



Chronic Lymphocytic Leukemia Overview

The information that follows is an overview of this type of cancer. It is based on the more detailed information in our document, *Leukemia-Chronic Lymphocytic*. This document and other information can be obtained by calling 1-800-227-2345 or visiting our Web site at www.cancer.org.

What is cancer?

The body is made up of trillions of living cells. Normal body cells grow, divide into 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.

What is chronic lymphocytic 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.

Normal bone marrow, blood, and lymph tissue

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

Bone marrow

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

Early blood cells are called *stem cells*. Blood stem cells go through a series of changes to make new blood cells and lymphocytes. They cannot make any other kinds of cells. (This makes them different from embryonic stem cells, which are formed from a developing fetus and can develop into most other cells in the body.) One type of blood stem cell makes new lymphocytes (lymphocytes are a type of white blood cell). The other type of blood stem cell can develop into 1 of the 3 main types of blood cells:

- Red blood cells
- White blood cells (other than lymphocytes)
- Platelets

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 waste product of cell activity. A shortage of red blood cells (called *anemia*) causes weakness, shortness of breath, and tiredness.

White blood cells: White blood cells help the body fight infections. Lymphocytes are one type of white blood cell, but there are other types, too. Lymphocytes are the main cells that make up lymphoid tissue, an important part of the immune system. Lymphoid tissue is found in lymph nodes, the thymus gland, the spleen, the tonsils and adenoids, and is scattered throughout the digestive and respiratory systems and the bone marrow.

There are 2 types of lymphocytes:

- B lymphocytes protect the body from invading germs. B lymphocytes are the cells that most often develop into chronic lymphocytic leukemia cells.
- T lymphocytes destroy cells that are infected with viruses.

Platelets: Platelets help prevent bleeding by plugging up holes of blood vessels caused by cuts or bruises. A person with a shortage of platelets can bruise or bleed easily.

Any of the blood-forming or lymphoid cells from the bone marrow can turn into leukemia cells. Once this happens, the cells don't go through their normal growth process and don't work the way they should. These cells also do not die as they should. So they build up, spill into the bloodstream, and spread to other organs.

Chronic lymphocytic leukemia

Chronic lymphocytic leukemia (CLL) starts in the white blood cells (called *lymphocytes*) in the bone marrow. It then invades the blood. Leukemia always starts in the bone marrow. It can spread to the lymph nodes, the spleen, liver, and other parts of the body. Leukemia cells tend to build up in the body over time. Many people don't have any symptoms for at least a few years. Compared to other types of leukemia, CLL usually grows slowly

Doctors have found that there seem to be 2 different kinds of CLL.

- One kind grows very slowly and rarely needs to be treated.
- The other kind grows faster and is more serious.

The leukemia cells from these 2 types look alike. But certain lab tests can tell them apart.

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

CLL 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.

Along with these main types, there are a few other, less common, types of leukemia. **The information here is only about chronic lymphocytic leukemia (CLL) of adults.** For information about other types of leukemia please see the separate American Cancer Society documents on these topics.

How many people get chronic lymphocytic leukemia?

The American Cancer Society's estimates for chronic lymphocytic leukemia (CLL) in the United States for 2014 are:

- About 15,720 new cases of CLL
- About 4,600 deaths from CLL

CLL accounts for about one-third of all cases of leukemia. It affects mainly older adults. The average age at the time the cancer is found is around 72 years. It is rarely seen in people under the age of 40 and is very rare in children. An average person's lifetime risk of getting CLL is about 1 in 200.

What are the risk factors for chronic lymphocytic leukemia?

The exact cause of most cases of chronic lymphocytic leukemia (CLL) is not known. But in recent years a great deal has been learned about how normal lymphocytes and CLL cells differ. Normal human cells grow based mainly on the information contained in each cell's DNA. DNA is the chemical that carries our genes – the instructions for how our cells function. Each time a cell prepares to divide into 2 new cells, it must make a new copy of the DNA. This process is not perfect, and mistakes can happen that may affect genes within the DNA.

Sometimes people inherit DNA changes (mutations) from a parent that greatly increase their risk of getting certain types of cancer. But inherited changes rarely cause CLL.

DNA changes linked to CLL usually occur during the person's lifetime, rather than having been inherited before birth.

Risk factors for chronic lymphocytic 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 having a risk factor, or even many risk factors, does not mean that you will get the disease. And many people who get the disease do not have any known risk factors. Even if a person has a risk factor and gets cancer, it is often very hard to know how much that risk factor might have contributed to the cancer. There are very few known risk factors for CLL.

Certain chemical exposures

Exposure to Agent Orange, an herbicide used during the Vietnam War, has been linked to an increased risk of CLL. Some studies suggest that farming and long-term exposure to pesticides may be linked to an increased risk of CLL, too. More research in this area is needed.

Family history

Close relatives (parents, siblings, or children) of CLL patients have an increased risk for this cancer.

Gender

CLL is slightly more common in men than women, but the reasons for this are not known.

Where you come from

CLL is more common in North America and Europe than in Asia.

There are no other proven risk factors for CLL. The risk of getting CLL does not seem to be linked to smoking, diet, radiation, or infections.

Can chronic lymphocytic leukemia be prevented?

Changing your lifestyle to avoid certain risk factors can prevent many types of cancer, but there are very few known risk factors for chronic lymphocytic leukemia (CLL), and most of these cannot be avoided. Most cases of CLL have no clear cause, so there is no way to prevent these cancers.

Signs and symptoms of chronic lymphocytic leukemia (CLL)

Symptoms of CLL are often very general and can include the following:

- Weakness
- Feeling very tired
- Weight loss
- Fever
- Night sweats
- Swollen lymph nodes (these can sometimes be felt as lumps under the skin)
- Pain or a sense of "fullness" in the belly (especially after eating a small meal), which is caused by an enlarged spleen

Many of the symptoms of advanced CLL happen because the leukemia cells replace the bone marrow's normal blood-making cells. As a result, people do not make enough red blood cells, normal white blood cells, and blood platelets.

- *Anemia* is a result of a shortage of red blood cells. Anemia causes weakness, tiredness, and shortness of breath.
- Not having enough normal white blood cells increases the risk of infection. Although people with leukemia may have very high white blood cell counts, the cells are not normal and do not protect against infection very well. A common term you may hear is *neutropenia*, which refers to low levels of a type of cell called a neutrophil.
- Not having enough blood platelets (*thrombocytopenia*) can lead to bruising, bleeding, frequent or severe nosebleeds, and bleeding from the gums.

People with CLL have a higher risk of infections. This is mainly because their immune systems are not working as well as they should. Infections may range from simple things like frequent colds or cold sores to pneumonia and other serious infections.

CLL may also affect the immune system in other ways. In some people with CLL, the immune system cells make abnormal antibodies that attack normal blood cells. This is known as *autoimmunity*.

CLL often enlarges the liver or spleen. If these organs are enlarged, you may notice fullness or swelling of the belly. You may also notice that you feel full after only a small meal.

The symptoms listed above may be caused by CLL, but they can also be caused by other problems.

Still, if you have any of these symptoms, see a doctor right away so the cause can be found and treated, if needed.

How is chronic lymphocytic leukemia found?

At this time, there are no special tests used to look for chronic lymphocytic leukemia (CLL) in people with no symptoms. Still, many people with CLL have no symptoms at the time their cancer is found. In these people, the cancer is found by blood tests done for some other reason.

Just because a person has some of the symptoms of CLL does not mean that they have this disease. The doctor will need to learn more.

Medical history and physical exam

If you have any signs or symptoms that suggest you might have leukemia, your doctor will want to take a complete medical history. The doctor will ask questions about your health, any symptoms you might have, and your family's health.

A physical exam tells the doctor about your general health, possible signs of leukemia, and other health problems. During the physical exam, your doctor will pay close attention to your lymph nodes and other areas that might be affected.

Testing for chronic lymphocytic leukemia

If symptoms or the results of the physical exam suggest you might have leukemia, the doctor will need to check samples of blood and bone marrow to be certain of the diagnosis. Other tissue and cell samples may also be taken to help guide treatment.

Blood tests

Blood samples for tests to check for CLL are most often taken from a vein in the arm.

Complete blood count and blood cell exam

The complete blood count (CBC) is a test that measures the different cells in the blood, such as the red blood cells, the white blood cells, and the platelets. This test is often done along with a test that further looks at the numbers of the different types of white blood cells. People with CLL have too many lymphocytes. Having more than 10,000 lymphocytes/mm³ (per cubic millimeter) of blood makes the diagnosis almost certain,

although it may need to be confirmed by more special tests. The patient will often have too few red blood cells and blood platelets as well.

Routine microscopic exams

A sample of blood will be looked at under a microscope by a doctor with special training (called a *pathologist*). The doctor looks at the size and shape of the cells as well as other features to classify the cells into specific types. An important goal of this process is to see if the cells look mature. The most immature cells are called *blasts*. These are not normally in the blood.

Special tests

CLL can be diagnosed with just certain special tests done on the blood. The test used most often is called flow cytometry, but others, like cytochemistry, FISH, immunocytochemistry, cytogenetics, and molecular genetic studies can be useful, too. These tests can also be used to look at bone marrow and lymph nodes. They are explained in *Leukemia: Chronic Lymphocytic Detailed Guide*.

Blood chemistry tests

People with leukemia will have tests done to measure the amount of certain chemicals in the blood. These tests do not tell if they have leukemia but can help tell how well their kidneys and liver are working. The test results also help the doctor decide whether treatment is needed to correct low or high blood levels of certain minerals.

Bone marrow procedures

The procedures to get bone marrow samples are called bone marrow aspiration and biopsy. Samples are most often taken from the back of the pelvic (hip) bone, but in some cases the aspiration can be taken from the breastbone or other bones.

In bone marrow *aspiration*, a thin needle is used to draw up a small amount of liquid bone marrow. The skin and the surface of the bone are first numbed, but the test can still cause some brief pain. During a bone marrow *biopsy*, a small cylinder of bone and marrow (about ½ inch 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 applied to the site to help prevent bleeding.

Both samples are usually taken at the same time. These tests are mostly used to tell how advanced the leukemia is before treatment starts. They are also done during treatment to see how well the treatment is working.

As with samples of blood, bone marrow samples are looked at under a microscope to see what cells are present. Doctors want to see if there are the normal numbers of blood-forming cells or whether leukemia cells have replaced these.

Although bone marrow tests are not often used to diagnose CLL, they can be useful to see how advanced it is.

Imaging tests

Imaging studies are ways of taking pictures of the inside of the body. There are many imaging tests that might be used for people with leukemia. They are not done to find leukemia but rather to help find out the extent of the disease and how well treatment is working.

CT (computed tomography) scans

These are special kinds of x-rays in which a beam moves around the body, taking pictures from different angles. Details in soft tissues, such as swollen lymph nodes in the chest or in other parts of the body, show up better on CT scans than on x-rays.

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.

Before the test, you may be asked to drink a contrast liquid or get an intravenous (IV) injection of a contrast dye that helps better outline organs in the body. Some people are allergic and get hives or, rarely, more serious problems like trouble breathing and low blood pressure. Be sure to tell the doctor if you have ever had a reaction to any contrast dye used for x-rays.

Sometimes a CT scan is combined with a PET scan in a test known as a *PET/CT scan*. For a PET scan, glucose (a form of sugar) that has a radioactive atom is put into the blood. Because cancer cells in the body grow quickly, they absorb large amounts of the radioactive sugar. A special camera can then create a picture of the areas of radioactivity in the body. The PET/CT scan combines both tests in one machine.

MRI (magnetic resonance imaging) scans

MRI scans use strong magnets and radio waves to make detailed pictures of the body. MRI scans are very helpful in looking at the brain and spinal cord. They take longer than CT scans, often up to an hour. A substance (gadolinium) may be put into a vein before the scan to better show details. The substance does not often cause allergic reactions.

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 be a choice for people with a fear of closed spaces. The MRI machine makes loud buzzing and thumping noises that some people may find disturbing. Some places give you headphones to block this out.

Ultrasound scans

This scan uses sound waves – not radiation – to get pictures of internal organs. Ultrasound can be used to look at lymph nodes near the surface of the body or to look for enlarged organs inside your belly. This is a very easy test to have. Most often, you simply lie on a table and a small wand (called a *transducer*) is moved over the part of the body being looked at.

Chest x-ray

A plain x-ray of your chest can be done in most outpatient settings. In patients with CLL, it isn't needed to find the cancer, but it may be used to see whether your lungs are normal or if you have an infection.

Staging for chronic lymphocytic leukemia

For most cancers, staging is the process of finding out how far the cancer has spread. A stage is usually assigned based on the size of the tumor and how far it has spread. This system generally does not apply to leukemia because leukemia does not usually form a solid mass or tumor.

Also, leukemia affects bone marrow and, in many cases, it has already spread to other organs in the body when it is found. For chronic lymphocytic leukemia (CLL), lab tests focus on giving a clear description of different features of the disease. These features, in turn, help predict the likely outcome for the patient and help to guide treatment decisions.

Staging systems

There are 2 different systems for staging CLL. Stages are often useful because they can help guide treatment and predict a person's outlook (prognosis).

- **Rai system:** This is used more often in the United States.
- **Binet system:** This is used more widely in Europe.

Rai staging system

In the Rai system there are 5 stages from 0 to IV (0 to 4). Then, doctors divide the Rai stages into 3 risk groups when choosing treatment options:

- Stage 0 is labeled low risk.
- Stages I and II are intermediate risk.
- Stages III and IV are called high risk.

Binet staging system

In the Binet staging system, CLL is classified by the number of affected lymphoid tissue groups (neck lymph nodes, groin lymph nodes, underarm lymph nodes, spleen, and liver) and by whether or not the patient has too few red blood cells (anemia) or too few blood platelets (thrombocytopenia). The Binet stages are the letters A (the lowest), B, and C.

Prognostic factors

Other factors besides the stage can help predict a patient's outlook. These factors are called *prognostic factors*. Factors that are linked to shorter survival time are called *adverse* prognostic factors. Those linked to longer survival are *favorable* prognostic factors.

Some of these are based on certain genetic changes or proteins on the CLL cells. Others are just based on the age and sex of the patient. Your doctor can tell you if any of these factors apply to you and what they mean.

How is chronic lymphocytic 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.

Making treatment choices

After leukemia is found and staged, your cancer care team will discuss your treatment options with you. The main treatment is usually chemotherapy ("chemo"), but because chronic lymphocytic leukemia often grows slowly, not everyone needs to be treated right away.

It is important to take time and think about your choices. In choosing a treatment plan, the stage of the leukemia and other prognostic factors (see "How is chronic lymphocytic leukemia staged?") are important. Other factors to keep in mind include whether or not you are having symptoms, your age and overall health, and the likely benefits and side effects of treatment.

In thinking about your treatment options it is often a good idea to get a second opinion, if possible. This may give you more information and help you feel more certain about the treatment plan you have chosen.

Chemotherapy for chronic lymphocytic leukemia

Chemotherapy (chemo) is the use of drugs to kill or control cancer cells. Often the drugs are given into a vein, into the cerebrospinal fluid (CSF), or are taken by mouth. Except when given into the CSF, the drugs enter the bloodstream and reach throughout the body. Chemo is useful for cancers like leukemia that aren't in one place at the time of treatment.

Doctors give chemo in cycles. A round of treatment is followed by a rest period to allow the body time to recover. Treatment cycles may last about 3 to 4 weeks.

Side effects of chemo

While chemo drugs kill cancer cells, they can damage normal cells, too. This happens because they target cells that grow quickly, such as cancer cells, but they also damage other fast growing cells.

Cells in the bone marrow, the lining of the mouth and intestines, and hair follicles all grow fast and are likely to be damaged by chemo. This can lead to side effects, such as:

- Short-term hair loss
- Mouth sores
- Nausea and vomiting
- Loss of appetite
- A higher risk of infection (due to low white blood cell counts)
- Easy bruising or bleeding (from low blood platelets)
- Extreme tiredness called fatigue (from low red blood cell counts)

These side effects usually go away after treatment ends. And there are often ways to manage side effects during treatment. For example, drugs can be taken along with chemo to prevent or reduce nausea and vomiting. Drugs known as *growth factors* are sometimes given to keep blood counts higher and reduce the chance of infection.

If your white blood cell counts are very low during treatment, it increases the risk of serious infection. Your doctor may tell you to take special steps to avoid germs. You can learn more about this in our document *Infections in People With Cancer*.

You might also need transfusions of platelets or red blood cells if levels of those cells get too low.

Tumor lysis syndrome can also be a side effect of chemo. It is most common in patients who had large numbers of leukemia cells in the body before treatment. That's why it happens most often with the first cycle of chemo. When the cells are killed, they break open and release their contents into the bloodstream. This can overwhelm the kidneys, which cannot get rid of all of these substances at once. This can lead to build up of certain minerals in the blood and even to kidney failure. Mineral build-up also can lead to problems with the heart and nervous system. Doctors work to prevent these problems by giving the patient extra fluids and certain drugs.

The section "Chemotherapy for chronic lymphocytic leukemia" in our *Chronic Lymphocytic Leukemia* detailed guide has more information on this topic.

You can learn more about chemotherapy treatments in our document *Understanding Chemotherapy: A Guide for Patients and Families*.

Monoclonal antibodies for chronic lymphocytic leukemia

Monoclonal antibodies are man-made versions of immune system proteins (antibodies) that are designed to attach to a certain place on the surface of cancer cells. They can help kill the cancer cells, sometimes by targeting them for the patient's own immune system.

The monoclonal antibodies used to treat chronic lymphocytic leukemia (CLL) are:

- Rituximab (Rituxan[®]),
- Alemtuzumab (Campath[®]),
- Ofatumumab (Arzerra[®]), and
- Obinutuzumab (Gazyva[™])

Rituximab is often given along with chemotherapy as a part of the first treatment for CLL. Alemtuzumab and ofatumumab are more often used after other treatments stop working. Obinutuzumab is a newer drug that can also be used as a part of the first treatment for CLL.

All of these drugs are given as injections, either under the skin or into a vein (IV). Common side effects include fever and chills that occur while the drugs are being given into a vein. Less often, a more serious reaction, like low blood pressure, may occur while the drug is being given.

Another side effect is a problem with infections. For example, rituximab, ofatumumab, and obinutuzumab all can cause old hepatitis infections to become active again. That is why your doctor will check your blood for signs of an old hepatitis infection before

treatment with either of these drugs starts. The risk of certain serious infections with alemtuzumab is so high that patients need to take antibiotics and antiviral medicines while on this drug.

Each drug can cause different side effects, so ask your doctor what you can expect.

More information can be found in the section “Monoclonal antibodies for chronic lymphocytic leukemia” in our detailed guide, *Chronic Lymphocytic Leukemia*.

Surgery for chronic lymphocytic leukemia

Surgery is rarely used in treating chronic lymphocytic leukemia (CLL). Because leukemia is a disease of blood and bone marrow, it is not possible to cure it with surgery.

Rarely, an operation may be done to remove the spleen. If leukemia spreads to the spleen it can enlarge the organ enough for it to press on other organs and cause problems. If this happens, removing the spleen can provide 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 normal functions is to remove worn-out blood cells from the bloodstream. If the spleen is enlarged, it may become too active in getting rid of blood cells, leading to a shortage of red blood cells or platelets. Taking out the spleen may help prevent this. And most people have no problem living without a spleen.

Radiation therapy for chronic lymphocytic leukemia

Radiation therapy, the use of high energy x-rays to kill cancer cells, is usually not part of the main treatment for chronic lymphocytic leukemia (CLL). For some people with an enlarged organ such as the spleen, radiation might be used to shrink the swelling. It is also useful in treating bone pain caused by growth of leukemia cells in the bone marrow.

Radiation therapy is sometimes given in low doses to the whole body, just before a stem cell transplant (see the section, "Stem cell transplant for chronic lymphocytic leukemia").

The main short-term side effects of radiation treatment are sunburn-like changes in the treated area, tiredness, and a higher chance of infection. Radiation to the belly (abdomen) can sometimes cause nausea, vomiting, or diarrhea.

You can learn more about radiation treatments in our document *Understanding Radiation Therapy: A Guide for Patients and Families*.

Leukapheresis for chronic lymphocytic leukemia

Sometimes very high numbers of leukemia cells in the blood cause problems with normal circulation. Chemotherapy (chemo) may not lower the number of cells until a few days after the first dose. In the meantime, a process called *leukapheresis* may be used before

chemo. For this, the patient's blood is passed through a special machine that removes white blood cells (including leukemia cells) and returns the rest of the blood cells and plasma to the patient. This treatment lowers blood counts right away. The effect is only for a short time, but it may help until the chemo has a chance to work.

Leukapheresis works quickly to get the leukemia cells down. But without further treatment like chemo to kill the cancer cells, the cell count will go back up again. Leukapheresis may be given to help the patient until chemo has a chance to work.

Stem cell transplant for chronic lymphocytic leukemia

As noted earlier, chemo can harm normal cells as well as cancer cells. A stem cell transplant (SCT) offers a way for doctors to use the very high doses of chemo needed for effective treatment. Although the drugs destroy the patient's bone marrow, transplanted stem cells can restore the blood-producing bone marrow stem cells.

Stem cells for transplantation are collected from the bone marrow or from the bloodstream (in a process called *apheresis*). Bone marrow transplant was more common in the past. Now it has been largely replaced by cells taken from the bloodstream.

These blood-forming stem cells can come from either the patient or from a donor whose tissue type closely matches that of the patient. The donor may be a brother or sister or, less often, a person not related to the patient.

It's not clear how helpful stem cell transplants are in patients with chronic lymphocytic leukemia (CLL), so many doctors recommend that they should be done as part of a clinical trial (see next section).

To learn more about stem cell transplants, please see the American Cancer Society document, *Stem Cell Transplant (Peripheral Blood, Bone Marrow, and Cord Blood Transplants)*.

Clinical trials for chronic lymphocytic 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 Web site 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 Web site 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, it is up to you 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.

You can get a lot more information on clinical trials, in our document called *Clinical Trials: What You Need to Know*. You can read it on our Web site or call our toll-free number and have it sent to you.

Complementary and alternative therapies for chronic lymphocytic 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 to 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 in general and to find out about the specific methods you are looking at.

If you want to use a non-standard treatment, learn all you can about the method 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.

Supportive care for chronic lymphocytic leukemia

Patients with chronic lymphocytic leukemia (CLL) often need treatments that are aimed at helping with problems related to the CLL and its treatment. This may include treatments aimed at helping with infections or low blood counts. Although treating the CLL may help these over time, other therapies may be needed as well.

For infections

Some things that can be done to prevent infections include giving antibiotics (or antiviral drugs) before the patient has any signs or symptoms (like a fever). If the patient has low levels of natural antibodies and keeps getting infections, giving antibodies as an infusion into a vein can help. Patients with CLL also should get certain vaccines to help prevent infection. Certain vaccines, though, contain live viruses and should be avoided. Talk to the doctor treating you for your CLL about what vaccines you should get.

Because people with CLL often have poor immune function, they should be sure to tell their doctors about any symptoms of infection right away. These include fever, chills, cough, and problems with their urine (like burning).

For blood count problems

Patients with CLL may need transfusions of red blood cells or platelets when those counts get low. Sometimes, though, low red blood cell or platelet counts are caused by the body destroying the cells. This, called *autoimmunity*, can be treated with medicines to suppress the immune system, like corticosteroids (prednisone, for example). If that type of treatment doesn't work. The doctor may recommend different drugs or even having the spleen removed (since the spleen is often the place where the body destroys the cells).

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

As you cope with cancer and cancer treatment, you need to have honest, open talks with your doctor. You should 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 is the stage (risk group) of my leukemia? What does that mean for me?
- Will I need other tests before we can decide on treatment?
- How much experience do you have treating this type of cancer?
- Should I get a second opinion?
- Should I be treated at this time? Why or why not?
- What are my treatment choices ?
- Which treatment do you recommend, and why?
- What risks and side effects are there with the treatments you recommend?
- What should I do to be ready for treatment?
- How long will treatment last? What will it be like? Where will it be done?
- How will treatment affect my daily activities?
- If I have any chemo side effects, what can I do to help reduce them,?
- What are the chances that my leukemia will come back after treatment?
- What will we do if the treatment doesn't work or if the leukemia recurs?
- What type of follow-up will I need after treatment?

- What is my outlook?

Be sure to add your own questions.

Moving on after treatment for chronic lymphocytic leukemia

Chronic lymphocytic leukemia (CLL) is rarely able to be cured. Still, most people live for many years with the disease, and treatment can help them live even longer. Some CLL patients can live for years without treatment, but sooner or later most need to be treated. Most patients with CLL are treated on and off for years. Treatment may stop for a while, but it never really ends. Learning to live with cancer that does not go away can be hard and very stressful. Our document called *When Cancer Doesn't Go Away* talks more about this.

Follow-up care

You will probably need frequent follow-up exams for many years after treatment, even if there are no signs of the disease. These follow-up visits are very important. Your doctors will ask questions about any problems you might have. They may do exams and lab tests or x-rays and scans to look for signs of cancer or treatment side effects. It is important that you report any new symptoms to the doctor right away so that the cause can be found and treated.

Check-ups may include careful physical exams, blood tests, and other tests as needed. A benefit of follow-up care is that it gives you a chance to discuss questions and concerns that can come up during and after your recovery.

Treatment of CLL is not expected to cure the disease. This means that even if there are no signs of leukemia after treatment (known as a complete remission), the leukemia is likely to come back again (recur) at some point. Further treatment will depend on what treatments you've had before, how long it's been since treatment, and your health. To learn more about dealing with a recurrence, you may also want to see our document, *When Your Cancer Comes Back: Cancer Recurrence*.

In most people with CLL, the immune system doesn't work the way it should, which may raise the risk for certain infections. Some chemo treatments for CLL may also raise this risk. Your doctor may recommend vaccines or other medicines to help prevent or control certain infections.

People with CLL are at increased risk of developing a second cancer. At least some of this increased risk may be due to the effects of CLL on the immune system. Treatments for CLL may also raise the risk of some cancers. The most common second cancers in people with CLL are skin and lung cancers, although other types of leukemia, lymphoma,

and other blood cancers are also possible. It is important to be aware of this increased risk and to report any symptoms to your doctor right away.

It is also important to keep medical insurance. If your cancer comes back, you don't want to worry about paying for treatment.

Seeing a new doctor

At some point after your cancer is found and treated, you may find yourself in the office of a new doctor. It is important that you be able to give your new doctor the exact 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 and always keep copies for yourself:

- 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 copy of the treatment summary
- If you had chemo or other medicines, a list of your drugs, drug doses, and when you took them

Lifestyle changes after chronic lymphocytic leukemia

Having cancer and dealing with treatment can take a lot of time and energy, but it can also 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.

Make healthier choices

Think about your life before you learned you had cancer. Were there things you did that might have made you less healthy? Maybe you drank too much alcohol, ate more than you needed, used tobacco, or didn't exercise very often.

Now is not the time to feel guilty or blame yourself. You can start making changes today that can have positive effects for the rest of your life. Not only will you feel better but 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 is hard for many people, but it can be even harder to do during and after cancer treatment. One of the best things you can do after treatment is to put healthy eating habits into place. You may be surprised at the long-term benefits of some simple changes. 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. You can read more in our document *Nutrition and Physical Activity During and After Cancer Treatment: Answers to Common Questions*.

Rest, fatigue, 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, please see our document, *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.
- It makes your muscles stronger.
- It reduces fatigue.
- It lowers anxiety and depression.
- It can make you feel generally happier.
- It helps 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 chronic lymphocytic 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 may also want to read our booklet *Distress in People with Cancer* online, or you can call us to request a free copy by mail.

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 lymphocytic leukemia stops working

When a person has had many different treatments and the cancer has not been cured, over time the cancer tends to resist all 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. You can learn more about the changes that occur when curative treatment stops working, and about planning ahead for yourself and your

family, in our documents called *Nearing the End of Life* and *Advance Directives*. You can read them online or call us to have free copies mailed to you.

At some point you may want to think about hospice care. Most of the time it 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.

You can learn more about this in our document *Hospice Care*.

What's new in chronic lymphocytic leukemia research?

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

Genetics of CLL

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 also learning why these cancer cells grow too fast, live too long, and don't develop into normal blood cells. Doctors are looking at how to use these changes to help them predict a person's outlook and whether they will need treatment.

New treatment combinations

There are many different drugs now used to treat CLL. Doctors are trying to find out which combinations of these drugs work the best and offer the best chance for long-term survival with the fewest side effects.

The role of stem cell transplants in CLL is still not well-defined. Doctors aren't sure which type of transplant might work best, or which drugs should be used along with the transplant. Studies are now being done to try to answer these questions.

New drugs for CLL

Dozens of new drugs are being tested for use against CLL. Also, a number of new *monoclonal antibodies* (man-made versions of immune system proteins) are now being studied for use in CLL treatment. Some of these antibodies are used alone to try to prompt the immune system to attack leukemia cells. Other antibodies are attached to substances that can poison cancer cells.

Other drugs being studied are called targeted therapy drugs. These drugs work differently than standard chemotherapy drugs. They try to target specific changes inside cells that cause them to become cancerous. One of these drugs, ibrutinib (Imbruvica™) was recently approved to treat patients with CLL.

More information about chronic lymphocytic leukemia

More information from your American Cancer Society

Here is more information you might find helpful. You also can order free copies of our documents from our toll-free number, 1-800-227-2345, or read them on our website, www.cancer.org.

Living with cancer

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

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

Distress in People With Cancer

When Your Cancer Doesn't Go Away

When Your Cancer Comes Back: Cancer Recurrence

Understanding cancer treatments

Bone Marrow and Peripheral Blood Stem Cell Transplant

Understanding Chemotherapy: A Guide for Patients and Families (also available in Spanish)

Understanding Radiation Therapy: A Guide for Patients and Families (also available in Spanish)

Chronic Lymphocytic Leukemia Detailed Guide (also in Spanish)

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 available in Spanish)

Helping Children When a Family Member Has Cancer: Dealing With Diagnosis (also available 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 websites*

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

Chronic lymphocytic leukemia

Leukemia & Lymphoma Society

Toll-free number: 1-800-955-4572

Web site: www.lls.org

National Cancer Institute

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

Web site: www.cancer.gov

Bone marrow and peripheral blood stem cell transplants

National Bone Marrow Transplant Link (nbmtLINK)

Toll-free number: 1-800-LINK-BMT (1-800-546-5268)

Web site: www.nbmtlink.org

Be the Match (formerly National Marrow Donor Program)

Toll-free number: 1-800-MARROW-2 (1-800-627-7692)

Web site: 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 anytime, day or night, for information and support. Call us at **1-800-227-2345** or visit www.cancer.org.

Last Medical Review: 8/5/2013

Last Revised: 11/4/2014

2013 Copyright American Cancer Society

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