For Leukemia patients and families to manage their care

Leukemia Education Awareness Package (LEAP)

Leukemia patients live with the effects of the disease and its treatment for the rest of their life. It is important that you follow the instructions in this booklet to keep yourself safe. This booklet was made by your health care team. It is meant to help you safely move from hospital to home life.

Read this booklet to help you:

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<table>
<thead>
<tr>
<th>Call 911 or go to the closest hospital Emergency Department if you have:</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Breathing problems</td>
</tr>
<tr>
<td>▪ shortness of breath</td>
</tr>
<tr>
<td>▪ wheezing</td>
</tr>
<tr>
<td>▪ chest pain</td>
</tr>
<tr>
<td>▪ blue lips</td>
</tr>
<tr>
<td>• A lot of bleeding</td>
</tr>
<tr>
<td>• Change in level of consciousness, or not feeling alert</td>
</tr>
<tr>
<td>• Throwing up that lasts more than 12 hours</td>
</tr>
<tr>
<td>• Headaches:</td>
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<tr>
<td>▪ that get worse</td>
</tr>
<tr>
<td>▪ that are new</td>
</tr>
<tr>
<td>▪ behind your eyes</td>
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<tr>
<td>▪ in the back of your head</td>
</tr>
<tr>
<td>• Fainting</td>
</tr>
<tr>
<td>• Unexplained, or non-stop pain</td>
</tr>
<tr>
<td>• Diarrhea (watery, or loose poo) lasting more than 12 hours</td>
</tr>
</tbody>
</table>
Call Princess Margaret Cancer Centre at 416-946-2000 if you have:

- Temperature is 38.0° C (100.4° F) or higher
- Problems with your central venous access device, such as:
  - pain and redness at the exit site
  - leaking or bleeding
  - swelling around the exit site, along the tunnel or down your neck, shoulders or arm
- Chills or shakes
- Changes in your skin color:
  - yellow
  - bruising
  - tiny reddish-purple dots
  - rashes
- Feel burning and/or see blood in your urine
- Notice a change (more or less) in the amount of urine you pass compared to normal
- Leaking or bleeding from your vagina or penis
- Feel pain during sex
- Dizzy or light-headed
- Major changes in appetite
- Feel symptoms of a cold or flu:
  - a lot of sneezing
  - runny nose
  - cough
  - sore throat
  - general aches and pains
- Eye discomfort (e.g. itchiness, dryness and pain from light)

This is not an emergency. But, your doctor or nurse will still need to help you manage this.
Understand your blood counts

What is a blood count?

A blood count is a test of your blood. The test is done by your nurse.

Blood counts are used to:

- Measure the minerals, nutrients and other parts that make up your blood
- Collect other important information about the cells in your blood

Why are blood counts important?

Blood counts help show your health care team how well your body is working. Parts of your blood counts may be too high or too low, which can affect your health. Your blood counts may change because of your cancer, your treatment, or other reasons.

How can you read your blood counts?

Blood tests done at the Princess Margaret Cancer Centre are always “complete blood tests”. Complete blood tests measure four parts of your blood:

- Hemoglobin (HgB),
- Platelets (PLT),
- White blood cells (WBC), and
- Neutrophils (Neut).

Keep reading to learn more about these four parts of your blood, and tips on how to keep track of each of them.
Hemoglobin (HgB)
Hemoglobin is the part in red blood cells that carries oxygen and nutrients to all the cells in your body.
- Normal range: 120-160 grams per Litre (g/L)
- During treatment: hemoglobin can drop to less than 80g/L and will vary for many weeks
- Red blood cell (RBC) transfusions may help bring your counts up when your hemoglobin is very low (around 70-80 g/L)

Platelets (PLT)
Platelets form clots to help you stop bleeding when you get hurt.
- Normal range: 150-400 billion per Litre (bil/L)
- During treatment: platelet count can drop to less than 10 bil/L but may eventually recover
- Platelet transfusions may help bring your counts back up when platelet count is low (10 bil/L), or if you show signs of bleeding

White blood cells (WBC)
Help your body fight infection and are an important part of your immune system.
- Normal Range: 4.0-11 bil/L
- During treatment: white blood cell count can drop to zero
- You may be given medications to fight and prevent infections

Neutrophils (Neut)
Neutrophils are a special type of white blood cell that help fight infections.
- Normal Range: 2.0-7.5 bil/L
- During treatment this count can drop to zero
- When your neutrophils are below 0.5 bil/L, you are considered neutropenic and are at more risk of getting infections
- Medications may be given to help prevent or fight infections
How can you track your blood counts?

Your health care team keeps track of your blood counts. Patients may ask for a copy of their blood test results after the test is done.

What are electrolytes?

Electrolytes are important because they help:

- Provide your body with nutrients
- Move waste out of your body
- Your nerves, muscles, heart and brain work the way they should

Your health care team may order an electrolyte count as well as a complete blood count. If your doctor or nurse orders this test, you may see some or all of the following parts on your blood count sheet.
<table>
<thead>
<tr>
<th>Electrolyte/Level</th>
<th>Function</th>
<th>Normal Range</th>
</tr>
</thead>
<tbody>
<tr>
<td>Potassium</td>
<td>Helps with pumping of the muscles (e.g. your heart).</td>
<td>3.2-5.0 mmol/L</td>
</tr>
<tr>
<td>Sodium</td>
<td>Helps balance the amount of water and blood in your body.</td>
<td>135-145 mmol/L</td>
</tr>
<tr>
<td>Calcium</td>
<td>Helps to maintain strong bones and assist in muscle and nerve function.</td>
<td>2.20-2.62 mmol/L</td>
</tr>
<tr>
<td>Magnesium</td>
<td>Maintains bone, muscle, nerve and immune system function.</td>
<td>0.70-1.1 mmol/L</td>
</tr>
<tr>
<td>Phosphate</td>
<td>Important for building and repairing bones, helps how nerves and muscles work.</td>
<td>0.80-1.4 mmol/L</td>
</tr>
<tr>
<td>Creatinine</td>
<td>Used to show how well kidneys are working.</td>
<td>50-98 mmol/L</td>
</tr>
</tbody>
</table>
Prevent infection

While in hospital and after you leave, you are at risk for infection. There are many ways you can get infections. It is important to know how you can protect yourself.

How can you prevent infection from people?

- √ Wash your hands often and for at least 15 seconds
- √ Keep a bottle of alcohol-based hand sanitizer on you at all times to wash hands often
- √ Ask people you meet to wash their hands
- √ Avoid large groups of people and people who feel sick
- √ Avoid contact with school-aged children since they tend to carry more germs
- √ Avoid public pools, washrooms and hot tubs
- √ Cover open cuts with clean bandages

How can you prevent infection from plants and the outdoors?

- √ Avoid potting soil, indoor plants, and gardening
- √ If you have plants, keep them in a separate room that you do not use often
- √ Do not rake leaves especially when they are wet
- √ Avoid standing water (e.g. blocked eaves troughs, planters, buckets)
- √ Avoid mouldy places (e.g. black mould in bathroom, basement or kitchen)
- √ Avoid dust and dirt
How can you prevent infection from animals?

- Avoid animal droppings, such as:
  1. cat litters
  2. bird cages
  3. fish tanks
- Have someone else take care of animal droppings
- Avoid outdoor ponds
- Be sure that your pet’s nails are trimmed to reduce the risk of them scratching you

Speak with your nurse or doctor if you have more questions about daily living with animals, plants and the outdoors.

How can you prevent infection from food?

With a weakened immune system, you are at risk of getting a serious illness from eating food that has bacteria or germs.

Bacteria or germs can be found in food when it is not properly stored, cooked or handled. You cannot always tell if food is spoiled by its look, smell or taste. If you are not sure about its safety it is best to throw it out.

There are four basic steps to follow when handling, storing, preparing, and shopping for food:

1. **Keep it clean:** Wash your hands, kitchen surfaces, and reusable shopping bags often with soap and water.
   - Wash your hands often, and dry your hands with a paper towel or cloth that is changed daily
   - Wash your hands after:
     - using the bathroom
     - taking out the garbage
     - touching your pet
• Keep a clean kitchen to lower the chance of germ spread from one surface to another:
  - kitchen surfaces
  - dishes and cutlery
  - can openers
  - the inside of the microwave

• Use at least three separate cutting boards. One for cooked foods, one for vegetables and one for raw meat, poultry, fish and seafood

• Wash cutting boards with hot, soapy water then rinse with hot water after each use

2. **Keep foods separate:** Raw foods (e.g. meat, chicken) must be kept apart from ready-to-eat foods (e.g. vegetables) to prevent germ spread.

• Avoid buying:
  - foods from open bins (e.g. bulk foods)
  - foods that are on display (e.g. raw meats on the deli counter, unwrapped bakery products)
  - fruits and vegetables that are bruised, damaged or overly ripe

• Check ‘best before’ dates. Choose foods with far away expiry dates (e.g. make sure to do this with milk, cheese and eggs)

• Put refrigerated foods into your shopping cart last. This will limit the amount of time the food sits at room temperature

• Buy packages that are properly sealed and cans with no dents, bulges, cracks or leaks

3. **Cook food to a high enough temperature that is safe to eat.**

• Germs that cause illness from food grow the fastest when the temperature is between 4°C (39°F) and 60°C (140°F). This is called the “temperature danger zone”
• Cook food until the thickest part reaches a safe temperature to eat. Check by using a digital thermometer, and clean the thermometer in warm, soapy water when you are done

• Try to cook foods to the temperatures listed below:
  ▪ Beef, Veal, Lamb: 71° C (160° F) for medium, 77° C (171° F) for well done
  ▪ Ground red meat: 71° C (160° F)
  ▪ Ground poultry: 74° C (165° F)
  ▪ Pork: 71° C (160° F)
  ▪ Egg dishes: 74° C (165° F)

• To reduce the chance of germ build-up, try to refrigerate, freeze, or eat the foods below within two hours of buying or cooking them:
  ▪ Meat
  ▪ Fish
  ▪ Eggs and other dairy products
  ▪ Fresh cut or peeled fruit or vegetables
  ▪ Sprouts
  ▪ Seafood
  ▪ Gravies and sauces

4. **Store food and leftovers right away in the fridge or freezer at 4° C (39° F) or below.** Check fridge temperature to make sure it is at or below 4° C (39° F).

• Store foods that need to be refrigerated or frozen as soon as you return home from grocery shopping. Do not leave them at room temperature

• Rotate food that is in the fridge or in the cupboard so the older items are used first

• Label frozen food with the date of purchase and preparation

Read the resource called “Food Safety: For patients with weakened immune systems” for more information on safe food handling.

Speak with your nurse or doctor if you have more questions about daily living with animals, plants and the outdoors.
Prevent falls and injury

Falls are a worry for patients with leukemia because your platelet count is often low. A fall can have a major impact on your health.

Many serious falls happen at home. It is important to know what you can do to stay safe and reduce your risk of falling.

How do falls happen?
- Poor lighting
- Poor footwear (e.g. slippers without grips)
- Clutter
- Mix of some medications
- Possible infection
- Body weakness

How can you prevent falls?
1. Use your cane or walker if you have one
2. Use handrails on stairs
3. Use bathroom safety fixtures (e.g. bath bench, bath mat, grab bars)
4. Wear your eyeglasses
5. Carry a cell phone or emergency alert button to call for help
6. Wear shoes with good grip
More ways to prevent falls:

1. Review your medications with a doctor often
2. Turn lights on in dark hallways and bathrooms, and use nightlights
3. Remove loose rugs
4. Reduce clutter
5. Look out for wet spots
6. Be mindful that pets can trip you
7. Slowly move to and from furniture

How can you prevent injury?

Change some of your activities of daily living to prevent injury or sickness at home.

8. Avoid doing things with risk of harm or bleeding (e.g. contact sports, body piercing, tattoos)
9. Wear safety gear while playing sports (e.g. bicycle helmet, knee pads, wrist guards)
10. Do not walk barefoot
11. Be careful using kitchen cutlery and sharp objects
Manage your Central Venous Access Device

Your Central Venous Access Device (CVAD) includes your Hickman or PICC.

Hickman

PICC

© UHN Patient Education
What do you need to know?

- Keep your CVAD clean and away from dirty surfaces
- Do not let anyone pull or play with your CVAD
- Do not allow pets to lie on your chest or come into contact with your CVAD

When should you ask for help?

Call Princess Margaret Cancer Centre at 416-946-2000 if:

- There is any redness, pain at or along the tunnel
- The catheter is dislodged or moves position (Do not try to push the line back in)
- You see yellow fluid or any discharge
- You see bleeding bigger than the size of a dime

What do you do if the Hickman/PICC comes loose?

- Ensure the clamp is closed or kink the lines right away
- Apply clean gauze or cover with anything clean
- If you are short of breath, lay on your left side and call 911

What do you do if your Hickman or PICC leaks or tears?

- Clamp or kink the lines above the leak or tear
- Call Princess Margaret Cancer Centre right away
How do you take care of your Central Venous Access Device?

When your Central Venous Access Device is not being used, it must always be clamped and have a special cap on the end.

You will need a dressing (bandages) on your exit site as long as you have sutures (stitches). This helps protect the area from infection. Your dressing must be clean and dry and stay in place all the time.

Change the dressing over your Central Venous Access Device, if:

- It is damp or wet
- It is dirty
- It is not sticking to your skin
- You have pain or discomfort around the device

It is helpful to have family members or friends learn how to clamp, clean and care for your Central Venous Access Device, in case you need help.
<table>
<thead>
<tr>
<th><strong>Can I bathe or shower with it in?</strong></th>
<th><strong>PICC (single or more than one lumen)</strong></th>
<th><strong>Hickman</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Yes</strong></td>
<td>Do not put your arm under water. Wrap your arm in a plastic bag/cellophane wrap and tape it to the skin to keep the PICC dry</td>
<td>Yes But do not have your site under water.</td>
</tr>
</tbody>
</table>

| **Can I swim with it in?** | **No** | **No** |

<table>
<thead>
<tr>
<th><strong>Do I need to have the bandages changed?</strong></th>
<th><strong>Yes</strong></th>
<th><strong>You do not need bandages once your sutures are removed.</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td>Once a week and if dressing gets wet, loose or dirty.</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

| **What happens if I go home with sutures?** | **They will be removed in the Transfusion or Clinic. The bandages must be changed once a week, and if the bandages get wet, loose or dirty.** |

<table>
<thead>
<tr>
<th><strong>Does it need to be flushed?</strong></th>
<th><strong>Yes</strong></th>
<th><strong>Yes</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td>Once a week for single lumen, every Monday, Wednesday and Friday for more than one lumen. Use Normal Saline 10ml and then Heparin 300 units.</td>
<td>Once a week in each lumen with Normal Saline 10ml and then Heparin 300 units.</td>
<td></td>
</tr>
</tbody>
</table>

| **How do I keep it secured?** | **Secure the PICC directly to the skin with a piece of tape away from the cap and clamp, and pin it to clothing.** | **Secure the Hickman directly to the skin with a piece of tape away from the cap and clamp, and pin it to clothing.** |

| **Any other restrictions?** | **No heavy lifting, no contact sports for example, shoveling snow, playing rugby.** | **No heavy lifting or contact sports, for example shoveling snow, playing rugby.** |
Emotional support and well-being

Patients and their families report that this can be an emotionally difficult time in their lives. A cancer diagnosis and treatment may make you feel sad, angry, nervous, afraid, or many other emotions. It is normal to feel this way.

Your health care team includes people who can help. You are encouraged to speak with your nursing team about your needs so that they can help you and your family. Their job is to support you at this time.

You can get support for your emotional, social and spiritual needs from:

- Nurses/doctors
- Social Workers
- Spiritual Care Providers

What support can you get from nurses and doctors?

Nurses and doctors help patients and families cope with the impact of their diagnosis. They have the knowledge and expertise to care for your physical needs. Nurses and doctors work closely with other members of your health care team to plan your care.

Nurses and doctors can help you with health care needs, such as:

- Set up health care for patients and caregivers (e.g. diagnostic tests, procedures)
- Physical comfort (e.g. helping with pain, nausea, mucositis – in infection in your mouth)
- Linking how you feel to your cancer and treatment (e.g. feeling tired because your hemoglobin is low)
- Social, emotional and mental support
What support can you get from Social Workers?

Social Workers help patients and families deal with cancer diagnosis and treatment. They are part of the Psychosocial Oncology and Palliative Care Program.

Social Workers help you with social and practical needs, such as:

- The emotional stress of diagnosis and treatment (e.g. feelings of fear, sadness, loss, anger)
- Money issues (e.g. income help, disability pensions)
- Drug costs
- Daily issues (e.g. rides to clinic visits, home care, and a list of community resources)
- Power of attorney

Social Workers can meet with you one-on-one, or in a group, to talk about:

- how you feel after being diagnosed with cancer
- the impact of your diagnosis on your family
- treatment-related choices and decisions
- coping at home
- physical changes to your body
- your hospital experience

If you would like to meet with a Social Worker, call the Psychosocial Oncology and Palliative Care Program at 416-946-4525. This service is free.

What support can you get from Spiritual Care Providers?

Spiritual Care Providers offer multi-faith support. They help you share your feelings and concerns in a way that respects your values and beliefs. Spiritual Care Providers help you with spiritual needs such as:

- Encouragement and comfort
- Support for loss and grief
- One-on-one counseling
- Prayer, meditation and reflection
- Religious and spiritual rituals
Every Wednesday from 10am to 11am, the Princess Margaret’s Spiritual Care Department offers free, multi-faith programs and support to patients and families. These programs and support include:

Labyrinth Walk, 1\textsuperscript{st} Wednesday of the month
\begin{itemize}
  \item The Labyrinth is an ancient spiritual tool, a walking meditation and a path of prayer.
\end{itemize}

Letting Cancer Speak, 2\textsuperscript{nd} Wednesday of the month
\begin{itemize}
  \item The courage to re-frame the life you have, not the life you imagined.
\end{itemize}

Care of Your Spirit, 3\textsuperscript{rd} Wednesday of the month
\begin{itemize}
  \item In this group we invite you to learn about spirituality and discover how it can support you in your cancer journey.
\end{itemize}

Spirituality through Tale and Tape, 4\textsuperscript{th} Wednesday of the month
\begin{itemize}
  \item Using a short movie, the wisdom of the participants, and the skills of a facilitator, a variety of spiritual themes will be uncovered.
\end{itemize}

You do not need to register beforehand, and all programs are held in the Princess Margaret Cancer Centre Boardroom (main floor, room M-805).
You may find sex and intimacy hard to talk about. This can affect our self-esteem, body image, relationships, and happiness.

It is normal to:
- Worry about having sex or intimacy after treatment
- Have a lot of questions
- Not know how to talk about this with your loved ones

You can speak with your nursing team or doctor anytime about this.

**Tips before you start sexual activities again after treatment**

1. Be mindful of how you feel and what your blood counts are
2. Try to talk openly with your partner about how you are feeling
3. Make sure to secure your Hickman or PICC to prevent it from coming loose

**Tips during sexual activities**

- Make sure to use condoms to prevent pregnancy and the spread of sexually transmitted infections
- Keep your body clean to reduce the spread of sexually transmitted infections
- Use water-based lubricants like KY-Jelly® to avoid pain or injury
- Avoid scented or petroleum-based lubricants like Vaseline® because they can cause irritation
- You may feel pain and discomfort during sex or physical intimacy. Talk to your doctor if you do.
- Men may notice some erectile difficulties after chemotherapy. Talk to your doctor if your performance is different.
Conserve your energy

It is normal to experience fatigue (tiredness) while you recover from treatment. While you recover, you may feel fatigue. What causes fatigue?

- Low blood counts
- Medications
- Disease
- Your body’s reaction to treatment

How can you reduce fatigue?

1. **Pace yourself**
   - Take breaks
   - Spread out the work you need to do throughout the day
   - Take slow breaths

2. **Plan your activities**
   - Make lists of your activities
   - Do hardest tasks when you have the most energy
   - Sit when you can
   - Keep important items close by
   - Slide heavy items along the counter
   - Breathe slowly

3. **Prioritize**
   - Do what is important first
   - Know that it is okay to say “no”

4. **Make it easier**
   - Sit when you can
   - Keep items close by and within reach
   - Use a cart to carry things
   - Slide heavy items along the counter
   - Use aids to save energy (e.g. cane, walker)

For more information on free resources and classes to help with fatigue, contact the Princess Margaret Fatigue Clinic at 416-946-4501, extension 2363.
Medications and sick days

It is always important to know what medications you are taking and why. Keep a current list of medications you are taking with you at all times. This will keep you safe and make sure you get the right health care.

What should you do when you meet your doctor, nurse, or pharmacist?

• List how much and how often you take your medications
• Speak with your doctor, nurse or pharmacist about any vitamins or herbal medicine you are taking
• Speak with your doctor before you or your family members get any shots (e.g. flu shots, childhood vaccines)
• Speak with your doctor before refilling medications
• Let your nurse know if you need help with paying for medications

How should you store medications at home?

• Take all of your medications as prescribed and at the same time every day for the number of days ordered by your doctor
• Use a pill box or request a blister pack from your pharmacy to organize your medications
• Store them in a dry and cool place, but not in the bathroom or fridge unless told to

How should you take medications at home?

• Do not drink alcohol, grapefruit or pomegranate juice with medications
• Use Tylenol as your only over-the-counter pain medication, since other pain medications may increase your risk of bleeding (e.g. Aspirin, Advil)
• Try to use the same pharmacy to fill prescriptions so that medications can be tracked
• Do not take medications that are not prescribed for you
Leaving the hospital

When you leave the hospital:
- You will be given an appointment at either the Hematology Clinic (2nd floor, Princess Margaret Cancer Centre) or Transfusion Unit (4th floor, Princess Margaret Cancer Centre)
- If you are booked for a Clinic appointment, get your blood work done at least one hour before your Clinic visit
- If you are booked in the Transfusion Unit, attend your appointment at the booked time

If you have a PICC or Hickman:
- Go to the Ambulance Waiting Area to have your blood work done (main floor, behind main elevators)
- If your appointment is in the Transfusion Unit, you will have your blood drawn there

If you DO NOT have a PICC or Hickman:
- Go to the Blood Collection Lab (main floor, next to the Outpatient Pharmacy) for both Transfusion and Clinic appointments
Important phone numbers

**Princess Margaret Cancer Centre**: 416-946-2000
After 5pm and until 7:30am on weekdays and 24 hours on weekends and holidays, call Princess Margaret, wait for the operator and ask to speak to the Nursing Supervisor.

If your follow-up visit is in Clinic: Call 416-946-2223

If your follow-up visit is in Transfusion: Call 416-946-5118

**Leukemia Nursing Triage**: 416-946-2223
- Press 1 to ask about or change an appointment
- Press 2 to speak with a nurse

Available Monday to Friday, 9am to 4pm
Or call your doctor’s office and leave a message

**Outpatient Pharmacy**: 416-946-6593
Open Monday to Friday, 9am to 5pm
Princess Margaret Cancer Centre, main floor

Please refer to the booklet entitled, “Patient resource guide” for more support resources.