Follow-Up Care Plan
Colorectal Cancer Information
PART 2 of 3

Moving Forward
after Colorectal Cancer

Information and Resources for Colorectal Cancer Patients in Manitoba after Completion of Treatment
PART 2 OF THE FOLLOW-UP CARE PLAN

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Refer to Part 1 and 3 of your Follow-Up Care Plan for information on your personalized cancer, treatment, support and resource information.

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

Generously supported by the CancerCare Manitoba Foundation
6. Cancer Recurrence: Signs to Watch For

For many people finishing cancer treatment, one of their biggest concerns is the worry that the cancer may return some day. Colorectal cancer treatment is changing rapidly and is becoming more successful. If colorectal cancer does return, it is usually in the first three years after diagnosis. This is why the follow-up testing you read about in Part 1: Your Personalized Information is more frequent in the first three years. After three years the chance of the cancer returning drops steadily year after year. If colorectal cancer returns, it is usually in the form of cancer cells that have spread to the liver or lungs. There is also a small risk of the cancer re-growing in the bowel where the surgery was done and of a new cancer growing in a different part of the colon (large intestine). This is why the recommended follow-up includes tests of the liver, lungs and colon. It is possible to treat the cancer successfully if these new cancers are found early and can be removed by a surgeon. If they cannot be removed, cure is usually not possible, but chemotherapy is available that can greatly extend your life.

Be alert for the signs of cancer recurrence! Please visit your main follow-up physician or nurse practitioner if you notice these changes in your health:

See your doctor as soon as possible if you notice:

- Blood in your stool
- Blood that you cough up
- Stool (bowel movement) that is very pale or black
- New lumps, especially in the neck area & groin
- Blood or air in the urine
- Stoma starting to stick out or protrude
- Yellow eyes and/or skin (jaundice)

See your doctor if these symptoms last more than one week:

- A change in your bowel movements, especially looser stools or constipation
- Pain in your abdomen or rectal area (or where the rectum / anus used to be)
- Unexplained or new pain that is persistent or worsening
- Vomiting that lasts more than a few days
- Shortness of breath
- Cough
- Nausea (feeling sick to the stomach)
- Loss of appetite
- Weight loss without trying
- Large change in energy level or ability to be active
7. Other Medical Tests and Cancer Screening

Talk with your family doctor or nurse practitioner about these other tests.

**Breast Cancer Screening:** Have a mammogram every 2 years starting at age 50. Call the Manitoba Breast Screening Program at 788-8000 or 1-800-903-9290 for an appointment. If you are under the age of 50 or if there is a family history of breast cancer, discuss earlier or more frequent screening with your family doctor or nurse practitioner.

**Cervical Cancer Screening:** Have a Pap Test every 2 years until age 69. Screening can be stopped if a woman is 70 years or older and has had three or more Negative Pap tests in the previous 10 years with no change in partner. Women with total hysterectomies for benign disease don't need Paps. Check your Pap Test history by calling the Manitoba Cervical Cancer Screening Program at 788-8626 or 1-866-616-8805.

**Prostate Cancer Screening:** Discuss whether you should get a PSA blood test every year or two (plus a prostate exam when possible.) Men who have received pelvic radiation may be at higher risk.

**Diabetes Screening:** Have a Fasting Plasma Glucose (FPG) test every 3 years starting at age 40.

**Cholesterol Screening:** Have a fasting cholesterol test at age 40 if you are a man, or age 50 if you are a woman. Start at a younger age if you have diabetes, early heart disease in a close relative, if you smoke or if you are overweight. This should be repeated every 2-3 years.

**Immunization:** Get an influenza shot every fall. Get the pneumococcal vaccine (pneumonia shot) once if you are 65 and older or have diabetes, heart or lung problems.

**Blood Pressure Checks:** Get your blood pressure checked every two years or more often if you have other risks for heart disease.

**Bone Density Screening:** Older patients who have received radiation treatment for rectal cancer are at a higher risk of breaking their hip (hip fracture) later on due to thinning of the bones (osteoporosis) related to radiation.
Follow-Up Care Plan Colorectal Cancer Information

8. Screening Recommendations for Your Family

It is important to talk to your family members about your diagnosis with colorectal cancer, since they may be at higher risk for developing the disease. These recommendations will help in finding colorectal cancer early, when it is highly curable. Family members should talk to their family physician / nurse practitioner about your diagnosis with cancer so the proper tests can be scheduled. Please note that these recommendations are for people with NO symptoms. If your family member has symptoms that may be cancer, they need to see their family physician or nurse practitioner.

For your parents, brothers, sisters and children (first-degree relatives)

- If you were diagnosed with colorectal cancer at the age of 60 or older, they need:
  - Fecal Occult Blood Test (FOBT) every 2 years starting at age 40.
  - On an individual basis, other screening tests may be appropriate, such as colonoscopy every 10 years or flexible sigmoidoscopy every 5 years, with or without FOBT

- If you were diagnosed with colorectal cancer before the age of 60, they need:
  - Colonoscopy every 5 years beginning at 40 years of age or 10 years earlier than the youngest diagnosis for colorectal cancer or polyps in the family, whichever is earlier.

- If you and at least one other close family member were diagnosed with colorectal cancer or adenomatous polyps at any age, they need:
  - Colonoscopy every 5 years beginning at 40 years of age or 10 years earlier than the youngest diagnosis for colorectal cancer or polyps in the family, whichever is earlier.

Note: Talk with your doctor about the possibility of an inherited (genetic) colorectal cancer syndrome if your family has:

- multiple family members with disease (colorectal cancer or adenomatous polyps)
- disease at a younger age (<45 years)
- Many cancers in multiple generations.

Your physician may consider referral for genetic testing and regular colonoscopy.
9. What to Expect After Cancer & Treatment

You may (or may not!) experience some of the following side effects after surgery and treatment for your cancer. There may be other effects that you also experience. Some of these problems can start immediately or can take months before appearing. As well, some side effects can improve with time, while others may go on for many years. Patients treated for rectal cancer are at particular risk for longer term side effects.

If any of these side-effects are a problem or are affecting what you are doing day to day, there may be things that can be done to ease or get rid of them. Talk about them with your health care provider. Detailed resource and contact information can be found in Section 13 – Colon and Rectal Cancer Support & Resources.

<table>
<thead>
<tr>
<th>Problem or Side Effect</th>
<th>Who to Seek Help from for Problem</th>
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</thead>
<tbody>
<tr>
<td><strong>Bowel Problems</strong> - due to Surgery and / or radiotherapy</td>
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<tr>
<td>• Urgent need to have a bowel movement (Quite common)</td>
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<tr>
<td>• Incontinence/loss of bowel control (Common)</td>
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<td>• Need to wear a pad (Common)</td>
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<tr>
<td>• Frequent bowel movements (Common)</td>
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<td>• Diarrhea (Common)</td>
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<td>• Constipation (Not as common)</td>
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<tr>
<td>• Bowel blockage (belly pain, nausea, vomiting, not able to pass gas or bowel movements) (Not as common)</td>
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<tr>
<td>Talk to your Family Doctor or Surgeon. Other helpful resources:</td>
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<tr>
<td>• CCMB Dietitian</td>
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<td>• Riverview Incontinence Program – physician / nurse referral needed</td>
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<tr>
<td>• Incontinence &amp; Pelvic Pain Clinic (Nova Physiotherapy &amp; Sports Injury Clinic)</td>
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<tr>
<td><strong>Urination Problems</strong> - due to Surgery and/or radiotherapy</td>
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<tr>
<td>• Frequent urination (Quite common)</td>
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<tr>
<td>• Difficulty emptying bladder (Common)</td>
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<tr>
<td>• Pad wearing (Common)</td>
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<td>• Wellness Institute at 7Oaks General Hospital – Physiotherapy Services</td>
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<td><strong>Stomach ache, cramping, pain in the pelvis (Not as common)</strong></td>
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<td>Talk to your Family Doctor</td>
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<tr>
<td><strong>Ostomy Issues (Common)</strong> - May include skin &amp; appliance problems, constipation, diarrhea, irrigation problems, lifestyle issues</td>
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<td>• Negative Feelings about body appearance (Common) – can impact sexuality issues</td>
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<tr>
<td>Talk to your Enterostomal Therapy Nurse. Talk to your Family Doctor and contact CCMB Patient &amp; Family Support Services for Individual or Family Counseling</td>
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<tr>
<td><strong>Male Sexual Problems</strong> (particularly with rectal cancer treatment)</td>
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<tr>
<td>• Problems with erections (Quite Common)</td>
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<tr>
<td>• Problems with ejaculation (Quite Common)</td>
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<tr>
<td><strong>Female Sexual Problems</strong></td>
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<tr>
<td>• Pain with sex (Common)</td>
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<tr>
<td>• Vaginal dryness (Common)</td>
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<tr>
<td>Contact the CCMB Sexuality Counselor directly or Patient &amp; Family Support Services for assistance.</td>
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| **Skin Changes** - due to radiation or surgery (Not as common) | Talk to your Radiation or Surgical Clinic Nurse.  
Talk to your Enterostomal Therapy Nurse if you have an ostomy. |
| **Nerve Damage / Neuropathy** - tingling, numbness or pain in hands or feet due to chemotherapy (Not as common) | Talk to your Family Doctor.  
The CCMB Pain and Symptom Clinic – physician / nurse referral needed. |
| Hernia (Not as common) When you have a stoma, a hernia can change how the ostomy appliance will sit on the belly & may require changes to products or use of a hernia support binder. | Talk to your Surgeon or your Enterostomal Therapy Nurse |
| **Unplanned Weight Loss** - losing weight without trying (Common) | Contact the CCMB Dietitian or talk to your Family Doctor. |
| **De-conditioning / Unwanted Weight Gain** - trouble with daily activities, exercising and/or unwanted weight gain (Quite Common) | Talk to your Family Doctor about being active and/or referral to a Registered Dietitian in your community.  
Access an Exercise Professional or Facility. |
| **Fatigue** (Common) | Talk to your Family Doctor or contact an Occupational Therapist |
| **Trouble Sleeping** (Common)  
**Memory & Concentration Problems** (Common)  
**Mood Swings** (Not as common)  
**Emotional Distress** (Common)  
**Fear of recurrence** (Common)  
**Anxiety** (Not as common)  
**Depression** (Not as common) | Talk to your Family Doctor and contact CCMB Patient & Family Support Services for Individual or Family Counseling and Support Groups. |

Notes on Problems or Side Effects: ______________________________________________________________
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10. Diet & Nutrition following Colorectal Cancer

Colon and Rectal cancer survivors with chronic bowel problems due to side effects of treatment or surgery may have difficulties when putting fruits, vegetables, whole grains, legumes and other fibre-containing foods back into their diet.

The tips below include suggestions to help manage diarrhea / frequent bowel movements and cramping and abdominal gas:

- Eat smaller, more frequent meals.
- Drink at least 6 - 8 cups (1.5 – 2 litres) of fluid per day.
- Drink fluid between meals rather than with meals.
- Limit drinks containing caffeine (such as coffee or cola soft drinks) and alcohol.
- Limit fatty or greasy foods (french fries, fried meats, bacon, potato chips, gravies and rich desserts)
- Limit spicy foods.
- Eat **more** foods that are high in soluble fibre such as oatmeal, oat bran, barley, white rice, bananas, white toast, applesauce and canned fruit such as peaches and pears.
- Eat **less** foods containing insoluble fibre such as wheat bran, whole grain breads and cereals, beans, peas, popcorn and raw vegetables (well-cooked vegetables are ok).
  - Peel and remove seeds of fruits and vegetables.
  - To reduce gas, limit your intake of these foods if they cause you problems: cabbage, onions, dried beans and peas, lentils, lettuce, cucumber, broccoli, cauliflower, radishes, brussel sprouts, corn, turnip, green pepper, sauerkraut, melons, grapes, raw apple, prunes, raisins. Avoid chewing gum, talking while eating, carbonated beverages and drinking with a straw.
- Once symptoms improve, slowly start to put foods back into your diet in small amounts, one at a time. If you get diarrhea, gas or cramping after re-starting a food, avoid that food and try it again at a later time.

For more recommendations and information maintaining a healthy body weight and eating well, please refer to Part 3 of the Follow-Up Care Plan, Moving Forward after Cancer Treatment booklet and the Canada Food Guide.

**Notes on Diet and Nutrition:**
11. Exercise & Activity following Colorectal Cancer

Being active after treatment for colon and rectal cancer is important whether you are getting back to activities you enjoy or starting a new healthy lifestyle plan. Research has shown a link between exercise and decreased rates of recurrence and increased rates of survival in colorectal cancer. Exercise can also combat the side effects of fatigue and sleep disturbances. Always check with your doctor before starting an exercise program.

Following treatment, you may need to take special precautions if you

- have anemia, a ‘low blood count’
- have problems with nerves that affect your balance or numbness or tingling
- are taking any pain medication or anti-inflammatory medications, be careful to not ‘over-do it’ and take care of any injuries immediately, as you may have masked pain.
- have weakened immune function
- have had surgery in your abdominal cavity, heavy lifting can cause a hernia. Be sure your incision has completely healed and gradually introduce weights while concentrating on breathing with exertion and not holding your breath & bearing down.

Exercising can speed up your food digestion. This can increase the need to go to bathroom during or immediately after exercising.

- Go to the bathroom before exercising and take short breaks to go to bathroom throughout.
- Know where the washrooms are or where there are washrooms along the way. An urgent time is usually right after you stop, so have easy access to the washroom at that time. Wear clothing that can be quickly and easily removed – do not tie your drawstrings in a knot!
- If you are using a medication recommended by your physician to combat diarrhea, take it prior to exercising.
- Sip water throughout your activity; do not gulp down large amounts before your activity or early on. The more vigorous the activity or the more you are sweating, the more water you should be consuming.
- If you are worried about having an ‘accident’ take an extra set of clothes along with you, as well as a plastic bag for soiled clothes and a wash cloth. Talk with your physician about this issue.

Exercising with an ostomy can be challenging at first. Talk with your Enterostomal Therapy Nurse about your activity and they will be able to help you. There may be specific supplies and techniques that can assist with issues such as sweating and adherence, protection and securing of appliances and solving other issues you may have.

For more recommendations and information on exercise, activity and healthy lifestyle please refer to Part 3 of the Follow-Up Care Plan, Moving Forward after Cancer Treatment booklet.
12. Cancer Transitions Workshop

CancerCare Manitoba is offering a program called “Cancer Transitions.” This is a free workshop for all patients following treatment that are in follow-up care. The focus is on taking control of your survivorship and getting back to wellness. It is also a chance to meet others who have been through a similar experience.

Topics include:
- Nutrition
- Exercise, including 30 minutes of light activity
- Emotional health and wellbeing
- What to expect in follow-up care
- Goal setting, and more!

There is a second, two hour booster session one month later, and peer support in between. Pre-registration is required and it is offered at different times throughout the year.

Although having cancer can leave you feeling like you have little control over your life, this session is intended to help you find out what you do to take more control and manage feelings of uncertainty. The session will help you in making a personal wellness plan that includes ways you can take care of your physical, emotional, social, and spiritual needs.

Please call Patient & Family Support Services for more information, dates and registration at 204-787-2109 or toll-free 1-866-561-1026 extension 2109.

13. Colorectal Cancer Support & Resources

Counseling: CCMB’s Patient and Family Support Services has psychosocial clinicians / counselors who specialize in working with people with colorectal cancer and their families/loved ones. They can see you individually, as a couple, as a family or any member of your family on their own. There are counselors available at both CCMB MacCharles and St. Boniface sites and some rural sites, as well as access through Manitoba Telehealth.

Call CCMB’s Patient and Family Support Services - Telephone: 204-787-2109 or toll-free 1-866-561-1026 extension 2109.

Support Groups: Professionally lead face-to-face and/or online groups provide an environment for those living with or after cancer to interact with others in similar situations.
- CancerCare Manitoba’s Colorectal Support Group in Winnipeg. Call the Program Leader at 204-787-4286 or Patient & Family Support Services at 204-787-2109 or toll-free 1-866-561-1026 ext.2109.
- Cancer Coaches: is a peer-support program of the Colorectal Cancer Association of Canada. Call toll-free: 1-877-50 COLON (26566) or email info@colorectal-cancer.ca
- Winnipeg Ostomy Association: Winnipeg chapter of the United Ostomy Association of Canada, peer support for all those living with an ostomy and their family and friends (not specific to cancer patients only.) Monthly newsletter and meetings. One on one visitor program is available. Phone 204-237-2022 or email woainfo@mts.net.

There are many other support programs and groups available through CCMB Patient & Family Support Services. Information is available in the Navigator newsletter, the CancerCare Manitoba website or by calling CCMB’s Patient and Family Support Services - Telephone: 204-787-2109 or toll-free 1-866-561-1026 extension 2109.
Sexuality Counseling: An expert nurse counselor is available at CCMB to meet with you and/or your partner to talk about any concerns you have about sexuality, and help you renew your sex life after cancer. Call the Clinical Nurse Specialist as follows:

In Winnipeg
• 204-787-4495
• can meet with you in person
If you need assistance, call CCMB's Patient and Family Support Services - Telephone: 204-787-2109 or toll-free 1-866-561-1026 ext. 2109.

In rural Manitoba
• toll free 1-866-561-1026 ext.4495
• can meet with you via videoconferencing

Diet & Nutrition: As discussed above, colorectal cancer survivors may have specific problems with eating due to long-term side effects of treatment. A dietitian will help you modify your diet to accommodate the difficulties you are experiencing in order to maintain optimal health. If you have difficulty eating a healthy diet, or if you have questions about nutrition, make an appointment with a Registered Dietitian.

• You can access a dietitian through CancerCare Manitoba Patient & Family Support Services (204-787-2109 or toll-free 1-866-561-1026 ext.2109.) They can also assist in referrals to dietitians in your community for weight-loss issues.

Incontinence Issues: There are nurses and physiotherapists who are incontinence specialists who can provide you with valuable advice and an exercise program to help you control your bladder/bowels. Advice may include a pelvic floor exercise program, dietary changes, changes in the timing of your visits to the bathroom, and hints to help you decrease the urgent feeling to empty your bladder.

• Physician or nurse referral to Riverview Incontinence Program: 204-478-6876 (fax)
• Incontinence & Pelvic Pain Clinic (Div. of Nova Physiotherapy & Sports Fitness Clinic): 204-982-9178
• Wellness Institute – Physiotherapy Services (urinary incontinence): 204-632-3910

Ostomy Services: You were registered with the Manitoba Ostomy Program by the Enterostomal Therapy (ET) nurse before you left the hospital after surgery if an ostomy was necessary. You are able to order your ostomy care supplies through the Manitoba Ostomy Program. Manitoba Health pays for your supplies. You should see your ET nurse once a year or whenever you are having problems, including with your supplies.

• Surgery at Health Sciences Centre, contact the HSC Enterostomal Therapy nurses: 204-787-3537
• Surgery at St. Boniface Hospital, contact the St. Boniface Enterostomal Therapy nurses: 204-237-2052
• For other hospitals, please call the ET nurses with the Manitoba Ostomy program at 204-938-5757 or 204-938-5758
• For the Brandon area call the Enterostomal Therapy nurse: 204-578-4205

Pain and Symptom Clinics: Following colorectal cancer and its treatment some people experience symptoms that may be difficult to manage, such as pain in the pelvis and bowel or bladder problems. You can be referred to a Pain and Symptom Management Clinic by a CCMB health care provider or your family doctor or nurse practitioner.

• Fax referrals to 204-786-0612

Websites – Colorectal Cancer Information: The Web is a great source of information about moving forward after cancer, but it is also full of misinformation. These websites are ones you can rely on!

CancerCare Manitoba (General Cancer Information and Support) www.cancercare.mb.ca
Cancerview Canada (General Cancer Information) www.cancerview.ca
Colorectal Cancer Association of Canada www.colorectal-cancer.ca
Canadian Cancer Society <click> Manitoba <click> Colorectal Cancer www.cancer.ca
American Society of Clinical Oncology “ASCO” Patient Site (USA) www.cancer.net
National Cancer Institute (USA) www.cancer.gov