



# FRANKLY SPEAKING **ABOUT CANCER**

A PROGRAM OF THE CANCER SUPPORT COMMUNITY



# COLORECTAL CANCER



If you or someone you care for has colorectal cancer, you are not alone. Colorectal cancer is one of the most common cancers in the United States. This booklet offers an introduction to colorectal cancer and its treatment in simple terms. It was written to provide useful information to help you learn about colorectal cancer, plan for treatment, and start to find the tools you need to cope with this disease. We hope it will help you face the next steps with more knowledge and confidence.

## What is Colorectal Cancer?

Colorectal cancer is cancer that forms in the colon or the rectum. The colon is the biggest part of the large intestine. The rectum is the piece that connects the colon to the anus. Both the colon and the rectum are part of the digestive system. They help remove solid waste from the body.

Colorectal cancer is sometimes called colon cancer or rectal cancer, depending on where it starts. The two cancers are looked at together because their treatments are similar.

Most colorectal cancers begin as growths called polyps. They can form on the inner lining of the colon or the rectum. Most polyps are not cancer, but some may develop into cancer over time. Polyps can be found early and removed through screening. Tests will show if they would have eventually become cancer. Doctors recommend more frequent screenings for people with pre-cancerous polyps.

## What are the Subtypes of Colorectal Cancer?

The two main types of colorectal cancer are colon cancer and rectal cancer. Most colorectal cancers are **adenocarcinomas**. They begin in the gland tissue that lines the organs.

They start as adenoma polyps that are harmless at first but grow into cancer over time.

Rarely, the following cancers may be found in the colorectal area:

**Carcinoid** – These cancers start in the cells that make hormones in the intestine. They are also called neuroendocrine tumors (NETs). They grow slowly and may be treated with surgery or hormone therapy.

**Gastrointestinal Stromal Tumors (GIST)** – These tumors can form anywhere in the GI tract but seldom show up in the colon. They are soft tissue **sarcomas**, which means they start in the soft tissue that connects bones or muscles. When they develop into cancer, they are considered sarcomas and treated as such.

**Lymphoma** – Lymphoma is a blood cancer that can start in the colon. Even if the cancer is found in the colon, it is treated as lymphoma. Colorectal lymphoma is rare.

## Talking About Colorectal Cancer

You may start to hear a lot of new words. Here are some key ones:

- Adjuvant therapy – Treatment given after surgery
- Colectomy/Colon Resection – Removal of the colon
- Neo-adjuvant therapy – Treatment given before surgery
- Proctectomy – Removal of the rectum
- Recurrence – Cancer that has returned after treatment
- Resectable – Can be removed with surgery (opposite of unresectable)
- Ostomy/ Colostomy/ Stoma – A new opening to the body made by surgeons so waste can leave the body. This opening is usually made in the abdomen.



## Diagnosis and Staging

Colorectal cancer is found through routine screening or after symptoms appear. The most common screening is a colonoscopy. It is recommended for people ages 45 and up. Other screenings include fecal (stool) tests, flexible sigmoidoscopy, and CT colonoscopy. Symptoms of colorectal cancer may include bleeding, pain or bloating, fatigue, change in bowels, or other stomach troubles.

### DIAGNOSIS

If your doctor suspects colorectal cancer, they will want to do a complete exam and run tests. They will try to learn as much as possible about the type of cancer, where it started, and where, if anywhere, it has spread. A complete cancer diagnosis often takes more than one appointment and may include:

- **Physical Exam:** Your doctor will check your stomach area and may perform a rectal exam. They will look for swelling, tenderness, or growths. Your doctor will also check the rest of your body. They will ask questions about your health and your personal and family health history.
- **Colonoscopy:** Your doctor will want to look at your colon and rectum. This will require a colonoscopy, an outpatient procedure done in a hospital. Most often, anesthesia and sedation are used. You will be asleep and not feel anything. Before the procedure, you will need to prepare your colon starting a couple days in advance. The hospital will give you instructions on what to eat and drink. It is very important to drink the colon prep fluid as recommended. During the colonoscopy, your doctor will insert a camera on a long, flexible tube through your anus and rectum and into your colon to look at it. They will remove any polyps and take samples of any other abnormal tissue from your colon.

This is called a biopsy. These samples will be sent to a lab where a pathologist will look at them under a microscope to search for cancer.

- **Blood Tests:** Your doctor will ask for a complete blood count (CBC). People with colorectal cancer lose blood in their stool, even if they cannot see it. This can result in low red blood cell count and anemia. There are treatments to help you feel stronger and less tired.
  - **Carcinoembryonic Antigen (CEA)** – Your doctor may test your blood for CEA, a protein made by cancer cells. Your doctor may test for CEA before starting treatment and then again during treatment. The follow-up test will help determine if treatment is working. These tests are typically ordered only after diagnosis to follow the disease.
  - **Circulating Tumor DNA (ctDNA)** – Your doctor may also want to test your blood for ctDNA. ctDNA lets your doctor know if there is tumor DNA present in your bloodstream.



- **Imaging Tests (Scans):** Doctors use different kinds of imaging to diagnosis colon cancer. These tests allow your doctor to see if the cancer has spread to other parts of the body.
  - **Computerized tomography (CT or CAT) Scan** – It is likely that you will have a CT scan at some point. You may have a CT scan of your chest, abdomen, and pelvis. It is a series of detailed pictures created by a computer linked to an x-ray machine. It can be used to measure the tumor’s size.
  - **MRI** – An MRI uses radio waves and a powerful magnet linked to a computer to create detailed pictures of the inside the body. These pictures can show the difference between normal and diseased tissue.
  - **Ultrasound** – This scan uses sound waves to create images. If you have rectal cancer, you may have an endoscopic ultrasound, in which a thin tube is inserted in the body.
  - **Other imaging tests** – Chest X-rays and PET scans are not routinely used for colorectal cancer. Your doctor may order them to see if or where cancer has spread.
- **Surgery:** Your final diagnosis and cancer stage may not be known until after you have surgery. A surgeon will remove the tumor and the tissue around the tumor (the margins). They also may remove fat and lymph nodes from the same area. A pathologist will look at the tissue that was removed during surgery to help determine the stage of the cancer.

## BIOMARKER TESTING

A complete colorectal diagnosis includes biomarker testing. Biomarkers are things about

cancer cells that make them different from normal cells. They can be measured in the blood, tissue, or bodily fluid. With colorectal cancer, these tests are run on a sample of tumor tissue.

All colorectal cancers should be tested for **MSI-High (microsatellite instability)** and **dMMR (Deficient mismatch repair)**. If your cancer is MSI-high or dMMR, your doctor may run another test. The second test will check for genes that increase risk of cancer in families, such as Lynch syndrome. The results of MSI-High and dMMR tests also can provide useful information about treatment for people with advanced disease.

Your doctor also may test for:

**PIK3CA (PI3 kinase)** – A positive test means that you may benefit from taking aspirin after colorectal cancer surgery.

**BRAF, HER2, KRAS, NRAS, and NTRK** – If you have advanced or metastatic colorectal cancer, ask to be tested for these biomarkers. They will be included in comprehensive biomarker testing. Even though this testing is helpful, it is not always offered. The results can tell you more about treatments that may or may not work.

## STAGING

Staging is a key part of diagnosis. If cancer is found, the doctor will need to know the stage, or extent, of the disease to determine the best treatment. Staging is used to find out whether the cancer has spread, and if so, to which parts of the body.

Doctors use the information they gather from blood tests, biopsies, and scans to get a full picture of the cancer. They assign a stage using the American Joint Committee on Cancer’s TNM staging system. The TNM system considers:

- **Tumor:** How far has the tumor grown into the wall of the colon or the rectum? How many layers does it go through?



- **Nodes:** Are there cancer cells in the lymph nodes? How many nodes are affected? Where?
- **Metastasis:** Has the cancer spread beyond the colon area to distant organs like the lungs, liver, bones, or brain?

Each factor is assigned a number. The letter X is used for factors that cannot be measured. For example, a tumor could be T3, N2, and M0. The numbers are grouped to assign a stage, 0 through IV (0 to 4). Four means that the cancer has grown and spread the most.

Here are the stages of colorectal cancer:

**Stage 0** – The cancer is found only in the inner lining of the colon or the rectum.

**Stage I** – The cancer has spread to the middle layers of the colon or rectum wall.

**Stage II** – Stage II is divided into IIA, IIB, and IIC. In all three groups, the cancer has not spread to the lymph nodes or distant organs.

- In IIA, the cancer has grown into the outer layer of the colon or rectum but has not gone through it.
- In IIB, the cancer has grown through the wall of the colon or rectum but has not grown into other nearby tissues or organs.
- In IIC, the cancer has started to grow in nearby tissues or organs.

**Stage III** – Stage III is divided into IIIA, IIIB, and IIIC. In all three groups, the cancer has spread to lymph nodes but it has not spread to distant organs or other parts of the body.

- In IIIA, the cancer has spread to the middle layers of the colon or rectum wall and has spread to as many as three lymph nodes. Or the cancer has not yet spread to the middle layer of colon or rectum wall but involves four to six lymph nodes.
- In IIIB, the cancer has spread to as many as three nearby lymph nodes. It also has spread

to the outer layers of the colon or rectum wall or beyond the wall into nearby fat or organs or through the peritoneum. (The peritoneum is a thin membrane that lines the inside of the abdomen.)

- In IIIC, the cancer has spread to four or more nearby lymph nodes. It also has spread to or beyond the outer of the colon or rectum wall, to nearby fat or organs, or through the peritoneum.

**Stage IV** – The cancer has spread to other parts of the body, such as the liver or lungs. Stage IV is divided into IVA, IVB, and IVC depending on the number of distant organs or body parts involved. Stage IVA involves one distant organ. Stage IVB cancer has spread to two or more distant organs. In stage IVC, the cancer has spread to the peritoneum, the tissue that lines the inside of the abdomen. Stage IV (4) is also called advanced or metastatic cancer.

## GRADING

Your doctor may assign a grade (G) to the cancer. The grade is a number between 1 and 43 that describes how the cancer cells look under a microscope. The cancer cells are compared to normal cells. The higher the number, the less the cells look like normal cells. GX is used when grading is not possible. The grade helps your doctor understand how fast the cancer is growing and how likely it is to spread. Cancer that is growing fast is described as aggressive.

## Choosing Your Treatment Team

Cancer treatment is complicated and changes all the time with new discoveries. You need a health care team you can trust to take the best care of you. The team will include doctors, nurses, and other health care professionals who work together.



This is often called “multidisciplinary care.” At some cancer centers, the team meets regularly to discuss cases. Their patients benefit from the wisdom of the whole group. Your team may include:

**Physicians:** Look for a **medical oncologist** who specializes in colorectal cancer. You also may see a **surgical oncologist** or **colorectal surgeon**, a **radiation oncologist**, and a **gastroenterologist**.

If you are having difficult symptoms, pain, or side effects, a **palliative care doctor** may be helpful. This person focuses on managing side effects and improving quality of life.

Look for doctors who have experience treating colorectal cancer, such as a board-certified colorectal surgeon. Choosing the right surgeon is especially important for both rectal and colon cancer.

**Nurses/PAs:** Your oncologists may work with **oncology nurses**, **oncology nurse practitioners**, or **physician assistants**. They may be the person you talk with the most, who answers your questions or helps you manage the side effects of treatment.

## QUESTIONS TO ASK DOCTORS YOU ARE CONSIDERING

- How many colorectal cancers have you treated?
- How do you stay up to date on the latest treatments? (Look for someone who attends scientific meetings or reads medical journals.)
- Do you work with other specialists as part of a team?
- What other support services do you offer to people with colorectal cancer?
- Do you offer treatment through clinical trials?

**Social worker:** This person can help you and your family find resources to cope with cancer, cope with treatment, and pay for care.

**Patient or nurse navigator/advocate:** Some cancer centers use patient navigators or nurse navigators. They help patients through the care system, from diagnosis through treatment and recovery.

**Nutritionist/Dietician:** Colorectal cancer affects eating. A registered dietician can recommend foods to help you eat comfortably and get the nutrients you need.

**Psychologist/Cancer Counselor/Clergy:** Cancer is a lot to deal with. Having someone to talk to can affect how you look at things. It may help you find or maintain the energy you need to get through treatment and take the best possible care of yourself. It is a good idea to seek support early on, so you have somewhere to turn when you need it.

## COMMUNICATE WITH YOUR TEAM

You’ve chosen your health care team. The next step is to make sure that you work with them in a way that is most helpful to you. Here are some tips for communicating with your health care team:

- Keep a running list of questions to bring to office visits.
- Bring a friend or family member to appointments to help listen and take notes.
- Ask about the best way to get your questions answered. Is it better to call, email, or bring a list to appointments? Do you need to schedule an extra appointment if your list is very long?
- Find out who to contact with questions and concerns between visits. Write down their contact information.



- Ask questions until you are sure you understand. You deserve to get your questions answered in a way that makes sense to you. It's okay to ask the same question again. Tell your doctor if you need something described in a different language or format (for example, a picture).
- Tell your team about:
  - Any side effects or symptoms you notice
  - Any natural treatments you are taking - including herbs, vitamins, supplements, or other complementary treatments
  - Medicines prescribed by any other doctor for other health conditions
- Make sure your treatment goals and preferences are known and honored.

## GET A SECOND OPINION

If you are unsure of your doctor or hospital for any reason, get a second opinion. Many people with cancer get a second or even third opinion from another oncologist or cancer center. Some doctors even encourage it.

Talking with other doctors can help you make a decision or confirm your current treatment plan. Another hospital or doctor may offer a different treatment or more useful support services. They may be a better fit for you in other ways. Do not worry about hurt feelings. You can always return to the first doctor if you want.

A second opinion may:

- Help you feel more confident that you are getting the best possible care
- Be especially helpful if one treatment stops working and you're looking for the next one to try
- Give you some new options for treatment or management of side effects

If possible, try to get a second opinion from a doctor at a National Cancer Institute cancer center or university hospital, especially if you have advanced or metastatic cancer.

## Treatment Planning

As you discuss treatment, you will be asked to make decisions when you are getting started and along the way. You might help choose the type of treatment, the timing of treatment, or the order of treatments. You may have the option to try a clinical trial. Making these choices is called treatment planning.

Good communication with your doctors will make treatment planning easier. Talk with them about your needs and preferences. Work to understand what they are saying about the stage and location of the cancer, and why one treatment might be more effective than another. The results of lab tests and biomarkers may affect your treatment options. Ask questions.

Treatment planning takes into account:

- The stage and location of the cancer
- Your symptoms
- The side effects of treatments
- Your goals for the treatment
- Your personal preferences



## Open to Options

If you are facing a cancer treatment decision, the Cancer Support Community's Open to Options program can help you prepare a list of personalized questions to share with your doctor. Our Open to Options® specialists can help you create a written list of specific questions about your treatment plan for your doctor. **Call 888-793-9355 to schedule an appointment or to find a Cancer Support Community near you.**

### Tips for Treatment Planning

- Take someone with you to appointments, for support and an extra set of eyes and ears. If you go to an appointment alone, bring a recorder or use a cell phone to record your conversation with your doctor. Be sure to ask your doctor if it is okay to record.
- Talk to your health care team or financial navigator about ways to manage treatment costs before you start treatment.
- If you feel your health care team is not addressing your concerns, consider getting a second opinion.
- Write down your questions before each doctor's visit. Keep a journal to track your side effects and results over time.
- Talk with your doctor about biomarker testing and how the test results may impact your treatment.
- Learn the words that doctors use to talk about colorectal cancer. This can help you better understand your test results and treatment options.

## Treatment Options

Treatment for colorectal cancer will depend on the stage and location of the cancer, your general health, and your preferences.

Try to learn about the options and work with your health care team to make decisions that are right for you.

### SURGERY

Surgery is usually the first treatment for colon cancer and for some rectal cancers. The goal is to remove as much of the cancer as possible. For early-stage cancers, it may be the only treatment needed.

#### Colon Cancer

In the very early stages, the cancer may be removed during a colonoscopy. The removal is called a **polypectomy** or a **local excision**.

If this is not possible, a **colon resection** may be recommended. The surgeon will remove all or part of the colon. It can be done one of two ways. In open surgery, the surgeon makes a long cut in the abdomen to remove the tumor. In laparoscopic surgery, the surgeon makes small cuts in the abdomen. They then use the camera and small tools to perform the surgery. Laparoscopic surgery usually has a shorter recovery time than open surgery.

#### Rectal Cancer

Several procedures are used to treat rectal cancer. As with colon cancer, some cancers can be removed during colonoscopy with a **polypectomy** or **local excision**. When that is not possible, the type of surgery depends on the stage and location of the cancer.

The doctor will try to preserve the anal sphincter. This muscle controls bowel movements. It helps with good bowel function. Approaches include:

- A small cancer that is contained within the inner layers of the rectum may be removed through the anus using one of these procedures:
  - **Transanal excision** is used for early-stage cancers found in the lower rectum.





- **Transanal endoscopic microsurgery (TEMS)** is used for cancers that are higher in the rectum.
- **Transanal minimally invasive surgery (TAMIS)** is a faster procedure with a shorter recovery.
- **Total Mesorectal Excision (TME)** – This procedure is done laparoscopically when the tumor is larger. A surgeon will remove the rectum as well as fat, blood vessels, and lymph nodes around it in one piece. **Transanal total mesorectal excision (TaTME)** is a newer version of TME. It may be used when cancer is found in the lower part of the rectum and can be reached through the anus. You may receive chemotherapy and radiation before a TME.
- If the cancer has spread widely, a more major surgery may be needed. A surgeon may remove organs such as the bladder, ovaries, cervix, or vagina. If possible, your doctor will try to spare the anal sphincter. Procedures include **low anterior resection** and **abdominoperineal resection with ostomy**.

Chemotherapy and radiation are often given before surgery. This will shrink the size of the tumor and possibly reduce the need to remove the anal sphincter. When the cancer has spread to the outer layers of the rectum wall or to the lymph nodes, chemotherapy and radiation may be given together. This is called chemoradiation.

Surgery for rectal cancer takes special skill because the cancer is harder to reach. Be sure to choose a surgeon who is very experienced with rectal cancer.

### Ostomy

If the cancer is blocking a passage, you may need an ostomy. This procedure makes a new path for stool and other waste. A surgeon creates a stoma (opening in your abdomen). They then connect

the end of your colon or small intestine to the opening. An ostomy bag that fastens to your skin over the stoma is used to collect waste. Some ostomies are reversible after the surgery heals and some are permanent. Types include:

- A **colostomy** bypasses part of the colon. It is used more often in rectal cancer than in colon cancer. Output from a colostomy may be semi-solid or solid depending on where the ostomy is created.
- An **ileostomy** bypasses the entire colon. It is made at the end of the small intestine (ileum). Ileostomy output is liquid.

The side effects of surgery for colorectal cancer may include pain, scarring, gas, cramps, and bloating. It may take a while for bowel function to recover. An ostomy requires special care.

### ABLATION

Ablation is any treatment that destroys tissue. It is used to treat small tumors, often in colorectal cancer that has started to spread to other parts of the body like the liver or lungs.

**Radiofrequency ablation** uses electric currents and heat to kill cancer cells. They are delivered through a probe. The probe is placed into the tumor either through the skin or through a cut in the body. **Cryoablation** freezes cancer cells to destroy them. The side effects of ablation can include soreness at the site, stomach pain, liver infection, internal bleeding, or fever.

### CHEMORADIATION

You may receive chemotherapy (“chemo”) and radiation during the same time period. This may be done before surgery to shrink the tumor. The chemo weakens the tumor cells. They are then more sensitive to radiation. This treatment is used for locally advanced rectal cancer. You may have the side effects of both treatments. Refer to chemotherapy and radiation to learn more.



## RADIATION THERAPY

Radiation therapy is the use of high-energy rays to kill or damage cancer cells. The goal is to damage as many cancer cells as possible without harming healthy tissue. To lessen damage, doses are very precise, and treatment is often spaced out.

Radiation is a common treatment for rectal cancer, less so for colon cancer. It often takes the form of external beam radiation. The radiation is given by a machine outside of the body. Less often, internal radiation (brachytherapy) is used. The radiation is placed in the body through the rectum.

You may have radiation before, during, or after surgery. When it is given before or after, it may be combined with chemotherapy. This is called chemoradiation. Radiation given during surgery is called intraoperative radiation therapy.

Common side effects include fatigue, burning or soreness at the site of the radiation, and loose or bloody stools. Radiation to the pelvic area can affect sexual health or fertility. If you still plan to have biological children, ask about fertility before you start treatment.

## CHEMOTHERAPY

Chemotherapy uses drugs to destroy cancer cells. It is a systemic (whole body) treatment. This treatment kills fast-growing cancer cells but can also harm fast-growing healthy cells. This can lead to side effects.

For colon cancer, chemotherapy may be given before or after surgery. When given after, it is called an “adjuvant” treatment. Given before, it is called a “neoadjuvant” treatment. You may receive more than one drug at a time, often through an IV to a vein. Some drugs come in pill form. Each chemotherapy drug has its own set of side effects and ways of working. Common side effects include nausea, vomiting, fatigue,

hair loss, numbness or tingling in the hands or feet, mouth sores, cognitive changes, and risk of infection.

## TARGETED THERAPY

Targeted therapy aims to more precisely attack cancer cells. These drugs target changes in the genes or proteins of cancer cells that help them grow, divide, and spread. They keep cancer from growing and spreading with less harm to cells that are not cancer. Targeted therapy is often given to patients with metastatic (advanced) colorectal cancer. It is not usually given before surgery (neoadjuvant) or after surgery (adjuvant).

Targeted drugs for colorectal cancer work in different ways. They block blood vessel growth or interfere with signals or proteins that lead to cancer growth. Some work against the biomarkers BRAF, EGFR, NTRK, or VEGF. Some are given through an IV to a vein. Others come in pill form. The side effects will vary depending on the type of drug. They may be similar to chemotherapy side effects. Certain drugs can cause high blood pressure or skin rashes or itching.

## IMMUNOTHERAPY

Immunotherapy uses the body’s natural defenses to find, attack, and kill cancer cells. It may help to think about it as boosting the immune system’s response. Immunotherapy may be used to treat advanced colorectal cancers that are MSI-High or dMMR positive.

The drugs used to treat colorectal cancer are considered checkpoint inhibitors. They include:

- **PD-1 inhibitors** – These drugs target a protein on immune cells called PD-1. This protein can prevent the immune system from attacking cancer cells. By blocking it, the drugs help the immune system fight cancer.
- **CTLA-4 inhibitors** – These drugs block a different protein that keeps immune cells



from attacking cancer cells. Given through a vein or an IV, they are sometimes used at the same time as a PD-1 inhibitor.

These drugs are given through an IV to a vein. Possible side effects include cough, decreased appetite, diarrhea, fatigue, fever, nausea, pain in the muscles or joints, and skin problems (rashes, itching). It is very important to report any side effects to your doctor right away. In rare cases, CTLA-4 inhibitors can cause severe reactions, even months after treatment.

## Managing Side Effects

How you feel can affect your mood and outlook. It is hard to stay positive when you are tired, in pain, or uncomfortable. Managing symptoms and side effects can not only make you feel better physically but emotionally as well. It helps to

learn about the side effects of treatment before you begin so you will know what to expect. When you know more, you can work with your health care team to manage your quality of life during and after treatment.

Here are a few examples of common side effects of colorectal cancer treatment:

**Changes in Bowels** – Colorectal cancer treatment can affect your bowels in different ways. Surgery can lead to changes in bowel function. You may notice more frequent or looser stools. Your health care team can offer advice on what and when to eat to retrain your bowels.

- Diarrhea is a common side effect of many treatments. Eating foods like bananas, toast, and rice may help. Medicines can work well against diarrhea too.

## KEY THINGS TO KNOW ABOUT CLINICAL TRIALS

You may consider participating in a clinical trial. Clinical trials are research studies to test new treatments or learn how to use existing treatments better. Today's standard treatments were developed in yesterday's clinical trials. Today's clinical trials may become tomorrow's standard treatments. It's important to know that:

- No one receives a placebo or “sugar pill” in place of appropriate treatments.
- Clinical trials test new treatments, new combinations of treatments, or better ways of using existing treatments.
- The U.S. Food and Drug Administration (FDA) and local review boards oversee all U.S. clinical trials to keep patients safe.
- If you join a clinical trial, you can leave at any time.
- Every doctor does not have the same trials.
- Often, the trial pays the costs of the drug being studied. Then, your health insurance and your copay cover “standard” treatment costs. Be sure to ask about the costs to you.
- There are phase I, phase II, and phase III clinical trials; make sure you understand the goals and risks of a clinical trial you join.
- Some clinical trials may make you ineligible for a future trial or treatment, so make sure to ask questions about this. See the resources below for help finding clinical trials that might be right for you.

In addition to talking with your doctor, you can look up clinical trials online if you know the type and stage of the cancer. Learn more here: [www.CancerSupportCommunity.org/Find-Clinical-Trial](http://www.CancerSupportCommunity.org/Find-Clinical-Trial)



- Constipation also can occur and can be helped with high-fiber foods, water or juices (especially prune), and light exercise like walking.

**Fatigue** – Fatigue is a feeling of tiredness that does not always go away with rest. It may be hard to accept that you cannot do as much as before. Try to pay attention to when you have energy. Notice the times of day and how long your energy lasts. Plan activities, work, or chores for those times. As much as you can, make time both to be active and to rest. Accept your limitations and ask for help when you need it.

**Nausea and vomiting** – Nausea and vomiting are very common. There are medicines that can be taken before and after symptoms appear. Some people find it helpful to eat smaller meals, focus on bland foods, and drink more liquids. You also might try ginger tea or gum or chamomile tea. Relaxation exercises, like mindfulness or meditation, can help too.

If side effects persist or are hard to manage, talk with your health care team. They can recommend medicines that might help. Your doctor may suggest lowering the dose of your treatment if needed. Ask to see a palliative care specialist if possible.

Learn more about the side effects of cancer treatment and how to manage them at [www.CancerSupportCommunity.org/Managing-Side-Effects](http://www.CancerSupportCommunity.org/Managing-Side-Effects).

## Coping with an Ostomy

It takes time to get used to living with an ostomy. There are some changes you may need to make. But you can go on to live an active and healthy life.

- **Telling people about the ostomy** – If you don't tell people about your ostomy and pouch, they won't be able to tell you have it. You may need to tell your boss because you

can't lift heavy items or because you need to use the bathroom more to manage the ostomy pouch.

- **Caring for the ostomy** – Change your pouch every three to seven days. If you have itching or burning, it means it's time to change the wafer (the part that goes against the skin and has a hole that fits around your stoma). If you wear a pouch for too long, it may damage your skin.
- **Emergency supply kit** – Carry an emergency kit with supplies such as pouches, an extra pre-cut flange, a roll of tape, a mirror, wet wipes, and cotton swabs.
- **Showering and bathing** – You can bathe with or without the pouch in place. If you want to take a shower or bath with the pouch off, you can. You can leave the pouch on while bathing or cover it with plastic to keep it dry.
- **Clothing to hide the ostomy** – It may take a while to find a look you are comfortable with that works with a pouch but there are more options now than ever before. Loose-fitting tops and bottoms can help hide the pouch. You may find belts or some waistbands uncomfortable. Clothes with higher or looser waistbands may work better. You can buy ostomy swimsuits through specialty shops and websites.
- **Odor control** – You can buy liquid and solid products to help control the odor of the pouch. Certain foods (such as asparagus, fish, garlic, and onions) can cause a stronger urine odor. You can lessen that by drinking more water or cranberry juice. Empty your pouch often. Always empty the pouch before you leave the house and when you will be away from a convenient toilet.



- **Diet changes** – You may want to limit foods and drinks that cause gas. These can include asparagus, beans, beer, broccoli, Brussels sprouts, cabbage, carbonated beverages, cauliflower, onions, and peas.
- **Physical activity** – You can do most physical activities after you heal from ostomy surgery. Talk with your doctor about the activities you want to do. They can advise on how and when to do them safely. Your doctor may suggest staying away from contact sports to avoid injuring the stoma. If contact sports are very important to you, let your doctor know.

They can recommend special products and things you can do to protect your stoma while you play. If you lift weights, ask your doctor when it is safe to start again. You can buy a special belt or binder to hold your ostomy bag in place for running, swimming, or other athletic activities. This can help prevent the ostomy bag from loosening and causing a leak.

- **Traveling with ostomy** – Pack extra supplies when you travel. If you are flying, keep some supplies in your carry-on bag in case your checked luggage gets lost. Limit what you eat before you travel.

## QUESTIONS TO ASK YOUR HEALTH CARE TEAM

There's a lot to know about a cancer diagnosis. Here are some questions to ask.

What is the exact name of the kind of cancer I have?

What is the type, subtype (if there is one), and stage?

Where did the cancer start?

Where is it located now?

[If you had a prior cancer] Is this the same type of cancer I had before?

Are there other biomarker tests, scans, or biopsies that should be done to help decide what treatment I should have?

Do you have a suggestion for where to go or someone to see for a second opinion?

Which treatment do you recommend and why?

For each treatment you consider, ask:

- What is the goal of this treatment?
- Where will treatment take place?
- How often will I go there and how long will it take?
- What are the possible side effects and how are they managed? Is there anything I can do in advance that can help?



## Cost of Care

Cancer treatment can be costly, even with health insurance. Keeping up with these costs might be overwhelming. Many people facing cancer say that financial worries about cancer costs are a big source of stress, and they don't know where to turn. There are resources that can help. Visit [www.CancerSupportCommunity.org/Cost](http://www.CancerSupportCommunity.org/Cost) for more information on managing health care costs.

## Coping with Colorectal Cancer

Cancer stirs up many feelings. It affects people who have it, their families, and loved ones. It is normal to feel sad, worried, shocked, stressed, or even panicked. The feelings may be mild or more serious. Remember that cancer can affect anyone. No one deserves cancer. And everyone with cancer deserves good care.

There are steps you can take to feel more in control and better able to move forward. It helps to:

- Learn about colorectal cancer and your treatment options.
- Communicate with your health care team. Ask questions and ask again until you understand the answers.
- Know if there are signs or symptoms that you should tell your care team about right away.
- Seek support.
- Take care of yourself. Take care of your body and mind. Try to eat healthy foods, be active, and spend time with people or on activities that bring you joy.
- Find things to look forward to, even small things like time with a friend, spring flowers blooming, or the next episode of a favorite show.

## FIND THE SUPPORT YOU NEED

- Share your feelings with friends, family members, a counselor, or a clergy person.
- A counselor or a therapist can help you cope with anxiety. Other things that can help are yoga, breathing, and relaxation exercises.
- Ask for help from friends and your community. The Cancer Support Community's [MyLifeLine.org](http://MyLifeLine.org) is a great way to coordinate this online.
- Contact the patient groups on the back page to find local and online support groups, helplines, and other ways to seek support from people who have colorectal cancer.
- Ask your health care team about resources for social, emotional, and practical support. Let them know about your concerns.
- If you search for information online, make sure you are using trusted websites. Turn to the back page to see a listing of trusted resources.



# Support for Colorectal Cancer Caregivers

Colorectal cancer affects not only those with the disease, but also the people who care for them. Caregiving for a person with colorectal cancer can be stressful and frustrating. You may feel angry, guilty, alone, afraid, or sad. If you are caring for a person with colorectal cancer:

## FIND SUPPORT

Share your feelings with others. Look for caregiver support groups, either in person or online. Ask the patient's cancer center if they have a support program for caregivers.

## LOOK FOR EXTRA HELP

Ask friends and family if they can help. If they offer, give them specific tasks. If you can afford it, consider hiring people to help care for the person with colorectal cancer. Or have them help with chores, childcare, or errands.

## TAKE BREAKS

Carve out time for yourself. Spend time with people important to you, and take time for activities you enjoy. Don't feel guilty about making time for yourself—it is important for your own health.

## TAKE CARE OF YOURSELF

Just as the person with colorectal cancer needs to pay attention to their diet, exercise, and sleep, so do you. If you smoke, find a smoking cessation program. Limit alcohol.

## LEARN ABOUT THE FAMILY AND MEDICAL LEAVE ACT (FMLA)

You may qualify to take up to 12 weeks of unpaid, job-protected leave to care for a seriously ill family member.

## LEARN ABOUT FINANCIAL ASSISTANCE

You may have high out-of-pocket costs from parking, transportation, and food as part of your caregiving duties. Ask the hospital where the person with cancer is receiving treatment if they can provide help with financial counseling for caregivers.



## COLORECTAL CANCER INFORMATION AND SUPPORT

Cancer Support Community · 1-888-793-9355 · [www.CancerSupportCommunity.org](http://www.CancerSupportCommunity.org)

American Cancer Society · 800-227-2345 · [www.Cancer.org](http://www.Cancer.org)

American Cancer Society Colorectal Page · [www.Cancer.org/cancer/colon-rectal-cancer](http://www.Cancer.org/cancer/colon-rectal-cancer)

Colorectal Cancer Alliance · 877-422-2030 · [www.ccalliance.org](http://www.ccalliance.org)

Fight Colorectal Cancer · 877-427-2111 · [www.FightColorectalCancer.org](http://www.FightColorectalCancer.org)

Patient Empowerment Network · [www.PowerfulPatients.org/Colon](http://www.PowerfulPatients.org/Colon)

United Ostomy Associations of America · 800-826-0826 · [www.Ostomy.org](http://www.Ostomy.org)

## CANCER SUPPORT COMMUNITY RESOURCES

**Cancer Support Helpline®** — Have questions, concerns or looking for resources? Call CSC's toll-free Cancer Support Helpline (888-793-9355), available in 200 languages Mon-Fri 9am-8pm ET and Sat 9am-5pm ET.

**Open to Options®** — Preparing for your next appointment? Our trained specialists can help you create a list of questions to share with your doctor. Make an appointment by calling 888-793-9355 or by contacting your local CSC or Gilda's Club.

**Frankly Speaking about Cancer®** — Trusted information for cancer patients and their loved ones is available through publications, online, and in-person programs.

**Services at Local CSCs and Gilda's Clubs** — With the help of 170 locations, CSC and Gilda's Club affiliates provide services free of charge to people touched by cancer. Attend support groups, educational sessions, wellness programs, and more at a location near you. [www.CancerSupportCommunity.org/FindLocation](http://www.CancerSupportCommunity.org/FindLocation).

**Cancer Experience Registry®** — Help others by sharing your cancer patient or cancer caregiver experience via survey at [www.CancerExperienceRegistry.org](http://www.CancerExperienceRegistry.org).

**MyLifeLine** — CSC's private, online community allows patients and caregivers to easily connect with friends and family to receive social, emotional, and practical support throughout the cancer journey and beyond. Sign up at [www.MyLifeLine.org](http://www.MyLifeLine.org).

**Grassroots Network** — Make sure your voice is heard by federal and state policy makers on issues affecting cancer patients and survivors by joining our Network at [www.CancerSupportCommunity.org/become-advocate](http://www.CancerSupportCommunity.org/become-advocate).

Photos are stock images posed by models.

The Cancer Support Community and its partners provide this information as a service. This publication is not intended to take the place of medical care or the advice of your doctor. We strongly suggest consulting your doctor or other health care professionals to answer questions and learn more.

This publication is available to download and print yourself at [www.CancerSupportCommunity.org/CRC](http://www.CancerSupportCommunity.org/CRC). For print copies of this publication or other information about coping with cancer, visit **Orders**. [CancerSupportCommunity.org](http://CancerSupportCommunity.org)

This publication was made possible through generous support from:



Frankly Speaking About  
Cancer: Colorectal Cancer  
PROGRAM PARTNER

