Leukemia-Chronic Myeloid (Myelogenous) Overview

This overview is based on the more detailed information in our document, *Leukemia-Chronic Myeloid*. You can get this document and other information by calling 1-800-227-2345 or visiting our website at www.cancer.org.

What is cancer?

The body is made up of trillions of living cells. Normal body cells grow, divide to make new cells, and die in an orderly way. During the early years of a person's life, normal cells divide faster to allow the person to grow. After the person becomes an adult, most cells divide only to replace worn-out, damaged, or dying cells.

Cancer begins when cells in a part of the body start to grow out of control. There are many kinds of cancer, but they all start because of this out-of-control growth of abnormal cells.

Cancer cell growth is different from normal cell growth. Instead of dying, cancer cells keep on growing and form new cancer cells. These cancer cells can grow into (invade) other tissues, something that normal cells cannot do. Being able to grow out of control and invade other tissues are what makes a cell a cancer cell.

In most cases the cancer cells form a tumor. But some cancers, like leukemia, rarely form tumors. Instead, these cancer cells are in the blood and bone marrow.

When cancer cells get into the bloodstream or lymph vessels, they can travel to other parts of the body. There they begin to grow and form new tumors that replace normal tissue. This process is called *metastasis*.

No matter where a cancer may spread, it is always named for the place where it started. For instance, breast cancer that has spread to the liver is still called breast cancer, not liver cancer. Likewise, prostate cancer that has spread to the bone is called metastatic prostate cancer, not bone cancer.

Different types of cancer can behave very differently. For example, lung cancer and breast cancer are very different diseases. They grow at different rates and respond to different treatments. That is why people with cancer need treatment that is aimed at their own kind of cancer.

Not all tumors are cancerous. Tumors that aren't cancer are called *benign*. Benign tumors can cause problems – they can grow very large and press on healthy organs and tissues. But they cannot grow into other tissues. Because of this, they also can't spread to other parts of the body (metastasize). These tumors are almost never life threatening.

Normal bone marrow, blood and lymph tissue

To understand the different types of leukemia, it helps to know a little about the blood and lymph systems.

Bone marrow

Bone marrow is the soft inner part of some bones like the skull, shoulder blades, ribs, pelvis, and backbones. Bone marrow is made up of blood-forming cells, fat cells, and tissues that help cells grow.

The cells that make blood are called *blood stem cells*. These stem cells only make new blood-forming cells. They are different from embryonic stem cells because they cannot make any other kinds of cells.

Stem cells divide to make new stem cells. But they also go through a series of changes to make blood cells. During this process they can become red blood cells, white blood cells, or platelets.

Platelets

Platelets aren't whole cells but rather are pieces of large cells that plug up holes in blood vessels caused by cuts or bruises. A person with a shortage of platelets can bruise or bleed easily.

Red blood cells

Red blood cells carry oxygen from the lungs to all other cells in the body. They also carry away carbon dioxide, a cell waste product. Not having enough red blood cells is called *anemia* and makes a person feel weak, short of breath, and tired.

White blood cells

White blood cells help the body fight infections. Lymphocytes are one type of white blood cell, but there are other types that together are called myeloid cells. In chronic myeloid leukemia, it’s the cells that become myeloid cells that become cancerous.

Lymph system

The immune system is made up mainly of lymph tissue (also known as lymphatic or lymphoid tissue). The main cell type active in lymph tissue is the *lymphocyte*, a kind of white blood cell. (White blood cells help the body fight infections.) The 2 main types of lymphocytes are called B cells and T cells. Normal T cells and B cells do different jobs within the immune system in order to find and kill germs.

What is chronic myeloid leukemia?

Chronic myeloid leukemia (CML), also known as chronic myelogenous leukemia, is a fairly slow growing cancer that starts in the bone marrow. It’s a type of leukemia that affects the myeloid cells -- cells that form blood cells, such as red blood cells, platelets, and many types of white blood cells.

In CML, leukemia cells tend to build up in the body over time. In many cases, people don't have any symptoms for at least a few years. CML can also change into a fast-growing, acute leukemia that invades almost any organ in the body. Most cases of CML occur in adults, but it is also very rarely found in children. As a rule, their treatment is the same as for adults.

What is leukemia?

Leukemia is a type of cancer that starts in cells that form new blood cells. These cells are found in the soft, inner part of the bones called the *bone marrow*.

Any blood-forming cell can turn into a leukemia cell. Once that happens, the cell can grow and divide to form many new cancer cells. These cells can take over the bone marrow, spill out into the bloodstream, and spread to other organs. The buildup of these cells can lead to a shortage of normal blood cells. Having too many leukemia cells can keep other cells in the body from working the way they should.

Leukemia is different from other types of cancer that start in organs such as the lungs, colon, or breast and then spread to the bone marrow. Cancers that start elsewhere and then spread to the bone marrow are not leukemia.

CML isn’t the only kind of leukemia. There are 4 main types of leukemia:

- Acute lymphocytic leukemia

- Acute myeloid leukemia
- Chronic lymphocytic leukemia
- Chronic myeloid leukemia

Knowing the exact type can help doctors better predict each patient's outlook (prognosis) and select the best treatment.

The rest of this information is about chronic myeloid leukemia (CML) in adults only.

How many people get chronic myeloid leukemia?

The American Cancer Society's estimates for chronic myeloid leukemia (CML) cancers in the United States for 2014 are:

- About 5,980 new cases of chronic myeloid leukemia (CML)
- About 810 deaths from CML

CML affects mostly adults; it is rarely seen in children. The average age of people with CML is around 64 years. The average person's lifetime risk of getting CML is about 1 in 588.

What are the risk factors for chronic myeloid leukemia?

A risk factor is something that affects a person's chance of getting a disease. Some risk factors, like smoking, can be controlled. Others, such as a person's age, can't be changed. But risk factors don't tell us everything. Having a risk factor, or even several risk factors, does not mean that you will get the disease. And many people who get the disease may not have had any known risk factors.

There are very few known risk factors for chronic myeloid leukemia (CML), they are:

- High dose radiation, such as an atomic bomb blast or nuclear reactor accident
- Age (the risk of getting CML goes up with age)
- Gender (this disease is slightly more common in males than females, but it's not known why)

There are no other proven risk factors for CML. The risk of getting CML does not seem to be linked to smoking, diet, or exposure to chemicals or infections. CML does not run in families.

Can chronic myeloid leukemia be prevented?

Most cases of chronic myeloid leukemia (CML) have no clear cause and there is no way to prevent them. Many types of cancer can be prevented by lifestyle changes to avoid certain risk factors, but this is not true for most cases of CML.

Signs and symptoms of chronic myeloid leukemia

Many people with chronic myeloid leukemia (CML) have no symptoms at the time their cancer is found. In these cases, the cancer is often found by blood tests done for some other reason. Even when there are symptoms, they may be very general.

General symptoms of CML can include the following:

- Weakness
- Feeling very tired most of the time (fatigue)
- Night sweats (that drench the sheets)
- Weight loss (without trying)
- Fever
- Bone pain
- An enlarged spleen (felt as a mass under the left side of the ribs)
- Pain or a sense of "fullness" in the belly
- Feeling full after eating even a small amount of food
- Bone or joint pain

But these symptoms aren't found only in CML. They can be caused by something other than cancer.

Low blood cell counts

CML can crowd out the normal blood-forming cells in the bone marrow. This can lead to low numbers of normal blood cells.

- **Anemia** is not having enough red blood cells. This can make you feel short of breath, tired, cold, lightheaded, and weak.
- **Leukopenia** is not having enough normal white blood cells. This increases the risk of infections. People with leukemia may have very high white blood cell counts, but the cells are not normal and do not fight infections.
- **Thrombocytopenia** is not having enough blood platelets. This can lead to easy bruising, bleeding, frequent or severe nosebleeds, and bleeding gums. Some people with CML have too many platelets, but the platelets don't work the way they should.

Low blood cell counts are also more often caused by things other than CML. Still, your doctor will want to check to find the cause so it can be treated.

How is chronic myeloid leukemia found?

At this time, there are no special tests that can find chronic myeloid leukemia (CML) early. The best thing to do is report any symptoms to a doctor right away. The doctor will take your medical history and do a physical exam. If symptoms suggest you might have leukemia, you will need certain tests to find out if you have the disease and, if so, what type it is.

Tests to find chronic myeloid leukemia

Testing for CML involves checking blood and samples of bone marrow.

Blood to test for CML is most often taken from a vein in your arm.

Samples of bone marrow are obtained in a procedure called a **bone marrow aspiration and biopsy**. Samples are most often taken from the back of the hip bone, but sometimes they may be taken from the breastbone or other bones.

In bone marrow *aspiration*, a hollow needle is used to pull out a small amount of liquid bone marrow. The skin and the surface of the bone are first numbed, but the test can still hurt. During a bone marrow *biopsy*, a small core of bone and marrow (about ½" long) is removed with a slightly larger needle that is twisted as it is pushed into the bone. The biopsy may also cause some brief pain. Once the biopsy is done, pressure and maybe an ice pack will be put over the site to help prevent bleeding.

Both samples are usually taken at the same time. These samples are sent to a lab, where they are looked at under a microscope. These tests are mostly used to tell how advanced

the leukemia is before treatment starts. They can also be done during treatment to tell how well the treatment is working.

Routine blood tests

One or more of these lab tests may be done, either to find CML or to help the doctor figure out how advanced the disease is.

Blood cell counts and blood cell exam: The *complete blood count* (CBC) is a test that measures the levels of different blood cells such as red blood cells, white blood cells, and platelets. This is often the first test done if your doctor suspects leukemia or another blood problem. Most patients with CML have too many white blood cells and sometimes not enough red blood cells or blood platelets. Even though these findings may suggest leukemia, this diagnosis usually needs to be confirmed with another blood test or a test of the bone marrow.

Blood chemistry tests: These tests measure the amount of certain chemicals in the blood, but they are not used to decide if a person has leukemia. In patients already known to have CML, these tests can help find liver or kidney problems caused by the spread of leukemia cells or by the side effects of certain drugs used for treatment. These tests also help the doctor decide whether treatment is needed to correct low or high blood levels of certain minerals.

Exam under a microscope

The samples of blood and bone marrow are looked at under a microscope by a doctor with special training (a pathologist). The doctor looks at the size and shape of the cells as well as other features to divide the cells into specific types. An important goal of this process is to see whether or not the cells look mature. The most immature cells are called *blasts*. Blasts do not work the way they should, and they can keep on forming new cells, crowding out normal, mature cells.

Genetic tests

Chromosomes are long chains of DNA found in every cell. The leukemia cells of most patients with CML contain an abnormal chromosome called the *Philadelphia chromosome*. The Philadelphia chromosome contains an abnormal gene called *BCR-ABL*. Even if the CML cells don’t contain a Philadelphia chromosome, they contain the *BCR-ABL* gene. Certain tests that look at genes or chromosomes, such as cytogenetics, FISH, and PCR, are used to look for the Philadelphia chromosome or the *BCR-ABL* gene. These tests can be done on samples of blood and/or bone marrow and are explained in our detailed guide, *Leukemia: Chronic Myeloid (Myelogenous).*

Imaging tests

Imaging tests are ways of taking pictures of the inside of the body. They are not used to find CML, but they may be done to help figure out if it involves certain organs (like the spleen).

CT (computed tomography) scans

The CT scan is a special kind of x-ray in which a beam moves around the body, taking pictures from many angles. CT scans are not usually needed to find CML in the first place, but may be done if your doctor thinks the leukemia is growing in an organ like your spleen.

A CT scanner has been described as a large donut, with a narrow table in the middle opening. You will need to lie still on the table while the scan is being done. CT scans take longer than regular x-rays, and you might feel a bit confined by the ring while the pictures are being taken.

Often before any pictures are taken, you may be asked to drink 1 to 2 pints of a liquid called *oral contrast*. This helps outline the intestine more clearly.

You may also have an IV (intravenous) line through which you get a different kind of contrast dye. This helps better outline blood vessels and internal organs. The IV dye injection can make you feel flushed or warm in the face or elsewhere. Some people get hives (itchy bumps). A few may have more serious allergic reactions like trouble breathing, feeling dizzy, or passing out. Before the scan, be sure to tell the doctor if you have ever had a reaction to any contrast material used for x-rays

MRI (magnetic resonance imaging)

MRI scans are very helpful in looking at the brain and spinal cord. This test uses powerful magnets and radio waves to make detailed pictures of the inside of the body. They take longer than CT scans, often up to an hour. You may need to lie inside a narrow tube for the test. This can upset people with a fear of enclosed spaces. Special, "open" MRI machines may help with this problem. The MRI machine makes loud thumps and buzzes that some people may find disturbing. Some places give you headphones to block this out.

Ultrasound

This test uses sound waves to make pictures of internal organs. Ultrasound can look for enlarged organs in the belly (abdomen). This is a very easy test to have done. For most scans, you lie on a table and a technician moves a kind of wand (transducer) over the part of the body being looked at, which is first smeared with a gel.

Chest x-ray

This is a plain x-ray of the chest. It isn't used to tell if someone has CML, but to look for lung problems.

Staging for chronic myeloid leukemia

Staging is the process of finding out how far a cancer has spread. Most types of cancer are staged based on the size of the tumor and how far it has spread from where it started. This system does not work for leukemias because they do not often form a solid mass or tumor. Also, leukemia starts in the bone marrow and, in many people, it has already spread to other organs when it is found.

For someone with chronic myeloid leukemia (CML), the outlook depends on other factors such as features of the cells shown in lab tests, and the results of imaging studies. This information helps guide treatment decisions.

Phases of chronic myeloid leukemia

CML is divided into 3 phases that help predict the patient's outlook. Doctors call these *phases* rather than stages. The phases are based on the number of immature white blood cells, called *blasts*, that are seen in the blood or bone marrow. From less to more serious, they are:

- Chronic phase
- Accelerated phase
- Blast phase (also called *acute phase* or *blast crisis*)

Most patients are diagnosed in the chronic phase. These patients usually have rather mild symptoms (if any).

Patients in the accelerated phase often have more symptoms, like fatigue, fever, poor appetite, and weight loss. They do not respond to treatment as well as during the chronic phase.

In the blast phase, patients often feel even worse. At this point the CML acts much like an aggressive acute leukemia.

Not all doctors agree with these cutoff points for the different phases. If you have questions about your CML phase, ask your doctor explain it to you.

How is chronic myeloid leukemia treated?

This information represents the views of the doctors and nurses serving on the American Cancer Society's Cancer Information Database Editorial Board. These views are based on their interpretation of studies published in medical journals, as well as their own professional experience.

The treatment information in this document is not official policy of the Society and is not intended as medical advice to replace the expertise and judgment of your cancer care team. It is intended to help you and your family make informed decisions, together with your doctor.

Your doctor may have reasons for suggesting a treatment plan different from these general treatment options. Don't hesitate to ask him or her questions about your treatment options.

This section starts with general comments about the types of treatments used for chronic myeloid leukemia (CML). After that we outline treatment options based on the phase of the disease. The treatments used most often for CML are:

- Targeted therapy
- Interferon
- Chemotherapy
- Stem cell transplant

Targeted therapies for chronic myeloid leukemia

The main treatment for chronic myeloid leukemia (CML) is drugs that target an abnormal protein (called a tyrosine kinase) in the leukemia cells. These drugs are called *tyrosine kinase inhibitors* (TKIs). Because these drugs target an abnormal protein in a cancer cell, they are also known as *targeted therapy* drugs.

It’s important to know that all TKIs can cause harm to the fetus if taken during pregnancy. They can also cause problems when you are taking other drugs or certain foods, like grapefruit or pomegranate. Tell your doctor about any medicines you take, including over-the-counter medicines and supplements, and to check with your doctor before starting any new medicine to be sure it’s safe.

All of these drugs are pills that are taken once a day.

The TKIs used to treat CML are:

- Imatinib (Gleevec)
- Dasatinib (Sprycel)
- Nilotinib (Tasigna)
- Bosutinib (Bosulif®)

- Ponatinib (Iclusig®): this is the only TKI that helps patients with CML if their leukemia cells have a certain gene change that means the other TKIs don't work. It has more serious side effects than the other TKIs.

Bosutinib and ponatinib aren't used as the first treatment for CML.

Nearly all patients respond to treatment with one of these drugs, and most of these responses last for many years. But they don't seem to cure CML (make it go away and stay away without more treatment). Because of this, doctors will start patients on one of these drugs, and give it to patients for as long as it seems to help. If one TKI stops working, doctors will often switch to another.

Side effects

Side effects of these drugs are usually mild, although more severe side effects can occur. There are often ways to treat these side effects if needed.

Common side effects are:

- Diarrhea
- Nausea
- Muscle pain
- Tiredness
- Itchy skin rashes
- Fluid build-up
- Drop in the white blood cell and/or platelet count

Fluid build-up can cause swelling around the eyes, feet, or belly. In rare cases the fluid may collect in the lungs or around the heart, which can cause trouble breathing. If you are taking one of these drugs, tell your doctor right away if you notice sudden weight gain, trouble breathing, or fluid build-up anywhere in your body.

The different drugs can also have other side effects, some of which may be serious. Ask your doctor to expect.

More information about the targeted drugs used to treat CML can be found in our detailed guide, *Leukemia: Chronic Myeloid*.

Interferon for chronic myeloid leukemia

Interferons are substances naturally made by some immune system cells. At one time interferon was one of the main treatments for chronic myeloid leukemia (CML), but the

new targeted drugs, as described above, are now the mainstay of treatment. Interferon can be used to slow the growth of leukemia cells and is injected (given as a shot) under the skin every day for several years.

Interferon can cause side effects. These include flu-like symptoms. Patients taking this drug may also have problems thinking and concentrating.

Side effects of interferon include:

- Muscle aches
- Bone pain
- Headaches
- Tiredness
- Nausea
- Vomiting
- Low blood cell counts
- Depression

These problems usually get better once treatment is over. But because treatment lasts for years, interferon can be hard to take. Some patients stop treatment because of these side effects.

Chemotherapy for chronic myeloid leukemia

Chemotherapy (chemo) is the use of drugs to kill cancer cells. Usually the drugs are given into a vein or taken by mouth. Once the drugs enter the bloodstream, they spread throughout the body. Any drug used to treat cancer (including imatinib/Gleevec and drugs like it) can be thought of as chemo, but here chemo means standard chemo drugs, those that kill all cells that grow and divide quickly.

Chemo was once the main treatment for patients with chronic myeloid leukemia (CML). But it is used much less often now that there are drugs like imatinib. Its main role at this time is as part of the treatment during a stem cell transplant. It may also be used by itself later in the course of disease if other treatments have stopped working.

Side effects of chemo

While chemo drugs kill cancer cells, they can also damage normal cells that are growing quickly. Possible side effects could include:

- Hair loss
- Mouth sores
- Loss of appetite
- Nausea and vomiting
- Increased risk of infection (from low white blood cell counts)
- Easy bruising or bleeding (from low blood platelet counts)
- Tiredness (from low red blood cell counts)

These side effects are usually short-term and go away once treatment is finished.

There are often ways to manage these side effects during treatment. For instance, there are drugs than can be taken along with the chemo to prevent or reduce nausea and vomiting. Drugs known as *growth factors* are sometimes given to keep blood counts up and reduce the chance of infection. . For more information on infections and how to avoid them, see *Infections in People With Cancer*.

You might be given antibiotics before you have signs of infection or at the earliest sign that you may be getting an infection. If your platelet counts are low, you might get platelet transfusions. You might also get medicines or red blood cell transfusions if low red blood cell counts are causing shortness of breath or tiredness.

Radiation treatment for chronic myeloid leukemia

Radiation treatment is the use of high energy x-rays to kill cancer cells. It is usually not part of the main treatment for patients with chronic myeloid leukemia (CML), but it is used in certain cases. For some people with an enlarged organ (such as the spleen), radiation might be used to shrink the swelling. It is also used to treat bone pain caused by leukemia cells growing in the bone marrow. Radiation is sometimes given to the whole body, just before a stem cell transplant (see the section "Bone marrow or peripheral blood stem cell transplant (SCT) for chronic myeloid leukemia"). The main short-term side effects of radiation treatment are sunburn-like changes in skin over the treated area, tiredness, and a higher risk of infection.

More information on radiation therapy can be found in the Radiation section of our website, or in *Understanding Radiation Therapy: A Guide for Patients and Families*.

Surgery for chronic myeloid leukemia

Because leukemia cells spread so widely throughout the bone marrow and to many other organs, surgery cannot cure this type of cancer.

Rarely, an operation may be done to remove the spleen. If leukemia spreads to the spleen it can cause the spleen to become large enough to press on other organs and cause problems. If this happens, chemo or radiation may be used to try to shrink the spleen. If that doesn't solve the problem, removing the spleen can give relief, but it does not cure the leukemia. Another reason to remove the spleen is to improve blood cell counts. One of the spleen's jobs is to remove worn-out blood cells from the bloodstream. If the spleen gets too big, it may become too active in removing blood cells, leading to a shortage of red blood cells or platelets.

Most people have no problem living without a spleen. But the risk for certain infections is increased, so doctors often recommend that specific vaccines be given before the spleen is removed.

Bone marrow or peripheral blood stem cell transplant for chronic myeloid leukemia

Normal doses of chemotherapy (chemo) can harm normal cells as well as cancer cells. A stem cell transplant offers doctors a way to use the very high doses of chemo needed to kill all the leukemia cells. Although the drugs destroy the patient's bone marrow, stem cells given after the chemo can restore the blood-making bone marrow stem cells. This is called a stem cell transplant (SCT).

These blood-forming stem cells can come from the bone marrow or peripheral blood from either the patient or from a donor whose tissue type closely matches that of the patient. For CML, a donor (or *allogeneic*) transplant is most often used. The donor may be a brother or sister or – less often – a person not related to the patient.

Some things to keep in mind

Before modern targeted therapy drugs like imatinib (Gleevec), SCT was commonly used to treat CML. That’s because before drugs like imatinib, less than half of patients lived more than 5 years after diagnosis. Now, these drugs are the standard treatment, and transplants are being used less often. Still, a SCT from a donor offers the only proven chance to cure this disease, and many doctors will recommend a transplant for younger patients, especially children. Transplant may also be recommended if the CML is not responding well to the new drugs.

For more information on stem cell transplants, see *Stem Cell Transplant (Peripheral Blood, Bone Marrow, and Cord Blood Transplants).*

Clinical trials for chronic myeloid leukemia

You may have had to make a lot of decisions since you've been told you have cancer. One of the most important decisions you will make is deciding which treatment is best

for you. You may have heard about clinical trials being done for your type of cancer. Or maybe someone on your health care team has mentioned a clinical trial to you.

Clinical trials are carefully controlled research studies that are done with patients who volunteer for them. They are done to get a closer look at promising new treatments or procedures.

If you would like to take part in a clinical trial, you should start by asking your doctor if your clinic or hospital conducts clinical trials. You can also call our clinical trials matching service for a list of clinical trials that meet your medical needs. You can reach this service at 1-800-303-5691 or on our website at www.cancer.org/clinicaltrials. You can also get a list of current clinical trials by calling the National Cancer Institute's Cancer Information Service toll-free at 1-800-4-CANCER (1-800-422-6237) or by visiting the NCI clinical trials website at www.cancer.gov/clinicaltrials.

There are requirements you must meet to take part in any clinical trial. If you do qualify for a clinical trial, you will have to decide whether or not to enter (enroll in) it.

Clinical trials are one way to get state-of-the art cancer treatment. In some cases they may be the only way to get access to newer treatments. They are also the only way for doctors to learn better methods to treat cancer. Still, they are not right for everyone.

For more information on clinical trials, see *Clinical Trials: What You Need to Know*.

Complementary and alternative therapies for chronic myeloid leukemia

When you have cancer you are likely to hear about ways to treat your cancer or relieve symptoms that your doctor hasn't mentioned. Everyone from friends and family to Internet groups and websites may offer ideas for what might help you. These methods can include vitamins, herbs, and special diets, or other methods such as acupuncture or massage, to name a few.

What are complementary and alternative therapies?

It can be confusing because not everyone uses these terms the same way, and they are used to refer to many different methods. We use *complementary* to refer to treatments that are used *along with* your regular medical care. *Alternative* treatments are used *instead of* a doctor's medical treatment.

Complementary methods: Most complementary treatment methods are not offered as cures for cancer. Mainly, they are used to help you feel better. Some examples of methods that are used along with regular treatment are meditation to reduce stress, acupuncture to help relieve pain, or peppermint tea to relieve nausea. Some

complementary methods are known to help, while others have not been tested. Some have been proven not be helpful, and a few are even harmful.

Alternative treatments: Alternative treatments may be offered as cancer cures. These treatments have not been proven safe and effective in clinical trials. Some of these methods may be harmful, or have life-threatening side effects. But the biggest danger in most cases is that you may lose the chance to be helped by standard medical treatment. Delays or interruptions in your medical treatments may give the cancer more time to grow and make it less likely that treatment will help.

Finding out more

It is easy to see why people with cancer think about alternative methods. You want to do all you can to fight the cancer, and the idea of a treatment with few or no side effects sounds great. Sometimes medical treatments like chemotherapy can be hard to take, or they may no longer be working. But the truth is that most of these alternative methods have not been tested and proven to work in treating cancer.

As you think about your options, here are 3 important steps you can take:

- Look for "red flags" that suggest fraud. Does the method promise to cure all or most cancers? Are you told not to have regular medical treatments? Is the treatment a "secret" that requires you to visit certain providers or travel to another country?
- Talk to your doctor or nurse about any method you are thinking of using.
- Contact us at 1-800-227-2345 to learn more about complementary and alternative methods.

The choice is yours

Decisions about how to treat or manage your cancer are always yours to make. If you want to use a non-standard treatment, learn all you can and talk to your doctor about it. With good information and the support of your health care team, you may be able to safely use the methods that can help you while avoiding those that could be harmful.

What are some questions I can ask my doctor about chronic myeloid leukemia?

As you cope with cancer and cancer treatment, you need to have honest, open talks with your doctor. Feel free to ask any question that's on your mind, no matter how small it might seem. Here are some questions you might want to ask. Be sure to add your own questions as you think of them. Nurses, social workers, and other members of the treatment team may also be able to answer many of your questions.

- What phase is my chronic myeloid leukemia (CML) in?
- What are my treatment choices?
- Which treatment do you recommend, and why?
- What side effects are there to the treatments you recommend?
- What can I do to be ready for treatment?
- How often will you test my blood or bone marrow to see how my treatment is working?
- Should we think about a stem cell transplant at this time?
- What are the chances that the leukemia will come back once I am in remission?

Be sure to add your own questions as well.

Moving on after treatment for chronic myeloid leukemia

For a few people with chronic myeloid leukemia (CML), treatment may remove or destroy the cancer. Completing treatment can be both stressful and exciting. You may be relieved to finish treatment, but find it hard not to worry about cancer coming back. (When cancer comes back after treatment, it is called *recurrence*.) This is a very common concern in people who have had cancer.

It may take a while before your fears lessen. But it may help to know that many cancer survivors have learned to live with this uncertainty and are leading full lives. See *Living With Uncertainty: The Fear of Cancer Recurrence* for more detailed information on this.

For most patients with CML, treatment doesn't end and they stay on stay on some type of treatment indefinitely. Often, the treatment keeps the CML in check, but it doesn't seem to cure this disease. Being on long-term treatment can be stressful. It has its own type of uncertainty. See *When Cancer Doesn't Go Away* for more about this.

Follow-up care

Even if there are no signs of the disease, your doctors will still want to watch you closely. It is very important to go to all of your follow-up doctor visits. During these, your doctors will ask questions about any problems you may have and may do exams and lab tests to look for signs of CML and treatment side effects. Almost any cancer treatment can have side effects. Some may last for a few weeks to months, but others can last the rest of your

life. This is the time for you to talk to your cancer care team about any changes or problems you notice and any questions or concerns you have.

It is important to keep health insurance. Tests and doctor visits cost a lot, and even though no one wants to think of their cancer coming back, this could happen.

Should your cancer come back, *When Your Cancer Comes Back: Cancer Recurrence* can give you information on how to manage and cope with this phase of your treatment.

Seeing a new doctor

At some point after your cancer diagnosis and treatment, you may find yourself seeing a new doctor who does not know anything about your medical history. It is important that you be able to give your new doctor the details of your diagnosis and treatment. Gathering these details soon after treatment may be easier than trying to get them at some point in the future. Make sure you have this information handy:

- A copy of your pathology report from any biopsy or surgery
- If you had surgery, a copy of your operative report
- If you were in the hospital, a copy of the discharge summary that the doctor wrote when you were sent home from the hospital
- If you had radiation treatment, a summary of the type and dose of radiation and when and where it was given
- If you had drug treatment (such as chemotherapy, interferon, or targeted therapies), a list of your drugs, drug doses, and when you took them

Lifestyle changes after treatment for chronic myeloid leukemia

You can't change the fact that you have had cancer. What you can change is how you live the rest of your life – making choices to help you stay healthy and feel as well as you can. This can be a time to look at your life in new ways. Maybe you are thinking about how to improve your health over the long term. Some people even start during cancer treatment.

Making healthier choices

For many people, having cancer helps them focus on their health in ways they may not have thought much about in the past. Are there things you could do that might make you healthier? Maybe you could try to eat better or get more exercise. Maybe you could cut down on alcohol, or give up tobacco. Even things like keeping your stress level under control may help. Now is a good time to think about making changes that can have

positive effects for the rest of your life. You will feel better and you will also be healthier.

You can start by working on those things that worry you most. Get help with those that are harder for you. For instance, if you are thinking about quitting smoking and need help, call us at 1-800-227-2345.

Eating better

Eating right can be hard for anyone, but it can get even tougher during and after cancer treatment. Treatment may change your sense of taste. Nausea can be a problem. You may not feel like eating and lose weight when you don't want to. Or you may have gained weight that you can't seem to lose. All of these things can be a challenge.

If treatment caused weight changes or eating or taste problems, do the best you can and keep in mind that these problems most often get better over time. You may find it helps to eat small portions every 2 to 3 hours until you feel better. You may also want to ask your cancer team about seeing a dietitian – an expert who can give you ideas on how to deal with these treatment side effects.

One of the best things you can do after cancer treatment is put healthy eating habits into place. You may be surprised at the long-term benefits of some simple changes, like eating a greater variety of healthy foods. Getting to and staying at a healthy weight, eating a healthy diet, and limiting your alcohol intake may lower your risk for a number of types of cancer, as well as having many other health benefits.

Rest, fatigue, work and exercise

Feeling tired (fatigue) is a very common problem during and after cancer treatment. This is not a normal type of tiredness but a "bone-weary" exhaustion that doesn't get better with rest. For some people, fatigue lasts a long time after treatment and can keep them from staying active. But exercise can actually help reduce fatigue and the sense of depression that sometimes comes with feeling so tired.

If you are very tired, though, you will need to balance activity with rest. It is OK to rest when you need to. To learn more about fatigue, see *Fatigue in People With Cancer* and *Anemia in People With Cancer*.

If you were very ill or weren't able to do much during treatment, it is normal that your fitness, staying power, and muscle strength declined. You need to find an exercise plan that fits your own needs. Talk with your health care team before starting. Get their input on your exercise plans. Then try to get an exercise buddy so that you're not doing it alone.

Exercise can improve your physical and emotional health.

- It improves your cardiovascular (heart and circulation) fitness.

- Along with a good diet, it will help you get to and stay at a healthy weight.
- It makes your muscles stronger.
- It reduces fatigue.
- It lowers anxiety and depression.
- It can make you feel generally happier.
- It can help you feel better about yourself.

Long term, we know that getting regular physical activity plays a role in helping to lower the risk of some cancers, as well as having other health benefits.

How does having chronic myeloid leukemia affect your emotional health?

Once your treatment ends, you may be surprised by the flood of emotions you go through. This happens to a lot of people. You may find that you think about the effect of your cancer on things like your family, friends, and career. Money may be a concern as the medical bills pile up. Or you may begin to think about the changes that cancer has brought to your relationship with your spouse or partner. Unexpected issues may also cause concern – for instance, as you get better and need fewer doctor visits, you will see your health care team less often. This can be hard for some people.

This is a good time to look for emotional and social support. You need people you can turn to. Support can come in many forms: family, friends, cancer support groups, church or spiritual groups, online support communities, or private counselors.

The cancer journey can feel very lonely. You don't need to go it alone. Your friends and family may feel shut out if you decide not to include them. Let them in – and let in anyone else who you feel may help. If you aren't sure who can help, call your American Cancer Society at 1-800-227-2345 and we can put you in touch with a group or resource that may work for you.

You can't change the fact that you have had cancer. What you can change is how you live the rest of your life – making healthy choices and helping your body and mind feel well.

If treatment for chronic myeloid leukemia stops working

If your leukemia keeps growing or comes back after one treatment, often another treatment will help. Over time, though, the leukemia will start to resist treatment. At this time you may have to weigh the possible benefits of a new treatment against the downsides, like treatment side effects and clinic visits.

This is likely to be the hardest time in your battle with cancer – when you have tried everything within reason and it's just not working anymore. Your doctor may offer you new treatment, but you will need to talk about whether the treatment is likely to improve your health or change your outlook for survival.

No matter what you decide to do, it is important for you to feel as good as possible. Make sure you are asking for and getting treatment for pain, nausea, or any other problems you may have. This type of treatment is called palliative treatment. It helps relieve symptoms but is not meant to cure the cancer.

At some point you may want to think about hospice care. Most of the time hospice care is given at home. Your cancer may be causing symptoms or problems that need to be treated. Hospice focuses on your comfort. You should know that having hospice care doesn't mean you can't have treatment for the problems caused by your cancer or other health issues. It just means that the purpose of your care is to help you live life as fully as possible and to feel as well as you can. To learn more about this, see *Hospice Care*.

Staying hopeful is important, too. Your hope for a cure may not be as bright, but there is still hope for good times with family and friends − times that are filled with happiness and meaning. Pausing at this time in your cancer treatment gives you a chance to focus on the most important things in your life. Now is the time to do some things you've always wanted to do and to stop doing the things you no longer want to do. Though the cancer may be beyond your control, there are still choices you can make.

What's new in chronic myeloid leukemia research?

Many studies of chronic myeloid leukemia (CML) are being done in labs and in clinical trials around the world.

Genetics of CML

Scientists are making progress in learning how changes in a person's DNA can cause normal bone marrow cells to change into leukemia. They are learning why these cancer cells grow too fast, live too long, and don't grow into normal blood cells. In recent years they have learned a lot about why cancer cells don't die off like normal cells. This information is being used to develop many new drugs.

Combining the targeted drugs with other treatments

Imatinib or other similar drugs used alone don't help everyone. Studies are now being done to see if combining these drugs with other treatments like chemo, interferon, or

cancer vaccines (see below) might work better than anyone treatment alone. Studies are also looking at whether targeted drugs might be used in stem cell transplants.

Cancer vaccines

Because leukemia cells are a kind of foreign cell, it is possible to get the body to take action against them. Researchers are looking at ways to do this with cancer vaccines – a substance injected into the body that boosts the immune system and causes it to attack certain cells. Some vaccines are now being studied for use against CML. More research into how to make and use vaccines is being done, too.

To learn more about chronic myeloid leukemia

From your American Cancer Society

Here is more information you might find helpful. You read them online or order free copies of our documents from our toll-free number, 1-800-227-2345.

Living with cancer

After Diagnosis: A Guide for Patients and Families (also in Spanish)

Anemia in People With Cancer

Distress in People With Cancer

Fatigue in People With Cancer

Nutrition for the Person With Cancer During Treatment: A Guide for Patients and Families (also in Spanish)

When Your Cancer Doesn’t Go Away

When Your Cancer Comes Back: Cancer Recurrence

Understanding cancer treatments

Stem Cell Transplant (Peripheral Blood, Bone Marrow, and Cord Blood Transplants)

A Guide to Chemotherapy (also in Spanish)

A Guide to Radiation Therapy (also in Spanish)

Targeted Therapy

Work, insurance, and finances

Health Insurance and Financial Assistance for the Cancer Patient

Returning to Work After Cancer Treatment

Working During Cancer Treatment

Family and caregiver concerns

Talking With Friends and Relatives About Your Cancer (also in Spanish)

What It Takes to Be a Caregiver

Caring for the Patient With Cancer at Home (also in Spanish)

Helping Children When a Family Member Has Cancer: Dealing With Diagnosis (also in Spanish)

When treatment is no longer working

Nearing the End of Life

Advance Directives

Hospice Care

Your American Cancer Society also has books that you might find helpful. Call us at 1-800-227-2345 or visit our bookstore online at cancer.org/bookstore to find out about costs or to place an order.

National organizations and Web sites*

Along with the American Cancer Society, other sources of information and support include:

Leukemia & Lymphoma Society
Toll-free number: 1-800-955-4572
Website: www.lls.org

National Bone Marrow Transplant Link (nbmtLink)
Toll-free number: 1-800-LINK-BMT (1-800-546-5268)
Website: www.nbmtlink.org

National Cancer Institute
Toll-free number1-800-4-CANCER (1-800-422-6237)
Website: www.cancer.gov

Be the Match (formerly National Marrow Donor Program)
Toll-free number: 1-800-MARROW2 (1-800-627-7692)
Website: www.bethematch.org

**Inclusion on this list does not imply endorsement by the American Cancer Society.*

No matter who you are we can help, contact us any time, day or night, for information and support. Call us at **1-800-227-2345** or visit www.cancer.org.

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For additional assistance please contact your American Cancer Society
1-800-227-2345 or www.cancer.org