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What

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You

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Need

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To

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Know

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About™

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# Leukemia

This booklet is about leukemia. The Cancer Information Service can help you learn more about this disease. The staff can talk with you in English or Spanish.

The number is 1-800-4-CANCER (1-800-422-6237). The number for deaf and hard of hearing callers with TTY equipment is 1-800-332-8615. The call is free.

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Este folleto es acerca de la leucemia. Llame al Servicio de Información sobre el Cáncer para saber más sobre esta enfermedad. Este servicio tiene personal que habla español.

El número a llamar es el 1-800-4-CANCER (1-800-422-6237). Personas con problemas de audición y que cuentan con equipo TTY pueden llamar al 1-800-332-8615. La llamada es gratis.

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## What You Need To Know About™ Leukemia

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**T**his National Cancer Institute (NCI) booklet has important information about *leukemia*,\* cancer that starts in blood cells. Each year, leukemia is diagnosed in about 29,000 adults and 2,000 children in the United States.

This booklet discusses possible causes, symptoms, diagnosis, treatment, and followup care. It also has information to help people with leukemia and their families cope with the disease.

Research is increasing what we know about leukemia. Scientists are studying its causes. They are also finding better ways to treat this disease. Because of research, adults and children with leukemia can look forward to a better quality of life and less chance of dying from the disease.

Information specialists at the NCI's Cancer Information Service at 1-800-4-CANCER can answer questions about cancer and can send NCI materials. Many NCI publications and fact sheets can be viewed on the Internet at **<http://cancer.gov/publications>**. People in the United States and its territories may use this Web site to order publications. This Web site also explains how people outside the United States can mail or fax their requests for NCI publications.

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\*Words that may be new to readers appear in *italics*. The "Dictionary" section explains these terms. Some words in the "Dictionary" have a "sounds-like" spelling to show how to pronounce them.

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## What Is Leukemia?

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**L**eukemia is a type of *cancer*. Cancer is a group of many related diseases. All cancers begin in *cells*, which make up *blood* and other *tissues*. Normally, cells grow and divide to form new cells as the body needs them. When cells grow old, they die, and new cells take their place.

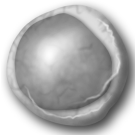
Sometimes this orderly process goes wrong. New cells form when the body does not need them, and old cells do not die when they should. Leukemia is cancer that begins in blood cells.

### Normal Blood Cells

Blood cells form in the *bone marrow*. Bone marrow is the soft material in the center of most bones.

Immature blood cells are called *stem cells* and *blasts*. Most blood cells mature in the bone marrow and then move into the *blood vessels*. Blood flowing through the blood vessels and heart is called the *peripheral blood*.

The bone marrow makes different types of blood cells. Each type has a special function:



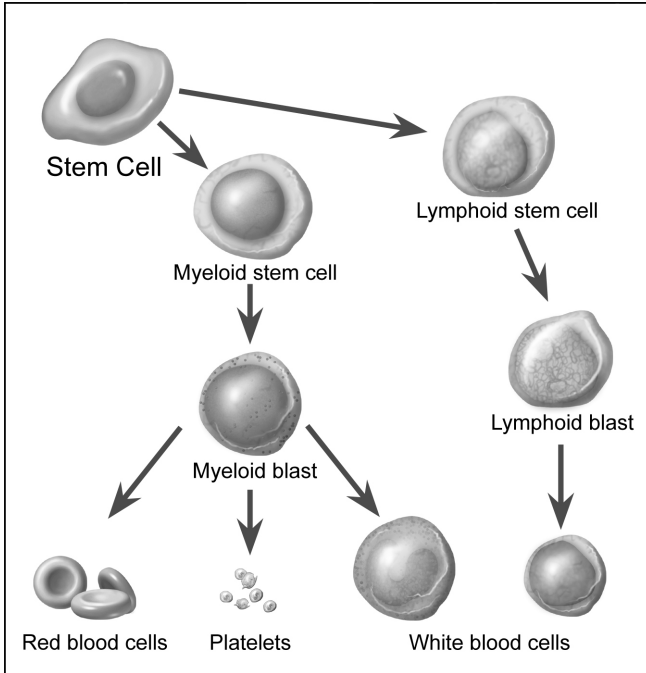
*White blood cells help fight infection.*



*Red blood cells carry oxygen to tissues throughout the body.*



*Platelets help form blood clots that control bleeding.*



Picture of blood cells maturing from stem cells.

## Leukemia Cells

In people with leukemia, the bone marrow produces abnormal white blood cells. The abnormal cells are leukemia cells. At first, leukemia cells function almost normally. In time, they may crowd out normal white blood cells, red blood cells, and platelets. This makes it hard for blood to do its work.

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## Types of Leukemia

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**T**he types of leukemia are grouped by how quickly the disease develops and gets worse. Leukemia is either *chronic* (gets worse slowly) or *acute* (gets worse quickly):

- ***Chronic leukemia***—Early in the disease, the abnormal blood cells can still do their work, and people with chronic leukemia may not have any *symptoms*. Slowly, chronic leukemia gets worse. It causes symptoms as the number of leukemia cells in the blood rises.
- ***Acute leukemia***—The blood cells are very abnormal. They cannot carry out their normal work. The number of abnormal cells increases rapidly. Acute leukemia worsens quickly.

The types of leukemia are also grouped by the type of white blood cell that is affected. Leukemia can arise in *lymphoid* cells or *myeloid* cells. Leukemia that affects lymphoid cells is called *lymphocytic* leukemia. Leukemia that affects myeloid cells is called myeloid leukemia or *myelogenous* leukemia.

There are four common types of leukemia:

- ***Chronic lymphocytic leukemia*** (*chronic lymphoblastic leukemia*, CLL) accounts for about 7,000 new cases of leukemia each year. Most often, people diagnosed with the disease are over age 55. It almost never affects children.
- ***Chronic myeloid leukemia*** (*chronic myelogenous leukemia*, CML) accounts for about 4,400 new cases of leukemia each year. It affects mainly adults.
- ***Acute lymphocytic leukemia*** (*acute lymphoblastic leukemia*, ALL) accounts for about 3,800 new cases of leukemia each year. It is the most common type of leukemia in young children. It also affects adults.

- **Acute myeloid leukemia** (*acute myelogenous leukemia*, AML) accounts for about 10,600 new cases of leukemia each year. It occurs in both adults and children.

*Hairy cell leukemia* is a rare type of chronic leukemia. This booklet does not deal with hairy cell leukemia or other rare types of leukemia. Together, these rare leukemias account for about 5,200 new cases of leukemia each year. The Cancer Information Service (1-800-4-CANCER) can provide information about these types of leukemia.

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## Leukemia: Who's at Risk?

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**N**o one knows the exact causes of leukemia. Doctors can seldom explain why one person gets this disease and another does not. However, research has shown that people with certain *risk factors* are more likely than others to develop leukemia. A risk factor is anything that increases a person's chance of developing a disease.

Studies have found the following risk factors for leukemia:

- **Very high levels of radiation**—People exposed to very high levels of radiation are much more likely than others to develop leukemia. Very high levels of radiation have been caused by atomic bomb explosions (such as those in Japan during World War II) and nuclear power plant accidents (such as the Chernobyl [also called Chornobyl] accident in 1986). Medical treatment that uses radiation can be another source of high-level exposure. Radiation used for diagnosis, however, exposes people to much lower levels of radiation and is not linked to leukemia.



- **Working with certain chemicals**—Exposure to high levels of *benzene* in the workplace can cause leukemia. Benzene is used widely in the chemical industry. *Formaldehyde* is also used by the chemical industry. Workers exposed to formaldehyde also may be at greater risk of leukemia.
- **Chemotherapy**—Cancer patients treated with certain cancer-fighting drugs sometimes later develop leukemia. For example, drugs known as *alkylating agents* are associated with the development of leukemia many years later.
- **Down syndrome** and certain other genetic diseases—Some diseases caused by abnormal *chromosomes* may increase the risk of leukemia.
- **Human T-cell leukemia virus-1 (HTLV-1)**—This virus causes a rare type of chronic lymphocytic leukemia known as human T-cell leukemia. However, leukemia does not appear to be contagious.
- **Myelodysplastic syndrome**—People with this blood disease are at increased risk of developing acute myeloid leukemia.

In the past, some studies suggested exposure to *electromagnetic fields* as another possible risk factor for leukemia. Electromagnetic fields are a type of low-energy radiation that comes from power lines and electric appliances. However, results from recent studies show that the evidence is weak for electromagnetic fields as a risk factor.

Most people who have known risk factors do not get leukemia. On the other hand, many who do get the disease have none of these risk factors. People who think they may be at risk of leukemia should discuss this concern with their doctor. The doctor may suggest ways to reduce the risk and can plan an appropriate schedule for checkups.

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## Symptoms

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**L**ike all blood cells, leukemia cells travel through the body. Depending on the number of abnormal cells and where these cells collect, patients with leukemia may have a number of symptoms.

Common symptoms of leukemia may include:

- Fevers or night sweats
- Frequent infections
- Feeling weak or tired
- Headache
- Bleeding and bruising easily (bleeding gums, purplish patches in the skin, or tiny red spots under the skin)
- Pain in the bones or joints
- Swelling or discomfort in the *abdomen* (from an enlarged *spleen*)
- Swollen *lymph nodes*, especially in the neck or armpit
- Weight loss

Such symptoms are not sure signs of leukemia. An infection or another problem also could cause these symptoms. Anyone with these symptoms should see a doctor as soon as possible. Only a doctor can diagnose and treat the problem.

In the early stages of chronic leukemia, the leukemia cells function almost normally. Symptoms may not appear for a long time. Doctors often find chronic leukemia during a routine checkup—before there are any symptoms. When symptoms do appear, they generally are mild at first and get worse gradually.



In acute leukemia, symptoms appear and get worse quickly. People with this disease go to their doctor because they feel sick. Other symptoms of acute leukemia are vomiting, confusion, loss of muscle control, and *seizures*. Leukemia cells also can collect in the *testicles* and cause swelling. Also, some patients develop sores in the eyes or on the skin. Leukemia also can affect the *digestive tract*, *kidneys*, *lungs*, or other parts of the body.

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## Diagnosis

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**I**f a person has symptoms that suggest leukemia, the doctor may do a physical exam and ask about the patient’s personal and family medical history. The doctor also may order laboratory tests, especially blood tests.

The exams and tests may include the following:

- **Physical exam**—The doctor checks for swelling of the *lymph nodes*, *spleen*, and *liver*.
- **Blood tests**—The lab checks the level of blood cells. Leukemia causes a very high level of white blood cells. It also causes low levels of platelets and *hemoglobin*, which is found inside red blood cells. The lab also may check the blood for signs that leukemia has affected the liver and kidneys.
- **Biopsy**—The doctor removes some bone marrow from the hipbone or another large bone. A *pathologist* examines the sample under a microscope. The removal of tissue to look for cancer cells is called a biopsy. A biopsy is the only sure way to know whether leukemia cells are in the bone marrow.

There are two ways the doctor can obtain bone marrow. Some patients will have both procedures:

- **Bone marrow aspiration**: The doctor uses a needle to remove samples of bone marrow.
- **Bone marrow biopsy**: The doctor uses a very thick needle to remove a small piece of bone and bone marrow.

*Local anesthesia* helps to make the patient more comfortable.

- **Cytogenetics**—The lab looks at the chromosomes of cells from samples of peripheral blood, bone marrow, or lymph nodes.
- **Spinal tap**—The doctor removes some of the *cerebrospinal fluid* (the fluid that fills the spaces in and around the brain and spinal cord). The doctor uses a long, thin needle to remove fluid from the spinal column. The procedure takes about 30 minutes and is performed with local anesthesia. The patient must lie flat for several hours afterward to keep from getting a headache. The lab checks the fluid for leukemia cells or other signs of problems.
- **Chest x-ray**—The x-ray can reveal signs of disease in the chest.

A person who needs a bone marrow aspiration or bone marrow biopsy may want to ask the doctor the following questions:

- Will you remove the sample of bone marrow from the hip or from another bone?
- How long will the procedure take? Will I be awake? Will it hurt?
- How soon will you have the results? Who will explain them to me?
- If I do have leukemia, who will talk to me about treatment? When?

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## Treatment

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**M**any people with leukemia want to take an active part in making decisions about their medical care. They want to learn all they can about their disease and their treatment choices. However, the shock and stress after a diagnosis of cancer can make it hard to think of

everything to ask the doctor. Often it helps to make a list of questions before an appointment. To help remember what the doctor says, patients may take notes or ask whether they may use a tape recorder. Some also want to have a family member or friend with them when they talk to the doctor—to take part in the discussion, to take notes, or just to listen.

The doctor may refer patients to doctors who specialize in treating leukemia, or patients may ask for a referral. Specialists who treat leukemia include *hematologists*, *medical oncologists*, and *radiation oncologists*. *Pediatric* oncologists and hematologists treat childhood leukemia.

Whenever possible, patients should be treated at a medical center that has doctors experienced in treating leukemia. If this is not possible, the patient's doctor may discuss the treatment plan with a specialist at such a center.

## Getting a Second Opinion

Sometimes it is helpful to have a second opinion about the diagnosis and the treatment plan. Some insurance companies require a second opinion; others may cover a second opinion if the patient or doctor requests it. There are a number of ways to find a doctor for a second opinion:

- The patient's doctor may be able to suggest a doctor who specializes in adult or childhood leukemia. At cancer centers, several specialists often work together as a team.
- The Cancer Information Service, at 1-800-4-CANCER, can tell callers about nearby treatment centers.
- A local or state medical society, a nearby hospital, or a medical school can usually provide the names of specialists.

- *The Official ABMS Directory of Board Certified Medical Specialists* lists doctors' names along with their specialty and their educational background. Board-certified doctors have met specific education and training requirements and have passed an examination given by a specialty board. The directory is available in most public libraries. The American Board of Medical Specialties (ABMS) also offers information about board certification by telephone and on the Internet. The toll-free telephone number is 1-866-ASK-ABMS (1-866-275-2267). The Internet address is <http://www.abms.org>.

## **Preparing for Treatment**

The doctor can describe treatment choices and discuss the results expected with each treatment option. The doctor and patient can work together to develop a treatment plan that fits the patient's needs.

Treatment depends on a number of factors, including the type of leukemia, the patient's age, whether leukemia cells are present in the cerebrospinal fluid, and whether the leukemia has been treated before. It also may depend on certain features of the leukemia cells. The doctor also takes into consideration the patient's symptoms and general health.

These are some questions a person may want to ask the doctor before treatment begins:

- What type of leukemia do I have?
- What are my treatment choices? Which do you recommend for me? Why?
- What are the benefits of each kind of treatment?
- What are the risks and possible *side effects* of each treatment?
- If I have pain, how will you help me?
- What is the treatment likely to cost?
- How will treatment affect my normal activities?
- Would a *clinical trial* (research study) be appropriate for me? Can you help me find one?

People do not need to ask all of their questions or understand all of the answers at one time. They will have other chances to ask the doctor to explain things that are not clear and to ask for more information.

## Methods of Treatment

The doctor is the best person to describe the treatment choices and discuss the expected results. Depending on the type and extent of the disease, patients may have *chemotherapy*, *biological therapy*, *radiation therapy*, or *bone marrow transplantation*. If the patient's spleen is enlarged, the doctor may suggest surgery to remove it. Some patients receive a combination of treatments.



People with acute leukemia need to be treated right away. The goal of treatment is to bring about a *remission*. Then, when signs and symptoms disappear, more therapy may be given to prevent a *relapse*. This type of therapy is called *maintenance therapy*. Many people with acute leukemia can be cured.

Chronic leukemia patients who do not have symptoms may not require immediate treatment. The doctor may suggest *watchful waiting* for some patients with chronic lymphocytic leukemia. The health care team will monitor the patient's health so that treatment can begin if symptoms occur or worsen. When treatment for chronic leukemia is needed, it can often control the disease and its symptoms. However, chronic



leukemia can seldom be cured. Patients may receive maintenance therapy to help keep the cancer in remission.

A patient may want to talk to the doctor about taking part in a clinical trial, a research study of new treatment methods. The section on “The Promise of Cancer Research” on page 26 has more information about clinical trials.

In addition to anticancer therapy, people with leukemia may have treatment to control pain and other symptoms of the cancer, to relieve the side effects of therapy, or to ease emotional problems. This kind of treatment is called *symptom management*, *supportive care*, or *palliative care*.

## Chemotherapy

Most patients with leukemia receive chemotherapy. This type of cancer treatment uses drugs to kill leukemia cells. Depending on the type of leukemia, the patient may receive a single drug or a combination of two or more drugs.

People with leukemia may receive chemotherapy in several different ways:

- **By mouth**
- **By injection directly into a vein** (*IV* or intravenous)
- **Through a *catheter*** (a thin, flexible tube) placed in a large vein, often in the upper chest—A catheter that stays in place is useful for patients who need many IV treatments. The health care professional injects drugs into the catheter, rather than directly into a vein. This method avoids the need for many injections, which can cause discomfort and injure the veins and skin.

- **By injection directly into the cerebrospinal fluid**—If the pathologist finds leukemia cells in the fluid that fills the spaces in and around the brain and spinal cord, the doctor may order *intrathecal chemotherapy*. The doctor injects drugs directly into the cerebrospinal fluid. This method is used because drugs given by IV injection or taken by mouth often do not reach cells in the brain and spinal cord. (A network of blood vessels filters blood going to the brain and spinal cord. This *blood-brain barrier* stops drugs from reaching the brain.)

The patient may receive the drugs in two ways:

- **Injection into the spine:** The doctor injects the drugs into the lower part of the spinal column.
- **Ommaya reservoir:** Children and some adult patients receive intrathecal chemotherapy through a special catheter called an Ommaya reservoir. The doctor places the catheter under the scalp. The doctor injects the anticancer drugs into the catheter. This method avoids the discomfort of injections into the spine.

Patients receive chemotherapy in cycles: a treatment period, then a recovery period, and then another treatment period. In some cases, the patient has chemotherapy as an outpatient at the hospital, at the doctor’s office, or at home. However, depending on which drugs are given, and the patient’s general health, a hospital stay may be necessary.

Some people with chronic myeloid leukemia receive a new type of treatment called *targeted therapy*. Targeted therapy blocks the production of leukemia cells but does not harm normal cells. Gleevec, also called STI-571, is the first targeted therapy approved for chronic myeloid leukemia.

## Biological Therapy

People with some types of leukemia have biological therapy. This type of treatment improves the body's natural defenses against cancer. The therapy is given by injection into a vein.

For some patients with chronic lymphocytic leukemia, the type of biological therapy used is a *monoclonal antibody*. This substance binds to the leukemia cells. This therapy enables the *immune system* to kill leukemia cells in the blood and bone marrow.

For some patients with chronic myeloid leukemia, the biological therapy is a natural substance called *interferon*. This substance can slow the growth of leukemia cells.

Patients may want to ask these questions about chemotherapy or biological therapy:

- Why do I need this treatment?
- What drugs will I get?
- Should I see my dentist before treatment begins?
- What will the treatment do?
- Will I have to stay in the hospital?
- How will we know the drugs are working?
- How long will I be on this treatment?
- Will I have side effects during treatment? How long will they last? What can I do about them?
- Can these drugs cause side effects later on?
- How often will I need checkups?

## Radiation Therapy

Radiation therapy (also called radiotherapy) uses high-energy rays to kill leukemia cells. For most patients, a large machine directs radiation at the spleen, the brain, or other parts of the body where leukemia cells have collected. Some patients receive radiation that is directed to the whole body. (*Total-body irradiation* usually is given before a bone marrow transplant.) Patients receive radiation therapy at a hospital or clinic.

These are some questions a person may want to ask the doctor before having radiation therapy:

- Why do I need this treatment?
- When will the treatments begin? How often will they be given? When will they end?
- How will I feel during therapy? Will there be side effects? How long will they last? What can we do about them?
- Can radiation therapy cause side effects later on?
- What can I do to take care of myself during therapy?
- How will we know if the radiation is working?
- Will I be able to continue my normal activities during treatment?
- How often will I need checkups?

## Stem Cell Transplantation

Some patients with leukemia have *stem cell transplantation*. A stem cell transplant allows a patient to be treated with high doses of drugs, radiation, or both. The high doses destroy both leukemia cells and normal blood cells in the bone marrow. Later, the patient receives healthy stem cells through a flexible tube that is placed in a large vein in the neck or chest area. New blood cells develop from the transplanted stem cells.

There are several types of stem cell transplantation:

- ***Bone marrow transplantation***—The stem cells come from bone marrow.
- ***Peripheral stem cell transplantation***—The stem cells come from peripheral blood.
- ***Umbilical cord blood transplantation***—For a child with no donor, the doctor may use stem cells from *umbilical cord blood*. The umbilical cord blood is from a newborn baby. Sometimes umbilical cord blood is frozen for use later.

Stem cells may come from the patient or from a donor:

- ***Autologous stem cell transplantation***—This type of transplant uses the patient’s own stem cells. The stem cells are removed from the patient, and the cells may be treated to kill any leukemia cells present. The stem cells are frozen and stored. After the patient receives high-dose chemotherapy or radiation therapy, the stored stem cells are thawed and returned to the patient.
- ***Allogeneic stem cell transplantation***—This type of transplant uses healthy stem cells from a donor. The patient’s brother, sister, or parent may be the donor. Sometimes the stem cells come from an unrelated donor. Doctors use blood tests to be sure the donor’s cells match the patient’s cells.

- ***Syngeneic stem cell transplantation***—This type of transplant uses stem cells from the patient’s healthy identical twin.

After a stem cell transplant, patients usually stay in the hospital for several weeks. The health care team protects patients from infection until the transplanted stem cells begin to produce enough white blood cells.

These are some questions a person may want to ask the doctor before having a stem cell transplant:

- What kind of stem cell transplant will I have? If I need a donor, how will we find one?
- How long will I be in the hospital? What care will I need when I leave the hospital?
- How will we know if the treatment is working?
- What are the risks and the side effects? What can we do about them?
- What changes in normal activities will be necessary?
- What is my chance of a full recovery? How long will that take?
- How often will I need checkups?

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## Side Effects of Cancer Treatment

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**B**ecause cancer treatment may damage healthy cells and tissues, unwanted side effects are common. Specific side effects depend on many factors, including the type and extent of the treatment. Side effects may not be the same for each person, and they may even change from one treatment session to the next. Before

treatment starts, health care providers will explain possible side effects and suggest ways to manage them.

The NCI provides helpful booklets about cancer treatments and coping with side effects, such as *Chemotherapy and You*, *Radiation Therapy and You*, and *Eating Hints for Cancer Patients*. See the “National Cancer Institute Information Resources” section on page 39 for other sources of information about side effects. NCI’s Web site includes a section called “Coping with Cancer” at [http://cancer.gov/cancer\\_information](http://cancer.gov/cancer_information). This section presents information about coping with fatigue, pain, and other problems.

## Chemotherapy

The side effects of chemotherapy depend mainly on the specific drugs and the dose. In general, anticancer drugs affect cells that divide rapidly, especially leukemia cells. Chemotherapy can also affect other rapidly dividing cells:

- **Blood cells:** These cells fight infection, help the blood to clot, and carry oxygen to all parts of the body. When blood cells are affected, patients are more likely to get infections, may bruise or bleed easily, and may feel very weak and tired.
- **Cells in hair roots:** Chemotherapy can lead to hair loss. The hair grows back, but the new hair may be somewhat different in color and texture.
- **Cells that line the digestive tract:** Chemotherapy can cause mouth and lip sores, nausea and vomiting, diarrhea, and poor appetite. Many of these side effects can be controlled with drugs.

Some anticancer drugs can affect a patient’s *fertility*. Women may have irregular menstrual periods or periods may stop altogether. Women may have symptoms of *menopause*, such as hot flashes and



vaginal dryness. Men may stop producing sperm. Because these changes may be permanent, some men have their sperm frozen and stored before treatment. Most children treated for leukemia appear to have normal fertility when they grow up. However, depending on the drugs and doses used and the age of the patient, some boys and girls may be *infertile* when they mature.

Because targeted therapy (sometimes used for chronic myeloid leukemia) affects only leukemia cells, it causes fewer side effects than most other anticancer drugs. However, Gleevec may cause patients to retain water. This may cause swelling or bloating.

## **Biological Therapy**

The side effects of biological therapy differ with the types of substances used, and from patient to patient. Rashes or swelling where the biological therapy is injected are common. Flu-like symptoms also may occur. The health care team may monitor the blood for signs of *anemia* and other problems.

## **Radiation Therapy**

Radiation therapy may cause patients to become very tired as treatment continues. Resting is important, but doctors usually advise patients to try to stay as active as they can. In addition, when patients receive radiation therapy, it is common for their skin to become red, dry, and tender in the treated area. Other side effects depend on the area of the body that is treated. If chemotherapy is given at the same time, the side effects may be worse. The doctor can suggest ways to ease these problems.

## Stem Cell Transplantation

Patients who have stem cell transplantation face an increased risk of infection, bleeding, and other side effects because of the large doses of chemotherapy and radiation they receive. In addition, *graft-versus-host disease* (GVHD) may occur in patients who receive stem cells from a donor's bone marrow. In GVHD, the donated stem cells react against the patient's tissues. Most often, the liver, skin, or digestive tract is affected. GVHD can be mild or very severe. It can occur any time after the transplant, even years later. *Steroids* or other drugs may help.

The NCI offers a fact sheet called, "Questions and Answers About Bone Marrow Transplantation and Peripheral Blood Stem Cell Transplantation."

It is available on the Internet at

**<http://cancer.gov/publications>**. Also, information specialists at the NCI's Cancer Information Service at 1-800-4-CANCER can send this fact sheet and answer questions about stem cell transplantation.

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## Supportive Care

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**L**eukemia and its treatment can lead to other health problems. Patients receive supportive care to prevent or control these problems and to improve their comfort and *quality of life* during treatment.

Because people with leukemia get infections very easily, they may receive antibiotics and other drugs to help protect them from infections. The health care team may advise them to stay away from crowds and from people with colds and other contagious diseases. If an infection develops, it can be serious and should be treated promptly. Patients may need to stay in the hospital for treatment.

Anemia and bleeding are other problems that often require supportive care. Patients may need *transfusions* of red blood cells to help them have more energy. Platelet transfusions can help reduce the risk of serious bleeding.

Dental care also is very important. Leukemia and chemotherapy can make the mouth sensitive, easily infected, and likely to bleed. Doctors often advise patients to have a complete dental exam and, if possible, undergo needed dental care before chemotherapy begins. Dentists show patients how to keep their mouth clean and healthy during treatment.

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## Nutrition

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**P**atients need to eat well during cancer therapy. They need enough calories to maintain a good weight and protein to keep up strength. Good nutrition often helps people with cancer feel better and have more energy.

But eating well can be difficult. Patients may not feel like eating if they are uncomfortable or tired. Also, the side effects of treatment, such as poor appetite, nausea, or vomiting, can be a problem. Foods may taste different.

The doctor, dietitian, or other health care provider can suggest ways to maintain a healthy diet. Patients and their families may want to read the National Cancer Institute booklet *Eating Hints for Cancer Patients*, which contains many useful ideas and recipes. The “National Cancer Institute Booklets” section on page 40 tells how to get this publication.

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## Followup Care

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**F**ollowup care after treatment for leukemia is an important part of the overall treatment plan. Regular checkups ensure that any changes in health are noted. The doctor can find problems and treat them as soon as possible. Checkups may include a careful physical exam, blood tests, x-rays, bone marrow aspiration, or spinal tap. The doctor can explain the followup plan—how often the patient must visit the doctor and what tests are needed.

The NCI has prepared a booklet for people who have completed their treatment to help answer questions about followup care and other concerns. *Facing Forward Series: Life After Cancer Treatment* provides tips for getting the most out of medical visits. It describes the kinds of help people may need.

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## Support for People with Leukemia

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**L**iving with a serious disease such as leukemia is not easy. Some people find they need help coping with the emotional and practical aspects of their disease. Support groups can help. In these groups, patients or their family members get together to share what they have learned about coping with the disease and the effects of treatment. Patients may want to talk with a member of their health care team about finding a support group. Groups may offer support in person, over the telephone, or on the Internet.

People living with cancer may worry about caring for their families, keeping their jobs, or continuing daily activities. Concerns about treatments and

managing side effects, hospital stays, and medical bills are also common. Doctors, nurses, and other members of the health care team can answer questions about treatment, working, or other activities. Meeting with a social worker, counselor, or member of the clergy can be helpful to those who want to talk about their feelings or discuss their concerns. Often, a social worker can suggest resources for financial aid, transportation, home care, or emotional support.

The Cancer Information Service can provide information to help patients and their families locate programs, services, and publications.

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## The Promise of Cancer Research

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**D**octors all over the country are conducting many types of clinical trials. These are research studies in which people take part voluntarily. Studies include new methods of treatment and supportive care for patients with leukemia. Research already has led to advances, and researchers continue to search for more effective approaches.

Patients who join these studies have the first chance to benefit from treatments that have shown promise in earlier research. They also make an important contribution to medical science by helping doctors learn more about the disease. Although clinical trials may pose some risks, researchers take very careful steps to protect their patients.

Researchers are testing new biological therapies and new anticancer drugs, doses, and treatment schedules. They also are working with various drugs and with combinations of drugs, biological therapy, radiation therapy, and stem cell transplantation.

Patients who are interested in being part of a clinical trial should talk with their doctor. They may want to read *Taking Part in Clinical Trials: What Cancer Patients Need To Know*. The NCI also offers an easy-to-read brochure called *If You Have Cancer . . . What You Should Know About Clinical Trials*. These NCI publications describe how research studies are carried out and explain their possible benefits and risks. NCI's Web site includes a section on clinical trials at [http://cancer.gov/clinical\\_trials](http://cancer.gov/clinical_trials). This section of the Web site provides general information about clinical trials. It also offers detailed information about ongoing studies of leukemia treatment. The Cancer Information Service at 1-800-4-CANCER can answer questions and provide information about clinical trials.

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## Dictionary

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**Abdomen** (AB-do-men): The area of the body that contains the pancreas, stomach, intestine, liver, gallbladder, and other organs.

**Acute**: Having an abrupt onset of symptoms of short duration; not chronic.

**Acute leukemia** (loo-KEE-mee-a): A rapidly progressing cancer that starts in blood cells.

**Acute lymphoblastic leukemia** (lim-fo-BLAST-ik loo-KEE-mee-a): ALL. A quickly progressing disease in which too many immature white blood cells (called lymphoblasts) are found in the blood and bone marrow. Also called acute lymphocytic leukemia.

**Acute lymphocytic leukemia** (lim-fo-SIT-ik loo-KEE-mee-a): ALL. A quickly progressing disease in which too many immature white blood cells (called lymphoblasts) are found in the blood and bone marrow. Also called acute lymphoblastic leukemia.

**Acute myelogenous leukemia** (mye-eh-LAH-jen-us loo-KEE-mee-a): AML. A quickly progressing disease in which too many immature blood-forming cells are found in the blood and bone marrow. Also called acute myeloid leukemia or acute nonlymphocytic leukemia.

**Acute myeloid leukemia** (MY-eh-loyd loo-KEE-mee-a): AML. A quickly progressing disease in which too many immature blood-forming cells are found in the blood and bone marrow. Also called acute myelogenous leukemia or acute nonlymphocytic leukemia.

**Alkylating agents:** A family of anticancer drugs that interferes with the cell's DNA and inhibits cancer cell growth.

**Allogeneic stem cell transplantation** (AL-o-jen-AY-ik): A procedure in which a person receives stem cells, the cells from which all blood cells develop, from a compatible, though not genetically identical, donor.

**Anemia** (a-NEE-mee-a): A condition in which the number of red blood cells is below normal.

**Autologous stem cell transplantation** (aw-TAHL-o-gus): A procedure in which stem cells are removed from a person, stored, and then given back after the person has intensive treatment.

**Benzene:** A chemical that can cause leukemia. It is used widely by the chemical industry. Other common sources of benzene include tobacco smoke, vehicle emissions, and gasoline fumes.

**Biological therapy** (by-o-LAHJ-i-kul): Treatment to stimulate or restore the ability of the immune system to fight infections and other diseases. Also used to lessen side effects that may be caused by some cancer treatments. Also known as immunotherapy, biotherapy, or biological response modifier (BRM) therapy.

**Biopsy** (BY-op-see): The removal of cells or tissues for examination under a microscope. When only a sample

of tissue is removed, the procedure is called an incisional biopsy or core biopsy. When an entire lump or suspicious area is removed, the procedure is called an excisional biopsy. When a sample of tissue or fluid is removed with a needle, the procedure is called a needle biopsy or fine-needle aspiration.

**Blasts:** Immature blood cells.

**Blood:** A tissue with red blood cells, white blood cells, platelets, and other substances suspended in fluid called plasma. Blood takes oxygen and nutrients to the tissues, and carries away wastes.

**Blood vessel:** A tube through which the blood circulates in the body. Blood vessels include a network of arteries, arterioles, capillaries, venules, and veins.

**Blood-brain barrier:** A network of blood vessels with closely spaced cells that makes it difficult for potentially toxic substances (such as anticancer drugs) to penetrate the blood vessel walls and enter the brain.

**Bone marrow:** The soft, sponge-like tissue in the center of most bones that produces white blood cells, red blood cells, and platelets.

**Bone marrow aspiration** (as-per-AY-shun): The removal of a small sample of bone marrow (usually from the hip) through a needle for examination under a microscope.

**Bone marrow biopsy** (BY-op-see): The removal of a sample of tissue from the bone marrow with a needle for examination under a microscope.

**Bone marrow transplantation** (trans-plan-TAY-shun): A procedure to replace bone marrow that has been destroyed by treatment with high doses of anticancer drugs or radiation. Transplantation may be autologous (an individual's own marrow saved before treatment), allogeneic (marrow donated by someone else), or syngeneic (marrow donated by an identical twin).



**Cancer:** A term for diseases in which abnormal cells divide without control. Cancer cells can invade nearby tissues and can spread through the bloodstream and lymphatic system to other parts of the body.

**Catheter** (KATH-i-ter): A flexible tube used to deliver fluids into or withdraw fluids from the body.

**Cell:** The individual unit that makes up all of the tissues of the body. All living things are made up of one or more cells.

**Cerebrospinal fluid** (seh-REE-bro-SPY-nal): CSF. The fluid flowing around the brain and spinal cord. Cerebrospinal fluid is produced in the ventricles in the brain.

**Chemotherapy** (kee-mo-THER-a-pee): Treatment with anticancer drugs.

**Chromosome** (KRO-mo-some): Part of a cell that contains genetic information. Except for sperm and eggs, all human cells contain 46 chromosomes.

**Chronic** (KRAHN-ik): A disease or condition that persists or progresses over a long period of time.

**Chronic leukemia** (KRAHN-ik loo-KEE-mee-a): A slowly progressing cancer that starts in blood cells.

**Chronic lymphoblastic leukemia** (KRAHN-ik lim-fo-BLAST-ik loo-KEE-mee-a): A slowly progressing disease in which too many immature white blood cells (called lymphoblasts) are found in the body.

**Chronic lymphocytic leukemia** (KRAHN-ik lim-fo-SIT-ik loo-KEE-mee-a): CLL. A slowly progressing disease in which too many white blood cells (called lymphocytes) are found in the body.

**Chronic myelogenous leukemia** (KRAHN-ik mye-eh-LAH-jen-us loo-KEE-mee-a): CML. A slowly progressing disease in which too many white blood cells are made in the bone marrow. Also called chronic myeloid leukemia or chronic granulocytic leukemia.

**Chronic myeloid leukemia** (KRAHN-ik MY-eh-loyd loo-KEE-mee-a): CML. A slowly progressing disease in which too many white blood cells are made in the bone marrow. Also called chronic myelogenous leukemia or chronic granulocytic leukemia.

**Clinical trial:** A type of research study that tests how well new medical treatments or other interventions work in people. Such studies test new methods of screening, prevention, diagnosis, or treatment of a disease. The study may be carried out in a clinic or other medical facility. Also called a clinical study.

**Cytogenetics** (SITE-o-juh-NET-iks): The study of chromosomal abnormalities.

**Digestive tract** (dye-JES-tiv): The organs through which food passes when food is eaten. These organs are the mouth, esophagus, stomach, small and large intestines, and rectum.

**Down syndrome:** A disorder caused by the presence of an extra chromosome 21 and characterized by mental retardation and distinguishing physical features.

**Electromagnetic field:** Low-energy radiation that comes from power lines and electric appliances.

**Fertility** (fer-TIL-i-tee): The ability to produce children.

**Formaldehyde** (for-MAL-duh-hide): Chemical used in the manufacturing and chemical industries, and by anatomists, embalmers, and pathologists. Workers exposed to formaldehyde may be at greater risk of leukemia and brain cancer.

**Graft-versus-host disease:** GVHD. A reaction of donated bone marrow or peripheral stem cells against the recipient's tissue.

**Hairy cell leukemia:** A type of chronic leukemia in which the abnormal white blood cells appear to be covered with tiny hairs when viewed under a microscope.

**Hematologist** (hee-ma-TOL-o-jist): A doctor who specializes in treating diseases of the blood.

**Hemoglobin** (HE-muh-GLOW-bun): The substance inside red blood cells that carries oxygen from the lungs to the tissues.

**Human T-cell leukemia virus-I**: HTLV-I. The cause of T-cell leukemia and certain types of lymphoma.

**Immune system** (im-YOON): The complex group of organs and cells that defends the body against infection or disease.

**Infection**: Invasion and multiplication of germs in the body. Infections can occur in any part of the body, and can be localized or systemic (spread throughout the body). The germs may be bacteria, viruses, yeast, or fungi. They can cause a fever and other problems, depending on the site of the infection. When the body's natural defense system is strong, it can often fight the germs and prevent infection. Cancer treatment can weaken the natural defense system.

**Infertile**: Unable to produce children.

**Interferon** (in-ter-FEER-on): A biological response modifier (a substance that can improve the body's natural response to infections and other diseases). Interferons interfere with the division of cancer cells and can slow tumor growth. There are several types of interferons, including interferon-alpha, -beta, and -gamma. The body normally produces these substances. They are also made in the laboratory to treat cancer and other diseases.

**Intrathecal chemotherapy** (in-tra-THEE-kal KEE-mo-THER-a-pee): Anticancer drugs that are injected into the fluid-filled space between the thin layers of tissue that cover the brain and spinal cord.

**IV**: Intravenous (in-tra-VEE-nus). Injected into a blood vessel.

***Kidneys*** (KID-nee-z): A pair of organs in the abdomen that remove waste from the blood (as urine), produce erythropoietin (a substance that stimulates red blood cell production), and play a role in blood pressure regulation.

***Leukemia*** (loo-KEE-mee-a): Cancer that starts in blood cells.

***Liver***: A large organ located in the upper abdomen. The liver cleanses the blood and aids in digestion by secreting bile.

***Local anesthesia*** (an-es-THEE-zha): Drugs that cause a temporary loss of feeling in one part of the body. The patient remains awake but cannot feel the part of the body treated with the anesthetic.

***Lungs***: A pair of organs in the chest that supply the body with oxygen.

***Lymph node*** (limf node): A rounded mass of lymphatic tissue that is surrounded by a capsule of connective tissue. Lymph nodes filter lymph (lymphatic fluid), and they store lymphocytes (white blood cells). They are located along lymphatic vessels. Also known as a lymph gland.

***Lymphocytic*** (lim-fo-SIT-ik): Referring to lymphocytes, a type of white blood cell.

***Lymphoid*** (LIM-foyd): Referring to lymphocytes, a type of white blood cell. Also refers to tissue in which lymphocytes develop.

***Maintenance therapy***: Treatment that is given to help a primary (original) treatment keep working. Maintenance therapy is often given to help keep cancer in remission.

***Medical oncologist*** (on-KOL-o-jist): A doctor who specializes in diagnosing and treating cancer using chemotherapy, hormonal therapy, and biological therapy. A medical oncologist often serves as the main caretaker of someone who has cancer and coordinates treatment provided by other specialists.

**Menopause** (MEN-o-pawz): The time of life when a woman's menstrual periods stop permanently. Also called "change of life."

**Monoclonal antibodies** (MAH-no-KLO-nul AN-tih-BAH-deez): Laboratory-produced substances that can locate and bind to cancer cells wherever they are in the body. Many monoclonal antibodies are used in cancer detection or therapy; each one recognizes a different protein on certain cancer cells. Monoclonal antibodies can be used alone, or they can be used to deliver drugs, toxins, or radioactive material directly to a tumor.

**Myelodysplastic syndrome** (MYE-eh-lo-dis-PLAS-tik SIN-drome): Disease in which the bone marrow does not function normally. Also called preleukemia or smoldering leukemia.

**Myelogenous** (my-eh-LAH-jen-us): Produced by, or originating in, the bone marrow.

**Myeloid** (MY-eh-loyd): Pertaining to, derived from, or having certain features of the bone marrow. In some cases, myeloid also pertains to certain types of non-lymphocyte white blood cells found in the bone marrow, including granulocytes, monocytes, and platelets. Also called myelogenous.

**Ommaya reservoir** (o-MY-a REZ-er-vwahr): A device surgically placed under the scalp and used to deliver anticancer drugs to the fluid surrounding the brain and spinal cord.

**Palliative care** (PAL-yut-iv): Care that prevents or relieves the symptoms of cancer or other diseases. Palliative care does not alter the course of a disease but can improve the quality of life. It attempts to meet the physical, emotional, spiritual, and practical needs of patients by helping to relieve pain, depression, or other problems. Also known as comfort care, supportive care, and symptom management.

***Pathologist*** (pa-THOL-o-jist): A doctor who identifies diseases by studying cells and tissues under a microscope.

***Pediatric*** (pee-dee-AT-rik): Having to do with children.

***Peripheral blood*** (per-IF-er-al): Blood circulating throughout the body.

***Peripheral stem cell transplantation*** (per-IF-er-al): A method of replacing blood-forming cells destroyed by cancer treatment. Immature blood cells (stem cells) in the circulating blood that are similar to those in the bone marrow are given to the patient after treatment. This helps the bone marrow recover and continue producing healthy blood cells. Transplantation may be autologous (an individual's own blood cells saved earlier), allogeneic (blood cells donated by someone else), or syngeneic (blood cells donated by an identical twin). Also called peripheral stem cell support.

***Platelets*** (PLAYT-lets): A type of blood cell that helps prevent bleeding by causing blood clots to form. Also called thrombocytes.

***Quality of life***: The overall enjoyment of life. Many clinical trials measure aspects of an individual's sense of well-being and ability to perform various activities to assess the effects of cancer and its treatment on the quality of life.

***Radiation*** (ray-dee-AY-shun): Energy released in the form of particles or electromagnetic waves. Common sources of radiation include radon gas, cosmic rays from outer space, and medical x-rays.

***Radiation oncologist*** (ray-dee-AY-shun on-KOL-o-jist): A doctor who specializes in using radiation to treat cancer.

***Radiation therapy*** (ray-dee-AY-shun): The use of high-energy radiation from x-rays, gamma rays, neutrons, and other sources to kill cancer cells and shrink tumors.

Radiation may come from a machine outside the body (external-beam radiation therapy), or from materials called radioisotopes. Radioisotopes produce radiation and can be placed in or near the tumor or in the area near cancer cells. This type of radiation treatment is called internal radiation therapy, implant radiation, interstitial radiation, or brachytherapy. Systemic radiation therapy uses a radioactive substance, such as a radiolabeled monoclonal antibody, that circulates throughout the body. Also called radiotherapy, irradiation, and x-ray therapy.

**Red blood cells:** RBCs. Cells that carry oxygen to all parts of the body. Also called erythrocytes.

**Relapse:** The return of signs and symptoms of cancer after a period of improvement.

**Remission:** A decrease in or disappearance of signs and symptoms of cancer. In partial remission, some, but not all, signs and symptoms of cancer have disappeared. In complete remission, all signs and symptoms of cancer have disappeared, although cancer still may be in the body.

**Risk factor:** Anything that increases a person's chance of developing a disease. Risk factors for cancer include a family history of cancer, use of tobacco products, certain foods, exposure to radiation or cancer-causing agents, and some genetic alterations.

**Seizures** (SEE-zhurz): Convulsions; sudden, involuntary movements of the muscles.

**Side effects:** Problems that occur when treatment affects healthy cells. Common side effects of cancer treatment are fatigue, nausea, vomiting, decreased blood cell counts, hair loss, and mouth sores.

**Spinal tap:** A procedure in which a needle is put into the lower part of the spinal column to collect cerebrospinal fluid or to give drugs. Also called a lumbar puncture.

**Spleen:** An organ that is part of the lymphatic system. The spleen produces lymphocytes, filters the blood, stores blood cells, and destroys old blood cells. It is located on the left side of the abdomen near the stomach.

**Stem cells:** Cells from which other types of cells can develop.

**Stem cell transplantation:** A method of replacing immature blood-forming cells that were destroyed by cancer treatment. The stem cells are given to the person after treatment to help the bone marrow recover and continue producing healthy blood cells.

**Steroids (STAIR-oydz):** Drugs used to relieve swelling and inflammation.

**Supportive care:** Care given to prevent, control, or relieve complications and side effects and to improve the comfort and quality of life of people who have cancer.

**Symptom:** An indication that a person has a condition or disease. Some examples of symptoms are headache, fever, fatigue, nausea, vomiting, and pain.

**Symptom management:** Care given to relieve the problems associated with a disease or its treatment. Symptom management improves the comfort and quality of life of people who have cancer.

**Syngeneic stem cell transplantation (SIN-juh-NAY-ik):** A procedure in which a person receives stem cells donated from the patient's healthy identical twin.

**Targeted therapy:** Drugs or substances that can identify and attack cancer cells. A monoclonal antibody is a type of targeted therapy.

**Testicles (TES-tih-kuls):** The two egg-shaped glands found inside the scrotum. They produce sperm and male hormones. Also called testes.



**Tissue** (TISH-oo): A group or layer of cells that are alike and that work together to perform a specific function.

**Total-body irradiation:** Radiation therapy to the entire body. Usually followed by bone marrow or peripheral stem cell transplantation.

**Transfusion** (trans-FYOO-zhun): The infusion of components of blood or whole blood into the bloodstream. The blood may be donated from another person, or it may have been taken from the person earlier and stored until needed.

**Umbilical cord blood** (um-BIL-i-kul): Blood from the umbilical cord of a newborn baby. This blood contains high concentrations of stem cells needed to produce new blood cells.

**Umbilical cord blood transplantation** (um-BIL-i-kul): The injection of umbilical cord blood to restore an individual's own blood production system suppressed by anticancer drugs, radiation therapy, or both. It is being studied in the treatment of cancer and severe blood disorders such as aplastic anemia. Cord blood contains high concentrations of stem cells needed to produce new blood cells.

**Watchful waiting:** Closely monitoring a patient's condition but withholding treatment until symptoms appear or change. Also called observation.

**White blood cell:** WBC. Refers to a blood cell that does not contain hemoglobin. White blood cells include lymphocytes, neutrophils, eosinophils, macrophages, and mast cells. These cells are made by bone marrow and help the body fight infections and other diseases.

**X-ray:** A type of high-energy radiation. In low doses, x-rays are used to diagnose diseases by making pictures of the inside of the body. In high doses, x-rays are used to treat cancer.

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## National Cancer Institute Information Resources

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**Y**ou may want more information for yourself, your family, and your doctor. The following National Cancer Institute (NCI) services are available to help you.

### Telephone

#### *Cancer Information Service (CIS)*

Provides accurate, up-to-date information on cancer to patients and their families, health professionals, and the general public. Information specialists translate the latest scientific information into understandable language and respond in English, Spanish, or on TTY equipment.

Toll-free: 1-800-4-CANCER (1-800-422-6237)

TTY: 1-800-332-8615

### Internet

#### **<http://cancer.gov>**

The NCI's Cancer.gov™ Web site provides information from numerous NCI sources. It offers current information on cancer prevention, screening, diagnosis, treatment, genetics, supportive care, and ongoing clinical trials. It also provides information about NCI's research programs and funding opportunities, cancer statistics, and the Institute itself. Cancer.gov contains CANCERLIT®, a database of citations and abstracts on cancer topics from scientific literature. Cancer.gov can be accessed at

**<http://cancer.gov>** on the Internet.

Cancer.gov also provides live, online assistance through LiveHelp. Information specialists are available

Monday through Friday from 9:00 AM to 10:00 PM Eastern Time. LiveHelp is at <http://cancer.gov> on the Internet.

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## National Cancer Institute Booklets

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**N**ational Cancer Institute (NCI) publications can be ordered by writing to the address below, and some can be viewed and downloaded from <http://cancer.gov/publications> on the Internet.

Publications Ordering Service  
National Cancer Institute  
Suite 3036A  
6116 Executive Boulevard, MSC 8322  
Bethesda, MD 20892-8322

In addition, people in the United States and its territories may order these and other NCI booklets by calling the Cancer Information Service at 1-800-4-CANCER. They may also order many NCI publications on-line at <http://cancer.gov/publications>.

### **Booklets About Cancer Treatment**

- *Radiation Therapy and You: A Guide to Self-Help During Treatment*
- *Chemotherapy and You: A Guide to Self-Help During Treatment*
- *Young People with Cancer: A Handbook for Parents*
- *Helping Yourself During Chemotherapy: 4 Steps for Patients*
- *Eating Hints for Cancer Patients*
- *Understanding Cancer Pain*
- *Pain Control: A Guide for People with Cancer and Their Families*

- *Get Relief From Cancer Pain*
- *Taking Part in Clinical Trials: What Cancer Patients Need To Know*
- *La quimioterapia y usted: Una guía de autoayuda durante el tratamiento del cáncer (Chemotherapy and You: A Guide to Self-Help During Treatment for Cancer)*
- *El dolor relacionado con el cáncer (Understanding Cancer Pain)*
- *La radioterapia y usted: Una guía de autoayuda durante el tratamiento del cáncer (Radiation Therapy and You: A Guide to Self-Help During Treatment)*
- *¿En qué consisten los estudios clínicos? Un folleto para los pacientes de cáncer (What Are Clinical Trials All About? A Guide for Cancer Patients)*

### **Booklets About Living with Cancer**

- *Advanced Cancer: Living Each Day*
- *Facing Forward Series:*
  - *Life After Cancer Treatment*
  - *Ways You Can Make a Difference in Cancer*
- *Taking Time: Support for People With Cancer and the People Who Care About Them*
- *When Cancer Recurs: Meeting the Challenge*

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