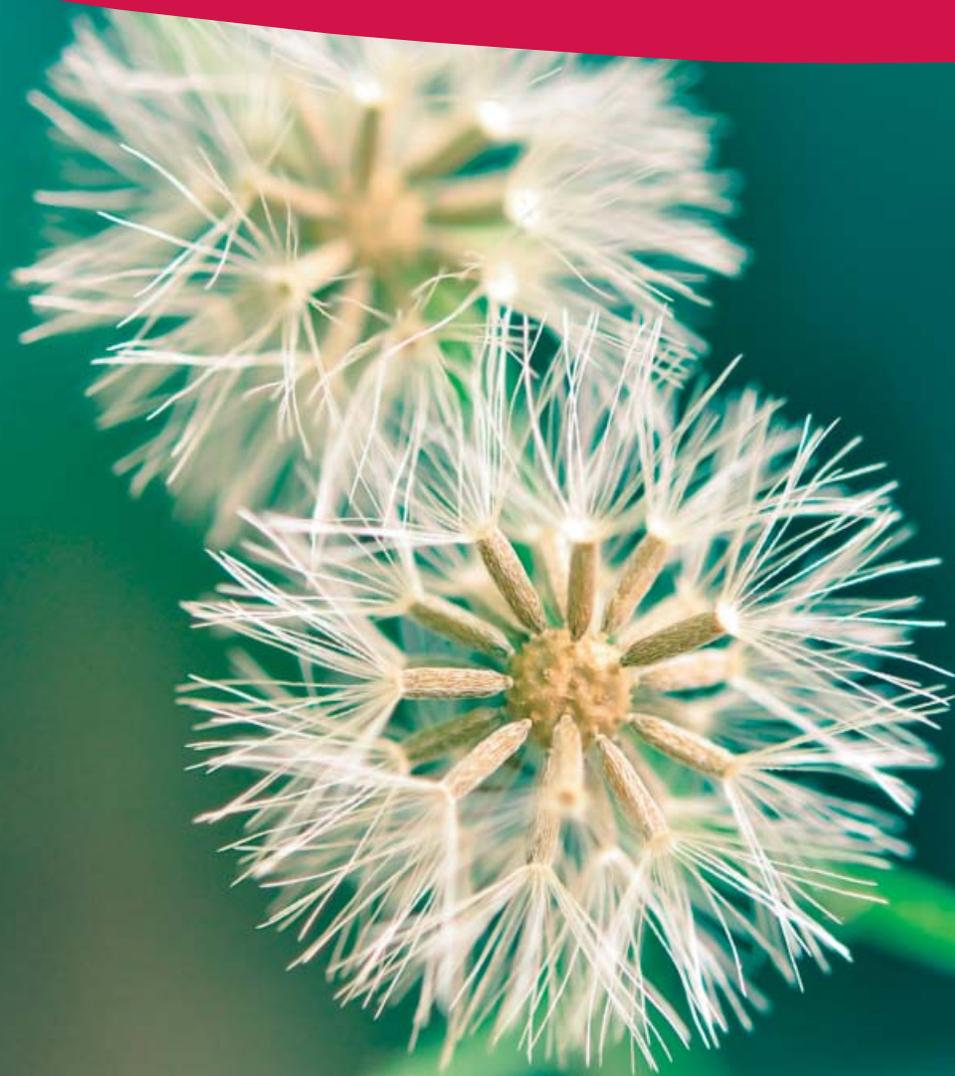


# Leukemia and Myelodysplastic Syndrome





# Introduction

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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 blood cancer, including leukemia or myelodysplastic syndrome (MDS), is important to help make treatment decisions and the unknown less frightening.

Cancer is a very complex and serious illness. The skill and knowledge of many experts is available at MD Anderson Cancer Center at Cooper to provide you with the best possible care.

The “team approach” plays an important role in the treatment of leukemia or MDS. The health care team at MD Anderson at Cooper dedicates itself to helping you and your family understand the disease and to providing support throughout your treatment. Please talk with us about your questions and concerns.

Sometimes the size of our center can be overwhelming and anxiety is a normal reaction. You will find that our staff and volunteers will do their best to make you feel comfortable. We are here to help you by providing assistance, education, and answers to any questions.



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# Outpatient Care

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When you first arrive for outpatient care at MD Anderson Cancer Center at Cooper or after you are discharged as an inpatient, you will be seen by your primary health care team. This team includes your primary doctor from the Lymphoma and Leukemia Center, who will be responsible for your care throughout outpatient treatment. He or she will make the 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 assistant (PA).

You will also have a clinic nurse who will assist the doctor in managing your care during each visit. Your clinic nurse will give you a business card or letter with the clinic's phone numbers to call with questions or problems.

Someone is available at MD Anderson at Cooper to help you Monday through Friday, from 8 a.m. to 5 p.m., at 856.735.6211.

If you need to speak to someone on the weekend, during holidays, or after hours, call Cooper University Hospital at 856.342.2000 and ask to speak to the oncology doctor on call or go to the emergency department.

It is important to 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 856.735.6213 to ask for a refill.

For those receiving chemotherapy, please note that a major side effect is infection. Symptoms of infection include:

- A fever of 100.4°F (38°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 have uncontrolled bleeding, go to the emergency department at Cooper University Hospital. If Cooper is not nearby, go to the closest emergency department and ask the physician to call Cooper to inform the oncologist on call of your condition. A transfer to Cooper can be arranged, if necessary.

# Inpatient Care

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While you are in the hospital, the inpatient health care team is responsible for your care. A staff physician from hematology/oncology, also known as your inpatient attending physician, will coordinate your care and make treatment decisions.

You may also be seen by a fellow, who is a physician pursuing special training in oncology (the study of cancer). He or she will communicate with your outpatient attending physician and coordinate your discharge when you have improved or completed inpatient treatment.

There are many other members of the health care team who will take part in your care, including a mid-level provider like an advanced practice nurse (APN) or physician assistant (PA). Other members of the team may include nurses, dietitians, pharmacists, the infusion therapy team, and social workers. The pharmacist, for example, will assist you with medications and discharge prescriptions, while the APN will help by providing care, education, and coordination of health care needs.

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

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

Upon discharge, you may need to take some medications home. Your health care team will try to give you 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 refill as needed.

# Types of Leukemia and Myelodysplastic Syndrome

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Leukemia is a cancer of the body's blood-forming tissues, such as bone marrow. The type of leukemia is determined by the kind of cell affected and the rate at which the disease progresses. Leukemia can progress quickly (acute) or slowly over time (chronic).

Acute leukemia involves a rapid overgrowth of very immature blood cells called myeloblasts or myeloid blasts. This condition is life-threatening because there are not enough normal functioning blood cells to prevent anemia, infection, and bleeding. A diagnosis of acute leukemia is made when there are 20 percent or more "blast cells" in the bone marrow or blood.

Chronic leukemia involves a slower accumulation of abnormal mature blood cells that only function normally for a period of time before causing any symptoms. 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, for example, is most common during childhood and in early adulthood, although it can be diagnosed in people over 30. Acute myelogenous leukemia occurs most often in adults. Chronic leukemia is more commonly diagnosed in individuals between the ages of 40 and 70 and rarely in young people. However, there are always exceptions.

When looking for a specific type of leukemia, your doctor will look at the 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 Leukemia

- 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 (16p13q22) 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 percent of cells in two or more myeloid lineages.
- AML and MDS, therapy-related:
  - Alkylating agent/radiation-related type.
- Topoisomerase II inhibitor-related type.
- AML, not otherwise categorized classified as:
  - AML, minimally differentiated.
  - AML without maturation.
  - AML with maturation.

- Acute basophilic leukemia.
- Acute panmyelosis with myelofibrosis.
- Myeloid sarcoma.
- Acute lymphoblastic leukemia (ALL) and lymphoblastic lymphoma.
- Acute myelomonocytic leukemia.
- Acute monoblastic/acute monocytic leukemia.
- Acute erythroid leukemia.
- Acute megakaryoblastic leukemia.

#### Chronic Leukemia

- 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.
- Aplastic anemia.

#### 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).

# Causes of Leukemia and Myelodysplastic Syndrome

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The specific cause of leukemia is still unknown. However, scientists suspect that there may be viral, genetic, environmental, or immunologic factors involved.

Some viruses can cause leukemia in animals. In humans, however, 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 had close contact with leukemia patients.

There may also be a genetic predisposition to leukemia. There are rare cases 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. However, this has only been true in extreme cases, such as atomic bomb survivors in Nagasaki and Hiroshima or industrial workers exposed to benzene. Exposure to ordinary X-rays, like those given in a hospital or physician office, is not believed to be dangerous.

People with immune-system deficiencies appear to be at greater risk for cancer because of their body's decreased ability to resist foreign cells. There is evidence that patients treated for other types of cancer with certain chemotherapy drugs 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, in most cases, the cause of leukemia is not known.

# Diagnosis of Leukemia and Myelodysplastic Syndrome

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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 the procedure begins, the aspiration site is numbed with anesthesia. During the procedure, a sample of bone marrow cells is removed from the hip bone with an aspiration 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.

RBCs, the major part of your blood, carry oxygen and carbon dioxide throughout the body. The percentage of RBCs in the blood is called hematocrit. The part of the RBC that carries oxygen is the 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.

WBCs include several different types. Each has its 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 the 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. When there are too few normal WBCs in the body, infections are more likely to occur.

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:

WBC = 1000 = 1.0K Neuts = 50% (0.5)  
1000 X 0.5 = 500 neutrophils

While anyone can catch a cold or other infections, it 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.

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 in the heart, veins, and arteries is called peripheral blood.

# Treatment of Leukemia and Myelodysplastic Syndrome

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Treatment for blood 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 only 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. Initial treatment time is typically from one to two years. During this time, your care is managed as an outpatient at MD Anderson Cancer Center at Cooper 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). CR in acute leukemia means the bone marrow has less than five percent blasts, the absolute neutrophil count 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 get CR. 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 many chemotherapy drugs include hair loss, nausea, vomiting, decreased blood counts, and infections.

## **How Is Chemotherapy Given?**

The insertion of a central venous catheter (CVC or port-a-cath) is commonly performed. A CVC is an intravenous (IV) catheter that is inserted into one of the major veins just below the collar bone (subclavian line) or in front of your elbow (PICC line) leading to your heart. It can safely remain in place for several weeks or months and is a good route for chemotherapy, blood products, and antibiotics to be administered. Sometimes the catheter may 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 bags. Many patients keep their catheters after they have been discharged from the hospital to use in outpatient treatment. You and a family member or friend may need to learn how to care for some types of catheters after discharge if it is not removed.

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 an attempt 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. 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 from 30 minutes to two hours after the procedure to allow the chemotherapy to be absorbed. A headache is a common side effect.

### **Radiation Therapy**

Radiation therapy may be 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 is sometimes given before a stem cell transplant.

### **Biological Therapy**

Biological therapy is sometimes used to treat leukemia. Biological therapies include growth factors, interleukins, and monoclonal antibodies. Some patients receive only biological therapy, while others 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.

### **Splenectomy**

A splenectomy is the surgical removal of the spleen. The spleen is located on the left side of the abdomen. 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 red blood cells. 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 can grow so large that it compresses on other organs and cause breathing difficulties. In that case, a splenectomy may be needed.

### **Stem Cell Transplant**

A stem cell transplant (SCT) (previously referred to as a bone marrow transplant) can be used to restore healthy bone marrow in people with leukemia. Although MD Anderson at Cooper does not

currently offer SCT, we will refer you to an outside center if this is the optimal choice of treatment for your disease.

SCT 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 stem cells from the bone marrow of matching donors, which could be a relative, an unrelated individual, or umbilical cord blood.

Like other leukemia treatments, SCT is based very much on the individual. 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.

### **Side Effects of Treatment**

The medical team carefully reviews each person's medical history and your physician will then recommend the best treatment. Responses and side effects 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 treatment. Only diagnostic tests, such as those that check blood counts and bone marrow, give this information.

When chemotherapy is the optional treatment, diagnostic tests are done at different times depending on the type of leukemia and the 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 for acute leukemia. Depending upon the results of the bone marrow test and blood cell counts, your doctor may order additional testing.

In response to the chemotherapy, the bone marrow is emptied of both normal and abnormal cells. During the time the bone marrow is "empty" and 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 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.

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 it when your WBC count drops.

Because of this, good personal hygiene is very important. Hand washing is the most important precaution for preventing infection. If you are unable to wash after shaking hands, use a hand sanitizer.

The nursing staff will help you maintain good personal hygiene, such as daily bathing and mouth care, if you cannot manage it yourself. Please ask your visitors who may be sick not to visit 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 seven days. Your doctor will tell you about the antibiotic treatment in detail.

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 an RBC transfusion as needed. As a general rule, RBCs are transfused when your hemoglobin is at least 8.0 or less.

It is important to try 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.

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 (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 them.

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.

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 these. 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.

Chemotherapy can also cause nausea or vomiting. Sometimes it can be triggered by certain smells or just thinking about the hospital and the treatment. 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 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, 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 a half of teaspoon (1/2 tsp.) of baking soda with eight ounces (8 oz.) 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 your mouth and throat.

Hair loss from the body and scalp is a common side effect of chemotherapy. Depending upon the type of chemotherapy you receive, your hair may completely fall out, get thinner, or remain intact. Hair loss can have a major impact on body image. Resources such as classes, videos, and printed materials are available to help you cope with this side effect of treatment.

It is natural not to want to eat or drink if you have a sore mouth or your stomach is upset, but it is still important to 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, who is available at your request, will be able to give you more information on right types of foods. A dietitian can also help cope with the loss of the pleasant aspects of eating, such as taste, by helping 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 try to drink at least six to 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, so juices or energy drinks are preferable. Talk to a dietitian if you are diabetic.

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

# Types of Blood Donations

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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) and platelet transfusions.

To help patients through these complications, family 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 American Red Cross will answer all questions about donating.

# Important Aspects of Your Care

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Several important aspects of your care are included here.

## **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 may arrange for you to attend physical therapy.

## **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 do 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, as well.

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 decreased amount 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 same birth control 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.

Immunocompromised patients should avoid:

- Animals less than six months old or less than one year for cats.
- Pets with diarrhea or respiratory illness.
- Cleaning litter boxes and contact with feces.
- Contact with reptiles, snakes, or lizards due to risk of salmonella.

Guidelines for healthy pets and patients:

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

### **At Home**

If you live outside the South Jersey area, your local doctor may manage your treatment, at some point, at home. Your clinic doctor will contact your local physician to discuss current status and future treatment at home and at MD Anderson at Cooper. Although your local doctor will be caring for you at home, your overall treatment will be coordinated by the MD Anderson at Cooper 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 the 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 has questions or concerns at any time, call your primary doctor at MD Anderson at Cooper.

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 needed. 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 asking. Remember that most people do not speak as openly about cancer as they do at MD Anderson at Cooper. At our facility, 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.

Some of the do’s and don’ts at home include:

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 100.4°F, go to the emergency department at Cooper University Hospital or, if you are not close by, go to your local hospital. If it is during business hours, you may call the nurse triage line at 856.735.6211.
- 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 (e.g. dates received, side effects, etc.).

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 cannot be transmitted.
- Stay at home or in your room all the time. Do not isolate yourself from friends or family.

# Resources

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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. Call 800.ACS.2345 (1.800.227.2345) or visit [www.cancer.org](http://www.cancer.org).

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. Call 800.4.CANCER (1.800.422.6237).

Leukemia and Lymphoma Society of America (LLS) 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. The New Jersey Chapter is located at: 14 Commerce Drive, Suite 301, Cranford, NJ, 07016. Call 908.956.6600, the National Home Office at 1.800.955.4572 from 9 a.m. to 6 p.m. (EST), or visit [www.leukemia-lymphoma.org](http://www.leukemia-lymphoma.org).

American Red Cross - Camden County Donor Center is located at: 5425 Marlton Pike, Pennsauken, NJ, 08109. Call 1.800.REDCROSS (1.800.733.2767) or visit [www.redcross.org/blood](http://www.redcross.org/blood).

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[MDAndersonCooper.org](http://MDAndersonCooper.org)

1.855.MDACOOPER  
(1.855.632.2667)