

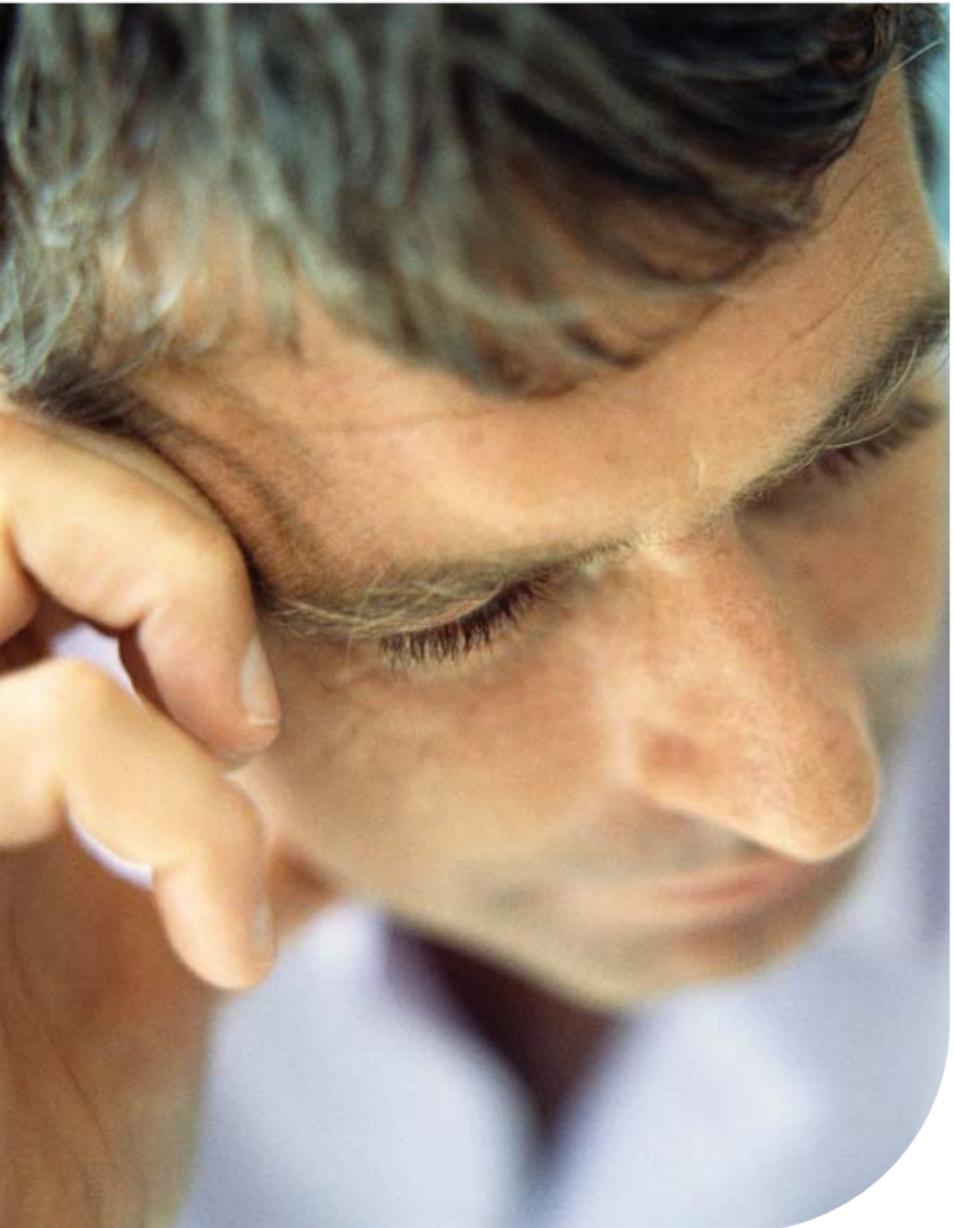


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Leukemia

Understanding your diagnosis



Let's Make Cancer History

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Leukemia

Understanding your diagnosis

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 will have to take in and the decisions you will need to make.

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

* This brochure is about leukemia in adults. For information about leukemia in children, contact our *Cancer Information Service* at 1 888 939-3333.

What is cancer?

Cancer is a disease that starts in our cells. Our bodies are made up of millions 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. Abnormal cells from the immune system or the blood usually do not form solid tumours. Most of these cancer cells circulate in the blood, bone marrow and lymphatic system.

What is leukemia?

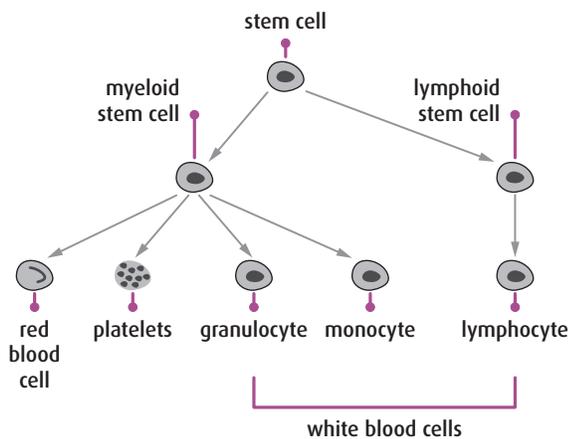
Leukemia is a cancer that starts in the stem cells of the bone marrow that make blood cells. Bone marrow is the soft, spongy material that fills the centre of most bones (where blood cells are made). Blood stem cells (immature blood cells) develop into either *myeloid stem cells* or *lymphoid stem cells*.

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

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

- White blood cells called *granulocytes* and *monocytes* destroy bacteria and help to 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.



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

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

The types of leukemia are further 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 rise very fast and the blood cannot 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 four 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 is important for your doctor to find out which type of leukemia you have so you can get the treatment that works best for that type.

Causes of leukemia

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

- being older
- previous treatment with radiation or chemotherapy for cancer or other conditions
- exposure to high levels of radiation, for example from nuclear fallout
- exposure to chemicals such as benzene
- smoking
- having a genetic disorder (such as Down syndrome) or abnormality (people with CML often have an abnormal chromosome called the *Philadelphia chromosome*)
- family history – having an inherited faulty gene or a family history of CLL
- having a blood disorder, such as myelodysplastic syndrome (also called MDS)
- having had a viral infection such as human T-cell leukemia/lymphoma virus (HTLV-1)

Some people develop leukemia without any of these risk factors.

Symptoms of leukemia

Symptoms start to appear as the number of leukemia cells grows and your bone marrow can no longer make the normal blood cells your body needs. Having too few normal white blood cells, red blood cells or platelets can cause a number of symptoms. In acute leukemia, symptoms appear and get worse quickly.

Acute leukemia (AML and ALL) can cause you to have too few normal white blood cells (a condition called *neutropenia*). You will not be able to fight infection very well. If you have too few red blood cells (*anemia*), you may feel very tired, be short of breath or look pale. Too few platelets (*thrombocytopenia*) can lead to unusual bleeding. You may bruise easily or notice small purple or red spots on your skin, especially on your arms and legs. Other general symptoms of acute leukemia may include:

- fever
- unexplained weight loss
- general discomfort
- sore throat
- swollen gums
- drenching night sweats
- headache
- vomiting
- vision problems
- bone or joint pain
- painless swelling of the lymph nodes

In the early stages of chronic leukemia (CML and CLL), the leukemia cells can function almost normally and cause no symptoms. The disease is often discovered during a routine blood test. When symptoms do appear, they generally are mild at first and get worse gradually. General symptoms of chronic leukemia may include:

- fatigue
- general discomfort
- loss of appetite
- unexplained weight loss
- drenching night sweats
- painless swelling of the lymph nodes

Often, these symptoms are not caused by leukemia. Other health problems can cause them, such as the flu or an infection. Testing is needed to make a diagnosis.

Diagnosing leukemia

After taking your medical history and completing a physical examination, your doctor may suspect you have leukemia. To confirm the diagnosis, your doctor will arrange special tests. These tests may also be used to classify the leukemia. You may have one or more of the following tests.

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 your kidneys, liver and other organs are working. These tests may suggest whether or not you have leukemia.

Imaging studies: Imaging studies allow tissues, organs and bones to be looked at in more detail. Using x-rays, ultrasounds, CT scans or MRIs, your healthcare team can get a picture of where the cancer is and see if it involves your organs, such as the spleen, liver or lymph nodes. These tests are usually painless and do not require an anesthetic.

Biopsy: A biopsy is usually necessary 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 in the bone marrow, they will be studied further to see how fast they are growing. There are two 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.

Both types of biopsies use a local anesthetic (freezing) to numb the area. It can be painful when cells are pulled into the syringe, but this lasts only a few seconds. Usually, bone marrow aspirations and biopsies are done in a clinic or hospital on an outpatient basis (you will not stay overnight).

If you have enlarged lymph nodes, a *lymph node biopsy* may be done. Clusters 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 will be used. A general anesthetic (you will be unconscious) may be necessary if the enlarged lymph node is deep in your chest or abdomen.

Lumbar puncture: A lumbar puncture (also called a *spinal tap*) may be done to see if the leukemia has spread to your nervous system. A needle is inserted between two vertebrae in the backbone and a small amount of cerebrospinal fluid is removed and checked for leukemia cells. Cerebrospinal fluid is the fluid that surrounds the spinal cord and the brain. A local anesthetic is used. A lumbar puncture takes about 30 minutes. You must lie flat for 1 to 2 hours afterward to lessen the chances of getting a headache.

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

Classification and subtypes

Once a diagnosis of leukemia has been made and your healthcare team has the information it needs, the leukemia will be 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 treatment is planned according to the subtype of leukemia you have*.

Treatments for leukemia

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

Treatments affect everyone in different ways. It's hard to predict which side effects you will have. Your healthcare team will tell you what to expect with each treatment. They will also let you know what side effects you should report right away and which ones you can wait to tell them about at your next appointment. If you notice any side effects or symptoms that you did not expect, talk to a member of your healthcare team as soon as possible.

* 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.

Patients often worry about the side effects of cancer treatment. However, side effects can often be well managed and even prevented. Be open with your healthcare team. Tell them your concerns and ask questions. They will help you get the care and information you need.

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

Chemotherapy: Chemotherapy may be given as pills or by injection. Chemotherapy drugs 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, hair loss and an increased risk of infection.

If the leukemia has spread to the nervous system, the chemotherapy drugs may be injected directly into the cerebrospinal fluid. This is called *intrathecal chemotherapy*. It is given with a local anesthetic.

Stem cell transplant: Sometimes high doses of chemotherapy are used to treat leukemia that has come back 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 will need 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 will be 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 will 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.

Radiation therapy: In *external beam radiation therapy*, a large machine is used to carefully aim a beam of radiation. The radiation damages the cells in the path of the beam – normal cells as well as cancer cells. Radiation side effects will be different depending on what part of the body receives the radiation. You may feel more tired than usual, have some diarrhea, or notice changes to the skin (it may be red or tender) where the treatment was given.

Radiation may be used for some types of leukemia to treat the disease or prevent it from spreading. If you need a stem cell transplant, you may also be given radiation to the whole body to destroy the bone marrow cells. This is called *total body irradiation*.

Biological therapy: Biological therapy uses your immune system to fight cancer or to help control side effects of other 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 two 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 also be used for CML (although people with CML are more likely to be treated with cancer growth inhibitors). Side effects of these drugs often cause 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.

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 people with CML, ALL and AML. These drugs are taken by pill or capsule. Side effects are most likely to occur 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 will watch the leukemia closely. You will visit your doctor regularly for a physical examination. Other tests may be done from time to time. Active treatment, such as chemotherapy or radiation, may be considered if signs of leukemia appear or change. Once the symptoms are controlled, you and your doctor may decide to return to a watchful waiting program.

Surgery: Surgery is rarely used to treat chronic leukemia, but some people with chronic leukemia will 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. 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 is done under 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.

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 for the participants. Ask your doctor if there is a clinical trial suitable as a treatment option for you. You may benefit and so may future cancer patients.

Complementary therapies: Complementary therapies are used *together with* conventional treatments. 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 for safety or effectiveness. It is still unknown whether they will harm you or be effective in the treatment of cancer.

If you are thinking about using a complementary or alternative therapy, it is important to find out 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 regular treatments.

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 will be taken regularly during and after treatment to check the levels of your white and red blood cells and platelets. When your white blood cell count is low, you will 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. 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.

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 could feel anxious as well. If you are worried about your treatment ending, talk to your healthcare team. They are there to help you through this transition period.

Living with cancer

There are many sources of help available for people with leukemia 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: Those 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 give you a ride to your doctor’s office.

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

Yourself: Try to stay positive. Staying positive is about figuring out how to deal with cancer in the best way that you can – and everyone will do this their own way. It doesn’t mean that you must seem happy or cheerful all the time or avoid talking or thinking about the difficulties of having leukemia. But it can mean looking after yourself by finding relaxing, enjoyable activities that refresh you mentally, spiritually or physically.

The Canadian Cancer Society *Helping you understand cancer*

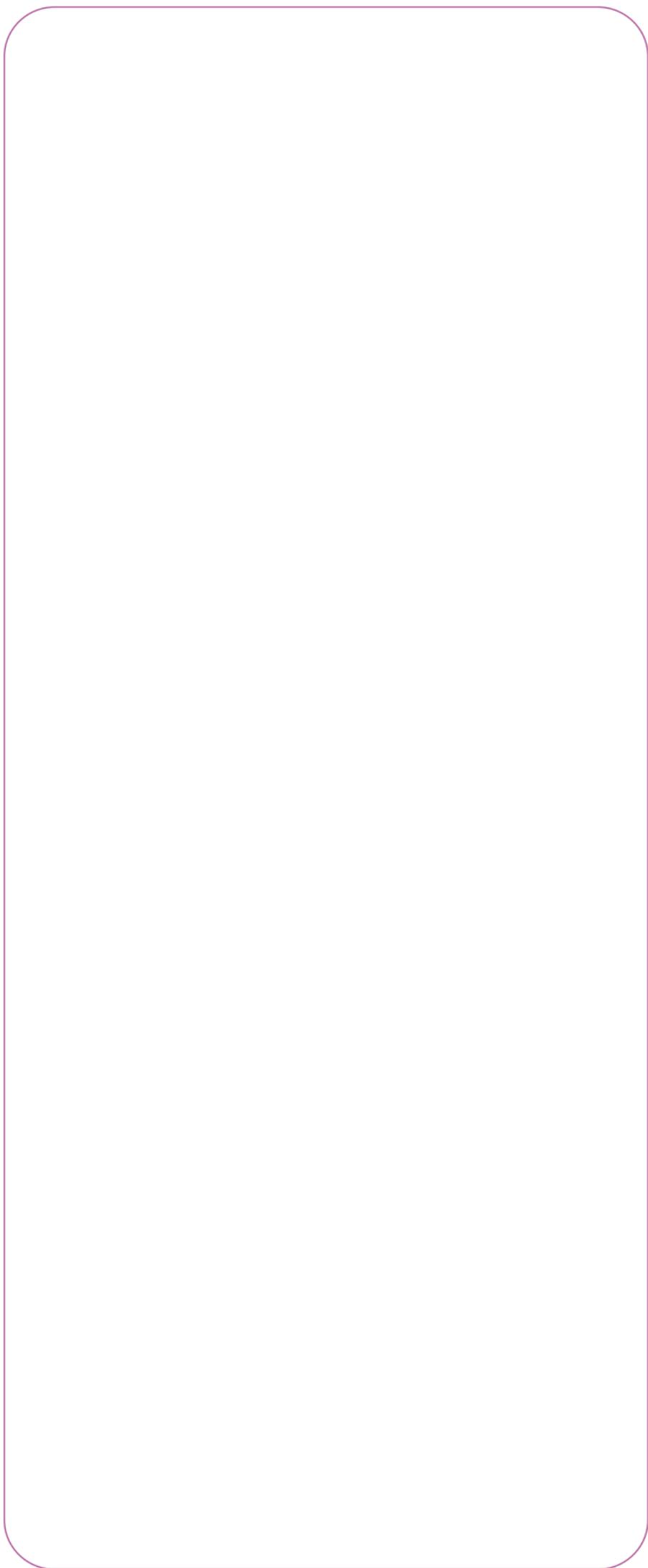
Now that you have been introduced to the basics of leukemia, you may want to learn more. Please contact the Canadian Cancer Society for more detailed information on leukemia. Our services are free and confidential.

If you would like to talk to someone who has had a similar cancer experience, we can help you connect with a trained volunteer – in person, over the phone or in a group setting.

To contact the Canadian Cancer Society:

- Call an information specialist toll-free at **1 888 939-3333** Monday to Friday 9 a.m. to 6 p.m.
- E-mail us at **info@cis.cancer.ca**.
- Visit our website at **www.cancer.ca**.
- Contact your local Canadian Cancer Society office.





What we do

Thanks to the work of our volunteers and staff, and the generosity of our donors, the Canadian Cancer Society is leading the way in the fight against cancer. The Canadian Cancer Society:

- funds excellent research for all types of cancer
- advocates for healthy public policy
- promotes healthy lifestyles to help reduce cancer risk
- provides information about cancer
- supports people living with cancer

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



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