Living with Leukemia
# Living with Leukemia

## Table of Contents

- MD Anderson Cancer Center ...................................................................................................................... 3
  - The Leukemia Center (Outpatient Care) ................................................................................................... 3
    - Emergency Center ................................................................................................................................. 3
    - MyChart Patient Website ....................................................................................................................... 3
    - Clinic Visits ......................................................................................................................................... 4
  - Inpatient Care ......................................................................................................................................... 4
  - Supportive Care Team ............................................................................................................................. 5
  - Blood and Bone Marrow .......................................................................................................................... 5
    - Red Blood Cells (RBCs) ......................................................................................................................... 5
    - White Blood Cells (WBCs) ..................................................................................................................... 5
    - Absolute Neutrophil Count (ANC) ......................................................................................................... 6
    - Platelets .............................................................................................................................................. 6
    - Bone Marrow ..................................................................................................................................... 6
  - Leukemia ................................................................................................................................................. 6
    - Acute Leukemia .................................................................................................................................. 7
    - Chronic Leukemia ................................................................................................................................. 7
  - Other Blood Disorders ............................................................................................................................ 7
    - Myelodysplastic Syndrome (MDS) ...................................................................................................... 7
  - Causes .................................................................................................................................................... 7
  - Diagnosis ............................................................................................................................................... 8
  - Treatment .............................................................................................................................................. 8
    - Chemotherapy .................................................................................................................................... 8
    - Central Line Insertion (CVC/PICC) ....................................................................................................... 9
    - Required Training Class ...................................................................................................................... 9
    - Spinal Tap (Lumbar Puncture) ............................................................................................................. 9
    - Radiation Therapy ............................................................................................................................... 9
    - Biological Therapy ............................................................................................................................... 10
    - Surgery ............................................................................................................................................... 10
    - Stem Cell Transplantation .................................................................................................................. 10
    - Leukemia Specialty Care Unit ............................................................................................................. 10
  - Treatment Side Effects ............................................................................................................................ 11
<table>
<thead>
<tr>
<th>Topic</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>Infection</td>
<td>11</td>
</tr>
<tr>
<td>Fatigue</td>
<td>11</td>
</tr>
<tr>
<td>Bleeding</td>
<td>12</td>
</tr>
<tr>
<td>Bowel Problems</td>
<td>12</td>
</tr>
<tr>
<td>Nausea and Vomiting</td>
<td>12</td>
</tr>
<tr>
<td>Sore Mouth</td>
<td>12</td>
</tr>
<tr>
<td>Hair Loss</td>
<td>13</td>
</tr>
<tr>
<td>Weight Loss and Nutrition</td>
<td>13</td>
</tr>
<tr>
<td>Types of Blood Donations</td>
<td>14</td>
</tr>
<tr>
<td>Where to Donate</td>
<td>14</td>
</tr>
<tr>
<td>Other Important Aspects of Your Care</td>
<td>14</td>
</tr>
<tr>
<td>Support for Caregivers</td>
<td>14</td>
</tr>
<tr>
<td>Exercise</td>
<td>15</td>
</tr>
<tr>
<td>Sexuality</td>
<td>15</td>
</tr>
<tr>
<td>Fertility</td>
<td>15</td>
</tr>
<tr>
<td>Pet Precautions</td>
<td>16</td>
</tr>
<tr>
<td>At Home</td>
<td>16</td>
</tr>
<tr>
<td>What to Expect at Home</td>
<td>17</td>
</tr>
<tr>
<td>MD Anderson Resources</td>
<td>18</td>
</tr>
<tr>
<td>Community Resources</td>
<td>18</td>
</tr>
</tbody>
</table>
The Leukemia Center (Outpatient Care)

As an outpatient, your primary health care team will include your main physician from the Leukemia Center, who will be responsible for your care throughout your outpatient treatment. Your leukemia physician makes 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).

A clinic nurse assists your physician in managing your care during each clinic visit. The nurse will give you information on how to contact the clinic with questions or problems.

The Leukemia Center staff are available to help you Monday through Friday, from 8 a.m. until 5 p.m., at 713-792-8760.

Emergency Center

Go to the Emergency Center right away if you have symptoms that require urgent attention, such as fever 101°F (38.3 °C) or higher. MD Anderson’s Emergency Center is open 24 hours a day, every day.

It is located in the Main Building on Floor 1 near the Café Corner, P1.3000.

MyChart Patient Website

MyChart is a secure personalized website and mobile app. Here, you will find your schedule and can send secure messages to members of your health care team. The system also lets you view portions of your medical record and read patient education information specific to your condition.
To sign up, you will need an activation code. Call askMDAnderson at 877-632-6789 or ask a staff member in your center for an activation code. Learn more at Mychart.mdanderson.org.

**Clinic Visits**

You will have bloodwork drawn before every appointment. Blood work can be drawn at the **Hematology Center Lab**, located within the Leukemia Center, Main Building on Floor 8 near Elevator B. The lab is open from 6 a.m. to 2 p.m., Monday through Friday.

Or, you may choose to have your bloodwork drawn at any of our lab locations, including our Houston area locations. If you are on a clinical trial, your research nurse will let you know if you need to have your bloodwork drawn in the Leukemia Center.

Sometimes, you may need to have scheduled an appointment for a bone marrow aspiration test to assess the status of your disease. This test is done in the **Bone Marrow Aspiration Clinic**. It is located in the Main Building on Floor 11 near Elevator B.

Together, you and your main leukemia physician will review the bone marrow results, and discuss your treatment response and plan based on your results.

You may be seen in the **Leukemia Fast Track Clinic** in between visits with your leukemia physician. This clinic is located within the Leukemia Center. It is open Monday through Friday, 8 a.m. to 12 p.m.

Bloodwork for your Fast Track appointment is drawn the day before or the morning of the appointment. The advanced practice provider will review your results and set up any needed transfusions, IV fluids, or electrolytes based on your lab results. We will monitor you closely for infections, side effects and any other problems you may have. Transfusions are given in the Ambulatory Treatment Center (ATC).

Throughout your treatment, it is very important that you tell your clinic care team about any problems or questions. It is important to watch for any signs or symptoms of infection. Go to the Emergency Center **right away** if you develop a fever of 101° F (38.3 °C) or higher, chills, night sweats or any other signs of infection.

**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.

Besides the physicians, there are many other health care team members who take part in your care. Each patient is assigned an advanced practice provider, either an advanced practice nurse (APN) or physician assistant (PA). Other members include nurses, dietitians, pharmacists, the infusion therapy team, physical therapists, social workers, case managers and chaplains. For example, the pharmacist assists you with your medicines and discharge prescriptions. The
advanced practice provider assists the physician in your care, provides education and coordinates your health care needs and discharge planning.

Members of your health care team will come to see you every day to discuss your treatment plans, current health status and answer any questions or concerns you may have. It helps to keep a notebook with you so you can take notes or write down questions and concerns to ask your health care team at a later time.

Each night there are on call teams. These teams include physicians and advanced practice nurses or physician assistants who stay in the hospital. The on call physician will care for you if you need medical attention during the night. This physician will have access to your medical chart and attending physician's daily notes, and any notes written by the fellow.

Upon discharge, you may need to take some medicines home with you. Your health care team will give you a list of the medicines you will continue taking and any new medicines started while you were in the hospital.

Your health care team will review the medicine list with you and arrange prescriptions that need to be filled and re-filled. Once medicines are given to you, they cannot be returned. Your pharmacist will confirm which medicines you need before having them filled.

Supportive Care Team

There are also a number of people on your supportive care team. They work together to manage your care and help prepare you for treatment. You may have appointments, tests and procedures in different specialty areas or need a referral to some of these services, such as clinical nutrition or rehabilitation services. No referral is needed to speak with the business center, patient advocacy, social work or chaplaincy.

Blood and Bone Marrow

It helps to know about what makes up normal blood and bone marrow so you can better understand what happens to your blood when you have leukemia. There are three major types of blood cells:

- Red blood cells (RBCs)
- White blood cells (WBCs)
- Platelets

These cells are made in the bone marrow and flow through the bloodstream in a liquid called plasma.

Red Blood Cells (RBCs)

Red blood cells are the major part of your blood. RBCs carry oxygen and carbon dioxide throughout your body. All body tissues need oxygen to work properly. When the bone marrow works as it should, the RBC count remains stable.

Anemia occurs when there are too few RBCs in the body. The leukemia itself, or the chemotherapy used to treat it, can cause anemia. Symptoms of anemia include feeling short of breath, weak and fatigue.

White Blood Cells (WBCs)

There are several different types of white blood cells. Each has its own role to protect the body from germs. The three main types:
• 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.

WBCs fight infection. Infections are more likely to occur when there are too few WBCs in the body.

**Absolute Neutrophil Count (ANC)**

Absolute neutrophil count (ANC) is a measure of the number of WBCs you have to fight infections. The ANC is listed as “Neutrophil Abs” on your lab report. Your lab report is printed out for you at every clinic visit and upon request if you are inpatient. It is helpful to know how to calculate your ANC in case you are admitted to your local hospital where it is not listed on your lab report.

To calculate your ANC, multiply the total number WBCs by the percentage of neutrophils. The K in the report means thousands.

For example:

\[
\text{WBC} = 1000 = 1.0K \\
\text{Neutrophil \%} = 50\% (0.5) \\
1000 \times 0.5 = 500 \text{ neutrophils}
\]

The ANC is 500 in this example, which means you have 500 neutrophils per deciliter of blood. While anyone can catch a cold or other infection, this is more likely to occur when your ANC falls below 1000. This means you are neutropenic and at a higher risk for infection. Ask your health care provider what you can do to help prevent infection while you are neutropenic.

Precautions include daily hygiene, skin protection, diet and things to avoid while you are neutropenic.

In general, your WBC count will fall within the first week you start chemotherapy and usually recovers between 21 to 28 days.

**Platelets**

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.

Thrombocytopenia (low platelets) can occur when leukemia is active or after having chemotherapy. Symptoms of thrombocytopenia include a high risk of bleeding, bruising, and petechiae (bleeding under skin).

**Bone Marrow**

Bone marrow is the soft tissue within bones where blood cells are made. All blood cells begin in the bone marrow as stem cells. Stem cells are very immature cells. They develop into mature RBCs, WBCs or platelets. With leukemia, the bone marrow makes too many immature cells and not enough RBC, WBC or platelets.

**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

This type of leukemia is an overgrowth of very immature blood cells. It is life-threatening because there are not enough mature blood cells to prevent anemia, infection and bleeding. Acute leukemia is diagnosed based on the percentage of blasts, or immature cells, in the bone marrow or blood. There are 2 major types of acute leukemia:

- Acute lymphoblastic leukemia is most common during childhood and in early adulthood.
- Acute myelogenous leukemia occurs more often in older adults.

Chronic 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.

Chronic leukemia is more common between ages 40 and 70 and is rare among young people.

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.

Other Blood Disorders

Myelodysplastic Syndrome (MDS)

This is a condition in which the bone marrow does not function normally. As a result, the bone marrow does not produce enough normal blood cells. The blood cells affected are white blood cells, red blood cells and platelets. Though MDS is not leukemia, some cases of MDS may, over time, progress to acute leukemia.

MDS is most often found in patients in their 60s and 70s. However, there are always exceptions.

Causes

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

There is no increased occurrence of leukemia among people such as friends, family and caregivers who have close contact with leukemia patients. It is not contagious. There may be a genetic (inherited) risk to leukemia. Although rare, a family could be born with a damaged gene that may increase their chances of developing leukemia.

Environmental factors, like smoking, obesity, high-dose radiation and exposure to certain toxic chemicals, such as benzene or pesticides, have been directly linked to leukemia. Exposure to ordinary x-rays, like chest x-rays, is not dangerous.

People with immune-system defects 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 with certain types of chemotherapy or high-dose radiation therapy for other cancers 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.
Diagnosis

The diagnosis of leukemia is based on blood and bone marrow results from the following tests:

**Bone marrow aspiration** – A sample of bone marrow cells is removed from the hipbone with a needle. The area is numbed with a local anesthetic before the procedure. 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** – A small piece of bone is removed from the hipbone. A local anesthetic is used to numb the area. A biopsy may be slightly more painful than a bone aspiration.

Treatment

Treatment for leukemia may include one or more of the following: chemotherapy, radiation therapy, biological therapy, surgery and stem cell transplantation.

Chemotherapy (chemo) is the most effective treatment for leukemia. It may involve one or a combination of anticancer treatments that destroy cancer cells. Certain types of leukemia are sometimes treated with radiation therapy or biological therapy.

Each type of leukemia is sensitive to different combinations of chemo. Medicines and length of treatment vary from person to person. Treatment time is usually from one to two years. During this time, your care will be managed in our outpatient center or with your local doctor.

Chemotherapy

Your treatment may consist of different chemo drugs and biological therapies. The short-term goal is for a complete remission. Complete remission in acute leukemia means that the bone marrow has less than 5% blasts, the absolute neutrophil count is over 1,000 and the platelet count is over 100,000. The long-term goal is to keep you disease-free and cured.

A cycle is the time period from the start of your chemo until either the blood and bone marrow cell counts are back to normal or when you are able to receive more treatment. One cycle is usually 3 to 4 weeks. This depends on when your blood counts recover and the type of chemotherapy. Your treatment may involve several cycles. Ask your leukemia physician how long these cycles will take to complete.

In some cases, the leukemia cells are destroyed only from the blood and not from the bone marrow during the first cycle of chemo. Then, a second cycle may be needed to destroy the leukemia cells in the bone marrow. A different chemo drug may be used to get a remission if the leukemia does not respond to 1 or 2 cycles of treatment or if a relapse occurs. Relapse is when leukemia cells continue to increase even with chemotherapy treatment.

Chemotherapy is given in several ways. These are called routes and are explained below.

**Central Line Insertion (CVC/PICC)**

A central line is a catheter (thin, flexible tube) that is inserted into a large vein that leads to the heart.
There are many different types of catheters and your physician will decide which kind is best for you.

A central venous catheter (CVC) refers to a tube that is inserted into a vein under the collarbone. A peripherally inserted central catheter (PICC) refers to a tube that is inserted into the upper arm. These catheters can stay in place for the entire time of your treatment.

Both the CVC and PICC can be used to give medicines, blood products, total parenteral nutrition feeding (IV feeding), and fluids. Blood may also be drawn from the catheter for lab tests if your physician approves.

Required Training Class

Most patients keep their central line in place after they leave the hospital to use as an outpatient. You and the person that will help you with your catheter care must attend the Catheter Care Class and schedule an appointment with Infusion Therapy to demonstrate the catheter care.

This class is located in the Main Building Infusion Therapy Classroom on Floor 8, near Elevator C, Room R8.2192. It is offered weekdays, Monday through Friday at 10:30 am and 1:30 pm, and on weekends at 10:30 am.

Spinal Tap (Lumbar Puncture)

Sometimes chemo is infused into the spinal canal through a spinal tap (lumbar puncture). This method of treatment is called intrathecal (IT) chemotherapy.

It is used when a patient is at high risk for developing central nervous system leukemia. Intrathecal chemo is used to destroy leukemia cells and decreases their growth in the spinal fluid.

- The physician or advanced practice provider will inject a local anesthetic to numb the lower part of your back. Once the area is numb, a needle is inserted between two bones in the lower back.
- You may feel pressure as the needle is inserted.
- A small amount of spinal fluid is removed through the needle. The fluid is placed in test tubes and sent to the lab. The fluid is tested for leukemia cells and infection.
- Once the spinal fluid is collected, the chemo is slowly injected into your spine. The needle is removed when the procedure is complete. You will need to lie flat in bed for 1 to 2 hours after the procedure to prevent a headache.

Radiation Therapy

Radiation therapy is used along with chemo 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 physician may direct the radiation to one specific area of the body where there is a collection of leukemia cells, such as the spleen or brain. Other patients may receive radiation that is directed to the whole body. This is called total-body irradiation. Sometimes, this type of radiation is given before a stem cell transplant.
Biological Therapy

Biotherapy, or immunotherapy, is also used to treat leukemia. It uses your own immune system to attack tumor cells. It can enhance or suppress your immune response to fight cancer. It can also lessen the side effects that may result from other leukemia treatments.

Biological therapies include growth factors, interleukins, monoclonal antibodies and other types of medicines. Some patients receive only biological therapy, while others also receive chemo at the same time. You will receive more information about biological therapy if it is used as a treatment for your type of leukemia.

Surgery

A splenectomy is a surgery to remove 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. Often, the spleen becomes enlarged from storing these cells. This makes it difficult for chemo to reduce the quantity of diseased cells. If the spleen is not removed, it sometimes grows so large that it can cause difficulty with breathing and squeeze or press against other organs. This surgery is done only if needed.

Stem Cell Transplantation

Stem cell transplantation (SCT), also known as a “bone marrow transplant,” is a type of treatment for leukemia patients. This treatment destroys leukemia bone marrow cells using high dose chemo and sometimes, radiation therapy. High-dose chemo also damages the bone marrow’s ability to produce cells. Healthy stem cells are then given through an IV to stimulate new bone marrow growth.

For leukemia patients donor cells for a stem cell transplant can be obtained from siblings, matched unrelated donors or umbilical cord donors. This is known as an allogeneic SCT. It involves infusing well-matched donor bone marrow or stem cells to you.

Stem cell transplant, like other leukemia treatments, is based very much on the patient. Many factors help your doctor decide which treatment to use, such as the type of leukemia you have, your past response to chemo treatment, whether there are stem cells available to use, your age and the status of your leukemia. Your physician will give you more information about stem cell transplant if it is a treatment option for you.

Leukemia Specialty Care Unit

Newly diagnosed patients with AML (age 50 and older) and ALL patients (age 60 and older on certain treatments) are admitted to a special area called the Leukemia Specialty Care Unit.

This area is located in the Main Building, Floor 20 near Elevator F, G20 East. It is designed to be as clean as possible to reduce the chance of infection while your immune system is low. You will probably stay in the specialty care room for three to four weeks. Specialty care rooms are different from regular hospital rooms in many ways.

- Staff and visitors must wear a gown, mask and gloves to enter the room.
• Visits with family are limited to decrease the chance of infection. Ask your health care team for more details.
• Visitors are screened at the G20 front desk. Visitors that are sick are not allowed to enter your room.
• Visitors under the age of 13 are not allowed in specialty care rooms.
• You are not able to leave your room except for tests or procedures that cannot be done inside your room once you are admitted to this unit.
• Water from the sink and shower are filtered.

**Treatment Side Effects**

Your health care team carefully reviews your medical history. Your physician will then recommend the best treatment. How a person responds to chemo and the side effects may differ from person to person or from one cycle to the next. Although treatment side effects can be serious, it is not a measure of how the leukemia responds to the chemo. Only diagnostic tests, such as blood counts and bone marrow tests, can give us this information.

Your health care team can help you manage and cope with common side effects of treatment. Ask your health care team for a copy of the “Chemotherapy Guide.”

**Infection**

In general, your white blood cell (WBC) count will fall within the first week after you start chemo. As a result, you may get an infection more easily.

Symptoms of infection include:
• Fever of 101°F Fahrenheit (38.3°C) or higher
• Chills
• Burning feeling when you urinate
• Cough
• Short of breath
• Pain at your CVC or PICC line

Go to an Emergency Center right away if you are an outpatient and have any of these symptoms. MD Anderson’s Emergency Center is open 24 hours a day, every day. From Holcombe Boulevard, turn at Entrance Marker 3. The entrance is on Bates Street near Garage 2. From inside the Main Building, go to Floor 1, near The Café Corner.

When you get to the Emergency Center, the health care team will check blood, urine, sputum, stool and throat cultures to see if there is an infection. These tests may show which bacteria is causing the infection. A chest x-ray may be done to check for lung infection.

**Hand washing is the most important precaution you can take to prevent infection.** Use a hand sanitizer if you are unable to wash your hands after shaking hands or touching items out in public, such as a grocery cart or door handle.

**Fatigue**

Your red blood cell count (RBC) will also go down soon after treatment. This drop is seen in either your hematocrit or hemoglobin levels. Both cause fatigue. A RBC transfusion may be given when your hemoglobin is at least 8.0 or lower. 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**

A decrease in the number of platelets is another side effect of chemotherapy. Nosebleeds, bleeding gums or blood in the urine or stool are likely to happen. Little red dots may appear on parts of your body, like the arms and legs. These dots are called “petechiae.” It occurs when the small blood vessels in the skin bleed. It is common to give a platelet transfusion when the platelet count is less than 12,000 or any time bleeding occurs. When your platelet count is low:

- Use a very soft toothbrush so you don’t irritate your gums.
- Use an electric shaver to shave, not a blade.
- Continue to floss if it is a routine part of your mouth care. But, do not go down to the gum line.
- Your doctor may prescribe medicines, such as hormones, if you have vaginal bleeding.

Try not to strain during bowel movements. It may cause rectal bleeding. Ask your physician to prescribe a stool softener if needed. Drink plenty of fluids to help keep your stools soft.

If you have a nose bleed or bleeding from a cut, apply direct pressure for 5 to 10 minutes.

**Bowel Problems**

You may experience diarrhea or constipation. Medicines can help, so let your physician or nurse know right away if you have either of them. High fiber foods, prunes or fruit juices may help relieve constipation. Drink at least eight, 8 ounce glasses of fluids each day. A dietitian can give you other food tips to help with these side effects.

**Nausea and Vomiting**

Chemo can also cause nausea or vomiting. Sometimes, certain smells or just thinking about the hospital or treatment can bring on nausea or vomiting. Eating dry toast or crackers can help. Avoid eating greasy foods. A dietitian can give you more food tips to help with symptoms and continue a healthy diet.

Nausea medicines can help. Ask your physician or nurse for medicine if you feel queasy. Some chemos can cause nausea for an entire day or more after treatment. Keep taking your nausea medicine for a day or so after chemo.

Some nausea medicines can make you sleepy. Do not drive while you take this medicine.

**Sore Mouth**

Sore mouth (stomatitis) is a common side effect of some chemo. You must keep your mouth as clean as possible to prevent infection. Use a baking soda rinse each day for mouth care.

- Make your own baking soda solution daily by mixing ½ teaspoon of baking soda with 8 ounces of water, unless otherwise instructed.
- Swish 1 to 2 ounces of the baking soda solution in your mouth for 30 seconds and then spit it out.
- Do mouth care 4 times daily, especially after meals.
Your physician may prescribe certain mouthwashes and sprays to prevent infection and make it easier to eat. Do not use over-the-counter mouthwashes. These have alcohol and may irritate your mouth. Try to avoid foods or drinks that are tangy, salty or sweet. These may make a sore mouth worse. Avoid very hot and spicy foods. These may slow down healing in your mouth and throat.

**Hair Loss**

Hair loss, both body and scalp, is a common side effect of chemo. You may or may not lose your hair or it may just thin out. It really depends on the chemo you get. Hair loss can have a major impact on body image. MD Anderson offers resources and services to help with hair loss.

**Beauty/Barber Shop**

Main Building, Floor 6, near Elevator F
Monday–Friday, 8:30 a.m. to 12:30 p.m., 1:30 to 3:30 p.m.
713-792-6039

Free services on a first-come, first-serve basis for patients include shampoos, haircuts, shaves, wigs, scarves and hats.

**Appearances Store**

Mays Clinic, Floor 2, near Elevator T
Monday–Friday, 8 a.m. to 4 p.m.
713-563-8200

Offers specialty clothing items for patients, such as head coverings.

**Weight Loss and Nutrition**

Although you may not want to eat or drink when you don't feel well, it is still important to nourish your body. Your body needs extra calories and protein to build strong new cells. If you begin to lose weight, try to eat 6 small meals or snacks a day. You can also add high-calorie, high-protein foods to your diet. Meet with your dietitian to get more information on these types of food.

A dietitian can also help caregivers choose the right foods and give tips on how to prepare them. Keep in mind that your appetite may be better in between treatments.

It is also very important to drink fluids during chemo. Try for at least eight, 8 ounce glasses of fluids each day. Try to drink high calorie drinks, like fruit juices, milk or protein supplements. Carbonated soft drinks have no nutrition benefits and may cause you to have gas or cramping.

If you don't feel well enough to eat, there are nutrition supplement drinks that can help your body get needed calories and protein. A member of your health care team will arrange for a dietitian to meet with you if you are a diabetic, have lost a lot of weight or have a lack of appetite. The dietitian can recommend nutritional supplements to help.

You may need to receive nutrients through a tube in your stomach or through an IV line if it becomes too difficult to eat or you lose too much weight.
Types of Blood Donations

Family members and friends are encouraged to donate blood or platelets at MD Anderson’s Blood Bank. It takes about 30 to 45 minutes to donate whole blood and up to 2 hours for platelet donation.

General donor requirements:
- Be in good general health and feeling well
- Be at least 17 years old
- Weigh at least 110 pounds
- Have a photo ID
- Not taking antibiotics or other medicines for an active infection
- Have eaten within 4 hours of donation

Most medicines are acceptable, including blood pressure, cholesterol, diabetes, thyroid, and anxiety and anti-depression.

If you have questions about donating, call the Blood Bank at 713-792-7777, www.mdanderson.org/bloodbank.

Where to Donate

Blood Donor Center – Main Building
Floor 2, near Elevator D
1515 Holcombe Blvd., Houston, TX 77030
Sunday, 10 a.m. to 3 p.m.
Monday–Thursday, 10 a.m. to 5 p.m.
Friday and Saturday, closed

Blood Donor Center – Mays Clinic
Floor 2, near the Tree Sculpture
1220 Holcombe Blvd., Houston, TX 77030
Tuesday – Thursday, 9 a.m. to 4 p.m.
Parking validated upon request for Mays Clinic Garage

Blood Donor Center – Holly Hall
2555 Holly Hall St., Houston, TX 77054
Tuesday – Thursday, 10 a.m. to 6 p.m.
Friday – Monday, 10 a.m. to 5 p.m.

Other Important Aspects of Your Care

Support for Caregivers

Caregivers may feel anxious about your care and daily needs. They need support too. Caregivers also need time alone just as you do. At first, your caregivers may feel uneasy about leaving you. This is normal. Your caregivers will have the opportunity to learn about MD Anderson resources and meet other caregivers who are also caring for a loved one.

Our 3 inpatient leukemia units (G11, G16 and G20) offer a number of support groups for inpatients and caregivers. These groups give patients and caregivers a chance to express feelings, and share experiences and ideas for dealing with certain situations. The sessions focus mainly on the emotional needs of the group members and medical information is only given if needed. Ask your health care team for more information about meeting dates and times.
myCancerConnection offers educational programs and one-on-one support by connecting people to a cancer support community of patients, survivors and caregivers. Visit the website at www.mdanderson.org/mycancerconnection for more details.

Exercise

Exercise is very important. It helps to maintain muscle tone, blood flow, breathing and also encourages a more positive attitude. The more time you spend out of the bed during the day, the better. If you need to rest or don’t feel well, take short naps or sit up in a chair. Although we encourage you to exercise, always check with your nurse before you leave the inpatient floor to take a walk.

Our rehabilitation services department can help you with exercise. Your physician can arrange for you to attend physical and occupational therapy. At home, you can do walking, stationary bike or a treadmill.

Sexuality

Sexual contact is part of a healthy, intimate relationship. Love, affection and intimacy can be expressed in a number of ways such as touching, closeness, tenderness and sharing. These do not have to stop when one partner is diagnosed with leukemia. For many, the need for intimacy increases. It is still possible to have sexual intercourse even though you have leukemia.

Leukemia and treatment side effects can have an effect on your body image and on the way you see yourself sexually. It is common to feel self-conscious when it comes to sexual intercourse because of the physical changes that occur with treatment. Your desire for intimacy, and your response to it, may be very low. Fatigue may decrease your desire too. Be sure you talk with your physician or nurse about this.

Others cannot “catch” leukemia through physical contact. It cannot be transmitted from one person to another. As long as your counts are not low, intimate contact is not dangerous. This means that there is only a slight risk of bleeding when your platelet count is less than 50,000. A water-based lubricant, if needed, may help reduce friction that could lead to bleeding during intercourse. Talk with your physician or nurse if you have any questions or concerns about sexual activity and your platelet counts.

Fertility

The side effects of chemo can cause certain physical changes. In men, most chemo drugs for leukemia can cause low sperm count or no sperm in the semen. Sperm production may return once you are done with chemo. Sperm banking before you begin chemo may be an option. Ask your nurse for more information.

In women, certain chemo drugs and doses may affect fertility – being able to become pregnant and carry a pregnancy to a live birth. Some cancer treatments can cause infertility – being unable to become pregnant after trying. Infertility can be temporary or permanent.

Once chemo is stopped and you are in remission, it may still be possible to have children. Before you start chemo it is important to discuss your family planning.
questions and concerns with your physician. Options to preserve fertility before treatment may include:

- Embryo freezing
- Ovarian tissue freezing
- Ovarian tranposition
- Medicines to suppress ovarian function

Fertility options after treatment may include:

- In vitro fertilization
- Frozen eggs or embryos
- Donor eggs or embryos
- Surrogacy

It is important to use a birth control method during your chemo because it can have harmful effects on a fetus. Chemotherapy is not an effective means of birth control and should not be relied on to prevent pregnancy. Women may use birth control pills, condoms and spermicidal foam or jelly for birth control. An intrauterine device (IUD) or diaphragm cannot be used. Ask your doctor or nurse if you have questions about which birth control method to use.

During your hospital stay, the staff will be sensitive to your privacy needs. Please let us know if you need some special time alone with your family or loved ones. An open conversation with your partner and your physician or nurse may help ease any fears and concerns you have about your sexuality.

Pet Precautions

Pet ownership has been linked to both emotional and physical health benefits. Most pets do not pose any great risk to patients with a compromised immune system. Here are some recommended pet ownership practices if you have pets at home or work with animals.

Patients with a compromised immune system should avoid:

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

Follow these guidelines for healthy pets and patients.

1. All new pets should be examined by a veterinarian. Pets must be up-to-date on vaccinations and worming/flea control programs.
2. Keep pets clean and brushed. Clip the nails short to reduce scratches.
3. Always wash your hands after you handle pets, especially before you eat.
4. Feed your pets prepared or store bought pet food only. Do not let your pet eat from garbage.
5. Give your pets clean tap water to drink.
6. Keep cats indoors as much as possible.

At Home

At some point, your treatment may be managed by your local doctor if you live outside the Houston area. Your leukemia physician will contact your local doctor to discuss your current status and your future treatment at home and in Houston. Although your local doctor will care for you at home, your overall treatment will still be managed by your MD Anderson health care team. Weekly blood tests may be needed.
and results sent to your leukemia physician to monitor the status of your leukemia. Before you leave, your leukemia physician will discuss your home treatment plan with you. Be sure to ask questions if any information is unclear. Call your leukemia physician if you or your local doctor have any questions or concerns.

Try to resume your normal routine when you get home, as much as possible. You will tire easily at first because you have not been active for many weeks. Start slow and work up to your prior level of activity. Be sure to rest and take breaks when needed. Your energy level will increase the sooner you get back to a normal routine and the more you stay active.

You may do what you did before you were diagnosed. Talk with your doctor if you have questions about work, school or other activities.

Some family and friends may feel unsure about asking how you are doing. For some, it may not be easy to talk openly about cancer. Think about what you want to communicate to your family and friends so you can start or lead the conversation. If you are comfortable talking about your illness, others probably will be too.

**What to Expect At Home**

**Low Blood Counts**
- Expect a drop in blood counts after chemotherapy.
- Take your temperature daily when your counts are low. If it is greater than 101°F, go right away to the MD Anderson Emergency Center.
  - If you are at home outside of the Houston area, go to your local emergency room.
- Stay out of crowds when your counts are low.
- Shave only with an electric razor when your counts are low to prevent bleeding and infection.
- Report symptoms of infection to your doctor.
- 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, causing you to bleed.
- Don't ignore signs of infection or physical changes.

**Daily Activities**
- 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 chemo treatments, such as dates received and side effects.
- Plan time with others. Leukemia is not contagious.
- Engage with friends or family.
MD Anderson Resources

For a complete list of MD Anderson resources, ask your health care team for a copy of the “Resources and Services Guide.”

The Leukemia Center
Monday–Friday, 8 a.m. to 5 p.m.
713-792-8760

Department of Social Work
713-792-6195

Clinical social work counselors help patients and caregivers cope with the impact of a cancer diagnosis. Social work services are free and do not require a referral. Social work offers counseling and help with advance care planning and resources related to community needs, support groups, employment and safety.

Case Management
713-745-2850

Case managers work with the care team to make sure patients have the resources they need. Case management can help coordinate home health, inpatient and outpatient rehabilitation, and home medical equipment.

The Learning Center
www.mdanderson.org/tlc

Trained librarians and health educators provide the latest information about health, coping and prevention.

Theodore N. Law Learning Center, Main Building
Floor 4, near Elevator A
Monday–Friday, 9 a.m. to 4 p.m.
713-745-8063

Levit Family Learning Center, Mays Clinic
Floor 2, near The Tree Sculpture
Monday–Friday, 9 a.m. to 4 p.m.
713-563-8010

askMDAnderson
877-632-6789

Get answers to questions about making an appointment at any MD Anderson location, understanding treatment options, learning about clinical trials and locating community cancer resources.

MyChart
MyChart.mdanderson.org

To sign up, you will need an activation code. Call askMDAnderson at 877-632-6789.

MyChart is a secure, personalized website and mobile app that helps you take an active role in managing your care at MD Anderson. With MyChart, you can review your schedule and send secure messages to members of your health care team. You also can view your medical record and patient education information.

Community Resources

Leukemia and Lymphoma Society
713-840-0483 Texas Gulf Coast Chapter
914-949-5213 National Home Office
www.lls.org

This organization supports 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.

Leukemia Texas
214-265-7393
www.leukemiatexas.org

This independent nonprofit corporation is dedicated to fighting leukemia through the funding of leukemia research and patient aid in Texas. Leukemia Texas provides financial assistance to leukemia patients needing help with their necessary treatment expenses.