



# Chronic Leukemia Cancer Care



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# Specialized Doctors and Personalized Care

Learning you have cancer can feel overwhelming. Your life suddenly changes and a cascade of emotions often follows, affecting you and your loved ones. You will likely have many questions as well. Your Kaiser Permanente cancer care team will provide you with the guidance, treatment, and support you need.

This booklet contains information about **chronic leukemia**. It explains what to expect and how your care team will work with you to make your treatment as comfortable and successful as possible.

Your care team includes skilled specialists who perform thousands of cancer treatments

every year. Our advanced equipment and techniques ensure that you receive the most current and highest quality care available.

We welcome your questions and encourage you and your family to talk with your care team about any concerns. We're here to help.



# Your Kaiser Permanente Cancer Care Team

A team of physicians and other health professionals will provide you with the best care and treatment possible. Our physicians are specialists from different fields, such as radiology, oncology, and surgery. They work together to create a treatment plan specifically for you.

Your care team will meet with you to:

- Explain the details of your diagnosis.
- Discuss your treatment options.
- Help you make decisions and prepare for treatment.

Having a care team is like getting a second, third, and fourth opinion right from the start.

We hope you'll feel comfortable with all members of your care team. Let us know if you have questions or concerns.



## Note to loved ones

Having a family member or friend go through this type of care may affect you too. At Kaiser Permanente, we'll provide you with resources to help.





### Physicians may include:

- **Medical Oncologist:** A doctor who specializes in treating cancer with drugs, such as chemotherapy, targeted therapy, and immunotherapy.
- **Radiation Oncologist:** A doctor who specializes in the use of radiation to treat cancer.
- **Interventional Radiologist:** A doctor who specializes in image-guided procedures to treat and diagnose diseases, such as CT-guided biopsies of other areas affected by chronic leukemia.

### Other health care professionals may include:

- **Oncology Nurse:** A nurse who specializes in caring for people who have cancer.
- **Physician's Assistant:** A health professional who practices medicine under the supervision of a physician and is often a member of the chronic leukemia care team.
- **Social Worker:** A health professional trained to talk with people and their families about emotional or physical needs, and to find them support services.
- **Registered Dietician:** A health professional with special training in the use of diet and nutrition to keep the body healthy.
- **Patient Care Coordinator or Discharge Planner:** A health professional who coordinates discharge from the hospital and makes sure you have the equipment and care you need at home.

You can use this table to keep track of the names and contact information for your care team so you have it all in one place.

PHYSICIAN	NAME	CONTACT INFORMATION
Primary Care Doctor		
Medical Oncologist		
Radiation Oncologist		
Surgeon		
Medical Center		Daytime: After Hours:
Other		



Your cancer care team may include physicians and other health professionals from different specialties. This team works together to provide the best care for you.

My Doctor Online app

Download our My Doctor Online app for free from the App Store or from Google Play to help you manage your care, including:



- Getting reminders and details of upcoming appointments.
- Emailing your doctor with nonurgent messages.
- Calling our 24/7 Appointment and Advice line.
- Finding maps and directions to Kaiser Permanente medical centers and medical office facilities.

# Learning about Chronic Leukemia

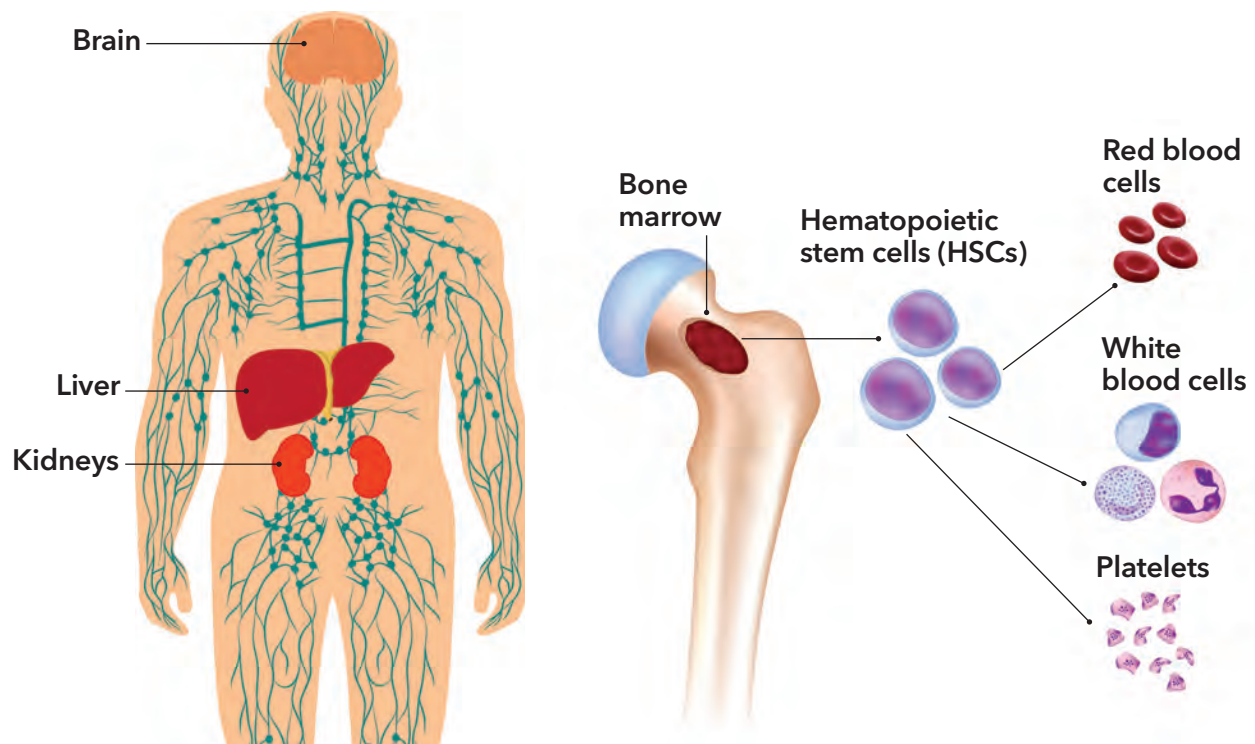
Unlike solid tumors that develop in an organ or tissue, leukemia is a cancer of the blood. It starts in the bone marrow, the spongy tissue inside large bones where blood cells are created. Normally, the bone marrow makes 3 types of blood cells:

- **White blood cells**, which fight infection.
- **Red blood cells**, which carry oxygen to every part of the body.
- **Platelets**, which stop bleeding by helping the blood clot.

Leukemia develops when immature blood cells growing in the bone marrow change and begin to multiply out of control. If they are present in large numbers, the abnormal blood cells can overwhelm the bone marrow, preventing the production of the healthy blood cells the body needs.

After filling bone marrow, the abnormal leukemia cells can enter the bloodstream and move into other organs and tissues, such as the lymph nodes, kidneys, liver, and brain. Leukemia cells can stop the healthy organ cells from functioning normally.

Chronic leukemia grows slowly, possibly over several years. It may have few symptoms in the early stages, because the healthy blood cells can partially mature and still maintain some function.



# Types of Chronic Leukemia



Leukemia affects different blood cells. The type of chronic leukemia is based on the blood cell affected and the severity of the cancer.

- **Chronic lymphocytic leukemia (CLL)** develops from white blood cells called lymphocytes. It's the most common type in adults.
- **Hairy cell leukemia (HCL)** is a type of CLL. It develops from an abnormal number of B lymphocytes, a white blood cell.
- **Chronic myelogenous leukemia (CML)** affects a group of blood cells called myeloid cells.

Once we identify the type of chronic leukemia, we can develop the best treatment plan for you.

# Diagnosing Chronic Leukemia

To diagnose chronic leukemia, we learn about your medical history to find out how long you've had symptoms. We also perform a physical exam to check for an enlarged spleen, swollen lymph nodes, and other signs of chronic leukemia.

Generally, the tests commonly used to diagnose chronic leukemia are:

- **Blood tests.** We look at the number of white blood cells, red blood cells, and platelets in your blood. We check for abnormal changes in the appearance of blood cells.
- **Bone marrow tests.** In a bone marrow aspiration and biopsy, we remove blood and bone marrow to look for leukemia cells under the microscope.
- **Genetic tests.** Specialized genetic tests take samples from your blood or bone marrow to look for chromosomal changes in the cancer cells.
- **Imaging scans.** CT scans and other imaging tests can help us determine if the cancer has spread to lymph nodes, the spleen, and other organs.

With some types of chronic leukemia, we may use additional diagnostic tests to learn more about the cancer.

- **Cytogenetic analysis** checks leukemia cells for changes in the amount or structure of the long strands of coiled DNA that contain genes (chromosomes). For example, part of a chromosome may be missing.
- **Immunophenotyping** looks for patterns of certain proteins on the surface of hairy cells (for hairy cell leukemia).

The results of your tests help us identify the best treatment options for you.



# Staging or Phases of Chronic Leukemia

For most cancers, stages are used to indicate the size of a solid tumor and how far it's spread. Because leukemia is a cancer of the blood, it doesn't form a solid mass. Instead, the bone marrow in the entire body can be affected, along with lymph nodes and certain organs, such as the spleen.

Some types of chronic leukemia are assessed based on stages, whereas others are based on phases.

Your care team uses this information to determine the best treatment plan for you.

## Stages of chronic lymphocytic leukemia (CLL)

For CLL, stages describe the extent of the disease based on blood cell counts and if certain organs are involved.

- **Stage 0** The number of lymphocytes in the blood is too high, but there are no other symptoms. Red blood cell and platelet counts are close to normal. The lymph nodes, liver, and spleen are normal size.
- **Stage I** The lymphocyte blood count is too high and lymph nodes are swollen. The red blood cell and platelet counts continue to be near normal. The liver and spleen are not enlarged.
- **Stage II** The number of lymphocytes in the blood is too high and the liver or spleen is enlarged. The lymph nodes may be normal or swollen. The red blood cell and platelet counts are near normal.
- **Stage III** The lymphocyte blood count is too high and the red blood cell count is too low. You may or may not have enlarged lymph nodes, liver, or spleen. Platelet counts remain near normal.
- **Stage IV** The lymphocyte blood count is too high and the platelet count is too low. You may or may not have low red blood cell counts, swollen lymph nodes, and an enlarged liver or spleen.

## Extent of hairy cell leukemia (HCL)

Unlike most cancers, hairy cell leukemia doesn't have stages. We use the results of your diagnostic test results to develop your treatment plan.

## Phases of chronic myelogenous leukemia (CML)

Instead of stages, CML is divided into 3 phases. The phases are based on how many immature white blood cells (blasts) are seen in the bone marrow and blood. We also consider the severity of your symptoms.

**Chronic phase.** This phase typically lasts several years. Most people are diagnosed at this earliest phase, when the bone marrow and blood contain less than 10 percent blast cells. You may have mild or no symptoms. If you have them, symptoms will likely go away once treatment begins.

**Accelerated phase.** When the disease progresses to this phase, blast cells make up 10 percent to 19 percent of the bone marrow or blood. With a higher amount of abnormal cells in the body, you may experience fever, weight loss, poor appetite, and other symptoms.

**Blast phase.** In this phase, blast cells make up more than 20 percent of the bone marrow or blood. You will likely experience fever, fatigue, weight loss, and other symptoms. This phase is also called blast crisis or acute phase because the CML cells start to become aggressive.



# Choosing Treatment That's Right for You

Treatment of chronic leukemia depends on the type. After we learn everything we can about your cancer, we'll talk about your treatment options and develop a plan that's right for you.

Sometimes chronic leukemia may not require immediate treatment. We'll continue to monitor you for signs that it's growing (called watchful waiting).

It can be difficult to know that you have cancer and not receive treatment. However, watchful waiting is the best approach for low-risk chronic leukemia. Treating it too early doesn't offer any benefits and can even cause unnecessary side effects.

You may receive one or a combination of treatment options for your chronic leukemia. Surgery isn't usually considered as a treatment.

## Treatment for types of chronic leukemia

**Chronic lymphocytic leukemia (CLL)** may not need to be treated right away in the early stages. During this watchful waiting, you'll have regular checkups to monitor your blood counts and symptoms. You'll begin treatment if blood counts worsen or you develop symptoms. In some cases, treatment is never needed because you may live for decades without symptoms.

Treatment options for CLL include:

- Chemotherapy
- Immunotherapy
- Targeted therapy (also called biological therapy)
- Radiation therapy
- Stem cell transplantation, in some cases

**Hairy cell leukemia (HCL)** treatment options usually include:

- Watchful waiting
- Chemotherapy
- Targeted therapy
- Immunotherapy

**Chronic myelogenous leukemia (CML)** treatment options usually include:

- Targeted therapy
- Immunotherapy
- Chemotherapy
- Stem cell transplantation, in some cases



### Questions to ask your care team

What are my treatment options?

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What are the risks and possible side effects of each treatment?

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What can I do to prepare for treatment?

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Will I need to stay in the hospital? If so, how long?

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# Chemotherapy

Chemotherapy uses drugs to kill cancer cells. It's usually given through intravenous (IV) infusion or sometimes as a pill. You may receive a combination of different types of chemotherapy drugs.

Chemotherapy is treatment that:

- Circulates throughout your entire body (systemic).
- Can destroy cancer cells that travel outside the lymphatic system.

Chemotherapy is given in cycles. The number of cycles you have depends on the type and stage or phase of your chronic leukemia. You'll receive treatment and then have a rest period so your body has time to recover.

You may have chemotherapy alone or in combination with other treatment options.

Chemotherapy may be used to treat CML if it stops responding to targeted therapy. It's also given before a stem cell transplant, if this treatment option is needed for CML or CLL.

## Chemotherapy side effects

Chemotherapy targets cells that grow and multiply rapidly, such as cancer cells. It can also affect normal cells that happen to quickly grow and divide, which can cause side effects. The severity depends on the type and dose of the drug and the length of time it's given.

You may experience one or more of these common side effects of chemotherapy:

- Hair loss
- Nausea and vomiting
- Loss of appetite
- Mouth sores
- Fatigue
- Diarrhea
- Low blood cell counts

Low blood cell counts are important to monitor because without enough healthy blood cells, you're at higher risk for infections, bleeding, and severe fatigue. If this is an issue, we may give you:

- Drugs to boost your blood counts
- Antibiotics to treat and prevent infections
- Transfusions of red blood cells and platelets

We can help you manage side effects. Most usually go away when treatment ends.



# Immunotherapy

Immunotherapy drugs work by using your body's immune system to recognize and destroy the cancer cells. This treatment may be used alone or in combination with chemotherapy.

**For chronic lymphocytic leukemia (CLL)**, immunotherapy drugs are called monoclonal antibodies. They're directed against a molecule (CD20) on the surface of the leukemia cells.

**For hairy cell leukemia (HCL)**, the immunotherapy drug is called interferon. It's given as an injection. It's usually reserved for HCL that doesn't respond to other therapies.

**For chronic myelogenous leukemia (CML)**, we may prescribe interferon if CML stops responding to targeted therapy drugs.

## Immunotherapy side effects

Interferon causes symptoms that are similar to the flu. We can give you medicines to help treat these side effects:

- Fever
- Chills
- Fatigue
- Muscle aches
- Headaches
- Hepatitis B reactivation (with CLL immunotherapy treatment)

We'll watch you closely for side effects. Let us know as soon as you start to notice any symptoms.



# Targeted Therapy

Targeted therapy uses drugs to block or attack specific parts of the cancer cell that help it survive and grow. This therapy is a treatment option for CML, CLL, and HCL.

These drugs are taken as a pill. They are very effective when taken continuously as prescribed.

You will likely take a targeted drug for many years to treat chronic leukemia. If the drug you're taking stops working, you may receive another type of targeted therapy drug.

## Targeted therapy side effects

Because targeted drugs only attack cancer cells, there's less damage to healthy cells. Side effects include:

- Fever
- Diarrhea
- Fatigue and weakness
- Nausea and vomiting
- Cough
- Headache
- Low blood cell counts

We'll watch you closely for side effects. Let us know as soon as you notice symptoms.

# Radiation Therapy

Radiation therapy uses high-energy radiation, such as X-rays, to kill cancer cells. The most common type delivers radiation from a machine outside the body (external-beam radiation therapy).

We may recommend radiation therapy for certain types and stages or phases of chronic leukemia. It might also be used to:

- Control cancer pain associated with an enlarged spleen or swollen lymph nodes.
- Treat the entire body before a stem cell transplant.

## Radiation therapy side effects

Radiation side effects depend on the area treated but may include:

- Skin changes, such as redness and dryness
- Fatigue
- Hair loss
- Nausea and vomiting
- Bowel discomfort or diarrhea

Let us know if you develop side effects so we can help manage them. Side effects usually go away after treatment ends.



# Stem Cell Transplant

Your body makes blood cells in the bone marrow. In leukemia, bone marrow is filled with cancer cells. Sometimes, we need to treat chronic leukemia with a stem cell transplant.

You're first given high doses of chemotherapy or whole-body radiation therapy. This destroys cancer cells throughout the body, along with the healthy cells in bone marrow.

Next, we replace stem cells in your bone marrow to help with healthy blood cell production. The type of transplant you have depends on the source of the stem cells.

- **Allogenic transplant.** Blood stem cells come from a donor with a matching tissue type. The closer the match, the better the chance your body will accept the donor stem cells and start producing normal blood cells.
- **Autologous transplant.** Stem cells from your own blood are frozen and stored. After high-dose chemotherapy, we'll put them back into your bloodstream. However, we don't typically use this type of transplant because it isn't an effective treatment for chronic leukemia.

## Stem cell transplant side effects

A complication of allogenic transplant (donor stem cells) is graft-versus-host disease (GVHD). This happens when the donor stem cells recognize your body as foreign and start attacking your:

- Skin tissue
- Digestive tract
- Liver
- Eyes
- Muscle
- Lungs

Symptoms of GVHD are:

- Skin rash and tightening (contractures)
- Yellowing of the skin and eyes
- Nausea
- Diarrhea
- Fatigue and weakness
- Breathing difficulties

We'll talk about what side effects to expect, and how we plan to prevent and manage them.



# Self-Care for Managing Side Effects

Your cancer care team is with you every step of the way. We'll suggest ways to control any treatment side effects that you may experience. Remember, these usually go away after treatment ends, although it may take a little time.

## **To reduce fatigue:**

- Get plenty of rest.
- Try light exercise every day.
- Use relaxation techniques like deep breathing or a simple meditation before bed to help you sleep better.

## **To control stomach problems:**

- Drink plenty of water.
- Have someone else cook for you if preparing meals makes you feel ill.
- Eat bland foods (bananas, rice, or toast) to control diarrhea.
- Eat high-fiber foods (bran or fruit) to limit constipation.
- Eat small meals or snacks throughout the day, instead of 3 meals a day.
- Take medications for nausea.

## **To care for hair, skin, or mouth problems:**

- Brush your teeth with a soft toothbrush after each meal.
- Rinse your mouth with half a teaspoon of salt or baking soda mixed in a glass of water.
- Use mild soaps when bathing.
- Apply thick lotions or creams daily over your entire skin to keep the skin moist.
- Avoid using products on the skin, including aloe gel or lotion, that contain alcohol.
- Take short (5 to 10 minute) low-temperature showers.
- Pat your skin dry, instead of rubbing. Avoid using washcloths.
- Protect your scalp by wearing sunscreen or a hat if you're losing hair. Hair usually grows back.

## **To reduce the risk of infection:**

- Wash your hands often.
- Avoid contact with people who are currently sick, such as with a cold or flu.

# Your Life, Your Way

We encourage you to live your life as normally as you can during treatment. It can help to stick to regular routines and continue doing things you enjoy as much as possible. After treatment ends and you've had time to recover and get stronger, it will be time to move forward with your life.

Some ways to help maintain control over your life are to:

- Communicate what you feel and ask for what you need.
- Keep a diary of treatments, medications, and side effects.
- Bring family or friends with you to appointments to help keep track of details. This can help them as well.
- Write down questions for your doctor and care team so you won't forget to ask them.
- Let your care team know about symptoms or problems—whether you're feeling better or worse, good or bad. They can respond when they know what's happening in your life.



**Our commitment to you continues after treatment.**

This includes follow-up, rehabilitation, and survivorship support services.

# Support at Every Step

Many aspects of your life may change after your diagnosis. People around you will also be concerned about your well-being. This can trigger a lot of different emotions.

For many people, reaching out to cancer survivors with similar experiences can be helpful. They can offer encouragement and understanding. It may help to know that others get through this even though it can be tough.

Recovering from cancer treatment can be both physically and emotionally difficult. It's common to feel anxious or even depressed after your treatment. You may have trouble sleeping and eating. This is normal.

We encourage you to share and discuss your emotions with those around you and with your care team. Kaiser Permanente also offers support services, including counseling, support groups, and psychiatric care.

Let us know how you're feeling. Your care team can respond to any symptoms or problems you may have.

Remember, we are here to support you in every way we can for as long as you need us.

We offer complete care for you and your family before, during, and after treatment. This includes:

- Individual counseling
- Symptom management
- Cancer support groups
- Nutrition counseling
- Health education classes
- Follow-up services
- Rehabilitation



# Clinical Trials

Clinical trials are research studies that involve cancer patients. They discover new ways to prevent, detect, diagnose, or treat cancer. Those who take part in clinical trials have an opportunity to contribute to our greater knowledge about cancer, and to help in the development of improved cancer prevention and treatments.

Kaiser Permanente is nationally recognized as a leading research organization. We are part of the **National Cancer Institute (NCI) Community Oncology Research Program**.

We participate in more than 70 clinical trials available to patients at any given time. Because of this, our patients have access to cutting edge treatment options and research.

We believe it's important for you to understand all of your treatment options, including being part of a clinical trial. If you're interested, talk with your cancer care team.





# Kaiser Permanente Resources

## Member Services Department

Member Services will help answer your questions and obtain the services or assistance you may need related to:

- Health plan benefits, premiums, and copay explanations
- Your enrollment status
- Registration on kp.org (so you can email your doctor or view visit summaries)
- Getting or replacing a member ID card
- Advance Health Care Directives and Durable Powers of Attorney
- Health plan coverage while traveling
- Information about health plan documents

You can offer suggestions or convey concerns to Member Services in person at your medical center, online, or by phone:

- Member Services Call Center: (800) 464-4000
- Senior Advantage and Medicare: (800) 443-0815

## Insurance and Employment

You may be concerned about how your treatments may affect your job and insurance status. Your care team will work with you to manage any side effects and minimize their impact on your normal schedule.

You may still need to change your regular work hours or take time off work to recover from treatments. If this happens, your care team social worker can connect you to insurance and employment resources to help manage changes. Ask your social worker for further information about California and federal regulations and programs, such as:

- State Disability Insurance (SDI)
- California Paid Family Leave Program
- Federal Family and Medical Leave Act (FMLA)

## Release of Medical Information (ROMI) Department

You may need to send part of your Kaiser Permanente (KP) medical record to another organization. For example, Kaiser Permanente members applying for disability insurance through the California Employment Development Department (EDD) may request copies of medical records to support their application. We only release medical information by request of the patient. Only members or their legal agent may authorize release of medical information.

To obtain information from your Kaiser Permanente medical record, your care team can direct you to the Release of Medical Information Department (ROMI), which will help you complete the necessary documentation.

If you need to forward medical information from a non-Kaiser Permanente physician to KP, you can ask your non-Kaiser Permanente provider to send the information directly to your Kaiser Permanente primary doctor (not to ROMI). Your Kaiser Permanente primary doctor will review outside medical records before including the information to your file.

If you are seeking medically related time off from work or applying for Family Medical Leave (FMLA), you do not need to request a form from ROMI. Instead, ask for "Work Status Activity Forms" from your doctor.



## Financial Services Department

If you have concerns or questions about medical bills, payments, refunds, or need financial assistance during or after a hospital stay, you can contact a Patient Financial Advisor in the Financial Services Department.

Financial Services is also responsible for billing all non-Kaiser Permanente plans on a patient's behalf, including Medicare, Medi-Cal, Third Party Liability (TPL), Coordination of Benefits (COB), Health Maintenance Organization (HMO), and secondary insurance companies.

Patient Financial Advisors are available to answer questions about alternative payment needs or to help locate resources and assist during and after a hospital stay. You can ask your care team or social worker about the best way to contact an Advisor at your facility.

# Additional Resources

- **Kaiser Permanente Cancer Care**  
[kp.org/mydoctor/cancer](http://kp.org/mydoctor/cancer)
- **American Cancer Society**  
[cancer.org](http://cancer.org)
- **National Cancer Institute**  
[cancer.gov](http://cancer.gov)
- **Cancer Care**  
[cancercare.org](http://cancercare.org)



This information is not intended to diagnose health problems or to take the place of medical advice or care you receive from your physician or other medical professional. If you have persistent health problems, or if you have additional questions, please consult with your doctor. If you have questions or need more information about your medication, please speak to your pharmacist.

Some photos may include models and not actual patients.

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