# Follow up Care for **Rectal Beyond** Cancer Patients





Follow up Care for **Rectal Living Beyond Cancer** Patients

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Your cancer treatments are now finished. You are joining a growing number of people living with cancer, who are often called cancer survivors. Follow up care is a very important part of your cancer care.

This guide describes your recommended follow up care plan. It will help you learn how to manage your life after cancer treatment, understand what you can do to reduce your risk of the cancer coming back, and explain the tests that are recommended for you. Your cancer doctor has also sent your health care providers (family doctor/nurse practitioner and, if needed, surgeon) a copy of your follow up care plan.

You and your health care providers are an important part of your follow up care. Your health care provider can contact your cancer doctor anytime. If needed, you will be referred back to your cancer doctor.

**Inherited risk of colorectal cancer:** Only 5-10% of colorectal cancer is hereditary (passed down through a family). However, it is important to identify individuals who could be at risk of inherited colorectal cancer as their screening and management options would be different from a person who developed colorectal cancer by chance. It is important to review your personal and family history of cancer with your health care provider to see if you should be referred for a genetic assessment. Because this decision is often based on family history information and your own personal medical history it is important to have accurate information about the cancer in your family. Not everyone who is referred for genetic assessment moves on to genetic testing. In families who need genetic testing, it is important that the best person is tested. Certain signs, like the age people were when they first had cancer, help to decide the best person in a family to test. The person who has the assessment may not be the person who is tested. The best place to start is with a discussion with your health care provider. Your health care provider can contact the Maritime Medical Genetics Service with any questions.

We hope this guide will be helpful. If you have any questions or concerns, please talk to your family doctor/nurse practitioner/surgeon or cancer patient navigator (if there is one in your area).

# Please know that you are not alone as you move forward in your recovery.

# WHAPPENS

Living Beyond Cancer Follow up Care for Rectal Cancer Patients

# What is Follow up Care?

### The goals of follow up care are to:

- **Provide support.** Follow up care visits allow you to discuss how you are doing and any problems you have, such as dealing with the side effects of your cancer treatment or fear of recurrence.
- Check for return of your cancer or a new cancer. Early detection of cancer is important. Treatment is more likely to be successful at an early stage.

### Follow up care for rectal cancer involves:

- Regular visits with your health care provider. These visits are very important to assess and talk about how you are doing and your current health. Your surgeon may also be involved in providing your follow up care.
- A blood test called CEA that may help find a return of cancer earlier.
- A Colonoscopy test that allows a doctor to look for polyps or second cancers with a scope (lighted tube).
- A Rectosigmoidoscopy test uses a flexible scope which is inserted into a patient's rectum to check for polyps, cancer, and other abnormalities.
- **X-rays or scans** For example: X-ray, CT scan or ultrasound. X-rays may be suggested for the chest, abdomen and the pelvis.

### Everyone in follow up care will not have exactly the same care because each follow up plan is based on your treatment and how it affected your body.

This plan is a guide and does not replace your health care provider's advice.

### **Notes and Questions**

### **Follow up Care Recommendations**

### For Rectal Cancer by Years after End of Treatment

If you are diagnosed with a genetic syndrome linked with rectal cancer you may have different follow up. Please discuss with your surgeon or medical oncologist.

Follow up Care	Year 1	Year 2 Year 3		Years 4 and 5
Health Care Provider Visit	Every 3 to 6 months	Every 3 to 6 months	Every 3 to 6 months	Every 6 months
CEA test	Every 3 to 6 months			Every 6 months
CT Scan		hest, abdomen a e annually (deper	When your health care provider feels it is needed	

After 5 years, you and your health care provider will discuss the need for future visits and tests.

### Follow up by Years after Surgery

To be coordinated with the attending surgeon.

Rectosigmoid- oscopy	6 months	18 and 24 months	36 months	Not necessary after three years
Colonoscopy	12 months	Year 4	Year 9	Ongoing
	A complete Yes colonoscopy col should be sho done. sig rec or		Yes, if previous colonoscopy shows no signs of a recurrent tumour or polyps.	every 3 to 5 years thereafter, as long as you are

### **Notes and Questions**

### **Returning Cancer: Signs to Watch For**

One of the biggest concerns for cancer patients is that the cancer may return some day. If rectal cancer does return, it is usually in the first two to five years after diagnosis. This is why the follow up care is so important. After five years, the chance of cancer returning drops year after year.

If your cancer returns, it is usually because cancer cells have spread to the liver or lungs. There is also a small risk of the cancer coming back in the bowel where the surgery was done or a new cancer growing in a different part of the bowel. This is why the follow up care has tests for the liver, lungs, colon and rectum. It is possible to treat the cancer if it is found early and can be removed. If it cannot be removed, cure is usually not possible, but chemotherapy will improve symptoms and may extend your life.

Know the signs to watch for. Please notify your health care provider if you have any of these changes in your health:

Notify your health care provider **right away** if you see:

- Blood in your bowel movement
- Blood that you cough up
- Bowel movement that is very pale or black
- Yellow eyes or skin (jaundice)
- New lumps, especially in the neck and groin
- Blood in your urine
- If you have an ostomy, a change in your stoma

See your health care provider if these symptoms last more than one week:

- A change in your bowel movements, like loose bowel movements or constipation
- Cough
- Pain in your abdomen or rectal area (or where the rectum/anus used to be)
- Nausea (feeling sick to your stomach)
- Pain that will not go away or is getting worse
- Vomiting that lasts more than a few days
- Shortness of breath
- Loss of appetite
- Weight loss without trying
- Drop in your energy level or ability to be active
- Sciatica (lower back pain that goes down your leg)
- Difficulty with urination or having a bowel movement

### **Cancer Screening and Other Tests**

Just like people who have not had rectal cancer, it is important for you to continue with routine screening for cancer and other diseases. Some examples are given below but others may be needed depending on your family history. Talk with your health care provider about cancer screening and other tests.

### **For Women**

**Cervical Cancer Screening:** Women should start screening for cervical cancer (also called a Pap test) within three years of becoming sexually active or upon reaching the age of 21, whichever comes later. Women who have never been sexually active do not need Pap screening. Pap testing should be done every three years. Women with a history of cancer of the cervix or who have been treated (by LEEP, laser, cryotherapy,

cone, hysterectomy) should be screened annually for life. Immunocompromised or HIV positive women should be screened annually for life. Women can discontinue having Pap tests at age 70 if they have had three or more negative Pap tests in the previous 10 years. Women who have had a total hysterectomy for benign causes with no treatment for abnormal cell growth on the cervix can discontinue Pap screening.

The screening guidelines only apply to women with no symptoms of cervical cancer who are, or have been, sexually active. If a woman is experiencing symptoms such as irregular bleeding or pain, she should speak with her health care provider. To learn more about cervical cancer screening guidelines, call Nova Scotia Cancer Care Program: **1-888-480-8588** or visit **www.nscancercare.ca**.

**Breast Cancer Screening:** Women 50 and over should have a mammogram every 2 years. If you have a strong family history or are currently using hormone replacement therapy a mammogram may be needed every year. Visit the Nova Scotia Breast Screening Program website **www.breastscreening.nshealth.ca** to learn more. Call **473-3960** or **1-800-565-0548** to book an appointment.

### **Cancer Screening and Other Tests (continued)**

### For Men

**Prostate Cancer:** Talk to your health care provider about your risk for prostate cancer and the benefits and harms of PSA testing. To learn more visit the Canadian Cancer Society's website **www.cancer.ca** or call **1-888-939-3333**.

### For Both Men and Women

**Diabetes Screening:** Starting at age 40, you should have a Fasting Plasma Glucose (FPG) test every 3 years. For those at high risk (family history, overweight, Aboriginal, African Nova Scotian, have a history of gestational diabetes or pre-diabetes, heart disease, increased cholesterol, increased blood pressure), more frequent and/or earlier

testing should be considered. To learn more, call the Canadian Diabetes Association **1-800-226-8464** or visit **www.diabetes.ca**.

**Cholesterol Screening:** You should have a 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, heart disease, if you smoke or if you are overweight. Talk with your health care provider about how often you should have this test.

**Blood Pressure Checks:** Get your blood pressure checked regularly by your health care provider.

### **Other Ways to Protect Your Health:**

**Immunization:** You should have a flu shot every fall. If you are 65 or older, have diabetes, heart or lung problems, you should also have a pneumonia vaccine. Ask your health care provider about the benefits and risks of getting a shingles vaccination.

**Protect Your Skin:** Having chemotherapy or radiation can make you more sensitive to harm from the sun and other sources of ultraviolet (UV) rays. Some prescription and over-the-counter medications can also make skin very sensitive to the sun. Protect yourself by being informed and using good sun protection practices at work, in your community and on vacation. Check the UV Index daily and practice sun safety as recommended. The higher the UV Index, the more protection is required. Plan activities in the shade, cover up with clothing and a wide-brimmed hat, wear sunglasses and use a broad spectrum sunscreen with a Sun Protection Factor (SPF) of 30 or higher. Avoid use of tanning beds.

### **Cancer Screening and Other Tests (continued)**

### Other Ways to Protect Your Health (continued)

**Limit or Avoid Alcohol:** Discuss risks associated with alcohol use with your health care provider. Drinking alcohol increases your risk for several types of cancer. Risk increases for some kinds of cancer with as little as one drink per day. The more you drink, the more your risk increases. The risk of cancer increases regardless of what type of alcohol you drink (beer, wine, cider, spirits or liqueur). If you do drink alcohol, follow the Canadian low risk drinking guidelines. If you do not drink alcohol, don't start.

Combining smoking with alcohol increases cancer risks even greater than the cancer risks that come from drinking alcohol or smoking on their own.

**Stop Using Tobacco\*:** Quitting smoking or other tobacco use after a cancer diagnosis does make a difference. It can result in fewer treatment and cancer-related complications. It can make your cancer treatments more effective, improve survival and reduce the chance of a recurrence or a second cancer. It is never too late to quit tobacco. Help is available. If you want to quit, talk to your health care provider or call 811 to be connected to a tobacco cessation counselor who can offer assistance over the phone and refer you to a quit program in your area. There is no cost and no referral is required. Online resources are also available at:

### https://tobaccofree.novascotia.ca/

\*Tobacco includes smoked tobacco (cigarettes, pipes, cigars) and smokeless.

**Dental Health:** Chemotherapy can cause dental problems. It is important that you have regular dental checkups. Your dentist will need to know that you had rectal cancer and the type of treatments you have received. Brushing with a soft tooth brush, and using toothpaste for sensitive teeth is recommended.

### Helpful websites can be found under Supports and Resources.

## What to Expect after Cancer Treatment

You may have some side effects after your surgery and/or cancer treatment. Some side effects can start right away or can take months to begin. Some side-effects improve with time, while others may go on for many years or may be permanent. These side effects may be physical or emotional.

If any of these side effects are a problem for you, talk to your health care provider. If there is a cancer patient navigator in your area they can also help. Call 1-866-524-1234.

Your health care provider or cancer patient navigator can provide you with support, connect you with other services and give you information about local resources.

If you visit a clinic with a group practice, it is best if only one health care provider is responsible for your follow up care.

Diarrhea

Constipation

### **Bowel Problems**

- Urgent need to have a bowel movement
- Loss of bowel control (incontinence)

What to do: Talk to your health care provider.

Bowel Blockage (pain, nausea, vomiting, not able to pass gas or bowel movements) is not as common as the other bowel problems noted above or the ostomy problems noted below.

What to do: This is an emergency, go to the emergency department right away.

### Low Anterior Resection Syndrome (LARS)

LARS is a change in bowel habits that may occur after surgery for rectal cancer. LARS includes a wide range of issues that can have a great impact on people's guality of life. Symptoms of LARS may include:

- Clustering of bowel movements (numerous bowel movements over a few hours)
- Incontinence (leakage while passing gas or Difficulty emptying bowels rarely complete loss of bowel control)
- Frequency or urgency of bowel movements
  No bowel movement for a day or two or more, and then

Frequent bowel movements

- many bowel movements another day
- Increased gas

What to do: There is no one best way to treat LARS and the right treatment is different for each person. Talk to your surgeon about your symptoms and how they can best be managed.

### **Ostomy Issues**

- Skin or appliance problems
- Constipation, diarrhea
- Irrigation problems

- Negative feelings about how your body looks
- Lifestyle issues
- Sexual health issues

Hernia – A hernia is a weakness in the wall of the abdomen that allows the contents to bulge out forming a lump or swelling. When you have a stoma, a hernia can change how the Ostomy appliance fits and you may need to change products or use a hernia support binder.

What to do: Talk to your Entrostomal Therapy Nurse, your health care provider or cancer patient navigator.

### Urination Problems

- Frequent urination Difficulty emptying your bladder
- Urgent need to urinate

Incontinence (loss of bladder control)

What to do: Contact your health care provider or cancer patient navigator.

Continued on next page

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### What to Expect after Cancer Treatment (continued)

### Pain in the Pelvis

What to do: Contact your health care provider or cancer patient navigator.

### **Nerve Damage/Neuropathy**

Tingling, numbness or pain in the hands or feet

What to do: Contact your health care provider or cancer patient navigator.

### Sexual Problems

Men

- Problems with sexual function (getting or
- keeping an erection, changes in ejaculation)
- Decreased or loss of sexual interest/desire Relationship difficulties

- Women
- Decreased or loss of sexual interest/desire, decreased ability to become aroused
- Pain during sex Vaginal dryness

Relationship difficulties

What to do: Contact your nurse where you received your cancer care or the cancer patient navigator. They can help you find resources such as the psychosocial oncology team and couples counselling. See the resources at end of this guide.

Fatigue and Less Energy	
Extreme tiredness	Usual activity feels harder to do
Weakness	Difficult to do physical activity

**Difficulty Sleeping** 

Difficulty falling asleep

Waking up through the night and not being able to go back to sleep

What to do: Tell your health care provider who will assess your fatigue and suggest ways to prevent or manage it. Regular exercise is one of the best ways to decrease your fatigue. There are resources available to help you learn more about your cancer-related fatigue. For more helpful hints see the websites section on page 17 of this guide.

### **Difficulty Returning to Work**

Many people experience distress at the idea of returning to work after treatment. When you do go back, you may find your work more challenging than before your cancer treatment.

What to do: Talk with your employer, your workplace's employee health staff and your health care provider about how to deal with your work related concerns.

### **Psychosocial Distress**

- Trouble sleeping
- Memory and concentration problems
- Mood swings

- Fear of cancer coming back Anxiety
- Depression

Emotional distress

What to do: Contact your nurse where you received your cancer care or the cancer patient navigator in your area (if available). They can help you find resources such as the psychosocial oncology team and social workers in your

## **Eating Well after Rectal Cancer**

Rectal cancer survivors may have problems when they start to eat fruits, vegetables, whole grains, legumes and other high fibre foods again. Each cancer survivor is unique. It is important to discuss your issues with your doctor or a dietitian.

For the QEII Cancer Care Program please call the clinical dietitian at **902-473-3972**. For the Cape Breton Cancer Centre please call the clinical dietitian at **902-567-8552**. Call your community Cancer Patient Navigator **1-866-524-1234** for referral to a dietitian in your community.

For patients with ostomies who have questions or concerns about their ostomy, please contact the Enterostomal Therapy Department at:

QEII Health Sciences Centre 902-473-7503

Cape Breton Regional Hospital call 902-567-8000 ext. 2335

Check with your community cancer patient navigator **(1-866-524-1234)** for referral to an Entrostomal Therapy Nurse in your area if you do not already have one.

# The tips below may help you with side effects of our surgery and/or treatment. Please discuss with your surgeon, Enterostomal Therapy Nurse or dietitian to determine what is best for you.

- Eat smaller, more frequent meals.
- When trying new foods start with very small servings.
- Drink at least 6 8 cups (1.5 2 litres) of fluid per day.
- Drink fluid between meals rather than with meals.
- Limit drinks with caffeine (such as coffee or cola soft drinks).
- Limit alcohol.
- Limit fatty or greasy foods (such as french fries, fried meats, bacon, potato chips, gravies and rich desserts).
- Limit spicy foods.
- Gradually eat more foods that are high in soluble fibre such as oatmeal, barley, white rice, bananas, white bread, applesauce and canned fruit such as peaches and pears.
- Eat less food with insoluble fibre such as wheat bran, whole grain breads and cereals, beans, peas, popcorn, any bran products and raw vegetables.
- Eat well cooked vegetables.
- Limit how much red meat you eat.
- Peel and remove seeds of fruits and vegetables.
- To reduce gas, limit these foods: 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.
- To reduce gas, avoid chewing gum, talking while eating, drinking carbonated beverages (pop) and drinking with a straw.

Once you feel better, 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.

## **Physical Activity after Rectal Cancer**

Whether you are getting back to activities you enjoy or starting new ones, being active after treatment for rectal cancer is important. Research has suggested a link between physical activity and decreased rates of cancer return and increased rates of survival in rectal cancer. Physical activity can also help with fatigue and sleep disturbances. Always check with your doctor/nurse practitioner before starting an exercise program.

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

- have anemia, a 'low red blood cell count'.
- have problems with your balance.
- Ave numbness or tingling in your hands or feet.
- are taking any pain or anti-inflammatory drugs. These drugs may mask pain so be careful to not "over-do-it" and take care of any injuries immediately.
- have weakened immune function.
- Ave had surgery in your abdominal cavity since heavy lifting can cause a hernia.

**Be sure your incision has completely healed before gradually introducing weights.** While lifting weights be sure to concentrate on breathing with exertion and do not hold your breath or bear down.

**Physical activity can speed up your digestion.** This can increase the need to go to the bathroom during or immediately after activity. Follow these helpful hints:

- Go to the bathroom before your activity and take short breaks to go to the bathroom.
- Know where the bathrooms are located along the way.
- An urgent time is usually right after you stop, so have easy access to the bathroom at that time.
- Wear clothing that can be quickly and easily removed.
- If you are using a medication for diarrhea, take it prior to exercising.
- Sip water during your activity do not gulp down large amounts.
- The harder the activity or the more you are sweating, the more water you should drink.
- If you are worried about having an 'accident' take an extra set of clothes along with you, as well as a wash cloth and a plastic bag for soiled clothes.

**Doing physical activity when you have an Ostomy can be hard, at first.** Talk with your Enterostomal Therapy Nurse about your activity and they will help you. There may be specific supplies and techniques that can assist with the issues you are having, such as protection and securing of appliances.

# **Programs for Cancer Survivors**

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### **Cancer Transitions**

QEII Cancer Care Program and the Cape Breton Cancer Centre offer a free six week program, Cancer Transitions, to help cancer survivors adjust to life after cancer.

### **Cancer Transitions covers these topics:**

- Get Back to Wellness Exercise for Wellness
- Eating Well Medical Care After Cancer

Emotional Health

For more information and to register: QEII Cancer Care Program call 902-473-3449; Cape Breton Cancer Centre call 902-567-8074

### Living Beyond Cancer: What Happens Next?

The Nova Scotia Health Authority offers a two and a half hour session that focuses on some of the key issues cancer survivors face in the months following active treatment. You may attend in person at the Bethune Ballroom, VG Site or via telehealth, at the Regional Hospital in your area.

### **Topics include:**

- What is Follow up Care
- Eating Well After Cancer
- What to Expect after Cancer Treatment
  - Physical Activity and Emotional and Practical Support.

For more information and to register call toll free 1-866-599-2267 and select option 3, or to register online please go to **www.nscancercare.ca** and click on I am a Cancer Survivor.

We now have Living Beyond Cancer video segments available to watch online. These can be found by visiting **library.nshealth.ca/cancer** and clicking on Cancer Patient Education Videos.

### **Your Way to Wellness**

Your Way to Wellness is a provincially sponsored, free program, led by volunteer lay leaders. The Program is designed to help people with chronic conditions learn skills to live a healthier life. Your Way to Wellness is offered once a week for a 2 ½ hour session over six weeks. Programs are offered all over Nova Scotia.

For more information, call toll free: 1-888-672-3444 or visit www.yourway.novascotia.ca

### **Programs for Cancer Survivors (continued)**

### **Group Learning Sessions for Cancer Patients and Families**

Some cancer patients and survivors experience treatment related side effects. There are a number of group teaching sessions which focus on the most common ones.

These sessions are not support groups, but participants have the opportunity to ask questions. Each session is 2 hours. Available resources and supports are discussed. Family and friends are also welcome to attend. For the date, time and location of upcoming sessions, please call **1-866-599-2267** and select option 3.

We now have video segments available to watch online. These can be found by visiting **library.nshealth.ca/cancer** and clicking on Cancer Patient Education Videos.

**Managing Your Cancer-related Fatigue:** Cancer-related fatigue (tiredness) is one of the most common side effects of cancer treatment. The sessions provide practical information about cancer-related fatigue and helpful management strategies.

**Taking Control of Your Cancer-related Worry and Anxiety:** Most people with cancer experience worry and some level of anxiety. This session provides practical information about cancer-related anxiety and helpful coping strategies (such as deep breathing relaxation).

**Taking Control of Your Cancer-related Sadness and Depression:** Many people with cancer experience sadness or depression. This session provides practical information about cancer-related sadness and depression and helpful coping strategies.

**Coping With Cancer-related Brain Fog:** Some cancer patients and survivors notice changes in their thinking and cognitive abilities during or after treatment. This is known as cancer-related brain fog. This session focuses on understanding cancer-related brain fog and management strategies.

\*Coping with Your Cancer-related Pain: Not everyone with cancer experiences pain but many people do. This session focuses on understanding cancer-related pain and management strategies such as medication, managing energy and relaxation.

\*This session is only available online at **library.nshealth.ca/cancer** and click on Cancer Patient Education Videos.

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Living Follow up Care for Beyond Rectal Cancer Patients

## **Support and Resources**

Cancer affects more than your body. It has an impact on your whole life. Many people who have had cancer find that talking with a professional counselor or therapist can be very helpful. Health care providers are the experts in treating cancer, but you are the expert in the way cancer affects your life. Counselling can help you to find strength and meaning. It can also help you cope, adjust, and find solutions to problems. You can go to counselling on your own or with members of your family.

The QEII Cancer Care Program has a psychosocial cancer team for people who have been diagnosed and treated for rectal cancer anywhere in the province of Nova Scotia. The team provides counselling to rectal cancer patients & their families. Team members include psychologists, psychiatrists, social workers, nurses and spiritual care providers.

Support can be provided to you by phone or in person. If you are having difficulty coping, you can ask your health care provider, your cancer doctor or another member of your cancer team to make a referral to a member of the psychosocial cancer team (QEII Cancer Care Program).

If you live in Sydney, please call the social worker at the Cape Breton Cancer Centre at **902-567-8551**. If you live outside Halifax and Sydney, check with your cancer patient navigator, social worker or health care provider to find out about services in your district. To reach your local cancer patient navigator please call **1-866-524-1234**.

### **Cancer Connection – Canadian Cancer Society**

The Canadian Cancer Society can connect patients or caregivers with fully screened and trained volunteers who have had cancer or cared for someone with cancer. Our volunteers listen, provide hope, offer encouragement, and share ideas for coping – all from their unique perspective as "someone who has been there."

Call 1-888-939-3333 to get connected or logon at www.cancerconnection.ca.

### **Colorectal Cancer Association of Canada – Cancer Coaches**

Cancer Coaches are volunteers with the Colorectal Cancer Association of Canada who share their experiences and information in various aspects of colorectal cancer. They can help address your concerns and answer your questions.

Login at archive.colorectalcancercanada.com/en/find-support/cancer-coaches/

### **Private Medical Insurance and Employee Assistance Programs**

Counselling is also covered under some private insurance plans (i.e. Blue Cross). There may be a yearly maximum as to how much your plan will pay. Contact your insurer for the details specific to your plan.

As well, many employers offer Employee Assistance Plans which offer a limited number of free counselling sessions. Please contact your Human Resources department for information.

### Support and Resources (continued)

### **Support Groups**

A support group is a group of people with similar problems or concerns. Support groups meet on a regular basis. There are many different cancer support groups. Some are for the patients. Others are for the family and/or friends of the patient. Others are open to anyone. Groups may be led by a health care professional or made up completely of peers. You can find support groups that meet face-to-face or online.

It may help to talk with the person running the group to see if the group offers what you need. You may want to check out a few different groups to find one that works best for you. It is hard to know if a support group will be right for you without going to at least two meetings.

A support group should make you feel comfortable enough to talk about what you think and feel. If it does not, speak with the facilitator privately. You may decide it is best not to continue going. Remember that it may take time to find a group that fits.

Find a support group in your area:

- Canadian Cancer Society at **1-800-639-0222** or visit **www.cancer.ca**.
- QEII Cancer Care Program in Halifax: **902-473-6067**.
- Social Worker at the Cape Breton Cancer Centre, Sydney: 902-567-8551.
- Cancer Patient Navigators: 1-866-524-1234.
- Check for posters in your cancer treatment centre.
- Ask people you know who have gone through, or who are currently dealing with cancer themselves.

Many people choose online support groups. These groups help people who may not wish to attend a face-to-face group. Be careful when looking for an online group. Anyone with internet access can create an online group, even if they do not have any qualifications.

If you are interested in online groups, contact **Cancer Chat Canada**, by visiting their website, **cancerchatcanada.ca**. Canadian cancer care professionals lead these groups. Most are available in any province or territory.

You can also call 211 to find local support groups.

### Support and Resources (continued)

### **Books**

After You Ring the Bell...10 Challenges for Cancer Survivor. Anne Katz. Oncology Nursing Society. 2012. Cancer is a Word Not a Sentence by Dr. Robert Buckman

Life after Cancer. A guide for cancer survivors. Canadian Cancer Society, 2008. Visit the CCS website: www.cancer.ca or call **1-888-939-3333**.

**Life After Cancer Treatment.** Facing Forward Series. U.S. Department of Health and Human Services. National Institutes of Health. 2004. Visit the NIH website:

www.cancer.gov/cancertopics/coping/life-after-treatment/page1

Living Well after Cancer. A guide for cancer survivors, their families and friends. The Cancer Council New South Wales, February, 2010. Visit the CCNSW website **www.cancercouncil.com.au** 

**Picking Up the Pieces. Moving Forward after surviving Cancer.** Sherri Magee and Kathy Scalzo. Raincoast Books, Rutgers University Press. 2007.

The Essential Cancer Treatment Nutrition Guide and Cookbook by Jean Lamantia

The Healing Circle by Dr. Timothy Walker and Dr. Rob Rutledge, 2011.

The Healing Journey: Overcoming the Crisis of Cancer by Alastair J Cunningham. 2010.

The Places that Scare You: A Guide to Fearlessness in Difficult Times by Pema Chodron

When someone You Love Has Completed Cancer Treatment. U.S. Department of Health and Human Services. National Institutes of Health. May, 2010. Visit the NIH website:

www.cancer.gov/cancertopics/coping/someone-you-love-completed-cancer-treatment.pdf When a Parent is Sick: Helping Parents Explain Serious Illness to Children. Joan Hamilton, Clinical Nurse Specialist, Cancer Care, QEII, Halifax.

Men Cancer Sex. Anne Katz. 2010. Oncology Nursing Society.

Women Cancer Sex. Anne Katz. 2009. Oncology Nursing Society.

### Support and Resources (continued)

### **Websites**

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!

### For Rectal Cancer Survivorship information, visit:

- American Society of Clinical Oncology (ASCO) Patient Site: www.cancer.net
- British Columbia Cancer Agency: **bccancer.bc.ca**
- Canadian Cancer Society: www.cancer.ca <click on> Nova Scotia or call 1-888-939-3333
- Nova Scotia Cancer Care Program: www.nscancercare.ca
- Colorectal Cancer Association of Canada: www.colorectalcancercanada.com or call 1-877-50-COLON
- Healing and Cancer: www.healingandcancer.org
- National Cancer Institute (USA): www.cancer.gov
- National Comprehensive Cancer Network: www.nccn.org/patients/resources/life\_after\_cancer
- National LGBT Cancer Network: **www.cancer-network.org**
- Ostomy Canada Society: www.ostomycanada.ca or call 1-888-969-9698
- Rainbow Health Ontario: www.rainbowhealthontario.ca

### For Physical Activity information, visit:

Canadian Cancer Society, Physical Activity After Treatment: www.cancer.ca/en/cancer-information/cancer-journey/life-after-cancer/your-wellness-plan/ physical-activity-after-treatment/?region=on.

The Canadian Society for Exercise Physiology (CSEP): www.csep.ca/CMFiles/Guidelines/CSEP\_PAGuidelines\_adults\_en.pdf.

### For Fatigue information, visit:

- Canadian Cancer Society: www.cancer.ca <click on> Cancer Information <click on> diagnosis and treatment <click on> managing side effects <click on> fatigue.
- American Cancer Society: www.cancer.org/treatment/treatments-and-side-effects/physicalside-effects/fatigue.
- www.youtube.com/watch?v=YTFPMYGe86s&feature=youtu.be

### Living Follow up Care for Beyond

Rectal Cancer Patients

### Support and Resources (continued)

### Websites (continued)

### For Sexual Health information, visit:

- Canadian Cancer Society: www.cancer.ca < click on> Cancer Information < click on> diagnosis and treatment, <click on> managing side effects
- American Cancer Society: www.cancer.org/treatment/treatments-and-side-effects/ physical-side-effects/fertility-and-sexual-side-effects

### For Information in Languages other than English

There are a number of reputable sources of cancer information in languages other than English. We suggest the following Canadian resources:

- British Columbia Cancer Agency: **bccancer.bc.ca**
- Canadian Cancer Society: www.cancer.ca or call 1-888-939-3333
- Cancer Care Manitoba: www.cancercare.mb.ca
- Cancer Council New South Wales: **www.cancercouncil.com.au**
- Vancouver Coastal Health: http://vch.eduhealth.ca

### **Notes and Questions**

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Living Follow up Care for Beyond Rectal Cancer Cancer Patients

# **Get Involved**

Cancer patients, families, and friends have unique, valuable perspectives to share about cancer care. It is important to hear from people who have experience with the cancer system in order to see what can be changed to better meet people's needs.

As a cancer survivor you may want to get involved with the Cancer Patient Family Network (CPFN). The CPFN is a program of Nova Scotia Cancer Care Program that connects cancer patients, survivors, family members, and friends with opportunities to improve the cancer system. As a member of the CPFN you will have opportunities to participate in focus groups and committees, complete surveys, and review patient education resources.

Contact Nova Scotia Cancer Care Program by calling toll-free **1-866-599-2267**, emailing **cancercareinfo@nshealth.ca**, or visiting **www.nscancercare.ca**. For more information about the Cancer Patient Family Network, please contact the Patient Engagement Coordinator at **902-473-2637** or email **CPFN@nshealth.ca**.

### **Notes and Questions**

### Living Beyond Cancer Follow up Care for Rectal Cancer Patients

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# Follow up Rectal Cancer Care Schedule

You can use	tnese	cnarts	το	кеер	track	OT	your	tollow	up	care.	

	Year 1	Year 2	Year 3	Year 4	Year 5
Family Doctor/Nurse Practitioner/Health Care Provider's Visit	YYYY/MM/DD	YYYY/MM/DD	YYYY/MM/DD	YYYY/MM/DD	YYYY/MM/DD
Every 3-6 months during Years 1-3,	YYYY/MM/DD	YYYY/MM/DD	YYYY/MM/DD		
every 6 months during Years 4-5.	YYYY/MM/DD	YYYY/MM/DD	YYYY/MM/DD	YYYY/MM/DD	YYYY/MM/DD
	YYYY/MM/DD	YYYY/MM/DD	YYYY/MM/DD		

	Year 1	Year 2	Year 3	Year 4	Year 5
CEA test at each doctor's visit	YYYY/MM/DD	YYYY/MM/DD	YYYY/MM/DD	YYYY/MM/DD	YYYY/MM/DD
	YYYY/MM/DD	YYYY/MM/DD	YYYY/MM/DD		
	YYYY/MM/DD	YYYY/MM/DD	YYYY/MM/DD	YYYY/MM/DD	YYYY/MM/DD
	YYYY/MM/DD	YYYY/MM/DD	YYYY/MM/DD		
CT Scan – Chest, Abdomen, Pelvis annually in Years 1-3. After Year 3, as your doctor feels it is needed.	YYYY/MM/DD	YYYY/MM/DD	YYYY/MM/DD	YYYY/MM/DD	YYYY/MM/DD

Rectosigmoidoscopy – number of months after surgery	YYYY/MM/DD (6 months)	YYYY/MM/DD (18 months) YYYY/MM/DD (24 months)	YYYY/MM/DD (36 months)		
Colonoscopy – number of years after surgery	YYYY/MM/DD (1 year)	YYYY/MM/DD (4 years)	YYYY/MM/DD (9 years)	Every 3-5 years later	

Living Beyond Cancer

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This booklet was approved by Nova Scotia Cancer Patient Education Committee, 2016 This booklet is to be updated every three years

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