

Acute Leukemia

Information for patients and families



"Riding the Dragon" A Cancer Journey | by Conrad Furey

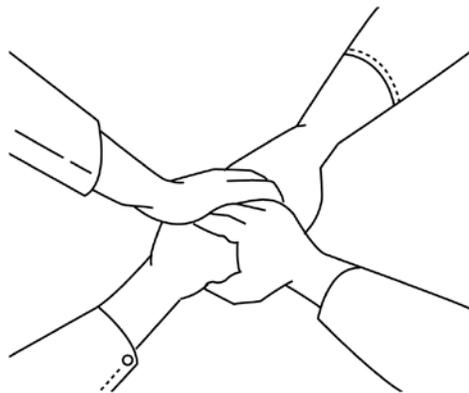
Acute leukemia

Information for patients and families

As members of your health care team, we understand what a difficult time this is for you and your family. Our patients and families often have many questions related to leukemia and its treatment. This book answers some common questions you may have about:

- leukemia and how it can be treated
- how to care for yourself during treatment
- what side effects to watch for and how to get help

During your care, your health care team works very closely with you and your family. Along the way, we are here to support you and provide more information as you want it. Please stay in touch with us during your treatment. We encourage you to ask questions and ask us to clarify information that you do not understand.



**The Hematology Team working together
with patients and families.**

Juravinski Hospital and Cancer Centre

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What is leukemia?

Leukemia is cancer of the white blood cells. There are different types of leukemia. Leukemia begins in the bone marrow, the soft centre of bones where these cells are made. Acute Leukemia means that the disease progresses quickly without treatment. In this book when we refer to leukemia, we are discussing Acute Leukemia.

The bone marrow makes different types of blood cells:

- white blood cells or leukocytes help the body fight germs, and prevent infections and disease – they are part of your immune system
- red blood cells contain hemoglobin, which carries oxygen to every part of the body
- platelets help blood form clots to prevent or stop bleeding

With leukemia, the body is making too many white blood cells. However, they are not fully formed and are not able to do the work of mature white blood cells. The abnormal white blood cells build up in the bone marrow and spill over into the bloodstream. This is not normal.

The abnormal white blood cells crowd out all the normal cells. As a result, sometimes the blood does not contain enough healthy red blood cells and platelets. Fewer normal cells can lead to serious health problems.

The most common kinds of acute leukemia are:

Acute Myelogenous Leukemia or AML

- **AML** is more common in adults. One third of these adults are over 60 years of age.
- **AML** is a cancer of the white blood cells. The bone marrow makes white blood cells. In AML, the myeloid cells become stuck at an immature stage and cannot grow into normal healthy white cells. It can also affect the production of other blood cells such as platelets and red blood cells.

Acute Lymphocytic Leukemia or ALL

- **ALL** is the most common type of leukemia in children. It can also affect older adults.
- **ALL** is a cancer of the white blood cell. The bone marrow makes white blood cells. In ALL, the lymphoid cells become stuck at an immature stage and cannot grow into normal healthy lymphoid cells which make antibodies to help the body fight infection. In ALL, the cancerous lymphoid cells keep multiplying and can also affect the production of other blood cells such as platelets and red blood cells.



If you have questions about the type of leukemia you have, please talk with a member of your health care team.

What causes leukemia?

The exact cause of leukemia is not known.

We do know that:

- Leukemia is not infectious. You can't "catch" it from another person.
- Leukemia is not usually inherited. In most cases, it was not passed on from your parents.
- Leukemia is not caused by something you ate, drank, smoked or did. There is no way you could have prevented getting leukemia.

Certain things are associated with a higher chance of getting leukemia.

These are called risk factors. Risk factors for leukemia include:

- exposure to high doses of radiation
- a long exposure to certain chemicals, such as benzene in the workplace
- certain genetic conditions such as Down's Syndrome
- previous treatment with chemotherapy or radiation for other cancers

However, very few people who get acute leukemia have these risk factors. In most cases, the cause is totally unknown.

What are the symptoms of leukemia?

With leukemia, fast-growing abnormal white blood cells crowd out the red blood cells and platelets in your blood. When there are not enough healthy blood cells, the symptoms of leukemia develop.

Symptoms of leukemia include:

- shortness of breath
- fast heart beat
- feeling tired
- looking pale
- weight loss
- generally feeling unwell
- night sweats
- fever
- infections
- easy bruising
- bleeding from the gums or nose
- blood in bowel movements
- bone pain

If abnormal white blood cells show up in other parts of your body, you may develop other symptoms, such as:

- sore and swollen gums, sores in your mouth
- discomfort or fullness in your abdomen
- swollen glands called lymph nodes
- headaches or blurred vision
- swollen testicles
- skin changes, but this is rare

However, many people have no symptoms or their symptoms are mild. Leukemia is sometimes found “by accident” when a blood test is done for some other reason.

How does the doctor know I have leukemia?

Some of the symptoms of leukemia are general or vague, like getting a cold or the flu. When you visited the doctor, he or she examined you and did some blood tests. The results showed that you might have leukemia. To confirm that it is leukemia, your doctor referred you to a specialist called a Hematologist for more specific tests.

Blood tests

With leukemia, the blood tests may show:

- abnormal white blood cells – there may be too few or too many
- fewer red blood cells than expected (low hemoglobin)
- fewer platelets than expected

Bone marrow test

Blood cells are made in the bone marrow. This is where the abnormal white blood cells first appear. Sometimes these “leukemic” or “blast” cells are only seen in the bone marrow, as they have not yet entered the bloodstream. To test the bone marrow, a sample is usually taken from the hipbone because this bone is so close to the skin.

Here’s how this test is done:

- the skin is cleansed
- the skin over the hipbone is numbed with a local anesthetic
- a sample of the liquid bone marrow and chip of bone are removed with a needle
- the samples are examined under a microscope

Lumbar puncture or spinal tap

Leukemic cells may also be found in spinal fluid. This clear fluid surrounds and cushions the brain and spinal cord. Leukemic cells can be found with ALL, rarely with AML. To test a sample of spinal fluid, patients with ALL may have a lumbar puncture, which is also called a spinal tap.

Here's how this test is done:

- a nurse will help you get into a position with your back curled, you will have to stay very still during the procedure
- the skin is cleansed
- the skin over the lower part of your backbone is numbed with a local anesthetic
- a sample of the spinal fluid is removed with a needle
- the fluid is examined under a microscope

After the test, you need to lie in bed for about 30 to 60 minutes. Your doctor or nurse practitioner will explain common side effects from the procedure such as a headache.

When the diagnosis is made

The Hematologist reviews the results of all the tests to confirm that you have leukemia. The doctor or nurse practitioner will tell you the diagnosis.

Hearing that you have cancer can be shocking. You may have trouble remembering the information. You may feel many emotions, such as fear, sadness or anger. All these feelings are normal. It will help to have support from your family, friends and health care providers at this time. You may have little time to recover from these feelings before treatment has to start, but you will feel better in time.

During your care, the health care team will continue to explain the disease and answer your questions.

How is acute leukemia treated?

The treatment for leukemia is not the same for everyone. Treatment is designed for each person. Most people start treatment in the hospital.

Your treatment will be based on:

- the type of leukemia you have
- your general physical health and other medical problems you might have
- the results of all your tests and examinations

The Hematologist will talk with you about the plans for your treatment.

The benefits and risks of treatment, and any alternatives will also be discussed with you.

There is a lot of information to understand and think about. Please ask any member of your health care team to explain and clarify things that you do not understand.

Treatment involves:

- chemotherapy – using medications to kill the cancer cells
- supportive care – using different methods to keep your body and mind as healthy as possible during treatment
- radiation – some types of leukemia may need radiation

Transplant

The Hematologist may discuss the option of a transplant after chemotherapy. This is a transfusion of healthy blood stem cells or bone marrow cells from a matched donor. Peripheral blood stem cells come from the bone marrow and are capable of forming all types of healthy blood cells. If this is an option for you, you will be provided with information and opportunities for discussion.

We encourage you to learn as much as possible about your treatment. Knowing what to expect can help you feel less anxious and better prepared.

Can leukemia be cured?

The goal of treatment is to bring about remission. Remission means that there are no more signs of cancer in the blood or bone marrow, and the blood cell counts are normal. About 3 out of 4 (75%) people with leukemia will reach remission. How long remission lasts can vary. It is possible for the leukemia to become active again. This is called relapse.

Please ask the Hematologist or Nurse Practitioner all your questions about your recovery from leukemia. These questions can be hard to answer. Whether you can reach remission will depend on many things, such as the type of leukemia and how well you respond to treatment. The doctor cannot predict exactly what will happen, but will answer your questions as best as possible.

Who will provide my treatment?

A team of health care providers will work together to plan and carry out your cancer treatment. Each person on the team has special knowledge and skills that contribute to your care.

The health care providers on your Hematology Team:

- Hematologist
- Nurses
- Pharmacist
- Physiotherapist
- Nurse Practitioner
- Dietitian
- Social Worker
- And many others

You and your family are important members of the health care team. We need your help to understand how the cancer and treatment are affecting you and your family.

What is chemotherapy?

Chemotherapy is one type of cancer treatment. It uses medications to kill cancer cells. (Chemotherapy is given intermittently (on and off) over a few months for AML and for 2 to 3 years for ALL).

Induction therapy

This is the first stage of chemotherapy. You will spend most of this time in the hospital. You will be given powerful chemotherapy medications to kill the leukemic cells and bring about remission. Because these medications are so strong, they can damage some of your normal cells. The normal cells are usually able to grow and recover after chemotherapy is finished. It can take about 4 weeks to recover from induction therapy.

After induction therapy, it looks like the blood cells are in remission, but some leukemic cells remain. Treatment has to continue or the leukemia will come back.

Consolidation therapy

Consolidation therapy begins after full recovery from induction therapy. Consolidation therapy kills any remaining leukemic cells with similar medications to those used in induction therapy. In general, recovery from consolidation therapy takes less time than for induction therapy. You may not need to stay in hospital during this phase of treatment.

Acute Lymphocytic Leukemia or ALL

If you have **ALL**, you will need radiation therapy and then more maintenance chemotherapy. It is less intensive than consolidation chemotherapy and does not usually require a hospital stay. Maintenance therapy may be given for a long time, up to 2 or 3 years.

What medications are used for chemotherapy?

Many kinds of medication can be used to treat leukemia. You may be given one medication or a combination of medications. Some medications work better together than alone.

Chemotherapy medications are:

- prescribed by your Hematologist or Nurse Practitioner
- prepared by Pharmacy Technicians
- given to you by Registered Nurses

Each team member can help you learn:

- how the medication works
- how and when the medication will be given
- the possible side effects
- how to prevent or manage side effects

Your chemotherapy is designed just for you. Your chemotherapy medications may be different from those given to other patients, even if they have the same type of leukemia.

Take only the medications ordered by your doctor or nurse practitioner. Check with them before taking any:

- medications you can buy at the drugstore without a prescription
- herbal supplements or remedies
- vitamins or mineral supplements

How will I get chemotherapy?

Chemotherapy medications may be given:

- by mouth – swallowing a pill, tablet or capsule (oral medication)
- through a vein (intravenous or central venous catheter)
- directly into the spinal fluid (intrathecal method)

Intravenous (IV) medications are given directly into the bloodstream through a vein, usually in your hand or arm. After the medication is given, the IV may be taken out.

Most people need a PICC - **P**eripherally **I**nserted **C**entral **C**atheter. This is a soft, thin, flexible tube that is put into a large vein in your arm. The catheter can also be used to take samples of blood and give you fluids, without giving you more needles. This catheter can stay in place for many months. When it is not being used, the catheter is capped, allowing you to move about freely. We may teach you how to care for the catheter before you go home.

To treat ALL, chemotherapy is often given directly into the spinal fluid during a lumbar puncture, as well as through a vein. This is called the intrathecal method. It is necessary because oral and intravenous chemotherapy do not work against leukemia in the spinal fluid.

The time required to give chemotherapy varies. Some medications can be prepared and given quickly, in less than an hour. Others take several hours to prepare and deliver. Your treatment may take a little longer if you are in a clinical trial (research study). Research usually requires some additional procedures and safety checks.

What side effects are possible from treatment?

Chemotherapy medications destroy cancer cells that are growing and multiplying quickly. Certain healthy cells that are fast-growing are also affected by chemotherapy. This harm to healthy cells is what causes side effects.

The healthy cells most commonly affected are in these areas:

- hair and nails
- the lining of the mouth, throat, esophagus, stomach and bowels
- sperm cells in men or egg cells in women
- bone marrow cells (white blood cells, red blood cells, platelets)

People react differently to chemotherapy medications. Some people have few side effects; others have many.

Common side effects from treatment include:

- fatigue
- hair loss
- sore mouth and gums (called mucositis)
- nausea and vomiting
- loss of appetite
- changes in taste
- diarrhea
- constipation
- discomfort or pain
- sexual changes
- infection from not having enough normal white blood cells
- bleeding from a low platelet count
- anemia from a low red blood cell count

How can I manage side effects?

You and your health care team will work together to prevent or lessen side effects. Here are some suggestions to deal with common side effects.

Managing fatigue

Fatigue means that you are very tired and have little energy. This is the most common side effect.

There are many reasons for fatigue, such as:

- a low red blood cell count
- physical stress from leukemia and its treatment
- trouble sleeping because you are worried or uncomfortable
- not eating or drinking as usual

To conserve your energy and help with fatigue:

- Rest for 20 to 30 minutes when you feel tired.
- Rest between activities so that you don't get overtired.
- Go to bed earlier.
- Ask for help with child care, housework or other tasks.
- Try to resolve any financial or work problems.

Try to keep your life as normal as possible. Continue to see your family and friends. Keep doing the activities you enjoy. Physical activity can help prevent fatigue.

If your red blood cell count is too low, you become anemic. As well as feeling tired, anemia can make you weak, pale, short of breath and make your heart beat faster. You may need to have a blood transfusion.

Coping with hair loss

You may lose some or all of your hair – on your head and body.

This usually happens within 2 or 3 weeks after chemotherapy begins.

People react differently to this loss. Some people choose to cut or shave off their hair when it begins to fall out; others wait. Some people like to wear a wig, cap or scarf on their head; others prefer not to cover their head. You can choose what is best for you.

Take care of your scalp by:

- using a mild shampoo such as baby shampoo
- using a soft brush
- not using curling irons, hot curlers or blow dryers
- not colouring or perming your hair
- covering your scalp or using a sunscreen if you are in the sun

Hair loss is usually temporary. Your hair should grow back when your chemotherapy treatments are finished.

Caring for your mouth

You will be taught how to do your mouth care. It is best to start mouth care before problems develop. Be very gentle as there is a chance of bleeding if your platelet count is low.

Suggestions for mouth care:

- Brush your teeth and gums gently with a soft toothbrush or a sponge called a toothette. Brush after meals and at bedtime.
- When your blood counts are low, rinse your mouth 4 times a day with an alcohol-free mouthwash. Do not floss your teeth or use toothpaste.

Suggestion for eating when your mouth is sore:

- Eat soft foods.
- Do not drink or eat foods that can irritate your mouth, such as foods that are:
 - very hot or very cold
 - hard or crunchy
 - salty or spicy
 - acidic, such as tomatoes and citrus fruit
- Avoid alcohol and tobacco products.

Some chemotherapy medications can cause nausea and vomiting. This is not a problem for everyone and anti-nausea medication prescribed by your doctor or nurse practitioner is very effective.

Here are some things you can do to prevent nausea and vomiting:

- Eat a low-fat meal before treatment.
- Limit spicy foods, fried foods and foods with strong smells.
- Take the anti-nausea medication recommended by your nurse or doctor.

Here are some things you can do to help with nausea and vomiting:

- Try reading, watching TV, listening to music or resting. This can help you relax and take your mind off the nausea.
- Drink sips of clear fluids.
- Have several small meals and snacks during the day. Eat slowly.
- Choose foods that settle your stomach, such as cereal or toast.
- Go outside or open a window to get fresh air.
- Take the anti-nausea medication recommended by your nurse or doctor regularly. If the medication is not working, talk with your nurse or doctor. Another medication may work better for you.

If you are not able to eat as usual, it is important to make every bite count. Choose foods and drinks that will give you protein and calories. The dietitian can help you choose foods and drinks that will give you enough nutrition, with as little stomach upset as possible. If you are not able to eat enough regular foods, you may need supplements – drinks that give you extra protein and calories.

Coping with changes in taste

You may notice that foods taste or smell different. If the foods you usually like taste or smell bad, you may lose your appetite.

You may have to experiment to find foods that you enjoy. Try eating bland foods. Avoid foods with strong flavours or smells. If you would like help to choose and prepare foods, talk with the dietitian.

You can expect this side effect to go away when the chemotherapy is stopped.

Controlling diarrhea

Diarrhea is when you have loose or watery bowel movements.

There are many reasons why diarrhea may occur. Diarrhea may be caused by infections, chemotherapy or other medications, as well as a change in your diet. Your team will try to find the cause and fix the problem.

If diarrhea continues, your body loses too much water. This can make you feel tired and sick. Diarrhea can also irritate hemorrhoids, and cause sores or cracks around your rectum. This problem can be serious as you have a greater chance of infection or bleeding.

If you have diarrhea:

- Tell your nurse each time you have a loose bowel movement. A sample may be collected and sent for testing. If an infection is suspected, then you will need to go into contact precautions (isolation) until we know for sure that it is not an infection causing the diarrhea. No medications are given until the results of the stool sample are known.
- Drink plenty of fluids, unless your doctor has told you to limit fluids. Each day try to drink 1.5 to 2 litres (6 to 8 cups) of water or other clear liquids such as broth.

Preventing and treating constipation

Constipation occurs when you have fewer bowel movements than usual or they become dry and hard. You may have to strain or push hard to have a bowel movement. Constipation may be caused by medication, or a change in diet or activity.

Constipation can lead to problems as hemorrhoids, sores or cracks around your rectum. These problems can be serious as you have a greater chance of infection or bleeding.

To keep your bowels moving smoothly:

- Eat foods high in fibre such as whole grain breads and cereals, fruits and vegetables.
- Drink plenty of fluids, unless your doctor has told you to limit fluids. Try to drink 1.5 to 2 litres (6 to 8 cups) of water or other liquids each day.
- Keep active with walking or regular light exercise.
- Take stool softeners or laxatives as recommended by your nurse or doctor.

Relieving discomfort and pain

Each person's experience with leukemia is different. Some people have discomfort or pain; others do not. Leukemia is generally not a painful cancer. If you have discomfort or pain, tell your nurse or doctor. They will help to find the cause and ways to relieve it.

There are many medications that can relieve pain, such as acetaminophen (Tylenol). Your doctor or nurse practitioner will choose one to control your pain as needed. Pain medications work best when you take them regularly.

Tell the nurse or doctor if the medication does not relieve the pain. Another medication may work better for you. You should not take any medication that contains Aspirin or ibuprofen (Advil or Motrin) as these increase the risk of bleeding. Please discuss any pain medication you wish to take with your doctor, pharmacist, or nurse practitioner.

Other comfort measures include:

- taking a warm bath or shower
- relaxation exercises
- using a special mattress or a sheepskin in your bed
- keeping active with walking or light exercise
- using creams or ointments, or sitz baths if you have constipation, diarrhea or hemorrhoid pain. Sitting in warm water is a sitz bath.
- taking a warm bath may help as well. Sometimes, adding epsom salts to the water can be comforting.

Coping with sexual changes

Changes related to sex are usually due to the side effects of treatment. Whether you have sexual side effects depends on the type of treatment, your age and your general health.

As long as there are no serious health concerns, you can continue to be sexually active. There is no risk to your partner of “catching” leukemia.

During treatment, you may feel ill and very tired. Treatment may also affect how you feel about yourself and how you respond to your partner. All of these changes can cause you to lose interest in sex or have trouble reaching orgasm.

Your partner may be concerned that sex will make you tired, or hurt you, as well as feel guilty or selfish about wanting to have sex.

You both may feel sad at the loss of your sexual relationship. It can help to talk honestly about your feelings. You can explore other ways of showing affection and being intimate, such as:

- doing something together that you both like
- holding each other close
- touching and kissing
- having a massage
- sharing your feelings

You can expect your usual sexual drive to gradually return when your treatment is completed.

Changes in fertility

Some chemotherapy medications can damage egg and sperm cells, making you infertile or sterile. This means that you are unable to have a child. Infertility does not affect your ability to have or enjoy sexual intercourse. This change may be temporary or permanent. If you want to have children, talk with your doctor or nurse practitioner before treatment begins.

Men may be able to have their sperm frozen and saved in a sperm bank. This must be done before treatment begins. As testing the sperm takes time, discuss this with your doctor as soon as possible.

Preventing pregnancy

Since not all chemotherapy medications can cause infertility, it may be possible to get pregnant during treatment. Because chemotherapy damages egg and sperm cells, there could be birth defects or harm to an unborn baby. For that reason, it is important to prevent pregnancy.

If you are sexually active during treatment, you should use birth control. Talk with your doctor or nurse practitioner about birth control that is right for you. Your doctor or nurse practitioner will tell you when it is safe to stop using birth control.

**If you have questions about sexuality, birth control or fertility
talk with a member of the health care team.**

Changes affecting women

Chemotherapy can affect your ovaries and the hormones they make. Your periods may become irregular or stop. Due to the risk of bleeding, you may need to take medication to stop your periods.

You may develop symptoms of menopause such as:

- feeling tired
- hot flashes or sweating
- mood changes
- thinning of the bones, called osteoporosis
- vaginal dryness, itching or burning

Vaginal dryness can make sexual activity uncomfortable or painful. Using a water-based lubricant can help. A gynecologist may suggest vaginal creams to build up the lining of the vagina.

The changes to your vagina can also increase your risk of getting an infection.

To prevent vaginal infections:

- use only water-based lubricants, not those with oil (such as petroleum jelly)
- wear cotton underwear and pantyhose with a cotton seat
- do not wear tight underwear, pants or shorts

If you think you have vaginal infection, tell your nurse or doctor so that it can be treated right away.

If you are pregnant when your cancer is discovered, it may be possible to delay chemotherapy until after your baby is born. Healthy children have been born to women with leukemia. However, having a baby while having leukemia is rare and it is not in the mother's nor the child's best interest. In some situations, women need to consider ending the pregnancy. If your fertility returns after chemotherapy, it is possible for you to have a healthy pregnancy and child.

Preventing and treating infections

During and after your treatment, the health care team will closely check the results of your blood tests. A low white blood count means that your blood does not have enough mature white cells to destroy bacteria, viruses or fungi. This is a warning that you may be at risk for an infection.

To prevent infection:

- wash your hands often
- keep your body clean
- get lots of rest
- eat healthy foods
- stay away from crowds and people who may be sick



Infection may occur anywhere in your body. Bacteria like warm, moist areas such as the mouth, nose, throat, lungs, or around the genitals and rectum. With few healthy white blood cells to fight these germs, an infection can become a serious problem.

Signs of infection which include:

- a temperature of 38°C or 100°F or more
- chills/shaking or feeling unwell; with or without a fever
- a cough with coloured phlegm or sputum
- red inflamed skin
- constant diarrhea
- increased shortness of breath
- pain or burning with urination
- sore throat

As instructed by your primary team, if you have any of these signs, call your primary team right away or go to Emergency. **Do not wait.**

If you go to Emergency, tell the staff that you are on chemotherapy. Do not take any type of acetaminophen (Tylenol), aspirin or ibuprofen (Advil). They may hide a fever.

Preventing bleeding

During and after your treatment, the health care team will closely check the results of your blood tests. A low platelet count is a warning that you may be at risk for bleeding. Your doctor will likely recommend a transfusion of platelets.

To prevent bleeding:

- be careful not to cut yourself when using sharp objects
- ask your health care provider before using scissors or nail clippers
- use an electric razor, if needed
- avoid sports and situations where you might injure yourself
- brush your teeth gently with a soft toothbrush or toothette
- talk with your doctor before you visit the dentist
- do not take any medications that contain aspirin or ibuprofen unless your doctor tells you to
- prevent constipation
- you may need to take medication to stop your periods

Learn the signs of bleeding, which are on the next page, so you can get medical help right away if you notice any of the signs.

Signs of bleeding include:

- you bruise easily
- tiny red spots on your skin that may look like a rash
- bleeding from your gums or nose
- coughing or vomiting up blood (black specks that look like coffee grounds)
- heavy menstrual periods
- pink or bloody urine
- bleeding from your rectum
- dark, tarry, black bowel movements
- a severe headache or fainting
- blurred vision

Call your doctor right away if you notice any signs of bleeding.

If your platelet count becomes too low, you may need a transfusion of platelets.

What is supportive care?

Supportive care helps you and your family through the cancer experience. We work together to plan and deliver the supportive care you and your family need.

Supportive care may include:

- healthy eating
- staying active
- relaxation
- getting enough rest and sleep
- coping with emotions and stress
- helping your family and children
- discussing financial concerns

Supportive Care Services at the Juravinski Hospital and Cancer Centre may include:

- Social Work
- Dietitians
- Mental Health Services Chaplaincy
- Aboriginal Patient Care Navigator
- Pain and Symptom Management

Healthy eating

It is important to eat well. Healthy eating can give you energy and keep your body in good condition during treatment and recovery.

Try to eat and drink as normally as possible. However, it can be hard to eat and drink when you feel ill, have little appetite or foods do not taste the same. If you would like help, talk with the dietitian. The dietitian can help you find ways to have a healthy diet.

To get the nutrition your body needs:

- have 5 or 6 small meals each day instead of 3 larger ones, and have snacks between meals and at bedtime
- choose foods and drinks that contain protein and calories to keep up your strength and weight
- have someone bring in your favourite foods

If you are not able to eat or drink enough, you may lose weight, become weak or dehydrated. The dietitian will work with you about increasing calories. You may need to drink nutrition supplements such as Boost, Ensure with added protein powder.

You may also need:

- intravenous fluids
- liquid food given through an intravenous, called Total Parenteral Nutrition or TPN
- food given through a tube directly into your stomach. This tube is called a nasogastric tube.

Staying active

Staying as active as possible keeps up your strength during treatment and helps you recover. Physical activity can also prevent many health problems, including fatigue.

During your hospital stay, we encourage you to be up and moving as much as possible. Continue to take care of yourself, such as walking to the bathroom and having a shower. Sit up for meals and when visiting.

Even if you are not feeling very well, there are gentle exercises or activities you can do.

To keep active when you are in bed:

- change your position often to relieve pressure on your skin
- do deep breathing exercises every 1 or 2 hours to expand your lungs and keep them clear of mucus
- stretch, lift, bend and move your arms and legs during the day to keep your muscles toned and the blood flowing

When you are out of bed, try to keep doing the daily activities you enjoy. You can walk or do other activities such as using an exercise bike.

If you would like help, talk with the physiotherapist.

Relaxation

Relaxation can be very helpful for your body and mind. It can help you cope with unpleasant sensations, nausea or pain.

Relaxation can simply mean sitting quietly, listening to music, reading or doing a hobby that takes your mind off your activities or worries. It can also involve learning exercises that relax your body and mind. Ask a member of your health care team to help you learn these ways to relax.

Learning relaxation exercises, like learning any new skill, takes time and practice. Step-by-step instructions for relaxation exercises usually include:

- setting aside a special time
- choosing a quiet comfortable place
- concentrating on your breathing
- relaxing parts of your body until you are completely relaxed

Relaxation that includes concentration on a pleasant experience or place is called guided imagery. Patients using guided imagery have found that while it does not remove the unpleasant experiences of chemotherapy, it does make it more bearable.

Meditation and yoga are other kinds of mental exercise that some people find helpful.

Getting enough rest and sleep

Rest and sleep are important for your recovery. In the hospital, you may find it harder to sleep because you are worried, uncomfortable or in different surroundings.

Let us know if you are having difficulty sleeping. The nurse can help you find ways to improve your rest and sleep. Your doctor may also suggest a medication to help you sleep.

While we welcome visitors and how important they are to your recovery, please remind them that you need your rest!

Coping with emotions and stress

Dealing with the diagnosis and treatment of cancer can be very stressful. You may have mixed emotions. Your feelings may change from day-to-day, even minute-to-minute.

It is normal to have feelings such as:

- fear of sickness, pain, death or the unknown
- sadness, anxiety, helplessness or anger
- feeling impatient, overwhelmed or out of control
- worries over money or your job

You may also feel hopeful, reflective or strengthened by your family or faith. Some people find this experience is a time for personal growth.

Here are some things that can help:

- Talk about your feelings and concerns with a member of the health care team. We can answer your questions and help you know what to expect.
- Talk about your feelings and concerns with someone you feel close to. Your family members and friends may be feeling the same things. They may not know how to bring it up or what to say.
- Talk with other people who have had a similar experience.
- Bring your personal belongings from home, which may comfort you such as family pictures, books, crafts and your own clothes.
- Help your body and mind with relaxation, eating well and activity.
- Continue to care for your spiritual needs. Hospital chaplains are available to help you.
- Try to keep a positive outlook. Take one day at a time. Focus on what you can do. Surround yourself with positive people.

You may need help to cope with the emotional aspects of cancer and its treatment. As well, you may need practical help with such things as your job, finances or insurance coverage. Your health care providers can help and connect you with the services you need.

Helping your family

The focus of our care is on patients and their families. We know that your family is also affected by your illness. They may have the same feelings and worries that you have. They may be unsure of how to talk to you or what they can do to help. Some of their responsibilities may need to change because you are not able to do what you usually do. **The focus is you!** Your top priority at this time is to regain your health.

Each of your family members will cope in their own way. Family members may cope with the reality of your illness by:

- Putting their lives on hold. They may want to be with you as much as possible.
- Trying to continue their daily lives. They may continue to work because they need the comfort of their usual daily routine.
- Planning time to rest and relax, so they will have more energy to better support you.

The health care team can help by giving your family information and emotional support. The social worker can offer practical help by identifying resources in the community to help your family with such things as:

- caring for children or parents
- financial concerns
- finding transportation and places to stay

Telling your child you have cancer

Having cancer affects all members of a family. Very young children to teens may feel something is different or has changed in their family. You may feel that your child is acting differently.

What you may notice about your child:

- crying more
- trouble sleeping or eating
- problems with school, homework and friends
- more emotional
- more quiet and withdrawn

Suggestions

It may be hard for you to discuss with your child that you have cancer. You know your child best. When you decide to tell your child, choose a time when you both are calm. Try to set some time aside when you are not feeling rushed.

Some common fears that children may have are:

- their parent will die from the cancer
- something they did caused the cancer
- who will take care of them

You may be worried about how to answer questions. Be clear and direct. We encourage you to be honest. You may find that you have to tell your child over and over again that you have cancer. Ask them how they are feeling. Discuss your feelings too.

If you wish, please ask to speak with a social worker.

Children's visits

We know that seeing your children is important to you and to them. Our goal is to keep your family together as much as possible. However, there are times when we must limit children's visits for your safety, or the safety of other patients. For this reason, Hematology (C4) has a policy about children's visits.

Your children may visit if:

- they are healthy at the time of their visit
- their immunizations are up-to-date
- they have not been exposed to a communicable illness such as chicken pox
- another adult comes to the hospital to care for the children during their visit

Your children will not be allowed to visit if there is **any chance** they could spread an infection to others. Many of our patients have low immune systems and are not well enough to tolerate even a common childhood illness.

If you have any questions about the visitor's policy, please talk with your nurse or ask to speak with the clinical manager.

What about complementary and alternative therapies?

You may wish to participate in complementary therapies in addition to our treatment or as part of your lifestyle. Some of these therapies include:

- meditation, hypnosis, yoga, art and music therapy
- acupuncture, therapeutic massage
- aromatherapy, Reiki
- naturopathic, homeopathic and Chinese medicine

Certain complementary therapies have been shown to be effective in relieving stress and symptoms such as nausea or fatigue. They can also add to the sense of well-being and control in your life.

However, not all complementary and alternative therapies have been studied and proven to be safe or effective.

- Herbal remedies and vitamin supplements can interact with your planned medical treatment or may even cause harm.
- Some therapies may be unsafe at certain times. For example, massage therapy is not appropriate when your platelet count is low.
- Even a product that claims to be “natural” may not be safe for you.

Please talk with the members of your health care team before using any complementary or alternative therapies. A health professional such as your Hematologist can discuss:

- the scientific evidence, including the risks and benefits of other therapies
- how to choose a certified practitioner to work with your care team

This will help you make an informed decision that is right for you.

It's important to keep the lines of communication open. Please let us know what you are taking and doing for your health, so that we can make a plan for your care that is as safe and effective as possible.

What follow-up care will I need?

After treatment you will need regular visits with your family doctor (or primary care provider) and your Hematologist. Your doctors will discuss your follow-up plan.

Your health will determine:

- how often you need to visit the doctors
- what tests you need and how often they are needed
- whether you need to visit other health care providers or specialists

You will need regular tests to make sure the leukemia has not returned.

These tests may include:

- blood tests
- physical examinations

Where can I get more information?

Patient and Family Resource Centre.

It is located on the main level of the JCC near the front entrance.

Phone: 905-387-9495, ext. 65109
Email: jccpfrcentre@hhsc.ca
Website: www.jcc.hhsc.ca/

Supportive Care – Juravinski Cancer Centre

905-387-9711, ext. 64315

Wellwood

Wellwood is a community service that provides information and support programs to people with cancer and their families, caregivers and health care providers.

Some of the services include:

- peer support programs/services
- creative expression programs
- information navigation services
- moving and coping programs

Wellwood has two locations, both of which are open to you for free programs. The hospital location is on the first floor (near the west elevators) of the Juravinski Hospital. The community location is at 501 Sanatorium Road (where Rice meets Sanatorium), near Chedoke Hospital. The community site has free parking.

Hospital 905-389-5884 or Community 905-667-8870
wellwood@hhsc.ca

Please feel free to drop in, email or call us for more information.

Websites

Information about leukemia is also available on the websites listed below. If you do not have a computer, you can access the internet in our Patient and Family Resource Centre or at your local branch of the Public Library.

Health information on the internet may not apply to your condition and health care needs. Please discuss the information you find with your health care team.

Canadian Cancer Society

www.cancer.ca or call Cancer Information Services: 1-888-939-3333

Cancer Care Ontario

www.cancercare.on.ca

You can also find support groups on-line. It can be helpful to share information and discuss concerns with others, but be cautious about taking advice from people you do not know. Before taking any action, talk with a member of your health care team.

Complementary or alternative therapy

For more information about complementary therapy call Cancer Information Service at 1-888-939-3333 and speak with an information specialist.

Information about alternative and complementary treatments can be found at the Memorial Sloan Kettering Cancer Centre or BC Cancer agency websites:

www.mskcc.org

Search for “Herbs, Botanicals & Other Products”

www.bccancer.bc.ca

Search for “Complementary Therapies”

