org/education/patients/find-a-hematologist** to use the American Society of Hematology’s (ASH) “Find a Hematologist.”

For more information, see the free LLS booklet *Choosing a Specialist or Treatment Center*.

Ask Your Doctor

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

When you meet with your doctor:

- Ask questions. Below are some of the questions to ask. See pages 39 to 41 for other questions you might want to ask.
 - What is my diagnosis?

- What are my treatment options?
- What are the side effects of treatment?
- Are there any clinical trials I can join?
- When should I begin treatment?
- How long will treatment last?
- Take notes. It may be helpful to write down the answers to your questions and review them later.
- Audio record information from the doctor and then listen to the recording later. Ask the doctor or staff members if recording is allowed. Most cell phones have a “record” function.
- Bring a caregiver, friend or family member who can listen to the doctor too and take notes and offer support.
- Make sure you understand what the doctor is saying. If, at first, you do not understand what the doctor is telling you, ask the doctor to go over the information again and explain it in different words.

If you either need more information or if you are not sure about your treatment choices, consider getting another opinion from a different doctor. This is called a “second opinion.”

If you are unsure or if you feel uncomfortable about how to tell your doctor you are going to get a second opinion, call an LLS Information Specialist at **(800) 955-4572** to discuss a way to approach your doctor that is a good fit for you. You may also want to check with your insurance company to be sure that a second opinion will be covered.

Note that many hospitals and treatment centers now offer digital “patient portals” where you can view your medical record and upcoming appointments, message your providers, view and pay bills, and more online. Ask how you can access your patient portal.

Fertility Concerns. Some cancer treatments can affect fertility (a person’s ability to have biological children in the future). Adults who have a blood cancer and may want to have children in the future, and parents of children who have leukemia should make sure that they talk with the doctor about whether the cancer treatments could affect fertility.

For more information, see the free LLS booklet *Fertility and Cancer*.

Treatment Options

Great progress has been made on the treatment of blood cancers providing patients and their caregivers with more hope than ever before.

Treatment options vary for different types of blood cancer. Treatment options depend on several factors including:

- Diagnosis and subtype
- Genetic analysis
- Patient's age
- Patient's overall health
- If the disease is either relapsed (disease that returns after treatment) or refractory (disease that does not respond to initial treatment)

A treatment plan might include:

- **The watch-and-wait approach**—Closely watching a patient's condition but not starting treatment unless signs and/or symptoms appear or existing ones change. Patients may think they should start treatment right away. But for people with low-risk (slow-growing) disease and no symptoms, it is often best not to start treatment immediately. With a watch-and-wait approach, patients can avoid the side effects of therapy until it is needed.
- **Chemotherapy**—Drugs that stop the growth of cancer cells, either by killing the cancer cells or by stopping them from dividing.
- **Targeted therapy**—A type of treatment that uses drugs or other substances to target specific molecules that cancer cells need to survive and spread.
- **Radiation therapy**—Treatment with x-rays or other high-energy rays to kill cancer cells.
- **Immunotherapy**—A type of therapy that uses substances to either stimulate or suppress the immune system to help the body fight cancer, infection, and other diseases. One example of this type of treatment is chimeric antigen receptor (CAR) T-cell therapy.
- **Stem cell transplantation**—A procedure in which a patient receives healthy stem cells (blood-forming cells) to replace their stem cells that have been destroyed by treatment with radiation or high doses of chemotherapy. The healthy stem cells may come from either the blood or bone marrow of the patient (autologous) or from either a related or unrelated donor (allogeneic).

- **Clinical trials**—A careful study done by doctors, either to test new drugs or treatments or evaluate new uses for approved drugs or treatments.
- **Blood transfusion**—A procedure in which whole blood or parts of blood are infused into a patient’s bloodstream through a vein.
- **Palliative (supportive) care**—Specialized medical care focused on providing relief from the signs and/or symptoms and stress of a serious illness. The goal of palliative care is to improve quality of life for both the patient and the family. (Note that palliative care is for all patients. Hospice care is a special type of palliative care for patients who have stopped treatment and are nearing end-of-life.)

A combination of any of the above treatments may be used as part of a patient’s treatment plan.

Surgery can be, but usually isn’t, a part of treatment for cancers that involve the blood and marrow.

Methods to Administer Drugs

Drug therapies can be given in several different ways, including:

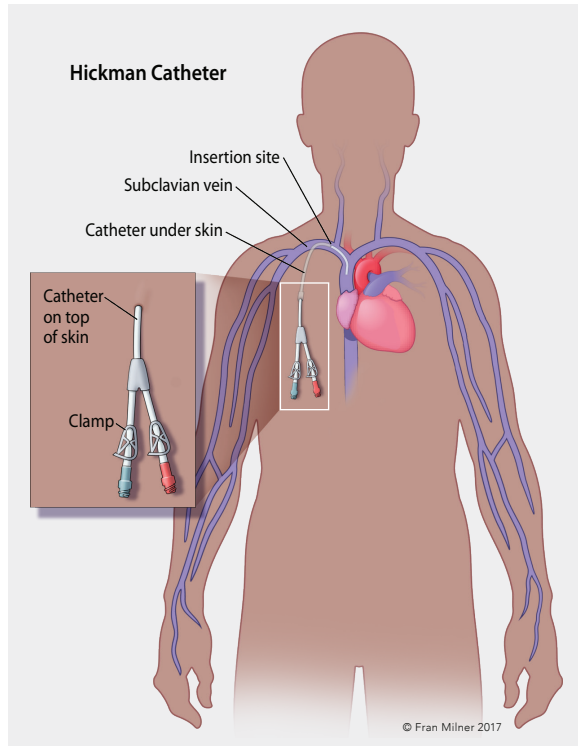
- **Intravenously (IV)**—into a vein
- **Orally (PO)**—by mouth as a pill, liquid or capsule
- **Intramuscularly (IM)**—injection into a muscle
- **Subcutaneously (SC)**—injection under the skin
- **Intrathecally**—into the cerebrospinal fluid (CSF)

Certain medications irritate the veins and make repeated IV placement difficult. Many patients find that chemotherapy drugs can be given more conveniently and comfortably through a central line with a port or a central venous catheter. Both can stay in place longer than a regular IV catheter.

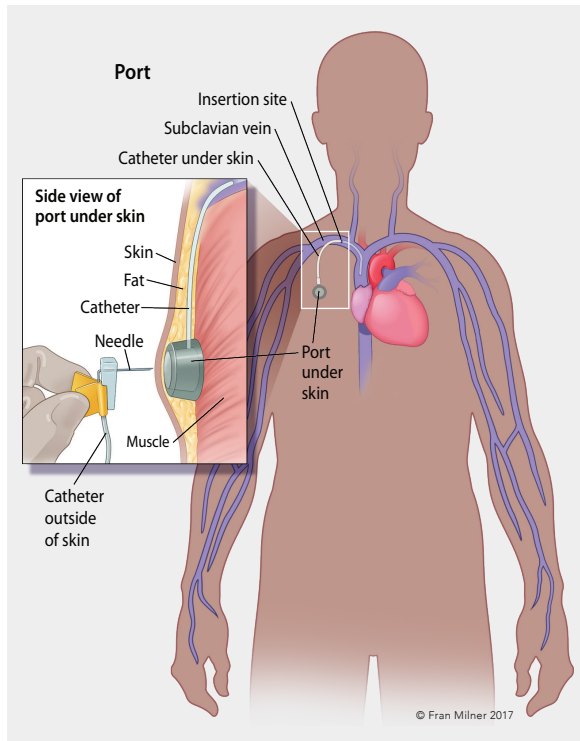
Treatment may be given either at home or in a clinic setting. Some treatment may require a stay in the hospital.

Oral Adherence. Many new myeloma drugs are taken orally (by mouth). “Oral adherence” means staying on a set plan by taking medication in pill or capsule form, as prescribed—on the right day and at the right time. When patients are at home, they must continue taking their medications exactly as prescribed.

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



Port: A port used with a central line.



Clinical Trials

There are new treatments under study for blood cancer patients of all ages. New treatments are studied in clinical trials. Clinical-trial researchers study new uses for approved drugs or treatments, such as changing the dose of the drug, giving the drug along with another type of treatment, or ordering drugs in new sequences. Different approaches may be more effective than established protocols in treating a disease.

There are clinical trials for:

- Newly diagnosed patients
- Patients who did not have a good response to treatment (refractory disease)
- Patients whose disease returned (relapsed disease)
- Patients who continue treatment after remission (no signs and/or symptoms of disease)

The protocols in a carefully conducted clinical trial may provide the best available therapy for you.

Ask your doctor if participating in a clinical trial may be right for you. For more information, please call **(800) 955-4572** to speak with an LLS Information Specialist who can provide more information about clinical trials. Patients and caregivers can work with **Clinical Trial Nurse Navigators** who will help search for clinical trials and personally assist patients and their caregivers throughout the entire clinical-trial process. Visit the Clinical Trial Support Center (CTSC) at www.LLS.org/CTSC for more information.

Blood Cancer in Children, Adolescents and Young Adults

Children, adolescents and young adults will likely face challenges specific to their age-group and often need different treatment plans than adults.

Children and Adolescents

Children and adolescents with blood cancer have special needs for their treatment and care. Usually, specialized cancer centers for children and adolescents can best meet these needs. These centers have pediatric oncologists, doctors who specialize in treating children with cancer.

Children may experience side effects from treatment, both in the short and long term. These effects include secondary cancers, heart disease, thyroid problems and fertility issues. Side effects can affect learning, growth, and social development. They can be managed through specialized care.

When children return to school, families will face new challenges. By being aware of possible side effects, parents can work with teachers and school administrators to help their children cope and manage their schoolwork.

For more on childhood blood cancer:

- Visit www.LLS.org/booklets to view *Learning & Living with Cancer: Advocating for your child's educational needs*.
- Visit www.LLS.org/FamilyWorkbook to find information for children and families.
- Visit www.LLS.org/SurvivorshipWorkbook to view or order the free workbook called *Navigating Life During and After a Blood Cancer Diagnosis*. There are three versions of this workbook: one for adults, one for young adults, and one for parents, children and adolescents.

Older Adolescents and Young Adults (AYA)

The term “older adolescents and young adults (AYA)” generally refers to people aged 15 to 39 years. Historically, the AYA population has been treated with either a pediatric protocol (treatment plan) or an adult protocol, depending on the treatment center. **However, for some blood cancers, such as acute leukemias, researchers have found that patients treated with pediatric protocols have improved rates of survival compared to patients of the same age who are treated with adult protocols.** Therefore, clinical trials are looking into the use of pediatric protocol options for AYA patients.

When an adolescent or young adult gets a blood cancer diagnosis, it may be the first time that they have had to cope with a serious illness. During treatment they may also need to navigate work, school, relationships, and/or caring for small children or aging parents.

For more on AYA blood cancer:

- Visit www.LLS.org/YoungAdults for resources and information.
- Visit www.LLS.org/booklets to view *Young Adults and Cancer*.
- Visit www.LLS.org/teens to view *A Teen's Guide to Everything Cancer*.

Leukemia

Leukemia is a type of blood cancer in which the bone marrow makes too many abnormal white blood cells. The abnormal cells may grow and survive better than normal cells. Over time, the abnormal cells crowd out and slow the development of normal cells.

Leukemia can be acute (severe and sudden onset) or chronic (disease progresses slowly).

The four main subtypes of leukemia include:

- Acute lymphoblastic leukemia (ALL)
- Acute myeloid leukemia (AML)
- Chronic lymphocytic leukemia (CLL)
- Chronic myeloid leukemia (CML)

Risk Factors

- Age—Leukemia is most common in people over 60 years of age. The most common types in adults are AML and CLL. Leukemia is the most common cancer diagnosed in children. Acute lymphoblastic leukemia is the most common form of leukemia in children.
- Sex—Males are more likely than females to develop leukemia.
- Ethnicity/race—CLL incidence is substantially lower among Asians and higher among Ashkenazi Jews. In the United States, ALL is more common in Hispanics and whites.
- Exposure to dangerous chemicals, such as benzene or Agent Orange (a herbicide used in the Vietnam War)
- Smoking
- Previous treatment with chemotherapy or radiation
- Exposure to very high doses of radiation (for example, high doses sustained by survivors of an atomic bomb blast or a nuclear reactor accident).
- Other blood cancers
- Genetic disorders, present at birth
- Family history—People with a first-degree relative who have CLL are at increased risk for CLL.
- Some people are born with certain gene mutations that may increase their risk for leukemia.

Signs and Symptoms

Many signs and symptoms of leukemia are the same as those caused by other illnesses. Most people with these signs or symptoms do not have leukemia.

- Tiredness
- Weakness
- Lightheadedness, dizziness or faintness
- Bone or joint pain
- Bruises 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
- Loss of appetite
- Unexplained weight loss
- Night sweats
- Feeling of fullness below the ribs (due to an enlarged spleen or liver)

Since chronic leukemias develop slowly, some people with chronic leukemia have no signs and/or symptoms at first. They may find out they have chronic leukemia after a routine blood test.

Diagnosing Leukemia

Blood and bone marrow tests are done to look for leukemia cells. A blood cell count may show either high or low numbers of white blood cells. Sometimes, the platelet count and red blood cell count are low. Bone marrow tests (aspiration and biopsy) are often done to look for chromosome abnormalities and the findings are used to confirm a diagnosis of leukemia. Doctors will also use these findings to help determine the leukemia subtype.

Treating Leukemia

There are specific treatments for each type of leukemia. It's very important to know the subtype for treatment planning.

Acute Leukemia. Patients with acute leukemia (ALL and AML) need to start treatment soon after diagnosis. Treatment for acute leukemia is often divided into phases:

- Induction therapy

- Consolidation therapy
- Maintenance therapy

Induction therapy is the first round of treatment with high-dose chemotherapy. Induction therapy is usually given over 4 to 6 weeks in the hospital. The goal of induction therapy is to achieve remission. A complete remission is achieved when the patient no longer has signs and/or symptoms of leukemia.

After induction therapy, some leukemia cells are likely still in the body. Consolidation therapy may include additional chemotherapy, either with or without stem cell transplantation.

Maintenance therapy is often given as an extended, less toxic course of treatment to prevent relapse after completing consolidation therapy. Not all patients will receive maintenance therapy.

Patients with either relapsed or refractory acute leukemia may be treated with:

- The same or different chemotherapy drugs
- Targeted therapies
- Stem cell transplantation
- Immunotherapy, such as chimeric antigen receptor (CAR) T-cell therapy
- Clinical trial

Chronic Leukemia. The goal of treatment for chronic leukemia is often to control and manage the disease so that the patient can return to activities of daily life.

Chronic Myeloid Leukemia. For patients with CML, tyrosine kinase inhibitors (TKIs) are the first line of treatment. These targeted-therapy drugs are taken by mouth. If the first TKI either does not work or causes unbearable side effects, the patient may try a different TKI. It is very important for patients to take TKIs exactly as prescribed by their doctor to achieve the best response. Some patients who meet specific criteria may be able to discontinue medication under their doctor's supervision and monitoring. This is called "treatment-free remission." **For more information, see the "Treatment-Free Remission" section in the free LLS booklet *Chronic Myeloid Leukemia*.**

Although most people with CML have a good response to TKIs, some patients may also receive chemotherapy, either with or without an allogeneic stem cell transplantation.

Chronic Lymphocytic Leukemia. Some patients who have CLL do not need treatment for long periods of time after diagnosis. During this time, (watch and wait) the patient will be closely monitored by their doctor and receive regular blood testing to see if the disease is stable or beginning to progress. Patients who do need treatment may receive chemotherapy, targeted therapy, or monoclonal antibody therapy, either alone or in combination. An allogeneic stem cell transplantation may also be a treatment option for certain high-risk patients, but, usually, it is not the first choice for treatment.

Patients with either relapsed or refractory chronic leukemia may be treated with:

- The same or different chemotherapy and/or other drug therapies
- Stem cell transplantation
- Immunotherapy, such as chimeric antigen receptor (CAR) T-cell therapy
- A clinical trial

Where Can I Learn More About Leukemia?

For more information about leukemia, visit www.LLS.org/booklets to view:

- *Acute Lymphoblastic Leukemia in Adults*
- *Acute Lymphoblastic Leukemia in Children and Teens*
- *The ALL Guide: Information for Patients and Caregivers*
- *Acute Myeloid Leukemia in Adults*
- *Acute Myeloid Leukemia in Children and Teens*
- *The AML Guide: Information for Patients and Caregivers*
- *Chronic Lymphocytic Leukemia*
- *The CLL Guide: Information for Patients and Caregivers*
- *Chronic Myeloid Leukemia*
- *The CML Guide: Information for Patients and Caregivers*

The disease booklets, listed above, contain detailed medical information. The “Guides” provide basic, easy-to-read information. “Fact sheets” are also available that provide information about more subtypes of leukemia.

Lymphoma

Lymphoma develops in a single lymphocyte, a type of white blood cell. Infection-fighting lymphocytes are present in a vast system in the body called the “lymphatic system.” Throughout the lymphatic system there are hundreds of lymph nodes, bean-shaped organs where lymphocytes gather together.

The two main types of lymphoma include:

- Hodgkin lymphoma (HL)
- Non-Hodgkin lymphoma (NHL)

About 82 percent of people with lymphoma have non-Hodgkin lymphoma. The other 18 percent have Hodgkin lymphoma. Some types of lymphoma are curable. Many patients with other types of lymphoma are able to keep their disease under control. These patients can have a good quality of life with medical treatment.

Hodgkin lymphoma is distinguished from other types of lymphoma primarily by the presence of what are called “Reed-Sternberg cells.” These cells are large, abnormal B lymphocytes that often have more than one nucleus and an owl-like appearance. These cells can be observed under a microscope and identified by special tests.

Risk Factors

- Age—HL is most common in adolescent and young adults (aged 15 to 29 years) and older adults (aged 75 to 79 years).
- Sex—HL is slightly more common in males than females.
- Obesity is a risk factor for diffuse large B-cell lymphoma (DLBCL).
- Immune suppression, such as that found in people with rheumatoid arthritis, lupus, HIV/AIDS and organ transplants
- Exposure to certain viruses and bacteria, such as Epstein-Barr virus (EBV), human T-cell lymphotropic virus-1 (HTLV-1), HIV/AIDS, *Helicobacter pylori* (*H pylori*), Hepatitis C, *Borrelia burgdorferi* (*B burgdorferi*), *Chlamydia psittaci* (*C psittaci*), and *Coxiella burnetti* (*C burnetti*)
- Occupational and environmental factors (for example, exposure to agricultural chemicals such as pesticides)
- Genetic disorders present at birth
- Family history

Signs and Symptoms

Many signs and symptoms of lymphoma are the same as those caused by other illnesses. Most people with these signs and/or symptoms do not have lymphoma.

- Swollen lymph nodes
- Fever
- Drenching night sweats
- Loss of appetite
- Weight loss
- Cough and shortness of breath
- Tiredness
- Itchy skin
- Rash
- Stomach pain or swelling and feeling of fullness (due to enlarged spleen)

Diagnosing Lymphoma

Doctors do a test called a “lymph node biopsy” to find out if a patient has lymphoma. For a lymph node biopsy, a surgeon uses a special needle to remove either all or part of an enlarged lymph node. The cells of the node are examined under a microscope to identify the disease. The doctor will order other tests to determine the stage of the disease (how far the disease has spread). These tests may include blood tests, bone marrow tests, imaging tests and heart and lung tests.

Treating Lymphoma

There are specific treatments for each type of lymphoma. It's very important to know the lymphoma subtype before planning treatment.

Hodgkin Lymphoma. Combination chemotherapy (treatment using more than one drug) is the most common treatment for Hodgkin lymphoma. Some patients may receive radiation therapy in addition to chemotherapy. Participation in a clinical trial is also an option. For patients with either relapsed or refractory disease, doctors may recommend a stem cell transplantation.

Non-Hodgkin Lymphoma. There are many different subtypes of NHL. The doctor has to take into account many factors to make a treatment plan for a patient with NHL, including:

- The subtype of NHL
- The stage and category of disease

- Factors such as fever, drenching night sweats and weight loss of more than 10 percent of body weight, referred to as “B symptoms”
- The presence of lymphoma in areas of the body outside the lymph nodes
- The patient’s overall health

Types of treatment include:

- The watch-and-wait approach (for slow-growing subtypes)
- Chemotherapy (the main type of treatment for NHL)
- Drug therapy
- Radiation therapy along with chemotherapy
- Stem cell transplantation
- Immunotherapy
- A clinical trial

Patients with either relapsed or refractory non-Hodgkin’s lymphoma may be treated with:

- Different chemotherapy or other drugs
- CAR T-cell therapy
- Stem cell transplantation
- A clinical trial

Where Can I Learn More About Lymphoma?

For more information about lymphoma, visit www.LLS.org/booklets to view:

- *Hodgkin Lymphoma*
- *The Lymphoma Guide*
- *Non-Hodgkin Lymphoma*

Hodgkin Lymphoma and *Non-Hodgkin Lymphoma* are disease booklets that contain detailed medical information. *The Lymphoma Guide* provides basic, easy-to-read information. Other booklets and fact sheets are also available that provide information about other lymphoma subtypes.

Myeloma

Myeloma starts with a change to a single plasma B cell. Plasma cells are a type of white blood cell that make antibodies to help the body fight infection. Instead of producing helpful antibodies that fight infection, the myeloma cells produce abnormal antibodies that are not needed by the body and do not help fight infection. These abnormal antibodies can also damage the kidneys.

While myeloma cells are most commonly found in the bone marrow, they may collect in other parts of the body and build up forming cell masses, called “plasmacytomas.” Plasmacytomas most commonly occur in the bones, skin, muscles, or lungs.

If the myeloma cells form a single cell mass, it is called a “solitary plasmacytoma.” Myeloma that is found in several areas of the body is called “multiple myeloma” Most patients with myeloma have multiple myeloma.

The term “smoldering myeloma” refers to a slow-growing type of myeloma. Usually, there are no signs and/or symptoms at diagnosis, and patients do not need to start treatment right away.

Risk Factors

- Age—Most people who develop myeloma are older than 50 years of age.
- Sex—More males than females develop myeloma.
- Race—Blacks are more likely to develop myeloma than whites.
- Medical history—The incidence is higher in people with a history of monoclonal gammopathy of unknown significance (MGUS).
- Environmental factors—Some studies are investigating a link between the development of myeloma and exposure to radiation or certain kinds of chemicals, such as pesticides, fertilizers and Agent Orange.
- Obesity—Research suggests that obese people have a higher incidence of myeloma.
- Firefighting—Some studies indicate that firefighters are at a higher risk for many types of cancer, including myeloma.
- Presence of chronic immunodeficiency
- Presence of known inflammatory diseases or conditions (for example, cardiovascular disease or type II diabetes)

Signs and Symptoms

In the early stages of myeloma, some people have no signs or symptoms of the disease. These people may find out they have myeloma after a regular medical checkup that shows changes in their blood and/or urine.

When people do have signs and/or symptoms of myeloma, the most common include:

- Fatigue, severe tiredness
- Bone pain or bone fractures with no known cause

Doctors sometimes use the acronym CRAB to describe signs of myeloma. The letters stand for:

- **C**—Calcium elevation: high levels of calcium in the blood, also known as hypercalcemia
- **R**—Renal failure: poor function of the kidneys that may be caused by deposits of myeloma protein in the kidneys
- **A**—Anemia: low red blood cell count
- **B**—Bone abnormalities called “lesions”

Treatment is usually recommended for patients who have one or more of these four signs.

Diagnosing Myeloma

A myeloma diagnosis is based on the results of blood and urine tests, bone marrow tests, and imaging tests. Tests are done to see if a protein called “monoclonal protein (M protein)” is present in the patient’s blood and urine. M protein is an antibody found in large amounts in either the blood or urine of people with myeloma. Measuring the amount of M protein is one way to tell the severity (in cancer, this is called the “stage”) of the myeloma. Other proteins, called “light chains” (also known as “Bence Jones proteins”), may be found in a myeloma patient’s urine. A special test is used to check for light chains. It is called a “serum free light chain test.” Imaging tests are used to examine the bones and check for decreased bone density, bone lesions, holes or breaks, or thinning of the bones.

Treating Myeloma

While there is no cure for myeloma, new treatments have improved patient quality of life and survival rates. The goals of myeloma treatment are to:

- Slow the growth of myeloma cells
- Reduce symptoms such as bone pain and fatigue
- Provide long periods of remission (when there are no signs of myeloma and/or the myeloma is not causing health problems)
- Lengthen survival time while preserving quality of life

The treatment plan for a patient depends on the type and stage of myeloma; the patient's age; and the patient's overall health.

Types of treatment include:

- The watch-and-wait approach for smoldering myeloma
- Combination drug therapy
- High-dose chemotherapy followed by a stem cell transplantation
- Immunotherapy, such as chimeric antigen receptor (CAR) T-cell therapy
- Radiation therapy for patients with localized disease
- A clinical trial

After a time, almost all myeloma patients experience a relapse (the cancer returns after treatment). If, initially, the patient had a good response to treatment with a particular drug or combination of drugs, those same drugs may be used to treat a disease relapse. Or, the patient may try a different drug or combination of drugs or may choose to participate in a clinical trial.

Where Can I Learn More About Myeloma?

For more information about myeloma, visit www.LLS.org/booklets to view the following free LLS booklets:

- *Myeloma*
- *The Myeloma Guide: Information for Patients and Caregivers*

Myeloma, the disease booklet, contains detailed medical information. *The Myeloma Guide* provides basic, easy-to-read information.

Myelodysplastic Syndromes

Myelodysplastic syndromes (MDS) are a group of blood cancers that start in the bone marrow with a change to a single stem cell. A normal stem cell mutates (changes) and the mutated cell multiplies into many MDS cells.

There are two types of MDS:

- Primary (no cause can be identified)
- Secondary (treatment-related and less common)

Most people diagnosed with MDS have primary MDS.

Risk Factors

- Age—The risk of developing MDS increases with age.
- Sex—Males are more likely than females to develop MDS.
- Prior cancer treatments—Some types of chemotherapy and radiation therapy may increase a person’s risk of developing MDS. This is called “secondary MDS” or “treatment-related” MDS.
- Genetic disorders present since birth
- Smoking and exposure to tobacco smoke
- Long-term workplace exposure to benzene among agricultural and industrial workers

Signs and Symptoms

- Tiredness
- Dizziness
- Shortness of breath
- Headaches
- Pale skin
- Frequent infections
- Fever
- Bruising easily
- Frequent and/or severe bleeding

Diagnosing MDS

An MDS diagnosis is established based on findings from a patient's blood and bone marrow tests.

Treating MDS

The treatment plan depends on the patient's MDS subtype, prognostic score and other factors, such as age and overall health. Patients who have symptoms caused by low blood cell counts are given supportive care to relieve symptoms. Drug therapy may be used to slow progression of the disease. Some patients can be cured with a stem cell transplant. Treatments for myelodysplastic syndromes include:

- Supportive care to address low blood cell counts
- The watch-and-wait approach
- Drug therapy
- Stem cell transplant
- Clinical-trial protocols

In the case of disease relapse, patients should repeat genetic testing because it is possible for patients to have new genetic changes. The results of the testing can help with treatment planning.

Where Can I Learn More About MDS?

For more information about MDS, visit www.LLS.org/booklets to view the free LLS booklets:

- *Myelodysplastic Syndromes*
- *The MDS Guide: Information for Patients and Caregivers*

Myelodysplastic Syndromes, the disease booklet, contains detailed medical information. *The MDS Guide* provides basic, easy-to-read information.

Myeloproliferative Neoplasms

Myeloproliferative neoplasms (MPNs) are a group of blood cancers in which the bone marrow overproduces one or more types of blood cells—red blood cells, white blood cells or platelets. MPNs usually develop slowly, over time, and different types of MPNs affect different types of blood cells.

Three classic types of MPNs are traditionally grouped together. They include:

- **Polycythemia vera (PV)**—This MPN leads to the overproduction of red blood cells in the bone marrow. These blood cells build up in the bone marrow and blood, causing the blood to thicken.
- **Essential thrombocythemia (ET)**—This MPN leads to the overproduction of platelets in the bone marrow. Too many platelets in the bloodstream may cause them to clump together and make it difficult for the blood to flow and may lead to the formation of a blood clot (thrombus).
- **Myelofibrosis (MF)**—This MPN leads to the buildup of scar tissue, called “fibrosis,” in the bone marrow. As the scar tissue builds up, the bone marrow cannot make enough healthy blood cells. The spleen and liver may start producing blood cells so these organs begin to increase in size.

Risk Factors

- **Age**—PV most often occurs in individuals who are over 60 years of age. The median age of diagnosis for ET falls between 50 and 60 years of age, although young people can develop it as well. Myelofibrosis is most commonly diagnosed in people aged 50 years and older.
- **Sex**—Males are more likely than females to develop PV. Females are more likely to be diagnosed with ET than males.
- **Prior MPN**—In a small number of patients, MF develops from PV or ET.
- **Family history**—PV and ET have been found to run in families in some cases. However, it may be the increased risk, not the disease itself, that is inherited.
- **Exposure to certain chemicals**, such as benzene and toluene, can increase the risk of MF.
- **Exposure to very high levels of radiation** (for example, an atomic bomb blast or nuclear reactor accident) can increase the risk of MF.

Signs and Symptoms

Polycythemia vera, ET and MF develop slowly and may not cause symptoms for many years. In many cases, MPNs are diagnosed based on findings from a blood test that was done for another reason. Symptoms differ depending on the specific type of MPN.

Signs and symptoms of MPNs include:

- Tiredness
- Itchy skin
- Reddened face and burning feeling on the skin
- Headaches, dizziness, weakness
- Difficulty concentrating
- Night sweats
- Insomnia
- Vision changes
- Ringing in the ears
- Shortness of breath
- Chest pain
- Bleeding or bruising easily
- Fever
- Frequent infections
- Numbness or tingling in the feet (peripheral neuropathy)
- Swelling and pain in the stomach
- Feeling of “fullness” after eating small amounts of food
- Weight loss
- Bone pain

The signs and symptoms of ET are linked to high platelet counts that cause the development of a blood clot (thrombus). The signs and/or symptoms of a blood clot include:

- Pain, swelling and redness in the arms or legs (due to deep vein thrombosis [DVT], a blood clot that develops in a vein that is deep inside the body)
- Shortness of breath, chest pain and cough (due to a pulmonary embolism, a blood clot in the lungs)
- Chest pain, shortness of breath and nausea (due to a heart attack caused by a blood clot)
- Headaches, dizziness, weakness or numbness on one side of the body, blurred or double vision, slurred speech (due to a stroke, caused by a blood clot that stops blood flow to the brain)

Diagnosing MPNs

An MPN diagnosis is established based on findings from a patient's blood and bone marrow tests. Molecular testing to check for JAK2 gene mutations or other mutations should also be performed. If possible, it is important to see an oncologist who specializes in treating patients who have an MPN.

Treating MPNs

There are specific treatments for each type MPN so it's very important to know the type of MPN before planning treatment.

JAK Inhibitors. The cause of MPNs is not fully understood. Researchers believe that proteins known as “Janus kinases (JAKs)” are involved. These proteins send signals that affect the production of blood cells. When JAKs send too many signals, too many blood cells are made. Drugs called “JAK inhibitors” are often used in the treatment of MPNs. These drugs work by reducing the signals sent by JAK proteins.

Polycythemia Vera (PV). The goal of PV treatment is to reduce the risks of blood clots (thrombi) and to manage symptoms by lowering the number of excess blood cells. Treatments include:

- Monitoring for blood clots or bleeding
- Managing risk of heart problems
- Low-dose aspirin
- Taking blood from a vein, similar to what is done when donating blood (phlebotomy)
- Medications to reduce the number of blood cells (cytoreductive therapy), including JAK inhibitors and chemotherapy
- Antihistamines, light therapy or other medications to reduce itching

Essential Thrombocythemia (ET). The goal of ET treatment is to prevent blood clots (thrombi). Treatments include:

- The watch-and-wait approach
- Low-dose aspirin, either with or without cytoreductive therapy
- Drawing blood through a vein and passing it through a machine to remove the platelets (platelet pheresis) in emergency situations
- Imaging tests to check for blood clots
- Managing risks of heart problems

Myelofibrosis (MF). The only treatment that can potentially cure MF is an allogeneic stem cell transplantation. However, this procedure is very risky for older patients and patients with other health problems. For most patients the goal of MF treatment is to manage symptoms and improve quality of life. Treatments include:

- The watch-and-wait approach
- Cytoreductive therapy, including JAK inhibitors and chemotherapy
- Treatment for anemia
- Surgery to remove the spleen
- Embolization of the spleen (injection to block blood flow to the spleen)
- Radiation therapy to shrink the spleen
- Allogeneic stem cell transplantation

Where Can I Learn More About MPNs?

For more information about MPNs, visit www.LLS.org/booklets to view the free LLS booklet:

- *Myeloproliferative Neoplasms: Myelofibrosis, Polycythemia Vera, and Essential Thrombocythemia*

Side Effects and Follow-up Care

Side Effects

The term “side effect” describes the way that a treatment affects healthy cells and often defines the negative or undesirable effects from a treatment.

Treatment side effects depend on the type of treatment. For example, the side effects of chemotherapy are different from the side effects of targeted therapies. Patients also react to treatments in different ways. Sometimes there are very mild side effects. Other side effects may be uncomfortable and difficult. Usually, side effects go away once treatment ends. Some side effects are serious, however, and they may last for a long time.

Patients with blood cancer should talk with their doctors about side effects before they begin any type of treatment.

Some side effects of blood cancer and treatment include:

- Low blood cell counts
 - Anemia (low number of red blood cells)
 - Thrombocytopenia (low number of platelets), which can cause bleeding issues
 - Neutropenia (low number of neutrophils, a type of white blood cell), which may lead to infections
- Constipation
- Hair loss
- Rashes or other skin changes
- Nausea
- Vomiting
- Joint pain
- Peripheral neuropathy (numbness, tingling or muscle weakness in the hands or feet)
- Fatigue
- Cognitive (thinking) changes
- Mouth sores
- Weight loss
- Diarrhea
- Weight gain

Not all patients will experience these side effects. Treatments to manage or prevent side effects can help patients feel more comfortable. There may be other side effects not listed here. Talk to your doctor about the possible side effects of your treatment.

For more information, see the full *Side-Effect Management* series at www.LLS.org/booklets (filter by “Side-Effect Management”).

Long-Term and Late Effects

Long-term effects are side effects of treatment that may last for months or even 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.

Long-term and late effects may include:

- Fatigue
- Neuropathy (nerve damage)
- Heart disease
- Thyroid problems
- Organ damage (lungs, kidneys)
- Bone issues, such as osteoporosis
- Fertility problems
- Secondary cancer
- Cognitive (thinking) changes
- Depression or symptoms of depression
- Anxiety disorder
- Post-traumatic stress disorder (PTSD)
- Other conditions

Children treated for blood cancer may also experience:

- Growth problems
- Learning problems

Not everyone who is treated for blood cancer 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.

To collect all the important information you need throughout diagnosis, treatment, follow-up care and long-term management of a blood cancer, visit www.LLS.org/SurvivorshipWorkbook to view the free LLS booklet *Navigating Life During and After a Blood Cancer Diagnosis*. There are three versions of this workbook: one for adults, one for young adults, and one for parents, children and adolescents.

Follow-up Care

Medical follow-up care is important for every blood cancer patient. Follow-up care helps the doctor see if the disease has either recurred or relapsed and allows the doctor to evaluate the patient for long-term and late effects.

Adults and children who have been treated for blood cancer should be seen by their primary care doctors and their hematologist-oncologists (cancer specialists) regularly for follow-up care. Patients should talk with their doctor about how often to have follow-up visits. Ask the doctor what tests will be needed and find out how often these tests should be done.

It is important to get and keep a record of cancer treatment, including the specific drugs and dosages used. This is so that the doctor can follow up on specific long-term effects that may be associated with treatment. Patients may also be able to access (and/or print out) these records via an online patient portal associated with their treatment center or healthcare team. If you are a patient, ask how you can access it.

Follow-up care includes physical exams and blood tests. Sometimes bone marrow tests are also needed. The doctor may advise longer periods of time between follow-up visits. This will happen if a patient:

- Continues to be free of signs and/or symptoms of blood cancer
- Does not need medical care for any long-term or late side effects

Survivorship Clinics. Survivorship clinics provide services that help cancer patients manage issues related to surviving cancer. A survivorship clinic may help patients deal with physical and emotional changes that may occur after cancer treatment. To find a survivorship clinic and other resources for child and adult survivors, ask the healthcare team for a referral, or contact an LLS Information Specialist at **(800) 955-4572**.

Take Care of Yourself

If you are a patient, here are some ways you can take care of yourself:

- Keep all your appointments with your doctor.
- Talk with the doctor about how you feel at each visit.
- Ask any questions you may have about side effects.
- People with a blood cancer may have more infections. Follow your doctor's advice for preventing infection.

- Eat healthy foods each day. It may help to eat four or five smaller meals instead of three larger ones.
- Contact your doctor if you feel tired, have a fever, or experience other symptoms.
- Do not smoke. Patients who smoke should get help to quit.
- Get enough rest and exercise. Check 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 your healthcare needs.
- Talk with family and friends about how you feel and about your treatment. When family and friends know about blood cancer and its treatment, they may worry less.
- Seek medical advice if you feel either sad and/or depressed and your mood does not improve over time. If you feel sad and/or depressed every day for a 2-week period, seek help. Depression is an illness. It should be treated—even when a person is being treated for blood cancer. Treatment for depression has benefits for people living with cancer.

For more ways to care for yourself, see the free LLS booklet *Healthy Behaviors*.

Health Terms

Anemia. A condition caused by a low number of red blood cells.

Antibody. A protein made by plasma cells. Antibodies help fight infection in the body.

Bence Jones protein. An abnormal protein made by myeloma cells. It is found in the urine of most patients with myeloma. It is also called **light chains** protein.

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

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

Bone marrow biopsy. A procedure to remove and examine bone marrow cells to see if they are normal. A very small amount of bone filled with bone marrow cells is taken from the body and the cells are looked at under a microscope.

Central line. A special tube (catheter) the doctor puts into a large vein of the patient. The vein is usually in the upper chest. The central line is used to give the patient chemotherapy drugs and blood cells. It can also be used to take blood samples from the patient.

Chemotherapy or drug therapy. Treatment that stops the growth of cancer cells, either by killing the cancer cells or by stopping them from dividing.

Chimeric antigen receptor (CAR) T-cell therapy. 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.

Chromosomes. Threadlike structures within cells that carry genes. Human cells have 23 pairs of chromosomes. The number or shape of chromosomes may be changed in blood cancer cells.

Clinical trial. A careful study done by doctors to test new drugs or treatments or new uses for approved drugs or treatments. The goal of clinical trials for blood cancers is to improve treatment and quality of life and to find cures.

Complete blood cell count. A test used to count the numbers of red blood cells, white blood cells and platelets in a blood sample.

Diagnose. To detect a disease based on a patient's signs, symptoms and test results. The doctor diagnoses a disease in a patient.

DNA. The molecules inside cells that carry genetic information and pass it from one generation to the next. DNA stands for "deoxyribonucleic acid."

Fertility. Ability to have biological children.

Hematologist. A doctor who treats blood diseases.

Hematologist-oncologist. A doctor who has special training in the diagnosis and treatment of blood cancers.

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

Immunotherapy. A type of therapy that either stimulates or suppresses the immune system to help the body fight cancer, infection, or other diseases.

Karyotype. An organized “map” of a person’s chromosomes. It exhibits the size, shape and number of chromosomes in a sample of cells.

Lymph node. Small bean-shaped structure that contains a large number of lymphocytes (white blood cells). Lymph nodes are a part of the body’s immune system. There are about 600 lymph nodes in the body.

Lymphatic system. The system that connects the lymph nodes. This network runs all throughout the body to carry infection-fighting cells. It is an important part of the immune system.

Lymphocyte. A type of white blood cell that is part of the immune system and fights infection.

Monoclonal antibody therapy. A treatment that targets and kills certain cancer cells. In general, it does not cause as many side effects as chemotherapy.

Monoclonal (M) protein. Short for monoclonal immunoglobulin, an abnormal protein made by myeloma cells. The amount of M protein in the blood can be measured. This measure is used to help estimate the seriousness of the myeloma.

Neutropenia. Condition caused by a low number of neutrophils, a type of white blood cell, which may lead to infections.

Oncologist. A doctor with special training for treating people who have cancer.

Palliative care. Specialized medical care focused on providing relief from the symptoms and stress of a serious illness. The goal of palliative (supportive) care is to improve quality of life for both the patient and the family.

Plasma. The liquid part of the blood.

Plasmacytoma. A mass made up of abnormal plasma B cells (myeloma cells).

Platelet. A type of blood cell that helps prevent bleeding. Platelets cause plugs clots to form in the blood vessels at the site of an injury.

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

Red blood cell. The type of blood cell that carries oxygen to all parts of the body. In healthy people, red blood cells make up almost half of the blood.

Refractory disease. Disease that has not responded to initial treatment. Refractory disease is disease that is either getting worse or staying the same (stable disease).

Relapsed disease. Disease that responded to treatment at first, but then returned.

Remission. A state when signs and/or symptoms of a disease disappear, usually following treatment.

Spleen. An organ on the left side of the body near the stomach. It contains lymphocytes and removes old or damaged cells from the blood.

Stem cell. A type of cell found in the bone marrow that will mature into a red blood cell, white blood cell or platelet.

Stem cell transplantation. A treatment that uses healthy stem cells to restore a patient's bone marrow that is damaged after receiving intensive chemotherapy and/or radiation therapy.

Targeted therapy. A type of treatment that uses drugs or other substances to target specific molecules that cancer cells need to survive and spread.

Thrombocytopenia. Condition caused by a low number of platelets, which can cause bleeding issues.

Tyrosine kinase inhibitor (TKI). A drug that blocks cell growth. Tyrosine kinase inhibitors are used to treat chronic myeloid leukemia.

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

Questions to Ask Members of Your Healthcare Team

Talk with the doctor and ask questions about how they plan to treat your (or your loved one's) blood cancer. This will help you to be actively involved in making decisions about medical care. You may want to ask members of your (or your loved one's) healthcare team some of the following questions.

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 have to make decisions?
5. What is my subtype?
6. What is the goal of treatment?
7. What are the treatment options?
8. Are there any clinical trials I could join?
9. When do you think treatment should begin?
10. How long will treatment last?
11. What are the benefits and risks of these treatments?
12. Is any one treatment recommended over the others?
13. How can potential side effects be prevented or managed?

Testing

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

Treatment

1. Will this treatment require a hospital stay?
2. Will going to work or attending school during treatment be a possibility?
3. Will I need someone to drive me home after treatment?
4. How will I know if the treatment is effective? What options are available if the treatment is not effective?
5. 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 my 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 find out if insurance will cover the costs of the treatment or the study (clinical trial) treatment?
4. Who is the best person to speak to about bills and insurance coverage?
5. If I do not have insurance coverage, how can the healthcare team help me get the treatment needed? Is there someone I can speak to for assistance?
6. If I get into a clinical trial, will I be responsible for paying treatment-related costs, such as tests, travel or clinical-trial drugs?

Follow-up Care and Long-term and Late Effects

1. Who should I work with to ensure lifelong follow-up care?
2. Will I 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 there are side effects later, how can I reach the healthcare team?
6. What information can my cancer care team provide to my primary care doctor about my cancer and treatment?

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

Resources and Information

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

For Help and Information

Consult with an Information Specialist. Information Specialists can assist you through cancer treatment, financial and social challenges and give accurate, up-to-date disease, treatment and support information. Our Information Specialists are highly trained oncology social workers and nurses. Language services are available. For more information, please:

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

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

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

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

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

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

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

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

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

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

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

Free Mobile Apps.

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

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

Connecting with Patients, Caregivers, and Community Resources

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

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

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

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

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

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

Additional Help

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; to airborne hazards and burn pits while serving in Iraq, Afghanistan and other areas of Southwest Asia; to contaminated water at Camp Lejeune between 1953-1987; or to ionizing radiation during service 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: <https://www.va.gov/disability/eligibility/hazardous-materials-exposure/>

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

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

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

For more information, please

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

Help with 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

Get support.
Reach out to our
Information Specialists.



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

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

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

(Language interpreters
can be requested.)



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

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

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