

MODULE 1: Learn About Recurrence and Follow-up

THIS DECISION AID IS FOR MEN AND WOMEN WHO HAD SURGERY for their colorectal cancer and are starting or continuing follow-up care.

The purpose of this decision aid is to help patients make informed decisions about their follow-up care. The information in this decision aid will prepare you to talk with your doctor about what is important to you in planning your follow-up care and what you would like considered or prioritized during follow-up care.

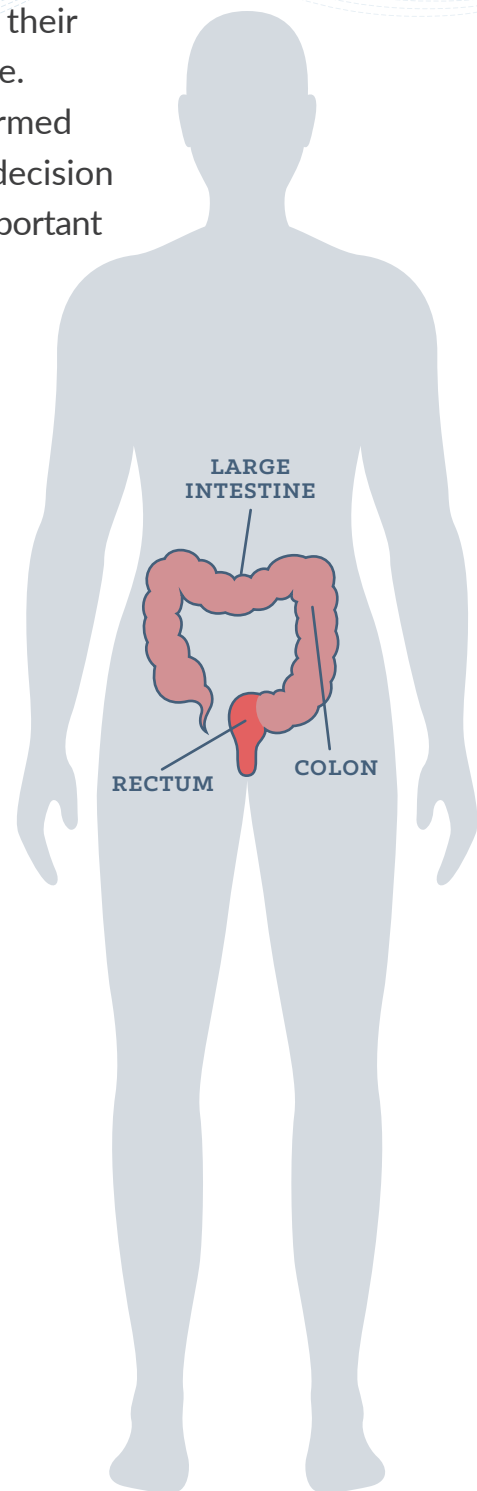
After reading this decision aid, you will learn about:

- » What is colorectal cancer recurrence
- » What is follow-up after surgery for colorectal cancer
- » What are the potential benefits and harms of follow-up after surgery for colorectal cancer
- » What are the types of treatment options if the colorectal cancer comes back

What is colorectal cancer?

Colorectal cancer or “colon cancer” is a type of cancer that starts in the colon or rectum. The colon and rectum are parts of the large intestine and are involved in digesting food. The colon makes up the first 4-6 feet of the large intestine and helps the body absorb water and breaks down body waste (called stool). Stool leaves the colon and moves into the rectum or the final 6 inches of the large intestine, where it is stored until it passes out of the body through the anus.

Colorectal cancer occurs when cells in the lining of the colon or rectum grow abnormally. Most colorectal cancers are *adenocarcinomas*, a type of cancer that forms in the cells that line the glands of the colon. There are other types of cancers that can develop within the colon and rectum but they are less common.



Follow-up Care

What is follow-up care for colorectal cancer?

The main purpose of follow-up care is to watch for signs of a cancer that comes back after treatment, this is called a cancer recurrence. Follow-up care can also find signs of a new cancer.

Follow-up care is also meant to help patients plan and maintain a healthy lifestyle, manage side effects from treatment, provide emotional support, and plan for future care.

How are follow-up schedules planned?



A person's individual risk of recurrence and overall health is used to decide what is included in follow-up and how often. Follow-up usually lasts for five years after surgery for colorectal cancer.

The risk of colorectal cancer recurrence is often determined by the stage and grade of the colon or rectal cancer. Talk with your doctor about your personal risk of recurrence and what you would like considered in your follow-up care plan. Knowing this information helps your health care team develop a follow-up care plan that is right for you.

What to expect during a follow-up visit?

Follow-up care begins after completing treatment for colorectal cancer and consists of routine office visits that may also include tests to look for signs of cancer recurrence. The frequency and types of tests included in a follow-up care plan are based on a person's individual risk of recurrence, their overall health and preferences for testing.

Although guidelines exist, there is disagreement about how often these exams should be performed once a person has completed their treatment for colorectal cancer.

During your follow-up visit, your doctor may recommend one or more of the tests below:



HISTORY AND PHYSICAL EXAM

During a routine follow-up visit, your doctor will review your medical history and perform a physical exam. Office visits are scheduled every three to 12 months for three to five years.



BLOOD TEST

A blood test is used to look for signs of cancer recurrence. This blood test is called a carcinoembryonic antigen (CEA) test. The CEA level is usually obtained at each office visit. Your doctor will watch for changes in your CEA level.

Imaging Tests

Imaging Tests are normally performed once a year for patients with stage 2 or 3 colorectal cancer. The goal of imaging tests is to detect some recurrent cancers before symptoms develop.

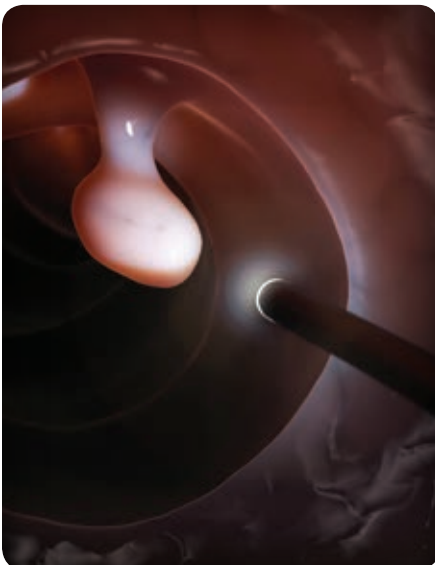
A CT (COMPUTED TOMOGRAPHY) SCAN is the most common imaging test used in follow-up care. A CT is an x-ray test that takes detailed pictures of your body. It usually requires drinking a liquid contrast solution, an i.v. for intravenous contrast, and sometimes a rectal tube for rectal contrast.

PET/CT (POSITRON EMISSION TOMOGRAPHY-CT) SCAN scans are used when there is a need for further evaluation of an abnormal finding from one of the other imaging tests. The main difference between PET scans and other imaging tests is that the PET scan takes pictures of the amount of sugar that is being used by an organ or tissue in your body. It is typically combined with a form of CT scan in order to aid in the interpretation of the images. PET scans are not typically used for routine follow-up because of low sensitivity for detecting small lesions. During a PET scan, you are injected with a slightly radioactive form of sugar called a radiotracer but the amount of radiation you are exposed to is low.



AN MRI (MAGNETIC RESONANCE IMAGING) SCAN uses strong magnets and radio waves to take detailed pictures of the body to look for recurrence in the abdomen or pelvis. The MRI test usually requires holding still for some period of time in an enclosed room during the exam. An MRI can be performed in place of a CT scan if a patient has allergies to the liquid contrast solution or in order to avoid radiation.

Colonoscopy



A colonoscopy can find a local cancer recurrence or a second colorectal cancer and can also prevent new colorectal cancers by removing polyps as they develop. This test requires you to drink a laxative solution to completely empty your bowels before the examination. It also typically requires an i.v. that will be used to give you medications to sedate you.

Colonoscopy is usually performed one year after the original diagnosis of colorectal cancer to check for polyps that may have been overlooked during the first procedure and to examine the surgical area for recurrence. After this initial procedure, colonoscopies are usually performed every three to ten years. Your doctor decides the frequency based upon your age, history of polyps, or other risk factors for cancer coming back or a new colorectal cancer developing.

Potential Harms/Concerns of Follow-up Testing

While follow-up testing is used to monitor for a cancer recurrence, there are also some possible harms. Your medical team will discuss concerns about follow-up tests with you in detail, write down any questions or concerns you have about follow-up testing and bring these notes with you to your next appointment.

FALSE ALARMS

Follow-up testing may show something that is concerning for recurrent cancer but turns out to be normal. However this can result in the need for invasive testing such as biopsies that were not needed. During a biopsy, a piece (or pieces) of tissue is removed to test for cancer. It may also take several months to sort out if an abnormal finding is associated with recurrent cancer or not.

CONTRAST TOXICITY

The intravenous dye that is used with certain imaging tests can result in rare but serious side effects. Over time, some patients may develop a serious allergic reaction to the intravenous dye and some may develop contrast-induced kidney injury but these events are rare.

COMPLICATIONS

Invasive procedures such as a biopsy are associated with a risk for complications. There is a small chance that the colon may be punctured during a colonoscopy. This can happen when the scope ruptures the wall of the colon during the procedure.

RADIATION EXPOSURE

Imaging tests that are used in follow-up care exposes a person to radiation, which may increase the risk for developing another cancer. The amount of radiation exposure varies between types of imaging tests. For example, a CT scan of the chest, abdomen and pelvis will expose a person to an amount of radiation that is similar to natural background radiation exposure over five years. A PET/CT scan will expose a person to an amount of radiation that is comparable to natural background radiation exposure over eight years.

What else should patients discuss with their doctor about their follow-up care?

These visits are an important time to talk openly with your doctor about any questions or concerns you have about your follow-up care. You and your doctor may discuss any of the following:

- » Your personal risk of recurrence or the chances of developing another type of cancer
- » Why and how often follow-up tests are conducted
- » Personal goals and expectations of follow-up care
- » Managing long-term treatment side-effects
- » How to cope with fear of recurrence and ways of managing your stress
- » Healthy lifestyle changes that may help improve your overall health
- » Information or additional resources such as support groups that might enhance follow-up care



Understanding Recurrence

What is recurrence?

Most patients will be cured by the initial treatment and will not develop recurrence. A recurrence is when the original colorectal cancer comes back. A recurrence happens when some cancer cells from the original colorectal cancer remain in the body after treatment and grow into tumors in the area of the original cancer or elsewhere in the body. These cells were present before your surgery to remove your cancer but could not be detected by tests or caused any health problems.

A cancer recurrence is most likely to happen within the first two to three years after the original diagnosis and treatment. It is very uncommon to develop a recurrence after five years from the original diagnosis and treatment.

Different people have different risks of recurrence, talk with your doctor about your personal risk of the cancer returning. Recurrent cancer does not mean that you have a new type of cancer. When a new type of cancer happens, it is called a second primary cancer.



WHAT ARE THE SYMPTOMS OF RECURRENCE?

Some people with recurrent cancer don't experience symptoms. Tell your doctor if you experience any of the following:

- » Changes in your bowel habits that can include more frequent stools or difficulty passing your stool
- » Loose or watery stools
- » Blood in your stool or very dark stools
- » New onset constipation
- » Loss of appetite
- » New persistent stomach pain that includes gas pains, cramps, or feeling bloated or full
- » Losing weight without trying
- » Constant fatigue or lack of energy

ARE THERE WAYS OF REDUCING THE RISK OF RECURRENCE?

There is no guarantee that your cancer will not come back, but there are lifestyle choices that will help to keep you healthy. Such as:



Eat more fruits, vegetables and whole grains



Reduce the amount of red and processed meats from your diet



Limit or avoid excessive alcohol consumption



Increase physical activity and maintain a regular exercise routine



Maintain a healthy weight



Quit smoking



Talk to your doctor about making healthy lifestyle choices.

Treatment Options for Recurrence

If testing shows that colorectal cancer has returned, your doctor will talk with you about treatment options. This is an individual decision that should be made with your doctor. Some patients may choose not to have treatment and some patients may not be eligible for treatment. In general, treatment for recurrent cancer is more difficult than treatment for the primary cancer.

Possible treatment options for recurrence include surgery, chemotherapy, or radiation. Chemotherapy is the most common treatment for recurrent colorectal cancer.

CHEMOTHERAPY has been shown to extend life for some patients. It is an option for patients who are not willing or unable to undergo surgery but can be associated with side effects that can affect quality of life.

RADIATION THERAPY may be an option for some patients and is typically used to treat pain associated with cancer recurrence.

SURGERY may be possible to remove the recurrent cancer. About 1 in 5 patients who develop recurrence will have the option of undergoing surgery (e.g. liver surgery or lung surgery) to remove the recurrent tumor. Surgery is the only treatment that can completely remove the recurrent cancer, but does not eliminate the risk for developing another recurrence.

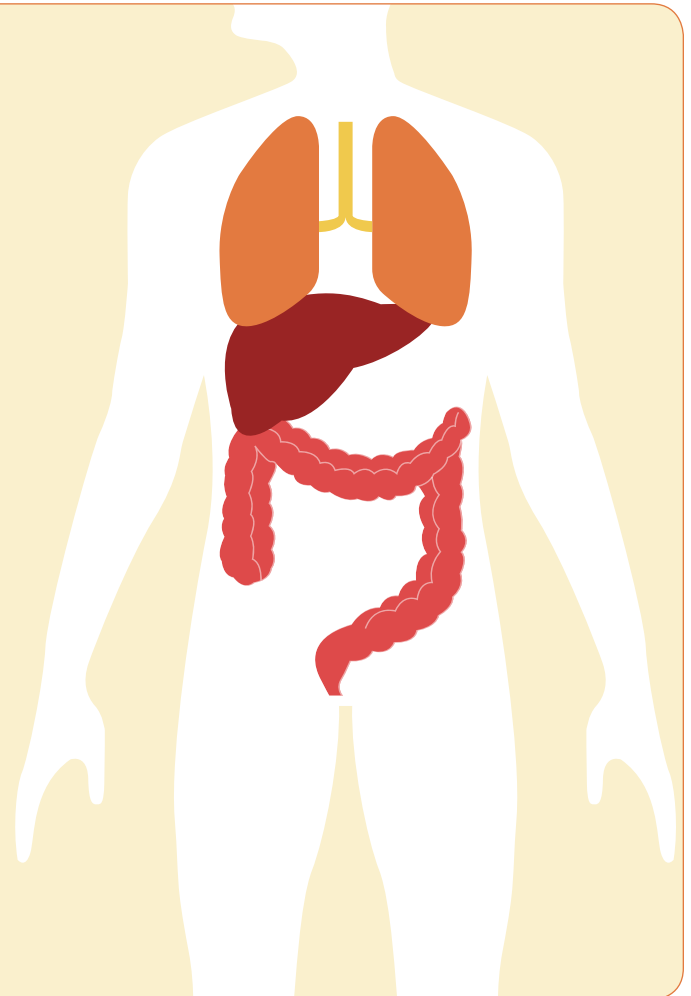
Types of recurrence

The different types of recurrent cancer are:

LOCAL RECURRENCE: the cancer has recurred in the same place as the original cancer.

REGIONAL RECURRENCE: the cancer has recurred in lymph nodes or areas of the body close to the original cancer site.

DISTANT RECURRENCE: cells from the original cancer grew and spread to a distant place in the body. For patients with colon cancer, a distant recurrence is most likely to happen in the liver, followed by the lungs. For patients with rectal cancer, a distant recurrence is most likely to happen in the lungs, followed by the liver. Other less common sites of a distant recurrence are in the lining of the abdominal cavity (also known as the peritoneum), ovaries, and distant lymph nodes.



Coping with fear of recurrence

While there is no guarantee that your cancer will not return, there are steps you can take that will help you feel more in control of how much the fear of recurrence affects your life.

TALK TO YOUR DOCTOR OR HEALTH CARE TEAM. Talk openly with your healthcare team about your concerns, it is entirely normal to feel worried that the cancer will come back. Your healthcare team can answer any questions or concerns that you have about your personal risk of cancer recurrence. Different people have different risks of cancer recurrence, your healthcare team is there to support you through this process and can provide you with information about your personal risk of recurrence. Your risk of recurrence is the highest during the first 3 years after treatment but goes down with time.



TALK TO A COUNSELOR. If you feel overwhelmed by thoughts of your cancer returning, ask your healthcare team for a referral to a counselor or a support group. Having someone to talk to can help ease your worries about your cancer returning. It is important to remind yourself that you are not alone and that having these fears about cancer returning is very normal. After treatment, most people experience these emotions but it's important to know that these fears tend to lessen over time.

KEEP A DAILY JOURNAL. At the end of each day, take notes about any worries or fears that might have gone through your mind throughout the day. In preparation for your next follow-up appointment, write down any questions you may have and be sure to bring your notes to the next appointment.

