

Leukemia Education Package and Your Care Needs During Treatment

In this booklet, you will learn about:

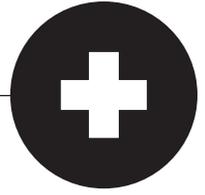
- Leukemia and your treatment options
- How to prevent infections
- How to manage your symptoms and side-effects
- How to manage your Central Venous Access Device (CVAD)
- Where to find support
- Who to contact

Adapted from the “Leukemia Education Awareness Package (LEAP)” with permission from the University Health Network Patient and Family Education Program. Additional information adapted from The Ottawa Hospital.

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Dealing with Emergencies



Please call 911 or go to your closest emergency room if you have:

Fever (temperature is 38.3°C (100.9°F) or higher at any time or 38.0°C (100.4°F) or higher for 1 hour)

- Breathing problems
 - Shortness of breath
 - Wheezing
 - Chest pain
 - Blue lips
- Bleeding that does not stop with pressure
- Change in level of consciousness (feeling more drowsy) or not feeling alert
- New confusion
- Seizures
- Throwing up that lasts more than 12 hours
- Headaches
 - That get worse
 - That are new and severe
 - Happen with a sore or stiff neck
 - With a fever
 - With coughing or having a bowel movement (poo)
 - With confusion or drowsiness
 - That wake you from your sleep
 - After a fall
- Fainting
- Unexplained or non-stop pain
- Diarrhea that lasts more than 12 hours

Please call Sunnybrook Health Sciences Centre if you:

- Have problems with your PICC line or Hickman line such as:
 - Pain or redness at the exit site
 - Leaking or bleeding
 - Swelling around the exit site, along the tunnel or down your neck, shoulders or arm
- Have chills or shakes
- Have changes in your skin colour:
 - Yellow
 - Heavy bruising
 - Tiny reddish-purple dots
 - Rashes
 - Blood blisters
- Feel burning or pain when you pee, foul smelling pee or see blood in your pee
- See a change in how much you pee (more or less) or unable to pee
- Have leaking or bleeding from your vagina or penis
- Feel dizzy or light-headed
- Major changes in appetite or eating habits
- Feel symptoms of a cold or flu:
 - A lot of sneezing
 - Runny nose
 - Cough
 - Sore throat
 - General aches and pains
- Have sore eyes like itchiness, dryness or pain when you look at the light

These symptoms are not an emergency, but your health care team will need to help you manage them

Complex Malignant Hematology Unit (C606)

Monday to Friday, 8:00 AM – 5:00 PM 416-480-6100 ext. 4312

After hours weekdays 5:00 PM – 8:00 AM, weekends and statutory holidays

Please call 416-480-4244 (locating) and ask to page the Leukemia Complex Malignant Hematology pager to speak to the Nurse Practitioner or Resident/Fellow On-call



What is Leukemia?



Leukemia is a type of cancer that affects the blood and bone marrow

- Leukemia affects the stem cells of the blood, which are cells that turn into different types of blood cells, including red blood cells, white blood cells and platelets
- The stem cell can get damaged and form leukemia cells (blasts), which can multiply, grow abnormally, and overcrowd the bone marrow
- This stops the bone marrow from making normal blood cells and doing what it normally does

Leukemia is classed by the type of cell (myeloid or lymphoid) and can be acute or chronic:

Acute Leukemia = starts suddenly, fast-growing, develops over days to weeks

- Acute Myeloid Leukemia (AML)
- Acute Lymphoblastic Leukemia (ALL)

Chronic Leukemia = slow growing, develops over months to years

- Chronic Myeloid Leukemia (CML)
- Chronic Lymphocytic Leukemia (CLL)
- Chronic Myelomonocytic Leukemia

How is leukemia diagnosed?

- History and physical examination
- Complete Blood Count (CBC) = shows the number of blood cells
- Blood film = shows the number and shape of blood cells
- Bone Marrow Aspiration and Biopsy = procedure to collect and look at bone marrow from inside your bones to confirm diagnosis and determine response to treatment

What are the Treatments for Leukemia?



Treatment depends on the type of leukemia, risk type, genetics, your age, general health and other medical issues

Chemotherapy

- Medications given to destroy cancer cells and improve the function of the bone marrow

Stem Cell Transplant

- Transferring blood stem cells from a donor and putting it into your blood; this option may not be for everyone

Supportive Care and Follow Up

- Transfusions, antibiotics, social work and mental health support if needed

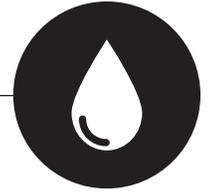
Clinical Trials

- Access to new anti-leukemia therapies that may be added to existing chemotherapy regimens or replace them

Palliative Care

- These include transfusions, antibiotics and treatment that maximizes quality of life

Understanding your Blood Work



Complete Blood Count (CBC)

What is a Complete Blood Count and differential?

- A complete blood count is a blood test done by a nurse or phlebotomist

What do complete blood counts measure?

- The level of blood cells in your blood that include red and white blood cells and platelets

What do differentials measure?

- The types of white blood cells you have passing through your blood

Why are blood counts important?

- Shows us how the leukemia and treatment affect your body
- Blood counts may change due to the leukemia itself, the chemotherapy treatment or other reasons
- Show us what supportive care treatments, like transfusions or antibiotics are needed if your blood counts are too low or too high

What are the types of blood cells in your blood?

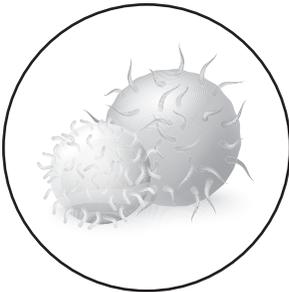
- Red blood cells (measured by hemoglobin)
- White blood cells that include
 - Neutrophils, which are a type of white blood cell
 - Blasts, which are the leukemia cells
- Platelets

Red Blood Cells and Hemoglobin



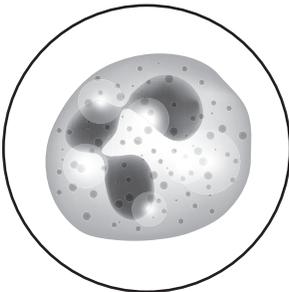
- Red blood cells carry oxygen and nutrients to all the cells in your body
- Hemoglobin is a part of the red blood cells that carries the oxygen
- Normal Range: 120-160 g/L
- During treatment: hemoglobin can drop to less than 70 to 80 g/L and will vary for many weeks
- Red blood cell (RBC) transfusions may help to bring your counts up when your hemoglobin is very low

White Blood Cells (WBC)



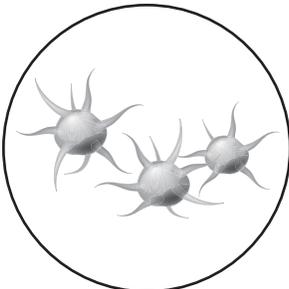
- White blood cells help to fight infection and are an important part of your immune system Normal Range: 4.0-11.0 bil/L
- During treatment: white blood cell count can be very low, it can drop to zero
- When your white blood cell count is low, you are at higher risk of getting infections. You may be given medications to prevent or fight infections.

Neutrophils



- Type of white blood cell that fights infection
- Normal Range: 2.0-7.5 bil/L
- During treatment your neutrophil count can be very low and can drop to zero
- When your neutrophil count is below 0.5 bil/L, you are considered neutropenic and are at higher risk of getting infections.
- When your neutrophil count is low, you may be given medications to prevent or fight infections

Platelets



- Platelets are cells that form clots to help stop bleeding
- Normal Range: 150-400 bil/L
- During treatment: platelet count may be very low (less than 10-20 bil/L)
- When your platelet count is low or show signs of bleeding (gum bleeding, nose bleeding), you may require a platelet transfusion

Electrolytes and Biochemistry Tests

What are Electrolytes?

Electrolytes are important because they help:

- Give your body nutrients
- Measure how your body gets rid of wastes
- Your nerves, muscles, heart and brain work the way they should

Types of Biochemistry Tests

Biochemistry Tests	Function	Normal Range
Potassium	Helps with pumping of muscles (like your heart)	3.5 to 5.0 mmol/L
Sodium	Helps balance the amount of water and blood in your body	135 to 145 mmol/L
Calcium	Helps keep your bones strong and helps muscles and nerves work	2.20 to 2.62 mmol/L
Magnesium	Maintains bone, muscle, nerve and immune system function	0.70 to 1.1 mmol/L
Phosphate	Important for building and repairing bones, helps nerves and muscles to work	0.80 to 1.4 mmol/L
Creatinine	Used to show how well kidneys are working	50 to 98 mmol/L

Importance of Fever and Febrile Neutropenia



What is Neutropenia?

- Neutropenia is when your neutrophil (type of white blood cell that fights infections) count is very low
- **Neutropenia raised your risk of getting an infection**

What causes Neutropenia?

- Leukemia affects the bone marrow which can affect the white blood cell (neutrophil) count
- Chemotherapy can lower your white blood cell (neutrophil) count 8-14 days after you get treatment
- Your white blood cell (neutrophil) count can start to rise 3-4 weeks after chemotherapy treatment

How to tell if you have a fever?

While you get chemotherapy treatments, take your temperature if you feel:

- Warm, chilled or unwell



You have a fever if your temperature is:

38.3°C (100.9°F) or higher at any time

OR

38.0°C (100.4°F) or higher for 1 hour

What do you do if you get a fever? (while on chemotherapy treatment)

1. Do not take Tylenol (acetaminophen) or Advil (ibuprofen) before you take your temperature. These medications may hide a fever.
2. Go to your closest hospital Emergency Department and show your Fever Advisory Card RIGHT AWAY.
3. Bring all of your medications, including herbal products and vitamins that you take
4. Tell the person checking you in and the triage nurse that you have cancer, the type of cancer, are receiving chemotherapy treatment and the last day you were treated



What is the fever card?

- A Fever Card tells you what to do if you get a fever while on chemotherapy treatment and alerts health care providers to your specific medical issue
- Patient and family members should present the card when they get to the Emergency Department
- Although your care is a priority, you may still have to wait while other patients with more serious concerns are being treated
- You should only use the card if you have a fever. If you go to the emergency department with another concern you do not need to show your card.

What are signs and symptoms of an infection?

Often the only sign of infection is a fever**

Seek medical attention right away if you have any of the following symptoms:

- Fever
- Chills, shaking, sweats, any “flu-like” symptoms

Let your nurse or doctor know if you have a sore throat, cough, shortness of breath or feel like you may have a fever

**Sometimes you may have a serious infection without a fever. If you have any new signs or symptoms and are worried, please call Sunnybrook Hospital 416-480-4244 (locating) and ask to page the Leukemia Complex Malignant Hematology pager to speak to the Nurse Practitioner or Resident/Fellow On-Call

Guidelines about infection risk

Most fevers in patients with low neutrophils happen even with good prevention and we often do not find a cause. Usually, they are from bacteria that live inside us. However, we do recommend that you follow these guidelines to help prevent infection.

- If you have a low white blood cell (neutrophil) count or neutropenia, you have a higher risk of infections
- You must watch for signs of infection and fever
- If you get a fever or have any signs and symptoms of an infection it is important to catch it early and get treated right away
- It is also important to lower your risk of developing infections from others, animals and food

Preventing Infections



While in hospital and at home, you are at risk for infection. There are many ways to get an infection. Here are some of the ways to help protect yourself from infections:

How can I prevent infection while I am in hospital?

- Clean hands often and well for at least 15 seconds, either using alcohol-based hand sanitizer or soap and water
- Ask any visitors to clean their hands before they come into your hospital room
- Remind your family and friends not to visit if they are sick or feeling unwell
- Wear a yellow mask at all times when outside of your own room to lower your chance of getting a cold or flu
- Wear a yellow mask in the hospital when you have visitors
- Let your nurse or doctor know if you have a sore throat, cough, shortness of breath or feel like you may have a fever

How can I prevent infection from other people?

- Wash your hands well for at least 15 seconds with soap and warm water or if using alcohol based sanitizer, rub hands until dry.
- Keep a bottle of alcohol-based hand sanitizer (with 70% alcohol) with you at all so you are able to clean your hands often especially after handling public surfaces (door handles, elevator buttons)
- Wash your hands often, especially after you use the washroom
- Wipe down telephones and door handles with disinfectant often
- Avoid large groups of people or crowds. If you go to public places, try to go when there are fewer people
- Avoid contact with people who feel sick, have flu-like illnesses, cough, cold or fevers
- Avoid public pools, hot tubs
- Cover open cuts with clean bandages

How can I prevent infection from plants and outdoors?

- Avoid gardening and potting soil
- No live plants while in hospital
- Avoid raking leaves, especially when they are wet
- Avoid standing water in blocked eaves troughs, planters, and buckets
- Avoid mouldy places, such as black mould in bathroom, basement or kitchen
- Avoid dust and dirt

How can I prevent infection from animals?

- Avoid animal droppings such as cat litter, bird cages, fish tanks
- Have someone else clean up animal droppings
- Avoid outdoor ponds
- Have your pet's nails trimmed to prevent them from scratching you
- Wash your hands immediately after touching or being near animals
- Avoid eating, drinking or putting anything in your mouth when you are around animals

How can I prevent infection from food?

When you have cancer you may have a weakened immune system, which can make you have a higher chance of getting sick from eating food that has bacteria or germs. Bacteria and germs can be found in food if it is not properly stored, cooked or handled. Your immune system is low and you are at high risk to food poisoning so don't eat or drink foods past their expiry date. Sometimes you may not be able to tell if food is spoiled from its look, smell or taste. If you are not sure if food is safe to eat, it is best to throw it out.

There are **4** basic steps to follow when you handle, cook, store or shop for food:

1 Keep it clean:

Wash your hands, kitchen surfaces, and reusable shopping bags often with soap and water

- Wash your hands often with soap and warm water, especially before you touch, prepare or eat food
- Dry your hands with a paper towel or cloth. You should use a new cloth each day.
- Wash the following with warm, soapy water to lower the chance of germs spreading from one surface to another:
 - Kitchen surfaces
 - Dishes, utensils and cutlery
 - Can openers
 - The inside of the microwave
- Use at least 3 separate cutting boards: one for cooked food, one for vegetables and one for raw meat, poultry, fish and seafood
- Wash cutting boards with hot, soapy water and rinse with hot water after each use

2 Keep foods separate:

Raw foods (such as meat or chicken) must be kept separate from ready-to-eat foods (such as vegetables) to prevent germs from spreading

- Avoid buying:
 - Foods from open bins (bulk foods)
 - Foods that are on display (raw meats on deli counter, unwrapped bakery products)
 - Fruits and vegetables that are bruised, damaged or too ripe
- Check “best before” dates. Choose foods with far away expiry dates, especially with milk, cheese and eggs
- Put refrigerated foods into your shopping cart last. This will lower 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

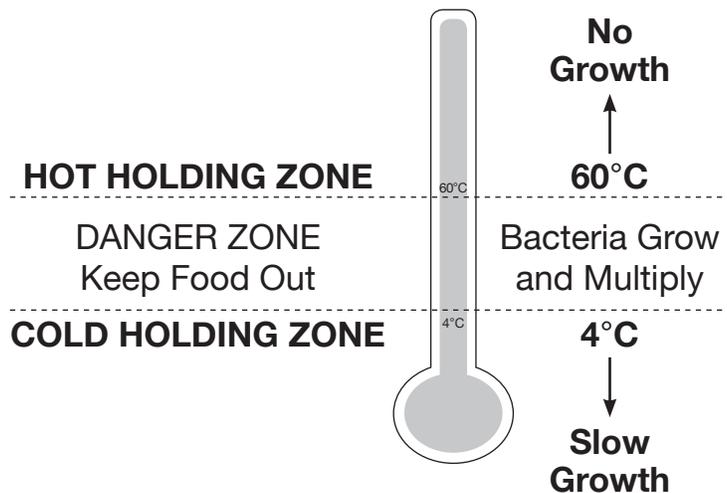
3 Cook food to a high enough temperature.

- 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 the temperature using a digital thermometer. Clean the thermometer using warm, soapy water after you use it.
- Try to cook foods to the following temperatures:
- To lower the chance of germ build-up, refrigerate, freeze or eat the foods within 2 hours of buying or cooking them:
 - Meat
 - Fish and seafood
 - Eggs and other dairy products
 - Fresh cut or peeled fruit or vegetables
 - 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 come home from grocery shopping. Do not leave them at room temperature
- Rotate food that is in the fridge or in the cupboard so older items are used first
- Label frozen food with the date that it was bought or made.
- There are safe time limits for home refrigerated foods and leftovers to keep them from spoiling. You can find these rules on this website: <https://www.foodsafety.gov/keep/charts/storagetimes.html>

Item	Temperature
Poultry	74°C (165°F)
Egg dishes	74°C (165°F)
Ground red meat	71°C (160°F)
Pork	71°C (160°F)
Beef Veal Lamb	77°C (171°F) for well done 71°C (160°F) for medium



Common Side Effects of Chemotherapy



Nausea and Vomiting

Some of the chemotherapy can cause nausea and vomiting. Nausea is when you are feeling sick to your stomach. Nausea and vomiting may occur hours to days after your treatment. You can have different types of medication during your treatment that will help with nausea and vomiting.

Some ways to help with the nausea and vomiting:

- Eat small meals often
- Avoid fatty, fried or spicy foods
- Stay in a sitting position for 30-60 minutes after your meals
- Take clear fluids such as broth, sports drinks, water

See the Cancer Care Ontario Symptom Management Guide on Nausea and Vomiting:
<https://www.cancercareontario.ca/en/symptom-management/3131>

Mouth Sores (Mucositis)

Chemotherapy can cause the lining of your mouth and throat to get swollen and sore. This is called mucositis. It can occur a few days after chemotherapy treatment and can last about 1 week. It can start with a dry, irritating, burning or painful feeling inside the mouth or throat. Good mouth care is important to prevent infections.

To help prevent or relieve mouth sores or sore mouth (mucositis):

- Rinse your mouth often
- Eat soft foods
- Use soft bristled toothbrushes
- Avoid commercial mouthwash with alcohol which can make mouth sores worse
- Avoid spicy, acidic, hard, crunchy foods

See the Cancer Care Ontario Symptom Management Guide on Mouth Sores:
<https://www.cancercareontario.ca/en/symptom-management/3156>

Diarrhea

Diarrhea can be a side effect of chemotherapy treatment. It is important to watch for the frequency and number of times you poop, especially if you have diarrhea. If you lose lots of fluid, you can become dehydrated. It is important to drink lots of fluid when you have diarrhea.

To help diarrhea:

- Eat small amounts often
- Drink lots of fluid
- Eat bland foods such as bananas, rice, toast, applesauce

See the Cancer Care Ontario Symptom Management Guide on Diarrhea:

<https://www.cancercareontario.ca/en/symptom-management/3151>

Fatigue

It is normal to have 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
- Stress

What can you do to help with your fatigue?

The most important step you can take is listen to your body.

1. Pace yourself

- Take breaks when you first start to feel tired
- Spread out the work you need to do throughout the day
- Take slow breaths
- Try not to rush
- Take naps

2. Plan your activities

- Make lists of your activities
- Do hardest tasks when you have the most energy
- Sit when you can
- Organize your space by keeping items you use the most close by
- Slide heavy items along the counter
- Breathe slowly
- Create a daily routine
- Try to exercise every day

3. Prioritize

- Do what is important first
- Know that it is okay to say “no”
- Sleep is important. Make sure you get a good night’s sleep

4. Make it easier

- Sit when you can
- Keep items close by and within reach
- Use a cart to carry heavy things
- Slide heavy items along the counter
- Use aids to save energy (for example: cane, walker)
- Ask for help
- Eliminate unnecessary tasks

5. Body positioning

- Change your position during the day
- Bend your knees when lifting heavy items
- Sleep on your back or side

6. Managing stress

- Recognize situations that cause you stress
- Use strategies to help you better manage your stress
(for example: deep breathing, meditation, mindfulness, exercise)

See the Cancer Care Ontario Symptom Management Guide on Fatigue:
<https://www.cancercareontario.ca/en/symptom-management/3991>

How to Manage your Central Venous Access Device

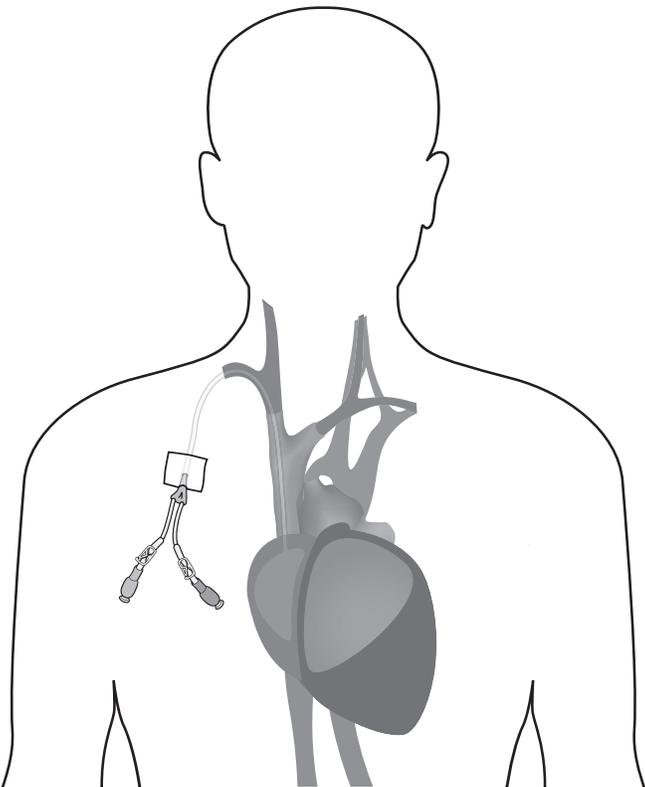


What is a Central Venous Access Device (CVAD)?

- A CVAD is an intravenous line that is put into a large vein in your body and travels to the upper chest
- It can be used to give intravenous medications and chemotherapy and to take blood tests
- Your Central Venous Access Device (CVAD) includes your Hickman or PICC.

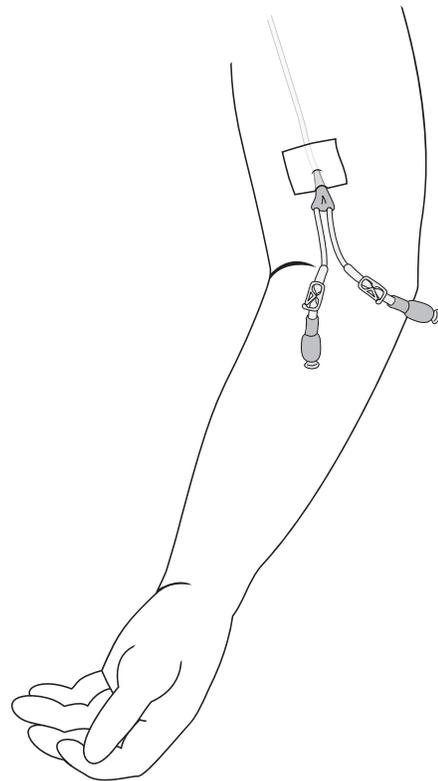
Hickman Line

A Hickman line is inserted in a large vein in your chest and sits usually on the right side of your chest.



PICC (Peripherally Inserted Central Catheter)

A PICC (Peripherally Inserted Central Catheter) is inserted through a vein in your upper arm and travels through the vein into the upper chest.



What do I 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 in contact with your CVAD

When should I ask for help?

Call the Hematology Nursing Site line if:

- You have any redness or pain at the catheter site or along the tunnel
- The catheter comes out or moves position (do not push the catheter back inside)
- You see any yellow fluid or discharge at the catheter site
- You see any bleeding bigger than the size of a dime at the catheter site

What do I do if the CVAD comes out or falls out?

- Make sure the clamp is closed or kink the lines right away
- Put clean gauze on the area or cover with anything clean
- If you are short of breath, lay on your left side and call 911.
- You may have to come into the hospital to have it put back in properly

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

- Clamp or kink the lines close to the site above the tear
- Call 911

How do you take care of your CVAD?

- If your CVAD is not being used, it must always be clamped and have a special cap on the end
- For the Hickman lines, you will need a dressing on your exit site until it heals. This will help protect the area from infection.
- Your dressing must be clean, dry and stay in place at all times. After it heals you do not need a dressing.

The dressing over your CVAD will have to be changed if:

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

	Hickman Line	PICC Line
Can I bathe or shower with it in?	<ul style="list-style-type: none"> • Yes you can shower with your Hickman once it is healed. • The Hickman line should be covered for a shower if there is a dressing on it until it is healed. • Do not submerge your Hickman or exit site in bath water 	<ul style="list-style-type: none"> • Yes you can shower • 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
Can I swim with it in?	<ul style="list-style-type: none"> • No 	<ul style="list-style-type: none"> • No
Do I need to have the dressing changed?	<ul style="list-style-type: none"> • Yes • Once a week • If the dressing gets wet, loose or dirty. • You do not need a dressing once your sutures are removed 	<ul style="list-style-type: none"> • Yes • Once a week • If the dressing is gets wet, loose or dirty
Does it need to be flushed?	<ul style="list-style-type: none"> • Yes • Once a week in each lumen with Normal Saline 10-20mL and then Heparin 300 units 	<ul style="list-style-type: none"> • Yes • Once a week in each lumen with Normal Saline 10-20mL
How do I keep it secured?	<ul style="list-style-type: none"> • Secure the Hickman directly to the skin with a piece of tape away from the cap and clamp. • Be careful around small children and pets as they may pull the line 	<ul style="list-style-type: none"> • Secure the PICC directly to the skin with a piece of tape away from the cap • Be careful around small children and pets as they may pull the line
Any other restrictions?	<ul style="list-style-type: none"> • No heavy lifting or contact sports, for example shoveling snow, playing contact sports (hockey, basketball) 	<p>No heavy lifting, no contact sports, for example shoveling snow, playing contact sports (hockey, basketball)</p>

Emotional Support and Well-being



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 has people who can help. Please speak with your health care 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 or doctors
- Patient and Family Support
 - Social Workers
 - Spiritual Care Providers
 - Registered Dietitian
 - Psychology and psychiatry
 - Occupational Therapist
 - Drug Reimbursement Specialist

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, social, psychological and emotional 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:

- Setting up health care for patients (for example, diagnostic tests, procedures)
- Physical comfort (for example helping with pain, nausea)
- Linking how you feel to your cancer and treatment (for example, feeling tired because your hemoglobin is low)
- Social, emotional and mental health support

What support can you get from social workers?

Social workers help patients and families deal with cancer diagnoses and treatment. They are part of the Patient and Family Support Program at the Odette Cancer Centre.

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

- The emotional stress of diagnosis and treatment (such as, feelings of fear, sadness, loss, anger)
- Financial issues (such as, income help, disability pensions)
- Drug coverage issues
- Transportation issues
- Home care concerns
- Community resources available to you
- Advanced Care Planning

Social workers can meet with you one-on-one or with your caregivers 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, please visit the patient and Family Support Offices (Odette Cancer Centre- T-wing ground floor TG-230), open Monday-Friday 8am-5pm or call 416-480-4623

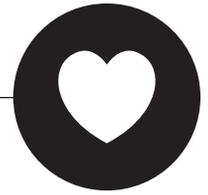
If you are admitted to hospital you can ask any member of your health care team to arrange an inpatient social work referral

What support can you get from Spiritual Care Practitioners?

Spiritual Care Practitioners (Chaplains) support the spiritual, emotional, and existential well-being of patients and families. They provide a safe space for patients and families to process their emotions and experiences. They support patients and families from a multi-faith context as well as a non-religious background.

- Helping people discover and explore what has meaning in their lives
- Grief support
- One on one counseling
- Prayer, meditation and reflection
- Requests for religious and spiritual rituals

Sexual Health and Intimacy



Many people find sex and intimacy hard to talk about. Not being able to talk about your worries can affect how you feel about yourself and your relationships with others.

It is normal to:

- Worry about being intimate with someone after treatment
- Have a lot of questions and worries about sex and intimacy after treatment
- Not know how to talk about this with your partner

There is support to help you with your worries, you can ask your health care team anytime and they can give you more information to find something that works for you.

Tips Before you start sexual activities after treatment

- Think about how you are feeling
- Know what your blood counts are and if you can start sexual activities
- Try to talk openly with your partner about how you are feeling
- Make sure to secure your Hickman line or PICC line to prevent it from coming loose during sex

Tips During Sexual Activities

- Use condoms to prevent pregnancy
- Use condoms to protect against sexually transmitted infections
- Maintain good hygiene
- Avoid lubricants with scents, chemicals or petroleum based because they may irritate your skin and damage condoms
- Sex and intimate activities might feel painful or uncomfortable, talk to your health care team if you feel this
- Men may notice some changes to erections after chemotherapy
- Talk to your health care team if these changes are bothering you

Conserve your Energy

It is normal to have 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
- Stress

Medications



It is important to know what medications you take and why. Keep a current list of what you take with you at all times.

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 over-the-counter medications (for example, non-prescription medications), vitamins, herbal medications you are taking, including cannabis or marijuana
- Speak with your doctor before you or your family members get any shots (such as flu shots, childhood vaccines)
- Speak with your doctor or pharmacist before you refill medications
- Let your health care team know if you need help paying for prescriptions
- Speak with your hospital pharmacist if you would like help updating your medication list or if you would like a schedule that might include your new chemotherapy medications

How should you store your 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
- Consider using a pill box or blister pack to organize your medications. You can speak to your hospital or community pharmacist about how to set this up
- Put your medications in a dry and cool place, but not in the bathroom or fridge unless told to do so by your doctor or pharmacist
- Store your medications out of the reach of young children

How should you take medications at home?

- Do not drink alcohol, grapefruit or pomegranate juice with medications. Speak to your health care team if you have questions or concerns about this
- Avoid taking pain medication that may raise your risk of bleeding (for example: Aspirin, Advil, Aleve, Ibuprofen, Naproxen)
- Do not take Tylenol (acetaminophen) before taking your temperature. This medication may hide a fever.
- 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

Advance Care Planning



What are Advance Care Planning (ACP) Conversations?

- Advance Care Planning (ACP) conversations are a way to think about what is important to you, what you value in life and about your health
- Advance Care Planning is about knowing who your Substitute Decision Maker(s) (SDMs) would be if you are not capable of making health care decisions for yourself
- Advance Care Planning is NOT about making decisions about your health today. It is to help SDMs understand what is important to you. This information that will guide them in making health care decisions on your behalf in the future should the need arise.
- Communicating what is important to you, what you value in life and about your health can help prepare your SDM and you to make health care decisions in the future

Why have ACP Conversations?

- You will be able to share what is important to you, what you value in life and about your health
- You will be more likely to receive the care that you identified as important to you
- Your SDM(s) will understand what is important to you so they can make the best decisions for you in the future should you ever be unable to make decisions for yourself

Who is your Substitute Decision Maker (SDM(s))?

- In Ontario everyone automatically has a Substitute Decision Maker (SDM)
- Your SDM is your closest living family member unless someone is legally appointed
- There might be more than one person at the same level. For example, if you don't have a spouse or partner, but have 3 children, all 3 children are your SDM(s). In the future, if you are not capable, all 3 would need to agree on any healthcare decision.

See the table below for the rank order of people who could be your SDM(s):

Decreasing Order of Authority	Court Appointed Guardian	Legally Appointed SDMs
	Attorney for Personal Care	
	Representative Appointed by Consent and Capacity Board	
	Spouse or Partner	Automatic Family Member SDMs
	Parents or Children	
	Parent with Right of Access Only	
	Siblings	
Any Other Relative	SDM of Last Resort	
Public Guardian and Trustee		

Recreated from *Ontario's Health Care Consent Act, 1996*



What is Palliative Care?

Palliative Care helps patients with a life-limiting disease by making the quality of their life, or death, better. Members of the Palliative Care Consult Team (PCCT) at Sunnybrook can help patients with the pain, symptoms and emotional concerns that often come with a serious illness. The PCCT are experts in helping patients and families make decisions for their current care and future care plans (a process called: *advance care planning*).

Why am I being cared for by Palliative Care?

During your time in hospital, your main health care team asked for help from the Palliative Care Consult Team because they are experts in pain and symptom management and supporting patients who may go home after their hospital stay. Having a member of the PCCT team visit you in hospital does not necessarily mean that your life expectancy is short.

What does the PCCT do?

The Palliative Care Consult Team are a group of doctors, nurses, a social worker, a chaplain and administrative staff. They provide care to patients admitted to Sunnybrook and patients who attend the clinics at the Odette Cancer Centre. The PCCT works with your main health care team to offer the best possible care to patients with advanced illness.

Is the Palliative Care Consult Team the same as the Palliative Care Unit at Sunnybrook?

No. They are two different services. The Palliative Care Unit (PCU) is a unit in the hospital where patients with a serious illness are admitted. The PCU staff offer care to patients who are at the end of their life. The PCU is located on the first floor of Kilgour Wing (K1E) and is designed to create a comfortable home-like space.

The Palliative Care Clinic at Odette Cancer Centre:

- Is made up of a doctor, nurses, pharmacists and social workers who have experience in managing complex cancer-related symptoms.
- Runs every Monday – Thursday afternoon and every other Friday morning.

Leaving the Hospital



When you leave the hospital:

- You will be given a follow-up appointment at the Odette Cancer Centre (T-wing 1st floor) or at an outpatient clinic in C606.
- If you are booked for a clinic appointment, get your blood work done before the appointment if instructed to do so.
- Make sure you understand your medications. A physician, Nurse Practitioner or Pharmacist can go over them with you.
- Make sure you know how your PICC or Hickman line will be cared for
- Make sure you know where to go in an emergency and who to call with questions.

Important Phone Numbers

Monday to Friday, 8:00 AM – 5:00 PM

- Please call the Complex Malignant Hematology Outpatient Unit (C606) phone number: 416-480-6100 ext. 4312

After hours weekdays 5:00 PM – 8:00 AM, weekends and statutory holidays

- Please call 416-480-4244 (locating) and ask to page the Leukemia Complex Malignant Hematology pager to speak to the Nurse Practitioner or Resident/Fellow On-call



Important Phone Numbers

Sunnybrook Health Sciences Centre: 416-480-6100

Monday to Friday, 8:00 AM – 5:00 PM

- Please call the Complex Malignant Hematology Outpatient Unit (C606) phone number: 416-480-6100 ext. 4312



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