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Introduction

This booklet was first written in 1980 by a registered nurse and social worker who were committed to the idea that patients who have a better understanding of leukemia can manage their disease. The information in this booklet has since been revised to include new concepts and discoveries in the treatment and support of patients with leukemia.

This booklet was written for you and your family. We hope it helps you to take an active role in your care. Your understanding of leukemia is important in helping you make treatment decisions and making the unknown less frightening.

Cancer is a very complex and serious illness. The skill and knowledge of many experts is available to provide you with the best possible care. The “team approach” plan is an important role in the treatment of leukemia at M. D. Anderson.

The health care team at M. D. Anderson Cancer Center dedicates itself to helping you and your family understand leukemia and supporting you throughout your treatment. Please talk with us about your questions and concerns.

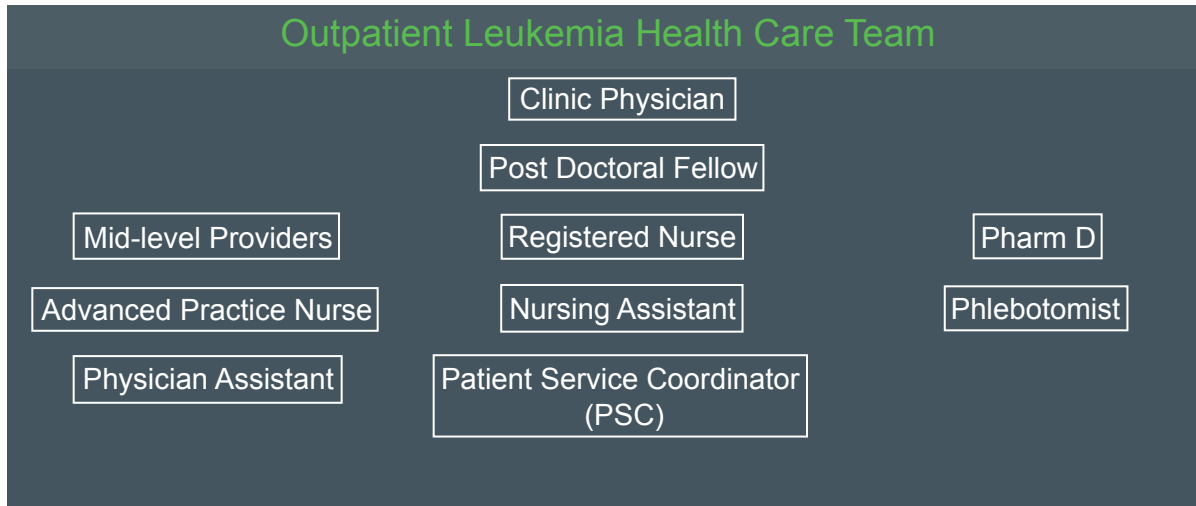
Sometimes a place the size of M. D. Anderson can be overwhelming and anxiety is a normal reaction. The clinic staff will do everything possible to assist you, teach you and answer your questions.

We dedicate this book to the memory of Kenneth B. McCredie MB, ChB., former Chief of the Leukemia Services at M. D. Anderson.

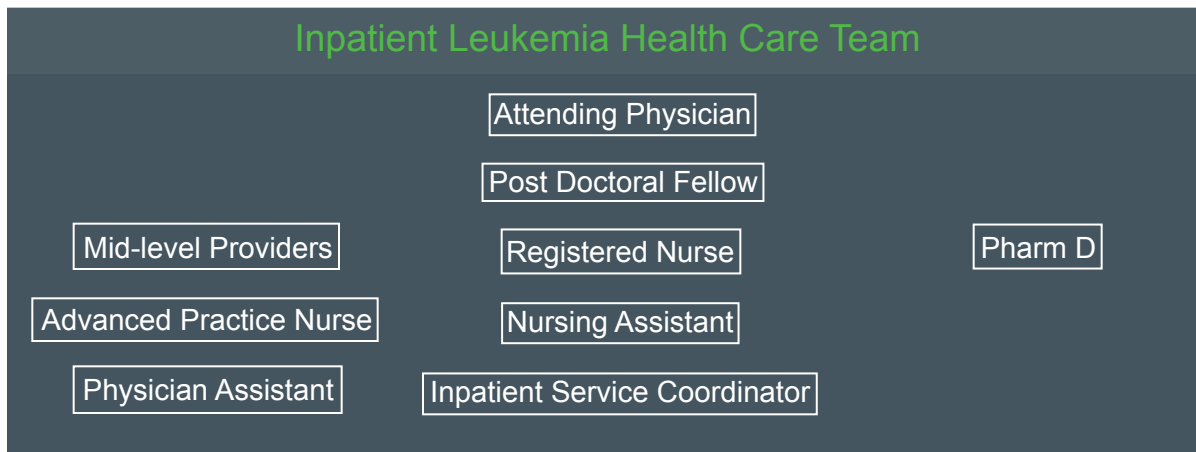
M. D. Anderson Cancer Center

M. D. Anderson's Adult Leukemia Service consists of two areas, the outpatient and inpatient care areas. The services that are provided and those responsible for your care are highlighted below.

Outpatient Leukemia Health Care Team



Inpatient Leukemia Health Care Team



Supportive Care Team



Outpatient Care

When you first arrive at M.D. Anderson Cancer Center, or after you are discharged from the inpatient care area, you will be seen by a primary health care team. Your primary health care team will include your primary doctor from the Leukemia Center, who will be responsible for your care throughout your outpatient treatment. He or she will make most of the treatment decisions with you. As part of your health care team, you may also have an **Advanced Practice Nurse (APN)** or a **Physician's Assistant (PA)**.

You will have a clinic nurse who will assist your doctor in managing your care during each clinic visit. Your clinic nurse will give you a business card or letter with the clinic phone numbers that you can call with questions or problems. Someone will be available in the Leukemia Center to help you Monday through Friday, from 8 a.m. until 5 p.m., at (713) 792-8760. If you need to speak to someone on the weekend, during holidays or after hours, call your doctor or midlevel provider or come to the Emergency Center. It is important that you count your pills at the beginning of each week to be sure you do not run out. If you are low on pills, call the clinic at (713) 792-8760 and ask for a refill.

myMDAnderson is a secure, personalized website for registered patients. It provides a convenient way to communicate with your care team regarding appointments and schedules, billing, prescriptions, and information updates. If you would like access to *myMDAnderson*, please see the front desk at the Leukemia Center to receive your login and password instructions. The URL (website address) for *myMDAnderson* is <https://my.mdanderson.org>.

The patient appointment line is another way for you to get your schedule after hours. To do so, you can call (713) 792-7000 or 1-800-889-2094.

The morning of your appointment, you will be scheduled for lab tests and/or a bone marrow aspiration. Your primary doctor may see you the morning or afternoon depending upon when the results of these tests are ready. He or she will discuss your treatment plan with you at that time. After reviewing the results with you, you and your doctor may decide that chemotherapy, a blood transfusion or other treatments are needed. If so, they will be given to you in our Ambulatory Treatment Center's Bed (ATC-B) or Transfusion unit (ATC-TU). After you see your doctor, you will be given a computer printout with the dates, times and places of your next appointments and treatments. This information can also be mailed to you. Please remember to always refer to your patient appointment letter (PAL) for the time and location of your appointments.

The Leukemia Center has a **Fast Track Laboratory Center** located in the Main Building on Floor 8 near Elevator B (within the Leukemia Center) where blood results are obtained within one to two hours and reviewed with you by an advanced practice nurse or physician's assistant. If appropriate, blood or platelet transfusions, potassium or magnesium infusions or other treatments will be ordered early each day. Prescriptions can also be renewed.

A major side effect of chemotherapy is infection. Symptoms of infection include:

- A fever of 101° F (38.3° C) or more for longer than two hours
- Severe chills
- Sudden onset of feeling bad, even if you do not have a fever

If you have any of the symptoms listed above or uncontrolled bleeding, go to the Emergency Center in the Main Building on Floor 1.

Inpatient Care

While you are in the hospital, the inpatient health care team is responsible for your care. A staff physician on the Leukemia Service, called your **Attending Physician**, is the doctor who will coordinate your care and make treatment decisions while you are an inpatient in the hospital. A **Fellow** is a physician who is getting special training in oncology, the study of cancer. They will communicate with your primary physician and discharge you to him or her when you have improved.

Besides the doctors, there are many other members of the health care team who take part in your care. Each patient is assigned a mid-level provider who may be either an advanced practice nurse (APN) or physician assistant (PA). Other members include nurses, dietitians, pharmacists, the infusion therapy team, a dental oncologist, a physical therapist, social workers and chaplains. For example, the pharmacist will assist you with your medications and discharge prescriptions. The advanced practice nurse assists the physician in your care, providing education and coordination of your health care needs.

Members of the health care team will come to see you every day to discuss your treatment plans, your current health status and any questions or concerns you may have. It is easy to forget any questions you may have when the health care team comes to see you. For this reason, you may want to keep a notebook to write down your questions and concerns as they occur to you.

Each night there are doctors who stay in the hospital “on call.” If you need medical attention during the night, the doctor on call will care for you. This doctor will have read the daily notes your attending physician and fellow recorded on your chart.

Upon discharge, you may need to take some medications home with you. Your health care team will arrange for you to have a one or two week supply, with refills available. Medications cannot be returned once you take them from the hospital, so it is best to get a small supply and get refills as needed.

What are the types of leukemia?

Leukemia is cancer of blood-forming tissue such as the bone marrow. Types of leukemia are grouped by the type of cell affected and by the rate of cell growth. Leukemia is either acute or chronic.

- **Acute leukemia** involves an overgrowth of very immature blood cells. This condition is life threatening because there are not enough mature blood cells to prevent anemia, infection and bleeding. A diagnosis of acute leukemia is made when there are 20 percent or more blasts or immature cells in the bone marrow.
- **Myelodysplastic Syndrome (MDS)** is a condition in which the bone marrow does not function normally and therefore does not produce enough normal blood cells. The blood cells affected are white blood cells, red blood cells and platelets. Some cases of MDS may, over time, progress to acute leukemia.
- **Chronic leukemia** involves an overgrowth of mature blood cells. Usually, people with chronic leukemia have enough mature blood cells to prevent serious bleeding and infection.

The types of leukemia tend to be linked with certain age groups. Acute lymphoblastic leukemia is most common during childhood and in early adulthood, although it is also diagnosed in adults 30 years old and older. Acute myelogenous leukemia occurs more often in adults. Chronic leukemia is more common between ages 40 and 70 and is rare among young people. MDS is most often found in patients nearing their 60's and 70's. However, there are always exceptions.

When your doctor is looking for a specific type of leukemia, he or she will look at chromosome number and appearance, features on the bone marrow cell surface and the appearance of the bone marrow cells under a microscope. The following is a list of the different types of leukemia.

Acute Leukemias

- Acute Undifferentiated Leukemia
- Acute Myelogenous Leukemia (AML)
- AML with recurrent genetic abnormalities
 - AML with t(8;21)(q22;q22)
 - AML with abnormal bone marrow eosinophils and inv (16) (p13q22) or t(16;16)(p13;q22)
 - Acute promyelocytic leukemia with t(15;17)(q22;q12), (PML/RAR alpha) and variants
 - AML with 11q23 (MLL) abnormalities
- AML with multilineage dysplasia
 - Following MDS or MDS/MPD
 - Dysplasia in at least 50% of cells in two or more myeloid lineages
- AML and MDS, therapy-related
 - Alkylating agent/radiation-related type
 - Topoisomerase II inhibitor-related type
 - Others
- AML, not otherwise categorized
Classified as:
 - AML, minimally differentiated
 - AML without maturation
 - AML with maturation
 - Acute myelomonocytic leukemia
 - Acute monoblastic/acute monocytic leukemia
- Acute erythroid leukemia
- Acute megakaryoblastic leukemia
- Acute basophilic leukemia
- Acute panmyelosis with myelofibrosis
- Myeloid sarcoma
- Acute Lymphoblastic Leukemia (ALL) and Lymphoblastic Lymphoma

Myelodysplastic Syndromes

- Refractory Anemia
- Refractory cytopenia with multilineage dysplasia
- Refractory anemia with ringed sideroblasts
- Myelodysplastic syndrome, unclassified
- Myelodysplastic syndrome associated with del(5q)
- Refractory Anemia with Excess Blasts (RAEB)

Chronic Leukemias

- Chronic Lymphocytic Leukemia (CLL)
 - Hairy Cell Leukemia
 - Mantle Cell Leukemia
 - Marginal Zone Leukemia
 - Splenic Lymphoma with Villous Lymphocytes
- Chronic Myelogenous Leukemia (CML)
- Myeloproliferative Syndromes
 - Polycythemia Vera
 - Essential Thrombocytosis
 - Idiopathic Myelofibrosis
 - Hypereosinophilic syndrome (HES)
 - Systemic Mastocytosis
- Other conditions
 - Aplastic anemia

What causes leukemia?

The specific cause of leukemia is still not known. Scientists suspect that viral, genetic, environmental or immunologic factors may be involved.

Some **viruses** cause leukemia in animals, but in humans, viruses cause only one rare type of leukemia. Even if a virus is involved, leukemia is not contagious. It cannot spread from one person to another. There is no increased occurrence of leukemia among people such as friends, family and caregivers who have close contact with leukemia patients.

There may be a **genetic predisposition** to leukemia. There are rare families where people born with chromosome damage may have genes that increase their chances of developing leukemia.

Environmental factors, such as high-dose radiation and exposure to certain toxic chemicals have been directly related to leukemia. But this has been true only in extreme cases, such as atomic bomb survivors in Nagasaki and Hiroshima or industrial workers exposed to benzene. Exposure to ordinary x-rays, like chest x-rays, is not believed to be dangerous.

People with **immune-system deficiencies** appear to be at greater risk for cancer because of the body's decreased ability to resist foreign cells. There is evidence that patients treated for other types of cancer with some types of chemotherapy and/or high-dose radiation therapy may later develop leukemia.

All of these factors may explain why a small number of people develop leukemia. But, among most people, the cause of leukemia is not known.

How is leukemia diagnosed?

The diagnosis of leukemia is based on the results of both blood and bone marrow tests such as **bone marrow aspiration** and **bone marrow biopsy**.

- Bone marrow aspiration – Before insertion of the bone marrow aspiration needle, the aspiration site is numbed with anesthesia. During this procedure, a sample of bone marrow cells is removed from the hip bone with a needle. Most people feel pressure as the needle is inserted and a few seconds of sharp pain when the bone marrow fluid is removed.
- Bone marrow biopsy – With a bone marrow biopsy, a small piece of bone is removed. A biopsy may be slightly more painful, but only during the time that the procedure is being done.

What makes up normal blood and bone marrow?

To better understand what happens to your blood when you have leukemia, it helps to know about what makes up normal blood and bone marrow. There are three major types of blood cells: **red blood cells (RBCs)**, **white blood cells (WBCs)** and **platelets**. These cells are made in the bone marrow and flow through the bloodstream in a liquid called plasma.

- **Red Blood Cells (RBCs)**, the major part of your blood, carries oxygen and carbon dioxide throughout your body. The percentage of RBCs in the blood is called hematocrit. The part of the RBC that carries oxygen is a protein called hemoglobin. All body tissues need oxygen to work properly. When the bone marrow is working normally, the RBC count remains stable. Anemia occurs when there are too few RBCs in the body. Leukemia itself, or the chemotherapy used to treat

it, can cause anemia. Symptoms of anemia include shortness of breath, weakness and fatigue.

- **White Blood Cells (WBCs)** include several different types. Each has their own role in protecting the body from germs. The three major types are **neutrophils, monocytes, and lymphocytes**. Neutrophils (also known as granulocytes or polys) kill most bacteria. Monocytes kill germs such as tuberculosis. Lymphocytes are responsible for killing viruses and for overall management of the immune system. When lymphocytes see foreign material, they increase the body's resistance to infection. WBCs play a major role in fighting infection. So infections are more likely to occur when there are too few normal WBCs in the body.
- **Absolute Neutrophil Count (ANC)** is a measure of the number of WBCs you have to fight infections. You can figure out your ANC by multiplying the total number WBCs by the percentage of neutrophils ("neuts"). The K in the report means thousands. For example:

$$\text{WBC} = 1000 = 1.0\text{K}$$

$$\text{Neuts} = 50\% (0.5)$$

$$1000 \times 0.5 = 500 \text{ neutrophils}$$

Also, when you receive your blood counts, this equation may also be written as polys plus bands = neutrophils. Further, while anyone can catch a cold or other infections, this is more likely to occur when your ANC falls below 500. Your WBC count will generally fall within the first week you start chemotherapy, but should be back to normal between 21 to 28 days after starting chemotherapy.

- **Platelets** are the cells that help control bleeding. When you cut yourself, the platelets collect at the site of the injury and form a plug to stop the bleeding.
- **Bone Marrow** is the soft tissue within the bones where blood cells are made. All blood cells begin in the bone marrow as **stem cells**. Stem cells are very immature cells. When there is a need, the stem cells are signaled to develop into mature RBCs, WBCs or platelets. This signaling is done with "growth factors."

The bone marrow is made up of blood cells at different stages of maturity. As each cell fully matures, it is released from the bone marrow to circulate in the bloodstream. The blood circulating outside of the bone marrow in the heart, veins and arteries is called **peripheral blood**.

How is leukemia treated?

Treatment for cancer may include one or more of the following: chemotherapy, radiation therapy, biological therapy, surgery and stem cell transplantation. The most effective treatment for leukemia is chemotherapy, which may involve one or a combination of anticancer drugs that destroy cancer cells. Specific types of leukemia are sometimes treated with radiation therapy or biological therapy.

Each type of leukemia is sensitive to different combinations of chemotherapy. Medications and length of treatment vary from person to person. Treatment time is usually from one to two years. During this time, your care is managed on an outpatient basis at M. D. Anderson Cancer Center or through your local doctor.

Chemotherapy

Your treatment may consist of different chemotherapy drugs and biological therapies. The short-term goal is for a complete remission (CR). A **complete remission** means that the bone marrow has less than 5% blasts, the absolute neutrophil counts is over 1,000 and the platelet count is over 100,000. The long-term goal is for an extended disease-free state and cure.

A **course** or **cycle** is the period of time from the start of your chemotherapy until either the blood and bone marrow cell counts are back to normal or when you are able to receive further treatment. In some cases, the leukemia cells are destroyed only from the blood and not from the bone marrow during the first course of chemotherapy. In these cases, a second course may be needed.

If the leukemia does not respond to one or two courses of treatment, a different drug program may be used to bring on a remission. A different drug program may also be used if a relapse occurs.

A specific treatment plan is called a **protocol**. Each protocol is usually named by letters with each letter standing for a particular drug. A protocol may be considered either standard or experimental therapy. Your doctor will discuss with you the advantages and disadvantages of a particular type of therapy.

Once your protocol is determined, you will receive more specific information about the drug(s) that will be used to treat your leukemia. Common side effects of most chemotherapy drugs include hair loss, nausea and vomiting, decreased blood counts and infections.

How is chemotherapy given?

Central Venous Catheter (CVC)

The insertion of a **central venous catheter (CVC)** is commonly performed. A CVC is an intravenous (IV) catheter that is inserted into one of the major veins just below the collar bone or in the vein in front of your elbow, leading to your heart. It can safely remain in place for several weeks or months and is a good route through which chemotherapy, blood products and antibiotics can be administered. The catheter can also be used for drawing blood.

There will be times when you will not require continuous infusions. A plug-like device, called a “heparin lock,” will be attached to the catheter at the insertion site. The heparin lock allows you to walk around without an IV pole and IV bags. Many patients keep their catheters after they have been discharged from the hospital to use when they are outpatients. You and a family member or friend are required to attend a catheter care class to learn how to manage the catheter on your own. An infusion therapy team member will give you a schedule of the classes.

Spinal Tap (Lumbar Puncture)

Sometimes chemotherapy medication is infused into the spinal canal through a **spinal tap (lumbar puncture)**. This method of treatment is called **intrathecal (IT) chemotherapy**. It is given when there is a high risk of developing central nervous system leukemia in order to prevent its occurrence. Chemotherapy given in this way destroys leukemia cells or decreases their growth in the spinal fluid.

- A spinal tap requires inserting a needle between two bones in the lower back after the area has been numbed with a local anesthetic.
- During a spinal tap, you may feel pressure as the needle is inserted through the numbed area.
- A small amount of fluid is withdrawn through the needle and tested for leukemia cells and infection.
- After the fluid specimen is withdrawn, the chemotherapy is given, and the needle is removed. You will need to lie flat in bed for 30 minutes to 2 hours after the procedure to allow the chemotherapy to be absorbed.

Radiation Therapy

Radiation Therapy is used along with chemotherapy for some kinds of leukemia. Radiation therapy (also called radiotherapy) uses high-energy rays to damage cancer cells and stop them from growing. The radiation comes from a large machine.

Radiation therapy for leukemia patients may be given in two ways. For some patients, the doctor may direct the radiation to one specific area of the body where there is a collection of leukemia cells, such as the spleen or testicles. Other patients may receive radiation that is directed to the whole body. This is called total-body irradiation. This type of radiation usually is given before a stem cell transplant.

Biological Therapy

Biological therapy is sometimes used to treat leukemia. Biological therapies include growth factors, interleukins, monoclonal antibodies, etc. Some patients receive only biological therapy, while others also receive chemotherapy at the same time. You will receive more detailed information about biological therapy if it is used as a treatment for your type of leukemia.

Surgery

A **splenectomy** is the surgical removal of the spleen. The spleen is located in the abdomen, on the left side. It acts as a filtering system for blood cells. When a patient has chronic leukemia, the spleen tends to collect leukemia cells, transfused platelets and RBCs. Frequently the spleen enlarges from storing these cells. This makes it difficult for the chemotherapy to reduce the quantity of diseased cells. If the spleen is not removed, it sometimes grows so large that it causes breathing difficulty and compresses other organs. In that case, a splenectomy may be needed.

Stem Cell Transplantation

Stem Cell Transplantation (SCT) is a form of treatment for leukemia patients. This type of treatment was previously referred to as a “bone marrow transplant.” This treatment consists of destroying leukemic bone marrow cells using high doses of chemotherapy and in some cases, radiation therapy. Because high-dose chemotherapy severely damages the bone marrow’s ability to produce cells, healthy stem cells are provided intravenously to stimulate new bone marrow growth.

There are two types of stem cell transplantation: **Autologous SCT** and **Allogeneic SCT**.

- Autologous SCT involves infusion of your own healthy bone marrow cells. Your doctor may plan to store some of your bone marrow while you are in remission for an autologous transplantation.
- Allogeneic SCT involves the infusion of compatible donor cells to you. These cells can be obtained from the bone marrow of a donor or stem cells. Adult stem cells or umbilical cord stem cells can be used for transplantation.

Like other leukemia treatments, SCT is highly individualized. Different factors will help your doctor decide what specific treatment to use, including the type of leukemia you have, your past response to chemotherapy treatment, the availability of stem cells for replacement, your age and the status of your leukemia. You will receive more information on this treatment option if you are a candidate for SCT.

What treatment side effects can I expect?

The medical team carefully reviews each person’s medical history and your physician will then recommend the best chemotherapy treatment. Responses and side effects to chemotherapy may differ from person to person or from one course to the next. The seriousness of side effects is not a measure of how the leukemia is responding to the chemotherapy. Only diagnostic tests such as blood counts and bone marrow tests will give this information.

Diagnostic tests are done at different times depending on the type of leukemia you have and the type of chemotherapy drug used. For example, a complete blood count (CBC) will often be done every 24 hours for acute leukemia, but will be done only once per week or less often for chronic leukemia. A bone marrow test will be done prior to the start of chemotherapy and again in two to three weeks in acute leukemia. Depending upon the results of the bone marrow test and blood cell counts, your doctor will order further bone marrow tests. In response to the chemotherapy, the bone marrow is emptied of both normal and abnormal cells. During the time the bone marrow is “empty,” no cells are produced. Both blood and bone marrow cell counts are usually back to normal between 21 and 31 days after the first day of chemotherapy, depending on the type of chemotherapy given and the person’s response to the treatment.

Since the side effects of chemotherapy are known, the medical team has developed standard care routines to help you cope with them. The most common side effects and how they can be managed are described in the following sections.

Infection

In general, your white blood cell (WBC) count will fall within the first week after you start chemotherapy. As a result, you will be more prone to infection. Blood, urine, sputum, stool and throat cultures are collected to find out if an infection exists. These cultures may identify the specific organism, also known as bacteria, causing the infection. A chest x-ray will be taken because many infections occur in the lungs. If you are likely to get a specific type of infection when you are not sick such as a sinus infection, urinary tract infection or pneumonia, you have an increased chance of getting this infection each time your WBC count drops. Because of this, good personal hygiene is very important. Handwashing is the most important precaution for preventing infection. If you are unable to wash your hands after shaking hands, use a hand sanitizer.

The nursing staff will help you maintain good personal hygiene if you can not manage it your self (i.e. daily bathing and good mouth care). Please ask your visitors who may be sick, or think they are sick, not to visit with you while they are ill. Even wearing a mask will not completely prevent the spread of infection. Infections are treated with antibiotics given intravenously or by mouth for at least 7 days. Your doctor will tell you about the antibiotic treatment in detail.


Fatigue

Your red blood cell count (RBC) will also decrease. This decrease can be seen by a drop in either your hematocrit or hemoglobin levels. Both will cause fatigue. You will be given a RBC transfusion as needed. As a general rule, red blood cells are transfused when your hemoglobin is at least 8.0 or lower. It is important to drink at least six to eight (8 oz.) glasses of fluids each day to flush the chemotherapy from your system. This should begin the day you start your chemotherapy and continue for four days after you have finished your treatment. If you are on IV fluids or fluid restrictions, check with your doctor or nurse before drinking this amount. As your RBC count drops, your heart may beat fast or you may feel lightheaded when you get up quickly. Report these side effects to your nurse or physician.

Bleeding

Another side effect of chemotherapy is a decrease in the number of platelets. If this happens, nosebleeds, bleeding gums or passing blood in the urine or stool are likely to happen. Little red dots may appear on parts of your body, especially the arms and legs. These dots are called **petechiae**, which means that there is bleeding from the capillaries, or small blood vessels in the skin. Platelet transfusions are usually, but not always, given when the platelet count is less than 10,000 or any time that bleeding occurs. Platelets are transfused only as needed because unnecessary transfusions may eventually cause your body to stop responding to platelet transfusions.

You must take special care of yourself when your platelet count is low. Use a very soft toothbrush to avoid irritating your gums and use an electric shaver rather than a blade for shaving. Dental flossing



can be continued if you had practiced this previously but do not go down to the gum line. If you do injure or cut yourself, you can stop the bleeding by putting direct pressure to the wound for five to ten minutes. If you have vaginal bleeding, your doctor may prescribe medications such as hormones. Try not to strain during bowel movements because it may cause rectal bleeding. A stool softener can be prescribed if needed. Again, try to drink plenty of fluids to help keep your stools soft. Vigorous exercise and contact sports should be avoided. Short walks are all right. Watch your energy tolerance and recovery – “Don’t push it.” Report any bleeding to your doctor or nurse.

Bowel Irritation

Other side effects you may experience are diarrhea or constipation. There are medications for each of these side effects, so let your doctor or nurse know right away if you have either of them. High fiber foods, prunes or fruit juices may help relieve constipation. It is good to drink at least eight (8 oz.) glasses of fluids each day. A dietitian will also be able to give you other food tips to help relieve these side effects.

Nausea and Vomiting

Chemotherapy can also cause nausea or vomiting. Sometimes, nausea or vomiting may be triggered by certain smells or just thinking about the hospital and about the treatment you will be receiving. Try to keep something, like dry toast or crackers, in your stomach throughout the day. A dietitian can give you other food tips that can decrease the symptoms and help you continue a healthy diet. Strong anti-nausea medications such as Zofran® and Kytril® are also available. You should feel free to ask for medication if you feel queasy at any time. Some chemotherapy drugs can cause nausea for an entire day or more after treatment. Therefore, your anti-nausea medication may be continued for a day or so after chemotherapy. Some anti-nausea medications can cause drowsiness so you may need to stop driving while you are taking this medication.

Sore Mouth

Sore mouth, also called stomatitis, is a common side effect of some chemotherapy treatments. You must keep your mouth as clean as possible to prevent infection. You should rinse your mouth four times each day with a baking soda solution, especially after meals. To make the baking soda solution, mix ½ teaspoon of baking soda to 8 ounces of water.

Certain mouthwashes and sprays may be prescribed to prevent infection and to make it easier for you to eat. **Do not** use commercial mouthwashes because they contain alcohol and may irritate your mouth. You may want to avoid foods or drinks that are tangy, salty or sweet, as they may worsen mouth soreness. Avoid extremely hot foods because they may slow the healing process in you mouth and throat.

Hair Loss

Hair loss, both body hair and scalp hair, is a common side effect of chemotherapy. Depending upon the chemotherapy you receive, you may not lose any hair, or it may just become thinner or may completely fall out. Hair loss can have a major impact on body image. Resources such as classes, videos and printed materials are available through The Learning Center to help you cope with this side effect of treatment. The M. D. Anderson Beauty and Barber Shop offer free services to patients. A variety of useful wigs and caps are also available.

Weight Loss

It is natural if you do not want to eat or drink if you have a sore mouth or your stomach is upset, but it is still important that you nourish your body. Your body needs extra calories and protein when you have leukemia to build strong new cells. This is not the time to go on a weight loss diet! If you begin to lose weight, try to eat six small meals or snacks a day and add high-calorie, high-protein foods to your diet. A dietitian will be able to give you more information on these types of food and they are available at your request. A dietitian can also help a family member cope with the loss of pleasant aspects of eating, such as taste by helping them choose the right foods and preparation style. Your appetite may be stronger in between treatments.

During chemotherapy it is also very important to drink lots of fluids. This means that you should drink at least eight (8 oz.) glasses of fluids each day. You may want to drink fluids that contain calories such as fruit juices, milk or protein supplements. Soft drinks, or carbonated beverages, may increase the intake of carbonation and result in gas or cramping. Soft drinks generally have no nutritional value and juices or energy drinks are preferable. Talk to a dietitian if you are diabetic.

If you cannot tolerate eating regular foods, there are liquid nutritional supplements available to help you get the amount of calories and protein that your body needs. The dietitian can help you choose the correct one.

If you are having difficulty eating, you may receive your nutrients through a tube in your stomach, through an intravenous (IV) line, or through intravenous hyperalimentation (IVH). Both methods can provide you with the nutrients that you need when you can not eat enough. You will be able to speak with a dietitian if you continue having eating problems and/or weight loss.

What are the types of blood donations?

Infection and bleeding are the most serious complications of leukemia and its treatment. The danger of these complications has been lessened with the use of whole blood and blood products such as red blood cell (RBC), platelet, and white blood cell (WBC) transfusions.

To help patients through these complications, family members and friends may be asked to donate blood or blood products when needed. Donors are always needed because blood and blood products are used in treatment against infection and bleeding. The M. D. Anderson's Donor Center can instruct you how often your family and friends can donate for you. For more information, call (713) 792-7777 or visit our website at <http://mdanderson.org/donateblood>.

Red Blood Cells (RBCs)

To be a blood donor, a social security number and picture identification (ID) are needed. The donor must also have the correct name and hospital number of the patient.

Before donating blood, all donors must meet the current guidelines of the American Association of Blood Banks (AABB) and the regulations and requirements of the Food and Drug Administration (FDA). At the time this booklet was printed, the current guidelines and regulations included:

- Being in general good health and feeling well
- Being 17 years of age or older
- Weighing at least 110 pounds (50 kg)
- Not having donated blood within the past eight weeks (56 days)
- Having a hemoglobin of 12.5 or above
- Bringing a list of your current medications

It is very important for a person not to donate blood if he or she has a history of:

- Hepatitis after the age of 11 years
- Heart, liver, kidney or lung disease
- Cancer
- Convulsions, fainting spells
- Abnormal bleeding
- Being at high risk for getting HIV/AIDS

Red blood cells are good for 42 days after they are donated. Each unit of whole blood that is donated can be separated into four separate products: (1) Packed red blood cells, (2) Plasma, (3) Platelets and (4) Cryoprecipitate.

The Family and Friends Blood Program

The Family and Friends Blood Program (FFBP) help manage the specific blood component requirements of each patient as well as providing the flexibility to maintain an adequate blood supply for all patients.

The units of blood collected from donors, whose donation is triggered by concern for a specific patient, will be credited to that patient's account as a replacement unit of blood. These units will be processed and placed in the general inventory for routine use. Patients who take advantage of this program will have priority access to blood or blood components (for transfusion) when needed during his or her hospital stay and beyond. Having priority access, however, is based on medical need.

Platelets (Single Donor)

By using a process called "apheresis," donors may donate platelets only and have their red blood cells returned. This process is done with a blood cell separator machine. Blood is drawn from one arm and flows through a sterile, disposable collection kit into the separator. The machine then spins the blood, separating out only the platelets. The remaining blood and plasma is returned in either the same arm or the other arm with no ill effects.

This process takes about 2 hours to complete. A donor may donate platelets every 48 to 72 hours, depending on the patient's condition and medical need. It takes about 72 hours for the donor's platelets to replace themselves.

Platelets have a life span of only a few days. Therefore, Single Donor Platelets (SDPs) are given to the patient within 24 hours of collection.

In addition to meeting the requirements for donating RBCs, those who want to donate platelets must:

- **Not** take aspirin 3 days before donating
- **Not** take antibiotics 3 days before donating
- **Not** take ibuprofen (Motrin®, Advil®) 24 hours before donating
- **Have** an acceptable hemoglobin, platelet and WBC count before each donation.

Some patients may develop antibodies to platelets following repeated transfusions. For this reason, potential donors may be screened in order to check for compatibility, or a good match. Direct family members, such as mother, father, brother, sister, son, or daughter, are often more compatible than friends, spouse or in-laws. If you have questions or concerns about platelet compatibility and donating, please discuss them with your doctor.

White Blood Cells (WBCs)

In some cases, patients may need to have a series of WBC transfusions. Healthy, blood-related family members are preferred for these transfusions, but non-family members can also donate WBCs. The same requirements apply for those donating WBCs as it does for RBC and platelet donors. After a careful screening process, donors are given an injection of Neupogen® and take Dexamethasone pills to help increase the production of white blood cells. A WBC collection may be done four or five times in a month depending on the donor situation.

Where can blood be donated?

Red Blood Cells (RBCs) and Platelets

- The Donor Center is located 2555 Holly Hall, Houston, TX 77054 (near Almeda) or the Main Building on Floor 2 near Elevator A (713) 792-4531, or the Mays Clinic Donor Room (713) 563-3182.

White Blood Cells (WBCs)

- WBC donors are screened at both Main Building on Floor 2 near Elevator A. (713) 792-4531, and at the Mays Clinic Donor Room (713) 563-3182. WBC collections are performed at the Main Building on Floor 2 near Elevator A.

Parking tickets are validated by the blood bank for anyone who donates blood products.

If you have any questions regarding any aspect of the donation process, please call (713) 792-7777 or page the Blood Bank Coordinator at (713) 404-2572, or visit our website at <http://www.mdanderson.org/donateblood>.

Other Important Aspects of Your Care

Support for the Family

Family members and friends feel many of the same anxieties as you do, and they need support too. They also need time alone just as you do. At first, they may feel uneasy leaving you. This anxiety will decrease with time as they meet other people in the same situation with whom they can eat, shop and talk.

A leukemia family group meets once a week with the social worker and the clinical nurse specialist to discuss family questions and/or concerns. The group meetings allow family members and friends to express feelings, share experiences and gather ideas for solving problems. Medical information is given when needed, but sessions focus mainly on the emotional needs of the group members. Each patient's disease is in a different stage of development, and the group meetings serve as settings where participants can draw support from one another and learn from each other's experiences. The sessions also provide a chance for group members to learn that many of their feelings and reactions are not unusual, but are to be expected, because of the seriousness of the patient's illness.

Exercise


The importance of exercise cannot be stressed enough. Not only does exercise maintain muscle tone, circulation and respiration, but it also encourages a more positive attitude. Although it is easier to lie in bed than to be up and about when you are not feeling well, this can quickly become a very difficult habit to break. The staff will have only your best interests in mind when they encourage you to exercise.

There is a physical therapy department in the hospital to assist you with exercise. Your doctor will arrange for you to attend physical therapy. You may leave the floor at any time, after checking with your nurse, to take a walk.

Sexuality

Sexual contact is part of a healthy, intimate relationship. Love, affection and intimacy can be expressed in a number of ways. The touching, closeness, tenderness and sharing found in an intimate relationship does not have to stop when one partner is diagnosed with leukemia. Indeed, the uncertainty and unfamiliarity of treatment increases the need for these comforts. Leukemia, and the side effects of its treatment, can have a major effect on your body image and on the way you see yourself sexually. Although sexual intercourse is still possible with a diagnosis of leukemia, it is common to feel self-conscious because of the physical changes that occur with treatment. Because of this, your desire for intimacy, along with your response to it, may be very low. If you are having a hard time coping with issues such as body image, desire and response and your identity as a man or woman, please let your nurse, doctor or social worker know. They will be able to provide you with more information. Fatigue may be a factor in decreased desire. Be sure to tell this to your doctor or nurse.

Your partner cannot "catch" leukemia through physical contact. Leukemia cannot be transmitted from one person to another nor will intimate contact be dangerous for you as long as your counts are not too low. There is minimal risk of bleeding as long as your platelet count is over 50,000. Water-based lubricant, if needed, may be helpful during intercourse. If you have any questions about sexual activity and whether your platelet counts are within acceptable limits, please be sure to discuss your concerns with your doctor, nurse or social worker.



The side effects of chemotherapy can cause certain physical changes in men and women. In men, most chemotherapy agents used to treat leukemia can cause a low sperm count or an absence of sperm in the semen. Sperm production may return after chemotherapy is discontinued. In women, temporary or permanent sterility may occur depending upon the drug dosage and type of chemotherapy. Because of the effects of chemotherapy on a fetus, it is important to use a birth control method during your chemotherapy treatments. **Chemotherapy is not an effective means of birth control** and should not be relied on to prevent pregnancy. Women may continue to use the birth control measure they used before diagnosis unless they used an intrauterine device (IUD) or a diaphragm. Methods that can be used include birth control pills, condoms and spermicidal foam or jelly. Please let your doctor or nurse know if you have any questions about which birth control method to use.

Having children may be possible after chemotherapy is discontinued and you are in remission. To ensure the safety of all concerned, family planning should be discussed with your doctor.

During your stay in the hospital, the staff will be sensitive to your needs for privacy. If you need some special time alone with your family or loved ones, please let us know and we will respect your wishes. Please remember that open communication between your partner and your doctor or nurse will help relieve many of the fears and concerns you may have about your sexuality.

Precautions with Pets

Pet ownership has been associated with both emotional and physical health benefits. The majority of pets do not pose any greater risk to immunocompromised patients than contact with an ill person. These are some guidelines developed from the Centers for Disease Control and the World Health Organization (WHO).

Immunocompromised patients should avoid:

1. Animals less than 6 months old or less than 1 year for cats
2. Pets with diarrhea or respiratory illness
3. Cleaning litter trays and contact with feces
4. Contact with reptiles, snakes, or lizards due to risk of salmonella

Guidelines for healthy pets and patients:

1. All new pets should be examined by a veterinarian to receive vaccinations, worming/flea control programs
2. Pets should be kept cleaned and brushed; nails should be clipped short to minimize scratches
3. Always wash your hands after handling pets (especially before eating)
4. Pets should only eat commercial diet for their species and not allowed to eat from garbage
5. Pets should be given only clean tap water
6. Cats should be kept indoors most of the time

At Home

If you live outside the Houston area, your local doctor may manage your treatment, at some point, at home. Your clinic doctor will contact your local doctor to discuss your current status and your future treatment at home and in Houston. Although your local doctor will be caring for you at home, your overall treatment will be coordinated by your M. D. Anderson health care team. It may be necessary for you to have weekly blood tests and to send the results to your clinic doctor so the status of your leukemia can be watched. When you discuss your home treatment plan with your clinic doctor before leaving, ask for a review of any information that maybe unclear to you. If you or your local doctor have questions or concerns at any time, call your primary M. D. Anderson doctor.

When you get home, you should continue your normal routine as much as possible. You probably will tire easily at first because you have not been active for many weeks. Slowly work up to your prior level of activity and take rest periods when you need them. It is best to get back into the swing of things as soon as possible. You will probably find, as you become more active again, that your disease will fade into the background.

As a rule, you may do what you did before your disease was diagnosed. Talk with your doctor if you have questions about work, school or other activities.

Family and friends will want to know how you are doing, but may feel awkward about asking. Remember that most people do not speak as openly about cancer as do people at M. D. Anderson, where the word “cancer” is not whispered and information is not kept from patients to “protect” them. It is up to you to set the pace for how people talk to you. If you are comfortable talking about your illness, others probably will be too.

Do's and Don'ts At Home

Do

- Expect a drop in blood counts after chemotherapy.
- Stay out of crowds when your counts are low.
- Take your temperature daily when your counts are low. If it is greater than 101°F, come to the Emergency Center, or if you are at home, go to your local doctor's Emergency Room. You may call the Leukemia Center at (713) 792-8760 to tell them that you are coming to the Emergency Center.
- Shave only with an electric razor when your counts are low to prevent bleeding and infection.
- Report symptoms of infection to your doctor.
- Eat a well-balanced diet.
- Use a soft toothbrush to prevent your gums from bleeding when your counts are low.
- Slowly return to normal activities.
- Keep a diary of your chemotherapy treatments (i.e. dates received, side effects).

Don't

- Take aspirin or any over-the-counter drugs that contain aspirin or ibuprofen. These drugs may mask, or hide, the symptoms of infection and prevent normal platelet function.
- Ignore signs of infection or physical changes.
- Be afraid of contact with others. Leukemia can not be transmitted.
- Stay at home or in your hotel all the time. Do not isolate yourself from friends or family.

Resources for Leukemia Patients and their Family

The Leukemia Center

Monday through Friday, 8 a.m. to 5 p.m.

(713) 792-8760

<http://www.mdanderson.org/leukemia>

The University of Texas M. D. Anderson Cancer Center

1515 Holcombe Boulevard

Houston, Texas USA 77030-4095

Telephone Country Code: 1

(713) 792-6161/ (800) 392-1611

<http://www.mdanderson.org>

M. D. Anderson Family Support Group

The family group meets once a week with the social worker and the clinical nurse specialist to discuss family questions and/or concerns.

The Learning Center

The Learning Center is a consumer health library with the latest information on cancer care, support, prevention and general health and wellness issues.

- (713) 745-8063, **Theodore N. Law Learning Center**, *Main Building*, Floor 4 near Elevator A
- (713) 563-8010, **Levit Family Learning Center**, *Mays Clinic*, Floor 2 near the Tree Sculpture
- (713) 745-0007, **Holden Foundation Learning Center**, *Jesse H. Jones Rotary House International*, Floor 1

M. D. Anderson Information Line

For up-to-date information about M. D. Anderson services, departments, programs, treatments and more, please call the M. D. Anderson Information Line.

(713) 792-3245/ (800) 392-1611, option 3

myMDAnderson

myMDAnderson is a secure, patient care Web site personalized to the user's specific cancer type and treatment. M. D. Anderson patients have direct access to their health care team 24 hours a day, seven days a week, wherever they have access to a computer.

<https://my.mdanderson.org/>

Community Resources for Patients and Their Families

American Cancer Society

The American Cancer Society (ACS) is a voluntary national health organization with local offices around the country. The ACS supports research, provides information about cancer, and offers many programs and services to patients and their families.

(800) ACS-2345 (1-800-227-2345)

www.cancer.org

Cancer Information Service

The Cancer Information Service (CIS) is a program of the National Cancer Institute (NCI). People who call the CIS speak with highly trained and caring information specialists who can answer questions about cancer screening tests, risks, symptoms, how cancer is diagnosed, the latest treatments and support organizations.

(800) 4-CANCER (1-800-422-6237)

Leukemia and Lymphoma Society of America (LSA)

This organization supports cancer research and provides information and financial help to patients with leukemia. It also offers support groups for patients and their families and provides referrals to other sources of help in the community.

Texas Gulf Coast Chapter 713-680-8088

National Home Office 1-800-955-4572, (9am – 6pm Eastern Standard Time)

www.leukemia-lymphoma.org

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