Colorectal Cancer Care
A Cancer Care Map for Patients

Understanding the process of care that a patient goes through in the diagnosis and treatment of colorectal cancer in BC.
This booklet shows the process of care that a typical patient goes through in the diagnosis and treatment of colorectal cancer in British Columbia. This Colorectal Cancer Patient Care Map is intended for patients and their families to help them understand the process of care, and is partly designed to highlight the role of surgery in the care of patients with colorectal cancer. Please note that this information is not meant to replace the advice, expertise or professional judgment of a physician trained in the management of colorectal cancer. Each patient’s care is individualized and those with unusual symptoms or complex colorectal cancer may have additional or different steps in their care.

If you are a patient, please note that your care may differ from that shown in this care map but may be still be appropriate for you. If you are uncertain, please discuss with your doctor.

This Colorectal Cancer Patient Care Map was developed as a collaboration by the Colorectal Surgical Tumour Group of the Surgical Oncology Network at the BC Cancer Agency and the colorectal surgeons at St. Paul’s Hospital, Vancouver, B.C.

An electronic copy of this Care Map can be found at the following locations:
www.bccancer.bc.ca/SON/ColorectalCancerCareMap
www.providencehealthcare.org/colorectalsurgery/cancer_info.html
Colorectal Cancer

What is cancer?

Each one of the trillions of cells that make up the body contains genetic “instructions” (DNA) that regulate how they grow into healthy cells, make copies of themselves, mature, and then die off. These instructions need to be followed very strictly for tissues and organs to function in a healthy, normal way.

When specific genetic information in a cell mutates or is changed, these instructions can be altered. The cells then grow and replicate in an uncontrolled, unhealthy way and can lead to a tumour. When the mutated cells develop the ability to spread to other tissues in the body, they have then become malignant or cancerous. Cancerous cells and tumours can invade and damage organs, disrupting the normal functioning of the body.

Tell me about the colon and rectum

The gastrointestinal tract starts at the mouth and ends at the anus. The colon and rectum are the last part of the gastrointestinal tract and form a continuous tube, up to two metres (six feet) long. While the small intestine, just before the colon, absorbs most of the nutrients from food you eat, the colon and rectum are mainly responsible for absorbing water and passing along waste matter for elimination via a bowel movement.

The colon is mainly located in the abdomen, and the rectum is mainly located in the pelvis. This difference is important because rectal cancers are treated somewhat differently than colon cancers.

What is a colonoscopy?

A colonoscopy is a test that can directly look inside the colon and rectum. During a colonoscopy, the colonoscope is inserted through the anus by the surgeon or gastroenterologist. The colonoscope is a long, thin, flexible tube with a light and a tiny camera on the end, which allows the entire colon and rectum to be viewed on a video screen. To make the test more comfortable, the doctor may suggest intravenous medication for sedation during the colonoscopy. Most patients have no problems tolerating a colonoscopy.

If a polyp is found, it can often be removed with the colonoscope. If a larger growth is found, a biopsy will be taken for further examination.
Tell me about colorectal cancer

The wall of the colon and rectum has four main layers (see Figure 2). Almost all colorectal cancers develop from the innermost layer, which is why colorectal cancer can be seen during a colonoscopy. A polyp may or may not be cancerous, which is why it is important to remove the polyp or take a biopsy to determine what it is.

The deeper the cancer invades into the wall, towards the outside of the colon or rectum, the more aggressive it is. Aggressive cancers can spread beyond the wall of the colon or rectum to the lymph nodes, to nearby organs, or to other parts of the body through the bloodstream or other means. Three factors determine the stage of the cancer: the depth of the cancer into the wall, the spread of the cancer into the lymph nodes, and the spread of the cancer into other organs. Sometimes these factors can be estimated before surgery using staging investigations (see page 7), but the final determination is only made once the cancerous part of the colon and rectum is removed surgically, and a pathologist examines the cancer under a microscope.

There are four stages of colon and rectal cancer:

- **STAGE I AND II** colorectal cancers are only in the colon and rectal wall. They are not in the lymph nodes and have not spread to other organs.
- **STAGE III** colorectal cancers have gone beyond the colon and rectal wall into the lymph nodes, but have not spread to other organs.
- **STAGE IV** colorectal cancers have spread into other organs, most commonly liver and lungs, either through the bloodstream or by direct invasion.

Early stage cancers have a higher cure rate than cancers found at later stages. The growth of cancer in the colon and rectum can cause blockage, bleeding, or can erode through the wall. When colorectal cancer spreads to other organs (metastasizes), it can interfere with the normal function of those organs and can be life-threatening.

**High risk factors** for colorectal cancer include history of colorectal cancer in younger family members (less than 50 years), pre-existing inflammatory bowel disease for over 10 years (Crohn's disease or ulcerative colitis), benign colorectal polyps, and previous colorectal cancer.

Other possible risk factors may include high fat/low fiber diet, obesity, lack of physical activity, smoking, excessive alcohol consumption, age, and history of colorectal cancer in elderly family members.

Colorectal cancer is the third most common cancer in Canada, and is the second most common cause of cancer deaths for Canadians. In 2012, about 23,000 Canadians were diagnosed and about 9,000 died of colorectal cancer. In the same year, about 2,800 British Columbians were diagnosed and about 1,100 died of the disease.

If detected early, over 90% of these cancers are completely curable.

Surgery is the most important treatment for colon or rectal cancer. Although radiation and chemotherapy can also be added, either before or after surgery depending on the exact nature of a patient's cancer diagnosis and stage, **colon and rectal cancer can generally only be cured with surgery**. After cancer treatment is finished, close patient follow-up is important to detect a cancer recurrence early enough that treatment might be beneficial.

(FIGURE 2) Staging Principles of Colorectal Cancer

A schematic diagram showing the layers of the colon or rectal wall and how the different stages of cancer are determined. Tumours can develop from the innermost layer, invade into the wall and towards the outside of the colon or rectum, and then spread to the lymph nodes and to other organs.

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Colorectal Cancer Care
FROM SUSPICION TO FOLLOW-UP

The steps outlined below follow a patient from the suspicion of colorectal cancer to diagnosis and staging, through to treatment and to follow-up.

1. DIAGNOSIS

Patient reports symptoms

Typically, the process begins when the patient reports symptoms to his or her family doctor. These symptoms may include, but are not limited to, bleeding with bowel movements, abdominal pain, bloating, nausea, vomiting, change in bowel habit such as constipation or diarrhea or inability to pass stools, and unexplained rapid weight loss. The presence of these symptoms does not automatically mean colorectal cancer, as many other diseases and conditions could result in these same symptoms.

Alternatively, patients who don’t have any of these symptoms may have positive screening test results. These screening tests may include testing of stool for blood, X-ray tests which show an abnormality in the bowel, or abnormal scope tests.

Tests to investigate symptoms or positive screening test results

If a family doctor feels that the symptoms or screening test results might be related to colorectal cancer, he or she makes a referral to a surgeon or gastroenterologist (a non-surgical abdominal specialist) for a consultation, with a review of symptoms and a physical examination. The family doctor may refer the patient directly to the BC Cancer Agency if there is a high suspicion of cancer. Any of these referrals are appropriate.

The timeline for testing will depend on the patient, severity of symptoms, and level of suspicion of colorectal cancer. Patients with more severe or highly suspicious symptoms will be assessed earlier than those who have no symptoms.

A colonoscopy is done by a surgeon or a gastroenterologist, and if possible, the entire colon needs to be examined. If the colon cannot be completely examined at the initial colonoscopy because of a tumour partially blocking the colon, a repeat colonoscopy should be conducted within six months after the cancer is surgically removed. This is so the portion of the colon above or “upstream” from the obstructing cancer can be examined for polyps or other growths.

The diagnosis of colorectal cancer is confirmed once the colonoscopy identifies a mass in the colon or rectum that is biopsied and a pathologist determines that the biopsy is cancer.

The next step is to determine how advanced the cancer is and if it has spread to other organs. This process is called staging the cancer.

2. STAGING

Tests for staging the cancer

Testing should be organized expeditiously by the surgeon, but sometimes may be ordered by the family doctor, gastroenterologist or oncologist. Standard testing consists of a CAT or CT scan of the abdomen and pelvis as well as an X-ray or CT scan of the chest. If a CT scan is not readily available or is not appropriate for a particular patient, an ultrasound of the abdomen may assess whether the cancer has spread to the liver. Other imaging tests are done only if symptoms suggest spread to other areas of the body or to look at suspicious areas found on the initial standard tests. Most people will not need other imaging tests (such as a PET scan) in order to receive the best care. A blood test for CEA is also done, as its level sometimes rises with colon or rectal cancer.

For rectal cancers, additional testing is required to determine how advanced the cancer is within the rectum and if the cancer has spread to the lymph nodes next to the rectum. This test may be an ultrasound inside the rectum, an MRI of the pelvis, or both in some cases.

Staging tests will help the surgeon decide whether surgery is the right treatment at this point, what kind of surgery will be required and, in the case of rectal cancer, whether radiation or chemotherapy is necessary before the surgery.
(CHART 1) Colorectal Cancer Care Process: Diagnosis to Follow-up

**DIAGNOSIS**
- Family doctor sees a patient with signs, symptoms, or tests which may indicate colon or rectal cancer
- Referral to surgeon (or gastroenterologist)
- Colonoscopy and biopsy
- **Colorectal cancer confirmed**

**STAGING**
- Abdomen/pelvis: CT or ultrasound
- Chest: CT or X-ray
- Blood test: CEA – “Marker” for colorectal cancer
- MRI and/or rectal ultrasound (rectal cancer only)
- **Preliminary stage determined** → **Cancer is OPERABLE**

**TREATMENT**
- Pre-op radiation +/- chemotherapy (some rectal cancers)
- Surgery: 3-7 days in hospital
- Visit with surgeon to discuss pathology: 2 weeks after discharge
- Recovery from surgery: 1-2 months
- Chemotherapy after surgery, if high risk

**FOLLOW-UP**
- For 5 years:
  - Doctor visits
  - Imaging tests: CT, X-ray, Ultrasound
  - Blood tests: CEA
  - Colonoscopy (more than 5 years)
- Doctors involved in follow-up:
  - Surgeon
  - Family doctor
  - Gastroenterologist
  - Medical oncologist
  - Radiation oncologist

(CHAART 2) Colorectal Cancer Care Map

**Cancer is OPERABLE**

- Colon
  - Surgery
  - Postoperative Chemotherapy (if high risk)
  - Follow-up for Recurrence or New Cancers (5 years)

- Rectum
  - Radiation (1 week)
  - Referral to BC Cancer Agency
  - Radiation + Chemotherapy (5 weeks)
  - Surgery (following week)
  - Surgery (after 6-8 weeks)
  - Determine final stage after surgery
3. TREATMENT

Determining whether the cancer is “operable”

Cancer is operable if it can be safely removed with surgery. Most colon and rectal cancers that haven’t spread significantly can be treated with the intent to cure by surgery and if necessary, radiation and chemotherapy. In some cases, even cancers which have spread to the liver and/or lungs may be curable.

If the cancer is not operable and surgery is not the best option, the surgeon may refer the patient to other, non-surgical cancer specialists (medical and radiation oncologists). They may offer chemotherapy or radiation and then repeat the staging process to see if the cancer has shrunk enough to allow cure by surgery. If not, a discussion between the patient and all his or her care givers (physician and non-physician) is held, at which time the patient’s goals of care are determined. These goals may be extending life (even in the absence of cure), relief of pain, prevention of bowel obstruction, treating anemia (from chronic blood loss from the cancer), or many others including hospice or comfort care. The surgeon, cancer specialists, or GP will then involve the appropriate physicians (which may include palliative care doctors) or other professionals. The patient is at the centre of this process, and everything is done to ensure he or she receives the most appropriate care possible in a sensitive and supportive manner.

Surgery

Surgery usually involves removing the segment of colon or rectum where the cancer is located along with any lymph nodes located near the tumour, with a margin of normal colon or rectum above and below the tumour. All are removed as a single package or specimen, and the two ends are reconnected if possible. Most operations for colon and rectal cancer take two to four hours.

For colon cancer and some early rectal cancers, the patient usually goes straight to surgery. For rectal cancers, surgery is sometimes preceded by radiation with or without chemotherapy. There may be a period of days or weeks between these treatments and the surgery, to allow additional time for the radiation to shrink down the tumour.

Depending on the situation, the surgeon may offer the patient laparoscopic surgery, also known as “keyhole surgery”. Multiple smaller incisions allow the surgeon to insert a camera and instruments so he or she can operate on a video screen. Laparoscopic surgery may allow faster recovery, earlier discharge from the hospital, and quicker return to normal activity and work.

In some cases, especially with rectal cancers, a temporary or permanent stoma may be required at the time of surgery in order to completely remove the cancer, especially if the cancer is very low in the rectum. Unless there are unusual circumstances during the operation, this possibility is usually discussed with the patient before surgery in the surgeon’s office. In very select rectal cancers, removing the tumour from the anus, without any external skin incisions, may be appropriate.

Almost all surgery for colon and rectal cancers is done under a general anesthetic. The patient is usually in the hospital for three to seven days following the surgery. If there are complications, the hospital stay will be longer. Before leaving the hospital, the patient must be tolerating solid food, the bowels must be working, and the pain must be controlled by pills only. After returning home, there will be a period of one to two months (or more) before the patient starts to feel “normal” again, due to the body focusing all of its energy into healing the organs from surgery.

STOMA, also called COLOSTOMY or ILEOSTOMY:
The bowel is brought out through the abdominal wall and sewn to the skin, to allow waste to empty into a special soft plastic pouch.
Treatment after surgery

After the cancer has been removed, a pathologist examines the cancer and the surrounding lymph nodes under a microscope and determines the final stage of the cancer. These pathology results will be discussed with the patient when they return for a post-surgical visit, which is often one or two weeks after the surgery. If there are cancer cells in the lymph nodes or if other high risk features are found, the surgeon will refer the patient to a medical oncologist at the BC Cancer Agency to discuss chemotherapy. The goal of chemotherapy is to prevent the cancer from recurring. Chemotherapy usually starts within 8 weeks after surgery, may be given orally (pills) or intravenously (through the vein) and will generally last for 6 months.

After surgery (and chemotherapy, if necessary), the next phase is surveillance or follow-up.

3. FOLLOW-UP

After the initial treatment with surgery, radiation and/or chemotherapy, patients with colon and rectal cancer will be followed for five years or more by their family doctor, surgeon, oncologist, gastroenterologist, or combination thereof. The follow-up will consist of visits to the doctor to review symptoms and do physical examinations, blood tests, X-ray tests, and colonoscopy to enable early detection of recurrence. Some cancers will involve a less intensive surveillance program than that described here. Colonoscopy will continue beyond the five year period, and the interval between colonoscopies will vary depending on the individual patient.

The recommended follow-up procedures are published and endorsed by the BC Cancer Agency, but may vary for individual patients. If the patient is under the care of a BC Cancer Agency oncologist, a letter with these follow-up recommendations will be sent to the family doctor or surgeon once the patient is discharged from the Agency.

Recommended Visits

- Visit your family doctor every three to six months for the first five years. Your doctor will examine you, review your symptoms, review your test results, and will discuss any concerns you may have. Continue to see your doctor annually after the first five years if possible.

Carcinoembryonic Antigen (CEA)

- The CEA is a tumour marker in the blood that may help detect a recurrence. A rising CEA may indicate a need to do further investigations.
- A blood test to measure CEA should be done every three months for the first three years then every six months for the next two years. There is no reason to continue beyond this time unless there are other symptoms.
Colonoscopy
- Follow-up colonoscopies are important as they may detect polyps or changes inside the bowel that may indicate a recurrence of cancer. You will be referred to a gastroenterologist or to your surgeon for a colonoscopy.
- A complete colonoscopy is recommended a year after your surgery, and again three to five years thereafter, depending on the findings. If you have been diagnosed with a hereditary cancer syndrome, these recommendations will differ. If the colonoscopy before surgery did not evaluate the entire colon, the colonoscopy will be done within six months after surgery.

Imaging & X-rays
- Liver and lung imaging is recommended every six months for the first three years, then once per year for two more years. Imaging may be done with an ultrasound or a CT scan for the liver, and a chest X-ray or CT scan for the chest.

SUMMARY OF KEY POINTS
- Once colorectal cancer is detected, the first step is staging the cancer.
- Surgery is the main method used to try to cure colorectal cancer.
- Radiation, sometimes with chemotherapy, is often administered before surgery for rectal cancer.
- Chemotherapy may be recommended after surgery for some colon and rectal cancers, especially if the cancers are stage III.
- After colorectal cancer treatment, follow-up is important for early detection of cancer recurrence.

<table>
<thead>
<tr>
<th>Follow-up</th>
<th>Dates</th>
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| Doctor visit & CEA                    | • Every three months for three years, then every six months for two more years  
• Rectal examination once a year     |
| Colonoscopy                           | • One year after surgery  
• Three years after surgery  
• If normal, then every five years afterward |
| CT abdomen/pelvis or Ultrasound of liver | • Every six months for three years, then every year for two more years |
| Chest X-ray or CT                     | • Every six months for five years                                    |
Resources

BC Cancer Agency
www.bccancer.bc.ca

*Abbotsford*
604.851.4710
1.877.547.3777 (in BC and Yukon)

*Centre for the North (Prince George)*
250.645.7300
1.855.775.7300 (in BC and Yukon)

*Fraser Valley*
604.930.2098
1.800.523.2885 (in BC and Yukon)

*Southern Interior*
250.712.3900
1.888.563.7773 (in BC and Yukon)

*Vancouver Centre*
604.877.6000
1.800.663.3333 (in BC and Yukon)

*Vancouver Island*
250.519.5500
1.800.670.3322 (in BC and Yukon)

*Canadian Cancer Society*
www.cancer.ca
1.888.939.3333

*Canadian Partnership Against Cancer*
www.partnershipagainstcancer.ca
www.cancerview.ca
1.877.360.1665

*Colorectal Cancer Association of Canada*
www.colorectal-cancer.ca
1.877.50COLON (26566)

*National Cancer Institute*
Colon Cancer Information
www.cancer.gov/cancertopics/pdq/treatment/colon/Patient

Rectal Cancer Information
www.cancer.gov/cancertopics/pdq/treatment/rectal/Patient

*American Society of Colon and Rectal Surgery*
www.fascrs.org
847.290.9184

My Important Contacts

Surgeon
Name
Phone
Address
Notes

Family Doctor
Name
Phone
Address
Notes

Resources

*BC Cancer Agency*
www.bccancer.bc.ca

*Canadian Cancer Society*
www.cancer.ca
1.888.939.3333

*Canadian Partnership Against Cancer*
www.partnershipagainstcancer.ca
www.cancerview.ca
1.877.360.1665

*Colorectal Cancer Association of Canada*
www.colorectal-cancer.ca
1.877.50COLON (26566)

*National Cancer Institute*
Colon Cancer Information
www.cancer.gov/cancertopics/pdq/treatment/colon/Patient

Rectal Cancer Information
www.cancer.gov/cancertopics/pdq/treatment/rectal/Patient

*American Society of Colon and Rectal Surgery*
www.fascrs.org
847.290.9184