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 website at www.cancer.org.

What is chronic lymphocytic leukemia?

Cancer starts when cells in the body begin to grow out of control. Cells in nearly any part of the body can become cancer, and can spread to other areas of the body. To learn more about how cancers start and spread, see *What Is Cancer?*

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.

Chronic lymphocytic leukemia (CLL) is a cancer of lymphocytes, cells that become the white blood cells. In CLL, the leukemia cells build up in the bone marrow and spill out into the blood stream. They can also build up in lymph nodes, the spleen, liver, and other parts of the body. CLL is a slow growing leukemia, and it often takes years before it causes symptoms.

Lymphoma is another cancer that starts in lymphocytes. In one kind of lymphoma, small lymphocytic lymphoma, the cancer cell is the same as the leukemia cell in CLL. These diseases can have different signs and symptoms, but are treated the same way.

Acute lymphocytic leukemia (ALL) is another cancer that occurs in the cells that become lymphocytes. The cells in ALL look more abnormal and less mature than the cells in CLL. ALL is a much faster growing leukemia than CLL.

In addition to CLL and ALL, there are 2 other main types of leukemia:

- Acute myeloid leukemia
• Chronic myeloid leukemia

These start in the early version of cells that become other kinds of blood cells (besides lymphocytes).

Different types of leukemia are treated differently.

Along with the 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.

**Normal bone marrow, blood, and lymph tissue**

Bone marrow is the soft inner part of some bones, such as bones of the skull, shoulder blades, ribs, pelvis, and backbones. All of the different types of blood cells are made in the bone marrow. Bone marrow is made up of a small number of blood stem cells, blood-forming cells, fat cells, and tissues that help the blood cells grow.

Blood stem cells go through a series of changes to make new blood cells. They can develop into 1 of the 3 main types of blood cell:

- Red blood cells, which carry oxygen from the lungs to the rest of the body and carry carbon dioxide from the body to the lungs.
- Platelets, which are pieces of cells that help your blood clot
- White blood cells, which fight infection

There are different types of white blood cells. Each has its own role in fighting infection. The 3 main types of white blood cells are granulocytes, monocytes, and lymphocytes.

Lymphocytes are in the bone marrow and blood, but are also the main cells that make up lymphoid tissue, which is a major part of the immune system. 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.

Any blood-forming cell can turn into a leukemia cell.
What are the 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. They are:

- Getting older
- Gender – men have a slightly higher risk than women
- Having close relatives with CLL
- Certain chemical exposures

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.

For more information about these risk factors, see *Leukemia: Chronic Lymphocytic*.

Can chronic lymphocytic leukemia be prevented?

Changing your lifestyle to avoid certain risk factors can prevent many types of cancer, but this isn’t true for chronic lymphocytic leukemia (CLL). Most cases of CLL have no clear cause, and there is no way known 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

• Infections that don’t seem to get better or keep coming back

• Abnormal bruising or bleeding

These symptoms 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.

Signs of CLL include:

• Increased white blood cell counts (this is the most common sign, and can often be found before symptoms develop)

• Anemia - a shortage of red blood cells.

• Low counts of blood platelets (thrombocytopenia)

Sometimes CLL is found in someone with no symptoms because of abnormal blood counts.

**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 and the disease is found because a blood count is done for some other reason.

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. He or she will also examine you and then may order some tests..

**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.
**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. A person with CLL will often have too few red blood cells and blood platelets as well.

**Special tests done on blood samples**

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*.

**Bone marrow tests**

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

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.

For these tests, the skin and the surface of the bone are first numbed. Then for the *aspiration*, a needle is used to draw up a small amount of liquid bone marrow. For the *biopsy*, a slightly larger needle is used to remove a small cylinder of bone and marrow (about ½ inch long).

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.

**Imaging tests**

Imaging tests are ways of taking pictures of the inside of the body. There are many imaging tests that might be used to help find out if leukemia has spread or to check 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, a radioactive sugar 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.
Staging of 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?

General treatment information

After leukemia is found and staged, your cancer care team will discuss your treatment options with you. All treatments can have side effects. Because available treatments do not generally cure chronic lymphocytic leukemia (CLL) and it isn’t clear that treatment helps patients live longer, treatment is often delayed until you have bothersome symptoms from the disease. Some patients can delay treatment for years. The main treatments for chronic lymphocytic leukemia are:

- Chemotherapy ("chemo")
- Monoclonal antibodies
- Targeted therapy

Many patients also benefit from supportive care. Other treatments, like leukapheresis and stem cell transplant are used less often.

Treatment is often given for a time (3 to 6 months) to improve symptoms caused by CLL. Then the patient is watched off treatment. If symptoms worsen again, more treatment is given.

Thinking about taking part in a clinical trial

Clinical trials are carefully controlled research studies that are done to get a closer look at promising new treatments or procedures. 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 best way for doctors to learn better methods to treat cancer. Still, they are not right for everyone.

If you would like to learn more about clinical trials that might be right for you, start by asking your doctor if your clinic or hospital conducts clinical trials. You can also call our clinical trials matching service at 1-800-303-5691 for a list of studies that meet your medical needs, or see the Clinical Trials section to learn more.
Considering complementary and alternative methods

You may hear about alternative or complementary methods that your doctor hasn’t mentioned to treat your cancer or relieve symptoms. These methods can include vitamins, herbs, and special diets, or other methods such as acupuncture or massage, to name a few.

Complementary methods refer to treatments that are used along with your regular medical care. Alternative treatments are used instead of a doctor’s medical treatment. Although some of these methods might be helpful in relieving symptoms or helping you feel better, many have not been proven to work. Some might even be dangerous.

Be sure to talk to your cancer care team about any method you are thinking about using. They can help you learn what is known (or not known) about the method, which can help you make an informed decision. See the Complementary and Alternative Medicine section to learn more.

Help getting through cancer treatment

Your cancer care team will be your first source of information and support, but there are other resources for help when you need it. Hospital- or clinic-based support services are an important part of your care. These might include nursing or social work services, financial aid, nutritional advice, rehab, or spiritual help.

The American Cancer Society also has programs and services – including rides to treatment, lodging, support groups, and more – to help you get through treatment. Call our National Cancer Information Center at 1-800-227-2345 and speak with one of our trained specialists on call 24 hours a day, every day.

The treatment information given here is not official policy of the American Cancer 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.

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 or are taken by mouth. The drugs enter the bloodstream and reach most of 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 can lead to some of the common short-term side effects, such as:

- Hair loss
- Mouth sores
- Nausea and vomiting
- Loss of appetite
- Low white blood cell counts, which can lead to a higher risk of serious infection
- Low blood platelets, which can lead to problems with bleeding and easy bruising
- Low red blood cell counts, which can lead to extreme tiredness and shortness of breath with exercise

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 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 *Chronic Lymphocytic Leukemia* has more information on this topic.

You can learn more about chemotherapy treatments in *A Guide to Chemotherapy*. 
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 or signal them to die.

These drugs can be given alone or along with chemotherapy to treat chronic lymphocytic leukemia (CLL). They all 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. Some of these drugs 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 some of these drugs. For one monoclonal antibody drug, the risk of certain serious infections with is so high that patients need to take antibiotics and antiviral medicines while on it.

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 *Leukemia - Chronic Lymphocytic*.

Targeted therapy for chronic lymphocytic leukemia

Newer anti-cancer drugs are called targeted therapy because they specifically target changes inside cells that cause them to be cancerous.

Targeted drugs are used to treat chronic lymphocytic leukemia (CLL) that is hard to treat, including cases that have stopped responding to other drugs.

For more information about targeted therapy drugs in the treatment of CLL, see *Leukemia - Chronic Lymphocytic*.

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. In this treatment, 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. Leukapheresis 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. Without further treatment like chemo to kill the cancer cells, the cell count will go back up again.

For more information about this, see *Leukemia - Chronic Lymphocytic*. 
Supportive care for chronic lymphocytic leukemia

People with chronic lymphocytic leukemia (CLL) often need supportive care treatments to help with problems related to the CLL and its treatment. For example, some people with CLL have problems with infections or low blood counts. Although treating the CLL may help these over time, other therapies may be needed as well.

For infections

To help prevent infections, you might be given antibiotics or antiviral drugs, even before you have any signs or symptoms (like a fever). If you have low levels of natural antibodies and keeps getting infections, getting antibodies as an infusion into a vein can help. People 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, be sure to tell your doctors about any symptoms of infection right away. These include fever, chills, cough, and problems with their urine (like burning).

For blood count problems

People 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 is called autoimmunity, and can be treated with medicines to suppress the immune system, like corticosteroids (prednisone, for example). If that type of treatment doesn’t work, your doctor may recommend different drugs or even having the spleen removed (since the spleen is often the place where the body destroys the cells).

For more information about this, see Leukemia: Chronic Lymphocytic.

Stem cell transplant for chronic lymphocytic leukemia

Chemotherapy (chemo) can harm normal cells as well as cancer cells. A stem cell transplant (SCT) might be used when very high doses of chemo are 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 bloodstream in a process called apheresis or they can come from the bone marrow. These blood-forming stem cells can come from either the patient before treatment with high-dose chemo or from a donor whose tissue type closely matches that of the patient. When treating chronic lymphocytic leukemia (CLL), stem cells from a donor are most often used.
To learn more about stem cell transplants, see Stem Cell Transplant (Peripheral Blood, Bone Marrow, and Cord Blood Transplants).

**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 write down any other questions as well.
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 people with CLL can live for years without treatment, but most eventually need to be treated. Most people 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. See *When Cancer Doesn't Go Away* for 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, see *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 *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, 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.
- 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 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 Distress in People with Cancer.

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 Nearing the End of Life and Advance Directives.

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 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 learning more about how changes in a person's DNA can cause normal bone marrow cells to turn 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

We have a lot more information that you might find helpful. Explore www.cancer.org or call our National Cancer Information Center toll-free number, 1-800-227-2345. We're here to help you any time, day or night.

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  
Website: www.lls.org

**National Cancer Institute**
Toll-free number: 1-800-4-CANCER (1-800-422-6237)  
Website: 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)  
Website: www.nbmtlink.org

**Be the Match (formerly National Marrow Donor Program)**
Toll-free number: 1-800-MARROW-2 (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 anytime, day or night, for information and support. Call us at 1-800-227-2345 or visit www.cancer.org.

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1-800-227-2345 or www.cancer.org