

ASCO<sup>®</sup>answers

# Colorectal Cancer



**Trusted Information to Help Manage Your Care from the  
American Society of Clinical Oncology**

**Cancer.Net<sup>™</sup>**

Doctor-Approved Patient Information from ASCO<sup>®</sup>



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ASCO furthers its mission through Cancer.Net and Conquer Cancer, the ASCO Foundation.

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**Conquer Cancer, the ASCO Foundation (www.conquer.org)**, funds research for every cancer, every patient, everywhere. As ASCO's foundation, Conquer Cancer supports groundbreaking research and education so both doctors and patients have the resources they need.

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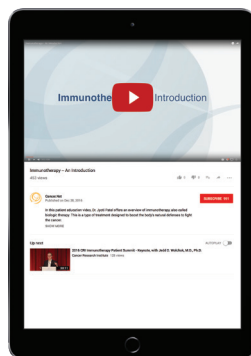
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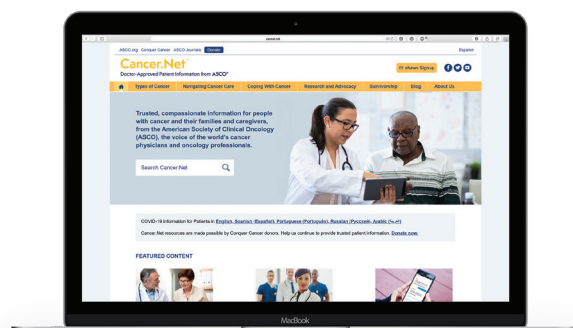
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# Introduction

It is one of many people's biggest fears—sitting in the doctor's office and hearing the word "cancer." People diagnosed with colorectal cancer often say they were stunned by their diagnosis and couldn't hear, much less remember, what was said afterward. However, absorbing the news of a cancer diagnosis is a key part of the coping process.

In the weeks to come, you may find it helpful to have family members or friends come to your appointments with you. They will not only give you some much-needed support, but they can also help listen to and remember the information your health care team gives you. Using this *ASCO Answers* guide may also be helpful. It was designed to explain some of the medical terms doctors may use when talking about your cancer and help you keep track of the specifics of your colorectal cancer diagnosis and treatment plan. Throughout this guide, you will find questions to ask your doctor, nurse, or another member of your health care team, as well as plenty of space to write down their answers or other important information. There are also checkboxes you can use to identify the tests, procedures, and treatments that will make up your cancer care plan.

However you choose to accurately keep track of this information, it is important to do so. Getting the facts about your diagnosis will help you make the best decisions based on your situation in the coming days. Additionally, being an informed, involved patient and voicing your questions and concerns will help you and your health care team form a partnership in your care. Tell your doctor and nurse how you prefer to receive information and how much you want to know about your diagnosis, treatment, and prognosis, which is the chance of recovery. Don't be afraid to ask questions or to let your health care team know you don't know what questions to ask.





# Colorectal Cancer Basics

Colorectal cancer begins when healthy cells in the lining of the colon or rectum change and grow out of control, forming a mass called a tumor. A tumor can be cancerous or benign. A cancerous tumor is malignant, meaning it can grow and spread to other parts of the body. A benign tumor means the tumor can grow but will not spread. These changes usually take years to develop. Both genetic and environmental factors can cause the changes. However, when a person has an uncommon inherited syndrome, changes can occur within months to years.



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**Colorectal cancer usually begins as a polyp that may develop on the inner wall of the colon or rectum as people get older.**

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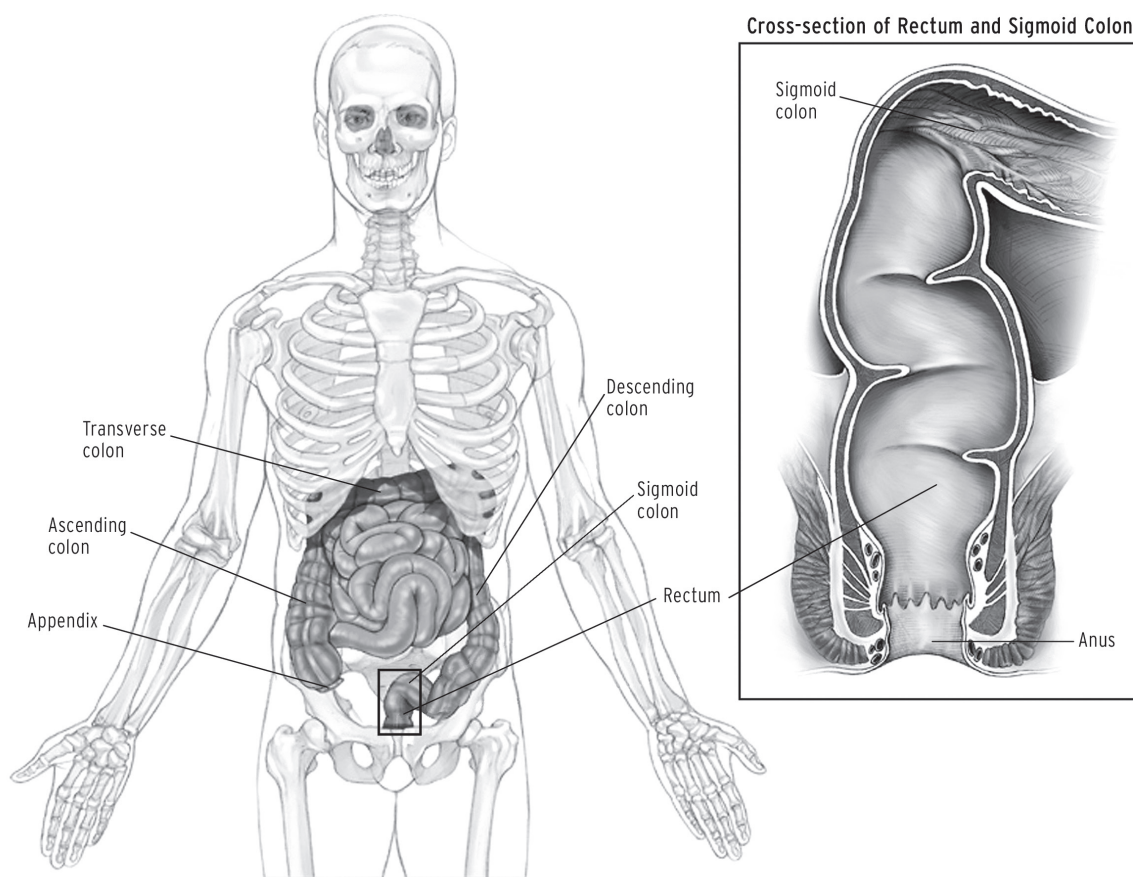
## **Anatomy of the colon and rectum**

The colon and rectum make up the large intestine, which plays an important role in the body's ability to process waste. The colon makes up the first 5 to 6 feet of the large intestine, and the rectum makes up the last 6 inches, ending at the anus.

The colon and rectum have 5 sections. The ascending colon is the portion that extends from a pouch called the cecum to the portion of the colon that is near the liver. The cecum is the beginning of the large intestine into which the small intestine empties; it's on the right side of the abdomen. The transverse colon crosses the top of the abdomen. The descending colon takes waste down the left side. Finally, the sigmoid colon at the bottom takes waste a few more inches, down to the rectum. Waste leaves the body through the anus.



ILLUSTRATION BY ROBERT MORREALE/VISUAL EXPLANATIONS, LLC.  
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Medical illustrations for many types of cancer are available at [www.cancer.net](http://www.cancer.net).

## About colorectal polyps

Colorectal cancer usually begins as a polyp, a noncancerous growth that may develop on the inner wall of the colon or rectum as people get older. If not treated or removed, a polyp can become a potentially life-threatening cancer. Finding and removing precancerous polyps can prevent colorectal cancer.

There are several forms of polyps. Adenomatous polyps, or adenomas, are growths that may become cancerous. They can be found with a colonoscopy. Polyps are most easily found during a colonoscopy because they usually bulge into the colon, forming a mound on the wall of the colon that can be found by the doctor.

About 10% of colon polyps are flat and hard to find with a colonoscopy unless a dye is used to highlight them. These flat polyps have a high risk of becoming cancerous, regardless of their size.

Hyperplastic polyps may also develop in the colon and rectum. They are not considered precancerous.



## Types of colorectal cancer

Colorectal cancer can begin in either the colon or the rectum. Cancer that begins in the colon is called colon cancer. Cancer that begins in the rectum is called rectal cancer.

Most colon and rectal cancers are a type of tumor called adenocarcinoma, which is cancer of the cells that line the inside tissue of the colon and rectum. This guide specifically covers adenocarcinoma. Other types of cancer that occur far less often but can begin in the colon or rectum include a neuroendocrine or carcinoid tumor, gastrointestinal stromal tumor (GIST), small cell carcinoma, and lymphoma. Learn about these kinds of cancer at [www.cancer.net/types](http://www.cancer.net/types).

## Colorectal cancer genetics

The cause of colorectal cancer is not known, but certain factors appear to increase the risk of developing the disease. One of these factors is genetic mutations, or changes, that can be passed from parents to their children.

Colorectal cancer is more likely to develop in a person who has had a parent, sibling, or child with colorectal cancer, particularly if the family member was diagnosed with colorectal cancer before age 60. Members of families with certain uncommon inherited conditions also have a significantly increased risk of developing colorectal cancer. These include familial adenomatous polyposis (FAP), attenuated familial adenomatous polyposis (AFAP), Gardner syndrome, Lynch syndrome, juvenile polyposis syndrome (JPS), Muir-Torre syndrome, MYH-associated polyposis (MAP), Peutz-Jeghers syndrome (PJS), and Turcot syndrome. Relatives of women with ovarian or uterine cancer may also have a higher risk.

Only genetic testing can determine whether a person has a genetic mutation; however, these tests are not recommended for everyone. Most experts strongly recommend that people who are considering genetic testing first talk with a genetic counselor. A genetic counselor is an expert trained to explain the risks and benefits of genetic testing.



### QUESTIONS TO ASK THE HEALTH CARE TEAM

- ▶ Who will be part of my health care team, and what will each member do?
- ▶ If I have a family history of colorectal cancer, should I see a genetic counselor? Should my family members?
- ▶ Where can I find more information about colorectal cancer?
- ▶ Does this hospital or cancer center have a learning resource center? If so, where is it located?
- ▶ If I have a question or problem, who should I call?



# Understanding Your Diagnosis

Doctors use many tests to find, or diagnose, cancer. They also do tests to learn if cancer has spread to another part of the body from where it started. If this happens, it is called metastasis. For example, imaging tests can show if the cancer has spread. Imaging tests show pictures of the inside of the body. Doctors may also do tests to learn which treatments could work best.

For most types of cancer, a biopsy is the only sure way for the doctor to know whether an area of the body has cancer. In a biopsy, the doctor takes a small sample of tissue for testing in a laboratory. If a biopsy is not possible, the doctor may suggest other tests that will help make a diagnosis.

Not every test is right for every person. Your doctor may consider factors such as your age, medical condition, signs and symptoms, and previous test results when deciding whether a specific diagnostic test is right for you. Talk with your doctor about the test(s) that will provide the most useful information about your condition.

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**Doctors use many different tests to diagnose cancer and find out if it has spread.**

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## Tests and procedures

### □ Colonoscopy

This procedure allows the doctor to look inside the entire rectum and colon while a patient is sedated. A flexible, lighted tube called a colonoscope is inserted into the rectum and the entire colon to look for polyps or cancer. During this procedure, a doctor can remove polyps or other tissue for further examination. If colorectal cancer is found, a complete diagnosis that accurately describes the location and spread of the cancer may not be possible until the tumor is surgically removed.

### □ Biopsy

A biopsy is the removal of a small amount of tissue for examination under a microscope. Other tests can suggest that cancer is present, but only a biopsy can make a definite diagnosis of colorectal cancer. A pathologist then analyzes the sample(s). A pathologist is a doctor who specializes in interpreting laboratory tests and evaluating cells, tissues, and organs to diagnose disease. A biopsy may be performed during



a colonoscopy, or it may be done on any tissue removed during surgery. Sometimes, a computed tomography (CT) scan or ultrasound is used to help perform a needle biopsy. A needle biopsy removes tissue through the skin with a needle that is guided into the tumor.

### ❑ Molecular testing of the tumor

Your doctor may recommend running laboratory tests on a tumor sample to identify specific genes, proteins, and other factors unique to the tumor. If you have metastatic or recurrent colorectal cancer, a sample of tissue from the area where it spread or came back is preferred for testing, if possible. Results of these tests will help decide whether your treatment options should include a type of treatment called targeted therapy.

### ❑ Blood tests

Because colorectal cancer often bleeds into the large intestine or rectum, people with the disease may have an abnormally low level of red blood cells and become anemic. As a result, a complete blood count (CBC) can indicate whether bleeding may be occurring.

Another blood test detects the levels of a protein called carcinoembryonic antigen (CEA). High levels of CEA may indicate that cancer has spread to other parts of the body. CEA is not a perfect test for colorectal cancer because levels are high for only about 60% of people with colorectal cancer that has spread to other organs. In addition, other medical conditions can cause CEA to increase. A CEA test is most often used to monitor colorectal cancer for patients who are already receiving treatment. It is not useful as a screening test.

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## ■ Imaging tests

### ❑ CT scan

A CT scan creates a 3-dimensional picture of the inside of the body using x-rays taken from different angles. A computer combines these images into a detailed, cross-sectional view that shows any abnormalities or tumors. For a person with colon cancer, a CT scan can check to see whether the cancer has spread to the lungs, liver, or other organs. It is often done before surgery. A CT scan can also be used to measure a tumor's size. Sometimes, a special dye called a contrast medium is given before the scan to provide better detail on the image. This dye can be injected into a patient's vein or given as a pill to swallow.

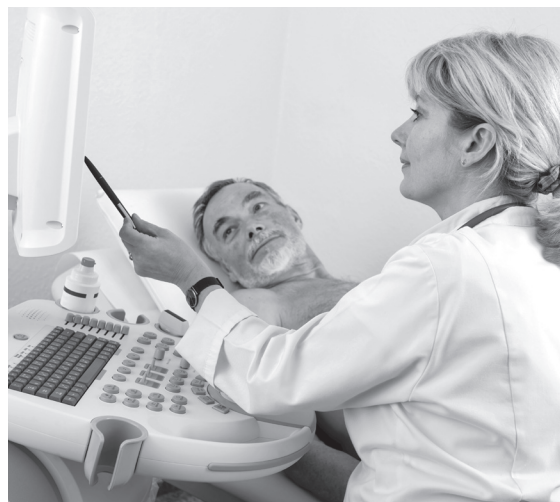


## ❑ Magnetic resonance imaging (MRI)

An MRI uses magnetic fields, not x-rays, to produce detailed images of the body. A special dye called a contrast medium is given before the scan to create a clearer picture. This dye can be injected into a patient's vein or given as a pill to swallow. An MRI is the best imaging test to find out where colorectal cancer has grown. An MRI can also be used to measure the tumor's size.

## ❑ Ultrasound

An ultrasound uses sound waves to create a picture of the internal organs to find out if cancer has spread. Endorectal ultrasound is commonly used to find out how deeply rectal cancer has grown and can be used to help plan treatment. During an endorectal ultrasound, a probe is inserted into the rectum. However, it cannot accurately detect cancer that has spread to nearby lymph nodes or beyond the pelvis. A traditional ultrasound may be used to view the liver, although CT scans or MRIs are preferred because they are better at finding tumors in the liver.



## ❑ Chest x-ray

An x-ray is a way to create a picture of structures inside the body, using a small amount of radiation. An x-ray of the chest helps doctors find out whether the cancer has spread to the lungs.

## ❑ Positron emission tomography (PET) scan or PET-CT scan

A PET scan is usually combined with a CT scan, called a PET-CT scan. However, you may hear your doctor refer to this procedure just as a PET scan. A PET scan is a way to create pictures of organs and tissues inside the body. A small amount of a radioactive sugar substance is injected into a patient's body. This sugar substance is taken up by cells that use the most energy. Because cancer tends to use energy actively, it absorbs more of the radioactive substance. A scanner then detects this substance to produce images of the inside of the body. PET scans are not regularly used for all patients with colorectal cancer, but there are specific situations in which your doctor may find them useful.



Learn more about what to expect when having common tests, procedures, and scans at [www.cancer.net/tests](http://www.cancer.net/tests).



## ■ Stages

People with colorectal cancer are often given a stage along with their diagnosis. The stage is a way of describing how deep the cancer has grown into the colon or rectal wall (T); if the cancer has spread to nearby lymph nodes and, if so, how many (N); and whether the cancer has spread to other parts of the body (M). Doctors use diagnostic tests to find out a cancer's stage, so staging may not be complete until all of the tests are finished. Knowing the stage will help your doctor decide which treatment plan will be most effective and can help predict your prognosis.

Doctors assign the stage of the cancer by combining the T, N, and M. The stage is then described using a number zero (0) through 4 (Roman numerals I through IV) and often a letter, such as A, B, or C. The stages of colorectal cancer are:

**Stage 0.** This is called cancer in situ. The cancer cells are only in the mucosa, or the inner lining, of the colon or rectum.

**Stage I.** The cancer has grown through the mucosa and has invaded the muscular layer of the colon or rectum. It has not spread to nearby tissue or lymph nodes.

**Stage IIA.** The cancer has grown through the wall of the colon or rectum and has not spread to nearby tissue or to the nearby lymph nodes.

**Stage IIB.** The cancer has grown through the layers of the muscle to the lining of the abdomen, called the visceral peritoneum. It has not spread to nearby lymph nodes or anywhere else in the body.

**Stage IIC.** The tumor has spread through the wall of the colon or rectum and has grown into nearby structures. It has not spread to nearby lymph nodes or anywhere else in the body.

**Stage IIIA.** The cancer has grown through the inner lining or into the muscle layers of the intestine. It has spread to 1 to 3 lymph nodes or to a nodule of tumor cells in tissues around the colon or rectum that do not appear to be lymph nodes. The cancer has not spread to other parts of the body.

**Stage IIIB.** The cancer has grown through the bowel wall or into surrounding organs. It has spread to 1 to 3 lymph nodes or to a nodule of tumor cells in tissues around the colon or rectum that do not appear to be lymph nodes. However, the cancer has not spread to other parts of the body.

**Stage IIIC.** The cancer of the colon, regardless of how deep it has grown, has spread to 4 or more lymph nodes but not to distant parts of the body.



**Stage IVA.** The cancer has spread to a single distant part of the body, such as the liver or lungs.

**Stage IVB.** The cancer has spread to more than 1 distant part of the body.

**Stage IVC.** The cancer has spread to the peritoneum. It may also have spread to other sites or organs.

**Recurrent.** The cancer has come back after treatment. The disease may be found in the colon, rectum, or in another part of the body. If the cancer does return, there will be another round of tests to learn about the extent of the recurrence. These tests and scans are often the same as those done at the time of the original diagnosis.

*Used with permission of the American College of Surgeons, Chicago, Illinois. The original and primary source for this information is the AJCC Cancer Staging Manual, Eighth Edition (2017), published by Springer International Publishing.*

## Grades

Doctors may also use the term “grade” when talking about colorectal cancer. The grade describes how much cancer cells look like healthy cells when viewed under a microscope. The grade of colorectal cancer may help your doctor predict how quickly the cancer will spread. If the cancer looks similar to healthy tissue and contains different cell groupings, it is called differentiated or a low-grade tumor. If the cancerous tissues look very different from healthy tissue, it is called poorly differentiated or a high-grade tumor. In general, the lower the tumor’s grade, the better the prognosis.



### QUESTIONS TO ASK THE HEALTH CARE TEAM ABOUT YOUR DIAGNOSIS

- ▶ Where is the cancer located?
- ▶ What stage and grade is the cancer? What does this mean?
- ▶ What other diagnostic tests or procedures may be necessary?
- ▶ How can I prepare myself for each test or procedure?
- ▶ Where do I need to go to have these tests?
- ▶ When will I get the results? How will I get the results (over the phone, at the next appointment, etc.)?
- ▶ Who will explain these results to me?
- ▶ Should I see another doctor for a second opinion? Can you give me names of doctors I could see?
- ▶ If I get a second opinion, will I have to repeat any tests or procedures?
- ▶ What is my prognosis?



# Colorectal Cancer Treatment

In cancer care, doctors with different specialties often work together to create an overall treatment plan that combines different types of treatments. For colorectal cancer, this team usually includes a gastroenterologist, which is a doctor who specializes in the function and disorders of the gastrointestinal tract, as well as a surgeon, medical oncologist, and radiation oncologist. Cancer care teams include a variety of other health care professionals, such as physician assistants, nurse practitioners, oncology nurses, social workers, pharmacists, counselors, dietitians, and others.



Your treatment options will depend on several factors, including the type and stage of cancer, possible side effects, and your preferences and overall health. Your care plan may also include treatment for symptoms and side effects, an important part of cancer care.

When making treatment decisions, you are also encouraged to consider participating in a clinical trial. A clinical trial is a research study that tests whether a new approach to treatment is safe, effective, and possibly better than the standard treatment.

Before treatment begins, it is important to discuss the goals and possible side effects of your treatment plan with your doctor, including the likelihood that the treatment will work and its potential effect on your quality of life. To start a conversation with your doctor, you may want to ask:

- ▶ What are my treatment options?
- ▶ Will I need more than 1 type of treatment?
- ▶ Based on the results of molecular testing, do you recommend targeted therapy? Why or why not?
- ▶ What treatment plan do you recommend for me? Why?
- ▶ What are the possible short-term and long-term side effects of each treatment? How can they be managed?
- ▶ What is the goal of the treatment(s) you are recommending? Is it to eliminate the cancer? To relieve my symptoms? Or both?
- ▶ What is the expected timeline for my treatment plan?
- ▶ When do I need to make a decision about starting treatment?





## **Surgery**

Surgery is the removal of the tumor and surrounding healthy tissue during an operation. This is the most common treatment for colorectal cancer and is often called surgical resection. Part of the healthy colon or rectum and nearby lymph nodes are also removed. Although both general surgeons and specialists may perform colorectal surgery, many people talk with specialists who have additional training and experience in colorectal surgery. A colorectal surgeon is a doctor who has received additional training to treat diseases of the colon, rectum, and anus. Colorectal surgeons used to be called proctologists.

In addition to surgical resection, surgical options for colorectal cancer include:

- ❑ **Laparoscopic surgery.** Some patients may be able to have laparoscopic colorectal cancer surgery. With this technique, several viewing scopes are passed into the abdomen while a patient is under anesthesia. Anesthesia is medicine that blocks the awareness of pain. The incisions are smaller and the recovery time is often shorter than with standard colon surgery. Laparoscopic surgery is as effective as conventional colon surgery in removing the cancer. Surgeons who perform laparoscopic surgery have been specially trained in that technique. There are other less invasive methods, like robotic surgery, that can be used in some cases by surgeons with specialized expertise.
- ❑ **Colostomy for rectal cancer.** Occasionally, a person with rectal cancer may need to have a colostomy. This is a surgical opening, or stoma, that connects the colon to the



abdominal surface so waste can exit the body. This waste is collected in a pouch worn by the patient. Sometimes, the colostomy is only temporary to allow the rectum to heal, but it may be permanent. With modern surgical techniques and the use of radiation therapy and chemotherapy before surgery, when needed, many people who receive treatment for rectal cancer do not need a permanent colostomy.

- ❑ **Radiofrequency ablation (RFA) or cryoablation.** Some patients may be able to have surgery on the liver or lungs to remove tumors that have spread to those organs. Other ways include using energy in the form of radiofrequency waves to heat the tumors, called RFA, or to freeze the tumor, called cryoablation. Not all liver or lung tumors can be treated with these approaches. RFA can be done through the skin or during surgery. While this can help avoid removing parts of the liver and lung tissue that might be removed in a regular surgery, there is also a chance that parts of a tumor will be left behind.

### Side effects of surgery

In general, the side effects of surgery include pain and tenderness in the area of the operation. The operation may also cause constipation or diarrhea, which usually goes away after a while. People who have a colostomy may have irritation around the stoma. A doctor, nurse, or specialist in colostomy management, called an enterostomal therapist, can teach a person how to clean the area and prevent infection.

Many people need to retrain their bowel after surgery, which may take some time and assistance. People should talk with their doctor if they do not regain good control of bowel function.



### QUESTIONS TO ASK THE HEALTH CARE TEAM ABOUT SURGERY

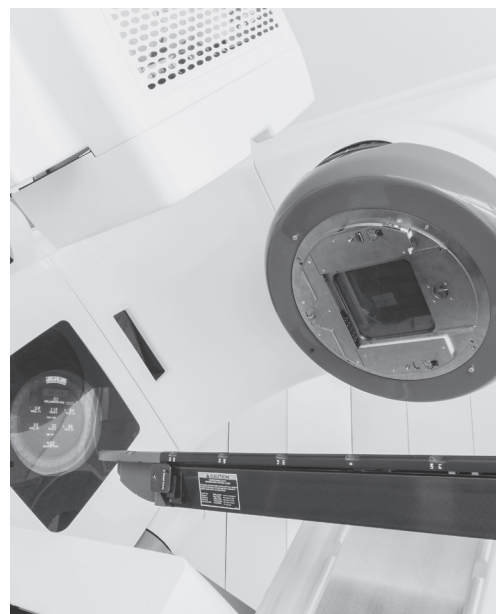
- ▶ Which type of surgery do you recommend? Why?
- ▶ What is the goal of this surgery?
- ▶ Will lymph nodes or any other tissue need to be removed?
- ▶ Will I need to be admitted to a hospital for this operation? If so, how long will I need to stay in the hospital?
- ▶ Will my tumor be stored? Where will it be stored? For how long? How can it be accessed in the future?
- ▶ Will I need to have a colostomy? If so, for how long?
- ▶ Will I have difficulty controlling my bowel function after surgery? If so, how will this side effect be managed?
- ▶ What kind of pain should I expect to feel after surgery? What can be done to manage this pain?
- ▶ What will my recovery from this type of surgery be like?



## Radiation therapy

Radiation therapy is the use of high-energy x-rays to destroy cancer cells. Radiation therapy is commonly used for treating rectal cancer because this type of tumor tends to come back near where it first started. A doctor who specializes in giving radiation therapy to treat cancer is called a radiation oncologist. A radiation therapy regimen, or schedule, usually consists of a specific number of treatments given over a set period of time.

- ❑ **External-beam radiation therapy.** External-beam radiation therapy uses a machine to deliver x-rays to where the cancer is located. Radiation treatment is usually given 5 days a week for several weeks and may be given in a doctor's office or at a hospital.



- ❑ **Stereotactic radiation therapy.** Stereotactic radiation therapy is a type of external-beam radiation therapy that may be used if a tumor has spread to the liver or lungs. This type of radiation therapy delivers a large, precise radiation dose to a small area. This technique can help save liver and lung tissue that might otherwise be removed during surgery. However, not all cancers that have spread to the liver or lungs can be treated in this way.

### Other types of radiation therapy

For some people, specialized radiation therapy techniques, such as intraoperative radiation therapy or brachytherapy, may help get rid of small areas of the tumor that could not be removed with surgery.

- ❑ **Intraoperative radiation therapy.** Intraoperative radiation therapy uses a single, high dose of radiation therapy given during surgery.
- ❑ **Brachytherapy.** Brachytherapy is the use of radioactive “seeds” placed inside the body. In 1 type of brachytherapy, tiny amounts of a radioactive substance called yttrium-90 are injected into the liver to treat colorectal cancer that has spread to the liver when surgery is not an option. Some studies suggest that this treatment may help slow the growth of cancer cells.



## Radiation therapy for rectal cancer

For rectal cancer, radiation therapy may be used before surgery, called neoadjuvant therapy, to shrink the tumor so it is easier to remove.

Radiation therapy can also be used after surgery, called adjuvant therapy, to destroy any remaining cancer cells. Chemotherapy is often given at the same time as radiation therapy, called chemoradiation therapy, to increase its effectiveness. Chemoradiation therapy is often used for rectal cancer before surgery to try to avoid a colostomy and decrease the chance that the cancer will recur.



## Side effects of radiation therapy

Side effects from radiation therapy may include fatigue, mild skin reactions, upset stomach, and loose bowel movements. It may also cause blockage of the bowel or bloody stools from bleeding through the rectum. Most side effects go away soon after treatment is finished. Long-term side effects, such as sexual problems and infertility (the inability to have or father a child) may occur after radiation therapy to the pelvis. Before treatment begins, talk with your doctor about the possible side effects and the available options for preventing and managing them.



### QUESTIONS TO ASK THE HEALTH CARE TEAM ABOUT RADIATION THERAPY

- ▶ Which type of radiation therapy do you recommend? Why?
- ▶ How often will my radiation treatments occur, and how long will I receive treatment?
- ▶ How much time will each treatment take?
- ▶ What will I experience when I receive radiation therapy? Will it hurt or cause me discomfort?
- ▶ What are the possible short-term and long-term side effects of this treatment? How will they be managed?



## Chemotherapy

Chemotherapy is the use of drugs to destroy cancer cells, usually by keeping the cancer cells from growing, dividing, and making more cells. Chemotherapy is usually given by a medical oncologist, a doctor who specializes in treating cancer with medication.

Systemic chemotherapy travels through the bloodstream to reach cancer cells throughout the body. Common ways to give chemotherapy include an intravenous (IV) tube placed into a vein using a needle or in a pill or capsule that is swallowed (orally).



A chemotherapy regimen, or schedule, usually consists of a specific number of cycles given over a set period of time. A patient may receive 1 drug at a time or a combination of different drugs at the same time.

Chemotherapy may be given after surgery to eliminate any remaining cancer cells. For some people with rectal cancer, the doctor will give chemotherapy and radiation therapy before surgery to reduce the size of a rectal tumor and reduce the chance of the cancer returning after treatment.

There are several common chemotherapy-based treatments and combinations for colorectal cancer. Your doctor may recommend 1 or more of them at different times during treatment:

- ☐ Fluorouracil (5-FU)
- ☐ Capecitabine (Xeloda), an oral form of 5-FU
- ☐ Irinotecan (Camptosar)
- ☐ Oxaliplatin (Eloxatin)
- ☐ Trifluridine/tipiracil (Lonsurf)
- ☐ 5-FU with leucovorin (folinic acid), a vitamin that improves the effectiveness of 5-FU
- ☐ Capecitabine, an oral form of 5-FU
- ☐ FOLFOX: 5-FU with leucovorin and oxaliplatin
- ☐ FOLFIRI: 5-FU with leucovorin and irinotecan
- ☐ XELIRI/CAPIRI: Capecitabine with irinotecan
- ☐ XELOX/CAPEOX: Capecitabine with oxaliplatin
- ☐ Any of the above with a targeted therapy (see page 18) of bevacizumab (Avastin), cetuximab (Erbix), or panitumumab (Vectibix)
- ☐ FOLFIRI with ziv-aflibercept (Zaltrap) or ramucirumab (Cyramza)



## Side effects of chemotherapy

Chemotherapy may cause vomiting, nausea, diarrhea, and mouth sores. However, medications to prevent or reduce these side effects are available. Because of the way drugs are given, these side effects are less severe than they have been in the past for most patients. In addition, patients may be unusually tired, and there is an increased risk of infection. Neuropathy, which is tingling, pain, or numbness in the feet or hands, may also occur with some drugs. Significant hair loss is an uncommon side effect of many of the drugs used to treat colorectal cancer, except irinotecan.

It is important to let your doctor know if you experience any of these or other side effects so that your symptoms can be managed. If side effects are particularly difficult, the dose of drug may be lowered or a treatment session may be postponed. Most chemotherapy side effects usually go away after treatment is finished.



### QUESTIONS TO ASK THE HEALTH CARE TEAM ABOUT CHEMOTHERAPY

- ▶ Which type of chemotherapy do you recommend? Why?
- ▶ How long will I need to have chemotherapy?
- ▶ How will the treatment be given?
- ▶ How will we know if it's working?
- ▶ How will chemotherapy affect my daily life? Will I be able to work, exercise, and perform my usual activities?
- ▶ What are the potential short-term and long-term side effects of each medication?
- ▶ Where can I get more information about the medication(s) I will be taking?
- ▶ If I am worried about the cost of treatment, who can help me?



## Targeted therapy

Targeted therapy is a treatment that targets the cancer's specific genes, proteins, or the tissue environment that contributes to cancer growth and survival. This type of treatment blocks the growth and spread of cancer cells and limits damage to healthy cells.

Not all tumors have the same targets. To find the most effective treatment, your doctor may run tests to identify the genes, proteins, and other factors in your tumor. This helps doctors better match each patient with the most effective treatment whenever possible.

In addition, research studies continue to find out more about specific molecular targets and new treatments directed at them. These drugs are becoming more important in the treatment of colorectal cancer.



Studies have shown that older patients are able to benefit from targeted therapies, similar to younger patients. In addition, the expected side effects are usually manageable in both older and younger patients.

For colorectal cancer, the following targeted therapies may be options.

### ❑ Anti-angiogenesis therapy

Anti-angiogenesis therapy is focused on stopping angiogenesis, which is the process of making new blood vessels. Because a tumor needs the nutrients delivered by blood vessels to grow and spread, the goal of anti-angiogenesis therapies is to “starve” the tumor.

❑ **Bevacizumab (Avastin).** When bevacizumab is given with chemotherapy, it increases the length of time people with advanced colorectal cancer live. In 2004, the U.S. Food and Drug Administration (FDA) approved bevacizumab along with chemotherapy as the first treatment, or first-line treatment, for advanced colorectal cancer. Recent studies have shown it is also effective as second-line therapy along with chemotherapy. There are 2 drugs similar to bevacizumab, bevacizumab-awwb (Mvasi) and bevacizumab-bvzr (Zirabev), that have also been approved by the FDA to treat advanced colorectal cancer. These are called biosimilars.

❑ **Regorafenib (Stivarga).** This drug is used to treat people with metastatic colorectal cancer who have already received certain types of chemotherapy and other targeted therapies.



- ❑ **Ziv-aflibercept (Zaltrap) and ramucirumab (Cyramza).** Either of these drugs can be combined with FOLFIRI chemotherapy as a second-line treatment for metastatic colorectal cancer.

### ❑ **Epidermal growth factor receptor (EGFR) inhibitors**

Researchers have found that drugs that block a protein called EGFR may be effective at stopping or slowing the growth of colorectal cancer.

- ❑ **Cetuximab (Erbix).** Cetuximab is an antibody made from mouse cells that still has some of the mouse structure.
- ❑ **Panitumumab (Vectibix).** Panitumumab is made entirely from human proteins and is less likely to cause an allergic reaction than cetuximab.

Recent studies show that cetuximab and panitumumab do not work as well for tumors that have specific mutations, or changes, to a gene called *RAS*. ASCO recommends that all people with metastatic colorectal cancer who may receive an EGFR inhibitor have their tumors tested for *RAS* gene mutations. If a tumor has a mutated form of the *RAS* gene, ASCO recommends that they do not receive EGFR inhibitors. Furthermore, the FDA now recommends that both cetuximab and panitumumab only be given to people with a tumor with non-mutated, sometimes called wild-type, *RAS* genes.

### ❑ **Combined targeted therapies**

Some tumors have a specific mutation, called *BRAF V600E*, that can be detected by an FDA-approved test. A class of targeted treatments called BRAF inhibitors can be used to treat tumors with this mutation. A combination using the BRAF inhibitor encorafenib (Braftovi) and cetuximab may be used to treat people with metastatic colorectal cancer with this mutation who have received at least 1 previous treatment.

### ❑ **Tumor-agnostic treatment**

Larotrectinib (Vitrakvi) and entrectinib (Rozlytrek) are types of targeted therapy that are not specific to a certain type of cancer but focuses on a specific genetic change called an *NTRK* fusion. This type of genetic change is rare but is found in a range of cancers, including colorectal cancer. These therapies are approved as a treatment for colorectal cancer that is metastatic or cannot be removed with surgery and has worsened with other treatments.

### **Side effects of targeted therapies**

Talk with your doctor about possible side effects for a specific medication and how they can be managed. The side effects of targeted treatments can include a rash to the face and upper body, which can be prevented or reduced with various treatments.



## Immunotherapy

Immunotherapy, also called biologic therapy, is designed to boost the body's natural defenses to fight the cancer. It uses materials made either by the body or in a laboratory to improve, target, or restore immune system function.

Checkpoint inhibitors are an important type of immunotherapy used to treat colorectal cancer.

- ❑ **Pembrolizumab (Keytruda).** Pembrolizumab targets PD-1, a receptor on tumor cells, preventing the tumor cells from hiding from the immune system. Pembrolizumab is used to treat unresectable or metastatic colorectal cancers that have a molecular feature called microsatellite instability (MSI-H) or mismatch repair deficiency (dMMR). Unresectable means surgery is not an option.
- ❑ **Nivolumab (Opdivo).** Nivolumab is used to treat people who are 12 or older and have MSI-H or dMMR metastatic colorectal cancer that has grown or spread after treatment with chemotherapy with a fluoropyrimidine (such as capecitabine and fluorouracil), oxaliplatin, and irinotecan.
- ❑ **Nivolumab and ipilimumab (Yervoy) combination.** This combination of checkpoint inhibitors is approved to treat patients who are 12 or older and have MSI-H or dMMR metastatic colorectal cancer that has grown or spread after treatment with chemotherapy with a fluoropyrimidine, oxaliplatin, and irinotecan.

### Side effects of immunotherapies

Different types of immunotherapy can cause different side effects. The most common side effects of immunotherapy may include fatigue, rash, diarrhea, nausea, fever, muscle pain, bone pain, joint pain, abdominal pain, itching, vomiting, cough, decreased appetite, and shortness of breath. Immunotherapy can increase the risk of inflammation in different organs in the body. Discuss with your doctor what to look out for if you are receiving immunotherapy.



#### QUESTIONS TO ASK THE HEALTH CARE TEAM ABOUT TARGETED THERAPY AND IMMUNOTHERAPY

- ▶ Has my tumor been tested for microsatellite instability and other molecular features?
- ▶ Based on my test results, is targeted therapy or immunotherapy an option? Why or why not?
- ▶ How long will I need to have this treatment?
- ▶ How will the treatment be given?
- ▶ What are the possible side effects of this treatment? How will side effects be managed?
- ▶ How will my treatment be monitored?
- ▶ If I am worried about managing the cost of treatment, who can help me?



## Clinical trials

Doctors and scientists are always looking for better ways to treat people with colorectal cancer. To make scientific advances, doctors create research studies involving volunteers, called clinical trials.

Many clinical trials focus on new treatments. Researchers want to learn if a new treatment is safe, effective, and possibly better than the treatment doctors use now. These types of studies evaluate new drugs, different combinations of treatments, new approaches to radiation therapy or surgery, and new methods of treatment. There are also clinical trials that study new ways to ease symptoms and side effects during treatment and ways to manage late effects that may occur after treatment.



Patients who participate in clinical trials can be some of the first to get a treatment before it is available to the public. However, there are some risks with a clinical trial, including possible side effects and the chance the new treatment may not work. People are encouraged to talk with their health care team about the pros and cons of joining a specific study.

People decide to participate in clinical trials for many reasons. For some people with colorectal cancer, a clinical trial is the best treatment option available. Because standard treatments are not perfect, patients are often willing to face the added uncertainty of a clinical trial in the hope of a better result. Other people volunteer for clinical trials because they know these studies are a way to contribute to the progress in treating colorectal cancer. Even if they do not benefit directly from the clinical trial, their participation may help other people with colorectal cancer in the future.

Insurance coverage of clinical trials costs differs by location and by study. In some programs, some of the patient's expenses from participating in the clinical trial are reimbursed. In others, they are not. It is important to talk with the research team and your insurance company first to learn if and how your treatment in a clinical trial will be covered.

Some people worry if they participate in a clinical trial they may receive no treatment by being given a placebo or a "sugar pill." Placebos are usually combined with standard treatment in most cancer clinical trials. Study participants will always be told when a placebo is used in a study.



To join a clinical trial, patients must participate in a process known as informed consent. During informed consent, the doctor should:

- ▶ Describe all of the patient's options, so that the person understands how the new treatment differs from the standard treatment.
- ▶ List all of the risks of the new treatment, which may or may not be different from the risks of standard treatment.
- ▶ Explain what will be required of each patient in order to participate in the clinical trial, including the number of doctor visits, tests, and the schedule of treatment.

Clinical trials also have certain rules called “eligibility criteria” that help structure the research and keep patients safe. You and the research team will carefully review these criteria together.

Keep in mind, even if you decide to participate in a clinical trial, you may stop participating at any time for any personal or medical reason.



To learn more about clinical trials, visit [www.cancer.net/clinicaltrials](http://www.cancer.net/clinicaltrials).



### QUESTIONS TO ASK THE HEALTH CARE TEAM ABOUT CLINICAL TRIALS

- ▶ How do clinical trials help people with colorectal cancer?
- ▶ What clinical trials are available for me? Where are they located, and how do I find out more about them?
- ▶ What happens during a clinical trial?
- ▶ How do the costs of participating in a clinical trial compare with the costs of standard treatment?
- ▶ Where can I learn more about clinical trials?



## Managing symptoms and side effects

In addition to treatment to slow, stop, or eliminate colorectal cancer, an important part of your care is relieving symptoms and side effects. This approach is called palliative care or supportive care.



Palliative care is any treatment that focuses on reducing a person's symptoms, improving quality of life, and supporting patients and their families. Any person, regardless of age or type and stage of cancer, may receive palliative care. Ideally palliative care should start as early as needed in the cancer treatment process and continue throughout all stages of the disease. It can be given at the same time as disease-directed treatment or on its own.

Palliative treatments vary widely and often include medication, nutritional changes, relaxation techniques, emotional support, and other therapies. You may also receive palliative treatments similar to those meant to eliminate the cancer, such as chemotherapy, surgery, and radiation therapy, so it is important to understand the goals of each treatment in your treatment plan.

Before treatment begins, talk with your health care team about the possible side effects of your specific treatment plan and palliative care options. During and after treatment, be sure to tell your doctor or another member of your health care team if you are experiencing a problem so it can be addressed as quickly as possible.



**For more information about palliative care, visit [www.cancer.net/palliativecare](http://www.cancer.net/palliativecare).**



### QUESTIONS TO ASK THE HEALTH CARE TEAM ABOUT PALLIATIVE CARE

- ▶ What can be done to manage any symptoms and side effects I may experience?
- ▶ Can you recommend someone who specializes in palliative care?
- ▶ Where can I receive palliative care services?
- ▶ What other support services are available to me? To my family?
- ▶ If I am worried about managing the cost of cancer care, who can help me?



## ■ Developing a treatment plan

In general, colorectal cancer that has been diagnosed as stage 0, I, II, or III can usually be cured with surgery. However, many patients with stage III colorectal cancer, and some with stage II, will receive chemotherapy after surgery to increase the chance of eliminating the disease. Patients with stage II and III rectal cancer will also receive radiation therapy with chemotherapy either before or after surgery. Stage IV is rarely curable, but it is treatable, and the growth of the cancer and the symptoms of the disease can be successfully managed. Clinical trials are also a treatment option for each stage.



### Stage 0

The usual treatment is a polypectomy, or removal of a polyp, during a colonoscopy. There is no additional surgery unless the polyp cannot be fully removed.

### Stage I

Surgical removal of the tumor and lymph nodes is usually the only treatment needed.

### Stage II

Surgery is often the first treatment. Patients with stage II colon cancer should talk with their doctor about whether more treatment is needed after surgery because some patients receive adjuvant chemotherapy. Adjuvant chemotherapy is treatment after surgery aimed at trying to destroy any remaining cancer cells. However, cure rates for surgery alone are quite good, and there are few benefits of additional treatment for people with this stage of colon cancer. A clinical trial is also an option after surgery.

For patients with stage II rectal cancer, radiation therapy is usually given in combination with chemotherapy, either before or after surgery. Additional chemotherapy may be given after surgery as well.

### Stage III

Treatment usually involves surgical removal of the tumor followed by adjuvant chemotherapy. A clinical trial is also an option. For patients with rectal cancer, radiation therapy may be used along with chemotherapy before or after surgery, along with adjuvant chemotherapy.



## Stage IV (metastatic)

At this stage the cancer has spread to another location in the body, such as the liver, lungs, peritoneum, or ovaries. Patients with this diagnosis are encouraged to talk with doctors who are experienced in treating this stage of cancer because there can be different opinions about the best treatment plan.

At this stage, surgery to remove the portion of the colon where the cancer started usually cannot eliminate the cancer, but it can help relieve blockage of the colon or other complications. Surgery may also be used to remove parts of other organs that contain cancer, called a resection, and can cure some people if a limited amount of cancer has spread to a single organ, such as the liver or lung. Even when curing the cancer is not possible, surgery may add months or even years to a person's life. Determining who can benefit from surgery for cancer that has spread to the liver is often a complicated process that involves doctors of multiple specialties working together to create the best plan.



Your health care team may recommend a treatment plan that includes a combination of surgery, radiation therapy, immunotherapy, targeted therapy, and chemotherapy, which can be used to slow the spread of the disease and often temporarily shrink a cancerous tumor. In addition, palliative care will be important to help relieve symptoms and side effects.

For most patients, a diagnosis of metastatic cancer is very stressful and difficult. Patients and their families are encouraged to talk about the way they are feeling with doctors, nurses, social workers, or other members of the health care team. It may also be helpful to talk with other patients, such as through a support group.



## Recurrent colorectal cancer

If colorectal cancer returns after the original treatment, it is called recurrent cancer. Cancer recurs because tiny areas of cancer cells are difficult to find and can sometimes remain in the body after treatment. Over time, these cells may multiply and grow large enough to be found and diagnosed. Colorectal cancer may come back in the same place (called a local recurrence), nearby (regional recurrence), or in another place (distant recurrence).

If a recurrence occurs, a new cycle of testing will begin again to learn as much as possible about the recurrence. After this testing is done, you and your doctor will talk about your treatment options. Generally, the treatment options for recurrent cancer are the same as those for metastatic cancer and include surgery, therapies using medication, radiation therapy, and palliative care. However, they may be used in a different combination or given at a different pace. Your doctor may also suggest clinical trials that are studying new ways to treat recurrent colorectal cancer.

People with recurrent cancer often experience emotions such as disbelief or fear. Patients are encouraged to talk with their health care team about these feelings and ask about support services to help them cope.



**For more information about colorectal cancer treatment, visit [www.cancer.net/colorectal](http://www.cancer.net/colorectal).**



### QUESTIONS TO ASK THE HEALTH CARE TEAM ABOUT YOUR TREATMENT PLAN

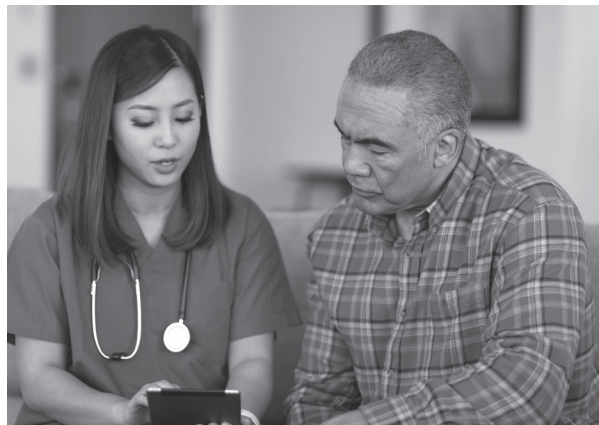
- ▶ Who will be coordinating my overall treatment and follow-up care?
- ▶ What is the goal of my treatment plan?
- ▶ What clinical trials are available for me?
- ▶ What is my prognosis?
- ▶ Who should I talk with about symptoms and side effects I experience during treatment?
- ▶ Who should I contact for support and emotional help for me? For my family?



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# Coping With Side Effects

Fearing the side effects of colorectal cancer treatment is common, but it may help to know that preventing and controlling side effects is a major focus of your health care team. Before starting treatment, talk with your health care team about which side effects are most likely to happen and which are not. Then, when treatment begins, let your health care team know what side effects you are experiencing so they can help manage them.



The specific side effects you may experience during and after treatment for colorectal cancer depend on a number of factors, including the cancer's stage, the length and dosage of treatment(s), and your overall health. Some of the potential physical, emotional, and social effects experienced by people receiving treatment for colorectal cancer are described in this section.

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**Preventing and controlling side effects is a major focus of your health care team.**

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## Physical effects

**Fatigue.** Cancer and its treatment often cause a persistent feeling of physical, emotional, or mental tiredness or exhaustion. Most people receiving cancer treatment experience some type of fatigue, which can make even a small effort, such as walking across a room, seem like too much. Fatigue can seriously affect all aspects of a person's life, from relationships with friends and family to the ability to perform at work. It is important to tell your doctor if you are experiencing fatigue because there are things your health care team can do to help.

**Changes in bowel function.** Colorectal cancer and its treatment may cause bowel problems, such as diarrhea, gas, loss of control of bowel movements, and increased urgency with bowel movements. The severity of these issues usually decreases as time passes, and most people find they settle into a new normal



following treatment. The same is true for people who have a colostomy as part of their surgery. Although it may take time to adjust, a colostomy should not keep you from doing the activities of your daily life. If you have concerns about your bowel function, talk with a member of your health care team for advice about how to manage these issues.

**Pain.** Pain can be caused by the tumor, be a side effect of cancer treatment, or result from causes not related to the cancer at all. Untreated pain can make other aspects of cancer seem worse, such as fatigue, weakness, nausea, constipation, sleep disturbances, depression, anxiety, and mental confusion. However, it is important to know that up to 95% of cancer pain can be treated successfully using medication or other strategies. Your doctor or a pain specialist can help you find an effective pain-relief strategy.



**For more information about managing cancer related pain, visit [www.cancer.net/pain](http://www.cancer.net/pain).**

**Nausea and vomiting.** Nausea and vomiting are common side effects of many cancer treatments. Nausea is feeling the urge to vomit or throw up. Vomiting may happen before treatment as a result of anxiety, within 24 hours after treatment, or 2 or more days after treatment. Mild nausea and vomiting can be quite uncomfortable, but they usually do not cause serious problems. Severe vomiting, on the other hand, can cause dehydration, electrolyte imbalances (loss of minerals from the body, such as potassium and sodium), weight loss, and depression. In addition to medications that help prevent nausea and vomiting, many people find that behavioral treatments can help control these side effects. Talk with your health care team about ways to change the expectation and fear of nausea and vomiting.

**Sexual problems.** Anyone being treated for colorectal cancer may experience sexual problems, including a decrease or loss of libido (sex drive); an inability to achieve or maintain sexual arousal, such as lubrication or an erection; the delay or absence of orgasm following normal arousal, such as premature ejaculation; and pain during sexual intercourse. Even though it may feel awkward, it is important to discuss these issues with your health care team. In addition, couples counseling may help you have productive conversations with your spouse or partner about how to cope with sexual side effects and support each other.

**Infertility.** Some treatments for colorectal cancer may cause temporary or permanent infertility. If this is a concern for you, talk with your doctor before treatment begins about the possible fertility-related side effects and options for preserving your fertility.



**Chemobrain.** Cancer survivors commonly use the term “chemobrain” to describe difficulties thinking clearly after cancer treatment. Cognitive side effects vary and sometimes make it hard to complete daily activities. People who experience severe problems concentrating, multitasking, or understanding or remembering things should talk with their doctor or another member of the health care team to learn about medication, cognitive rehabilitation and training, and other ways to manage these challenges.



For more information about managing side effects, visit [www.cancer.net/sideeffects](http://www.cancer.net/sideeffects).

## Emotional and social effects

In addition to physical side effects, you may experience emotional and social effects. For many people, the diagnosis and treatment of colorectal cancer is stressful and can trigger difficult emotions. Physical changes that may occur during treatment, such as having a colostomy, may make you feel uncomfortable and self-conscious. You may also feel differently about yourself and your body because of changes that aren't visible to others, such as fatigue, infertility, or sexual side effects.

Research has shown that sharing fears and anxieties with family, friends, counselors, clergy, or support groups helps strengthen patients emotionally and perhaps even physically. If it is not easy for you to open up to others, you may want to express your feelings in other ways, such as:

- ▶ Writing in a journal or starting a blog
- ▶ Doing artistic projects, such as painting
- ▶ Praying or meditating
- ▶ Reading
- ▶ Slowing down and reflecting



However, even with outlets to express their feelings, sometimes people with colorectal cancer and those closest to them continue to experience emotional and social challenges. If you are feeling anxious, depressed, or stressed about your diagnosis and treatment, talk with a member of your health care team, such as an oncology nurse. Oncology nurses have a wealth of experience and knowledge about cancer, cancer treatment, and side effects. They can also provide you with emotional and social support, as well as help you develop effective coping strategies.



An oncology social worker can also be helpful. This health care professional can help you navigate the health care system; find support to manage the day-to-day challenges of living with cancer; and provide counseling, education, information services, discharge and home care planning services, and referrals to community resources for you and your family and friends. Oncology social workers practice in many settings, including cancer centers, hospitals, doctors' offices, cancer-related agencies, hospices, and private practices. If there is not an oncology social worker at the place where you receive treatment, call the nearest cancer center or university/teaching hospital to ask if there is one on staff.



**Learn more about coping with the physical and emotional effects of colorectal cancer at [www.cancer.net/coping](http://www.cancer.net/coping). For a list of support organizations and other resources, visit [www.cancer.net/support](http://www.cancer.net/support).**



### **QUESTIONS TO ASK THE HEALTH CARE TEAM ABOUT SIDE EFFECTS**

- ▶ What are the potential short-term and long-term side effects of my treatment plan?
- ▶ Are there ways to help me prepare for treatment and decrease the chance of experiencing side effects?
- ▶ What can be done to manage any side effects I may experience?
- ▶ What support services are available to me? To my family?
- ▶ Could my treatment plan affect my sexual health? If so, how and for how long?
- ▶ Could my treatment plan affect my ability to become pregnant or have children? If so, should I talk with a fertility specialist before treatment begins?



# Follow-Up Care

After treatment for colorectal cancer ends, talk with your doctor about developing a survivorship care plan. This plan will include regular physical examinations and medical tests to monitor your recovery for the coming months and years. It will also involve managing any ongoing or late effects of treatment.

The tests your doctor recommends and how often you need to have them will be based on your risk of recurrence and your overall health. In general, you will visit your doctor and receive follow-up screening more often earlier in your recovery.

ASCO has developed a list of follow-up care recommendations. These recommendations are mainly focused on people who had stage II or stage III colorectal cancer. It is less certain what testing should be done for people who had stage I colorectal cancer because this stage is less likely to come back. If you have had surgery for metastatic colorectal cancer, it is important to talk with your doctor about creating a survivorship care plan specifically for you, since there is currently no standardized follow-up care schedule for this stage of colorectal cancer. It is also important to remember that these follow-up care recommendations are for people who had colorectal cancer that was not inherited.

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**Care for colorectal cancer does not end when active treatment has finished.**

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## Recommended follow-up tests

**Regular visits with your doctor.** Doctor visits are recommended every 3 to 6 months for 5 years after diagnosis. Regularly scheduled appointments help increase the likelihood of finding a treatable recurrence, as can keeping an eye out for signs that the cancer has come back.

The symptoms of a potential recurrence include:

- ▶ A change in bowel habits
- ▶ Diarrhea, constipation, or feeling that the bowel does not empty completely
- ▶ Bright red or very dark blood in the stool
- ▶ Stools that look narrower or thinner than normal
- ▶ Discomfort in the abdomen, including frequent gas pains, bloating, fullness, and cramps
- ▶ Weight loss with no known explanation
- ▶ Constant tiredness or fatigue
- ▶ Unexplained iron-deficiency anemia





Talk with your doctor if these symptoms last for several weeks or become more severe. However, it is also possible that these symptoms may be caused by a medical condition that is not cancer, especially for general symptoms like abdominal discomfort, bloating, and irregular bowel movements.

**CEA test.** This is a blood test that detects the levels of the CEA protein. High levels of CEA may mean that a cancer has spread to other parts of the body. CEA testing is recommended every 3 to 6 months for 5 years.

**CT scan.** CT scans of the abdomen and chest are recommended each year for 3 to 5 years. If you have a high risk of recurrence, your doctor may recommend CT scans every 6 to 12 months for the first 3 to 5 years. If you had rectal cancer, a CT scan of the pelvis may also be recommended, but how often you need this test depends on your risk of recurrence.

**Colonoscopy.** This test allows the doctor to look for polyps or second cancers in the entire rectum and colon. You should expect to have a colonoscopy 1 year after surgery. How often you need this test after that depends on the results. For example, if polyps are found, you may need to have another colonoscopy sooner. In general, this test typically occurs every 3 to 5 years. Some people, such as those with specific inherited conditions, may require colonoscopy screening more frequently. Talk with your doctor about an appropriate schedule for colonoscopy testing based on your medical history and risk of recurrence.

**Rectosigmoidoscopy.** This test helps a doctor check the rectum for polyps, cancer, and other abnormalities. If you had rectal cancer, but did not have radiation therapy to the pelvis, this test is recommended every 6 months. However, rectosigmoidoscopy may be recommended even if you had radiation therapy for rectal cancer, but it depends on your risk of recurrence.



## **General follow-up care schedule**

### **First year after treatment**

- ☐ Physical examination and CEA testing every 3 to 6 months
- ☐ Abdominal and chest CT scan every 6 to 12 months for people at high risk for recurrence
- ☐ For rectal cancer survivors, a pelvic CT scan every 6 to 12 months
- ☐ Colonoscopy 1 year after surgery
- ☐ Rectosigmoidoscopy every 6 months for people with rectal cancer who did not have radiation therapy to the pelvis

### **Second year after treatment**

- ☐ Physical examination and CEA testing every 3 to 6 months
- ☐ CT scan every 6 to 12 months for people at high risk for recurrence
- ☐ For rectal cancer survivors, a pelvic CT scan every 6 to 12 months
- ☐ Rectosigmoidoscopy every 6 months for people with rectal cancer who did not have radiation therapy to the pelvis

### **Third year after treatment**

- ☐ Physical examination and CEA testing every 3 to 6 months
- ☐ CT scan every 6 to 12 months for people at high risk for recurrence
- ☐ For rectal cancer survivors, a pelvic CT scan every 6 to 12 months
- ☐ Rectosigmoidoscopy every 6 months for people with rectal cancer who did not have radiation therapy to the pelvis

### **Fourth year after treatment**

- ☐ Physical examination and CEA testing every 3 to 6 months
- ☐ Annual CT scan, if recommended.
- ☐ For rectal cancer survivors, a pelvic CT scan each year
- ☐ Rectosigmoidoscopy every 6 months for people with rectal cancer who did not have radiation therapy to the pelvis

### **Fifth year after treatment**

- ☐ Physical examination and CEA testing every 3 to 6 months
- ☐ Annual CT scan, if recommended.
- ☐ For rectal cancer survivors, a pelvic CT scan each year
- ☐ Rectosigmoidoscopy every 6 months for people with rectal cancer who did not have radiation therapy to the pelvis



## Other recommendations

People recovering from colorectal cancer are also encouraged to follow established guidelines for good health, such as maintaining a healthy weight, not smoking, minimizing alcohol intake, eating a balanced diet, and having recommended cancer screening tests. Talk with your doctor to develop a plan that is best for your needs. Moderate exercise can help rebuild your strength and energy level. In addition, some studies suggest that regular exercise may reduce the risk of recurrence, but more research is needed. Your health care team can help you create a safe exercise plan based on your needs, physical abilities, and fitness level.



### QUESTIONS TO ASK THE HEALTH CARE TEAM ABOUT FOLLOW-UP CARE

- ▶ What is the chance that the cancer will come back after treatment?
- ▶ Is there anything I can do to reduce the risk of recurrence?
- ▶ Which follow-up tests will I need, and how often will I need them?
- ▶ Who will be leading my follow-up care?
- ▶ What signs or symptoms should I tell you about right away?
- ▶ If I move or need to switch doctors, how do I make sure I continue with my recommended follow-up care schedule?
- ▶ What type of follow-up care do I need once I have reached 5 years after finishing treatment?



# Colorectal Cancer Dictionary

**Adjuvant therapy:** Treatment given after the main treatment to reduce the chance of cancer coming back by eliminating any remaining cancer cells. It usually refers to chemotherapy and/or radiation therapy given after surgery.

**Benign:** A tumor that is not cancerous. The tumor does not usually invade nearby tissue or spread to other parts of the body.

**Biopsy:** The removal of a small amount of tissue for examination under a microscope. Other tests can suggest colorectal cancer is present, but only a biopsy can make a definite diagnosis.

**Brachytherapy:** Radiation treatment given using small radioactive “seeds” or pellets placed inside the body near the tumor. Also called internal radiation therapy.

**BRAF:** A gene that may be mutated, or changed, in some colorectal tumors.

**Carcinoembryonic antigen (CEA) test:** A blood test that detects the level of a protein called carcinoembryonic antigen (CEA). High levels of CEA may indicate that a cancer has spread to other parts of the body. CEA is not a perfect test for colorectal cancer because levels are high for only about 60% of people with colorectal cancer that has spread to other organs. CEA tests are most often used to monitor colorectal cancer for patients already receiving treatment and are not used as screening tests.

**Checkpoint inhibitors:** Cancer drugs often made of antibodies that use the body’s immune system to fight cancer cells. Checkpoint inhibitors are a type of immunotherapy.

**Chemoradiation therapy:** Chemotherapy that is given at the same time as radiation therapy to increase the effectiveness of the radiation therapy.

**Chemotherapy:** The use of drugs to destroy cancer cells, usually by keeping the cancer cells from growing, dividing, and making more cells.

**Clinical trial:** A research study that involves volunteers. Many clinical trials test new treatments and/or prevention methods to find out whether they are safe, effective, and possibly better than the current standard of care, which is the best known treatment.

**Colonoscopy:** A screening or diagnostic test that allows the doctor to look inside the entire rectum and colon while a patient is sedated. A flexible, lighted tube called a colonoscope is inserted into the rectum and the entire colon to look for polyps or cancer. During this procedure, a doctor can remove polyps or other tissue for further examination.

**Colostomy:** A surgical opening that connects the large intestine to the abdominal surface, providing a pathway for waste to exit the body. The waste is then collected in a pouch worn by the patient.



**Complete blood count (CBC):** A CBC is a common blood test that provides important information about the amount of white blood cells, red blood cells, and platelets. It is used to help diagnose some types of cancer, tell if a cancer has spread to the bone marrow, and help determine how your body is reacting to cancer treatments. If you are being treated with chemotherapy, your doctor will likely monitor your blood cell counts regularly using CBCs.

**Computed tomography (CT or CAT) scan:** An imaging technique that creates a picture of the inside of the body using an x-ray machine. A computer combines these images into a detailed, 3D view that shows any abnormalities or tumors.

**Cryoablation:** A cancer surgery that uses energy in the form of radiofrequency waves to freeze tumors; see also radiofrequency ablation (RFA).

**Cure:** To fully restore health. This term is sometimes used when a cancer has not returned for at least 5 years after treatment. However, the concept of “cure” is difficult to apply to cancer because undetected cancer cells can sometimes remain in the body after treatment, causing the cancer to return later. Recurrence after 5 years is still possible.

**Enterostomal therapist:** A health care professional who specializes in caring for patients with a colostomy or other stoma.

**Epidermal growth factor receptor (EGFR):** In a healthy cell, EGFR allows cells to grow and divide. However, when there are too many of these receptors caused by a genetic mutation, cancer cells continue to grow and divide. Researchers have found that drugs that block EGFR may be effective for stopping or slowing the growth of colorectal cancer.

**External-beam radiation therapy:** Radiation therapy given from a machine located outside the body.

**First-line treatment:** The first treatment given aimed at getting rid of the cancer.

**Grade:** A way of describing how much a tumor looks like healthy colorectal tissue when viewed under a microscope. Healthy tissue usually contains many different types of cells grouped together. If the cancer looks similar to healthy tissue and contains different cell groupings, it is called differentiated or a low-grade tumor. If the cancerous tissue looks very different from healthy tissue, it is called poorly differentiated or a high-grade tumor. The cancer’s grade can help a doctor predict how quickly the cancer will spread.

**Imaging test:** A procedure that creates pictures of internal body parts, tissues, or organs to make a diagnosis, plan treatment, check whether treatment is working, or observe a disease over time.

**Immunotherapy:** A type of therapy that boosts the body’s natural defenses to fight the cancer.



**In situ:** In place. Refers to cancer that has not spread to nearby tissue. Also called localized or noninvasive cancer.

**Intraoperative radiation therapy:** Cancer therapy that uses a single, high dose of radiation therapy given during surgery.

**Invasive cancer:** Cancer that has spread outside the layer of tissue in which it started and has the potential to grow into other tissues or other parts of the body. Also called infiltrating cancer.

**Laboratory test:** A procedure that evaluates a sample of blood, urine, or another substance from the body to make a diagnosis, plan treatment, check whether treatment is working, or observe a disease over time.

**Late effects:** Side effects of cancer treatment that occur months or years after treatment has finished.

**Learning resource center:** A location in a hospital or cancer center where patients and families can get information about health-related topics and learn about support resources. Also called a health or hospital library.

**Lymph nodes:** Small, bean-shaped organs that help fight infection.

**Lymphatic system:** A network of small vessels, ducts, and organs that carry fluid to and from the bloodstream and body tissues. Cancer can spread to other parts of the body through the lymphatic system.

**Malignant:** Refers to a tumor that is cancerous. It may invade nearby healthy tissue or spread to other parts of the body.

**Metastasis:** The spread of cancer from the place where it began to another part of the body. This occurs when cancer cells break away from the primary tumor and travel through the blood or the lymphatic system to the lymph nodes, lungs, liver, or other organs.

**Neoadjuvant therapy:** Treatment given before the main treatment. It may include chemotherapy and/or radiation therapy given before surgery to shrink a tumor so it is easier to remove.

**Oncologist:** A doctor who specializes in treating cancer.

**Palliative care:** Any type of treatment that concentrates on reducing a patient's symptoms or treatment-related side effects, improving quality of life, and supporting patients and their families. Also called supportive care.

**Pathologist:** A doctor who specializes in interpreting laboratory tests and evaluating cells, tissues, and organs to diagnose disease.

**Polyp:** A noncancerous growth that may develop on the inner wall of the colon or rectum as people get older. If not treated or removed, a polyp can develop into cancer. There are several forms of polyps. Adenomatous polyps, or adenomas, are growths that may become cancerous and can be detected with a colonoscopy.

**Polypectomy:** The surgical removal of a polyp.



**Positron emission tomography (PET) scan or PET-CT scan:** A diagnostic test used to create pictures of organs and tissues inside the body. A PET scan is usually combined with a CT scan, called a PET-CT scan. However, you may hear your doctor refer to this procedure just as a PET scan.

**Primary site:** The area in the body where a cancer started.

**Prognosis:** Chance of recovery; a prediction of the outcome of a disease.

**Psychosocial effects:** Emotional and social concerns related to cancer and cancer treatment that can greatly affect patients' well-being. These may include lack of information and support; emotional difficulties, including depression and anxiety; lack of transportation; disruptions to work, school, and family life; and insufficient financial resources.

**Quality of life:** An overall sense of well-being and satisfaction with life.

**Radiation therapy:** The use of high-energy x-rays or other particles to destroy cancer cells. Also called radiotherapy.

**Radiofrequency ablation (RFA):** A cancer surgery that uses energy in the form of radiofrequency waves to heat the tumors; see also cryoablation.

**RAS:** A gene that may be mutated, or changed, in some colorectal tumors. People who have a tumor with a mutated form of the *RAS* gene should not receive EGFR inhibitors.

**Rectosigmoidoscopy:** A test that helps a doctor check the rectum for polyps, cancer, and other abnormalities.

**Recurrence:** Cancer that has returned after a period during which the cancer could not be detected. Local recurrence means that the cancer has come back in the same general area where the original cancer was located. Regional recurrence refers to cancer that has come back in the lymph nodes or other tissues near the original cancer site, usually by direct spread. Distant recurrence refers to cancer that has come back and has spread to other parts of the body, usually by traveling through the lymphatic system or bloodstream.

**Regimen:** A treatment plan that includes which treatments and procedures will be done, medications and their doses, the schedule of treatments, and how long the treatment will last.

**Response:** How the cancer reacts to the treatment; how effective the treatment is.

**Risk:** The likelihood of an event.

**Screening:** The process of checking whether a person has a disease or has an increased chance of developing a disease when the person has no symptoms.

**Secondary cancer:** Describes either a new primary cancer, which is a different type of cancer that develops after treatment for the first type of cancer, or cancer that has spread to other parts of the body from the place where it started (see Metastasis).

**Second-line therapy:** Treatment given if the first treatment doesn't work or stops working.

**Side effect:** An undesirable result of treatment, such as fatigue, nausea, vomiting, or skin rash.



**Sigmoidoscopy:** A screening or diagnostic test that allows a doctor to see inside the lower 20 inches of the sigmoid colon and rectum.

**Stage:** A way of describing where the cancer is located, if or where it has spread, and whether it is affecting other parts of the body.

**Standard of care:** Care that experts agree or research shows is the most appropriate and/or effective for a specific disease.

**Stoma:** A surgically constructed opening, such as a colostomy.

**Surgery:** The removal of cancerous tissue from the body during an operation.

**Targeted treatment:** Treatment that targets specific genes, proteins, or other molecules that contribute to cancer growth and survival.

**Tumor:** A mass formed when healthy cells change and grow out of control. A tumor can be cancerous or benign. A cancerous tumor is malignant, meaning it can spread to other parts of the body. A benign tumor means the tumor can grow but will not spread.



For more definitions of common terms you may hear before, during, and after treatment, visit [www.cancer.net/cancerterms](http://www.cancer.net/cancerterms).



# My Health Care Team

Gastroenterologist: \_\_\_\_\_

Contact Information: \_\_\_\_\_

\_\_\_\_\_  
\_\_\_\_\_

Counselor/Therapist: \_\_\_\_\_

Contact Information: \_\_\_\_\_

\_\_\_\_\_  
\_\_\_\_\_

Medical Oncologist: \_\_\_\_\_

Contact Information: \_\_\_\_\_

\_\_\_\_\_  
\_\_\_\_\_

Nutritionist/Dietitian: \_\_\_\_\_

Contact Information: \_\_\_\_\_

\_\_\_\_\_  
\_\_\_\_\_

Radiation Oncologist: \_\_\_\_\_

Contact Information: \_\_\_\_\_

\_\_\_\_\_  
\_\_\_\_\_

Pharmacist: \_\_\_\_\_

Pharmacy: \_\_\_\_\_

Contact Information: \_\_\_\_\_

\_\_\_\_\_  
\_\_\_\_\_

Surgeon/Surgical Oncologist: \_\_\_\_\_

Contact Information: \_\_\_\_\_

\_\_\_\_\_  
\_\_\_\_\_

## Other Team Members:

Name: \_\_\_\_\_

Contact Information: \_\_\_\_\_

\_\_\_\_\_  
\_\_\_\_\_

Primary Care Doctor: \_\_\_\_\_

Contact Information: \_\_\_\_\_

\_\_\_\_\_  
\_\_\_\_\_

Name: \_\_\_\_\_

Contact Information: \_\_\_\_\_

\_\_\_\_\_  
\_\_\_\_\_

Oncology Nurse: \_\_\_\_\_

Contact Information: \_\_\_\_\_

\_\_\_\_\_  
\_\_\_\_\_

Name: \_\_\_\_\_

Contact Information: \_\_\_\_\_

\_\_\_\_\_  
\_\_\_\_\_

Oncology Social Worker: \_\_\_\_\_

Contact Information: \_\_\_\_\_

\_\_\_\_\_  
\_\_\_\_\_

Name: \_\_\_\_\_

Contact Information: \_\_\_\_\_

\_\_\_\_\_  
\_\_\_\_\_



# Diagnosis Summary

## PRIMARY TUMOR LOCATION:

- ☐ Colon
- ☐ Rectum

## TYPE:

- ☐ Adenocarcinoma
- ☐ Lymphoma
- ☐ Gastrointestinal stromal tumor (GIST)
- ☐ Neuroendocrine (carcinoid) tumor

## STAGE:

- |                                    |                                     |                                    |
|------------------------------------|-------------------------------------|------------------------------------|
| <input type="checkbox"/> Stage 0   | <input type="checkbox"/> Stage IIIA | <input type="checkbox"/> Stage IVA |
| <input type="checkbox"/> Stage I   | <input type="checkbox"/> Stage IIIB | <input type="checkbox"/> Stage IVB |
| <input type="checkbox"/> Stage IIA | <input type="checkbox"/> Stage IIIC | <input type="checkbox"/> Stage IVC |
| <input type="checkbox"/> Stage IIB |                                     | <input type="checkbox"/> Recurrent |
| <input type="checkbox"/> Stage IIC |                                     |                                    |

## GRADE:

- ☐ GX—The tumor grade cannot be identified.
- ☐ G1—The cells are more like normal cells, called well differentiated.
- ☐ G2—The cells are somewhat like normal cells, called moderately differentiated.
- ☐ G3—The cells look less like normal cells, called poorly differentiated.
- ☐ G4—The cells barely look like normal cells, called undifferentiated.

## MY TREATMENT PLAN

- ☐ Surgery
- ☐ Radiation therapy
- ☐ Chemotherapy
- ☐ Targeted therapy
- ☐ Immunotherapy
- ☐ Clinical trial
- ☐ Palliative care

## TREATMENT GOALS

- ☐ Eliminate the cancer
- ☐ Slow cancer growth/spread
- ☐ Shrink the tumor
- ☐ Relieve symptoms
- ☐ Manage side effects
- ☐ Other:

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# My Follow-Up Care Plan

Use this page to help discuss your follow-up care with your doctor and keep track of their recommendations. Talk with a member of your health care team if you have any questions.

Need for ongoing (adjuvant) treatment for cancer: ☐ Yes ☐ No

Additional treatment name	Purpose	For how long

## SCHEDULE OF FOLLOW-UP VISITS

Doctor's name	When/How often

## CANCER SURVEILLANCE/OTHER RECOMMENDED TESTS

Test/Procedure	When/How often

It is important to continue to see your primary care doctor for all general health care recommended for a person of your age, including screening tests for other cancers, when appropriate. You should also tell your doctor about:

1. Anything that could be a brand new symptom
2. Anything that continues to be a persistent symptom
3. Anything you are worried about that might be related to the cancer coming back

Signs or symptoms to tell the doctor about right away: \_\_\_\_\_

\_\_\_\_\_

Possible late and long-term effects: \_\_\_\_\_

\_\_\_\_\_

What concerns do you have as you transition into survivorship?

- |   |   |   |
|---|---|---|
| <input type="checkbox"/> Emotional and mental health    | <input type="checkbox"/> Insurance                    | <input type="checkbox"/> Sexual health    |
| <input type="checkbox"/> Fatigue                        | <input type="checkbox"/> Memory or concentration loss | <input type="checkbox"/> Stopping smoking |
| <input type="checkbox"/> Fertility                      | <input type="checkbox"/> Parenting                    | <input type="checkbox"/> Weight changes   |
| <input type="checkbox"/> Financial advice or assistance | <input type="checkbox"/> Physical functioning         | <input type="checkbox"/> Other: _____     |
|   | <input type="checkbox"/> School/Work                  |   |





 **Notes**

## Notes



[illegible]



## Looking for More Patient Information Resources?

Visit [www.cancer.net/ascoanswers](http://www.cancer.net/ascoanswers) to see all of the available titles in the *ASCO Answers* series.

***ASCO Answers Guides*** are comprehensive manuals, covering specific cancer types, survivorship, and caregiving. Worksheets and checklists for managing care are included.

***ASCO Answers Fact Sheets*** are brief introductions to different cancer types and topics in diagnosis, treatment, and side effects. More than 70 fact sheets are available, including translations in Spanish, Portuguese, and more.

***ASCO Answers Booklets*** are in-depth guides to specific topics in cancer care, including advanced cancer care planning, pain, cost of care, managing weight, palliative care, and stopping tobacco use.

***Patients and Caregivers:*** For more educational materials, visit [www.cancer.net/ascoanswers](http://www.cancer.net/ascoanswers) to find and download all of our available materials.

***Oncology Professionals:*** Bulk quantities of high-quality print materials can be purchased at [www.cancer.net/estore](http://www.cancer.net/estore) or by calling 1-888-273-3508. For free promotional materials for your practice, email [contactus@cancer.net](mailto:contactus@cancer.net).

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**KNOWLEDGE CONQUERS CANCER**

**AMERICAN SOCIETY OF CLINICAL ONCOLOGY**

2318 Mill Road, Suite 800

Alexandria, VA 22314

Phone: 571-483-1300

Fax: 571-366-9530

[www.asco.org](http://www.asco.org) | [www.cancer.net](http://www.cancer.net)

For more information about ASCO's patient information resources,  
call toll-free 888-651-3038 or e-mail [contactus@cancer.net](mailto:contactus@cancer.net).

To order more copies of this booklet,  
call 888-273-3508 or visit [www.cancer.net/estore](http://www.cancer.net/estore).

**WE WANT TO HEAR FROM YOU**

If you found this material helpful or if you have comments or suggestions  
about how it could be better, please let us know at [contactus@cancer.net](mailto:contactus@cancer.net).