Patient Education

Symptom Management Through Treatment

A Reference Guide for Patients and Caregivers

Included in this guide:

- **POTENTIAL** side effects and tips on how to manage them
- Blood transfusion information
- Exercise recommendations
- Frequently asked questions on infection control

PLEASE REMEMBER:

- **You may not experience all the side effects in this guide**
- Your health care team will monitor and support you through any side effects that you may experience.

The Leukemia/Bone Marrow
Transplant Program of BC

Managing Side Effects

What are side effects?

Side effects are symptoms / changes in your body caused by the treatment you received. Side effects from cancer treatment are very common. They can happen any time after treatment begins. They may occur as soon as you start taking medications, a few days after starting treatment, or only after you have been taking a medication for a while.

When will the side effects go away?

Side effects from treatment tend to feel the worst when your white blood cells are low. You will notice most side effects / symptoms start to improve when your white blood cells start to recover and normalize. Other symptoms may take longer to go away.

While reading through this booklet, please remember:

1. **Always tell your health care team about any side effects / symptoms you notice, even if they seem minor.** We rely on you to tell us how you're feeling. When you let us know of a side effect early, it may be managed better and with less chance of complications. Controlling one problem may also relieve others.
2. **Everyone is different** and each treatment plan is specific to each patient. It is normal for some people to have more side effects than others. Don't feel discouraged if you have a different experience than someone else.
3. **Some side effects are more common than others.**
4. **For every side effect**, there are medications, comfort measures and recommendations from your health care team to help you manage them.
5. **Each side effect can vary** from mild to severe. You may not get a severe case of any side effect. Side effects that you may experience depend on:
    - your treatment schedule
    - the drugs you get
    - how your body reacts
    - your general physical health

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Infection and Fever

The chemotherapy you receive lowers your white blood cells. Normally, your white blood cells protect you from the bacteria, viruses and other harmful organisms you encounter every day. Without your white blood cells, any type of germ can make you very sick with an infection. An infection is the invasion and spread of harmful bacteria, viruses, fungi, etc. that may or may not be normally found in your body.

Having a fever is a common but serious symptom. It is an important signal that tells us your body may be fighting an infection. We act quickly when you have a fever to stop an infection from causing serious harm.

Most patients on our units have weak immune systems (low white blood cells). We take extra care to protect everyone through infection prevention.

What can help:

- Take your antibiotics, antifungals and antivirals as instructed. These medications help protect you from infections while your white blood cells are low.
- Proper handwashing is the best way to prevent infections. You and all of your family members and visitors should wash your/their hands often with soap and water, especially before eating and after using the toilet. Carry a bottle of waterless hand sanitizer when you are out of your home.
- Check your temperature twice a day in the morning and early evening. Check it more often if you're feeling unwell.
- Do not take (acetaminophen) Tylenol® unless we instruct you to.
- Call us immediately if you have any signs of an infection including:
  - A fever of 38°C (100°F) or higher.
  - Chills or shaking
  - Burning or pain when you urinate.
- Family and friends should NOT visit you if they have any signs of illness (i.e. new cough, fever, diarrhea, vomiting, sore throat, runny nose, etc.).
- Shower daily or every other day. Keep your body clean.
- Clean your anal area gently and thoroughly after a bowel movement. Wipe from the front (genitals) to the back (rectum) to avoid urinary tract infections.

- Avoid touching your face and mouth with your hands.
- Avoid crowded areas such as malls, markets, buses, and movie theatres.
- Do not go swimming or use hot tubs if you have a CVC IV line or a low white cell count.
- See the "*Food Safety for Patients with Weakened Immune Systems*" booklet for tips on how to prepare food safely, and safer food choices to eat during this time.
- See page 42 for more infection control suggestions.

How and When to Take Your Temperature:

- Take your temperature with a digital thermometer in Celsius twice a day: when you get up in the morning &Y in the early evening (around 4 pm).
- Take your temperature more often if you don't feel well.
- Don't take your temperature after eating or drinking, wait 5 minutes.
- Clean your thermometer with warm water and dish soap, then allow it to air dry.
- Call us immediately if you have a fever of 38°C (100°F) or higher. We will give you instructions to follow.

Fevers and Acetaminophen (Tylenol®)

Acetaminophen (Tylenol®) is commonly used as a pain medication; however, it also hides or "masks" a fever. Tylenol may bring down your temperature. It will not fight any infection in your body. This is why great caution must be used when taking Tylenol.

- Do not take Tylenol® unless we instruct you to.
- Always check your temperature before taking Tylenol®.
- If you have a temperature between 37.5°C – 37.9°C, do not take Tylenol®. Recheck your temperature in 20-30 minutes. If you develop a fever, contact us.
- Keep Tylenol in your medicine cabinet. Sometimes fevers may continue after new antibiotics have started. Tylenol can bring you relief by bringing down a high fever and relieving aches. Our team will tell you when it is safe to take Tylenol®.

Anemia

Anemia is a condition in which you don't have enough healthy red blood cells to carry adequate oxygen to the body's tissues. There are many forms of anemia, and each form of anemia has its own cause.

Some treatments can reduce your red blood cells and cause anemia. If you have anemia, you may feel very tired, dizzy or short of breath. You may have pale skin and feel weak or cold. The symptoms will go away as your body makes more red blood cells. We monitor your blood tests and use hemoglobin, a protein attached to red blood cells, to determine if you need a blood transfusion.

What can help:

- Tell your health care team if you are feeling dizzy or weak. Depending on what your blood results are, you may receive a blood transfusion (see page 34)
- Move slowly to avoid getting dizzy. When you get out of bed, sit on the side of the bed for a while before you stand up. Once you stand up, ensure you feel stable on your feet before you start walking.
- If you're feeling weak or dizzy, call a nurse (or family member when at home) to help you to your chair or the bathroom. This is not an imposition; it is much safer for you to accept help than for you to fall and injure yourself.
- Try to eat foods that are high in iron, such as green, leafy vegetables, liver and cooked red meats. A dietitian can help you choose foods that may help you feel better.
- Limit your activities. Do only what you have to or what is most important.

Bleeding and Bruising

Some chemotherapy drugs can cause your body to make fewer platelets. Platelets are cells that help the blood to clot and stop bleeding. Without enough platelets, you may get bruises even when you haven't bumped into anything.

We use blood tests to monitor your platelet levels. We generally give you a platelet transfusion when your levels drop low, you are bleeding, or before certain procedures.

What can help:

- Talk to your nurse or doctor about any bleeding or bruising issues. Depending on your blood results, we may give you a platelet transfusion (see page 34).
- Be extra careful to not bump, cut or burn yourself. Make sure you are steady on your feet and seek assistance as needed, so you do not have a fall.
- Blow your nose gently to prevent a nosebleed. Do not pick your nose.
- Use a very soft toothbrush or cotton swabs to clean your teeth.
- Use an electric shaver instead of a razor.
- If you are female and are having bleeding or spotting from your period, talk to your nurse or doctor. Please only use pads, do not use tampons.
- Petechiae ("puh-tee-kee-ah") are small purple or red spots on your skin that usually appear in clusters. They happen with a lower platelet count and although they are not harmful, need to monitor them.
- Be extra careful when you use a knife, scissors or any sharp tool.
- Call us immediately if you have any of the following:
  - Vomit that looks like coffee grounds
  - Black, tarry bowel movements
  - Bright red blood in your urine or stool

Blood Transfusions

What is a transfusion?

Many different products are made from human blood. If you receive any of these products, it is called a transfusion. These products are given through a needle inserted into your vein.

Why are transfusions needed?

Receiving blood products when they are needed can save your life. A transfusion may be needed if:

- you lose more than 20% of your blood - this would be more than 4 cups
- you are anemic (have low levels of red blood cells) and medicine has not helped
- your platelets or clotting factors are low or not working properly.

Where does donor blood come from?

Whole blood is collected from volunteer donors, by the Canadian Blood Services. Donated blood is tested and then separated into its different parts. Benefits are carefully weighed against the risks before any blood products are given. If you need a transfusion, you will be given only the part you need. Canada's blood supply is known as one of the safest in the world.

What can be transfused?

Red Blood Cells: Red cells carry the oxygen in your blood to vital organs. At present, there is no proven substitute for red blood cells. A red cell transfusion may be necessary to prevent damage to your organs due to lack of oxygen.

Platelets: Platelets are needed to prevent or stop bleeding by forming blood clots at the site of injury. Platelet transfusions may be required for patients who have a low number of platelets, or if your platelets are not working properly.

Plasma: Plasma is a fluid that contains many substances including the proteins that help blood clot.

Albumin: Albumin is a protein from plasma that can be used to replace fluid that has been lost.

Immunoglobulin Preparations: Immunoglobulins are proteins that help fight infection.

What are the risks of transfusion?

Your doctor will discuss the risks of blood transfusion with you and your family. As most blood products come from other human beings, there are associated risks. Some reactions that can occur are:

- **Allergic:** These are common, usually mild and easily treated with medications. Severe allergic reactions are rare but can occur.
- **Fever:** A reaction to donor blood products may result in a fever. This may happen during or shortly after the transfusion. The fever may or may not need treatment. The symptoms may include feeling cold or having chills. Patients who have had a fever reaction with transfusion in the past should tell their nurse.
- **Hemolytic Transfusion Reaction:** This rare reaction happens when the patient's blood destroys the donor red cells. A bad hemolytic reaction can result in kidney failure. Careful blood testing is used to ensure the correct blood is given to prevent this reaction.
- **Transmitted Infections**: The chance of long-term infection (such as Hepatitis B or C, HIV or West Nile Virus… etc.), resulting in injury or death is very small. At this time, risks cannot be completely removed by available testing or processing.

What are the risks of not having a transfusion?

The red blood cells carry the oxygen in your blood to vital organs such as the brain or heart. A decrease in oxygen could result in damage to these organs. Transfusion may be needed to prevent such damage. Based on your condition, your doctors will decide when a transfusion is needed.

What are the alternatives to transfusion?

Alternatives may be available to you depending on your condition. You will need to discuss with your doctor other options such as drugs that stimulate red cell production and IV fluids to dilute your blood.

If you choose to refuse blood and/or blood products, you must complete a “Refusal to Accept” form for each admission and/or each course of treatment. In the absence of written refusal, medical staff will give blood and/or blood products if considered necessary to preserve life or health. For more information, please speak to your doctor.

Appetite Changes

While you're receiving treatment, your body needs more energy than usual. Eating helps you heal. Getting enough calories, proteins, vitamins and minerals will help prevent muscle and weight loss and may also cause less treatment side effects.

You may not feel like eating because of nausea or because of a sore or dry mouth. Appetite loss, fatigue, taste changes, stress or depression can make you want to eat more or less than usual.

Tips when you lose your appetite:

- Ask your nurse for a referral to one of our dietitians. They can offer helpful suggestions specific to your situation.
- Eat whatever you can manage, even if this means eating the same foods for a while. Your taste sensations will eventually improve.
- Instead of big meals, eat smaller meals and snacks more often.
- Relax and take your time while eating. Eat when your energy is highest.
- Eat what works for you. Eat breakfast foods at suppertime if you feel like it.
- Save your favourite foods for when you are feeling better. Eating your favourite food when nauseated can make you not like them.
- Try to add calories and protein to meals: peanut butter, higher fat milk, cream, eggs, cheese, yogurt, tofu, gravies, ice cream, nuts, beans.
- Higher nutrient fluids: fuller fat milk, smoothies, meal replacement drinks, cream soups, and hot chocolate. (Caution: dairy products can cause diarrhea).
- Light exercise and a walk before meals can help boost your appetite.
- Try the "mind over matter" approach. Even though you may not feel like eating or not find it enjoyable, think of food as something your body needs for you to heal, much like a medicine.
- Be patient with yourself, your appetite will come back.
- For help with taste changes, look up "Food ideas to cope with taste" on www.bccancer.bc.ca or talk to your dietitian.

Appetite Changes (continued)

What should I drink during treatment?

- Drink enough fluids to keep your urine pale yellow. If you notice your urine becoming darker in color, try to drink more fluids.
- Try to drink 1.5 - 2 liters of fluid every day, even if you are on intravenous fluids. Water, juice, soups, sports drinks and even Jello are all good fluids to drink.
- Coffee, tea, and sugary soft drinks (i.e., Coke®) count as fluid. They should be limited if possible. They can cause you to urinate more (a "diuretic" effect) or have difficulty sleeping.
- Meal replacement drinks are also a good source of calories and nutrients (Ensure®, Boost®, Resource®, etc.) Protein powder can be added to meals, ice cream and smoothies to add nutrients to your diet when your appetite is low.

Some people find it hard to drink 2 liters of fluid. Most manage by drinking small amounts (½ cup or even just sips) throughout the day. Everyone will find their own preferences and any fluid is better than nothing, especially if you're having trouble eating.

Please also see sections on *Nausea and Vomiting, Mouth and Throat Soreness.*

Resource Booklet:

***Eating Well When You Have Cancer.* Canadian Cancer Society**

Go to www.cancer.ca search "eating well when you have cancer" and click on the result "Eating Well When You Have Cancer".

Mouth and Throat Soreness (Mucositis)

It can be common to develop a dry or sore mouth several days after chemotherapy. This is referred to as mucositis (“mew-co-SYE-tiss”). You may notice small canker sores on the inside of your cheeks or lips, under your tongue or on the base of your gums.

What can help:

- Tell your nurse or doctor if you have pain or notice sores in your mouth or throat. Special mouth rinses can numb your mouth and throat to make it easier to swallow. Pain medications can also be used for comfort and to help you eat.
- Brush your teeth with a soft toothbrush. You will be prescribed a special mouth rinse to use before breakfast and at bedtime. Add water it if tastes too strong.
- Use lip balm to keep lips moist and prevent cracking.
- It is safe to floss if this is your usual routine. Stop if you notice bleeding gums.
- Try soft foods that are moist, soft, bland and easy to chew or swallow such as eggs, smoothies, cream soups, yogurts, cooked cereal, mashed potatoes, ice cream and ground meats. Gravies, sauces and soups can help soften foods.
- Eat whatever you can manage but try to avoid hot, spicy, acidic, hard or crunchy foods such as toast and hard tacos.
- Ice chips, hard candies and popsicles can help relieve dry and sore mouth.
- Remove dentures as often as you can to give your gums a rest. Keep dentures clean.

Total Parenteral Nutrition

Sometimes treatment side effects can make it more difficult to eat. This is normal and can be caused by nausea, appetite loss, or a sore mouth and throat. Every day, our team assesses how much you’re able eat and will offer suggestions on how to make the most of your meals.

If you lose a lot of weight, have severe diarrhea or are not able to eat and drink enough to get the extra nutrition you need, you might temporarily receive TPN (Total Parenteral Nutrition). TPN is a supplemental nutrition, except that it is given intravenously (IV) through your CVC IV line. **TPN is only used in patients receiving an inpatient transplant.**

Nausea and Vomiting

Nausea is when you are feeling sick to your stomach and feel like you have to throw up (vomit). Some diet suggestions are listed but **eat whatever you can manage**.

What can help:

- Talk to your nurse, doctor and dietitian.
- Take prescribed anti-nausea pills as instructed and take more “as needed”.
- Instead of big meals, eat smaller meals and snacks more often.
- Avoid foods that are very sweet, greasy, fried or spicy or that have a strong smell.
- After eating, avoid lying down for at least half an hour.
- Relax and take your time while eating.
- Save your favorite foods for when you are feeling better. Eating your favorite food when nauseated can make you not like them.
- Sip water and other liquids (ginger ale, sports drinks, broth) throughout the day.
- If you’re feeling nauseated, take deep slow breaths through your mouth or place a cool cloth over your eyes and forehead.
- Distract yourself by listening to music, watching a movie or talking to loved ones.
- Smelling (not eating) aromatherapy oils can be helpful with nausea.
- Cannabis has anti-nausea effects although its use on hospital property is restricted. For more information, talk to your team and refer to the “*Cannabis Information”* handout.

Some people feel nauseated before treatment because they feel anxious and expect to be sick. To avoid this “**anticipatory nausea**”, try the tips below.

- Try relaxation techniques before treatment begins, (see *Anxiety and Stress* tips).
- Distract yourself or talk to someone. Keep your thoughts away from feeling sick.
- Your doctor can also prescribe medicine to help you relax and have less nausea.

If you're feeling nauseated, some foods and fluids that may be easier to eat include:

- Broth, water, peppermint tea, ginger tea
- Popsicles, watered-down juices, Gatorade®, "flat" pops (i.e. ginger ale)
- Jell-O®, sherbet
- Soda crackers, Melba toast, pretzels, dry cereals, dry toast, plain cookies
- Boiled potatoes, noodles, rice, congee
- Light soup – chicken and rice, vegetable
- Boiled or baked lean meat, poultry and fish
- Skim or 1% milk, low fat yogurt, cheese
- Applesauce and fresh, frozen or canned fruit and vegetables

Avoid foods that can make nausea worse (but eat whatever you can manage!)

- Fried meats, fried eggs, sausage, bacon
- Broccoli, brussel sprouts, onion, garlic
- Doughnuts, pastries, coffee, other rich sauces and foods

When Should I take "As Needed" Anti-Nausea Medications?

Your doctor will prescribe you anti-nausea medications to take "as needed." They can be given in pill or capsule form or, while you're in hospital, intravenously (IV).

Anti-nausea medicines work best when you take them before or as you're starting to feel sick. They may not work as well if you take them just as you are about to throw up (vomit). If you're feeling nauseated and one medication doesn't work after an hour, try a different one. Tell your doctor or nurse if these medications do not relieve nausea and vomiting. They can make suggestions or prescribe other medicines.

If you have nausea and vomiting at certain times of the day, take or ask for your anti-nausea medicine at least 30 minutes before that time. For example, if you often have nausea or vomit before meals, take an anti-nausea medication at least 30 minutes before your meal. If you vomit within 1 hour of taking your anti-nausea pill, you can take another pill.

Anti-nausea medications can cause side effects, including sleepiness, constipation, or diarrhea. **Most people feel that these side effects are worth the benefit of having their nausea relieved.**

Constipation

Constipation means you’re not having bowel movements as often as you used to. Your stool becomes hard and dry, and having a bowel movement can be difficult or painful.

Changes in your normal bowel movements may be caused by drug treatments for cancer or other drugs you’re taking to manage nausea, diarrhea, depression, blood pressure changes or pain. Constipation can also happen because you’ve changed your eating habits, you’re drinking less liquid, or you’re less active.

What can help:

- Talk to your nurse, dietitian and doctor. They can help suggest stool softeners, laxatives and other diet options that can help with constipation symptoms.
- Add more fiber to your diet a little at a time. Examples of foods with high fiber are whole grain breads and cereals, brown rice, vegetables, fruit (including dried fruit), legumes, beans, seeds and nuts.
- Drink plenty of liquids throughout the day. Try water, fruit or vegetable juices, teas and lemonade. Hot or warm liquids like cocoa, tea or lemon water can also help.
- Eat natural laxatives such as prunes, prune juice, coffee, and papaya.
- Be more physically active, even short walks may be beneficial.
- Do not strain to have a bowel movement. This can cause issues with bleeding, infection and hemorrhoids. It can even cause you to faint on the toilet.
- Do not use any rectal suppositories or enemas while receiving treatment. They can cause bleeding and increase your risk of infection.

Diarrhea

Diarrhea means you have soft, loose or watery stools more than 3 times in a day. You may also have cramps and bloating or feel an urgent need to have a bowel movement.

Some drugs can cause diarrhea. Diarrhea can also be caused by infections or drugs used to treat constipation. It's important to tell your healthcare team if you have diarrhea so they can determine the cause and manage it.

What can help:

- Tell your nurse or doctor if you have diarrhea. Depending on how frequent it is, a sample may be taken to test for infection.
- Use soft toilet paper. Clean your bum with mild soap and water after each episode of diarrhea. Rinse well and pat dry with soft toilet paper.
- Tell your nurse or doctor if you have any pain or bleeding in your rectal area. Drink plenty of fluids, at least 8 to 10 large glasses a day. Try water, broth, fruit juices, Jell-O and sport drinks.
- Eat high potassium foods such as bananas, meats and potatoes.
- Limit the use of irritants such as coffee, chocolate and prune juice.
- Ask your doctor before taking any over-the-counter medications for diarrhea.
- Consider using a sitz bath, a basin that sits on your toilet. This allows you to soak your genitals and rectal area to help clean and relieve pain. Sitz baths are available on the inpatient unit and at any local pharmacy. Do not insert anything into your bum, such as rectal suppositories or enemas
- Ask your nurse about the use of protective barrier creams to reduce the amount of skin irritation from frequent wiping.

Hemorrhoids

Hemorrhoids are a common problem people have. They are swollen veins found both inside and outside the anus. Hemorrhoids can worsen because of chemotherapy side effects.

Hemorrhoids can cause bleeding during bowel movements, itching and rectal pain. You may notice streaks of blood on toilet paper or bright red blood in the toilet bowl. Some hemorrhoids can become very sensitive and painful. This can lead to difficulties having a bowel movement, constipation and difficulty sitting in a chair.

What can help:

- Tell your nurse or doctor. This is very important when you notice any type of bleeding from your rectum.
- Do not strain while on the toilet. This can make hemorrhoids worse.
- Use soft toilet paper. Clean your bum with mild soap and water after each bowel movement. Rinse well and pat dry with soft toilet paper. Although it can be painful, cleaning well will help lessen your risk of infection and skin irritation.
- Try to keep your bowel movements softer to reduce pain. Talk to your health care team about medications and diet changes to help keep your stools soft. Recommendations can be found in the section on constipation.
- Your doctor can prescribe creams or sometimes pain medications that can relieve discomfort and make it easier to pass a bowel movement. Do not insert any creams into your bum, they should only be applied to the surrounding skin.
- Consider using a sitz bath, a basin that sits on your toilet. This allows you to soak your genitals and rectal area to help clean and relieve pain. Sitz baths are available on the inpatient unit and at any local pharmacy.
- Seat cushions can help with discomfort while sitting. Occupational therapists can provide one on the inpatient unit or coccyx cushions can be purchased at a local pharmacy. DO NOT use a donut cushion – this is not supportive.

Pain

Pain is more than just hurting. It's also uncomfortable and upsetting. When you're in pain, it can be harder to fight cancer or perform day-to-day activities.

Discussing what causes your pain, what type of pain it is and its patterns can help you and your health care team prevent or lessen it. For example:

- Where do you feel pain? When did it start? What makes it better or worse?
- What does the pain feel like? Is it dull, sharp, burning, pinching, stabbing?
- How strong is the pain from 0 to 10, (0 is no pain, 10 is worst pain imaginable)

What can help manage pain:

- **Tell your health care team** if you are experiencing pain. They can suggest comfort measures and sometimes pain medications that can help your body relax and rest. Your body needs rest and relaxation to be able to heal.

- **Avoiding pain medicine side effects:** Tell your healthcare team if you have any side effects from your pain medicine. Many people choose not to take or stop taking their medication because of side effects, but they can often be managed.

- **Constipation** is a key side effect of all strong (narcotic) pain medications. It is important to carefully follow a bowel routine. Talk to your team and see the section on Constipation.

- **Try to stop pain before it gets worse:** Sometimes people wait until their pain is bad or unbearable before taking medicine. Pain is easier to control when it's mild. If you wait, your pain can get worse, it may take longer for the pain to get better or go away, or you may need larger doses to bring the pain under control.

- **Try relaxation techniques.** Relaxation can help relieve tension and pain. If possible, **continue to stay active.** Gentle stretching and movement may help.

Resource Booklet:

Pain Relief: A Guide for People with Cancer. Canadian Cancer Society

Go to www.cancer.ca search "pain relief" and select "Pain Relief: A guide for people with cancer"

Exercise and Staying Active

Be as active as possible during treatment and recovery. Being active can reduce stress or anxiety, improve your mood and self-esteem, boost your energy, improve your appetite, help you sleep and prevent loss of muscle mass and help you regain your strength during recovery. It can also help with side effects like nausea, fatigue and constipation.

Check with your doctor and physiotherapist before starting any exercise program. This is true even if you exercised regularly before being diagnosed.

Some general safety precautions include:

- Avoid public places, such as gyms, if you have low white blood cell counts or a weakened immune system. Walking around the block is a great option.
- Pace yourself and remember to walk shorter distances.
- If you get short of breath or tired, slow down or sit and rest before continuing. A wheeled walker is a great tool to help you walk and take seated rests as needed.
- Avoid uneven surfaces or any exercises that could cause a fall or injury.
- Do not swim if your white blood cell counts are low or you have a central IV line.
- **If platelets are under 100,** no massage or heavy resistance exercise.
- When your **platelets are below 20** avoid any resistance exercise.

After treatment recovery, build your exercise routine slowly and ask your doctor before starting sports and activities that put you at risk of injury.

General exercise guidelines during and after treatment

Each person’s exercise program is unique and should be based on what is safe and works for that person. There may be times when you do not feel able to exercise. The goal is to be as active as you comfortably can be to do the things you want to do. The goal is to maintain your strength and endurance during treatment.

These tips may help:

- Start slow with something simple like walking and slowly increase how often and how long you walk.
- If you are unwell, listen to your body and do what you can
- Try to incorporate some movement into your day, even if you are feeling unwell. Sometimes a few minutes sitting up in a chair can make you feel better.
- Even short movement breaks are beneficial if a longer exercise session is not tolerable.
- Vary activities to include strength, stretching and aerobic activities such as walking or using a stationary bike.
- Make exercise enjoyable by exercising with a friend or listening to music.
- Drink plenty of fluids before, during and after exercise. Rest when you are tired.
- **On the inpatient unit**:
    - Walk in the halls 3 – 6 times a day, or as much as you are able.
    - Try to be up in your chair and walk around the room. Sit in your chair for meals.
    - Do arm and leg exercises daily when advised by your physiotherapist, especially if you are not walking much.
    - Ask for an “ADL tracker” to guide and monitor your activites.

Physiotherapists (PT) will help you maintain and regain your strength through treatment and recovery. They help you design an activity program based on your needs.

Occupational Therapists (OT) will help you manage everyday activities, moving safely, coping with symptoms and any equipment needs you may have to get you through the day.

Our PT and OT teams will introduce themselves to you when you are on the inpatient unit. On the outpatient Daycare unit, PT and OT are available by referral.

Exercising your lungs: Deep Breathing and Coughing

When you are not able to move around very well and/or your white blood cell count is low, it is easier to develop a lung infection. A lung infection (i.e. pneumonia) can lengthen the amount of time you spend in hospital.

Staying active and deep breathing exercises are important ways to prevent a lung infection:

1. Find a comfortable position such as lying on your back with your knees bent, lying on your side, or in a sitting position
2. Place your hands on your stomach and take a deep breath in through your nose. Continue until your lungs feel full of air and you notice your stomach pushing against your hand.
3. Slowly blow air out in one long, slow breath through pursed lips. When you breathe out, try to make your stomach sink in. Try to do 5 deep breaths.
4. Take another deep breath, hold for 3 seconds then huff out 3 times. Huffing is a short sharp pant or like pretending to create a mist on a pane of glass. On the third huff, cough deeply from your lungs, not your throat.
5. Try to build to 5 coughing exercises, or as many as you are able.
6. These exercises can be done every hour while you're awake. Set an achievable goal (i.e. doing breathing exercises 3 times a day) and build from there.

Simplified Deep Breathing and Coughing:

- Take a slow, deep breath in through your nose. Hold your breath for 3 seconds and then breathe out through your mouth. Do a strong cough (from low in your lungs, not from your throat). This can be done sitting or while walking.

Ask our team about an **incentive spirometer**, a simple device that can help with deep breathing.

Fatigue

Fatigue is the term used to describe lack of energy, feeling weak and tired. It is the most common symptom felt by people with cancer and tends to be the last side effect to go away after treatment.

What to do:

- Balance your rest and activity through the day. Pace yourself.
- Try to limit the length of visits with family and friends.
- Light exercise such as walking around the block can help boost your energy. When going for walks, space them in two to three small time blocks, rather than one large walk.
- Plan activities when you are more rested.
- Sit when possible while completing a task. Sit to dress and shower.
- Delegate tasks to family and friends (e.g., meal prep, laundry, and shopping).

For more information on fatigue management please speak with your occupational therapist.

These educational videos, created by our program, are also helpful:

Introduction to Energy Conservation	**Five Principles of Energy Conservation**	**Using the 5 P's At Home**

Ways to cope with fatigue for both patients and caregivers:

The following pages in this booklet can also help you manage fatigue: *Anxiety and Stress, Appetite Changes, Exercise, Sleep Changes.*

- **Rest when you need to**. Take short naps of 15 or 30 minutes rather than longer naps during the day. Too much rest or too little, can make you feel more tired. Save your longest sleep for the night.
- **Balance your rest and activity.** Keep track of when you feel most tired and when you have more energy so you can plan activities at the best time.
- Try to **limit the length of visits** with family and friends. Although people have good intentions and want to help, sometimes it is best to just say no. In hospital, ask your nurse if you need help limiting the length of time visitors stay.
- Update family and friends with group texts/emails or social media (or delegate this task).
- **Let others help**. Ask friends and family to grocery shop, cook, do laundry or babysit.
- **Drink plenty of fluids**, especially water. Frequent smaller meals can be easier than 3 large meals.
- **Light exercise** such as walking around the block or unit can boost your energy.
- Anxiety, stress and emotions can be exhausting. See tips in *Anxiety and Stress.*
- **Find support.** Talk to someone about how your fatigue makes you feel. Join a support group in person or online. You can find more information on support groups in the "*Resources and Support"* booklet.

To save energy and time involved in meal preparations:

- Keep easy to prepare foods and snacks on hand and in the freezer.
- Order take-out from restaurants. To find a reputable restaurant, click "VCH Inspection Reports website" at: www.vch.ca search "Restaurant Inspections and Reports". Scroll down and click on "Restaurants Inspections and Reports". Click on "View inspection reports".
- Most major grocery stores allow you to enter your grocery list online. You can pick up your order in the store for free, or have it delivered for a fee.

Fertility Changes

Fertility problems for a man means he cannot get a woman pregnant. For a woman, this means she cannot get pregnant or cannot carry a pregnancy to term. Some chemotherapy and radiation treatments can cause temporary fertility problems, and sometimes they can cause permanent fertility problems. Infertility does not affect your ability to have or enjoy sexual intercourse.

Men may be able to have their sperm frozen and saved in a sperm bank before treatment begins; **discuss this with your doctor as soon as possible.** For newly diagnosed females, talk to your doctor but it is usually not possible to arrange for embryo (egg) freezing before starting treatment. This is a lengthy process that can take 2 to 6 weeks. Unfortunately, any delay in cancer treatment could be life threatening. It is sometimes possible for females to deliver healthy babies after treatment is complete.

Preventing Pregnancy

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

If you are sexually active during treatment, please use birth control. Talk with your doctor about birth control and when it is safe to stop using it.

Coping with Changes in Fertility

Infertility can be very hard to come to terms with. The sense of loss can be strong for women and men of all ages. It can be very difficult to learn that you may no longer be able to have biological children. It can be devastating if you wanted to have a child or wanted more children. Some people are able to accept it and feel that coping with cancer is more important. Others seem to accept the news calmly when they begin treatment, but find that it affects them more deeply later, once the treatment is over.

You may feel you have lost a part of yourself if you can't have biological children. You may be very sad or angry that the treatment has caused changes to your body. Your self-confidence may be affected. It can help to talk to your partner, a relative or friend about how you are feeling. See www.fertilefuture.ca for more information.

Olive Fertility www.olivefertility.com has clinics in Vancouver, Surrey and North Vancouver. This is where most male patients have sperm banking done.

Hair Loss

Some chemotherapy drugs can cause temporary hair loss or thinning. Hair loss usually starts 2 or 3 weeks after treatment begins. It may start gradually, or your hair may come out in clumps. Hair loss can happen anywhere on your body.

Hair loss is usually temporary. Your hair may begin to grow back while you're still having treatment, or it may take 3 to 6 months after treatment to start growing back. Some people find that their new hair is curlier or slightly different in color than before.

What can help:

- Be gentle with your hair. Use a mild shampoo and a soft hairbrush.
- Consider cutting your hair short before it falls out. Longer hair comes out easier and makes hair loss more noticeable. A family member or salon can help you cut or shave your hair. This is your choice and you will know if and when you feel comfortable to do so.
- Use hats, head scarves, turbans or wigs to keep your head warm and protected.
- Protect your scalp from the sun using a hat or scarf. Use sunscreen.
- If you're interested in a wig, choose one before your hair falls out. You'll be able to find a close match to your own hair color and style more easily, or something fun!
- Ask your insurance company if it will cover the cost of a wig. If not, you can deduct the cost as a medical expense on your income tax return.
- People close to you, especially young children, may need to be reassured when they see that you are losing your hair.
- Talk about your feelings. Hair loss can sometimes be hard to accept.

- BC Cancer has more information on hair loss and a free "wig bank." Type "hair loss" on www.cancer.bc.ca or call 1 (888) 939 3333
- Learn about the Look Good Feel Better Program at 1 (800) 914 5665 or www.lgfb.ca

Anxiety and Stress

Cancer treatment can affect every part of your life, including your body, feelings, relationships, self-image and sexuality. Some patients say that the emotional impact of treatment can be harder to manage than the physical changes.

Anxiety is feeling afraid, overwhelmed or very worried. Feeling anxious when you have cancer is normal. If your anxiety becomes worse and starts to take over your thoughts and your daily life, tell your healthcare team. They can recommend someone you can talk to or give you medicine that can help.

Your emotions can change from day to day, or minute to minute. Your emotions may also change because of the step of the treatment process you are in. Some emotions can be caused or made worse by certain chemotherapy drugs as well as some hormonal therapies, steroids and pain medicines.

Some other feelings you may have include:

- Hopelessness, anxiety, helplessness, uncertainty, impatience, isolation
- Being out of control and overwhelmed
- Fear of sickness, death or the unknown

Depression

Depression means feeling sad, hopeless, tearful or discouraged or feeling the loss of pleasure in nearly all activities. These feelings can come and go. It could be a sign of clinical depression if:

- The feelings become worse or last a long time.
- You also feel worthless or guilty or have regular thoughts of death or suicide.
- You also have changes in appetite, weight, sleep or have a hard time concentrating.
- The feelings start to take over your thoughts and negatively affect your daily life.

Depression can and should be treated. It is not a sign of weakness. A person who is clinically depressed cannot just “cheer up” by will power alone. There are treatment options, counselling and anti-depressant medications available that can help.

What to watch for (possible signs of depression):

- Feeling hopeless or worthless
- Crying a lot or being tearful
- Not sleeping or sleeping too much
- Overeating or having no interest in eating
- Thoughts of harming yourself

What can help symptoms of anxiety, stress and depression:

- Let your health care team know you are feeling anxious. We can listen and help reassure you. Ask us questions so you will know what to expect.
- Talk to someone who has gone through the experience of anxiety, stress, or depression by connecting with a peer support program. More information on support groups and other resources can be found in "*Resources and Support.*"
- Eat well, get enough sleep and stay active. Try to take a few 10-15 minute walks each day to boost your mood and energy.
- Distract yourself by focusing on or doing an activity you enjoy. This will give you some relief from your thoughts and feelings. This may include: reading, meditation, listening to music, watching a favourite TV show or movie, painting, sketching, knitting, spending time with family and friends, etc.
- Put on headphones, close your eyes, and listen to something that will make you feel relaxed or happy: music, guided meditation, audiobooks, podcasts, etc.
- Set realistic small goals ("take one day at a time"). When you feel overwhelmed or you think what lays ahead will be too long or tiring, try taking it one day or even one hour at a time. This helps focus you on the here and now and see your progress one step at a time.
- Share your feelings with people you trust or spend time with people who make you laugh

Please see Resources and Support booklet or connect with your social worker or occupational therapist for more resources and information.

Memory Changes and Trouble Concentrating

Chemotherapy and some other medications can cause memory changes (sometimes called “brain fog” or “chemo brain”) You may notice you are forgetting things more often, having trouble focusing, or having trouble doing more than one thing at once (multi-tasking).

Your memory, attention and concentration will get better after treatment is over, but you may notice problems for a few months or longer after your treatment.

What can help:

Try to get enough sleep, track your fatigue levels and take movement breaks as well as brain breaks to decrease input. Write things down and ask others for help.

Attention: this is your ability to focus

- Reduce distractions – use noise cancelling headphones, find a quiet space
- Focus on one thing at a time
- Pace yourself and take your time

Memory:

Internal strategies:

- Repeat or rehearse what you need to remember.
- Use all your senses – say it, write it and see it.
- Make links to memories or stories.
- Use routines to support.

External Strategies:

- Journal/record the information.
- Use a planner, calendar or post it notes.
- Use technology – set alarms, use lists or notes and calendar apps.

Language – difficulty finding your words

- Describe the word, talk about it.
- Think of a similar word or use the opposite.
- Use gestures.
- Take your time and keep talking.
- Use scripts - “Sorry I need a minute”; “Do you know the word I am searching for?”.

Talk about your “invisible illness”. Brain fog and/or fatigue is something that cannot easily be seen by others. Your brain fog and fatigue might be hard to understand by those around you. To help others understand what you are feeling. Try the following:

- Tell people what you are going through.
- Tell others what makes these symptoms worse.
- Ask people you trust to assist you with difficult tasks and delegate as able.
- Share education material to your loved ones to increase their knowledge and understanding – this will offer them ways to be supportive.

Muscle and Nerve Problems

Some drugs can make your muscles feel weak or make you lose your balance. They can affect your nerves, causing numbness or a tingling (pins and needles) or burning feeling in your hands or feet.

Usually, these side effects are temporary. For some people, they may last for several months after treatment is over or be permanent.

Let your healthcare team know if you have any symptoms of weak muscles, numbness or tingling in your fingers. Your occupational therapist and physical therapist are important resources.

What can help:

- Be careful with sharp objects so you do not cut yourself.
- Check the bottom of your feet for cuts or other wounds.
- Move slowly and use handrails when you go up and down stairs.
- Use no-slip mats in the bath and shower; install grab bars.
- In your house, keep all areas clear so you do not trip.
- Protect your feet with shoes, socks or slippers.
- Use gloves when taking food out of the freezer.
- Test the water temperature with a thermometer before taking a bath.
- Regular exercise and activity can prevent weakness.

What to watch for – Signs of muscle or nerve problems:

- Tingling, burning, weakness or numbness in your hands or feet.
- Sensitivity to hot and cold or being less able to feel hot and cold.
- Pain when walking.
- Weak, sore, tired or achy muscles.
- Shaking, trembling, or losing your balance.
- Increased difficulty doing your day-to-day tasks (i.e. walking, stairs, picking up objects, buttoning your clothes, etc.).

Talk to your healthcare team if you have any of these problems.

Self-Image and Sexuality

Sexual health is an important part of your wellbeing. It can increase feelings of connection and satisfaction within a partnership, reduce stress/anxiety and depression, improve self-esteem and improve sleep.

Side effects of treatment (such as hair loss, weight changes, fatigue and emotional changes) can affect your sexuality. Common sexual changes include body image concerns, low sexual desire, difficulties with erections, pain during sexual activity, and relationship changes.

Here are some tips to cope with changes in your self-image and sexuality:

- Give yourself permission to have questions and concerns about your sexual health.
- Talk openly with your partner before and during sexual activities.
- Talk with your healthcare team. Questions can include:
    - Do I need to stop having sex during cancer treatment?
    - Will I need to keep using birth control during cancer treatment?
    - How will my fertility be impacted by cancer treatment?
    - How will my sexual function be impacted by cancer treatment?
- Try longer foreplay or touch new areas of your body to see what you respond to.
- Type "*sexuality*" into the BC Cancer website www.bccancer.bc.ca and the Canadian Cancer Society's website www.cancer.ca for more information.
- Being physically active improves self-image and energy.
- Learn about the Look Good Feel Better program in *"Resources and Support".*

It is safe to engage in sexual intercourse once your blood counts have recovered. In general, platelets should be higher than 50 and white blood cells should be 1.0 or higher. Please check with your doctor.

It is important to **use some sort of birth control** to prevent pregnancy while you're receiving cancer treatment. If a pregnancy happens with an egg or sperm that has been damaged by chemotherapy or radiation, there is an increased risk for birth defects.

Suggestions to make sex more comfortable:

- Use a water or silicone-based lubrication that is BPA and Phthalate free to help with comfort and dryness. Avoid lubes that have “tingly sensations” or are flavored/scented.
- Find positions that are comfortable. Use pillows as extra support.
- If you don’t have the energy for sex, there are other ways to be affectionate with your partner such as kissing, cuddling, and gentle massage.
- Try using sex videos or toys when libido is low, or you are tired.
- Use medical grade silicone vibrators or personal assistive devices. Wash them before and after in hot soapy water. Do not use antibacterial wipes on them.
- Avoid oral sex if your partner has active cold sores.
- Wash your hands before and after sex or masturbation.

Skin Changes

Some chemotherapy drugs and other medications can cause skin rashes, redness, itching, dryness, peeling or acne-like blemishes. A rash usually starts within a few weeks of starting treatment. It may start as redness or a warm feeling like a sunburn. The color of your skin may become darker. Some drugs may make your fingernails and toenails become darker, ridged, yellow, brittle or cracked.

These skin conditions usually go away once treatment is over. Your healthcare team can suggest a treatment specific to your symptoms (i.e. creams, or antihistamines – Benadryl® - to reduce itchiness.)

What may help:

- Tell and show your health care team any skin changes right away.
- Wash with a gentle soap to reduce your risk of skin irritation and infections. Wear loose, comfortable clothes.
- In the shower, use warm water instead of hot. Gently pat your skin dry rather than rubbing it.
- Use a gentle moisturizer to soften your skin and help it heal if it becomes dry or cracked.
- If your skin feels itchy or irritated, try gentle massage or pressure on the area. You can also apply a cool, damp cloth to itchy areas.
- Keep your nails short and clean. Use cuticle cream instead of cutting the cuticles.
- If you cut or scrape your skin, clean the area at once with warm water and soap.
- Petechiae (“puh-tee-KEE-ah”) are small purple or red spots on your skin that happen with a lower platelet count. They are not harmful but need to be watched.
- Your skin will become more sensitive: Protect your skin from the sun by wearing a wide-brimmed hat and clothing that covers your arms and legs. Apply sunscreen with a SPF of at least 30 when you go outside, even if it is cloudy.
- Avoid hot water bottles and heating pads, they can seriously burn your skin.

Sleep Pattern Changes

Having trouble sleeping (insomnia) is a common problem during treatment. You may have insomnia if you are unable to fall asleep, wake up often during the night or wake up very early and can't go back to sleep.

Pain, anxiety, depression and some medicines can affect your sleep. Insomnia makes it harder to cope with other side effects of treatment. It can affect your mood and energy level, cause fatigue and make it hard to think and concentrate.

What can help:

- Take only short naps (15-30 minutes) during the day.
- Be as active as you can during the day. This can give you more energy for the day and help you sleep better at night.
- Go to bed and get up at the same time every day.
- Your doctor can give you a sleeping pill to help you sleep, especially on the inpatient unit. Think of this as a short-term solution. Do not depend on it to sleep.
- Relax before bedtime – have a warm shower, read, listen to music, audiobooks or podcasts. Avoid looking at cell phone screens and other electronic devices.
- Do not have caffeine at least 6 hours before bedtime. Caffeine is found in coffee, tea (black, green, iced), chocolate, and soft drinks (i.e. colas and Mountain Dew®). Try not to eat a heavy meal or drink within 2 hours of bedtime.
- Make sure your bed, pillows and sheets are comfortable. Block out distracting light or use a sleep mask. Ear plugs are available on the inpatient unit.
- Get up and go into another room if you're tossing and turning in bed. Read or watch TV until you feel sleepy enough to return to bed.
- On the inpatient unit, your allied health care team can help with sleeping issues and other strategies to make you more comfortable.

Choosing A Caregiver

When Do I Need a Caregiver?

- It is strongly recommended to have a caregiver when you are receiving treatment as an outpatient.
- There may be times where a caregiver is medically required. This means you need at least one family member or friend who can provide you with physical and emotional support.
- Social workers can help caregivers who are planning time off work to explore financial benefits, and request supporting documentation.

How Do I Choose My Caregiver?

- Caregivers can be family, friends or hired professionals **please note that caregivers cannot be provided by hospitals, health authorities, or L/BMT Program.*
- Caregivers should be someone you are comfortable around, is comfortable around you, who knows you well, and is able to help you through your treatment.
- A caregiver should be at least 19 years of age.
- For us to best care for you, your caregiver must be able and comfortable to communicate with the medical team. Translation and interpretation services can be provided if needed.

How Many Caregivers Do I Need?

- It is possible to have one identified caregiver for the duration of your treatment. However, we understand that this can be challenging from a practical and emotional lens for the caregiver. Therefore, rotating caregivers are also an option.
- If one primary caregiver is identified, we suggest arranging visits from family and friends to ensure caregiving tasks do not fall entirely on one person.
- Having rotating caregivers allows each to rest, relax and have time away from the hospital, and prevent burnout.

Caregiver Responsibilities

Caregiver duties and responsibilities depend on what your loved one needs; you can help by:

- Coordinating services, such as transportation to and from the clinic.
- Attending appointments, making notes, asking questions
- Providing emotional support.
- Providing support at home:
    - Reminding you to take oral medications.
    - Identifying changes in your condition to the clinical team.
    - Calling the BMT triage nursing line or obtaining urgent medical care, if needed.
    - Helping you care for your central venous catheter (if applicable).
- Maintaining the home environment (e.g., household cleaning, pet care, laundry)
- Activities of daily living (e.g., grocery shopping, preparing food, picking up prescriptions)
- Serving as a communication link with other family members and friends

Resources for Caregivers

Go to www.bloodcancer.ca Search “Caring for a loved one with a blood cancer”. Click on the second result.

Go to www.cancer.ca Search “caregiver”. Select any of the results that you feel may apply to your situation.

If you feel you are experiencing caregiver burnout. Please connect with one of our social workers.

Frequently Asked Questions on Infection Control

Do I need to have my home or lodgings professionally cleaned?

No professional cleaning is needed. You could perform an initial thorough cleaning of your home in the same way you would do a good "spring cleaning". There is no evidence that shows the need for intensive cleaning beyond normal day to day chores.

Until your blood counts have fully recovered, general housekeeping is best left for someone else to do. Any commercial cleaning soap or solution can be used. It does not need to be "anti-bacterial".

The following are suggestions and not strict rules; please use your best judgement.

- Dust and vacuum once a week (Patients should try to avoid entering that room for 30 minutes afterwards.)
- Clean kitchen and bathroom sinks, tubs, shower area, and toilets with a cleaner that kills mildew.
- Regularly wipe down areas that are touched frequently such as light switches, doorknobs, electronic devices, appliance handles, etc.
- Change bed linens weekly or as needed.
- Consider the last time any filters (air conditioning, heaters, and humidifiers) were checked. Some filters may need to be cleaned or replaced.

Patients receiving active treatment should not renovate your home as this may increase their exposure to molds. Talk to your doctor before starting any renovations.

Do I need the flu shot? Does my family need the flu shot?

Generally, yes. If necessary, your doctor will recommend that you get a flu vaccine before your treatment starts. Having a flu shot (with a needle) requires your platelets to be above at least 50. Your family members, caregivers, and close household contacts should arrange to get a flu shot every year.

For both patients and family members, we recommend the flu shot injection. Nasal spray vaccinations contain a "live" virus that can be passed on to those with weak immune systems and extra precautions need to be taken.

Am I safe around children, pets, and other people living with me?

While your immune system is low (i.e. your neutrophils are less than 1.0):

Children are often not careful with their handwashing and may have infections that could make you sick. We do not want to prevent you from spending time with children but while your immune system is low, you should try not to touch or kiss them if they have a runny nose or cough.

Common Pets such as cats and dogs are fine to handle. Birds, rodents, and reptiles can potentially carry more bacteria, and handling is not recommended until your counts have recovered (or longer if you have had a stem cell transplant). Avoid changing litter boxes, cages or picking up your pet's waste during your treatment and recovery; they can contain harmful organisms such as toxoplasma gondii and cytomegalovirus. Pets should not sleep in your bed while your immune system is low. Be sure to wash your hands after petting and handling your pets. Speak with your doctor if you have a job involving animals, such as a veterinarian, farmer, etc.

Other people living in your home need to stay away from you if they are sick with an infection (i.e. new cough, fever, diarrhea, vomiting, sore throat, runny nose, etc.).

Should I avoid those who have just received a "live" vaccination (MMR, VZV, chicken pox, rotavirus, etc.)?

In general, your close contacts should receive MMR, MMRV, varicella or herpes zoster vaccines as appropriate for their age. This is the best way to protect you and your loved ones. "Live" vaccines contain a weakened form of a bacteria or virus. These vaccines are safe for the general public, but the bacteria or virus can be passed on to those with weakened immune systems. **The only time to avoid contact with those receiving live vaccinations is:**

- During your first month after a stem transplant (your immune system is severely weakened).
- The person receiving the vaccine has developed a varicella-like rash (rare). Avoid contact until the rash has subsided.
- Contacts have received the live nasal spray influenza (flu) vaccine within the last 2 weeks. We recommend the injection flu vaccine instead, as it contains the inactivated virus that cannot be passed on.
- Ask your doctor about other rare live vaccinations from other countries (i.e. avoid those who have received the live oral polio vaccination within the last month).

What are shingles? And why should I watch for the symptoms of shingles?

Shingles are caused by the Herpes Zoster/Varicella zoster virus (VZV), the virus that causes chickenpox. Most people have been "exposed" to the virus in their lifetime, either by having chickenpox or receiving the varicella vaccine. Once this exposure happens, the virus remains "dormant" (it is inactive and never leaves your body). When your immune system is low (e.g., after a transplant), the dormant VZV virus can become active again and cause shingles. Shingles is contagious and can be passed on to others.

What are the symptoms of shingles?

The symptoms often occur in a stirp or band on one side of the body. This is because the infection usually follows the path of a nerve. Lesions are usually in groups of raised, red blisters. They may look like clear pimples. They are usually quite sore and itchy. These blisters may break and ooze fluid. This fluid is contagious to others. When the blisters are dried and form a scab, they are no longer contagious.

How can I prevent shingles?

If you have never had chickenpox or the varicella vaccine, you must avoid anyone with chickenpox or shingles. If you are exposed, tell your physician as soon as possible. If you have previously had chicken pox or the varicella vaccine, take Valtrex®

Can I garden and care for house plants?

You don't need to get rid of your houseplants but avoid any gardening until your counts have recovered. This is because soil contains bacteria, fungi and molds. Patients receiving a transplant should wait longer to garden; specific instructions will be given to you. When you are able to return to gardening, be sure to wear gloves for at least 6 months.

Can I take public transport during treatment?

While your immune system is recovering, please avoid public transit such as the train, buses or handyDART. Public transit is very crowded and you could pick up an infection easily. If you need to use the ferries, avoid the more crowded areas. If you are concerned about picking up an infection, wear a mask.

Can I drive while receiving treatment?

Most patients find they feel too weak or tired to drive. To be safe, we recommend not driving at any time before, during and after treatment, until you feel you have fully recovered. Please do not drive yourself to clinic appointments as you may need a blood transfusion or other medications that will sedate you. You might also be taking medications that could make you feel drowsy, (i.e. Ativan®, Benadryl®, Gravol®). Please arrange for someone to drive you to the hospital.

Can I go swimming? Is tap water safe?

In general, while you have a central line in place (Hickman®, Trifusion®, PICC) you should not wade or swim in any pool or body of water. While your immune system is low, do not drink water from a well, especially a private well. Drinking or swimming in these bodies of water can lead to serious infections such as cryptosporidium. Municipal tap water is safe to drink and bottled water is not required. Local health departments will issue warnings about water safety. If such a warning is issued in your area, it is important to follow the instructions for boiling water.

Can I drink alcohol?

Chemotherapy and other medications can greatly stress and damage the liver. Some treatments, like a stem cell transplant can cause your liver to be sensitive and unable to fully function. All alcoholic beverages should be avoided during treatment and for at least 3 months for those people who have received a stem cell transplant. This period may be longer for some patients. Check with your doctor before having beer, wine and other alcoholic beverages.

Can I smoke?

If you smoke, we suggest that you quit immediately. Smoking includes cigarettes, vaping, cigars, pipes, marijuana, inhaling cocaine and chewing tobacco. Stopping these activities is important to:

- Prevent serious respiratory infections (i.e. pneumonia, fungal infections) when your immune system is low.
- Prevent new cancers from developing.

No one should smoke inside your home. Avoid secondhand smoke in public.

VGH is a smoke free environment. This includes the grounds at the hospital. There are many effective aids to help you stop smoking. If you need assistance with quitting smoking, please talk to your health care team, or see www.quitnow.ca 1 877 455 2233.

When can I travel after treatment?

Please check with your doctor before making any travel plans, we usually recommend waiting 6 months from recovery before air travel and travelling to other countries; longer for underdeveloped countries. It is important for your neutrophil and platelet counts to be at a safe level for travel.

Are herbal supplements and traditional Chinese medicines safe?

Tell your doctor or pharmacist about any herbal supplements or therapies you may be taking. We generally recommend not taking any supplements during your treatment. Although research in this area is limited, we do know that some herbal remedies, such as St. John’s Wort and Echinacea, may be quite harmful to recovering patients. Most common herbal teas are safe.

Returning to Work

Returning to work is a common source of stress for people after their treatment. When your doctor has given you permission and you feel ready to return to work, it is best to do it slowly and over time.

Going back to work helps get you get back into a more “normal” routine, but you may still be thinking about your treatment experience and will need to balance your work schedule with your follow-up medical visits. You may also be dealing with side effects, such as:

- Low energy.
- Feeling anxious or worried about returning to work.
- You may have troubling thoughts about family, relationship issues or financial concerns.

These side effects can affect your ability to focus concentrate.

Here are some tips to help you return to work:

- Talk to your doctor. It is important to talk to your doctor about your return to work plans so you get medical support and guidance. Your doctor can give you advice on when you can consider returning to work. They can also give you and/or your workplace tips on what needs to be considered given your physical needs.
- Be patient with yourself. It is important to pay attention to your body. Each person is different and each person’s return to work plan will look different. It is important to accept that.
- Forcing yourself to move ahead before you are ready may result in needing to take even more time off from work.
- Before you return to work, make a plan. Consider if you want to share information about your illness with your coworkers. How much and how you share this information is fully up to you. Do not feel that your coworkers need to know everything. You have a right to keep your personal situation private.
- BC Cancer’s Vocational Rehabilitation Program can help you with the return to work/school process, finding new work or new training, explore how to discuss heath concerns with those at work/school and more. For more information and to book an appointment, call 1-800-663-3333 Ext. 672194.

Complementary and Alternative Therapy

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, art and music therapy.
- 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. Some therapies may be unsafe at certain times. For example:

- Herbal remedies and vitamin supplements can interact with your planned medical treatment or may even cause harm. (i.e. St. John's Wort and Echinacea). Most common herbal teas are safe.
- Massage therapy & acupuncture are not safe 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. We 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.

Coping Tips from Former Patients

- Give yourself permission to feel anxious and stressed about whatever it is that is bothering you. At the same time, try to keep incidents in perspective, and not overreact to small setbacks or minor crises. These are all to be expected when dealing with a serious illness.
- If you have an anxiety attack, try to think about what may have set it off. If you cannot pinpoint it, discuss it with someone close to you or a counsellor.
- Try to become aware of your body's symptoms. Don't let them scare you, let them talk to you.
- Listen very closely to your "self-talk". Are you filling yourself with negative thoughts about a certain situation? What can you say to yourself that will be more comforting?
- Listen to what those around you are saying. Are you consistently around negative people who want to drag you down with them? If so, how can you change your reaction to their negativity so you will be less affected by it?
- Do not overwhelm yourself with high expectations and "should haves." Set realistic goals regarding what and how much you are able to do. Remember that you are doing the best you can and making the best decisions with the information that you are given.
- Recognize that role changes are difficult to negotiate in the best of circumstances. Do not be hard on yourself when you experience impatience, frustration, sadness, or anger.
- Give yourself positive reinforcements for even the smallest accomplishments.
- Give yourself frequent praise and rewards for your patience and endurance.
- Be willing to walk away from difficult situations to calm down. Try a new approach later.
- Take one day at a time. Try not to worry about what might happen, as there will always be unknowns on your journey.
- Use your sense of humor! It relieves stress and can be a positive emotional release.

Where Can I Get More Information?

Ask a member of your health care team for any of the materials listed below. You can read or order them online. They can also be found on the inpatient unit near the public washrooms (room 15020) or on the Daycare patient library (room 631).

- Chemotherapy and Other Drug Therapies (Canadian Cancer Society)
- Coping When You Have Cancer (Canadian Cancer Society)
- Eating Well When You Have Cancer (Canadian Cancer Society)
- Pain Relief: A Guide for People with Cancer (Canadian Cancer Society)
- Sex, Intimacy and Cancer (Canadian Cancer Society)
- Resources and Support (Leukemia/BMT Program of BC)
- Cannabis Information for Patients (Leukemia/BMT Program of BC)

Find these booklets, videos and more information at:

The Leukemia Bone Marrow Transplant Program of BC:
www.leukemiabmtprogram.org

The Leukemia & Lymphoma Society of Canada: 1-833-222-4884
www.bloodcancers.ca
Click Patients & Caregivers → Free Information Booklets

BC Cancer: 1-800-663-3333
www.bccancer.bc.ca

The Canadian Cancer Society: 1-888-939-3333
www.cancer.ca
Click Support and Services → Publications

Please note that the information contained in this manual is not intended to replace the advice of your health care team. Use this as a reference and education guide. Consult your health care team if you have any questions or concerns. Author: Amy Healy 06/2019, Sally Moore 11/2025, Patsy Vanee 11/2025, Annabel Francis 02/2025 Nikki Stiver 02/2025, Tanisha Bors 02/2025, Nogol Salehi 02/2025, Gretchen Olund 02/2025, Amy Chen 02/2025, Prachi Sony 02/2025 Editors: Claudine Kee 02/2025, Mimi Gee 08/2025. Reviewed by Dr. Reyna Altook 11/2025.

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