

# Metastatic Colorectal Cancer

Receiving a metastatic colorectal cancer diagnosis can be overwhelming. It may be a challenge to figure out what resources are available to you. This fact sheet will help you understand your diagnosis, possible treatment options, and how to plan for care. It includes questions for you to review with your care team. It also has additional resources to help you be an active member in the treatment planning process.

## WHAT IS METASTATIC COLORECTAL CANCER

Metastatic colorectal cancer (mCRC) is a cancer that begins in the lowest part of the digestive system. It can form in the large intestine, colon, or rectum. Sometimes colorectal cancer is called colon cancer or rectal cancer, depending on where it starts. When cancer spreads to other organs or the lymph nodes, it is considered metastatic. For some people, mCRC may be the first cancer diagnosis they receive. Others may receive a mCRC diagnosis after the disease has come back or progressed. mCRC may also be called stage IV colorectal cancer.

To learn more about Colorectal Cancer, visit [www.CancerSupportCommunity.org/Colorectal-Cancer](http://www.CancerSupportCommunity.org/Colorectal-Cancer).



## DIAGNOSIS

If your doctor suspects colorectal cancer, they will perform a series of exams and tests. They will try to learn as much as possible about the type of cancer, where it started, and where 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.
- **Colonoscopy:** Your doctor will insert a camera on a long, flexible tube through your anus and rectum to check your colon.
- **Blood Tests:** Your doctor will ask for a complete blood count (CBC).
- **Imaging Tests (Scans):** Your doctor may use different kinds of imaging to diagnosis colorectal cancer. This may include a computerized tomography (CT or CAT) scan. They may also request an MRI scan. These tests allow your doctor to see where the cancer is and if it has spread to other parts of the body.

## KNOWING YOUR HISTORY: GENETIC TESTING

Genetic testing looks for mutations or changes in your genes. This is especially important if you have a family history of colorectal cancer. Genetic testing results can tell you and your doctor if you are at risk for certain conditions. This includes familial adenomatous polyposis (FAP) or Lynch syndrome. These conditions can increase a person's risk of developing colorectal cancer. If you have genetic testing, share the results with your loved ones even if they are negative. This information can help others take the necessary steps for their health.

### YOUR HEALTH CARE TEAM

You are the expert in your cancer experience. You will work with your care team to make decisions that help you to achieve your health goals. Here are some people you may work with:

**Gastroenterologist:** A doctor trained in diagnosing and treating diseases of the digestive system. Often, you will first meet with a gastroenterologist for a colonoscopy.

**Medical oncologist:** A doctor who is specially trained to diagnose and treat cancer. They use chemotherapy and other drugs to treat cancer.

**Radiation oncologist:** A doctor who is specially trained to treat cancer with radiation therapy.

**Colorectal surgeon:** This doctor specializes in performing surgery in the colon and rectum.

**Nurses:** You will have the most direct contact with your nurses. Oncology nurses have special training in caring for people with cancer.

**Palliative care doctor:** This person focuses on improving patients' quality of life. They can be helpful if you are having difficult

symptoms, pain, or side effects. Palliative care is different from end-of-life care or hospice. You can see a palliative care doctor at any point during your treatment.

**Genetic counselor:** This person is trained to identify a person's risk of having any inherited conditions. If you go through genetic testing, they will review the test results with you. They can support you and your family as you make any decisions based on these results.

**Registered oncology dietitian:** This person specializes in working with cancer patients. They can help you maintain a healthy diet and get proper nutrition throughout treatment and recovery.

**Oncology social worker:** This person assists with the social and emotional needs of cancer patients. Social workers can help you and your family members find support groups and other psychosocial resources.

**Patient or nurse navigator:** Navigators help you manage your care. They help schedule appointments, get answers to your questions, and support you during your treatment.





## BIOMARKER TESTING

Biomarker testing looks for biomarkers in your cancer sample. A biomarker is a sign of disease or abnormal function. It can be measured in a sample of your blood, tissue, or bodily fluid. In cancer, biomarkers are often used to help choose the best treatment for you. These biomarkers can be proteins, genes, or gene mutations. They are often referred to by a 3 or 4 letter abbreviation. Biomarkers can tell your doctor what subtype of cancer you have.

Biomarker testing helps your doctor match the right drugs to the specific subtype of cancer you have. For mCRC, a sample of your cancer is collected from your blood, bodily fluids, or tissue taken during surgery or biopsy. Your sample is sent to a lab. The test looks for biomarkers in your cancer sample. Common biomarkers that can cause colorectal cancer cells to grow and divide include KRAS, NRAS, and BRAF. Your cancer may not respond to the same treatment options that other mCRC patients receive

depending on the biomarkers present. The test results can help determine what treatment options may be best for you.

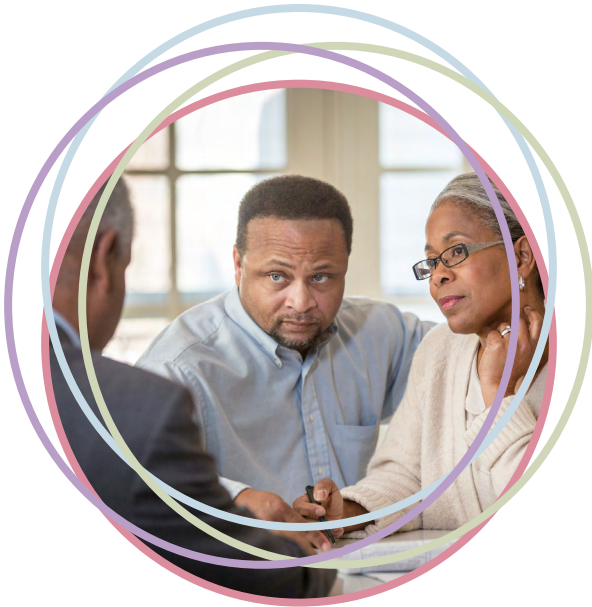
## TREATMENT PLANNING

After receiving a cancer diagnosis, you and your care team should talk about next steps and treatment options. You might help choose the type of treatment, the timing of treatment, or the order of treatments. You may have the option to join a clinical trial. Making these choices is called treatment planning. As you are making treatment decisions, think about how you want your life to be and what your goals are. Make sure you and your loved one's voices are included when making these decisions.

mCRC has multiple treatment options, including:

**Chemotherapy** (also called chemo) uses drugs to destroy or damage fast-growing cells like cancer cells. It is used to shrink tumors, slow cancer's growth, relieve symptoms, or help people live longer.





Chemotherapy drugs may be given through an IV in the vein, orally by a pill, or by injection.

**Targeted therapy** uses drugs to target specific changes in cancer cells that help them grow, divide, and spread. Targeted therapy drugs are designed to be more precise. They fight cancer cells while causing less harm to other cells in the body.

**Immunotherapy** works with the body's immune system to find, attack, and kill cancer cells. These drugs can work in different ways. Some boost the immune system, so it can fight cancer better. Other immunotherapy drugs help the immune system better recognize cancer cells.

**Radiation therapy** is when strong energy beams are used to shrink tumors, relieve pain and pressure, decrease symptoms, and improve quality of life.

**Surgery** can be a treatment option for some diagnosed with mCRC. In some areas of the body, the cancer can be surgically removed.

When an organ in the body is not working well, doctors may recommend a surgical **ostomy**. An ostomy is an opening in the skin created during surgery. This opening allows waste like feces or urine to exit the

body into an external pouch. Some ostomies are temporary and are only needed for a short period of time. This may be due to the side effects of a cancer treatment or a medical complication. A permanent ostomy may be needed if certain organs can no longer function or are removed.

**Palliative care** addresses possible symptoms caused by the cancer or side effects from treatment, such as pain. It is different from hospice care and end of life care. Palliative care may help you with physical, social, emotional, or spiritual concerns while you are in active treatment. Palliative care or supportive care helps you maintain your best possible quality of life.

**Hospice care** can provide care and maximize comfort and quality of life to people affected by cancer at the end of life. Hospice care is provided by a trained nurse or health care worker. A hospice team is available to meet your physical and emotional needs, as well as the emotional needs of your family.

**Clinical trials** find new and better ways to treat cancer. A clinical trial may be the only way to gain access to a promising new treatment option. Today, the U.S. Food and Drug Administration (FDA) oversees clinical trials to keep all patients safe.

## 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).



## QUESTIONS TO ASK YOUR HEALTH CARE TEAM

Should I be tested for inherited cancer syndromes?

Have you tested my tumor for biomarkers? If so, how will this impact my treatment?  
If not, can it be tested?

What are my treatment options?

Do I qualify for any clinical trials?

What are the potential side effects of treatment? How can I prepare for them?

How and when will you determine if the treatment is working?

Will I need an ostomy? If so, how will having an ostomy change my daily life?

What support services are available to me, my family, and my caregivers?

How do I go about getting a second opinion?

Is there a financial counselor or support specialist I can talk to about the cost of care?

Can we talk about advance care planning?





## **IMPACT OF COLORECTAL CANCER TREATMENT**

Treatment for metastatic colorectal cancer may physically change your body. Whether due to surgery, weight change, or hair loss, you may feel like your body is different from before the diagnosis. Body changes may have a negative impact on your body image or the thoughts and feelings you have towards your physical appearance. Talking with your care team about what changes may occur can help you mentally prepare. You can also meet with social workers and licensed counselors to share your feelings and find helpful coping mechanisms.

## **ADVANCE CARE PLANNING**

Learning you have cancer can change the way you think about things. You may make different choices than you did before. It is common to have thoughts or concerns about end of life. This may help you recognize what and who is most important to you and make time for it or them. It also can become a source of worry and sadness.

It is important to seek support or talk with loved ones when these concerns become too much.

It is also normal to want to know about life expectancy or prognosis after an advanced cancer diagnosis. Many patients and their families find it helpful to have this information. It can help you feel more in control and help with future treatment planning. It is OK to talk with your doctor about this. They may not be able to determine your life expectancy exactly, but they can give possible averages based on the condition of your cancer. Your care team can work with you and your family to make the best decisions for you.

Another way to feel more in control of life is to make sure that your legal documents are in order. Advance care planning is the ongoing process of making decisions about what a person wants their care to look like through these documents. If you have prepared them before, revisit them to see if you want to make any changes.



If you have not, reach out to a lawyer or use online resources to do so now. Aim to make a:

- **Will** – a document that plans for the distribution of your property and money. You will be asked to identify legal guardians for your children under the age of 18. You also may need to make plans for your pets.
- **Living will or advanced directive** – a document that details your wishes about medical treatment if a time should come when you can no longer say what you want.
- **Health care proxy or medical power of attorney** – a document that allows you to name a trusted person to make decisions about your medical care if you cannot do so yourself.
- **Financial power of attorney** – this document names a trusted person who is able to make financial decisions and payments for your health care needs if you are unable to do so yourself.

- **Do Not Resuscitate (DNR) Order** – an order that your doctor writes on your chart if you do not want “heroic measures” taken in the event of a cardiac or respiratory arrest. This is used if you stop breathing or your heart stops working and you are not revived right away. The order says that you do not want to be put on machines that will keep your body alive even though you’re unconscious.

## FINDING SUPPORT

Support can come in many forms. You may need different kinds of support at different times. People diagnosed with mCRC tend to gain a great deal of support from others who have had similar experiences. It is a good idea to find support early on so that it is there when you need it. Contact organizations that specialize in colorectal cancer for social and emotional support. It can also be helpful to talk to your care team about what your needs are, and how they can help.

## CANCER SUPPORT HELPLINE®

If you need help finding resources or want help getting information about cancer, call CSC’s toll-free Cancer Support Helpline® at 888-793-9355. It is staffed by community navigators and resource specialists who can assist you Monday - Thursday 11:00 a.m.- 8:00 p.m. ET and Friday 11:00 a.m.- 6:00 p.m. ET.

## COLORECTAL CANCER RESOURCES

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

Colorectal Cancer Alliance · 1-877-422-2030 · [www.CCAlliance.org](http://www.CCAlliance.org)

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

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

Fight Colorectal Cancer · 1-877-427-2111 · [www.FightColorectalCancer.org](http://www.FightColorectalCancer.org)

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

United Ostomy Associations of America · 1-800-826-0826 · [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-Thurs 11am-8pm ET and Fri 11am-6pm 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 190 locations, CSC and Gilda's Club network partners 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).

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

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