

# Leukemia Information

## Follow-Up Care Plan

► PART 2 OF 3

Information and resources for  
leukemia patients in Manitoba  
after completion of treatment.



**Moving *Forward***

*after Leukemia*



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# Introduction

## Moving Forward after Leukemia

This booklet is Part 2 (of 3) of the Follow-Up Care Plan package. It provides leukemia specific information about:

- follow up care
- side effects you might be experiencing and what the best course of action might be
- post treatment programs you may be interested in

Part 1 - the Personalized Follow-Up Care Plan and Treatment Summary outlines your personal follow up schedule (including necessary tests and appointments, what symptoms to watch for, and a summary of the treatments you received to treat the leukemia). If you misplace your Part 1, please call your hematologist's office. A new copy can be provided for you.

Part 3 - the Moving Forward after Cancer booklet is a general resource focused on wellness and health promotion, the reduction of future risk, and resources and supports available in Manitoba after being treated for any type of cancer.

Part 2 and 3 are available online at [movingforwardaftercancer.ca](http://movingforwardaftercancer.ca).

Please go to [www.movingforwardaftercancer.ca](http://www.movingforwardaftercancer.ca) for additional information that you may find helpful, such as videos and links to various websites.

## Moving Forward after Cancer Treatment



## Follow-Up Care Plan

►PART 3 OF 3



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**Important Caution:** This summary document does not prescribe or recommend any particular medical treatment or care for cancer or any other disease and does not substitute for the independent medical judgment of the treating professional.

# Recurrence: Are You Worried Your Leukemia May Return?

## What to Watch For

You may be relieved to finish treatment, but find it hard not to worry about your leukemia coming back. (When cancer comes back after treatment, it is called *recurrence*). This is a very common concern for people who have had cancer.

For some, leukemia may return after many years of remission. Part of follow-up is regular monitoring to ensure disease recurrence is detected early. For some people, learning to live with leukemia as a chronic disease can be difficult and stressful.

After treatment, your health care providers will still want to monitor you closely. It is very important to attend all of your follow-up appointments. During these visits, your health care providers will ask about any problems you may have, examine you, and may order tests to look for signs of cancer or treatment side effects.

**Part 1 “Your Personalized Information”** of your follow-up care plan outlines what appointments and tests you should have over the next five years to watch for signs of recurrence.

Your primary care provider will refer you back to CancerCare Manitoba for consultation with the hematologist/oncologist, if s/he is concerned about your leukemia returning.

## Be Alert To The Following Signs:

Please visit your primary care provider if you notice any of these changes in your health **as soon as possible** as they may indicate a recurrence:

- Easy bruising or bleeding
- Unplanned weight loss
- Drenching night sweats
- Fever or frequent infections
- Fatigue or shortness of breath
- Dizziness

Please refer to **Part 3 “Moving Forward After Cancer Treatment”** for the primary care, medical tests and screening you should have after being diagnosed with leukemia.

## Testing For Your Family?

There are currently no screening recommendations or tests for your family members. However, it is important to talk to your family about your leukemia. Family members should talk to their primary care provider about your leukemia diagnosis so they can be aware of symptoms that should be reported to their primary care provider. This will help make sure your family member gets the right care if, and when, they need it.

# What to Expect After Leukemia & Treatment

The unexpected effects of cancer are not always physical problems. There are emotional and psychological impacts of cancer and treatment as well.

You may (or may not) experience some of the following physical, emotional, and psychological effects after treatment for leukemia. You may experience other symptoms not listed below, as everyone's experience is unique. Some of these problems may start immediately while some may take months or even years before they appear, or they may never appear.

It may take time to see your side effects improve or go away. You may need to work with your health care team to try various strategies, medications, and therapies to find what works. Sometimes side effects go away on their own, while others may last for a very long time.

If any of these effects are stopping you from doing your usual activities, **talk about them with your health care provider.**

*\*Detailed resource and contact information can be found in the Leukemia Support and Resources section of this book.\**

Problem or Effect	What You Can Do At Home	Who Can Help You with the Problem
<p>Anxiety - feeling worried and unable to relax</p> <p>It is very common to experience increased anxiety during and after treatment as you cope with many life changes, decisions, and challenges</p>	<ul style="list-style-type: none"> <li>• Learn what triggers your anxiety and what helps you relax</li> <li>• Seek support from your family, friends, spiritual or religious groups, support groups, and counsellors</li> <li>• Practice mind body activities such as breathing techniques, restorative yoga, meditation, guided imagery, soothing music, and mindfulness</li> </ul>	<ul style="list-style-type: none"> <li>• Talk to your primary care provider about how you are feeling.</li> <li>• Call CancerCare Manitoba's Patient and Family Support Services at 204-787-2109 or 1-866-561-1026 extension 2109 for counselling and support programs.</li> </ul>
<p>Depression</p> <ul style="list-style-type: none"> <li>• feeling sad, irritable, or hopeless</li> <li>• loss of appetite</li> <li>• trouble sleeping</li> <li>• mood swings</li> </ul> <p>Depression is common after treatment for cancer, since many people fear the cancer will return. Many people have difficulty coping with the diagnosis of cancer and/or treatment. If these feelings persist, seek help.</p>	<ul style="list-style-type: none"> <li>• Getting adequate sleep, activity, time outside/in the sun, and social interaction can be helpful. Often the same things you don't feel like doing when you are down are actually the things that help manage a depressed mood.</li> <li>• Practice mind body activities such as breathing techniques, restorative yoga, meditation, guided imagery, soothing music, and mindfulness</li> <li>• Join support groups and peer counselling networks</li> <li>• Exercise as you are able</li> </ul>	<ul style="list-style-type: none"> <li>• Talk to your primary care provider about how you are feeling.</li> <li>• Call CancerCare Manitoba's Patient and Family Support Services at 204-787-2109 or 1-866-561-1026 extension 2109 for counselling and other programs.</li> <li>• <b>If you have any thoughts about harming yourself or anyone else, call the crisis line at 204-786-8686, call 911 or go to the nearest emergency room immediately.</b></li> </ul>

# What to Expect After Leukemia & Treatment

Problem or Effect	What You Can Do At Home	Who Can Help You with the Problem
<p>Diabetes or high blood sugar can sometimes be brought on by treatment with steroids</p>	<ul style="list-style-type: none"> <li>Follow the Canada Food Guide and use the healthy eating tips found in Part 3 - Moving Forward After Cancer Treatment.</li> </ul>	<ul style="list-style-type: none"> <li>Talk to your primary care provider about a referral for a diabetic education session</li> <li>Talk to your primary care provider about a referral to a dietitian or an endocrine specialist</li> </ul>
<p>Fatigue (feeling constantly tired)</p>	<ul style="list-style-type: none"> <li>Exercise - be physically active if you can (start with 10 minutes twice a day)</li> <li>Rest when you feel tired and nap during the day if you need to (be careful not to nap too late in the day as this can affect your ability to sleep at night)</li> <li>Examine your sleeping environment and make improvements where possible</li> <li>Try eating five to six small meals a day instead of three large ones - this helps your body to stay energized throughout the day</li> <li>Drink lots of fluids</li> <li>Practice mind/body activities such as breathing techniques, restorative yoga, guided imagery, soothing music, and mindfulness.</li> </ul>	<ul style="list-style-type: none"> <li>Talk to your primary care provider and/or ask for a referral to an Occupational Therapist.</li> <li>Contact CancerCare Manitoba's Patient and Family Support Services at 204-787-2109 or 1-866-561-1026 extension 2109.</li> </ul>
<p>Heart problems including congestive heart failure (difficulty pumping blood) and heart disease</p> <p><i>Can happen after radiation therapy to the chest or after anthracycline chemotherapy treatment.</i></p>	<ul style="list-style-type: none"> <li>Manage activities and rest when you feel tired</li> <li>Work to minimize and manage stress</li> <li>Minimize your risk by eating a healthy diet, exercising regularly, and not smoking</li> </ul>	<ul style="list-style-type: none"> <li>Talk to your primary care provider and/or ask for a referral to a Cardiologist</li> <li>Contact CancerCare Manitoba's Patient and Family Support Services at 204-787-2109 or 1-866-561-1026 extension 2109.</li> </ul>

Problem or Effect	What You Can Do At Home	Who Can Help You with the Problem
<p>Hot flashes and night sweats</p> <p><i>This might be treatment induced menopause - menopause can also cause vaginal dryness, sleep problems, mood changes, weight gain, and dry skin.</i></p>	<ul style="list-style-type: none"> <li>• Use fans when warm</li> <li>• Wear natural and moisture-wicking fabrics and dress in layers</li> <li>• Avoid drinking caffeine in the evening</li> <li>• Choose cold food and drinks</li> <li>• Sleep in a cold room</li> <li>• Adjust bed covers (lighter/ moisture-wicking)</li> </ul>	<ul style="list-style-type: none"> <li>• Talk to your primary care provider and your Leukemia team about a prescription for medication that can help you with this.</li> <li>• Contact the CancerCare Manitoba Sexuality Counsellor directly at 204-787-4495 or 1-866-561-1026 extension 4495.</li> </ul>
<p>Infertility</p> <p>Treatment for cancer can affect your ability to have a baby in the future. This can be upsetting and most people need support and information.</p>	<ul style="list-style-type: none"> <li>• Communication with your partner is very important</li> </ul>	<ul style="list-style-type: none"> <li>• Talk to your primary care provider about a referral to the Heartland Fertility Clinic, 204-779-8888. <i>You can also contact them directly, however they do need details of your cancer history and treatment.</i></li> </ul>
<p>Intimacy and sexuality</p> <p>(Relationship intimacy and sexuality, including body image and sexual activity)</p>	<ul style="list-style-type: none"> <li>• Communicate openly with your partner about what you are thinking and feeling</li> <li>• Spend time touching and talking - sexuality is about connection and not just about sex</li> <li>• Be patient and kind with yourself and your partner as you recover</li> </ul>	<ul style="list-style-type: none"> <li>• Contact the CancerCare Manitoba Sexuality Counsellor directly at 204-787-4495 or 1-866-561-1026 extension 4495.</li> <li>• Call CancerCare Manitoba's Patient and Family Support Services at 204-787-2109 or 1-866-561-1026 extension 2109.</li> </ul>
<p>Loss of muscle strength and/or weight gain</p> <p>(Trouble with daily activities, exercising, and/or unwanted weight gain)</p>	<ul style="list-style-type: none"> <li>• Follow the Canada Food Guide for healthy eating recommendations</li> <li>• Keep a food diary</li> <li>• Participate in regular activity, such as walking, yoga, or pilates</li> <li>• Start with ten minutes twice a day and work your way up to your new goal!</li> </ul>	<ul style="list-style-type: none"> <li>• Talk to your primary care provider about being active and/or ask for a referral to a registered dietitian in your community.</li> <li>• Ask for a referral to a physiotherapist or athletic therapist if further support is needed.</li> <li>• Look for an exercise facility in your community.</li> </ul>
<p>Lung problems (difficulty breathing or catching your breath, as well as other lung problems)</p> <p><i>Can happen after radiation therapy to the chest or after anthracycline chemotherapy treatment.</i></p>	<ul style="list-style-type: none"> <li>• Manage activities and rest when you feel tired</li> <li>• Try to quit smoking if you smoke</li> </ul>	<ul style="list-style-type: none"> <li>• Talk to your primary care provider and/or ask for a referral to a Respiriologist</li> <li>• Contact CancerCare Manitoba's Quit Smoking Program at 204-787-1202 or 1-888-775-9899.</li> </ul>

# What to Expect After Leukemia & Treatment

Problem or Effect	What You Can Do At Home	Who Can Help You with the Problem
Memory and concentration problems (also known as brain fog or chemo brain)	<ul style="list-style-type: none"> <li>• Use a daytimer to track appointments and medications</li> <li>• Create lists as reminders of outstanding tasks</li> <li>• Place items (such as car keys, cell phones, planners) in the same place</li> <li>• Allow extra time to accomplish personal and work related activities</li> <li>• “Exercise” the brain through activities like Sudoku or memory games</li> </ul>	<ul style="list-style-type: none"> <li>• Talk to your primary care provider and/or ask for a referral to an Occupational Therapist.</li> <li>• Contact CancerCare Manitoba’s Patient and Family Support Services at 204-787-2109 or 1-866-561-1026 extension 2109.</li> </ul>
Osteoporosis and bone loss <i>Can happen after you have taken steroids</i>	<ul style="list-style-type: none"> <li>• Try to eat calcium rich foods such as fortified orange juice, kefir, fortified soy beverages, yogurt, cheese, milk, beans, tofu, nuts, green leafy vegetables, and fish with bones (e.g. canned salmon, sardines, etc.)</li> <li>• Try to quit smoking if you smoke</li> <li>• Stay active and participate in regular exercise</li> </ul>	<ul style="list-style-type: none"> <li>• Talk to your primary care provider about a referral for a bone density scan and ask if you should take a vitamin D or calcium supplement</li> </ul>
Peripheral neuropathy (tingling, numbness, or pain in the hands or feet, burning sensation)	<ul style="list-style-type: none"> <li>• Avoid walking barefoot</li> <li>• Use care and caution when trimming finger and toe nails</li> <li>• Use creams or lotions that have been recommended by your oncologist or nurse</li> <li>• Maintain activity and exercise regularly, however use caution so you can avoid injury</li> </ul>	<ul style="list-style-type: none"> <li>• Talk to your primary care provider or your Leukemia team as there are several medications that can help manage the symptoms of nerve damage.</li> <li>• CancerCare Manitoba Pain &amp; Symptom clinics (physician or nurse referral needed)</li> </ul>
Thyroid issues - if you have had previous radiation to the neck you might have a change in thyroid levels. Some signs of thyroid change are: <ul style="list-style-type: none"> <li>• Difficulty sleeping</li> <li>• Being sensitive to temperature changes</li> <li>• Unexpected weight gain</li> <li>• Change in hair and skin</li> </ul>	<ul style="list-style-type: none"> <li>• Unfortunately, there are not many things you can try at home to deal with this problem. It is best to contact your primary care provider and discuss the issue.</li> </ul>	<ul style="list-style-type: none"> <li>• Check with your primary care provider or nursing station to see if you are at risk. A blood test can check if medication or supplements should be prescribed.</li> </ul>

# Diet and Exercise Following Leukemia

## Diet

There are no specific diet recommendations for those who have been diagnosed and treated for leukemia. For recommendations and information about maintaining a healthy body weight and eating well, please refer to **Part 3 - Moving Forward After Cancer Treatment booklet** and **the Canada Food Guide**.

## Exercise

Being physically active after treatment for leukemia is important whether you are getting back to activities you enjoy or starting a new healthy lifestyle plan. Though it is limited, research on exercise and cancer has observed improved quality of life and less fatigue, peripheral neuropathy, depression, anxiety and sleep dysfunction with Canadian Public Health exercise recommendations. For more recommendations, information and tips on how to get started with exercise and activity, see the **Part 3 - Moving Forward After Cancer Treatment booklet**. **Always check with your primary care provider before starting an exercise plan.**

## Exercise Precautions Following Leukemia

- If you have weakened immune function, avoid gyms and other public places until your white blood cell count is normal. If you had a blood/marrow transplant, your doctor may tell you to avoid exposure to public places such as gyms, where the likelihood of exposure to germs is high.
- If you have significant peripheral neuropathy (nerve damage) from your cancer treatment that affects your coordination and/or balance (such as numbness, tingling, or burning in your fingers, hands, feet or legs), your ability to exercise may be limited. Focus on 'stable' exercise such as a stationary reclining bicycle, rather than walking outdoors or on a treadmill.
- If you are experiencing severe fatigue as a result of your therapy, you may not feel up to exercising. Start with basic movements and activities such as stretching or tai chi.
- You should not exercise if you are at risk of infection, are in pain or experiencing other side effects that are not well-controlled.
- If you have heart problems related to cancer or not, a proper medical exam should be done before you start any exercise program.
- Part 3 - Moving Forward After Cancer Treatment has further precautions you may need to take when starting to exercise.

# Leukemia Supports & Resources in Manitoba



## Support Groups

**CancerCare Manitoba Young Adult Cancer Survivors (YACS) Support Group:** Held the 1st Thursday of the month. For more information call 204-787-4122.

**CancerChat Canada** has professionally led face-to-face and online support groups provide an environment for those affected by cancer with an opportunity to talk with others in similar situations. Call 1-877-547-3777 extension 645234 or go to [www.cancerchatcanada.ca](http://www.cancerchatcanada.ca).



## Online Support Groups

**Leukemia Lymphoma Society of Canada** has online chat groups. [www.llscanada.org/#/resourcecenter/](http://www.llscanada.org/#/resourcecenter/)

Please see the **Additional Resources and Supports section in the Part 3 - Moving Forward After Cancer Treatment** booklet for other support groups you can access.

**Websites – Cancer Information:** The Web is a great source of information, but it is also full of misinformation. These websites are ones you can rely on to provide you with accurate information:



<b>Leukemia and Lymphoma Society of Canada</b>	<a href="http://www.llscanada.org">www.llscanada.org</a>
<b>Young Adults Cancer Canada (YACC)</b>	<a href="http://www.youngadultcancer.ca">www.youngadultcancer.ca</a>

# Glossary

**Anthracyclines:** a type of chemotherapy medication used to treat leukemia. Examples are doxorubicin, daunorubicin, idarubicin. These medications are given intravenously and are usually orange-red in colour.

**Anxiety:** a state of being uneasy, apprehensive, or worried about what may happen; concern about a possible future event.

**Bone Density:** the amount of mineral matter per square centimeter of bone.

**Calcium:** a mineral component of bone.

**Chemotherapy:** medications with cancer-fighting abilities to treat cancer. Chemotherapy medications are sometimes referred to as anticancer agents.

**De-conditioning:** the loss of physical fitness.

**Depression:** a common condition that affects your mood, resulting in feelings of sadness, hopelessness, inadequacy, worry, and dejection. Depression can affect your appetite, your motivation to perform daily activities, and your relationships.

**Diagnosis:** identification of a disease by means of a medical examination, signs, symptoms, laboratory tests and radiological findings.

**Dietitian:** licensed professional with specialized training in human nutrition who advises individuals on healthy eating.

**Fatigue:** physical or mental exhaustion; weariness.

**Hematologist:** physician who specializes in diagnosing and treating blood disorders.

**Hypertension:** high blood pressure.

**Lymph nodes:** The lymphatic system is part of the body's immune system. It collects fluid, waste material, and other things (like viruses and bacteria) that are in the body tissues, outside the bloodstream. Lymph vessels are a lot like the veins that collect and carry blood through the body. But instead of carrying blood, these vessels carry the clear watery fluid called lymph. Lymph nodes are small structures that work as filters for harmful substances. Cancer can appear in the lymph nodes in 2 ways: it can either start there or it can spread there from somewhere else. There are hundreds of lymph nodes throughout the body.

**Leukemia:** cancer in the blood stem cells.

**Medical Oncologist:** physician who specializes in the diagnosis and treatment of cancer with drugs.

**Occupational Therapist:** a specialist in the treatment of physical or mental illness that works to improve a person's ability to perform daily activities.

**Physician Assistant (PA):** medically educated clinicians who practice medicine within a familiarized relationship with physicians. The PA practice of medicine includes diagnoses, obtaining medical histories, performing physical exams, ordering and interpreting diagnostic studies, providing therapeutic procedures, prescribing medications, and educating and counselling patients.

**Psychosocial Clinician:** a person with specialized training to talk with you and help you to regain social, emotional, and spiritual health. They specialize in assisting you with the quality of life aspects of cancer.

**Radiation (therapy):** use of gamma rays or high-energy x-rays to damage or destroy cancer cells.

**Radiation Oncologist:** physician who specializes in diagnosis and treatment of cancer and other diseases through the use of radiation therapy.

**Recurrence:** the return of cancer after a period of time when the person was considered cancer-free (remission).

**Remission:** a period of time during a serious illness when there are few or no signs or symptoms of the illness.

**Side Effects:** non-intended symptoms caused by medicine or treatment, such as nausea, rash, anxiety, or constipation.

**Steroid:** a type of drug used to treat injury or illness by reducing swelling and other effects of the immune system.

**Symptom:** a sign or indication of a particular disease or disorder.

