



Canadian
Cancer
Society

Leukemia

Understanding your diagnosis



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When you first hear that you have cancer, you may feel alone and afraid. You may be overwhelmed by the large amount of information you have to take in and the decisions you need to make.

“ *All I could hear was ‘cancer.’ I heard my doctor say something like, ‘We’re going to start your treatment as soon as possible.’ I didn’t hear one word after that.* ”

The introductory information in this brochure can help you and your family take the first steps in learning about leukemia. A better understanding may give you a feeling of control and help you work with your healthcare team to choose the best care for you.

For more information

The information in this brochure provides an introduction to leukemia. More in-depth information is available on cancer.ca. You can also call our Cancer Information Service at 1-888-939-3333 to learn more about cancer, diagnosis, treatment, support and the services we offer.

Check out our video series on common cancer topics. These short, simple videos cover subjects like *What is cancer?* and *Coping when you’re first diagnosed*.

Find the series at cancer.ca/cancerbasics.

What is cancer?

Cancer is a disease that starts in our cells. Our bodies are made up of trillions of cells, grouped together to form tissues and organs such as muscles and bones, the lungs and the liver. Genes inside each cell order it to grow, work, reproduce and die. Normally, our cells obey these orders and we remain healthy.

But sometimes the instructions in some cells get mixed up, causing them to behave abnormally. These cells grow and divide uncontrollably.

Abnormal cells from most organs form solid lumps, or tumours. But abnormal cells from the immune system or blood usually do not form solid tumours. When you have leukemia, most of these cancer cells circulate in the blood, bone marrow and lymphatic system.

What is leukemia?

Leukemia is a cancer that starts in the bone marrow stem cells that make blood cells. Bone marrow is the soft, spongy material in the centre of most bones (where blood cells are made). Blood stem cells (immature blood cells) develop into myeloid stem cells or lymphoid stem cells.

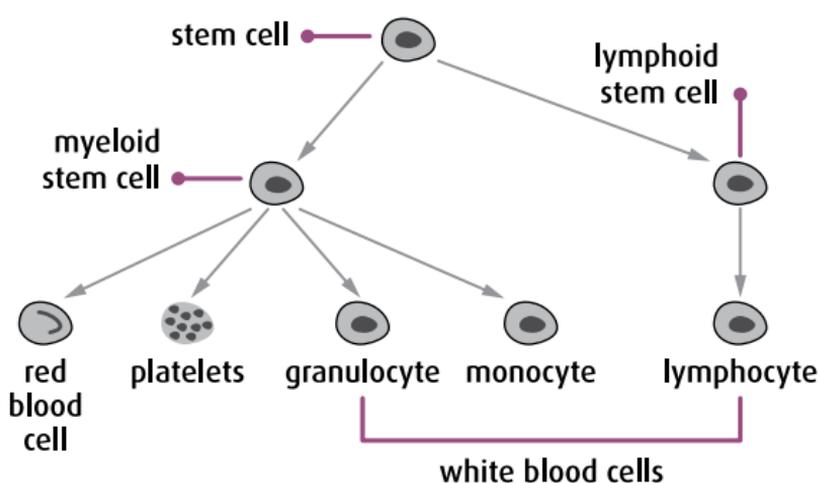
Myeloid stem cells develop into one of 3 types of mature blood cells:

- Red blood cells carry oxygen to all tissues of the body.
- Platelets form clots in damaged blood vessels to stop bleeding.

- White blood cells called granulocytes and monocytes destroy bacteria and help fight infection.

Lymphoid stem cells develop into lymphocytes. Lymphocytes are another type of white blood cell that is usually found in the lymph nodes and lymphatic system, such as the spleen and the blood. Lymphocytes make antibodies to help fight infection.

Development of Blood Cells



Leukemia develops when the blood stem cells in the bone marrow make abnormal blood cells. These abnormal cells are called leukemia cells. Over time, the leukemia cells crowd out normal blood cells. This makes it hard for the white blood cells, red blood cells and platelets to do their jobs.

Types of leukemia

There are different types of leukemia. The types of leukemia are first grouped according to the type of stem cell they developed from:

- Myelogenous leukemias develop from abnormal myeloid stem cells.
- Lymphocytic leukemias (also known as lymphoblastic leukemias) develop from abnormal lymphoid stem cells.

The types of leukemia are then grouped according to how quickly the leukemia develops and grows:

- Acute leukemias start suddenly, developing within days or weeks. The number of leukemia cells in the blood can grow very fast and the blood can't do its job. Acute leukemias get worse quickly and need to be treated right away.
- Chronic leukemias develop slowly over months or years and may not cause any symptoms early in the disease. Symptoms start to appear as the number of leukemia cells in the blood or bone marrow increases.

There are 4 main types of leukemia:

- acute myelogenous leukemia (AML)
- acute lymphocytic leukemia (ALL)
- chronic myelogenous leukemia (CML)
- chronic lymphocytic leukemia (CLL)

Because each type of leukemia develops and grows differently, each type is treated differently. It's important to find out which type of leukemia you have so you can get the treatment that works best for that type.

Diagnosing leukemia

Your doctor may suspect you have leukemia after taking your medical history and doing a physical exam. To confirm the diagnosis, your doctor will arrange special tests. These tests may also be used to classify the leukemia and help plan treatment.

Symptoms of acute leukemia may be similar to the flu and may develop suddenly within days or weeks.

In the early stages of chronic leukemia, many people have few or no symptoms. Symptoms usually develop gradually. The disease is often found during a routine blood test.

The symptoms of leukemia include:

- fatigue
- a general feeling of discomfort or illness (called malaise)
- loss of appetite
- weight loss
- fever
- anemia (shortness of breath, paleness, rapid heartbeat, weakness, dizziness)
- bleeding (bruising, frequent or severe nose bleeds, bleeding gums, mid-cycle or heavy menstrual flow, red spots on the skin)
- frequent infections (for example, cold sores or infection in the lungs, urinary system or gums or around the anus)
- vomiting
- headache
- sore throat
- night sweats
- bone or joint pain

- swollen lymph nodes in the neck, underarm, groin or above the collarbone
- vision problems
- sores in the eyes
- swelling of the testicles

Other health problems can cause some of the same symptoms. The process of diagnosis may seem long and frustrating, but it's important for the doctor to make sure there are no other possible reasons for a health problem.

Your doctor will do one or more of the following tests to make a diagnosis.

Blood tests: Blood is taken and studied to see if the different types of blood cells are normal in number and appearance. The results can also show how well organs are working and may suggest whether or not you have leukemia.

Bleeding and clotting factors may also be tested. These tests measure certain substances in the blood to see how well the body can clot blood. If you have leukemia, you may have abnormal levels of blood clotting factors.

Cytogenetics: Cytogenetic tests (also called chromosome analyses) are done on a sample of your bone marrow to look for changes in the chromosomes in the cells. Chromosomes are the part of a cell that has your genetic information. In the different types of leukemia, there are often specific genetic abnormalities that cause changes in the chromosomes in leukemia cells. These tests help identify the type of leukemia you have and which treatment may work best for you.

Biopsy: A biopsy is usually needed to make a definite diagnosis of leukemia. To diagnose leukemia, cells are removed from the bone marrow, usually from the back of the hip bone. The cells are checked under a microscope. If leukemia cells are found, they are studied further to see how fast they are growing. There are 2 ways to get a bone marrow sample.

- For a bone marrow aspiration, the doctor uses a thin needle to remove samples of bone marrow.
- A bone marrow biopsy uses a thicker needle to remove a sample of bone marrow and a small piece of bone.

Aspirations and biopsies use a local anesthetic to freeze the area. It can be painful when cells are pulled into the syringe, but this lasts only a few seconds. Usually you will be an outpatient (you won't stay overnight) in a clinic or hospital where bone marrow aspirations and biopsies are done.

Lymph node biopsy: If you have enlarged (swollen) lymph nodes, you may need a lymph node biopsy. Groups of lymph nodes are found throughout your body. They are part of your lymph or immune system. A lymph node biopsy may remove part or all of a lymph node. If the enlarged lymph node can be easily reached with a needle, a local anesthetic (freezing) is used. If the enlarged lymph node is deep in your chest or abdomen, you may need a general anesthetic (you will be unconscious).

Imaging studies: Imaging studies allow tissues, organs and bones to be looked at in more detail. Using x-rays, CT scans, MRIs or ultrasounds, your healthcare team can get a picture of where the cancer is and which organs may be involved. These tests are usually painless, and you don't need an anesthetic.

Further testing: Your doctor may order more tests to find out if the cancer has spread and to help plan your treatment.

Will I be OK?

Most people with cancer want to know what to expect. Can they be cured?

A prognosis is your doctor's best estimate of how cancer will affect you and how it will respond to treatment. A prognosis looks at many factors including:

- the type and stage, or phase, of the cancer
- the treatments chosen and how you respond to treatment
- your age, sex and overall health

Even with all this information, it can still be very hard for your doctor to say exactly what will happen. Each person's situation is different.

Your doctor is the only person who can give a prognosis. Ask your doctor about the factors that affect your prognosis and what they mean for you.

Subtypes of leukemia

Once a diagnosis of leukemia has been made and your healthcare team has the information it needs, the leukemia is classified into subtypes. The subtype is based on the unique characteristics of the leukemia cell seen under the microscope. For example, ALL is classified into subtypes based on the type of lymphocyte that has become cancerous (B cell or T cell) and by how mature the cell is.

Knowing your subtype is important because your healthcare team will plan your treatment according to the subtype of leukemia you have.*

Treatments for leukemia

Your healthcare team considers your general health and the type and subtype of leukemia to recommend the best treatments for you. You'll work together with your healthcare team to make the final treatment choices. Talk to them if you have questions or concerns.

Talk to your doctor about your fertility options before starting treatment

Some treatments can affect your ability to have children. Loss of fertility may be temporary or permanent, depending on your age and the radiation you receive. Stem cell transplants and some of the chemotherapy drugs used to treat leukemia may also cause fertility problems. Talk to your doctor before starting treatment about ways to maintain your fertility.

* There are many ways to classify leukemia and many subtypes. For information on a particular subtype of leukemia, contact our Cancer Information Service at 1-888-939-3333.

For leukemia, you might receive one or more of the following treatments.

Chemotherapy: Chemotherapy uses drugs to treat cancer. Chemotherapy drugs may be given as pills or by injection (with a needle). They interfere with the ability of cancer cells to grow and spread, but they also damage healthy cells. Although healthy cells can recover over time, you may experience side effects from your treatment like nausea, vomiting, loss of appetite, fatigue and an increased risk of infection.

Stem cell transplant: Sometimes high doses of chemotherapy are used to treat leukemia that has come back (recurred) or if there is a high risk that it may come back. High-dose chemotherapy destroys the bone marrow cells as well as the leukemia cells, so the bone marrow needs to be replaced with a transplant of stem cells. All blood cells develop from stem cells found in the bone marrow and in the bloodstream.

Before high-dose chemotherapy is given, stem cells are taken from you or from a donor whose bone marrow is a close match to your own. Soon after the chemotherapy treatment, the stem cells are put back into your blood. Within a few weeks, the new stem cells start to make blood cells.

A stem cell transplant is a risky and complex procedure. For this reason, stem cell transplants are done in specialized transplant centres or hospitals by a team of highly trained healthcare professionals. Side effects can be very serious

and may even be life-threatening. You will be watched very closely after a stem cell transplant and carefully followed up for a period of time after leaving the hospital.

It may take several months to fully recover after a stem cell transplant.

A **reduced-intensity transplant** uses a lower dose of chemotherapy before the stem cell transplant. It may be used if you are not able to cope with the side effects of a high dose of the drug because of your age or if you have other health problems.

Radiation therapy: In external beam radiation therapy, a large machine is used to carefully aim a beam of radiation at the cancer cells. The radiation damages the cells in the path of the beam - normal cells as well as cancer cells.

Radiation side effects depend on what part of the body receives the radiation. You may feel more tired than usual or notice changes to the skin (it may be red or tender) where the treatment was given.

For more information on treatment, you may want to read our booklets *Chemotherapy and Other Drug Therapies* and *Radiation Therapy*.

Targeted therapy: Targeted therapies use drugs that attack specific types of cancer cells without damaging healthy cells. Cancer growth inhibitors are a type of targeted therapy. They interfere with a cancer cell's ability to grow and divide. Some cancer growth inhibitors can be used to treat CML, ALL and AML. These

drugs are taken by pill or capsule. You may feel tired or have flu-like symptoms during the first few months of treatment. Side effects may get better as treatment continues.

Watchful waiting: Watchful waiting is a treatment option that may be offered to people with CLL who have no symptoms. Watchful waiting means your healthcare team watches the leukemia closely. You will visit your doctor regularly for physical exams. And other tests may be done from time to time. Active treatment, such as chemotherapy or radiation, may be considered if symptoms of leukemia appear or change. Once the symptoms are controlled, you and your doctor may decide to return to watchful waiting.

Surgery: In rare cases, people with chronic leukemia need to have their spleen removed. The spleen is located in the abdomen and is attached to the stomach, left kidney and colon. In chronic leukemia, the spleen may become enlarged (swollen). An enlarged spleen can cause discomfort and pain. It also destroys red blood cells and platelets, causing anemia and bleeding. If chemotherapy or radiation doesn't shrink the spleen, then it may be removed by surgery. Surgery to remove the spleen is called splenectomy. It's done under a general anesthetic (you will be unconscious).

After surgery, you may have some pain or bleeding. These side effects are temporary and can usually be controlled. Without a spleen, you may be more at risk of infections.

Biological therapy: Biological therapy (sometimes called immunotherapy) uses your immune system to fight cancer or to help control side effects of cancer treatments. Natural body substances or drugs made from natural body substances are used to boost the body's own defences against illness.

There are 2 forms of biological therapy used to treat leukemia - monoclonal antibodies and interferon alfa. Both are given by injection. Monoclonal antibodies are sometimes used to treat people with CLL, ALL and AML. Interferon alfa may be used for CML (although people with CML are more likely to be treated with cancer growth inhibitors). Common side effects of these drugs are flu-like symptoms, such as chills, fever, muscle aches, weakness and nausea. More serious side effects are rare. Some people may have a severe skin rash, breathing problems or low blood pressure. The side effects usually disappear once treatment is finished. Be sure to discuss the risks and benefits of this treatment with your healthcare team.

Clinical treatment trials: Clinical treatment trials investigate new approaches to treating cancer, such as new drugs, new types of treatments or combinations of existing treatments. They are closely monitored to make sure that they are safe and effective for the participants. Ask your doctor if any clinical trials are available as a suitable treatment option for you. You may benefit and so may future cancer patients.

Our brochure *Clinical Trials* has more information, including how to find a clinical trial.

Complementary therapies: Complementary therapies – for example, massage therapy or acupuncture – are used *together with* conventional cancer treatments, often to help ease tension and stress as well as other side effects of treatment. They don't treat the cancer itself. More research is needed to understand if these therapies are effective and how they work.

Alternative therapies are used *instead of* conventional treatments. Alternative therapies haven't been tested enough for safety or effectiveness. Using alternative treatments alone for cancer may have serious health effects.

If you're thinking about using a complementary or alternative therapy, learn as much as you can about the therapy and talk to your healthcare team. It's possible that the therapy might interfere with test results or other treatments.

Side effects of treatments

Some cancer treatments cause side effects, such as fatigue, hair loss or nausea. Because treatments affect everyone differently, it's hard to predict which side effects – if any – you may have.

Side effects can often be well managed and even prevented. If you're worried about side effects, tell your healthcare team about your concerns and ask questions. They can tell you which side effects you should report right away and which ones can wait until your next appointment.

If you notice any side effects or symptoms that you didn't expect, talk to a member of your healthcare team as soon as possible. They'll help you get the care and information you need.

After treatment

Follow-up care helps you and your healthcare team monitor your progress and your recovery from treatment. At first, your follow-up care may be managed by one of the specialists from your healthcare team. Later on, it may be managed by your family doctor.

The schedule of follow-up visits is different for each person. You might see your doctor more often in the first year after treatment, especially if you had a stem cell transplant. It can take the immune system a year or longer to recover from a stem cell transplant. The time between follow-up appointments may become longer as time goes on. You should report new symptoms and symptoms that don't go away to your doctor without waiting for your next scheduled appointment.

Blood samples are taken regularly as part of follow-up to check the levels of your white and red blood cells and platelets. If your white blood cell count is low, you need to protect yourself from infections. You may be given antibiotics and other drugs to help prevent infections. Your doctor may advise you to stay away from crowds and from people with colds and other contagious diseases. If you get an infection or get sick, you should contact your doctor right away. You may need to stay in the hospital for treatment.

Some people with leukemia experience low energy and fatigue after treatment. This may be caused by anemia (too few red blood cells). Anemia can be treated with red blood cell transfusions. Platelet transfusions can help reduce the risk of serious bleeding.

Self-image and sexuality: It's natural to be concerned about the effects of leukemia and its treatment on your sexuality. You may be worried about how your body looks after treatment, about having sex with a partner or that you may be rejected. It may help to talk about these feelings with someone you trust. Your doctor can also refer you to specialists and counsellors who can help you with the emotional side effects of leukemia treatment.

Our booklet *Sex, Intimacy and Cancer* has more detailed information.

The end of cancer treatment may bring mixed emotions. You may be glad the treatments are over and look forward to returning to your normal activities. But you might feel anxious as well. If you're worried about the end of your treatment, talk to your healthcare team. They're there to help you through this transition period.

Living with cancer

Our booklet *Coping When You Have Cancer* has more detailed information and resources.

Many sources of help are available for people with cancer and for their caregivers.

Your healthcare team: If you need practical help or emotional support, members of your healthcare team may be able to suggest services in your community or refer you to cancer centre staff or mental health professionals.

Family and friends: People closest to you can be very supportive. Accept offers of help. When someone says, “Let me know how I can help,” tell them what they can do. Maybe they can run errands, cook a meal or drive you to your doctor’s office.

People who’ve had a similar experience: Talking with and learning from others who’ve had similar experiences can be helpful. Consider visiting a support group or talking with a cancer survivor in person, over the telephone or online. Try more than one option to see which one works best for you.

Yourself: Coping well with cancer doesn’t mean that you have to be happy or cheerful all the time. But it can mean looking after yourself by finding relaxing, enjoyable activities that refresh you mentally, spiritually or physically. Take some time to find coping strategies to help you through this experience. You may also want to talk to a counsellor for more help.

Talking to someone who's been there

If you would like to talk to someone who's had a similar cancer experience, you can connect by phone with a trained volunteer who will listen, provide hope and suggest ideas for coping – all from the shared perspective of someone who's been there.

Register for this free program at match.cancer.ca or call us at 1-888-939-3333.

Want to connect with people online?

If you'd like to join our online community, visit CancerConnection.ca. You can read news, join discussion groups, get support and help others at the same time. You'll find caring, supportive people there.

What causes leukemia?

There is no single cause of leukemia, but some factors increase the risk of developing it.

Men are more likely than women to develop leukemia. And the risk for developing most types of leukemia increases with age. Some people develop leukemia without any risk factors, while others who have these factors do not get it.

Risk factors for leukemia include:

- exposure to high levels of radiation, for example, from a nuclear accident
- previous treatment with radiation or chemotherapy for cancer or other conditions, especially if the treatments were combined
- exposure to chemicals such as benzene and formaldehyde
- having a genetic disorder such as Down syndrome, Fanconi anemia, ataxia-telangiectasia or Bloom syndrome

Canadian Cancer Society

We're here for you.

When you have questions about treatment, diagnosis, care or services, we will help you find answers.

Call our toll-free number 1 888 939-3333.



Ask a trained cancer information specialist your questions about cancer. Call us or email info@cis.cancer.ca.



Connect with people online to join discussions, get support and help others. Visit CancerConnection.ca.



Browse Canada's most trusted online source of information on all types of cancer. Visit cancer.ca.

Our services are free and confidential. Many are available in other languages through interpreters.

Tell us what you think

Email cancerinfo@cancer.ca and tell us how we can make this publication better.



What we do

The Canadian Cancer Society fights cancer by:

- doing everything we can to prevent cancer
- funding research to outsmart cancer
- empowering, informing and supporting Canadians living with cancer
- advocating for public policies to improve the health of Canadians
- rallying Canadians to get involved in the fight against cancer

Contact us for up-to-date information about cancer and our services or to make a donation.



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