



Understanding chronic lymphocytic leukemia (CLL)

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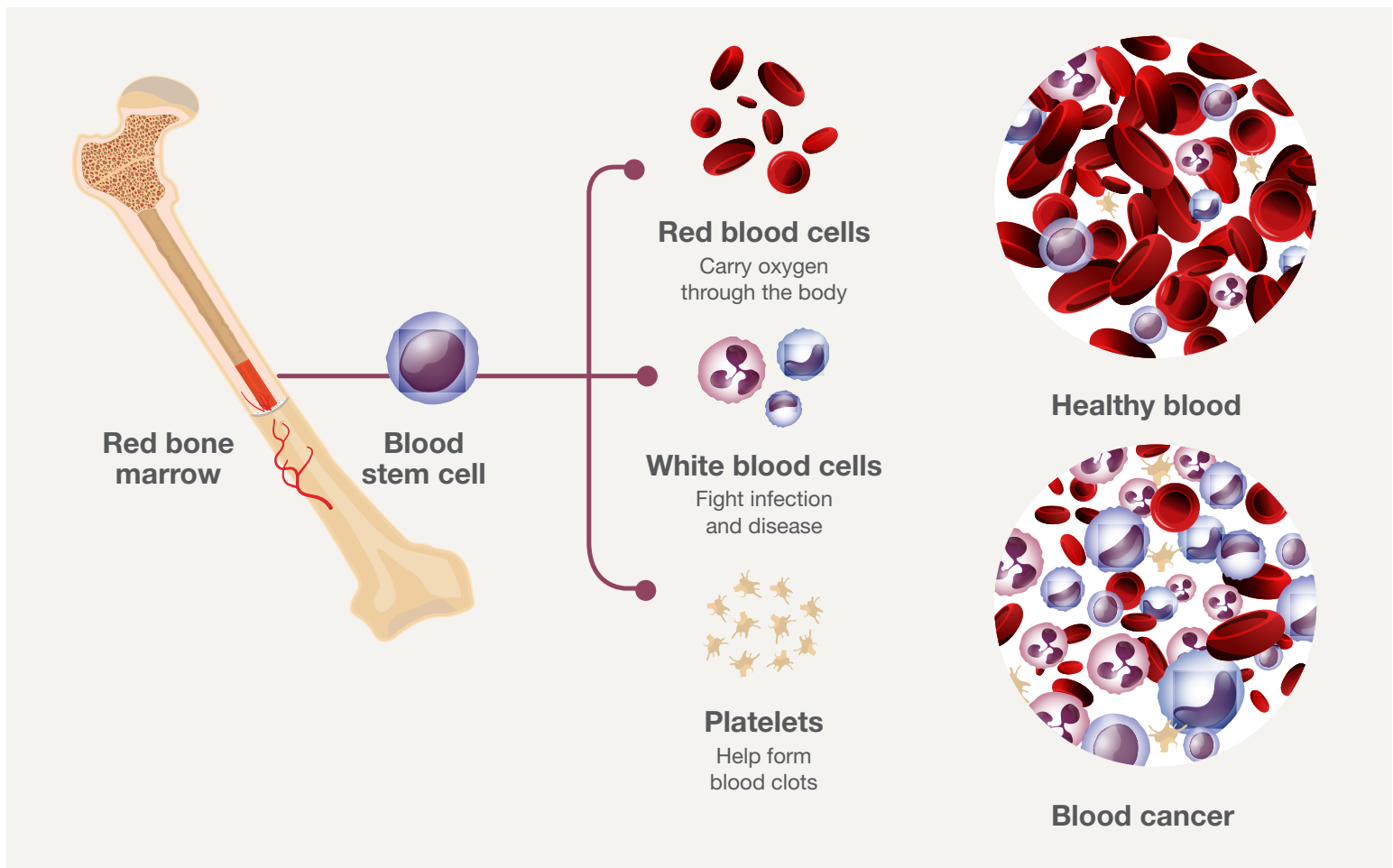
Understanding your diagnosis of CLL

This guide will help you and your loved ones understand your diagnosis of CLL. In order to manage your diagnosis, basic information will be covered regarding treatment options and lifestyle modifications. The topics in this booklet will assist you in asking the right questions so that you can have an informed conversation with your healthcare providers and counsellors.

This resource does not take the place of discussions with your physician and healthcare team. After reading this booklet, you should ask any questions that you may have to a member of your healthcare team.

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Bone marrow and blood cell formation



Understanding CLL

What is leukemia?

Bone marrow is the spongy tissue inside some of the bones in the body, including the hip and thigh bones. The bone marrow produces different types of cells: white blood cells, red blood cells and platelets. Normally, the bone marrow produces these cells by making blood stem cells (immature cells) which become mature blood cells over time.

Cancers are diseases of the cells where some of the body's cells begin to divide without stopping and spread into surrounding tissues. Leukemia is a cancer that starts in the blood stem cells, which affects the number of mature red blood cells, white blood cells (lymphocytes) and platelets in your blood.

In CLL, too many blood stem cells are produced and do not become healthy white blood cells. The immature lymphocytes are also called leukemia cells. These lymphocytes are not able to fight infection very well. Also, as the number of lymphocytes increases in the blood and bone marrow, there is less room for healthy lymphocytes, red blood cells and platelets. This may cause infection, anemia, abnormal bleeding, weakness and shortness of breath.

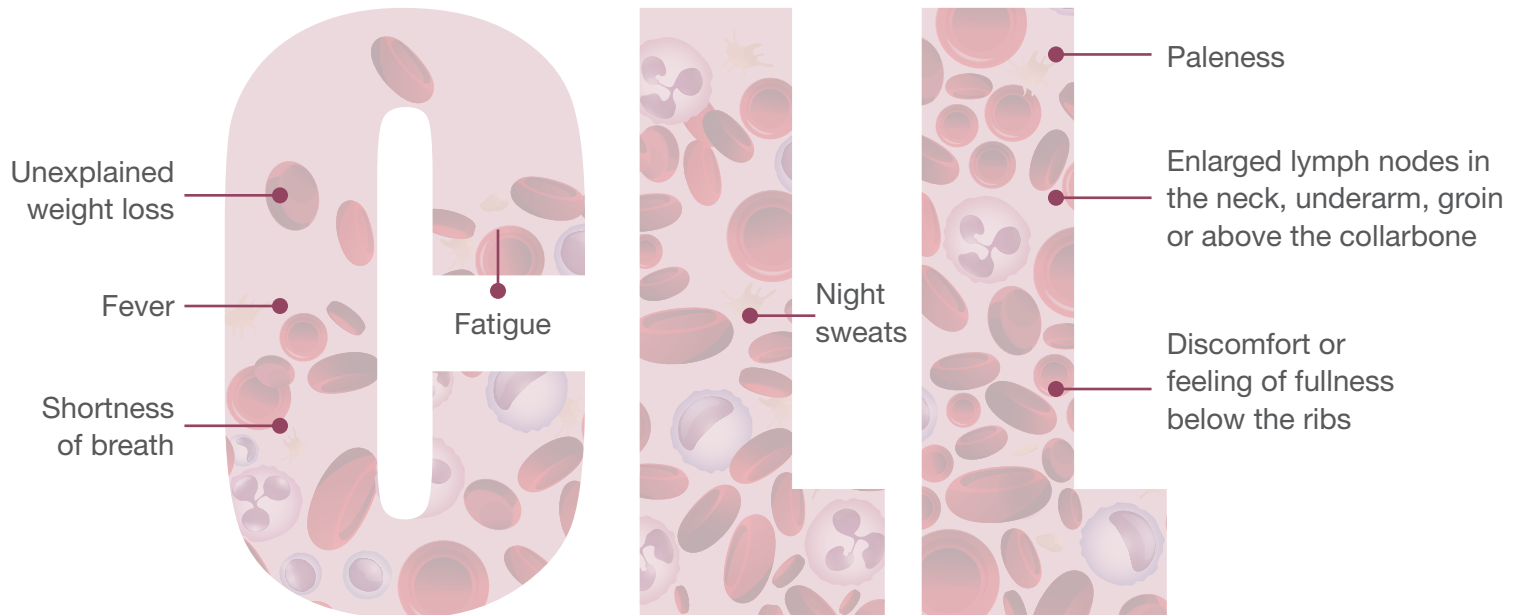
Signs and symptoms of CLL

What are the common signs and symptoms of CLL?

CLL usually does not cause any noticeable signs or symptoms other than swollen lymph nodes and fatigue. Other health conditions can cause the same symptoms as leukemia.

However, CLL leads to an abnormal number of white blood cells circulating in the body. This is often detected after a routine examination through blood tests. The high number of white blood cells leads doctors to consider the possibility of CLL.

The following symptoms are commonly typical of CLL:



What are the causes and risk factors for CLL?

Doctors are not certain what causes CLL. It is believed that something happens to cause a genetic mutation in the DNA of blood-producing cells. This mutation causes the blood cells to produce abnormal, ineffective lymphocytes.

Factors that may increase the risk of CLL include:

- Age – The risk of CLL increases as you get older. About 9 out of 10 people with CLL are over age 50 and on average, are in their 70s.
- Family history – A family history of CLL or other blood and bone marrow cancers may increase your risk.
- Gender – CLL occurs more often in men than in women.
- Race/ethnicity – CLL is less common in people of Asian descent.

Questions to ask your healthcare provider about CLL

- What is the status of my CLL?
- How does the disease progress?
- How long does it take for the disease to progress?
- What is the outlook (prognosis) for my CLL?



How does your doctor know that you have CLL?

Blood tests

Some or all of the following blood sample tests may be performed or requested by your doctor. Your medical team will decide which tests are needed.

Your doctor will perform a routine blood test to determine the number of lymphocytes in your blood. People with CLL usually have more than 10,000 lymphocytes/mm³ (per cubic millimeter) of blood, which strongly suggests CLL. You might also have low levels of red blood cells and platelets. Other tests are required for confirmation.

Your blood will be examined with a microscope by a pathologist who will count each different kind of blood cell to determine if you have CLL.

Flow cytometry

Flow cytometry is an important test for CLL and uses a machine that looks for specific substances (markers) on or in the lymphocytes.

Other blood tests

You need a certain amount of antibodies to fight infections. Because the lymphocytes that produce antibodies do not function properly in CLL, it is necessary to determine the level of antibodies in your blood.

Tests to confirm that you have CLL



Bone marrow tests

The blood tests described above are often enough to diagnose CLL. Testing the bone marrow can help determine how advanced it is. Therefore, bone marrow tests are often performed before starting treatment and may be repeated during and after treatment to determine whether your treatment is working.

Bone marrow aspiration and biopsy are done to get bone marrow samples for testing. These samples are usually collected at the same time from the hip bone.

Bone marrow aspiration is performed with local anaesthesia, so you will remain awake, but your hip bone and the surrounding region will be “frozen” with an anaesthetic given by injection. This may cause brief stinging or burning. A hollow needle is then put into the bone to remove a small amount of liquid bone marrow by suction.

A bone marrow biopsy is usually done immediately after the aspiration. A very small piece (core) of bone and marrow is sampled. This can cause a feeling of pressure or tugging, but it usually doesn’t hurt.



Microscopic examination of biopsy samples

A cancer specialist will look at the bone marrow sample with a microscope. They will look at the size, shape and other features of the lymphocytes in the samples to determine whether they appear mature or immature. The presence of mature lymphocytes indicates CLL.



Immunoglobulin test

Immunoglobulins, or “antibodies”, are proteins in the blood that fight infection. Antibodies are produced by lymphocytes, but people with CLL often have low levels of antibodies, which increases the risk of infection.



Genetic tests

The genetic composition of chromosomes in CLL patients may be altered because part of a chromosome is missing. The arrangement, size, shape and number of your chromosomes must be evaluated.

Types of treatment

Watchful waiting

Watchful waiting, also called active surveillance, involves carefully watching for signs that the CLL is progressing. This may be an option if there is evidence of CLL without showing symptoms. Treatment is started if the disease progresses.

Chemotherapy

Chemotherapy is the main treatment for intermediate or high-risk CLL, as well as for CLL that comes back after an initial response to treatment (relapsed CLL) and CLL that has not responded to any treatments attempted (refractory CLL). Chemotherapy is used to control and improve low red blood cell and platelet count and to shrink lymph nodes and the spleen, which become swollen by the high number of lymphocytes in them.

Targeted therapy

Targeted therapy drugs may be used in combination with chemotherapy. Targeted therapy may be given for intermediate- or high-risk CLL or when CLL has relapsed or is not responding to chemotherapy.

Surgery

Sometimes surgery is used to remove the spleen. This may be done if the spleen is enlarged and painful, or if chemotherapy or radiation therapy does not shrink the spleen. Removing the spleen may also help to improve blood cell counts.

Radiation therapy

Radiation therapy, as part of the treatment plan, is used in several ways. This treatment is used to shrink an enlarged spleen if chemotherapy does not work, to reduce pain caused by the growth of leukemia cells in the bone marrow or to shrink enlarged lymph nodes in one area of the body.

Supportive therapy

- Antibiotics, antivirals or antifungals to prevent or fight infections

- Intravenous infusion of immunoglobulins (IVIg) to prevent recurrent infections

- Transfusion of blood products to replace blood cells when counts are low

Supportive therapy is given to treat the complications caused by treatments for CLL and by the disease itself. Supportive therapy may include:

- Growth factors, that stimulate the body to make white blood cells

- Drugs to bring down high levels of some chemicals in the blood that increase when many cancer cells die at the beginning of treatment (tumour lysis syndrome)

- Laboratory procedures to remove large numbers of lymphocytes from the blood (leukapheresis)

Some examples of questions to ask your healthcare provider about treatment options

- What is the status of my disease?
- What are my treatment options?
- Why are you recommending this option?
- What are the possible risks and benefits?
- What side effects may I have?
- Will I need to stay in the hospital?
- How will we know if the treatment is working?
- How will this affect my day-to-day life?

Treatment considerations

Treatment options and recommendations depend on several factors, such as the type and severity of your leukemia, possible side effects, your preferences, age and overall health. The goal of treatment is to reduce symptoms and to produce a long-term remission. However, because CLL often develops slowly, many people may not need treatment right away, and some may never need treatment at all.

Side effects of treatment

Side effects can happen with any type of treatment for CLL, but everyone's experience is different. Some people have many side effects, while other people have few or none at all.

Follow-up care

Follow-up care after treatment is an important part of cancer care. Follow-up for CLL is often provided by the cancer specialists (oncologists or hematologists) and your family doctor. Your healthcare team will work with you to determine your specific needs for follow-up care.

Schedule for follow-up visits

Follow-up visits for CLL are usually scheduled for many years after treatment even if there are no signs of the disease. The appointments will become less frequent, but you will need to see your doctor regularly for a long period of time.

Some examples of questions to ask your healthcare provider about side effects

- What are the possible side effects of my treatment?
- Can side effects be prevented or managed?
- When should I call you if I am having side effects?
- Whom can I contact if I can't reach you?



Be involved in your treatment plan

When it comes to your health, your role is important. Remember to be involved in your course of treatment.

Your healthcare team

After your diagnosis of CLL, you will meet with your healthcare team. Your team will include a number of healthcare professionals who will help you along the course of your treatment. Your team may include an oncologist, hematologist, pharmacist, nurse, social worker and a dietitian. Each member of the team will work to provide you with resources and support during your treatment. You will also receive supportive care coordinated by the members of your healthcare team.

Therapy programs

Complementary therapy programs are offered at many cancer centers and local hospitals, which have yoga, acupuncture and meditation programs.

Accepting help

You may be hesitant to accept help, but your family members and close friends really want to support you and provide assistance. You can remind them of the following:

- They should act as usual when they are with you.
- They should listen to your complaints without immediately proposing a solution.
- They must not forget that you are still the person that they have always known.

You can also provide a more specific answer by listing your immediate and future needs, which might include the following:

- Taking care of your children or pets
- Grocery shopping or preparing meals
- Transporting you to and from your medical appointments

When a family member becomes ill, the usual roles and responsibilities of each member of the family can change.

- You may need your children to become more involved in taking care of daily chores.
- Your partner may have to manage the bills, run errands and do more of the tasks to maintain your home and property.
- Your partner may feel the need to find employment.



Be aware of your feelings

Since you learned about your diagnosis, you may have experienced a variety of emotions. However, it is important to remember that if these feelings disrupt your daily routine, it may be helpful to seek professional advice.

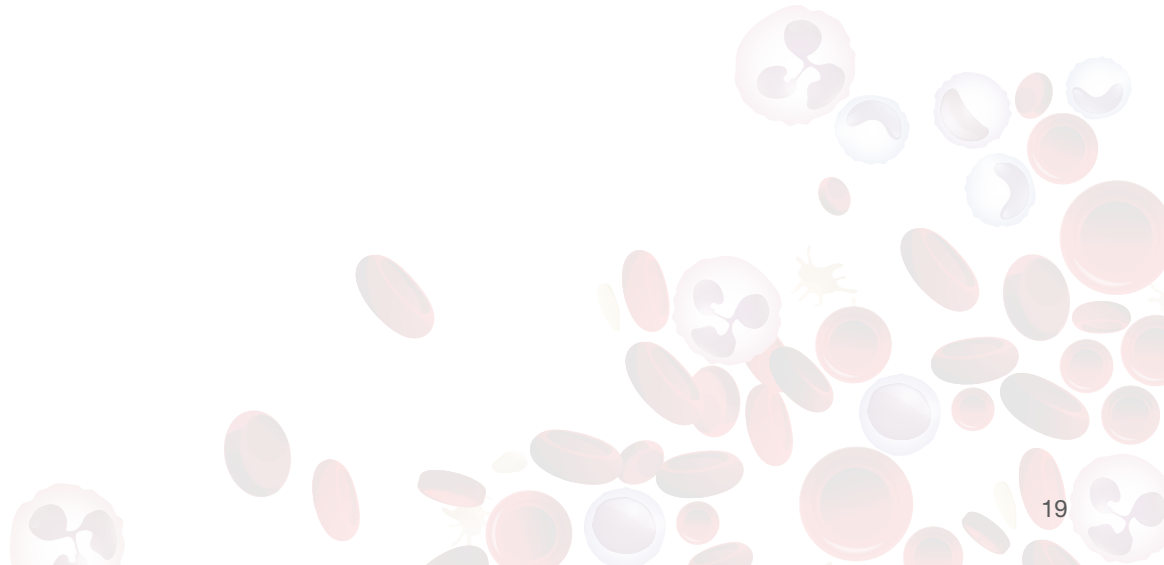
Speak to your healthcare professional about how you are feeling.

Share your feelings

Talking about your feelings can help you to accept them. Start by confiding in a close friend or family member. If this is not possible, you can seek help from professionals who know how to help you deal with the situation.

Join a support group

Although you may sometimes feel alone, remember that there are many others who are experiencing the same difficulties. Join a support group. This could be a very valuable experience which might teach you how to manage your feelings. Some groups meet in person and others exchange information via the Internet. Some people speak openly and others prefer to listen. You will not be forced to do anything that makes you feel uncomfortable. Your healthcare team will certainly be able to guide you to a support group close to you.



Managing your finances

Take time off from work

Depending which treatment you will receive, you may have to take some time away from work. To determine how much sick leave you should ask for, meet with someone in your employer's human resources department or someone from your insurance company.

Ask for help managing your finances

During the different stages of your treatment, you may not have enough time or energy to manage your finances. Think of asking a family member or a close friend to take care of your bills, insurance forms and other financial aspects to help you keep things organized. Knowing that your finances are being taken care of will eliminate one preoccupation during this difficult time.

How to support someone living with CLL

Here are a few things you can do to help take care of a loved one living with CLL:

- Listen. One of the most valuable things you can do as a caregiver is listen to your loved one's needs and concerns.
- Stay organized. Helping your loved one schedule their doctor's visits and preparing a list of questions to ask during the appointment can all be useful ways of staying organized throughout this treatment journey.
- Help them with their daily needs. Whether that be preparing meals or running errands, taking on these simple tasks can provide great relief to your loved one.
- Educate yourself. Learning more about CLL and the treatment options available may help you and your loved one understand the information available and clarify what you can do to help.

Take care of yourself

- Give yourself time to understand and work through your emotions. It may be helpful to share your feelings with other loved ones, join a support group, or speak with a mental health professional.
- Make time for yourself. Find nice things to do for yourself each day; even just a few minutes can help.
- Seek help from others. Reach out to your support group and find things they can do or arrange for you, such as appointments or errands.
- Find a quiet time for reflection each day. Remember the things you need to maintain a healthy mind, body, and spirit.

Notes

To assist you in keeping your healthcare team information in one place, write in their contact information in the area provided below.

Use this page to write down the name and contact numbers of the members of your healthcare team.

Name _____
Title _____
Phone _____
Address _____

Email _____

Name _____
Title _____
Phone _____
Address _____

Email _____

Name _____
Title _____
Phone _____
Address _____

Email _____

Other important numbers

Nurse _____
Religious or spiritual advisor _____
Pharmacy _____
Hospital _____
Emergency contact _____

Glossary

Anemia: A symptom characterized by a low number of red blood cells in the blood and may cause paleness.

Biopsy: The removal of cells or tissues for examination by a pathologist, a doctor specialised in the analysis of blood, body fluids and tissues. The pathologist can examine the samples with a microscope or perform tests on them. There are many types of biopsy procedures.

Chromosome: The structure within cells that contain coded instructions for cell behavior (genes).

Chronic lymphocytic leukemia (CLL): Leukemia in which immature blood stem cells, the blast cells (myeloblast and lymphoblast) are overproduced and don't develop normally.

Clinical trial: A type of research that assesses health tests or treatments.

Complete blood count (CBC): Test used to determine the number of red blood cells, white blood cells and platelets in a blood sample.

Cytogenetics: Study of the chromosomes using a microscope.

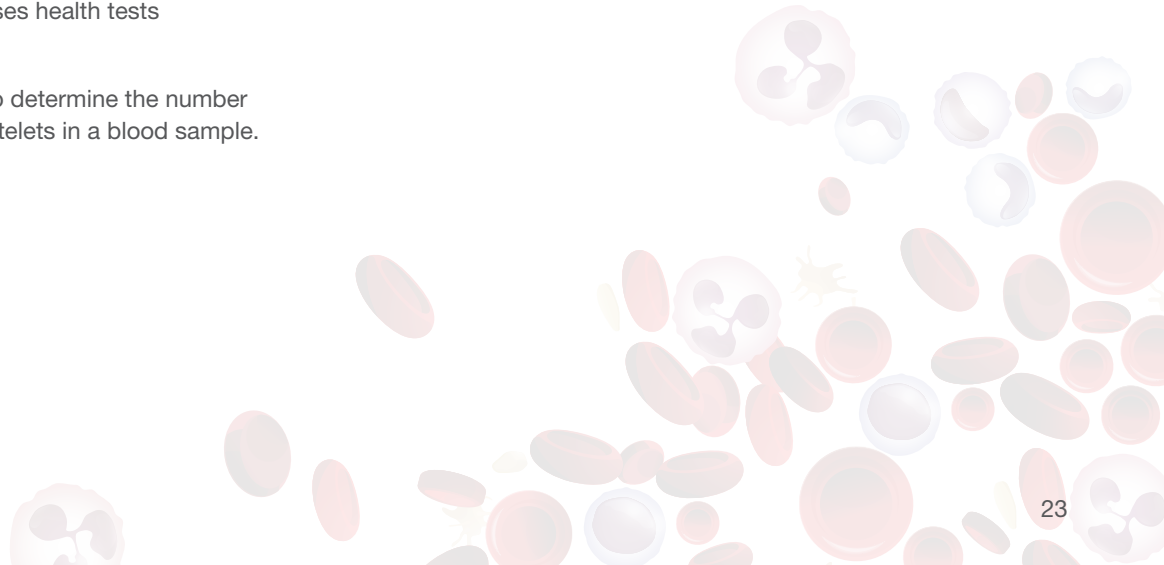
Deoxyribonucleic acid (DNA): A chain of chemicals in cells that contains coded instructions for making and controlling cells. Also called the "blueprint of life".

Hematologist: A doctor who has special training in diagnosing and treating blood disorders.

Oncologist: A doctor who has special training in diagnosing and treating cancer. Some oncologists specialize in a particular type of cancer treatment.

Platelets: A type of blood cell that helps control bleeding.

Stem cell: A cell from which blood cells and other cells develop.





Resources

National Comprehensive Cancer Network

A not-for-profit alliance of 28 leading cancer centers devoted to patient care, research, and education.

National Comprehensive Cancer Network

<http://NCCN.org/patients>

Health Canada's Clinical Trials Database

Health Canada's database about clinical trials provides Canadians with a list of precise information about ongoing clinical trials.

Health Canada's Clinical Trials Database

<https://www.canada.ca/en/health-canada/services/drugs-health-products/drug-products/health-canada-clinical-trials-database.html>

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