



support ▪ knowledge ▪ hope

A COMPANION AND REFERENCE GUIDE FOR PEOPLE WITH COLORECTAL CANCER



We have written this guide for people who have been diagnosed with colorectal cancer or for people with general questions about the disease. A diagnosis of cancer and undergoing treatment can be unsettling, even frightening. We hope that this guide gives you useful information and support during this stressful time. We also hope that it helps you take an active role in your treatment, if you are receiving treatment, and in your recovery. Feel free to share the guide with your friends and family. It may answer some of their questions about colorectal cancer.

This guide is the result of the work of many dedicated nurses, doctors, pharmacists, and patients. We thank them for their valuable input and tremendous help.

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introduction

They are words that you never thought you'd hear: colon cancer, bowel cancer, rectal cancer. Don't worry if you are in shock, afraid, or angry. These are normal reactions. It takes time to understand what is going on and what it all means.

Cancer is a word that no one wants to hear. And the colon and rectum are areas of the body that no one really talks about. You may feel a bit embarrassed and awkward, but know that you are not alone.

Living with cancer has been compared to taking a journey, travelling into unknown territory. But the more you know, the more in control you may feel. This guide is designed to be a road map for people who have just been diagnosed with colorectal cancer – cancers of the colon and rectum. Written with the help of health care professionals and people with colorectal cancer, we hope that it gives you some of the facts you may need on your journey. It contains information about the digestive system, diagnosis and treatment, and suggestions about coping with your treatment and life beyond it. Share it with your friends and family, or anyone who is interested in colorectal cancer. It may help answer some of their questions.

This guide can't supply all the answers, but we hope it provides some. We also hope it will help and encourage you to discuss other questions with your health care team. Don't be afraid to ask for more information. We've included Discussion checklists at the end of each section to make it easier for you.

You'll find yourself learning a new language on this journey. At the back of this guide, we've included a glossary to help you understand some of the new words and terms you'll encounter.

Remember, this is not a journey you are taking alone. Colorectal cancer is the fourth most commonly diagnosed cancer in Canada. The Canadian Cancer Society estimates that approximately 19,600 new cases were diagnosed in 2005.*

Don't be afraid to ask for help. You have your friends and family, and others who have been diagnosed with colorectal cancer. Ask someone to accompany you when you have medical appointments. Often, there's too much information

*Based on National Cancer Institute of Canada estimates, 2005.



for one person to remember in one sitting. Having a second set of ears at appointments, and someone taking notes, can go a long way toward helping you understand all the facts.

Other sources of support are the various professionals who will make up your health care team. You may get a bit tired of explaining what is going on to so many new people. Or you may be intimidated by the team approach. But treating cancer is complex, and a cancer diagnosis will affect more than your colon. It's stressful – physically, emotionally, spiritually, practically, and possibly financially. The members of your health care team are all experts in their fields, there to help you live your life. Take advantage of their expertise and experience. No question is too silly or trivial.

In the next section, we briefly describe the members of the team you may meet and their areas of expertise. Keep in mind that hospitals and medical practice can be different in different areas of the country. You may meet different professionals during your treatment. The list below is intended to be a general introduction.

Canadians' risk of developing colon cancer or dying from colon cancer has been declining over the past 15 years. But with the aging of Canada's population and Canada's growing population, the total number of Canadians affected by colorectal cancer is rising.

With advances in treatment and screening, the good news is that if colorectal cancer is caught early, the chances of a cure are high. In over 90% of cases, colorectal cancer can be successfully treated if it is caught early.

Your health care team

Gastroenterologist: A doctor who specializes in diseases of the gastrointestinal tract – the esophagus, stomach, the small intestine, and the large intestine (the bowel). A gastroenterologist may perform your colonoscopy or sigmoidoscopy (page 20; diagnostic imaging tests are discussed on page 22).

Pathologist: A medical doctor who specializes in diagnosing disease by studying tissue and cells under a microscope. A pathologist determines what type of cancer cells make up the cancerous tissue (e.g., adenocarcinoma) and provides some of the information needed for your health care team to stage your disease (e.g., cancer that has moved beyond its origin may be classified as Stage III or Dukes C).

Surgeon: Surgery to remove cancer may be carried out by a general surgeon or a surgical oncologist, depending upon where you receive treatment. A surgeon who specializes in surgeries related to cancer is a surgical oncologist.

Medical oncologist: A doctor who specializes in treating cancer, using therapies such as chemotherapy, hormone therapy, biologic treatments, and other medications (therapies for treating colorectal cancer are discussed on page 37). Sometimes, medical oncologists are called oncologists.

General practitioner: Your family doctor will still be involved in your care and will be kept up to date on your progress by your oncologist. Although your general practitioner will be aware of your cancer, your oncology team will usually manage your treatment for you.

Oncology nurse: A registered nurse who specializes in treating and caring for people with cancer and their families. You may see an oncology nurse if you are referred to an oncology unit in your local hospital, a cancer centre, or satellite clinic for additional therapy, such as chemotherapy, radiation therapy, or biologic therapy.





Advanced oncology nurse practitioner: A registered nurse with special education and training to provide primary health care, including many tasks customarily performed by a physician. This may include managing symptoms and side effects of treatment, counselling patients in coping strategies, teaching self-care skills, and monitoring your response to treatment.

Pharmacist: A person who specializes in preparing, dispensing, and monitoring medication. A pharmacist who works in cancer care has specialized knowledge about the medications that you will take as part of your treatment. He or she can give you expert advice on medications and their side effects. He or she can also answer questions about paying for your drugs, if this is an issue.

Radiation oncologist: A doctor who specializes in prescribing radiation to treat cancer (the way radiation therapy is given is discussed on page 68).

Radiation technician: If you have radiation therapy, you will also meet a radiation technician (also called a radiotherapist or radiation therapist). He or she is the person who will help give the therapy, creates moulds, and helps position your body to receive radiation treatment.

Radiologist: A doctor who is trained to diagnose disease by using imaging techniques, including x-ray, ultrasound, CT scanning, magnetic resonance imaging (MRI), radioisotope scanning, or positron emission tomography (PET) scanning.

Registered dietitian: An expert in the field of food and nutrition. A dietitian can help make sure you are eating properly when you may not be feeling hungry, offer suggestions about meals while you are recovering from surgery, or help you maintain your energy levels during your treatment.

Clinical psychologist: A clinical psychologist, working with an oncology team, is an expert in the social and psychological impact of cancer on patients and

their families. He or she offers counselling either on an individual basis or in a group, where you are encouraged to express your feelings.

Social worker: A diagnosis of cancer can lead to substantial stress. A social worker is available to offer support to patients and their families at this time. A social worker may help you in a number of ways. He or she may help you cope when you feel isolated or lonely or he or she may also help make sure you have the financial resources you need.

Clinical trials nurse: A specially trained registered nurse who is involved in the care of patients who are participating in a clinical trial (e.g., a clinical investigation to test new treatments). A clinical trials nurse organizes and records treatments, blood work, and x-rays, and may arrange for follow-up appointments. He or she also helps patients understand the treatment, facilitates decision-making, and provides support.

Volunteers and support groups: Volunteers from the Canadian Cancer Society and other groups can help you deal with the practical side of treatment, like driving you to treatment appointments. Support groups can connect you to other patients who have or have had colorectal cancer. Talking to someone “who has been there” can often help you deal with the stress of your diagnosis and treatment (see pages 90-93 for ways to contact these and other organizations).

“I felt that my team was listening to me – my oncologist, my own GP, and the surgeon.... I was given good information and I could contact them when I had concerns. The cancer clinic was 24/7, so you could call them, too. I knew they were there and that was really important. With some of the side effects, you just don’t know what you are going through. I was glad that they were there to support me.” – Muriel, colorectal cancer patient





understanding colorectal cancer

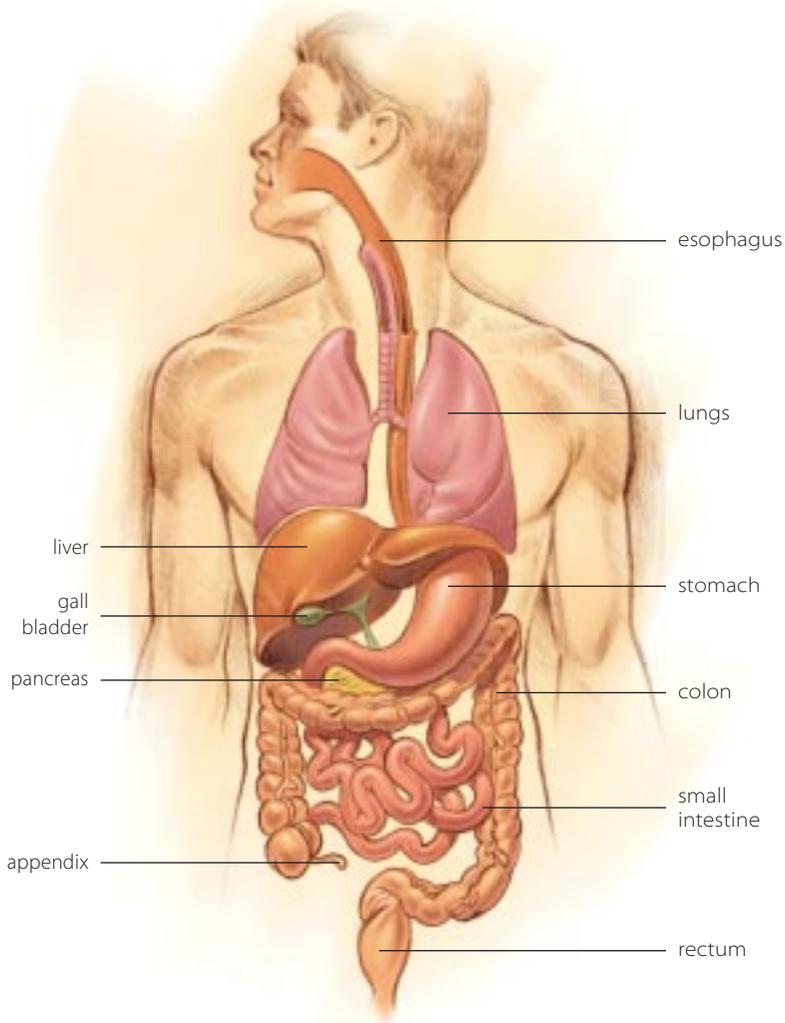
To better understand colorectal cancer, you need to know about the colon and digestive system and how they work.



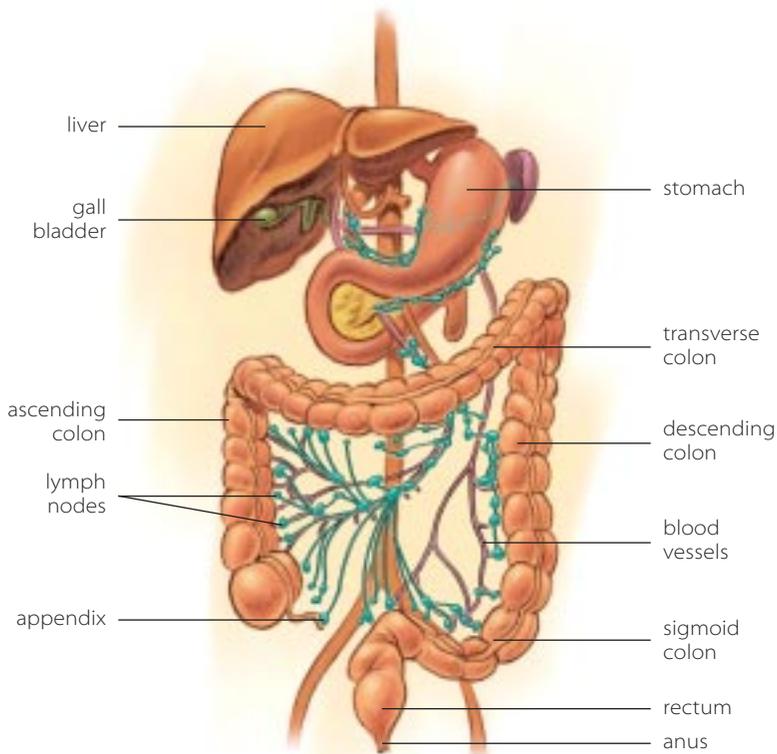
The digestive system

Everyone eats. It's the way the body takes in energy and the nutrients it needs to function. Unfortunately, not everything we eat is needed by the body. Your digestive system takes what you eat, removes the fats, proteins, and sugars your body needs (along with any vitamins and minerals required), and pushes what's left out of the body.

Digestion starts with the mouth and ends with the rectum. Once food is swallowed, it moves down the esophagus, which connects the mouth to the stomach. In the stomach, the food is mixed with the liquid you drink and digestive juices, breaking it down into smaller parts that the body can use. It then moves into the small intestine, where it mixes with special digestive chemicals, supplied by the liver and pancreas, to further break down the food. The small intestine then absorbs what your body needs from the mix.



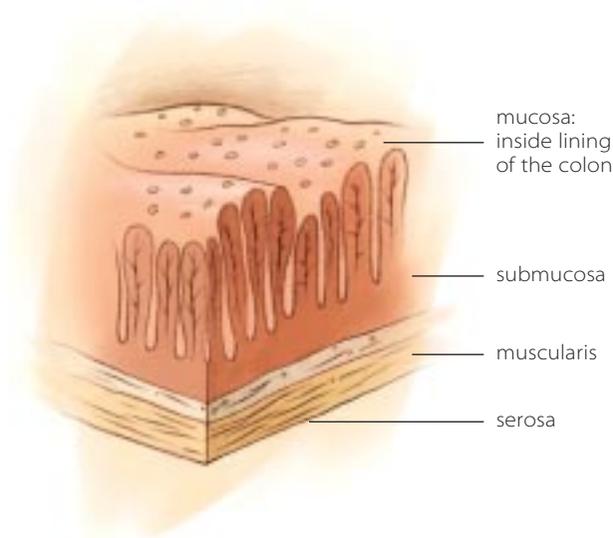
The digestive system



Role of the large intestine

The large intestine (the bowel) is the next step in the digestive process. Connected to the small intestine, it's made up of 2 parts: the colon, an approximately 5-foot-long tube, and the rectum, the last 6 to 8 inches of the large intestine before the anus. The colon is divided into 4 parts that move from the lower right of your abdomen (see diagrams), up across the area under your lower lungs, down the left side of the abdomen and then into the pelvic area to connect with your rectum. The sigmoid colon and the rectum store the feces, or stool, until you are ready to have a bowel movement. Waste leaves the body by way of the anus.





As the leftover material moves through the large intestine, water is removed to make it a semi-solid mass. The colon uses its layers of muscle to push the material through its length. In all, the colon is made up of 4 layers: the inside lining, or mucosa; the submucosa, the layer between the inside lining and the muscle layers; the muscularis (muscle layers); and the serosa, or the outer lining. Outside the outer layer are lymph nodes, which sit in a layer of fatty tissue, the mesentery. These nodes act as filters in the lymph system, a system that moves cells in the immune system around the body.

Colorectal cancer

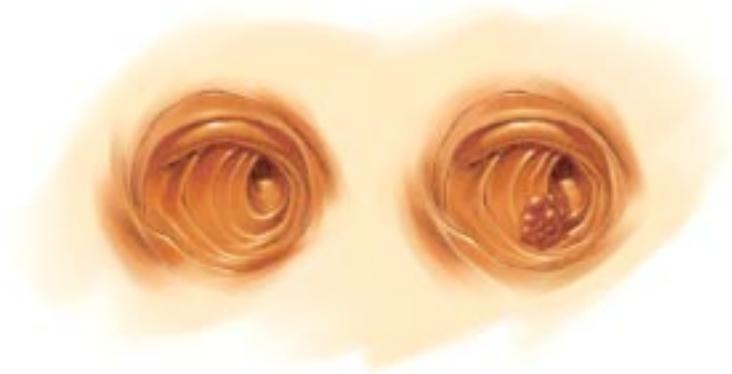
Basically, cancer is the abnormal, uncontrolled growth of cells. This uncontrolled growth leads to the destruction of normal, healthy tissue and cells. Colorectal cancer is any cancer that occurs in the large intestine, made up of the colon and the rectum. There are different types of colon cancer. This guide focuses on adenocarcinomas, which make up over 90% of cases of colorectal cancer.

Your body maintains a balance, constantly making millions of cells to replace cells that have died because of damage or age. Cancer starts when the balance is disturbed. A cell develops a change, or mutation. The mutation can cause it to begin making more cells than it needs to replace the dying cells. The out-of-control cells can then form a mass of tissue called a tumour. Tumours may be benign (non-cancerous) or malignant (cancerous). If a tumour is cancerous, the tumour is able to invade nearby tissues and can spread beyond where it started growing; for example, moving from the colon to the liver. When a cancerous tumour has done this, it's said to have metastasized.

Nearly all colorectal cancers (99%) start as polyps, which are benign tumours of the inner lining of the bowel. These polyps can grow over time, and cells in some polyps tend to change into cancers. But not all polyps turn into cancer, only about 1 in 20. Nor do polyps turn into cancer overnight. It can take years for a polyp to turn cancerous. That's why early detection is so important. If these growths are caught early, they can be removed before cancer develops or before it spreads.

You may be asking what causes a polyp to go bad or become cancerous. Most often, some change occurs to the instructions that tell the cell when to die or to reproduce. These changes or mutations occur in the cell's genetic material, or DNA.





Inside of a
normal colon

Polyp growing
on lining of colon

Symptoms of colorectal cancer

Colorectal cancer has some definite symptoms. But other conditions may also cause these symptoms. People with these symptoms need to undergo tests to discover what is causing the problem. The most common symptoms are blood in the stool or a change in bowel habits, including diarrhea, constipation, a feeling that the bowel is not completely emptying, and/or stools that are narrower than usual. Other signs of colon cancer are general abdominal discomfort, vomiting, constant tiredness, and weight loss with no known reason.

However, it's better to catch the disease before symptoms appear, which is why screening is so important. Having a family member (mother, father, brothers, or sisters) diagnosed with colorectal cancer increases a person's risk of developing it. That's why you should discuss your diagnosis and the importance of screening with your family. Read Appendix 1 for more information on screening.

Possible signs of colorectal cancer

Remember that these symptoms may be associated with other conditions. It is a good idea to have the symptom(s) investigated.

- Blood in the stool (it can be either bright red or dark in colour)
- A change in normal bowel habits – diarrhea or constipation or both – that lasts more than a few days
- A strong and continuing need to move your bowels but with little stool. This may sometimes be associated with pain
- A feeling that the bowel isn't completely empty
- Stools that are narrower than usual
- Cramping, either frequent or constant, or stomach discomfort such as bloating or fullness that lasts more than a few days
- Constant fatigue
- Unexplained weight loss
- Anemia: A decrease in the number of red blood cells, which leads to fatigue because you have less circulating oxygen

Causes and risk factors

When people are diagnosed with cancer, they often wonder if something they did caused it. Doctors don't know exactly what causes colorectal cancer, but some things definitely increase the risk of developing it. The risk of developing colorectal cancer increases with age, particularly after the age of 50. Most people who are diagnosed are over the age of 70. But this doesn't mean that people who are younger don't get the disease.

About 10% of colorectal cancers diagnosed are found in people with a hereditary condition that makes it more likely that they will develop colorectal cancer. These conditions include familial adenomatous polyposis and hereditary nonpolyposis colon cancer (HNPCC, or Lynch syndrome). People related to those with these hereditary conditions should be tested for these syndromes and checked regularly.

People in other high-risk groups make up another 23% of colorectal cancers diagnosed. These high-risk groups include people who have had colorectal cancer or adenomas (benign polyps found in the colon are a type of adenoma) before; people with a close relative (mother, father, brothers, sisters) who has had colorectal cancer or adenomas; and people with a previous history of cancer of the ovary, lining of the uterus, or breast.

For people with no blood connection to someone who has had colorectal cancer, some additional risk factors are:

- A history of ulcerative colitis or Crohn's disease
- A diet high in red meat and low in fruits and vegetables
- Obesity
- Lack of exercise
- Drinking alcohol, especially beer, and smoking

Let your family know that you have been diagnosed with colorectal cancer, since family members are at higher risk for developing the disease. Caught at an early stage, colorectal cancer is highly curable. Let your family know about the symptoms and the importance of screening. Suggest that your family members discuss your diagnosis with their doctor.



important tests

Yes, the tests that find colorectal cancer can be uncomfortable, and the preparation for them is unpleasant. However, let's put the discomfort and unpleasantness in perspective. Are they worth risking your life over?

“What I did as soon as I realized that I was seeing many different doctors and that some were asking me questions, I got a binder, a little loose-leaf binder, and I started writing down everything. It has been invaluable when I’ve been seeing doctors. Every process of my medical care, I’ve been writing down who I saw, what I was treated with, and what my symptoms were, everything.”

– Muriel, colorectal cancer patient

Some information may help dispel some of your fears. Below we give a brief description of the important tests and what they do.

Tests for colorectal cancer

Digital rectal examination (DRE): The DRE is a physical exam in which the doctor or nurse practitioner inserts a lubricated, gloved finger into the rectum to feel for any abnormalities.

Fecal occult blood test (FOBT): The FOBT looks for blood hidden (occult) in your stool. Three separate stool samples are collected. Then the samples are tested using chemicals to find out if there is blood present. If blood is detected, it doesn’t necessarily mean that you have colorectal cancer. Blood in the stool may be caused by hemorrhoids, ulcers, and other conditions. But if blood is detected, you will need to have other tests to find out what’s causing the bleeding.

This test is often recommended in Canada as a regular screening test after age 50, and earlier for people who are at a higher risk for colorectal cancer. It’s suggested that people over that age who have no other risk factors have this test at least every 2 years.





Air contrast barium enema: To do this special type of x-ray, a white substance called barium is inserted into the colon. The barium outlines the wall of the colon, showing if there are any abnormalities present. Air is also inserted into the colon to provide the radiologist with a better picture of the area. The radiologist or technician will have you move into different positions to get the best possible information. You will then be asked to empty your colon and the radiologist or technician will take more images.

For the test to provide the best images, you will need to empty your colon before the procedure. Your doctor, nurse, or x-ray department will give you instructions. Generally, you will have to take a laxative or other medication, and probably be on a clear liquid diet the day before the test is scheduled. This is common for most tests that take images of your colon.

Sigmoidoscopy: This test may be called flexible sigmoidoscopy. During this test, a lubricated flexible scope consisting of a hollow tube with a light is gently inserted into your anus. (The tube is about 25 inches long.) Images of the colon are captured as the tube progresses. The doctor can then see any polyps, tumours, or other problems in the rectum or sigmoid colon. You will be given instructions on how to empty your colon before the test to ensure the best results. This test may be performed by a physician, gastroenterologist, internist, or surgeon. If polyps are discovered during this test, you will need to undergo a colonoscopy to look for other polyps.

Colonoscopy: Colonoscopy is similar to sigmoidoscopy, but allows the doctor to see the rectum and entire colon. (The colonoscope is about 2 times as long as the sigmoidoscope.) Polyps found during this examination can be removed and studied for abnormal cells. Because this test is more involved, you will be sedated during the procedure. You will also need to clear the colon to ensure clear view of your colon. A surgeon or gastroenterologist usually performs this test.

Biopsy: A biopsy is the process of taking tissue and studying it under a microscope to see if cancer is present. With colorectal cancer, tissue and polyps can be removed from the colon and rectum during a colonoscopy or sigmoidoscopy. A pathologist looks at any polyps and tissue removed from your colon to see if any cancer is present.

Physical exam: It's important that your doctor and health care team know as much as possible about the state of your health before, during, and after your treatment. A complete physical exam will assess this and will allow the doctor to look for any other abnormalities. During the exam, the doctor will also ask about symptoms and your general medical history. All of this information will help develop your treatment plan.

Lab tests (blood work)

Several types of blood tests are used to help diagnose cancer and monitor your health before and after treatment.

Complete blood count, or CBC: A blood screening that counts the number of blood cells – red cells, white cells, and platelets – that circulate in the bloodstream. This test is often used while you are taking chemotherapy and radiation therapy. Blood tests taken before you start each chemotherapy and weekly during your radiation treatment will give your health care team information about how your immune system is functioning and if you have enough white blood cells to continue with your next round of treatment.

Liver function tests: These blood tests measure chemicals in your blood to show how well your liver is working.

Renal function tests: These blood tests may be used to monitor your kidney health by measuring chemicals in your blood.

CEA: Stands for carcinoembryonic antigen, a specific protein known as a tumour marker that is associated with colorectal cancer. An increased level of CEA in your blood may indicate the presence of colon cancer. But other cancers and other diseases (hepatitis, liver injury, gallbladder problems, or bowel inflammation) may also increase your CEA level. Your CEA level may also be increased if you are a smoker. So the results of a CEA test must be used cautiously. This test can't be used to screen for colorectal cancer but it is useful once colorectal cancer is diagnosed. It may be used to monitor how your treatment is working, and once you are finished treatment, testing for CEA may provide clues about whether the cancer has returned.

Imaging tests

There are several options available for looking at what's going on inside your body. Which tests are used will be determined by where the cancer is and whether your health care team suspects that it has spread. Below you'll find the tests listed and some information about when the tests are used.

X-rays: You may need x-rays of your chest and abdomen to detect whether the cancer has spread. X-rays may also be used to see if there is another underlying medical condition such as pneumonia or a bowel obstruction.

CT scan: CT scan stands for "computerized axial tomography" or "computed tomography." This test is like an x-ray, but it shows images of your organs and tissues in 3 dimensions. A CT scan can show whether cancer has spread to the brain, bones, or other organs.

MRI scan: A "magnetic resonance imaging" scan, or MRI, produces high-quality images on a computer screen. An MRI may be used to study the brain, blood vessels, or internal organs.

PET scan: Positron emission tomography, or PET, uses small amounts of radiation to make detailed pictures of parts of your body. The PET scan shows how tissues and organs in your body work. Whether or not your body is working properly can give the doctors valuable information about your cancer. This test may be used if you have a rising CEA and a negative CT scan.

Ultrasound: An ultrasound uses high-frequency sound waves to create an image of a specific area of the body. You are probably more familiar with ultrasounds given to pregnant women to monitor the growth of the fetus. Ultrasound of the abdomen is often used to view the liver. For people with rectal cancer, a transrectal ultrasound, which involves using a special ultrasound probe in the rectum, may be used to see how far the cancer has spread.

Bone scan: A bone scan may be conducted in cases where doctors suspect the cancer has spread to the bone.

CT scan stands for “computerized axial tomography” or “computed tomography.” This test uses x-rays to get information from which images can be generated, showing the inside of the body. In this way, internal organs of the body can be visualized, making this test more specific than plain x-rays. A CT scan can show where tumours are located in tissues and whether cancer has spread to the brain, bones, or other organs.

An **MRI scan** is a “magnetic resonance imaging” scan. An MRI produces high-quality images on a computer screen. An MRI may be used to study the brain, blood vessels, or internal organs.



Discussion checklist

Here are some questions you might want to discuss with your health care team. You may have more. Don't be afraid to ask them. You may find that you think about questions after you've left your appointment or between appointments. Try making a list and taking it with you to jog your memory.

- ___ What tests will be done? Why?
- ___ What are the side effects of the tests?
- ___ Will I have a biopsy? If I have already had a biopsy to diagnose my cancer, will I have more biopsies? Why? Will the tissue be collected during my colonoscopy or during surgery?
- ___ How long will this test take? Will I be awake? Will there be pain during and/or after?
- ___ What do I need to do to prepare for these tests?
- ___ How long will it take to get the results of the biopsy or any other tests?
- ___ Whom do I speak to about the results of my biopsy and my other tests?
- ___ Other questions you may have:



Tests after colorectal cancer treatment

Once your treatment is completed, your health care team will need to follow your health to make sure the cancer doesn't return, or if it does, to catch it early so that new treatment can begin as quickly as possible. Realistically, the doctor's office or hospital is probably the last place you want to visit after your treatment is finished. And some of the tests are unpleasant. But *follow-up* is important. Look at follow-up as an opportunity to confirm that everything is going well.

Follow-up tests are the tests commonly used to screen for and diagnose colorectal cancer. We discuss the common scenario for follow-up testing in the section "Overview of the treatment options," found on page 34.

"You are on a roller coaster. It's now been 10 months....You are up and down, up and down all the time. The chemo, and the surgery, and the 'this' and the 'that,' and the tests. It's a whole new way of life. It just changes everything. It changes your perspective; it changes your way of thinking."

– Wife of a colorectal cancer patient





colorectal cancer: staging

Once your diagnosis is confirmed, the next step is finding out exactly where the cancer is located – on the wall of the colon only versus through the wall of the colon and into the lymph nodes or in other parts of the body. This process is called staging.

Once determined, the stage of the cancer then helps your health care team decide the type of treatment you will receive. You may have surgery, chemotherapy, radiation therapy, or a combination of these treatments. With colorectal cancer, staging often can't be completed until after the polyp or tumour and surrounding tissue (collected during surgery) have been studied by a pathologist to see what type of cancer cells are there (e.g., adenocarcinoma).

The names for staging are commonly accepted in the medical community, so if you are treated at different centres, doctors can quickly pass on a lot of information about your cancer to medical personnel at other centres. That being said, your specific treatment plan is developed from the details of your case. You may meet someone who also has Stage III cancer, but depending on the tumour, the person's health, and other factors, his or her treatment may be much different.

Two ways to stage cancer are used in Canadian hospitals. One is the revised classification system called the Astler-Coller modification of the Dukes system. The original Dukes system only had 3 stages; a 4th has been added to include cancer that has spread beyond the colon.



The staging system that is most commonly used is the TNM, or Tumour-Node-Metastases system. Doctors determine the tumour size based on how deeply the tumour has grown through the bowel wall, whether there are lymph nodes affected by the cancer, and whether the cancer has spread to other parts of the body. They then use this information to describe the cancer. Numbers are used to further explain each category. For example, a cancer may be staged as T2N0M0, which means a tumour that has grown into the wall of the colon but has not grown into the muscle layer (T2); it doesn't involve any lymph nodes (N0); and there is no spread of cancer to another part of the body (M0). Look at the table for a summary of all the stages.

Table 1: Simplified description of TNM and Modified Dukes system staging

Stage	TNM	Modified Dukes System	Description
0			Cancer cells on the inside surface of the colon, rectum, or polyp.
I	T1-2N0M0	A, B1	Cancer cells on the surface of the colon or rectum and in the second layer (the submucosa) (T1, A) or into but not through the third layer of the colon or rectum (the muscularis) (T2, B1).
II	T3-4N0M0	B2	Cancer cells through the muscle layers of the colon or rectum; no cancer cells in lymph nodes.
III	T1-4N1-2M0	C	Cancer cells in lymph nodes. The tumour may or may not have grown through the bowel wall.
IV	T1-4N0-2M1	D	Cancer cells in distant organs (liver or lungs). Lymph nodes may or may not be involved.

Note: The numbers following the letters in the classification name provide further information about where the cancer cells have been found. For example, the numbers after the N indicate how many lymph nodes are cancerous and where they are located. The numbers after the T indicate the depth of invasion into the wall of the bowel. The numbers after the M indicate no spread (0) or spread to other parts of the body (1).



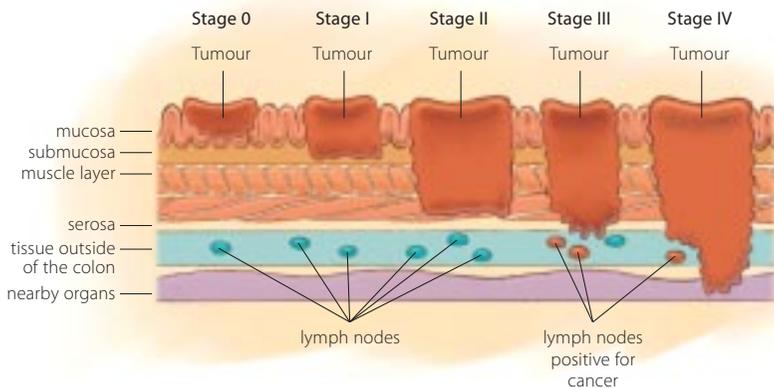


Table 1 compares the 2 staging systems. Below we describe each stage and the most commonly used treatments for that stage. Remember, everyone's case is treated differently, so your treatment may be different. For most colorectal cancers, the primary treatment is surgery to remove the cancer. If the cancer is more advanced, additional therapy with radiation or chemotherapy may be considered after surgery. We provide more details about the specific treatments in later sections.



Stage 0

Cancer cells have been discovered, but the cells remain on the surface of the inside of the colon or rectum. They have not begun to move into the wall of the colon or rectum. Stage 0 is often called cancer *in situ*, Latin for cancer “in place.”

How the cancer is treated

To stop the cancer from spreading, the cancerous cells are removed or may have already been removed during your diagnostic colonoscopy or sigmoidoscopy. If the polyps are large, you may have to have surgery to remove them. If a large area of your colon or rectum is involved, you may undergo a bowel resection. We talk more about this procedure in the Surgery section found on page 44, but briefly, a bowel resection involves removing a section of your colon and reattaching the 2 ends.

Stage I, T1-2N0M0, Modified Dukes Stages A and B1

Cancer has grown beyond the surface of the colon or rectum and into the second layer (the submucosa) or third layer (the muscularis) of the colon or rectum, but not completely through the third layer. The cancer is no longer resting on the lining of the colon or rectum. Under the TNM system such cancer is either T1N0M0 or T2N0M0. Under the Modified Dukes system, cancer is Stage A if it has not moved beyond the second layer and Stage B1 if it has grown into the third layer.

How the cancer is treated

Surgery to remove the cancerous area is the main treatment. Nine out of 10 patients with this stage of cancer are cured by removing it. No further treatment is necessary after surgery.

Stage II, T3-4N0M0, Modified Dukes Stage B2

The cancer has grown through the muscle layers of the colon or rectum. Sometimes it is still confined to the fatty tissues surrounding the bowel (T3), but sometimes it has grown right into a nearby organ; for example, the bladder (T4). No lymph nodes show signs of cancer, and there is no spread to distant organs (T3N0M0 or T4N0M0).

How the cancer is treated

Again surgery is the main treatment. The surgeon removes the cancerous area and surrounding tissues. If the cancer has spread to another nearby organ, that spot of cancer or the lesion is also removed by surgery.

Researchers are still investigating whether chemotherapy given in addition to surgery, called “adjuvant chemotherapy,” decreases risk of cancer recurrence and increases survival in Stage II colon cancer. You may be asked to participate in a research study or clinical trial to help answer this question. We talk about clinical trials later in this guide. Adjuvant chemotherapy may also be offered to those people whose cancer has signs that suggest that it may spread.

Stage II rectal cancer treatment varies from one patient to another, but often includes adjuvant radiation and chemotherapy in addition to surgery. Patients who receive radiation before surgery may not need to have chemotherapy after surgery. Your health care team will decide which treatment plan is best for your type of cancer.

Stage III, T1-4N1-2M0, Modified Dukes Stage C

The cancer has spread through the colon or rectum wall and involves nearby lymph nodes. Under the TNM system, this type of cancer may be classified as T1-4N1-2M0, where the number 1 or 2 beside the “N” indicates how many lymph nodes are involved: N1 – 1 to 3 nodes or N2 – 4 or more. The fewer lymph nodes that are involved, the better the prognosis.

How the cancer is treated

Surgery to remove the cancer in the colon or rectum is followed by adjuvant chemotherapy to kill any cancer cells that may be circulating in the body. The most widely used chemotherapy treatment contains 5-fluorouracil and leucovorin for 6 months. New chemotherapy medications (e.g., capecitabine and oxaliplatin) and new regimens (e.g., FOLFOX) are becoming available in this area and your doctor may discuss these with you. For example, many cancer centres now offer chemotherapy with capecitabine, which is taken in tablet form, as an alternative to 5-fluorouracil and leucovorin, which must be taken intravenously.

Radiation therapy may be used to treat Stage III rectal cancer.

Stage IV, T1-4N0-2M1, Modified Dukes Stage D

At this stage cancer has spread beyond the local area of the colon or rectum to distant organs in the body, such as the liver or lungs. This is referred to as metastatic disease, or cancer that has spread beyond the initial site of growth.

How the cancer is treated

The aim of treatment with this stage is to control the cancer’s growth and relieve any symptoms that it may be causing. The primary cancer (the cancer



in the colon or rectum) will likely be removed, if possible. Sometimes, the primary cancer can't be removed. In this case, radiation or chemotherapy may be used to try to shrink the cancer. Surgery may also be used to remove cancer that has grown in other areas of the body, called secondary tumours. Radiation therapy may be used at the sites of other tumours to relieve bleeding, obstruction, or pain. Chemotherapy may be used to relieve your symptoms and prolong survival. You may want to consider entering a clinical trial testing new drugs or biologic therapies.

Discussion checklist

Here are some questions you might have that concern staging. You may have others. Don't be afraid to ask them.

- ___ What kind of colorectal cancer do I have? Where is it located?
- ___ What stage is it?
- ___ Can you tell me what other lab tests were done on the tumour tissue?
What were the results?
- ___ What kind of treatments should I be considering now?
How long is each treatment?
- ___ Other questions you may have:





overview of the treatment options

Your initial testing is over and the doctor has confirmed the diagnosis and determined the stage of your disease. Now comes the time to use this knowledge to find the types of treatment that will work best for you.

Don't be afraid to discuss the treatment options with your health care team. It is important that you understand the recommended treatment, the possible results and complications, and the potential side effects. Unless you have an obstructed bowel or some other medical emergency, taking a few days to think about what you should do will not affect the outcome of your treatment.

Your treatment plan will be developed specifically for you. Don't be surprised if you meet another colorectal cancer patient who has a different treatment plan.

Treatment for colorectal cancer has improved greatly in the past few years, and new research is constantly underway. The good news is that if the cancer is caught early, there's a great chance of a total cure. And the cure rates for more advanced disease are improving all the time.

But before we start, we need to define some terms you may hear during discussions about your treatment. Medical professionals may use the terms "local" and "systemic" to describe a therapy. A local treatment, like surgery or radiation therapy, is confined to the affected part of the body. Systemic treatments, like chemotherapy, treat the entire body. They usually travel through the bloodstream and allow the treatment to kill any cancer cells in distant parts of the body.



“Adjuvant therapy” is another term that you may hear but not recognize. It describes treatment that is given after and in addition to surgery. For example, you may receive adjuvant chemotherapy after your surgery to increase the chances of destroying any remaining cancer cells. “Neoadjuvant therapy” is therapy given before surgery. With rectal cancer, neoadjuvant radiation therapy or radiation therapy plus chemotherapy may be given to shrink a tumour before a surgeon operates to remove it. Remember, neoadjuvant and adjuvant are simply terms that describe when you get therapy, and can involve radiation, chemotherapy, or biologic therapy.

Other terms that you might hear include first-line, second-line, or third-line therapy. These refer to systemic treatment (e.g., chemotherapy) when treating metastatic or advanced colorectal cancer. First-line is the first kind of treatment given to patients after spread of their cancer has been diagnosed. Second- and then third-line therapies are given when first-line therapy has failed to work or is no longer working.

We briefly describe the typical treatments in the next section. Your treatment may be different. The section of this guide on Staging (page 26) talks about when each treatment is usually used. We discuss the most common treatments – surgery, radiation, and chemotherapy – in more detail later on in this guide.

“I just focused on what was the next process. From when I was diagnosed and from when I met the surgeon and then what the surgeon said medically to be done. Every step, I just concentrated on what we are doing next.... That was my focus. And then once the surgeon identified that it was more serious than he thought, that it was a Stage III and moving into the chemotherapy. And I just kept moving on.” – Muriel, colorectal cancer patient

Types of therapy

Surgery

Surgery is the main treatment for colorectal cancer. Because colorectal cancer tends to grow slowly and stay in the same location, especially if it has been caught early, it can be removed to stop its spread and prevent its recurrence. In cancers that are caught early, surgery may be the only treatment required. In cancers at more advanced stages, other therapies in addition to surgery may be required to remove the cancer completely and improve the chances of a cure.

Chemotherapy

Chemotherapy uses special medications to kill cancer cells. It can kill cancer cells in all parts of the body, and it can also kill healthy normal cells. Because it travels throughout the body, it's called a systemic therapy. Chemotherapy may be given as an adjuvant therapy after surgery for colorectal cancer or for metastatic disease. Sometimes a combination of 2 or 3 drugs may be given.

Radiation therapy

Also known as radiotherapy, radiation therapy uses high-energy x-rays to kill cancer cells. Your radiation oncologist targets these rays at a specific part of the body to kill the cancer cells there. Radiation therapy is used more frequently to treat rectal cancer. Radiation therapy is often given as a neoadjuvant or adjuvant therapy.



Biologic therapy

Biologic therapy is another kind of systemic therapy that travels throughout the body to treat the cancer wherever it is. Biologic therapy uses agents that make use of the special characteristics of cancer cells.

Unlike chemotherapy, most biologic therapy is intended to better target or bind to cancer cells and affect the normal tissues to a lesser degree. Remember, chemotherapy affects cancer cells as well as normal cells. Researchers are constantly studying ways to use biologic therapies to treat cancers, including colorectal cancer. Two such biologic therapies, bevacizumab and cetuximab, are currently being tested with positive results and may soon be available for the treatment of colorectal cancer. You may also hear them referred to as monoclonal antibodies. You may be asked to enter a clinical trial to test how well biologic therapy works in colorectal cancer disease (see page 39 for details about clinical trials). For more information on specific types of biologic therapy, see the section on Future directions of colorectal cancer treatment.

Combination therapy

Depending on your case, your doctor may discuss using a combination of therapies. For example, you might receive both surgery and systemic therapy (chemotherapy or biologic therapy), surgery and radiation therapy, or all 3. Combination therapy may also mean a combination of chemotherapy medications and/or biologic agents. If you are taking more than 1 type of chemotherapy medication, this is known as “combination chemotherapy.”

Local versus systemic treatment

You may hear the terms “local treatment” and “systemic treatment” to describe the type of treatment you are receiving.

Local treatment refers to any treatment that is targeted to a particular part of the body. An example of this is radiation therapy: the high-energy x-rays are directed to a specific region, such as your abdomen or your rectal area. However, even though it is local it can kill healthy cells in nearby organs or tissues, leading to possible side effects.

Systemic treatment, on the other hand, is a treatment that travels throughout the whole body. Chemotherapy is an example of this. These medications work to kill cancer cells in your body, but in the process, also kill some healthy cells, leading to possible side effects.

Clinical trials

Research in colorectal cancer is advancing daily, as scientists and researchers look at new ways of preventing, detecting, and treating the disease. You may be interested in participating in clinical trials.

Clinical trials are conducted to evaluate the effectiveness and safety of new drugs, drug combinations, or any new treatments. Phase I trials investigate the dose of the drug that is safe, how the body uses the treatment, and the best way to give the drug. Phase II trials study the effectiveness of the drug, and whether it has the potential to help patients. For patients who have tried standard treatment options, Phase I or Phase II studies of an experimental therapy may offer an alternative. Phase III trials test the drug’s potential to help in a large group of patients. The “new” treatment is often tested against

the standard treatment. Another type of clinical trial is a Phase IV trial. It is conducted after a drug has been approved for sale. It continues to study the drug and, often, to see how well it works against other treatments.

Patients who qualify to be part of a Phase III study will be randomly selected to join either the new treatment group or the standard treatment group – a randomized trial. Even when the treatment period is over, patients are often monitored for a long time, so researchers can see which treatment yields better long-term results, and which has fewer side effects.

Clinical trials help doctors make treatment decisions about which treatments are more effective and safer. A standard colorectal treatment is considered the “standard” because clinical trials have shown that no other treatments work better or are safer. For patients who haven’t had success with standard treatments, clinical trials may offer an alternative, with new experimental drugs. There are potential risks. Because the treatment is new, less information on rare side effects or other problems may be available. And you cannot predict if the new treatment will be effective for you. If you enter a trial, the risk will be explained to you. If you are considering entry into a trial, current standard treatment options will also be discussed with you so that you have all the information you need to make your decision.

If you enter a clinical trial, you will probably get to know a clinical trials nurse. He or she is a specially trained nurse who is involved in the care of patients who are participating in a clinical trial. Clinical trials nurses organize and record treatments, blood work, and x-rays, arrange for follow-up appointments, monitor progress and side effects, and provide teaching and counselling as needed.

You can find out more about current clinical trials by getting in touch with your doctor, cancer centre, or cancer clinic.

Other therapies

Alternative therapies

Herbal remedies, high-dose vitamins, and severe or strict diets are common examples of treatments called alternative therapies. Many alternative medicines have not been scientifically studied, so often it is not known how they will react and possibly interfere with your cancer therapy. For this reason, it is suggested that you do not take any alternative medicines without first checking with your doctor, pharmacist, or nurse.

Complementary therapies

Therapies such as peer and group support, therapeutic touch, yoga, meditation, and visualization exercises fall under this category. Complementary therapies can be used in conjunction with traditional cancer treatment, and may help improve a patient's sense of well-being and reduce a patient's stress.

What about side effects?

With each treatment comes the possibility of experiencing some side effects. And you may have heard some horror stories about cancer treatment. Fortunately, researchers have studied ways to minimize side effects as well as ways to improve treatment. There are things that your health care team and you can do to reduce the unpleasant aspects of your treatment. In the following sections, we will give more detail about the side effects of each type of therapy and offer some suggestions that may help you deal with those side effects.



Follow-up care

After you've completed your treatment, whether it be surgery or a combination of treatments, you'll need to stay in touch with your doctor to ensure the early detection of any recurrences of cancer. Discussing any changes in your health with your health care team is an important part of your follow-up care. If your colorectal cancer recurs, this will usually happen within the first 5 years after you have finished treatment, typically within the first 3 years. To monitor your health during this time, you will probably visit your doctor every 3 to 6 months for a physical exam. This exam will include questions about how you feel; a check of your heart, lungs, and abdomen to check for anything unusual, such as liver enlargement; a digital rectal exam; and blood tests. Talk with your doctor about how often you need to be seen.

A respected North American guideline recommends a colonoscopy within a year of the end of your primary treatment to look for new polyps. Your oncologist may follow a different protocol. If nothing is detected, it is recommended to have a colonoscopy repeated every 3 to 5 years to check for any polyps or cancer that may have returned. A CEA test, especially if you have had Stage II or Stage III cancer, may also be performed. An elevated level of CEA may indicate the return of cancer, and additional testing might be needed. Remember that CEA test results need to be interpreted with caution, because a CEA level may be high for many reasons.

Your doctor will let you know about other tests. Some of these tests may happen through your family doctor's office, while others may be ordered through your oncologist's office. Remember to stay in touch with your family doctor, who is responsible for your overall health.

You can help yourself by staying in good health and keeping an eye out for symptoms of colorectal cancer (see the box on page 15). If you detect symptoms, talk to your doctor. They may not be a sign of the return of cancer, but just a sign of something minor. But if they are something more serious, remember that you have caught the problem early.

Discussion checklist

Here are some general questions about treatment. In the sections following, you will find more detailed descriptions of the 3 main treatments, in addition to other treatments we have included. If you have questions that don't appear here, don't be afraid to ask them.

- ___ Why do I need this type of therapy?
- ___ What kinds of medications will I be taking? What kinds of side effects can I expect?
- ___ What can I do to help prevent or minimize the side effects from my therapy?
- ___ What is the treatment schedule? How long will I be on this treatment?
- ___ What follow-up care do you recommend?
- ___ Is there a clinical trial I can participate in?
- ___ What kind of psychosocial support is available to me and my family as we go through the treatment?
- ___ Other questions you may have:





primary treatment: surgery

Surgery is the primary treatment for colorectal cancer. Its goal is to remove all of the cancerous tissue before it spreads. Surgeons also work to protect your body to minimize any lasting injury.

Of Stage I colorectal cancers, over 90% can be cured with surgery alone. With Stage II cancers, about 70% of colorectal cancers can be cured with surgery alone.

Colon cancer: Colon cancer tends to develop in a predictable way. It starts on the inside lining of the colon, then grows through the wall of the colon to the lymph nodes and nearby organs, and finally spreads to other distant organs like the liver. This process can take years.

To increase the chances of a complete cure, your surgeon will remove the section of the colon with cancer, some surrounding tissue, and the nearby lymph nodes. The surgeon will also remove the mesentery, the fatty connective tissue that keeps the colon in place. Usually about 10 to 12 inches, but sometimes more, of the colon needs to be removed. The 2 ends of the remaining colon are reattached. If the cancer is caught very early, at the polyp stage, only removal of the polyps or a smaller portion of the colon may be necessary.

Removal of part of the colon is called a partial resection or a colectomy. The joining of the 2 pieces remaining is called an anastomosis. You may need a colostomy, which creates an opening to the outside of the abdomen, called a stoma, to allow waste to pass from the top part of the colon to the outside of the body. A bag or pouch is attached to the stoma to catch the waste. Colostomies are performed more commonly in cases of rectal cancer, but they may be needed in certain cases of colon cancer. If you need a colostomy, your health care team will show you how to care for the stoma.



Surgery generally takes between 2 and 5 hours, depending on the extent of the cancer. Often the surgical team won't know the extent until they perform the surgery. Your hospital stay will probably range from 6 to 10 days, with your overall recovery time lasting from 4 to 6 weeks. These time ranges are very general. What happens in your case will depend on your overall health, the size of the cancer, the location of the cancer in the colon and elsewhere, and other factors. Talk to your surgeon about what you can expect.

A pathologist will examine the tissue removed to ensure all the cancer has been eliminated. You may hear the term "margin." It refers to the distance between the cancer and the edge of healthy tissue removed. A wide margin or large border of healthy tissue usually indicates that the cancer has been removed completely from the colon. If cancer cells are present in the margins, then further surgery may be needed.

Rectal cancer: With rectal cancer, the situation is a bit more complicated. Because there are so many other organs in that area of the body – uterus, ovaries, bladder, vagina, and prostate – the surgery can be more complex. And some rectal cancers may grow into the muscles that support the anus. Doctors have to balance removing the cancer and saving the patient's life with attempting to preserve the function of the other organs. A surgeon will try to remove all of the abnormal tissue, while trying to protect you from complications like impotence, other sexual dysfunction, and bladder problems. The patient may have to have a colostomy if too much of the muscle surrounding the anus needs to be removed. This is more likely to happen if the tumour is at the lower part of the rectum.

In many cases, the colostomy is temporary. Once the 2 ends of the colon have healed, they can be reattached and normal function returns. However, if too much muscle has been removed, a permanent colostomy is needed.

Radiation and/or chemotherapy may be used before surgery in rectal cancer to shrink tumours. Studies have shown that these therapies are also effective after surgery, increasing the chances that all cancer cells have been killed.

See page 50 for more information about chemotherapy and radiation therapy for colorectal cancer.

When some people think of colorectal cancer, they may think of a colostomy, which creates an opening from the large intestine to the outside of the abdomen. This opening bypasses the anus, letting waste empty into a bag attached to the opening. In reality, only a small percentage of colorectal surgeries result in a colostomy.

The complications

With surgery, recovery time will be needed. There will likely be some pain. But there are ways to keep the pain under control. Complications may also occur. While the potential complications listed below sound scary, remember surgeons don't cut unless the operation is necessary. The risk of complications needs to be balanced with the risk that the cancer will spread. And the risk of complications is fairly low. After the surgery, the chance that you will have to make changes to your diet is fairly low, unlike with some stomach surgeries.

We've listed some of the more common complications. Discuss them with your health care team.

Blood loss: There may be more blood loss than anticipated and you may require a blood transfusion. Ask your doctor whether you should consider donating blood ahead of time. However, there may not be time to do this before the surgery or you may already be anemic.

Risk of infection: With any surgical procedure, there is a risk of infection. This is a particular concern with abdominal surgery. To help prevent infection, you may be given antibiotics (called prophylactic antibiotics) to take before the procedure. You should find out what signs to look for that might indicate infection.

Anastomotic leak: After your surgery the rejoined ends of the colon, the anastomosis, may leak gastric contents into the abdomen. This can cause pain and infection. This complication is more common with lower anterior resections, surgery to the end of the colon, closer to the rectum.

Bowel obstruction: A bowel obstruction may occur because of the formation of scar tissue. Your doctor or nurse will ask you if you are passing gas, to find out when this normal function has begun. Be sure to ask your doctor about the signs of obstruction.

Discussion checklist

Check off the items that you and your health care team have discussed.
Add any other questions you may have.

- What are the risks and benefits of surgery?
- What kind of surgery will I have? What can you tell me about the procedure?
- What may happen if the situation becomes more complicated once the surgery starts?
- When will I find out the results of the surgery?
- How long will the operation take? Will I require more than 1 operation?
- What are the typical complications of this type of surgery? What should I watch for? Who and when should I call about anything that I notice?
- Are there any long-term side effects I should know about?
- Other questions you may have:

“With the local surgery, it’s not bad. They basically remove a part of your intestine and that’s it. It’s important that after the surgery you take good care of yourself and follow doctor’s orders. Honestly, my husband was back to his old self within a month. And when he started the chemotherapy, he started it very well, because he was in shape.” – Wife of a colorectal patient





additional therapies: chemotherapy and radiation

Most patients with colorectal cancer will have surgery to remove the cancerous tissue. After surgery, additional therapies (chemotherapy and/or radiation therapy) are usually given to make sure any remaining cancer cells are killed. For some patients, surgery may not be possible. In these cases, chemotherapy and/or radiation will be the primary treatment for colorectal cancer.

Chemotherapy

Simply put, chemotherapy uses medication to kill fast-growing cells, including cancer cells. Chemotherapy may be used to prevent cancer from spreading to other areas of the body and to kill the cancer where it is. It may affect other fast-growing cells, like those in your immune system, cells in the bone marrow, the cells that grow your hair, and the cells that line your mouth and digestive system. The good news is that healthy cells recover quickly. Cancer cells don't. And some new types of chemotherapy drugs are most attracted to cancer cells, minimizing their effect on healthy cells.

Everyone's experience is unique, so it's difficult to predict how you will react to chemotherapy.

Early disease setting: Adjuvant chemotherapy

Colon cancer: With colon cancer, chemotherapy is usually given to patients with disease that has spread through the muscle layers of the colon or has spread to the lymph nodes (Stage II, III disease). The primary medications used belong to a class of agents called fluoropyrimidines. 5-fluorouracil (5-FU) and capecitabine are commonly used medications belonging to this class. 5-FU is



administered intravenously by bolus or by continuous infusion over a period of time, and is often used in combination with leucovorin. Studies have shown that combining 5-FU with leucovorin improves the action of 5-FU. An alternative treatment that has been shown to work as well as 5-FU and leucovorin is capecitabine, which is available in oral tablets that can be taken at home. Any of these treatments typically last about 6 months.

Recent research has shown that combining 5-FU and leucovorin with oxaliplatin (all given intravenously) can improve the results achieved with 5-FU and leucovorin alone. Your doctor may discuss any of the above options with you to find the treatment that is best suited to you.

Chemotherapy is sometimes offered to people with Stage II colon cancer if their type of cancer has a high risk of returning or if their cancer suggests that chemotherapy will improve their prognosis. Chemotherapy is routinely offered to people with Stage III colon cancer, because it improves their chances of long-term survival.

Rectal cancer: With cancer of the rectum, adjuvant treatment is different. It is routinely offered to people with either Stage II or Stage III cancer. If patients receive it after surgery, they are usually given a few cycles of chemotherapy, then a few cycles of chemotherapy along with radiation, and then a few more cycles of chemotherapy. This treatment lasts for about 6 months. The combined radiation and chemotherapy part of the treatment lasts 5 weeks. In this situation, the chemotherapy medications offered may be 5-FU alone or 5-FU plus leucovorin. Sometimes 5-FU is given by continuous infusion. In this case, a small handheld pump may be used to deliver the chemotherapy to allow you to stay at home, instead of in the hospital, to receive your treatment. In other cases, you might be required to remain in the hospital while you receive your chemotherapy, even if it's through a pump. Talk to your health care team about what you can expect.

Advanced disease setting

When colon and rectal cancer have spread to other organs like the liver and the lungs (Stage IV disease), chemotherapy may be offered to control the disease and improve the patient's quality of life. Chemotherapy may be used to shrink a tumour before surgery in advanced cancers (called neoadjuvant therapy). This type of treatment could consist of 5-FU in combination with other drugs, such as leucovorin, irinotecan (CPT-11), or oxaliplatin.

Additional drugs that may be used when cancer has spread include capecitabine and raltitrexed. Researchers and doctors are looking for better ways to treat advanced disease and you may be asked to enter a clinical trial. To read more about this, turn to the section on Future developments in colorectal cancer treatment (page 74; also see Clinical trials, page 39).

How chemotherapy works

Chemotherapy destroys cancer cells in 2 ways, by stopping cancer cells from growing or multiplying, or by causing cancer cell death.

Several chemotherapy medications are used today to treat colorectal cancer. Sometimes they are used alone; in many cases, one drug is used in combination with others. This is known as combination chemotherapy. For more information on the drugs and the combinations in which they may be used, please turn to Appendix 2.

You can receive chemotherapy in a number of ways. The main methods include:

- By vein, or intravenously (IV): medication given through an IV line
- By mouth, or orally: a pill, capsule, or liquid to swallow



- By venous access device (VAD): This method is still considered intravenous, but instead of using an IV line, a small device is placed under the skin in the upper chest (e.g., PORT-A-CATH®) or forearm (e.g., PAS-PORT), or a thin tube is placed in a large vein to give medications (e.g., a Hickman catheter for the chest or a PICC line for the forearm). Along with delivering chemotherapy, blood can also be taken through the VAD, reducing the number of needle pricks you may need and reducing any complications that may occur because of them.

The treatment schedule

When you receive treatment depends on the type of chemotherapy regimen you and your doctor decide is best for you. Standard chemotherapy regimens usually last at least 6 months. Each round of chemotherapy medication is called a “cycle,” and this is made up of the time it takes to give the treatment plus the rest time until the next treatment. Your course of treatment will be made up of several cycles. For example, if you need to take your chemotherapy every 4 weeks over 6 months (about 24 weeks), you are taking 6 cycles of chemotherapy over a course of 24 weeks.



Studies have shown that it is best to maintain the highest dose of medication possible, while still allowing you to cope with the side effects and stay on your schedule. Your goal will be to follow the schedule that you and your doctor develop as closely as possible and take your chemotherapy medications on schedule. Sometimes, the health care team may delay your chemotherapy – for instance, if your white blood cell count

is too low, which puts you at an increased risk of infection. However, this delay is usually short and your treatment will be restarted when your blood cell count returns to normal.

During your first treatment don't be surprised if you are asked to stay a little bit longer after you've received your treatment so that the health care team can watch how you react to the therapy. It is recommended that you bring a friend or family member to your first treatment so that they also learn about the side effects of treatment and what signs to watch for. They can also help you by being an "extra set of ears" and by driving you home after your treatment. Some types of chemotherapy and/or supportive medications (e.g., antiemetics) may make driving difficult.

The side effects of chemotherapy

The side effects of chemotherapy can range from mild to severe. They depend on the type of chemotherapy you are taking and your reaction to the treatment. Your side effects may be different from someone else receiving the same drugs. Another thing to keep in mind is that some side effects may happen the day of your treatment, while others may occur days, several weeks, or even years following your chemotherapy.

Talk to your health care team about the kinds of side effects you can expect. Knowing this information ahead of time will help you prepare for what may happen.

Here's a list of the common side effects and how to manage them. Remember, your team is there to help you adjust to and cope with any possible side effects.

Nausea and vomiting: After your chemotherapy, you may experience a sick feeling in your stomach (nausea) or vomiting. To help reduce these side effects, you may be given some medication before and after your chemotherapy.



How do I manage the nausea and vomiting?

- Drink plenty of water – 8 to 10 glasses a day. Remember, anything with caffeine and alcohol in it can dehydrate you. Try to avoid these drinks
- Take your anti-nausea and anti-vomiting drugs as prescribed. These medications work better if you start to take them before you notice symptoms instead of when they are really bad
- Eat small meals frequently
- Try to eat a small meal or snack before you have chemotherapy
- Avoid spicy foods and very hot, very cold, or overly acidic foods
- Avoid strong odours such as fish or perfume
- Try relaxation, meditation, and/or deep breathing techniques to help you relax when you feel sick
- Talk to your doctor, nurse, or pharmacist if the anti-nausea drugs that you are taking are not working. Other medications can be used instead

Diarrhea: Some chemotherapy medications may upset the cells on the lining of your digestive system, leading to diarrhea. The danger is that this may leave you low on fluids (dehydrated) and chemicals called electrolytes that the body uses to keep everything working properly. When you have diarrhea, food moves through the digestive system too quickly, before the body can absorb the vitamins, minerals, energy-containing compounds, and water it needs. Medications may be necessary. Talk to your health care team if you have diarrhea that lasts for more than 24 hours. Diarrhea is not merely a discomfort. It may make you very sick.

How can I manage diarrhea?

- Talk to your health care team about the possibility of diarrhea and whether you should take Imodium® (loperamide) if it happens
- Drink lots of water – 8 to 10 glasses a day
- If you have diarrhea, stick to clear liquids that won't upset the bowel and will be easily absorbed into the bloodstream. Liquids like clear juices, Jell-O®, flat ginger ale, Gatorade®, chicken broth, or weak decaffeinated tea are good choices. These will allow the body to stock up on the water and electrolytes that have been lost
- Start returning to a normal diet slowly, about 12 to 14 hours after the diarrhea has stopped. The BRAT diet is a good way to ease back into normal eating. It's made up of foods that are low in fibre and tend to bind up material in the colon. They are Bananas, Rice, Applesauce, and decaffeinated Tea
- Avoid foods that make the bowel work too hard until things return to normal. Foods to avoid include foods that cause gas, spicy foods, fatty foods, high-fibre foods, and milk products
- Diarrhea can irritate the skin around the anus. Be gentle when cleaning after a bowel movement. You may want to wash yourself with warm water or diaper wipes instead of using toilet paper. If the skin becomes really irritated, consider using diaper rash ointment to protect the skin and help healing

STOP TAKING YOUR CHEMOTHERAPY MEDICATIONS AND CALL YOUR ONCOLOGY HEALTH CARE TEAM IMMEDIATELY OR SEEK MEDICAL ATTENTION IF YOU EXPERIENCE:

- An extra 4 bowel movements a day or any diarrhea at night
- An increase in loose, watery fluid in your colostomy bag
- Any diarrhea in combination with soreness of the mouth affecting your ability to drink enough fluids

Infections: Chemotherapy affects fast-growing cells, including your blood cells. If the number of white blood cells is low, you may be at increased risk of infections. White blood cells are an important part of the immune system, helping your body fight off foreign invaders. Signs of infection include fever (greater than 38°C or 101°F), chills, sore throat, rash, diarrhea, or redness, swelling, or pain around a cut or sore or your stoma (if you have a colostomy). If you experience fever, chills, or other signs of infection, call your health care team **IMMEDIATELY** or seek medical attention. Sometimes, the only sign of an infection is fever. It's important to seek medical attention if you have a fever. You may urgently need tests and, if necessary, antibiotics. Make sure you talk to your health care team about what you need to watch out for and what to do if you have signs of infection.

How do I prevent infections?

- Wash your hands with soap often – especially before and after meals, and after going to the washroom
- Avoid contact with people who have colds or other contagious diseases, and crowded places

- Keep your hands away from your mouth and face
- Be careful to avoid cuts and scrapes. Don't tear or cut the cuticles of your nails – use a nail file if you need to trim your nails. Avoid sharp objects such as razors or knives; use an electric razor to shave. Wear shoes to protect your feet
- Use gloves if you are gardening or cleaning up after children or animals
- If you get cuts or scrapes, keep them clean
- Use a soft toothbrush
- Moisturize your skin with lotion or oil if it becomes dry or cracked

Signs that you might have an infection

- Fever (greater than 38°C or 101°F)
- Chills or shakes
- Sore throat, cough, or sinus congestion
- Diarrhea
- Redness, swelling, or pain around a wound or your stoma (if you have a colostomy)
- Burning when you pass urine

Remember, if you experience any signs of infection, call your health care team **IMMEDIATELY** or seek medical attention.



Hand and foot skin reactions: With some types of chemotherapy medications the palms of your hands and the bottoms of your feet may tingle or become red, numb, painful, or swollen. The skin may peel if you develop a rash. The skin may also become dry or itchy. If these symptoms become serious and lead to blisters, severe pain, or ulcers, they may interfere with your normal daily activities. Also, if the skin breaks infection can start. It's important if you have hand and/or feet reactions to tell your health care team. The sooner you seek medical attention, the sooner the reactions can be treated.

How do I prevent hand and foot skin reactions?

- Keep hands and feet clean. Use lukewarm water and gently pat to dry. Avoid hot water
- Avoid tight-fitting shoes or things that may rub or put pressure on your hands and feet
- Keep hands and feet moisturized with a hypoallergenic thick cream (ask your health care team to make a recommendation)

How do I manage hand and foot skin reactions?

- Tell your health care team if you have any signs of hand or foot reactions. You may be prescribed vitamin B6 (also called pyridoxine) to manage the symptoms. Your health care team may need to temporarily put your chemotherapy medications on hold or adjust the dose of your chemotherapy medications



IF YOU HAVE ANY OF THESE SYMPTOMS ON THE PALMS OF YOUR HANDS OR BOTTOM OF YOUR FEET CALL YOUR HEALTH CARE TEAM

- Pain
- Redness
- Swelling
- Ulcers or blisters
- Numbness or tingling



If caught early, most of these side effects usually improve within 2 to 3 days. If they don't improve within 2 to 3 days, call your health care team again. After side effects have improved, your doctor will decide when your chemotherapy medication will start again.

Mouth sores (mucositis): You may experience mouth sores or dry mouth, usually 1 to 2 weeks after your chemotherapy. Let your health care team know if you have any changes in your mouth, especially painful sores or white patches in your mouth and/or cracked lips. You may be prescribed some medication to help relieve the symptom(s).

How do I manage mouth sores?

- Rinse your mouth with a mixture made from 1 teaspoon of baking soda or salt and 1 litre of water four times/day or at least after meals
- Chew on ice chips if you have discomfort or pain. Some patients also find that frozen yogurt, ice milk, milkshakes, smoothies, or frozen grapes help to soothe the mouth
- Try eating soft, bland foods like puddings, milkshakes, and cream soups. Avoid spicy foods or foods that are acidic or rough in texture

- Eat food that is at room temperature
- Do not use commercial mouthwashes that contain alcohol – ask your doctor or nurse about a mouthwash or rinse that is good to use
- Use a soft toothbrush. If you experience bleeding from your gums when brushing, switch to a soft sponge. Remember, it's important to keep your mouth clean
- Do not drink alcohol or smoke
- Sucking on ice chips or popsicles while getting certain chemotherapies may help you avoid mouth sores. Ask your health care team if you should do this
- Talk to your doctor or nurse if you find it too painful to eat. You may want to talk to a dietitian about food choices, especially if you find it hard to eat or have no desire to eat

Heartburn: If you have heartburn, talk to your nurse, doctor, or pharmacist. Over-the-counter medications may relieve your heartburn. Or you may need a prescription from your doctor. But because any medication or herbal remedy may affect how chemotherapy treatment works, check with your health care team before taking anything.

How do I manage heartburn?

- Avoid spicy foods
- Eat dry toast
- Avoid milk – this may increase your heartburn
- Sit up while eating and remain in a sitting position or upright position for at least 15 minutes after eating
- Raise the head of your bed to stop stomach acid from moving up the esophagus

- Talk to your nurse, doctor, or pharmacist about possible medications that may help
- Talk to a dietitian about food choices

Hair loss: Total hair loss (alopecia) doesn't happen as often with colorectal cancer treatments compared to other types of chemotherapy used to treat other cancers. Hair loss happens because the chemotherapy affects the cells that are responsible for hair growth. A few days or weeks after your chemotherapy, you may notice more hair on your pillow, in the shower, or on your brush. Your scalp may be very tender because your hair is breaking off. You may also lose hair in other places on your body, like your eyebrows, arms, legs, and pubic area. You may end up losing all or just some of your hair.

If you do lose your hair, this loss is only temporary. However, when your hair begins to grow in, you may find it is a little different than it used to be.

How do I manage hair loss?

To prepare for hair loss, you may want to:

- Discuss with your health care team the drugs you will be taking to better understand if you may have hair loss, and to help you decide if you should buy a wig
- If you have personal health insurance, you may be able to get financial coverage in part or in full for your wig. Talk with your nurse or social worker if you need more information about coverage
- Buy a wig while you still have hair – there are many styles and options these days for patients undergoing chemotherapy. Ask your nurse or social worker for a suggestion about where to buy your wig. They can recommend a store that will help you get the right fit, and shopping before you lose your hair lets you match your own hair colour and style to the wig

- Avoid using dyes or perms while on chemotherapy, and for 3 months or at least until your first hair cut following chemotherapy, because the harsh chemicals can further damage your hair
- Try hats, caps, or scarves to protect your head from the sun or cold
- You may want to prepare others, especially if you have younger children, for your hair loss by explaining in advance what may happen
- Cut your hair before you start losing it
- Talk to your health care team about how to care for your scalp if you lose your hair
- Women can participate in the *Look Good, Feel Better™* program. Check with your health care team about whether this program is available to you in your local area

Fatigue: Chemotherapy can cause extreme tiredness or fatigue. This differs from patient to patient and with the kind of chemotherapy taken. You should feel a return of energy levels by the time your chemotherapy is over, but you may still feel some fatigue after your chemotherapy ends. Talk to your health care team about how you can deal with your fatigue. They may do tests to check if your hemoglobin levels are low (which means you have less circulating oxygen in your blood; see definition of anemia, page 65). If your hemoglobin level is low, they may offer a medication to improve this condition. Infrequently, blood transfusion may be required.

How do I manage fatigue?

- Try to eat a balanced diet and don't skip meals. Some people find it helpful to graze throughout the day to keep their energy levels up
- Stay as active as you can. Some people need to take some time off work, while others can go on with their normal routine. It all depends on what is right for you

- Cut back on high-stress activities
- Have an afternoon nap, but keep your longest sleep for the night
- Keep track of your energy patterns. Do the things you really want when you have the most energy. Remember, you may not be able to do everything you normally do. Let other people help you
- Drink 8-10 glasses of water a day

Constipation: Some chemotherapy medications may cause constipation or a change in your bowel habits. Drink plenty of fluids, keep active, and, if necessary, take a mild stool softener. If you find that constipation is a problem, talk to your doctor or nurse.

Anemia: Anemia is a drop in the number of red blood cells. Chemotherapy may cause mild to moderate anemia. If this happens, you may feel very tired due to a lack of circulating oxygen in your red blood cells. Ask your doctor about medications that can help your body make more red blood cells. Infrequently, a blood transfusion may be prescribed if your red blood cells are very low.

Neutropenia: Neutropenia is a decrease in the number of white blood cells called neutrophils that your body makes, and it may be caused by chemotherapy. Because white blood cells help fight infection, having too few can increase your risk of infection. To watch for this, you have regular blood tests while on chemotherapy, usually before each cycle of treatment or more often if you have a fever or your health care team feels you need them.

Thrombocytopenia: Chemotherapy can also lower the number of another type of blood cell called platelets, causing thrombocytopenia. Platelets are blood cells that help form blood clots and they help control bleeding and bruising. Too few of these can lead to easy bruising or increase the risk of bleeding heavily. If this is a concern, you may receive a transfusion of platelets to correct the problem. Talk to your doctor or nurse about symptoms to look for and what to do if they happen.



Things to watch for while on chemotherapy

Here are some key things to remember. They will help you prevent or manage side effects and know when you need talk to your doctor, nurse, or pharmacist.

- **Fever.** If you develop a temperature greater than 38°C or 101°F, call your health care team immediately or seek medical attention. This may be a sign of a low white blood cell count or an infection. You may need antibiotics.
- **Drink lots of liquids!** Keep yourself hydrated, especially if you experience diarrhea or nausea. Call your doctor if you throw up, feel sick to your stomach, or have diarrhea for more than 24 hours.
- **Use a non-alcohol-based mouth rinse.** Rinse your mouth out frequently with a mixture of baking soda or salt (1 teaspoon) and warm water (1 litre). This helps prevent infection – and painful sores – from forming in your mouth. Rinsing with club soda is another option. Or your doctor or nurse may recommend a store-bought non-alcohol-based mouth rinse.
- **Be alert for anything “different” or new.** If you notice a change in how you feel – say, you develop a sore throat or diarrhea – call your health care team. They can help decide if you may need further help. Catch problems early. It’s easier to treat something small before it becomes serious.
- **Sun sensitivity.** Some chemotherapy medications might increase your skin’s sensitivity to the sun. Be sure to wear protective sunscreen when you are out in the sun, or wear clothing that covers your skin. Wearing a hat is a good idea.

Discussion checklist

Check off the items that you and your health care team have discussed.

Add any other questions you may have.

- Why do I need chemotherapy?
- What are the risks and benefits of chemotherapy?
- What kind(s) of chemotherapy medication(s) will I be taking?
What can you tell me about them?
- How often will I take chemotherapy?
- How long will it take for me to know if the chemotherapy is working?
Will I be able to tell?
- How many cycles of chemotherapy will I require?
- What are the typical side effects for this type of chemotherapy?
How can I manage them? Who and when should I call about
any side effects I'm experiencing?
- Are there any long-term side effects I should know about?
- Who can help me deal emotionally with the chemotherapy experience?
- Other questions you may have:

“The first thing is your approach to the chemotherapy. It has to be a very positive approach, saying that this chemotherapy is your friend and it is going to help you.... There are a lot of important side effects with the chemotherapy, but I think you have to be very positive. Think: These side effects are very minor, they are only for a short period of time, and it could help you. So if you look at chemotherapy from that aspect, it will help you surmount a lot.”

– Pasquale, colorectal cancer patient

Radiation therapy

Radiation therapy (also called “radiotherapy”) uses high-energy x-rays to kill cancer cells. Unlike chemotherapy, which affects the whole body, radiation therapy is considered a local therapy, since it targets only a specific part of your body. This therapy may be used along with chemotherapy to eliminate any remaining cancer cells in other parts of your body. Research has shown that radiation therapy is effective for the treatment of rectal cancer. Radiation is aimed at the pelvic area where the cancer was located, and is used in cases where the cancer has spread to the bone.

In rectal cancer, radiation may also be given before surgery, with or without chemotherapy. For some patients, giving radiation before surgery makes it easier to completely remove the cancer, and may reduce the chances that a colostomy will be necessary. There is no definite proof to know whether it is better to give the radiation before or after surgery.



How radiation therapy works

The radiation beam of the x-ray machine will direct the rays to the area where the cancer is. The radiation oncologist will determine this specifically for you. Sometimes, the term "radiation field" is used to describe the general area that is being irradiated. With colorectal cancer, radiation is aimed at the pelvis. Again, depending on your own individual situation, you may receive radiation in a very small area or a very broad area.

The rays will damage the cells in the targeted area so that they eventually die. If there are healthy cells in the area they may die too; for this reason, radiation oncologists take great care to protect the healthy cells from the radiation beam. Healthy, normal cells repair themselves from radiation damage more completely than cancer cells do.

Before your first treatment, you will have a planning session with a radiation oncologist. During this session (or sessions), the radiation oncologist will determine exactly where the x-ray beam will be directed. He or she will use a marking pen to mark the places where the x-rays will go. For this procedure, you will be lying down on a table, under a machine that delivers the radiation. Your radiation therapist will ensure that the parts of your body that should not receive radiation are protected.



The treatment schedule

The schedule of your radiation treatment is specifically designed for you. If your doctor recommends combination therapy (surgery, chemotherapy, and radiation therapy), you may start radiation treatment before, during, or after chemotherapy, or before or after surgery.

Your radiation therapy will also depend on the amount of tissue being treated. Typically, your treatment is given 5 days a week over a period of 1 to 6 weeks.

The side effects of radiation therapy

Most side effects are specific to the area being treated, but fatigue is common. Here is a list of the most common side effects and how to manage them.

Fatigue: Feeling tired or out of energy is the most common side effect of radiation. Depending on the frequency of radiation and the specific nature of the radiation therapy, each patient experiences different levels of fatigue.

How do I manage fatigue?

- Try to eat a balanced diet and don't skip meals. Some people find it helpful to graze throughout the day to keep their energy levels up
- Stay as active as you can. Some people need to take some time off work, while others can go on with their normal routine. It all depends on what is right for you
- Cut back on high-stress activities
- Have an afternoon nap, but keep your longest sleep for the night
- Keep track of your energy patterns. Do the things you really want when you have the most energy. Remember, you may not be able to do everything you normally do. Let other people help you
- Drink 8 to 10 glasses of water a day

Skin reactions: Your skin may become itchy, red, warm, dry, and more sensitive. In fact, this irritation may resemble a sunburn: bright red and peeling, with a tan that develops later. Typically, if you experience skin irritations, they will worsen within the first 2 weeks after radiation is finished – but will gradually begin to heal. If your skin blisters and opens, talk to your doctor or nurse as soon as possible about what to do. Remember, an open sore can become infected. It's important that you avoid infection.

How do I manage skin reactions?

- Keep your skin dry during the course of treatment, but make sure your skin is sufficiently moisturized with a cream or lotion that your nurse, pharmacist, or doctor recommends
- Wear fabrics that breathe, like cotton
- Leave the affected area open to air when possible
- Bathe or shower as you normally would, but avoid using soap in the areas receiving radiation; to dry yourself off, pat your skin with a towel
- If skin is peeling or blistered, you might try a cortisone cream or aloe vera lotion – ask your doctor, nurse, or pharmacist for a recommendation
- Keep the area protected from the sun



Nausea and vomiting: Nausea and vomiting may also be a problem. To help reduce this side effect, you may be given some medication before and/or after your radiation therapy.

How do I manage nausea and vomiting?

- Drink plenty of water – 8 to 10 glasses a day. Remember, anything with caffeine and alcohol in it can dehydrate you. Try to avoid these drinks
- Take your anti-nausea and anti-vomiting drugs as prescribed. These medications work better if you take them before you notice symptoms instead of when they are really bad
- Eat small meals frequently
- Before you have radiation therapy, make sure you've eaten something
- Avoid spicy foods and very hot, very cold, or overly acidic foods
- Avoid strong odours such as fish or perfume
- Try relaxation, meditation, and/or deep breathing techniques to help you relax when you feel sick
- Talk to your doctor, nurse, or pharmacist if the anti-nausea drugs that you are taking are not working. Other medications can be used instead

Discussion checklist

Check off the items that you and your health care team have discussed.

Ask any other questions you may have.

- What is the goal of my radiation therapy?
- When will my radiation therapy begin?
- How will I feel during therapy?
- How will I know if treatment is successful?
- What can I do to take care of myself during therapy?
- How long will I have to protect my skin from the sun?
- What other side effects, besides skin reactions and fatigue, might occur with radiation therapy?
- Are there alternatives to radiation therapy?
- Who can help me get to my radiation appointments?
- Is there financial assistance available to me if I have to travel a distance for radiation treatment? Who can I talk to about this?
- Who can help me deal emotionally with the radiation experience?
- Other questions you may have:





future developments in colorectal cancer treatment

New treatments and improved combinations of therapies

Researchers constantly test new drugs and combinations of treatments to find more effective cancer therapies.

Targeted therapies: Targeted therapies are types of biologic therapy that aim specific substances against key biological steps that are necessary for cancer growth. The goal is to find ways to stop or inhibit these steps without damaging normal cells in the body. This is different from chemotherapy, which targets any fast-growing cells in the body (cancer cells and normal cells).

Targeted therapies involve chemical compounds that block these key steps or chemical reactions. There are 2 types of targeted therapy: so-called “small molecules” or larger structures such as monoclonal antibodies. Targeted therapies are manufactured agents that target cancer cells and disrupt the way the cancer cells grow.

Researchers are currently studying how various compounds make cancer cells grow. Their goal is to discover very specific therapies to interrupt the steps in cancer cell growth. Some of the compounds under study include:

- VEGF (vascular endothelial growth factor), which promotes the growth of new blood vessels to the tumour. Agents that target VEGF (called anti-angiogenesis agents) attack cancer by preventing a tumour from building the

blood supply that “feeds” it the oxygen and nutrients that it needs to grow. Bevacizumab is a monoclonal antibody that interferes with the formation of new blood vessels, thereby starving the tumour. Positive results with the addition of bevacizumab to some combinations of 5-FU, leucovorin, irinotecan, and oxaliplatin have been reported for patients with metastatic colorectal cancer

- Tyrosine kinases, which are key enzyme components of some complexes within cells that promote cancer cell growth
- EGFR (epidermal growth factor receptor), which promotes cell growth and encourages cells to multiply. Cetuximab is an antibody that targets the EGFR. This agent has shown positive results when used in combination with irinotecan in patients with metastatic colorectal cancer whose disease progressed after previous irinotecan treatment

Tumour vaccines: We know that the immune system is responsible for protecting our bodies from infection and illness. Using this knowledge, researchers are exploring ways to use the immune system to produce antibodies that will respond to cancer cells. Remember that chemotherapy kills cancer cells and also affects normal cells. Right now, vaccines are being tested to prevent the return of colorectal cancer by causing the immune system to attack CEA-producing cancer cells and to treat metastatic disease.

Improved combinations of therapy: Research continues on different combinations of drug therapies, chemotherapy, and radiation, to try to improve cure rates. Work also continues on investigating different combinations of chemotherapy medications. Promising examples that have come out of this research include FOLFIRI (irinotecan, 5-FU bolus plus leucovorin, and infusional 5-FU), FOLFOX (oxaliplatin, 5-FU bolus plus leucovorin, and infusional 5-FU), and IFL (irinotecan, 5-FU, leucovorin) plus bevacizumab.



The next 10 years offer the chance for great progress, as we learn how best to use these and other new drugs to treat colorectal cancer more effectively. You may be asked to take part in a clinical trial for some new treatment for this cancer.

Improved tests for detection and monitoring

Despite all the attention and the benefits of early detection, the number of people who undergo regular screening for colorectal cancer is low. Some people may not want to undergo the tests because they are complicated and invasive. Researchers are trying to develop ways to look inside the colon without using a sigmoidoscope or colonoscope and without the unpleasant preparation and procedure of those tests. Improving screening tests will also help people treated for colon cancer because the screening tests are also used to monitor patients after their treatment.

Currently, a “virtual colonoscopy” using a CT scan is being studied. However, it still requires similar preparation to a traditional colonoscopy (cleaning the bowel before the procedure), and if something suspicious is detected, people still need to undergo a traditional colonoscopy. Work continues on improving the accuracy of this procedure.

Researchers are also studying ways to look for genetic mutations in stool samples, mutations that may indicate cancer. Although these tests are not yet very accurate, studies have shown some promise on the test’s ability to detect cancer, and research continues. Scientists are also working on developing reliable tests to analyze blood or mucus for signs of colorectal cancer.



living with colorectal cancer

Any cancer diagnosis is traumatic. Your diagnosis will change your life, but it doesn't have to take over your life. The surgery, radiation, and/or chemotherapy may affect your body for months after the treatments.

But you can control some aspects of this challenging journey. One of the keys to keeping colorectal cancer in perspective is learning how to manage the way it affects your physical and emotional life. Staying strong – physically and mentally – will let you keep living your life while you are on treatment and beyond. Remember, there are many survivors out there.

And don't think you have to go through this alone. You have your family and friends, your health care team, and others who have lived through this experience to rely on. Have someone come to medical appointments with you to help you make sense of what is happening. Take advantage of friends' offers to help you with day-to-day activities. Having someone help with your shopping or dropping off dinner can make a big difference.

Below you'll find some facts and tips about keeping yourself healthy – body and soul – during your treatment and beyond.

Activity

Staying physically active is good for you. Exercise is important – it can help raise your energy level and improve your overall emotional well-being. But don't think you have to train to run a marathon to receive the benefits. Activities as simple as walking or gardening can do the trick. Anything that gets you moving can give you a boost, increase your appetite, and decrease your stress level. Group activities such as golfing or curling give you the added benefit of being with other people while staying active.

Listen to your body and don't overdo it. Do what feels right. Exercise only if it feels right to you and rest often. You might want to ask your doctor or nurse for suggestions about what type of activity might be best for you.

“You need to lead a very active life. The more you stay idle, the more you have time to think, and that’s not good. You have to stay very active. Be it with a sport, be it with a hobby, be it with a walk, or being with friends. This is what helped a lot.” – Pasquale, colorectal cancer patient

Medications

Certain medications, such as acetylsalicylic acid (ASA) and over-the-counter heartburn medications, may interfere with your cancer treatment. Before you take any medication, check with your doctor, pharmacist, or nurse to make sure it won't react with your cancer treatment.

You may be on several different drugs as part of your cancer treatment. If there is ever a medical emergency, the medical staff will need to know what medications you are taking. Having a list of the medications that you are currently taking makes answering their questions a lot easier. Keep a credit-card-sized list in your wallet or purse and update it as needed. It's a good idea to give a copy to the person who is likely to be with you at appointments or during emergencies.

Dental health

If you need dental work completed, let your dentist know that you have been receiving or are about to receive treatment for cancer. Also, let your doctor or nurse know that you are planning a dental appointment. Your dentist may want to have your blood counts checked before doing anything. If your blood counts are low, he or she may decide to delay dental work.

Mental health and depression

Part of your physical well-being depends on your emotional well-being – when you feel mentally and emotionally healthy, you are better prepared to take on the challenges facing your body. And living with cancer can be difficult emotionally. You may be thinking about questions about life and death and examining your relationships with the people around you. For some cancer patients, the emotional challenges of fighting cancer can lead to feelings of deep sadness or depression. Concern and anxiety over the cancer can also trigger depression. The medications prescribed may cause mood swings.

If you are feeling down or overwhelmed, ask for help. Your support team knows that fighting cancer can be a tough emotional battle, and they can help. Don't be afraid to talk to them.

“I heard that people will shy away when you have this kind of sickness [cancer], either because of ignorance of the subject or for other reasons. But with us, honestly, it was just the opposite. They have offered their help even more than they normally would.” – Wife of a colorectal cancer patient

Diet

You may find that your appetite changes during treatment. You may feel like eating more or less than before. Stress or the medications you are taking may be the cause. You may also notice a change in how some foods taste. Some chemotherapy patients find that some foods have a metallic taste.



Part of keeping healthy is eating a well-balanced diet. When you eat well, you will feel more energetic, giving you the strength you need to cope. In addition, eating a well-balanced diet will help you maintain an ideal weight. If you are trying to lose weight, it is recommended that you wait until after you've finished cancer treatment. At that point, you should talk to your nurse or doctor about whether it's appropriate to start losing weight, and how.

If you find that you are not as hungry, here are a few tips that might help you ensure you have the energy you need.

- Eat small meals throughout the day instead of 3 large meals. Whenever you are feeling hungry, eat something; keep healthy snacks available
- To encourage your appetite, take a walk or do some exercise before your meal
- Have a friend or family member prepare food for you ahead of time so you can have it ready in the fridge for when you're feeling hungry
- Avoid coffee and tea. Drink milk, milkshakes, or juice

- If you find that red meat has a bitter taste, you may want to try marinating (soaking) it in soy sauce, fruit juice, or wine vinegar before cooking. Eating with plastic cutlery instead of metal cutlery may also help. If the bitter taste persists, or you don't want to eat red meat, try eating other foods that are rich in protein: chicken, dairy goods, ham, eggs, fish, nuts, seeds, legumes, tofu, or soy beverages are all good alternatives
- Consult one of the many cancer-related cookbooks available – ask your dietitian for a recommendation

If you find that you are hungrier than usual, talk to your doctor, nurse, or dietitian about how you can control any potential weight gain

Appearance

Some cancer treatments may make some patients feel less physically attractive. Fatigue, hair loss, skin problems, or brittle nails seem to make things worse. The good news is that these side effects are temporary – they won't stay around much longer than the end of your treatment. There are also ways to manage some of these changes. Ask your health care team about how to take care of your skin during cancer treatment.

Look Good, Feel Better™ is a free, national public service program that helps women with cancer learn how to cope with appearance-related side effects of their treatment. If you want to learn more about their beauty workshops and consultations, ask your health care team or call 1-800-914-5665.

If you are having chemotherapy, ask your doctor or nurse if the drugs you will be taking involve a risk of hair loss. If so, you may want to plan in advance what you want to do: some patients cover their heads with scarves, hats, or wigs; others decide not to do anything at all. The choice is yours. Read more about hair loss on page 63 in the Chemotherapy section.



Sex and sexuality

Your body will go through some changes during your treatment. Though these changes may not be visible, you may feel different. For some people, cancer treatment can be very stressful or tiring and they may not be as interested in sex. For other people, their sexual drive may be the same as before cancer treatment. Still others may find that the experience has brought them closer to their partner. Just as your response to treatment is individual, your feelings towards sex are your own. If you are finding that your sexual drive is lower than usual, know that this is probably temporary.

In some cases, the surgery used to treat rectal and anal cancer carries the risk of impotence, which may be temporary or permanent. Talk to your doctor if you have any questions or concerns.

Cancer treatment can take a particularly heavy toll on your body and it might take a little bit of time for you to feel “back to normal” again. Talk to your partner and let him or her know how you’re feeling. Keeping the lines of communication open at this time is very important.

Women may have a feeling of vaginal dryness, burning, or itchiness from the chemotherapy or radiation. Using a personal lubricant may help you feel more comfortable, especially during sexual intercourse. It’s a good idea to use a condom if engaging in sexual intercourse within 48 hours of receiving chemotherapy or while on infusional chemotherapy. Irregular menstrual cycles are another side effect of chemotherapy. Some women find that their menstrual periods stop altogether. Once chemotherapy stops, it is possible that regular menstrual periods may begin again.

If you have worries or concerns, talk to your health care team. They have helped many other people and will not be embarrassed by your questions. Remember, they are there to help.



Pregnancy and fertility

For women, becoming pregnant during your cancer treatment is not recommended because the drugs or other treatments may harm the unborn child. If there is a chance that you may become pregnant, it is important to use some form of birth control. Talk to your doctor, pharmacist, or nurse about the best birth control options for you and your partner.

If you are thinking of having children in the future, there are a few things you should know. The long-term effects of chemotherapy may include sterility or premature menopause. The risk of this happening varies with the type of chemotherapy you receive and your age. Talk to your doctor to find out more about your own risks and if you should consider sperm banking or egg harvesting.

Staying out of the sun

Undergoing chemotherapy and radiation makes you more sensitive to the sun; therefore, it is important that you use sun protection. This includes using sunblock or sunscreen (minimum SPF 30), and wearing a wide-brimmed hat, long-sleeved tops, long pants, and sunglasses. Be especially careful to protect yourself from the sun during radiation therapy and for 6 months following your therapy. The Canadian Cancer Society has excellent and current information on its Web site regarding sun protection in their SunSense Guidelines.

Work

How soon you feel ready to return to work is up to you. Some people can work during their treatment. Others may need to take time off. Others may not be able to return to work. Talk to your health care team about your options. If you are having chemotherapy, you may want to wait until you've finished 1 to 2 months of treatment to see how it affects you before making any decisions about work.

Talk to your social worker for guidance on how to access sick leave and disability, and for help filling out forms.

Remember, every patient has a different reaction to cancer treatment. Listen to your body and take enough time to recover. That way you'll be in good shape when you return to work.

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"My husband and I have focused our life. Knowing the cancer that I have has a very high percentage of recurrence within 5 years of surgery, we've changed our lifestyle. We moved our retirement up and we've done the things now that we were going to do 7 years from now. We've just changed our whole life." – Muriel, colorectal cancer patient

Cancer in remission

Remission describes the time when cancer is under control and the person is free from its signs and symptoms. Living in remission seems like a victory, but not a complete one. Having to deal with the uncertainty of cancer returning can be very stressful – no one wants to think that they will have to fight cancer a second or third time. The most important thing you can do is to take care of yourself. Do what you can to live a healthy lifestyle, and listen to your doctor's advice about medical check-ups.

Part of feeling healthy is paying attention to any worries that you have about cancer returning. You may want to talk to your social worker, psychologist, nurse, or your friends and family about these concerns. Or, talking to patients who "have been there" may help. Ask your doctor or nurse about getting in touch with a patient group or counsellor.

"It's going to be a very quality time. It's going to be with people I want to be with and I'm going to be doing things with people that I want to do things with. It's going to be really important." – Muriel, colorectal cancer patient



information and support

"If there were articles [on the Internet] that seemed relevant, I'd speak to the oncologist about them. And he'd really reassure me. He'd tell me that 'this is fine' and 'this is not really the way it is.'"

– Wife of a colorectal cancer patient

You may feel the need to learn as much as you can about colorectal cancer or you may just have some specific questions about your treatment. On the following pages you'll find some places to start your search. This list isn't complete. We've listed some of the organizations and sources of information that we have found helpful. We've included Web sites and phone numbers to help you contact the people and places that interest you.

Keep in mind that while the Internet can be a great source of information, not all of the information is completely accurate, nor can it replace the information and advice you receive from your health care team. Be sure to ask your health care team about any information that you find on the Internet.

Another great source of information, tips on how to get by, and encouragement, is local support groups. Ask your health care team to recommend organizations in your community. Contact your local branch of the Canadian Cancer Society for more information. Also, ask for help at your local library reference desk. They may be able to put you in touch with resources in your community and help you with Internet searches.

Resources available

Organizations

Canadian Cancer Society

National organization with provincial divisions and local offices that can provide information pamphlets and help with the practical matters of treatment. Available in French and English. Also offers the *Reach to Recovery*® support program.

Cancer Information Service Line: 888-939-3333

<http://www.cancer.ca>

Cancer Connection

Telephone-based peer support service offered by the Canadian Cancer Society. Available in French and English.

Telephone: 800-263-6750

CancerNet

Information resource supported by the National Cancer Institute of the United States Department of Health and Human Services. Offers pamphlets and brochures on cancer in general and treatment options for different types of cancer. Available in English and Spanish.

<http://www.cancer.gov/cancerinfo/types/colon-and-rectal>

National Coalition for Cancer Survivorship

A U.S.-based advocacy organization led by survivors that works exclusively on behalf of people with all types of cancer and their families. Available in English only.

<http://www.canceradvocacy.org>



Colorectal Cancer Association of Canada (CCAC)

Non-profit organization dedicated to supporting people with colorectal cancer, their families, and caregivers with support groups in several cities across Canada. Available in French and English.

Telephone: 416-920-4333; 514-875-7745;

toll-free: 877-50-COLON (877-502-6566)

<http://www.ccac-accc.ca>

WellSpring

A network of centres providing emotional and psychological support to people and families coping with cancer in Ontario. Available in English and Chinese.

Telephone: 877-499-9904

<http://www.wellspring.ca>

British Columbia Cancer Agency

Provides facts on treatment and side effects for both patients and health care professionals. Available in English only.

<http://www.bccancer.bc.ca/default.htm>

Cancer Care Manitoba

Provides information on cancer, treatment, and side effects, as well as patient and family support services. Available in English only.

<http://www.cancercare.mb.ca>

Cancer Care Ontario

Provides facts and information on cancer, treatments, and other resources for patients and family members. Web site available in English only.

Resource materials available in both English and French.

<http://www.cancercare.on.ca>

Health Canada Online

Information from the Canadian government on cancer. Available in French and English.

<http://www.hc-sc.gc.ca/english/diseases/cancer.html>



Look Good, Feel Better™

A national program designed to help women cope with the changes in appearance that cancer treatment can bring. Available in French and English.

Telephone: 800-914-5665

<http://www.lgfb.ca/>; email: lgfb@lgfb.ca

Hope and Cope

Supports cancer patients and their families at the Montreal Jewish General Hospital. Available in French and English.

Telephone: 514-340-8255

<http://www.jgh.ca/departments/hopecope>

American Cancer Society

Information on cancer provided by the American Cancer Society.

Available in English and Spanish. Some materials available in Asian languages.

Telephone: 800-ACS-2345

<http://www.cancer.org>

National Colorectal Cancer Research Alliance

U.S.-based group that provides information about colorectal cancer, supports research, and promotes screening. Available in English only.

<http://www.nccra.org>

Book

Adrouny, A. Richard. *Understanding Colorectal Cancer*. Jackson, Mississippi: University Press of Mississippi, 2002.

You can also visit your local hospital or community library to borrow books and videos on colorectal cancer.

Resources available in French

Organizations

La Fondation québécoise du cancer

Patient advocacy group based in Quebec.

Telephone: 514-527-2194

<http://www.fqc.qc.ca/>

Belle et bien dans sa peau

Telephone: 800-914-5665

http://www.lgfb.ca/fr/ab_welcome.html

“Some of the information is devastating, but it’s the reality of it. And we always [think] what if I had known, what should I have done. You have to go past the guilt and the self-recrimination. You have to go past that and live today. You have to decide this is where I’m at today and this is how we’re going to move on today.” – Muriel, colorectal cancer patient



appendices

Appendix 1

Screening recommendations for colorectal cancer

Early detection and removal of pre-cancerous polyps prevent colorectal cancer. And early detection of cancer increases the likelihood of a cure. To catch colorectal cancer early, it's recommended that certain groups of people undergo screening. Below we outline the people who may benefit from screening.

Research has shown that certain people have a higher risk of colorectal cancer, especially as they get older. If you are older than age 50, talk to your doctor or nurse about screening for colorectal cancer. The Canadian Task Force on Preventative Health Care recommends that people over 50, with no other risk factors but age, undergo a fecal occult blood test every 1 to 2 years. This test detects blood in your stool, which is one of the symptoms of colorectal cancer. More information about this test can be found in the Important tests section in this guide (see page 18). If this test is positive, you will probably need to undergo a colonoscopy to determine whether the blood in your stool is being caused by colorectal cancer.

People in other high-risk groups should consider screening before the age of 50. Studies have shown that people in high-risk groups make up 23% of colorectal cancers diagnosed. These high-risk groups include:

- People who have had colorectal cancer or adenomas (non-cancerous tumours made up of cells that line some of the glands of the body) before
- People with a close relative (mother, father, brothers, sisters) who has had colorectal cancer or adenomas

- People with a previous history of cancer of the ovary, lining of the uterus, or breast

Some risk factors for everyone are:

- A history of ulcerative colitis or Crohn's disease
- A diet high in red meat and low in fruits and vegetables
- Being overweight or obese
- Lack of exercise
- Drinking alcohol, especially beer, and smoking

People in one of these higher risk groups should talk to their doctor about what screening tests are best and at what age they should start having screening tests.

Remember, the earlier colorectal cancer is caught, the better. If you have been diagnosed with colorectal cancer, let your family know and discuss the benefits of screening with them.

Reducing the risk

In addition to screening, there are things you can do that may reduce the risk of developing colorectal cancer:

- Eat lots of fruits and vegetables and high-fibre foods, and eat red meat in moderation. Such diets have been shown to reduce the risk of colon cancer and many other types of cancers
- Exercise regularly, at least 3 times a week

- Try to stay close to your ideal weight. Obesity is also a risk factor for many other diseases, including heart disease and diabetes
- Drink alcohol in moderation (2 drinks or fewer per day)
- Quit smoking
- Talk to your doctor or nurse for more information about reducing your risk of developing colorectal cancer

Appendix 2

Examples of drugs and drug regimens for the treatment of colorectal cancer

Table 1 gives a quick description of some drugs used to treat colorectal cancer and table 2 lists examples of chemotherapy regimens.

Because of the large number of drugs used to treat cancer and the new ones that are being developed, it is impossible to list all of the available drugs in this guide. As well, because the side effects vary from patient to patient, we have not listed specific side effects beside each drug or drug regimen. Always ask your doctor, pharmacist, or nurse if you have any questions about the drugs you will be receiving or the side effects of your treatment. Make sure you know when you need to contact your health care team about any side effects you may experience.



Table 1: Examples of chemotherapy medications used to treat colorectal cancer

Name	Trade name	How administered	Used to treat
5-fluorouracil or 5-FU	Adrucil®	Intravenously	Adjuvant chemotherapy in Stage II and Stage III disease and treatment of metastatic disease (Stage IV)
Calcium folinate or folinic acid or calcium leucovorin	Leucovorin®	Intravenously	Administered with 5-FU to make it more effective in all of its uses
Capecitabine	Xeloda®	By mouth	Adjuvant chemotherapy in Stage II and Stage III disease and treatment of metastatic disease (Stage IV)
Irinotecan or CPT-11	Camptosar®	Intravenously	Metastatic disease (Stage IV)
Oxaliplatin	Eloxatin**	Intravenously	Adjuvant chemotherapy in Stage II and Stage III disease and treatment of metastatic disease (Stage IV)
Floxuridine*	FUDR	Hepatic infusion pump	Metastatic disease (Stage IV) that has spread only to the liver
Raltitrexed	Tomudex®	Intravenously	Metastatic disease (Stage IV)

*Available through Health Canada's Special Access Programme

Adrucil® is a registered trademark of Pfizer Canada Inc.

Leucovorin® is a registered trademark of Mayne Pharma Canada Inc.

Xeloda® is a registered trademark of Hoffmann-La Roche Limited.

Camptosar® is a registered trademark of Pfizer Canada Inc.

Eloxatin® is a registered trademark of Sanofi-Aventis.

Tomudex® is a registered trademark of AstraZeneca Canada Inc.



Table 2: Examples of regimens combining biologic therapy and chemotherapy medications for the treatment of colorectal cancer

Biologic therapy	Used in combination with chemotherapy medications
Avastin® (bevacizumab)	5-FU (5-fluorouracil) plus Leucovorin plus Irinotecan
Avastin® (bevacizumab)	5-FU (5-fluorouracil) plus Leucovorin plus Oxaliplatin
Erbix® (cetuximab)	Irinotecan

Avastin® is a registered trademark of Genentech Inc. and Hoffmann-La Roche Limited.

Erbix® is a registered trademark of ImClone Systems Inc. and Bristol-Myers Squibb Canada Inc.

“I referred my daughters to the information that I was getting so that they could read about it, so that they could learn about it. Because it is a genetic disease, my daughters are perhaps prone to it. I didn’t know this until I started reading everything on it. I want them to be as informed as possible, so that they can make sure that they aren’t going to face what I was facing.”

– Muriel, colorectal cancer patient



Table 3: Examples of regimens combining chemotherapy medications for the treatment of colorectal cancer

Common regimens in Stage III colorectal cancer

Chemotherapy regimen	Combination of medications
Mayo Clinic	5-FU (5-fluorouracil) plus Leucovorin (daily boluses* of 5-FU and leucovorin for 5 consecutive days every 4 weeks)
Roswell Park	5-FU (5-fluorouracil) plus Leucovorin (once a week bolus of 5-FU and leucovorin for 6 weeks every 8 weeks)
FOLFOX	5-FU (5-fluorouracil; bolus followed by continuous infusion for a period of time, usually more than 24 hours) plus Leucovorin (short infusion) plus Oxaliplatin (short infusion) (every 2 weeks)
Xeloda*	Capecitabine (oral tablet) (twice daily for 14 days, every 3 weeks)

*Bolus: The drug is administered quickly by IV instead of over a long period of time.



Common regimens in Stage IV colorectal cancer

Chemotherapy regimen	Combination of medications
FOLFIRI	5-FU (5-fluorouracil; bolus followed by continuous infusion) plus Leucovorin (short infusion) plus Irinotecan (short infusion) (every 2 weeks)
FOLFOX	5-FU (5-fluorouracil; bolus followed by continuous infusion) plus Leucovorin (short infusion) plus Oxaliplatin (short infusion) (every 2 weeks)
CAPOX or XELOX	Capecitabine (oral tablets twice daily for 14 days) plus Oxaliplatin (short infusion on first day) (every 2 weeks)
CAPIRI or XELIRI	Capecitabine (oral tablets twice daily for 14 days) plus Irinotecan (short infusion on first day) (every 2 weeks)

Note: Chemotherapy treatment for Stage II colorectal cancer varies from one patient to another. If you are diagnosed with Stage II colorectal cancer, your health care team will talk to you about which treatment options are best for you.

Always ask your health care team about what side effects you may have with a given drug, and when you should contact the team if certain symptoms occur. It's crucial to know when you need to contact your health care team about serious side effects.





glossary

A

Absolute neutrophil count: A count of the proportion of neutrophils (a type of white blood cell) in the blood that is used to determine if you are at risk of infection, and if your chemotherapy should be delayed or the dose reduced.

Abdomen: The area of the body between the chest and the hips. It contains the stomach, small and large intestines, liver, spleen, and many other organs.

Adenocarcinoma: Cancerous tumour affecting a gland.

Adenoma: A benign tumour with a structure resembling a gland, or a tumour that starts in a gland. Polyps found in the colon are considered to be a type of adenoma.

Adjuvant therapy: Therapy given in addition to the main treatment for cancer. In the case of colorectal cancer, surgery is usually the primary treatment. An example of adjuvant therapy would be giving chemotherapy after surgery.

Advanced oncology nurse practitioner: A registered nurse with special education and training to provide primary health care, including many tasks customarily performed by a physician.

Alopecia: Loss of hair from the scalp and/or body. Hair loss is usually temporary and may be partial or total depending on the person, the drug, and the dose.

Alternative therapies: A broad range of treatments, including herbal remedies, vitamin supplements, strict or severe diets, ozone injections, and heat therapy. Because many of these alternative therapies have not been studied to determine their effectiveness or their potential interference with other therapies, it's important that you consult your doctor, pharmacist, or nurse before trying any alternative therapies.

Anastomosis: Joining of the 2 parts of the colon after removal of cancerous tissue.

Anemia: Term used to describe a reduction of normal levels of hemoglobin (the measure of your red blood cell count).

Antibiotic: Medication that fights bacterial infections.

Antibody: Special type of protein made by the body's immune system. It disarms or destroys a specific foreign agent (called an antigen) when it appears in the body.

Antiemetic: Medication that prevents or relieves nausea and vomiting.

Antigen: Foreign agent that stimulates the body's immune system to produce antibodies against it. Examples include an organism (virus or bacteria), transplanted cell, or chemical compound.



Antimetabolite: An anticancer substance contained in chemotherapy medications. These substances are very much like substances needed by cells for normal growth. When present, the tumour cell uses the antimetabolite, which then interferes with the way the cell functions normally, causing the cell to starve.

Assay: A test to determine the size, amount, or characteristics of a sample, or a test designed to detect whether something is present or absent in a sample.

B

B-lymphocytes: Lymphocytes (white blood cells) that are responsible for the production of antibodies that help fight infection.

Benign tumour: Non-cancerous growth that does not spread to surrounding tissues and that rarely recurs after it has been completely removed.

Bevacizumab: Biologic therapy used to treat colorectal cancer.

Biologic therapy: Newer class of medications designed to specifically target cancer cell growth and activity. Monoclonal antibodies are an example.

Biopsy: Surgical procedure that involves removing a small piece of tissue or cells. The removed cells are then studied under a microscope to help make a diagnosis. The process of removing tissue or cells is known as “taking a biopsy.”

Blood count: Number of red blood cells, white blood cells, and/or platelets in a sample of blood.

Bolus: Administration of a drug quickly by IV instead of over a long period of time.

Bone marrow: Soft tissue and fluid found in the cavities of bones. Bone marrow contains stem cells, which make different types of blood cells – red blood cells, white blood cells, and platelets.

Bowel: Also called the large intestine or colon. It connects the small intestine to the rectum. Responsible for removing water from material as it passes through the digestive system.

Bowel obstruction: Situation where the bowel, or colon, becomes blocked or clogged, preventing the movement of feces through the large intestine.

C

CEA: Short form for carcinoembryonic antigen, a protein marker found in the bloodstream. An increased level of this compound may indicate colorectal cancer. It may also be increased in the presence of other diseases and in people who smoke.

CT scan: Formally known as computerized axial tomography (CAT scan), a CT scan takes 3-D images of structures in your body. This scan is very effective at confirming if there is cancer in the liver, lungs, brain, bones, or other parts of the body.

Calcium folinate: Also called folinic acid or calcium leucovorin. A chemotherapy agent that is used in combination with 5-FU to enhance 5-FU's activity in the treatment of colorectal cancer.

Cancer: Uncontrolled, abnormal growth of cells that can invade and destroy healthy tissues. Cancer is a general term used to name more than 100 diseases. While all cancers can spread to other parts of the body, not all do.

Cancer *in situ*: Early stage of cancer in which tumour cells have not yet invaded surrounding tissues.

Capecitabine: A chemotherapy medication taken by mouth that is changed in the body to 5-fluorouracil, for the treatment of colorectal cancer.

Carcinogen: Cancer-causing substance; for example, cigarette smoke.

Catheter (central line): Small, thin tube that is inserted into a part of your body. It is sometimes used in cancer treatment to make taking blood or giving medications easier.

Cell: The basic structure of living tissues. All plants and animals are made up of 1 or more cells. An amoeba, for example, is made up of 1 cell. Human beings are made up of trillions of cells.

Cetuximab: Biologic therapy given intravenously to treat colorectal cancer.

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

Chemotherapy cycle: The time it takes to give the chemotherapy treatment plus the rest time until the next treatment. Each round of chemotherapy medication is called a cycle.

Clinical trials: Research studies (e.g., to test new treatments). Strict rules are followed to make sure patients are well informed about the purpose, risks, and benefits of any study before they agree to join a clinical trial.

Clinical trials nurse: Specially trained nurse who is involved in the care of patients who are participating in a clinical trial. A clinical trials nurse organizes and records treatments, blood work, and x-rays, arranges for follow-up appointments, and provides information and support.



Colon: An approximately 5-foot-long muscular tube located in the abdomen that removes excess water from stools or feces before they exit from the body.

Colonoscopy: Procedure that uses a fibre-optic tube to look inside the colon.

Colorectal cancer: Abnormal growth of malignant cells in the colon or rectum.

Colostomy: The creation of an opening from the colon to the outside of the body to allow the elimination of feces. May be either temporary or permanent.

Combination chemotherapy: Use of 2 or more anticancer drugs to treat the cancer of 1 patient.

Combination therapy: Use of 2 or more types of treatment on 1 cancer patient (e.g., chemotherapy and radiation therapy).

Complementary therapies: Complementary therapies can be used along with traditional cancer treatment, and may help improve a patient's sense of well-being and reduce stress. These therapies include peer and group support, therapeutic touch, yoga, meditation, and visualization exercises.

Complete blood count (CBC): Blood test that measures hemoglobin level (protein in red blood cells that carries oxygen), hematocrit (the percentage of red blood cells in whole blood), total and differential WBC (white blood cell) count, and platelet (structures that help blood form clots) count.

Compound: A substance that consists of 2 or more chemical elements in union.

D

Dehydration: Excessive loss of water from the body. It may be caused by vomiting or diarrhea.

Diagnosis: Identification of a disease from signs, symptoms, laboratory tests, radiological results, and physical findings.

E

EGFR: A protein found in large numbers on the surface of many types of tumour cells, which helps promote cancer cell growth and cell division.

Enzymes: Substances that promote specific chemical reactions; for example, the digestion of food in the intestine.

Etiology: Factors that cause disease.

Excision: Surgical removal of an organ or tissue.

F

5-FU: Short form for 5-fluorouracil. Chemotherapy medication commonly used to treat colorectal cancer.

Familial adenomatous polyposis (FAP): Rare, inherited disease of the gastrointestinal system where thousands of polyps grow on the lining of the intestine. If the polyps are not removed, the patient may eventually develop cancer. Often doctors recommend a complete removal of the large intestine to prevent cancer from occurring.

Febrile neutropenia: Serious condition in which a fever develops in patients who have a low white blood cell count (specifically neutrophils). Fever indicates the presence of an infection, which, in most cases, originates from germs and bacteria that reside in the intestines or skin. Febrile neutropenia is a medical emergency and must be dealt with immediately. Any temperature over 101°F (Fahrenheit) or 38°C (Celsius) should be promptly reported to your health care team.

Feces: Material expelled from the anus during bowel movements. It consists mostly of waste from food eaten.

Fibre-optic tube: Used to transmit an image via a bundle of thin, flexible glass or plastic fibres.

Floxuridine: A chemotherapy medication given by injection for the treatment of colorectal cancer.

G

Genes: Biological units of heredity that transfer traits from cell to cell and from parents to child.

Granulocyte colony-stimulating factor (G-CSF): Drug that stimulates the production of neutrophils (a type of white blood cell).

H

Hemoglobin: Protein in red blood cells that carries oxygen. Measuring hemoglobin levels can determine the presence of anemia.

Hereditary nonpolyposis colorectal cancer (HNPCC): Hereditary condition where polyps in the large intestine are more likely to develop into colorectal cancer than polyps discovered in people without the condition. People with this condition are only slightly more likely to develop polyps than the general population. People in families with this condition should discuss early, regular screening with their doctors. May also be called Lynch syndrome.



I

Immune system: System in the body that defends against disease.

Immunology: Study of the body's natural ability to defend itself against organisms or foreign substances.

Immunotherapy: Treatment that stimulates the body's immune system to produce antibodies to fight disease. Anticancer vaccines are an example of immunotherapy.

Infection: Invasion of the body tissues by micro-organisms such as bacteria and viruses.

Infusion: A method of getting fluids that contain an anticancer drug into the body. The rate at which a drug is flowed into the body is monitored and controlled by a pump, infuser, or by gravity, moving the fluid through a tube and into a vein.

Injection: Use of a syringe and needle to introduce fluids into the body. Injections are given under the skin (subcutaneously), in a muscle (intramuscularly), or in a vein (intravenously).

Intramuscular: Injection of a drug into a muscle. The drug is then absorbed into the bloodstream.

Intravenous: Fluids or drugs are put directly into a vein. Commonly called IV, short for intravenous. ("Venous" means vein.) Anticancer drugs are often given by IV injection.

Invasive cancer: Cancer that has spread from its original location to nearby tissues or organs.

Irinotecan: Also called CPT-11. A chemotherapy medication given by intravenous injection for the treatment of colorectal cancer.

Irradiation: Another term for radiation therapy. To irradiate is to give radiation therapy.

L

Lactate dehydrogenase (LDH): Enzyme that is present in most cell types that helps indicate cellular damage. Higher levels of lactate dehydrogenase signal aggressive tumours.

Large intestine: The final section of the digestive system. It comprises 6 parts: the cecum, the ascending colon, the transverse colon, the descending colon, the sigmoid colon, and the rectum. The large intestine pushes food waste through these parts, removing excess water, and turning feces into semi-solid waste that can be expelled from the body.

Local cancer: Cancer that's confined entirely to the organ where the cancer began.

Local treatment/therapy: Treatment that targets cells in the tumour and the area close to it. An example is radiation therapy.

Localized: Restricted to the site of origin without evidence of spread.

Lower anterior resection: Name of a specific procedure to remove cancer from the rectum.

Lymph: Clear, yellowish fluid that carries lymphocytes (a type of white blood cell), antibodies, and nutrients throughout the body.

Lymph nodes: Bean-shaped glands that filter out impurities in lymphatic fluid.

Lymphatic system: System of vessels that carry lymph fluid between lymph nodes located throughout the body.

Lymphocyte: A type of white blood cell that plays a central role in the immune response.

M

MRI: Stands for magnetic resonance imaging. This is an imaging technique that uses a large magnet and a computer to develop images of the soft tissues of the body, such as organs in the abdomen.

Malignancy: Tumour consisting of cancer cells. Cells from a malignant growth can break away and start secondary tumours elsewhere in the body.

Malignant: Term meaning cancerous.

Medical oncologist: Doctor who specializes in drugs for the treatment of cancer.

Metastasis (metastatic cancer): Spread of cancer cells from the original tumour to other parts of the body by way of the lymph system or bloodstream.

Monoclonal antibody: Antibody of a single specific type produced by a family of cells (clone), which is derived from 1 parent cell. Monoclonal antibodies are designed to attack specific cells to prevent the further spread of cancer.

Mucositis: Inflammation of the mucous membranes; for example the lining of the mouth or throat.

N

Nausea: Feeling the need to vomit.

Neoadjuvant: Describes therapy or treatment given before primary therapy. For instance, radiation therapy or chemotherapy given to reduce the size of a tumour before surgery to remove the tumour.



Neutropenia (neutropenic): Condition that describes an abnormal decrease in the level of neutrophils, a type of white blood cell in your body. This decrease of white blood cells can make your body more susceptible to infections. Neutropenia can be caused by chemotherapy, and may be treated with a granulocyte colony-stimulating factor medication.

Neutrophil: The most abundant type of white blood cell, it acts as the first line of defence against infection. Neutrophils can be damaged by chemotherapy or other drugs.

O

Oncogene: Gene that is an altered version of a normal gene that is involved in the control of cell growth and division.

Oncologist: Physician who specializes in diagnosing and treating cancer.

Oncology: Study and treatment of cancer.

Oncology nurse: A registered nurse who specializes in treating and caring for patients with cancer.

Oxaliplatin: A chemotherapy medication usually given in combination with other medications to treat colorectal cancer.

P

Pathologist: Physician who is trained in laboratory medicine and who examines tissues taken from biopsies to describe the type of cell making up the cancerous tissue.

Pathology: Study of changes to body tissues and fluids caused by disease.

Pelvic examination: Examination of the vagina, cervix, uterus, and ovaries.

Pelvic field: Area of the body that includes the pelvis where radiation treatment may be given.

Pelvis: Lower part of the trunk of the body.

Pharmacist: Person who specializes in preparing, dispensing, and monitoring drugs. He or she can give you expert advice on drug use and about any side effects that you may experience if you are taking drugs.

Physiotherapy: Use of exercises to help improve joint movement, to reduce swelling, and to reduce pain associated with surgery. Conducted with the help of a physical therapist or physiotherapist.



Platelets: Elements in the blood that form clots to help prevent bleeding, or to help stop bleeding after an injury.

Polyp: Benign tumours found on the inner lining of the bowel.

Primary cancer: Where the cancer started before it spread.

Prognosis: The prediction of how a patient will do after diagnosis.

R

Radiation field: Term used to describe the area of the body that will receive radiation treatment.

Radiation oncologist: Doctor who has had special training in using radiation to treat human disease.

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

Radiologist: Physician trained to diagnose disease by using such procedures as x-ray, ultrasound, radioisotope scans, CT scans, and magnetic resonance imaging.

Raltitrexed: A chemotherapy medication given intravenously and used for the treatment of colorectal cancer.

Rectum: Last section of the large intestine that connects the sigmoid colon to the anus. It stores feces until they are expelled from the body.

Regimen: Term used to describe the drugs, dosage, frequency, timing, and total amounts of chemotherapy medications that you will receive.

Registered dietitian: Qualified expert in the field of food and nutrition. He or she provides people with nutritional assessments and counselling. He or she also turns scientific information about food and nutrition into practical advice that people can use in their daily lives.

Relapse: The return of disease after remission.

Remission: The period of time when cancer is under control and the person is free from its signs and symptoms.

Risk factors: Things that increase your chances of getting a disease. Risk factors can be environmental or hereditary.



S

Sexual dysfunction: Sex-related difficulty.

Side effects: Symptoms caused by certain drugs or treatments.

Sigmoid colon: Section of the large intestine that joins the descending colon to the rectum.

Sigmoidoscopy: May be called flexible sigmoidoscopy. A lubricated flexible scope consisting of a hollow tube with a light is gently inserted into the anus to look for polyps and other abnormalities in the rectum and sigmoid colon.

Staging: Method of classifying cancer according to the extent of its spread. Staging helps to determine treatment methods and to predict the course of the disease.

Stem cell: Type of cell that is responsible for forming all kinds of cells.

Stoma: Opening in the abdomen that connects the colon to the outside of the body to allow for the passage of stool.

Stomatitis: An inflammatory condition of the mouth.

Stool: Solid waste from the digestive tract. (See Feces)

Subcutaneous: Injection of drugs by needle just below the skin.

Surgeon: Doctor who performs surgery.

Syringe: Device that consists of a tube and a plunger. It is used to withdraw fluids from, or inject fluids into, the body.

Systemic treatment: Treatment using substances that travel through the bloodstream, reaching and affecting cells all over the body. Chemotherapy is an example of a systemic treatment.

T

Targeted therapy: Newer class of drugs designed to specifically target cancer cell growth and activity. Monoclonal antibodies are an example.

Therapy: Treatment of disease.

Thrombocytopenia: Condition that describes a drop in your platelet count below normal levels. Thrombocytopenia may lead to bleeding problems.

Toxicity: A side effect resulting from treatment, toxicity is unwanted damage to your body's healthy cells.

Tumour: Mass of abnormally growing cells that serve no useful bodily function. Tumours can be either benign or malignant.

Tumour bulk: Term used to describe the actual amount of tumour present in your body.

U

Ultrasound imaging: A diagnostic technique that uses sound waves to detect abnormal bodily structures. Sound waves are bounced off internal organs; a computer picks up their echoes, processes the information, and forms a detailed picture of the area.

Upper abdominal field: The area in the upper abdomen that is treated by radiation therapy.

Uterus: Organ in females for nourishing the fetus during development before birth. Also called the womb.

V

VAD (venous access device): A small device placed under the skin of the chest or forearm that allows medications to be injected directly into a vein and for blood to be drawn from the vein.

VEGF: A protein that binds to blood vessels and stimulates the formation of new blood vessels to supply tumours the oxygen and nutrients they need to grow.

W

White blood cells: White blood cells are responsible for defending the body and fighting infection caused by bacteria and viruses. Chemotherapy often causes a reduction in the number of white blood cells, thus raising a patient's risk of developing an infection. The decrease in white blood cells is called leucopenia.

Wide surgical resection: Removal of cancerous tissue and area of normal colon and lymph nodes near the cancer.





colorectal cancer index

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notes

“Some of the information is devastating, but it's the reality of it. And we always [think] what if I had known, what should I have done. You have to go past the guilt and the self-recrimination. You have to go past that and live today. You have to decide this is where I'm at today and this is how we're going to move on today.” – Muriel, colorectal cancer patient



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This patient guide meets Canadian Association of Nurses in Oncology (CANO) guidelines for educational content and will further the quality of nursing care by providing educational support to patients with colorectal cancer.



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