



**STAGE III & STAGE IV COLORECTAL CANCER**



**DIAGNOSIS & TREATMENT**

**YOUR  
GUIDE  
★ IN THE ★  
FIGHT**

FIGHT COLORECTAL CANCER



# *YOUR* GUIDE ★ *IN THE* ★ FIGHT

## **FIGHT COLORECTAL CANCER**

### **DISCLAIMER**

The information and services provided by Fight Colorectal Cancer are for general informational purposes only and are not intended to be substitutes for professional medical advice, diagnoses, or treatment. If you are ill, or suspect that you are ill, see a doctor immediately. In an emergency, call 911 or go to the nearest emergency room. Fight Colorectal Cancer never recommends or endorses any specific physicians, products, or treatments for any condition.

### **FIGHT COLORECTAL CANCER**

We FIGHT to cure colorectal cancer and serve as relentless champions of hope for all affected by this disease through informed patient support, impactful policy change, and breakthrough research endeavors.

### **YOUR GUIDE IN THE FIGHT**

If you have recently been diagnosed with stage III or IV colorectal cancer (CRC), or have a loved one with the disease, this guide will give you invaluable information about how to interpret the diagnosis, realize your treatment options, and plan your path. You have options, and we will help you navigate the many decisions you will need to make.

Your Guide in the Fight is a three-part book designed to empower and point you towards trusted, credible resources.

*Your Guide in the Fight* offers information, tips, and tools to:

- Navigate your cancer treatment
- Gather information for treatment
- Manage symptoms
- Find resources for personal strength, organization and support
- Manage details from diagnosis to survivorship

### **LOOK FOR THE ICONS**



Tips and Tricks



Additional Resources



More information can be found on another page or part

# DIAGNOSIS & TREATMENT

# 1

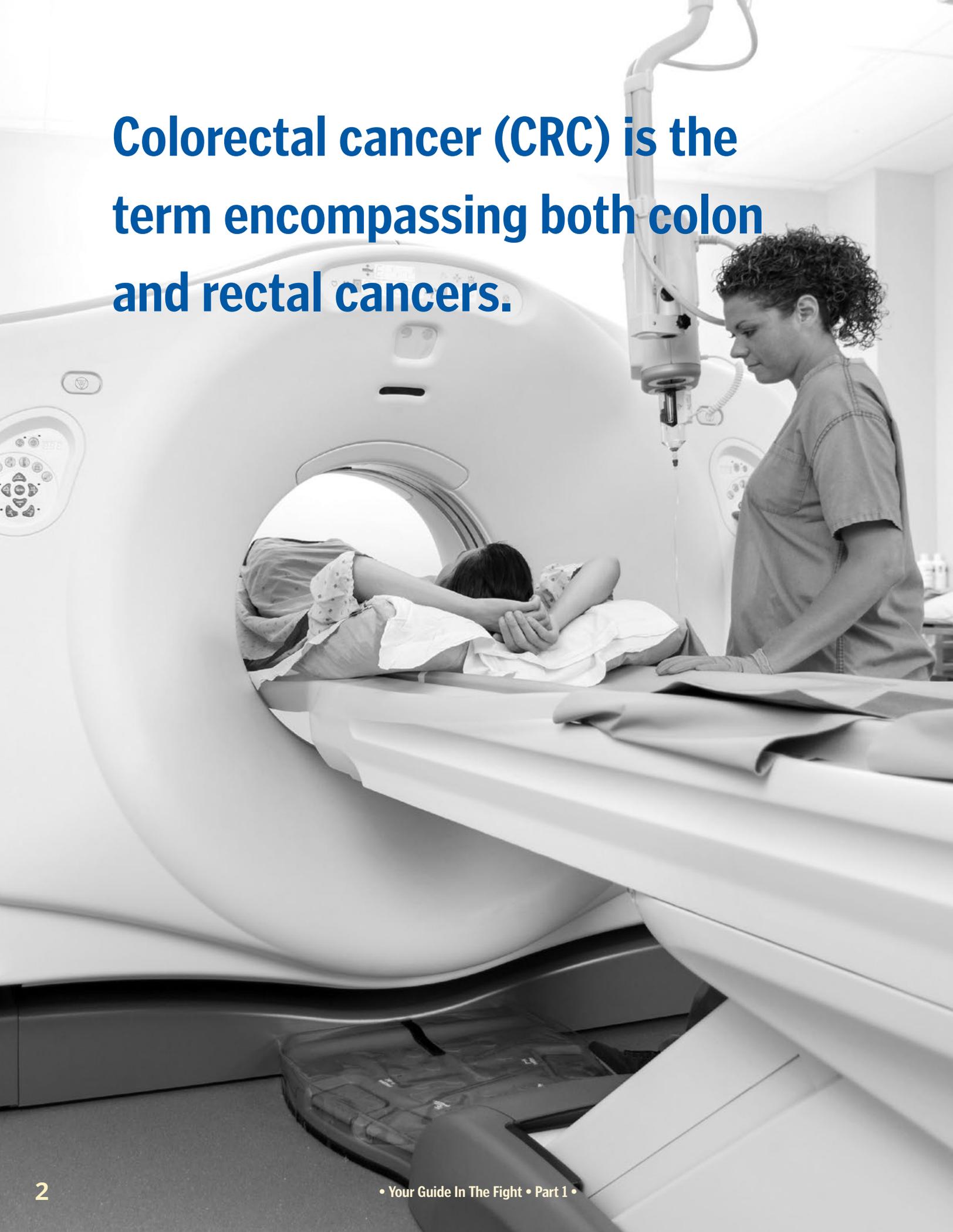
PAGE • TABLE OF CONTENTS

- 3 • Stage III and Stage IV Colorectal Cancer
- 7 • Understanding Your Diagnosis
- 11 • Talking to the Right People
- 17 • Finding Reliable Information on the Internet
- 21 • Understanding Your Treatment Options

## WHAT YOU WILL KNOW AFTER READING PART 1

- MY DIAGNOSIS
- WHO IS ON MY TREATMENT TEAM
- MY POTENTIAL TREATMENT OPTIONS
- USEFUL ONLINE RESOURCES

**Colorectal cancer (CRC) is the term encompassing both colon and rectal cancers.**



# STAGE III & STAGE IV COLORECTAL CANCER 1

---

Colorectal cancer occurs when abnormal cells form tumors in tissues of the intestines and digestive system.

THE EXACT TYPE OF colon or rectal cancer found depends on where the abnormal cells first began and how fast they grew and spread. Colorectal cancer (CRC) is the term encompassing both cancer types. CRC may have no symptoms at first, but as the tumor grows it can disrupt the body's ability to digest food and remove

waste. This may cause potentially severe bowel and abdominal problems.

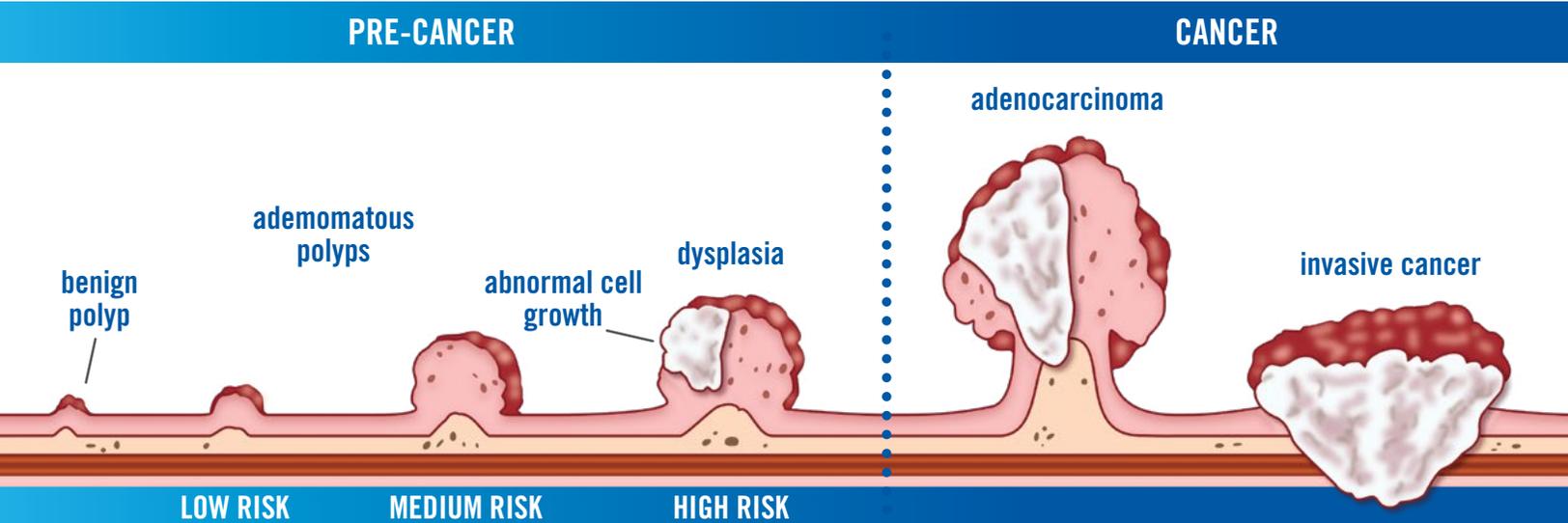
At first, the tumor is contained within the colon or rectum. This is called **local CRC**. Over time, cancerous cells may move to nearby lymph nodes, and then to other parts of the body. Stage III colorectal cancer means

that cancer cells spread to lymph nodes. Stage IV colorectal cancer (also called late-stage or metastatic CRC) means the cancer is advanced, and cancer cells have spread (**metastasized**) to form tumors in other areas of the body, such as the liver or lungs.



## COLORECTAL CANCER TERMS

- **Colon Cancer** is cancer that starts in the colon. It is sometimes called bowel cancer
- **Rectal Cancer** is cancer that forms in the tissues of the rectum (the last five to six inches of the large intestine closest to the anus)
- **Metastatic Colorectal Cancer** is cancer that spread beyond its original location in the colon or rectum
- **Recurrent Cancer** is cancer that returned after being diagnosed and treated
- **Lymph Nodes** are small, bean-shaped structures found throughout the body that filter substances in a fluid called lymph to help fight infection and disease
- **Cancer Staging** is a process that determines the extent that the cancer has grown or spread. A person's cancer stage at diagnosis will affect their treatment plan
- **Computed Tomography (CT) Scan** is a test which shows far more detail than a typical X-ray, allows doctors to see inside your body with the use of X-rays and a computer
- **Positron Emission Tomography (PET) Scan** is a test that allows your doctor to look for diseases in your body using a special dye containing radioactive tracer
- **Magnetic Resonance Imaging (MRI)** scan makes detailed pictures of the inside of your body through the use of powerful magnets, radio waves, and a computer



## Colorectal Cancer Stages

Stage	Stage Description
0	The cancer is in its earliest stage. This stage is also known as carcinoma in situ or intramucosal carcinoma (Tis). It has not grown beyond the inner layer (mucosa) of the colon or rectum.
I	The cancer has grown through the muscularis mucosa into the submucosa (T1), and it may also have grown into the muscularis propria (T2). It has not spread to nearby lymph nodes (N0) or to distant sites (M0).
IIA	The cancer has grown into the outermost layers of the colon or rectum, but has not gone through them (T3). It has not reached nearby organs and has not spread to nearby lymph nodes (N0) or to distant sites (M0).
IIB	The cancer has grown through the wall of the colon or rectum, but has not grown into other nearby tissues or organs (T4a). It has not yet spread to nearby lymph nodes (N0) or to distant sites (M0).
IIC	The cancer has grown through the wall of the colon or rectum and is attached to, or has grown into other nearby tissues or organs (T4b). It has not yet spread to nearby lymph nodes (N0) or to distant sites (M0).
IIIA	<p>The cancer has grown through the mucosa into the submucosa (T1), and it may also have grown into the muscularis propria (T2). It has spread to one to three nearby lymph nodes (N1) or into areas of fat near the lymph nodes but not the nodes themselves (N1c). It has not spread to distant sites (M0).</p> <p>or</p> <p>The cancer has grown through the mucosa into the submucosa (T1). It has spread to 4 to 6 nearby lymph nodes (N2a). It has not spread to distant sites (M0).</p>
IIIB	<p>The cancer has grown into the outermost layers of the colon or rectum (T3) or through the visceral peritoneum (T4a) but has not reached nearby organs. It has spread to 1 to 3 nearby lymph nodes (N1a or N1b) or into areas of fat near the lymph nodes, but not the nodes themselves (N1c). It has not spread to distant sites (M0).</p> <p>or</p> <p>The cancer has grown into the muscularis propria (T2) or into the outermost layers of the colon or rectum (T3). It has spread to four to six nearby lymph nodes (N2a). It has not spread to distant sites (M0).</p> <p>or</p> <p>The cancer has grown through the mucosa into the submucosa (T1), and it may also have grown into the muscularis propria (T2). It has spread to 7 or more nearby lymph nodes (N2b). It has not spread to distant sites (M0).</p>
IIIC	<p>The cancer has grown through the wall of the colon or rectum (including the visceral peritoneum) but has not reached nearby organs (T4a). It has spread to 4 to 6 nearby lymph nodes (N2a). It has not spread to distant sites (M0).</p> <p>or</p> <p>The cancer has grown into the outermost layers of the colon or rectum (T3) or through the visceral peritoneum (T4a), but has not reached nearby organs. It has spread to seven or more nearby lymph nodes (N2b). It has not spread to distant sites (M0).</p> <p>or</p> <p>The cancer has grown through the wall of the colon or rectum and is attached to, or has grown into, other nearby tissues or organs (T4b). It has spread to at least one nearby lymph node or into areas of fat near the lymph nodes (N1 or N2). It has not spread to distant sites (M0).</p>
IVA	The cancer may or may not have grown through the wall of the colon or rectum (Any T). It might or might not have spread to nearby lymph nodes. (Any N). It has spread to one distant organ (such as the liver or lung) or distant set of lymph nodes, but not to distant parts of the peritoneum (the lining of the abdominal cavity) (M1a).
IVB	The cancer might or might not have grown through the wall of the colon or rectum (Any T). It might or might not have spread to nearby lymph nodes (Any N). It has spread to more than one distant organ (such as the liver or lung) or distant set of lymph nodes, but not to distant parts of the peritoneum (the lining of the abdominal cavity) (M1b).
IVC	The cancer might or might not have grown through the wall of the colon or rectum (Any T). It might or might not have spread to nearby lymph nodes (Any N). It has spread to distant parts of the peritoneum (the lining of the abdominal cavity), and may or may not have spread to distant organs or lymph nodes (M1c).

Source: American Cancer Society - <https://www.cancer.org/cancer/colon-rectal-cancer/detection-diagnosis-staging/staged.html>



# UNDERSTANDING YOUR DIAGNOSIS

# 2

You may feel a range of emotions after a cancer diagnosis, including pressure to begin treatment immediately. However, there are steps you and your doctor must take before starting treatment.

STAGING IS AN IMPORTANT PART of your diagnosis, prognosis, and treatment planning. Once established, your cancer stage will stay the same, even if the cancer **progresses** (continues to grow) **recurs** (comes back) or is in **remission** (no evidence of disease).

Your doctor will assign a clinical stage to your cancer based on blood tests and scans, in addition to your medical history and physical exam.

- Blood tests to look for certain enzymes
- Diagnostic scans, such as CT, MRI, and PET scans to show where the cancer is located

Doctors will conduct a **biopsy** (a surgical procedure to remove tumor cells) so a pathologist can determine whether or not the cells appear normal.

Testing your tumor for *biomarkers* (so you can “know your tumor type”) may help you understand if there are abnormal cell functions. Biomarker testing (also called tumor or genomic testing) may provide insight into **prognosis** (outlook or chance of recovery from CRC) and can help to predict your cancer’s response to a specific treatment. Biomarker testing helps guide treatment recommendations and decisions.

 More information on biomarker testing can be found on pages 26-27.

During the initial diagnosis phase, you will also learn about the grade of your cancer. Tumors with a large number of highly abnormal cells are called high grade, and they are known to reproduce and spread faster than cells in low-grade tumors.

To complete the staging process, CRC is classified according to the TNM system (tumor, node, metastasis) developed by the American Joint Committee on Cancer (AJCC):

- **Tumor:** How far the tumor extends from the inner lining of the colon or rectum through the layers of its walls
- **Nodes:** Whether cancer cells are found in the lymph nodes by the colon
- **Metastasis:** Whether cancer has spread beyond the large bowel and its adjacent tissues, to organs like the lungs or liver

After doctors classify a tumor with the TNM system, an overall stage is assigned, ranging from stage 0 to stage IV.

If you have stage II, III, or IV, you may receive a further classification such as A, B, or C, which helps your treatment team determine the best treatment options for your diagnosis.



### CONCERNS?

If you have concerns regarding any part of your medical treatment or with your medical provider, ask for a second opinion.

“Getting an accurate diagnosis takes time. If you feel any uncertainty, get a second or even third opinion. A good doctor welcomes second opinions.”

- Rose Hausmann, Stage IV fighter

## Stages of Colorectal Cancer Based on the TNM Classification System

Primary Tumor (T)	Stage	TNM Classification
<p><b>TX:</b> Primary tumor cannot be evaluated</p> <p><b>T0:</b> No evidence of primary tumor</p> <p><b>Tis:</b> "Carcinoma in situ" or CIS (abnormal cells are present but not yet cancer)</p> <p><b>T1, T2, T3, T4:</b> Size and/or extent of the primary tumor. The higher the T number, the larger the tumor and/or the more it has grown into nearby tissues.</p>	0	Tis, N0, M0
	I	T1-T2, N0, M0
	IIA	T3, N0, M0
	IIB	T4a, N0, M0
	IIC	T4b, N0, M0
	IIIA	T1-T2, N1, M0 T1, N2a, M0
	IIIB	T3-T4a, N1, M0 T2-T3, N2a, M0 T1-T2, N2b, M0
	IIIC	T4a, N2a, M0 T3-T4a, N2b, M0 T4b, N1-N2, M0
	IVA	Any T, Any N, M1a
	IVB	Any T, Any N, M1b

### Regional Lymph Nodes (N)

**NX:** Regional lymph nodes cannot be evaluated

**N0:** No regional lymph node involvement

**N1, N2, N3:** Degree of regional lymph node involvement (number and location of lymph nodes)

### Distant Metastasis (M)

**MX:** Distant metastasis cannot be evaluated

**M0:** No distant metastasis

**M1, M1a, M1b:** Degree of metastasis

**Finding the right people for your healthcare team can take time, and that's okay.**

# TALKING TO THE RIGHT PEOPLE

# 3

After you are diagnosed with colorectal cancer, you will need to work with a reliable healthcare team.

FINDING THE RIGHT PEOPLE for your healthcare team can take time, and that's okay. You're hiring each specialist for a very important job - hire people you want to work with!

Remember, you can meet with more than one doctor to ensure that you're working with a team that suits your needs. **Second opinions are a common way to get more information** and may help you access different treatment options or clinical trials.

 Information on clinical trials can be found on pages 30-31.

FIND DOCTORS AND SPECIALISTS THAT:

- 1 You respect
- 2 You can talk to easily
- 3 Don't make you feel rushed
- 4 Answer your questions
- 5 Help you gather information to make thoughtful treatment decisions

## KEY MEMBERS OF YOUR TEAM

A CANCER DIAGNOSIS requires a **multidisciplinary team** – a group of healthcare professionals with specialized skills and expertise.

Effective teamwork requires collaboration and communication, especially when it comes to treatment recommendations for comprehensive, high-quality care. It is important to ensure all your providers communicate with you and one another.



### TREATMENT TEAM

**ENDOSCOPIST:** A specialist trained in the use of an endoscope. Usually, the biopsy will be taken by the gastroenterologist or endoscopist at the time of colonoscopy.

**SURGEON OR SURGICAL ONCOLOGIST:** This specialist is the doctor who will perform your surgery. Look for a surgeon experienced with colon and rectal cancer. (This is especially important for rectal cancers.)

 For a referral, contact the American Society of Colon and Rectal Surgeons: [fascrs.org](http://fascrs.org)

If you are considering liver or lung surgery, you should consult with a specialist experienced with colorectal cancer metastasis.

**MEDICAL ONCOLOGIST:** This doctor specializes in the general diagnosis and treatment of cancer. Medical oncologists are experts in medications like chemotherapy, targeted therapy, and immunotherapies to treat cancer.

 For a medical oncologist, contact the American Society of Clinical Oncology [Cancer.net](http://Cancer.net) or call **888.651.3038**

**RADIATION ONCOLOGIST:** This doctor specializes in treating cancer with radiation therapy to target and kill cancer cells. Radiation treatment is often used to treat rectal cancers.

 For a radiation oncologist, contact The American Society for Radiation Oncology [astro.org](http://astro.org) or call **703-502-1550**

**ONCOLOGY NURSE:** This nurse specializes in treating side effects that result from colorectal cancer treatment. An oncology nurse may administer your treatment and can be a key resource for information and support.

**PALLIATIVE CARE DOCTOR / NURSE:** This specialist can work with your treatment team to relieve pain and manage other uncomfortable side effects. Palliative care can begin at the time of diagnosis and can continue throughout treatment.

 For more information about palliative care, read **Part 2** of *Your Guide in the Fight*.



### SUPPORT TEAM

**ONCOLOGY SOCIAL WORKER:** Social workers provide many services to cancer patients and their families. They can serve as a bridge to your medical team and offer advice and resources to help you.

**PHYSICAL/OCCUPATIONAL THERAPISTS:** You may require rehabilitation during and after treatment. A physical or occupational therapist may work with you to reach optimal physical function.



“Cancer affects far more than the body—it affects our spirit, our sense of ourselves in the world, our sense of meaning—even our sense of what’s true or not. As an oncology chaplain, I walk beside those touched by cancer, providing a compassionate presence, exploring those questions as they unfold... trusting that such connections help keep us afloat.”

- Michael Eselun, BCC Chaplain

**FERTILITY SPECIALIST:** If you are of childbearing age and considering family planning, discuss fertility preservation with your doctor before beginning treatment. Your doctor may refer you to a fertility specialist to discuss fertility preservation methods.

 For questions to ask a specialist, see page 16.

**GENETIC COUNSELOR:** In some cases, doctors may recommend seeing a genetic counselor. There are a number of genetic syndromes linked with a higher likelihood of developing colorectal cancer. Learning if you have one of the syndromes is important for treatment decisions and for alerting family members.

 For detailed information on family history, read **Part 2** of *Your Guide in the Fight* and visit [FightCRC.org](http://FightCRC.org) to download a copy of the Genetics Mini Magazine.

**HOSPICE CARE:** Hospice care teams focus on providing the best quality of life to an individual at the end of life. Unlike palliative care, hospice care is usually provided to patients with a life expectancy of less than 6 months.

 For more detailed information about hospice care, read **Part 3** of *Your Guide in the Fight*.

#### **PSYCHO-ONCOLOGIST / THERAPIST:**

These mental health professionals are trained to help you address the many challenges associated with cancer. These challenges could include adjusting to the diagnosis, the stresses of medical treatment, emotional needs, relationship navigation, and more.

**REGISTERED DIETITIAN:** A dietitian will educate you on how to eat well during and after treatment. You may find that your eating habits change during treatment. Knowing what to eat can help you stay nourished.

**CHAPLAIN/SPIRITUAL CARE:** Chaplains have the unique role of addressing existential questions asked by a patient. You can request to talk to a chaplain, or your hospital may ask you if you’d like to speak to one.



#### **PEER-TO-PEER**

**PATIENT NAVIGATOR:** These are trained individuals who guide you through the cancer continuum – from diagnosis to survivorship. They are trained to direct you to support services and any additional resources you may need.

## COMMUNICATING WITH YOUR HEALTHCARE TEAM

To ensure you have productive conversations with your healthcare team at each appointment, do your best to stay organized. Here are some tips to help get you started.

### 1 CARRY A NOTEBOOK

**Write Questions:** Write down all questions that come to mind. When you get answers, write those down too. You'll likely ask about everything from common treatment reactions to follow-up plans and logistics.

**Track Side Effects:** Keep track of symptoms or side effects that make you uncomfortable or stop you from doing things you enjoy. Use the list as a reminder to ask about relieving those problems.

 Additional resources:  
[FightCRC.org/Resources](https://www.fightcrc.org/resources)

**Keep Track of Medication:** Write a list of all supplements, vitamins, prescriptions, or over-the-counter (OTC) medications you are taking (including medication for diabetes, cholesterol or anything else).

Each of your physicians must know this information because some medications and supplements can adversely affect your treatment or may react badly with cancer drugs. Keep your list in one place so you, your caregiver, and your doctors can keep track.

**Make a “To do” List:** Keep a to-do list with your calendar to help you remember what medications to take and when, remind

you of your next appointment, and help you track when you need help with work, family, school, or other responsibilities.

### 2 BRING SOMEONE WITH YOU TO APPOINTMENTS

A second set of ears and eyes can be helpful at appointments. This can help you manage all the information about your diagnosis and treatment. A friend or family member can help you remember things and can also take notes.

### 3 USE AN ONLINE PLANNER & GET HELP WHEN YOU NEED IT

Ask your family and friends for help when you need it. An online planner can let friends and family know how to help you with everyday tasks like driving you to medical appointments, preparing dinner, watching kids, or making phone calls.

Consider resources like:

 **Lotsa Helping Hands**  
a web-based caregiving coordination service  
[RCI.LotsaHelpingHands.com](https://www.RCI.LotsaHelpingHands.com)

 **My Lifeline**  
a patient website to update family and friends and post requests  
[MyLifeLine.org](https://www.MyLifeLine.org)

 **iCancerHealth**  
an app to help you manage cancer care  
[FightCRC.org/iCancerHealth](https://www.FightCRC.org/iCancerHealth)



## FINDING TREATMENT SERVICES

Investigate your options. Learn what hospitals or medical facilities are in your town or city and the services available to you. This is especially important if you have metastatic CRC, as some treatment options are not available in community clinics. You may need to look to other cities.

- ✂ For a complete list of National Comprehensive Cancer Network institutions with a full range of experienced staff visit [NCCN.org](https://www.nccn.org)
- ✂ Call Fight CRC's toll-free resource line (**1.877.427.2111**) to speak directly with a counselor from Cancer Support Community. They can connect callers to local or national resources, including support groups, transportation services, and other programs. Available in 200 languages from 9am-9pm EST, Monday-Friday.



## FAMILY PLANNING

Treatment for colorectal cancer can affect fertility in several ways, for both men and women. If you're considering family planning, it is best to have the discussion with your care team as early as possible, and before treatment begins. This allows time for referral to a fertility specialist to learn about your risk of infertility and pursue fertility preservation. Also, fertility preservation is expensive and costs vary between geographic regions. Make sure to talk to your insurance to find out if they will cover your fertility treatment. There are a few organizations that help with costs. These include Walgreens® (<https://www.walgreens.com/topic/specialty-pharmacy/fertility-preservation.jsp>) and Livestrong® (<https://www.livestrong.org/we-can-help/livestrong-fertility>)

Questions to ask my care team **before** starting treatment:

- Q: What are my options to preserve my fertility?
- Q: How will my treatment plan affect my plans to have children in the future?
- Q: Will this treatment make me infertile? And if so, for how long?
- Q: Will my fertility preservation have any effect on my cancer treatments?
- Q: Are there any effects my treatment may have on my ability to carry a child in the future?
- Q: Can you refer me to a fertility specialist who has experience in treating cancer patients?

# FINDING RELIABLE INFORMATION ON THE INTERNET

# 4

Your treatment team is your best resource for information.

IF YOU CHOOSE TO research colorectal cancer on the Internet, take care to find information that is reliable and appropriate for your particular diagnosis. Be cautious. Not all online health information is accurate.

Many websites offer information about colorectal cancer and how to treat it. Before you believe everything you read, pay attention to the source of information. Avoid clicking on sites that randomly pop up and don't provide trustworthy information.



## CREDIBLE SOURCES

These organizations all provide trustworthy information:

- Fight Colorectal Cancer  
[FightColorectalCancer.org](https://www.fightcolorectal.org)
- American Cancer Society  
[Cancer.org](https://www.cancer.org)
- Comprehensive Cancer Centers  
[CancerCenters.Cancer.gov](https://www.cancercenters.org)
- National Cancer Institute  
[Cancer.gov](https://www.cancer.gov)

## OUR TOP SITES FOR RELIABLE INFORMATION:

These websites offer good, reliable information on colorectal cancer:

- [HealthOnNet.org](http://HealthOnNet.org) (search tool)
- [HealthFinder.gov](http://HealthFinder.gov) (healthy living, personalized health advice)
- [ncbi.nlm.nih.gov/pubmed](http://ncbi.nlm.nih.gov/pubmed) (scientific journal articles)
- [UpToDate.com](http://UpToDate.com) (peer reviewed, evidence-based medicine)
- [Cancer.gov/Types/Colorectal](http://Cancer.gov/Types/Colorectal) (information on colorectal cancer)
- [nlm.nih.gov/MedlinePlus](http://nlm.nih.gov/MedlinePlus) (health information)

It can't be overemphasized how important it is to be critical about health information you read. The same online tips apply to social media, like Facebook and Twitter. Find and follow sources you TRUST.



## WHEN SEARCHING FOR AND READING INFORMATION ONLINE:

- If you are reviewing scientific journal articles, ask your doctor to help you interpret the article's findings
- Don't hesitate to ask your treatment team to validate what you read
- Consider the top level domain:
  - A government agency has **".gov"** in the address
  - An educational institution is indicated by **".edu"** in the address
  - A professional organization like a scientific or research society will be identified as **".org"**

### NOTES

---



---



---



---



---



---

## GET STARTED ONLINE...

Fight CRC is committed to providing patients and caregivers with reliable and relevant information. We provide fact sheets, webinars, blogs, magazines, and podcasts that cover a range of topics from treatment options to survivorship.

- Bookmark our website:  
[FightCRC.org](https://fightcrc.org)

- Join our Inspire page:  
[FightCRC.org/Inspire](https://fightcrc.org/Inspire)

- @FightCRC   

---

## HOW TO READ SURVIVAL STATISTICS

Many patients ask: “How long do I have?” Don’t be surprised if your doctor doesn’t give you a firm answer. While doctors can share average statistics for people with diagnoses similar to yours, the truth is every case is unique and yours is too!

Doctors use different statistics and terms to discuss survival. Based on the type of statistic, you might run across differences in what you’re told.

### TYPES OF SURVIVAL STATISTICS:

**Five-Year Overall Survival:** the percentage of patients alive at five years after diagnosis, including deaths from cancer and other illnesses

**Five-Year Relative Survival:** the percentage of patients alive at five years after diagnosis, not including deaths from other illnesses

**Median Overall Survival:** the time at which 50 percent of patients are still alive after a diagnosis or particular treatment

**Median Disease-Free Survival:** the time at which 50 percent of patients are still alive without evidence of tumor recurrence

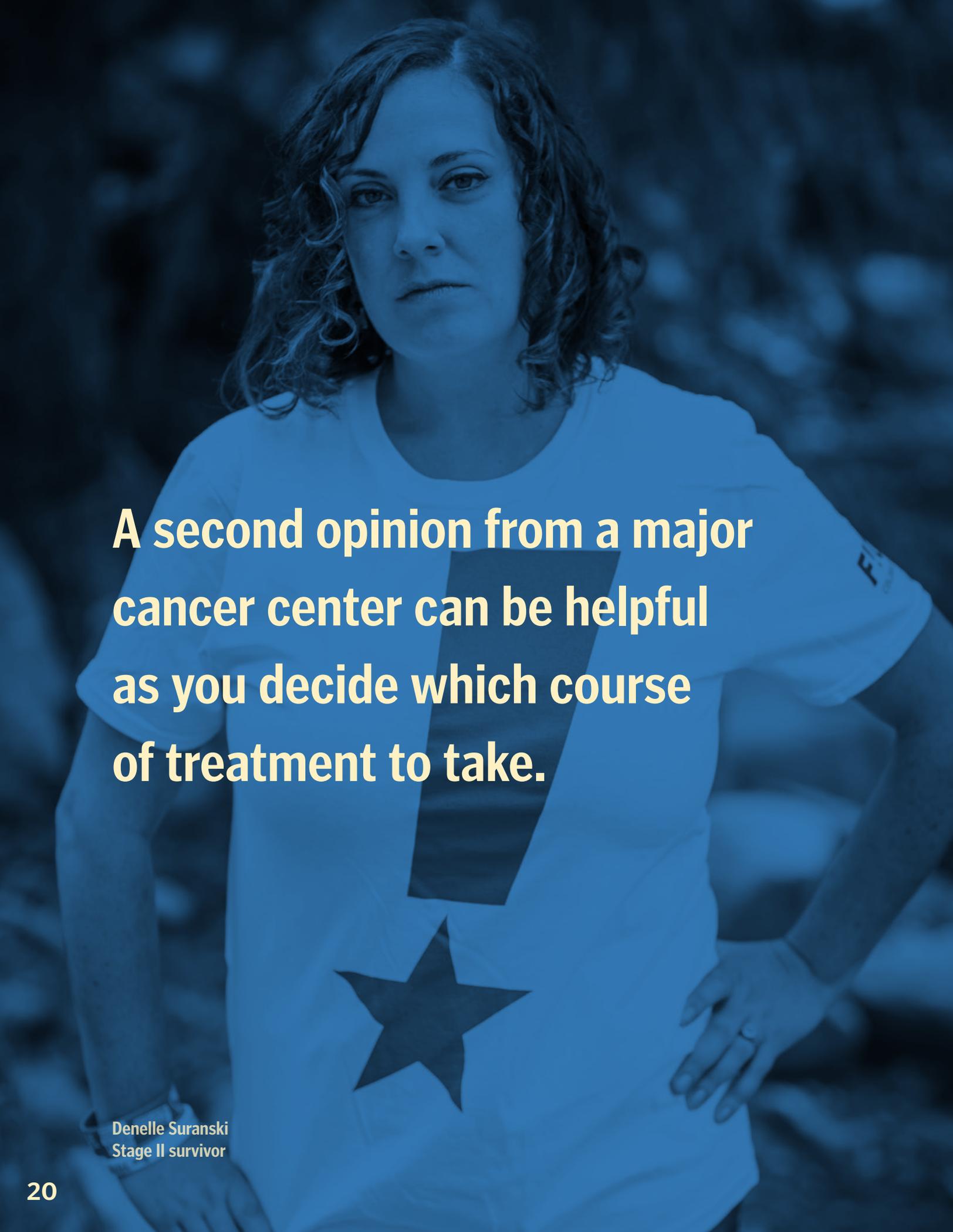
**Progression-Free Survival:** the time it takes from the start of a treatment for the cancer to grow or spread

**Recurrence:** A return of cancer after it has been initially treated (for example, a person whose cancer comes back after treatment is said to have a “recurrence”)

Doctors give survival statistics based on historical information. The numbers do not reflect current standards of care or recent improvements in chemotherapy, surgery, and radiation therapy. Improvement in treatments over time has increased the relative survival for people diagnosed at stage III and stage IV CRC.

**Remember: survival statistics may not predict the outcome of your case!**

While most cases of metastatic cancer cannot be cured, new treatments have greatly increased the time people live with advanced disease. We don’t have a cure for all metastatic CRC patients yet; however, some stage IV patients have been cured, particularly those with surgically removable metastases only to the liver.



**A second opinion from a major cancer center can be helpful as you decide which course of treatment to take.**

Denelle Suranski  
Stage II survivor

# UNDERSTANDING YOUR TREATMENT OPTIONS

# 5

Your treatment may include combinations of surgery, chemotherapy, immunotherapy, or radiation.

YOU MAY RECEIVE THE standard of care, or be offered treatment on a clinical trial. Ideally, you can work with a multidisciplinary team to discuss all of your treatment options and possible combinations.

 More on clinical trials on pages 32-33.

A second opinion from a major cancer center can be helpful as you decide which course of treatment to take.

Understanding your treatment options is an essential step. This section will explain the types of treatments and how combined treatments are used for stage III, stage IV, and recurrent CRC.

## TREATMENT TERMS

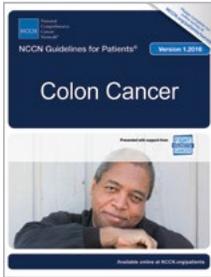
- **Primary treatment:** the main treatment for cancer
- **Neoadjuvant treatment:** given before surgery
- **Adjuvant treatment:** given after surgery
- **First-line treatment:** the first treatment given to patients with metastatic CRC
- **Second-line treatment:** treatment given if the first treatment for metastatic CRC fails

 **Remember:** you play a key role in choosing your treatment plan. Don't hesitate to ask your treatment team questions!

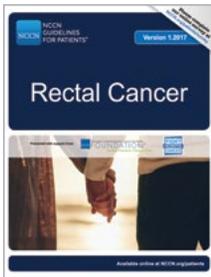
## WATCHFUL WAITING

According to the National Cancer Institute, “watchful waiting” is sometimes used in conditions that progress slowly. It is also used when the risks of treatment are greater than the possible benefits. During watchful waiting, patients may be given certain tests and exams. Talk to your doctor about this approach for your specific colon or rectal cancer.

## NCCN GUIDELINES FOR PATIENTS



The National Comprehensive Cancer Network (NCCN) is a “not-for-profit alliance of centers that develops practice guidelines to help in making informed treatment decisions.”



Fight CRC supports NCCN and their tools, which you can use as a reference. NCCN Guidelines for Patients® are easy-to-understand resources based on the same guidelines used

by your treatment team for all CRC stages.

 For more information visit: [NCCN.org](http://NCCN.org)

## FACTORS THAT MAY AFFECT YOUR TREATMENT PLAN

- The stage of cancer (whether it has spread through the colon or rectal wall, to lymph nodes, or has spread in the body) See page 9 for more info on CRC staging.
- Your overall health and how well your body can handle treatment
- Whether or not the cancer has blocked the colon or made a hole in the colon wall
- Whether or not surgery completely removed the tumor and all metastatic tumors that could be detected
- The specific tumor type, defined by laboratory tests known as biomarkers. Results from this test will help doctors personalize your treatment plan

**Remember: If you have stage III or IV CRC, ask your doctor to have a biomarker test, and make sure you know your MSI status. For more about biomarkers, see page 26.**

Your choice of treatment may also depend upon your personal preferences.

If you have...	Your personal preference might be to...	So your doctor may suggest...
Rectal Cancer	Avoid a permanent colostomy	Chemotherapy and radiation before surgery to shrink the tumor, so a smaller portion of your rectum can be surgically removed
Stage III CRC	Change your lifestyle to help prevent a recurrence	Specific diet and exercise modifications you can adopt after treatment
Metastatic cancer that's spread to the liver	Shrink your metastatic disease enough to allow for liver surgery	Talking with an experienced liver surgeon who can advise on different techniques to shrink tumors before surgery
A tumor that's pressing on a nerve and causing pain	Reduce pain through treatment	Talking with an interventional radiologist to see if targeted radiation or radiofrequency ablation could help

## GENERAL TREATMENT OPTIONS

### SURGERY

If you have been diagnosed with colon cancer, your first treatment may be surgery to remove the primary tumor. If you have been diagnosed with rectal cancer, you may receive radiation and chemotherapy before surgery.

HERE IS WHAT TO EXPECT:

#### *BEFORE* surgery:

- Your blood counts will be measured
- Your blood chemistry and CEA levels will be evaluated (read more about CEA on page 26)
- You will have a CT scan of the chest, abdomen and pelvis, or a PET scan, to determine exactly where the cancer is located. Many rectal cancer patients will have an MRI and/or an endorectal ultrasound

#### *AFTER* surgery:

- The same tests noted above are often done again after surgery to compare results
- Surgery alone is not enough to best treat stage III or stage IV CRC, so your medical team will likely recommend that you undergo additional treatment

Questions to ask BEFORE your initial surgery...	Questions to ask AFTER your initial surgery...
What stage of cancer do my pre-surgical diagnostic tests indicate I have?	What is my post-surgical diagnosis?
How many operations for this kind of cancer does the recommended surgical specialist perform each year? (Ideally you will work with a surgical oncologist, general surgeon or colorectal surgeon who conducts at least 12 operations yearly on your type of cancer.)	What is the stage of my cancer?
Is the specialist a certified colorectal surgeon? (This training is especially important for rectal cancer treatment.)	What additional tests should be done to increase the accuracy of my diagnosis and determine my need for additional treatment?
Should I have my tumor tested prior to surgery?	What can I do to help recover from surgery?
Will a temporary or permanent ostomy be necessary?	How soon can I return to normal activity?
Do I need chemotherapy and/or radiation therapy before or after surgery?	Is there anything I should avoid doing immediately after surgery (for example, vigorous exercise)?
How many lymph nodes do you anticipate will be removed during surgery? (At least 12 should be removed, although the surgeon may not know this answer for sure until after the pathology report is back.)	Who should I call if I have questions?

### Additional Questions to Ask Your Doctor if You're Stage IV or a Recurrent Survivor:

- Q: Where do I have metastatic tumors?
- Q: Can they be removed or treated?
- Q: How do I obtain a copy of my pathology report and testing information?
- Q: If an ostomy was performed:  
Can an ostomy expert on staff help me learn how to use the appliance?
- Q: What follow-up care or follow-up treatment will I need?

## OSTOMY

You may require a colostomy as part of your surgical treatment. Whether temporary or permanent, an ostomy creates a new path for your body's waste through a stoma, which leads your colon directly through an opening in your abdomen. An ostomy pouch fastens to the skin around the stoma to collect waste.

Whether the ostomy is temporary or permanent, **people with ostomies can live as fully as everyone else.**

Before you leave the hospital with a stoma, an ostomy nurse should show you how to:

- Empty and replace the pouch
- Carefully care for and clean the skin around your stoma
- Manage your diet and daily activities
- Determine which problems require a call to your doctor

Be patient if it takes time to get used to dealing with your ostomy pouch. If you need to try different kinds until you find the one that works best for you.

Some patients may be offered ostomy reversal surgery after treatment, while for others, it may not ever be recommended or cannot be done. The reversal is an additional surgery requiring several weeks for recovery. Talk to your doctors if a reversal surgery is something for you to consider in the future.



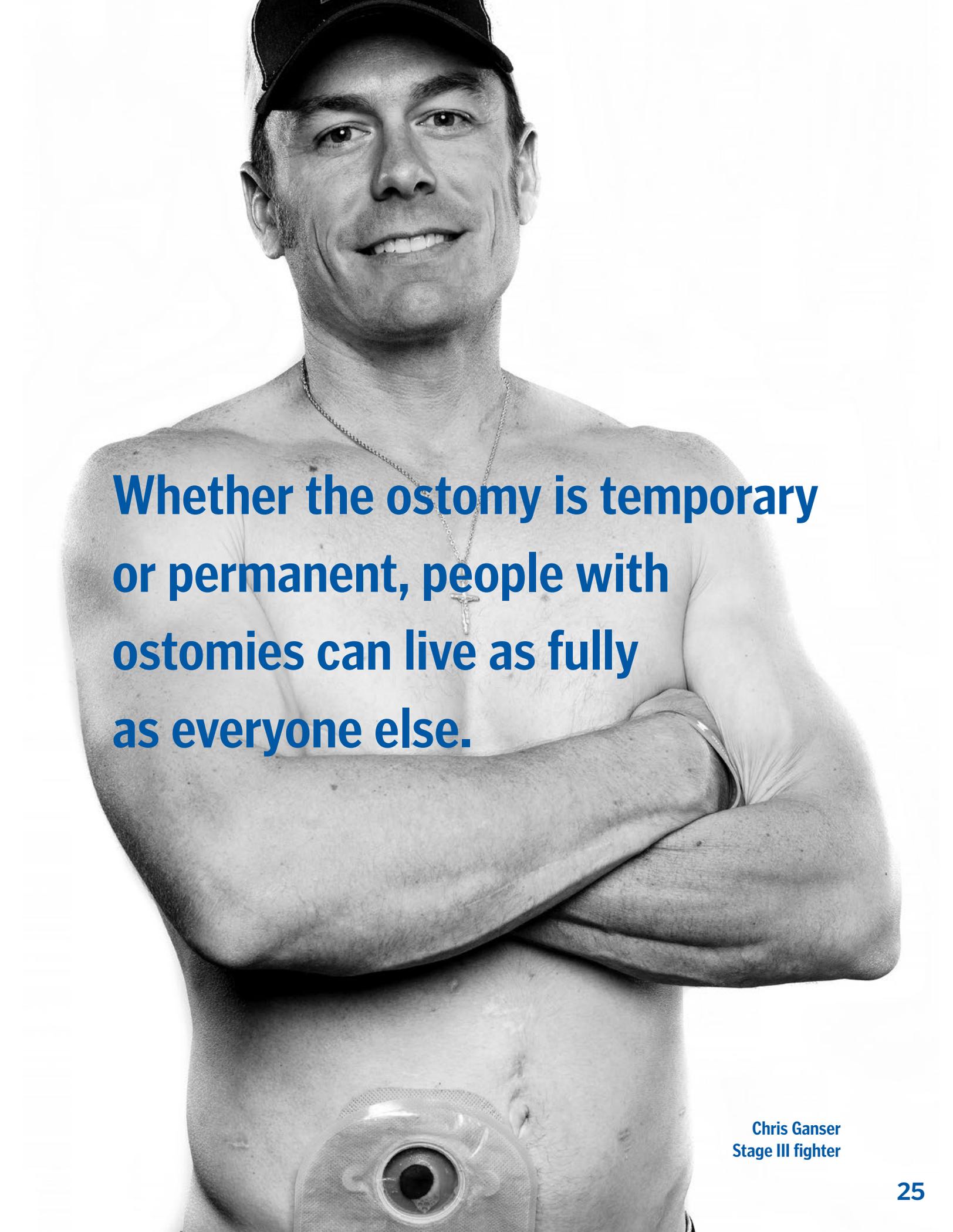
"I had a couple months to prepare and in the end I was okay with having to have a permanent colostomy. For me, I saw it as my lifeline to continue to live. I still swim, walk, and climb mountains. I do what I want to do. But you need to be very honest and upfront with your doctor. Don't be afraid to ask questions."

- Pam Seijo, Stage III survivor



### TIPS FOR ADJUSTING TO AN OSTOMY

- Ask what supplies are necessary
- Ask if there's an ostomy nurse who can help you at home after surgery
- Ask how to recognize potential problems before they occur
- Ask about alternative pouching systems if yours is uncomfortable
- Contact a local ostomy organization for support:
  - The United Ostomy Association of America: [Ostomy.org](http://Ostomy.org)



**Whether the ostomy is temporary  
or permanent, people with  
ostomies can live as fully  
as everyone else.**

**Chris Ganser  
Stage III fighter**

## BIOMARKER TESTS

You need to be tested for certain biomarkers, also called biological markers, before you receive treatment. This process is called “tumor or genomic testing” or “biomarker testing.” Biomarker testing can help your healthcare team determine treatments that may or may not be right for you.

By choosing a treatment plan that best matches your tumor type, you may experience fewer side effects and improved health. This approach to planning treatment is known as “personalized medicine.”

**Personalized medicine** uses specific information about your body and tumor to help diagnose and plan treatment, as well as find out how well the treatment is working based on your body’s biology.

### COMMON BIOMARKER TESTS FOR COLORECTAL CANCER

#### Genetic Mutations:

**KRAS and NRAS (RAS) testing:** KRAS and NRAS are genes that play an important role in instructing colorectal cancer cells to grow and divide as part of the

epidermal growth factor receptor (EGFR) process. If a biomarker test indicates a KRAS or NRAS mutation, drugs that target EGFR (like cetuximab, and panitumumab) may not be beneficial. In addition, the sidedness of your tumor—whether it arises in the right versus left colon—may affect the treatment implications of KRAS and NRAS testing.

This test is typically for stage IV patients and for any stage with a recurrence.

 *All stage IV colon and rectal cancer patients should receive KRAS and NRAS testing BEFORE chemotherapy begins.*

**BRAF testing:** BRAF is also a gene that signals cells to divide. Patients with mutant BRAF genes do not respond to EGFR-targeting drugs, and generally have a poorer prognosis. Like KRAS and NRAS testing, this test is typically recommended for stage IV patients, although it is sometimes done in patients with stage III cancer. This test can be done at the same time as KRAS and NRAS testing. The BRAF V600e mutation is a particularly aggressive cancer that requires aggressive treatment.

Vemurafenib is a drug that was included as a therapeutic option to treat BRAF V600e CRC in the 2018 version of the National Comprehensive Cancer Network’s Clinical Practice Guideline.

**PIK3CA testing:** There is some suggestion that aspirin use may help decrease the risk of recurrent colorectal cancer in patients who have the PIK3CA mutation.

#### Protein Specific:

**Carcinoembryonic antigen (CEA) testing:** CEA is a protein known as a tumor marker that may be elevated in CRC patients. Increasing levels of CEA may indicate that cancer is growing while decreasing levels may indicate that treatment is working.

**NTRK:** TRK fusions are a genetic abnormality that occurs when one of the **NTRK genes** become connected (fused) to another gene. Only a very small subset of colorectal cancer patients present with TRK, however those patients may have the option of being treated with larotrectinib (Vitrakvi®).

## DNA Abnormalities:

**Microsatellite Instability High (MSI-High) Testing:** MSI-H is what “happens” when the genes that regulate DNA function don’t work correctly. These DNA regulating genes, known as Mismatch Repair Genes (MMR), work like genetic “spell checkers” in a word processing program by correcting errors in DNA as cells divide just like spell check corrects typos. When problems occur in these spell-checking MMR genes, it means that areas of DNA start to become unstable. A high frequency of instability is called MSI-H and is found in about 15% of colon tumors. It can be found in tumors associated with genetic syndromes like Lynch syndrome, though most tumors that show MSI-H are still sporadic (not due to a genetic predisposition). A test of blood cells can tell if the finding is inherited or acquired. It is important to make this distinction because with inherited MSI, there is a higher risk of developing a second cancer, in addition to colorectal. Because of this, people with inherited MSI and their relatives may need extra screening tests. Relatives can be tested with a simple blood test if a patient has an inherited MSI-H tumor (Lynch syndrome). Patients with MSI-H tumors may respond differently to certain treatments. It is important to test tumors for this trait. It can also help determine if a patient developed colorectal cancer related to an inherited family syndrome.

## Tumor Sidedness:

There may be a difference in biology, depending on the side of the colon that cancer originates (right versus left). Based on the research, patients with right-sided tumors may not have the same results and success rates if EGFR-inhibitor therapy is

## BIOMARKER TYPES

- **Prognostic markers:** used to describe the course of a patient’s disease, not to predict a response to treatment
- **Predictive biomarkers:** determine if a patient will respond well to a particular targeted treatment

used as the first-line of treatment when compared to patients with left-sided tumors.

Ask your doctor about whether or not your treatment plan will be different based on the “sidedness of your tumor”.

***NOTE: There are very few biomarkers that have been scientifically shown to be meaningful in colorectal cancer, although research is moving aggressively in this area. For example, Fight CRC is monitoring HER2 (or human epidermal growth factor receptor 2). Talk with your healthcare team to see which biomarker tests are appropriate for you and check back at [FightCRC.org](http://FightCRC.org) for research updates.***

 For more detailed information about biomarkers and biomarker testing, visit [FightCRC.org/Biomarked](http://FightCRC.org/Biomarked) and request the Biomarked packet.

## CHEMOTHERAPY

If you have stage III or stage IV CRC, you will likely need some form of chemotherapy. It may be used alone or in combination with other targeted therapies.

Chemotherapy is used to stop or limit the growth of rapidly dividing cancer cells. It can be taken a few different ways:

- **Oral chemotherapy:** taken by mouth
- **Intravenous chemotherapy:** injected into a vein to reach cancer cells throughout the body (systemically)
- **Regional chemotherapy:** placed directly into the abdomen so the drugs mostly affect cancer cells in that area

Side effects will depend on how your chemotherapy is given and the type of chemotherapy drug you receive. Since chemotherapy attacks all rapidly dividing cells, healthy cells from all over the body may be impacted, too.

It's common to have side effects such as mouth sores, fatigue, and stomach irritation, for example. If you have side effects that you were not prepared for, or side effects that are severe, don't hesitate to call your doctor!

 For more information on side effects and side effect management, read **Part 2** of *Your Guide in the Fight*.

## ORAL CHEMOTHERAPY

Oral chemotherapy, offered as a tablet or capsule to be swallowed at home, is absorbed by the stomach. It is as strong as other forms of chemotherapy and works just as well as long as it's taken on schedule - daily, weekly, monthly, or otherwise scheduled by your doctor.

Oral chemotherapy, such as capecitabine (Xeloda®), or oral targeted therapy, such as regorafenib (Stivarga®), can cause the same side effects as other forms of chemotherapy. Your doctor will want to know about any problems you have when taking oral medication. It is important to take your pills exactly as prescribed - this is called **treatment adherence**.

 Talk with your doctor or nurse about the importance of taking your medication on time and as directed.

- **Specialty pharmacy:** a drug supplier who distributes drugs that treat complex conditions (like cancer) and are high cost - or more complex than - other drugs, which are usually provided by a standard retail pharmacy

If you are prescribed an oral chemotherapy or an oral targeted therapy, you will work with a specialty pharmacist to fulfill your prescription. Your specialty pharmacist should be considered part of your healthcare team.

Often, specialty pharmacies deliver your medication by mail, so be sure to ask your healthcare team the name of the specialty pharmacy you should be expecting to hear from. Make sure you understand exactly how to take your medication and notify them about any side effects that you experience.

## TARGETED THERAPY

Targeted therapies are drugs that block the growth of cancer by interfering with the molecules involved in tumor growth and spreading. Most targeted therapies are either small-molecule drugs or monoclonal antibodies.

- **Small-molecule drugs:** drugs that attack proteins inside cancer cells
- **Monoclonal antibodies:** drugs that attack proteins outside of cancer cells or on the cell surface

① More information on targeted therapy can be found on page 40.

### NOTES

---

---

---

---

---

---

---

---

---

---

---



## RADIATION THERAPY

Radiation therapy is not often used to treat colon cancer. When used for colon cancer, it is most often to treat tumors that have grown next to or into other organs. Radiation therapy may also be used to relieve side effects and improve quality of life.

If you have stage III or IV rectal cancer, radiation therapy may be recommended.

Radiation uses high-energy x-rays or other types of radiation to kill cancer cells. There are several types of radiation therapy. The intensity of radiation treatment and the way radiation therapy is given depends upon the type, location, and stage of the cancer being treated. Interventional radiology procedures are sometimes used when a tumor cannot be surgically removed. These techniques generally involve no large incisions and are associated with less risk, less pain, and shorter recovery times than open surgical procedures.

## TYPES OF RADIATION TREATMENT:

**External beam radiotherapy (EBRT)** uses a machine outside the body to direct radiation toward the cancer. This is the most common approach.

**Internal radiotherapy** uses a radioactive substance sealed in needles, seeds, wires, or catheters and placed directly into or near the cancer.

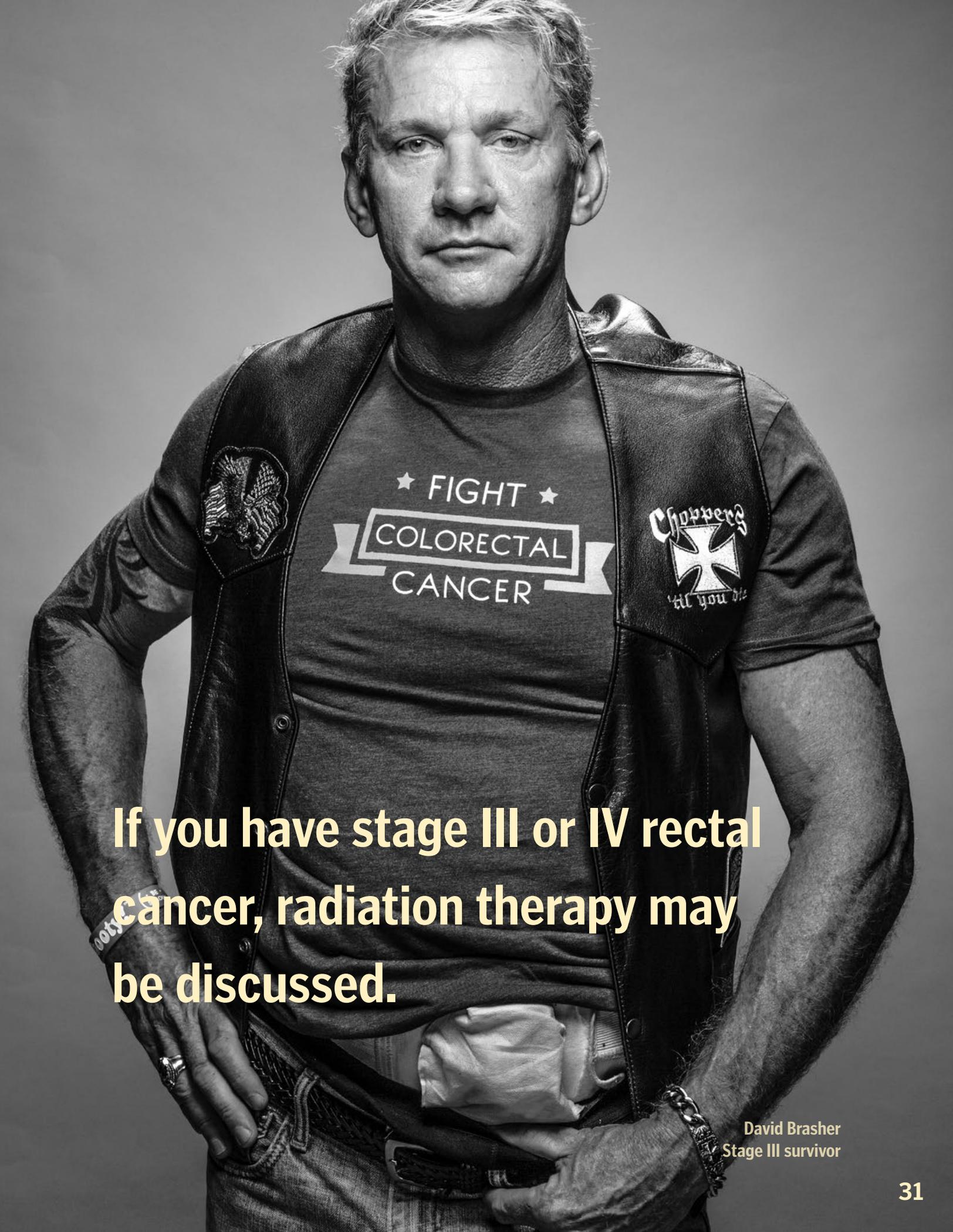
**Intensity-modulated radiotherapy (IMRT)** is a form of external beam radiation therapy. It uses small beams of varying intensity to give the highest possible doses to the tumor while avoiding as much healthy tissue exposure as possible.

**Selective Internal Radiation (SIR-Spheres® Microspheres or Theraspheres®)** are tiny beads covered with radioactive material that are injected into the liver to target liver metastases. They are a permanent implant for single-use, providing a high-energy isotope to kill cancer cells in the liver from metastasized CRC.

**Intraoperative radiotherapy (IORT)** is given during surgery for late-stage or recurrent cancer.

**Radiofrequency ablation** (using high intensity heat to destroy a tumor) or cryosurgery (the use of extreme cold to destroy a tumor) is used for patients whose tumors can't be removed by surgery.

**Radio surgery** delivers a single high dose fraction of radiation directed to the tumor to try to eliminate a tumor in a single site, such as the liver or the lung.



**If you have stage III or IV rectal cancer, radiation therapy may be discussed.**

David Brasher  
Stage III survivor

## IMMUNOTHERAPY

Immunotherapy is treatment that uses certain parts of a person's immune system to fight diseases such as cancer. The goal of immunotherapy is to boost a patient's immune reaction to the cancer cells, allowing them to fight the disease more effectively.

Checkpoint inhibitors are a type of immunotherapy that work by targeting molecules that serve as brakes on the immune response. Currently, immunotherapy for colorectal cancer is only effective in a small portion of patients who are considered microsatellite unstable, or MSI-High. (Read page 27 on biomarkers to learn more about MSI)

## CLINICAL TRIALS

It's a good idea to talk with your healthcare team to learn about clinical trials. Clinical trials test new treatments like drug therapy, surgery, radiation, and combination procedures for CRC and other cancers. There are also clinical trials that test new ways to stop cancer from recurring and reduce the side effects of cancer treatment.

All treatments go through the clinical trial process before the Food and Drug Administration (FDA) approves them for public use. Trials are designed to protect participants, while collecting information to show whether or not an experimental treatment is safe and effective. Most often patients participate in clinical trials because they hope a new treatment will benefit them, or they want to contribute to the future of medicine.



### THE FIGHT CRC CLINICAL TRIAL FINDER:

Visit Fight CRC's one-stop place to find and learn more about high-impact clinical trials for CRC patients. The Fight CRC Clinical Trial Finder is a tool that lets you search for clinical trials that are open in your geography, and for which you may be eligible. The current data are limited to MSS (microsatellite-stable) and stage IV CRC patients. Visit [TrialFinder.FightCRC.org](https://TrialFinder.FightCRC.org)

Clinical trials require a patient to qualify or be eligible to participate based on specific medical criteria.

If you're interested in a clinical trial, you will be provided clear information about the study before you decide to participate. Once on a clinical trial, your treatment team will closely monitor you. You'll report how you're doing throughout the trial and have the option to drop out at any time.

There are many types of clinical trial designs. A common type is called a randomized clinical trial (RCT). Some phase II and all phase III trials are randomized, meaning participants are divided into groups where one group gets the standard of care while the other gets the new treatment, with or without the standard of care. This allows the groups to be compared, and is considered best scientific practice. Most trials are not placebo controlled; therefore, all patients receive treatment.

Progress has been made in treating CRC over the past decades, in part due to patient participation in clinical trials. Ask your treatment team if you qualify for any clinical trials.

## QUESTIONS TO ASK YOUR TREATMENT TEAM REGARDING CLINICAL TRIALS:

- Q: Am I eligible for a clinical trial? Do you feel that a trial is a good choice for me?
- Q: How do the possible risks and benefits of the new treatment compare with other treatment options?
- Q: Are there extra procedures or visits in the trial compared with standard care?
- Q: Who will pay for the trial?
- Q: What is the standard treatment for someone in my situation?
- Q: What will my treatment schedule look like?
- Q: What are the short- and long-term side effects of the treatment you are recommending?
- Q: How will my health be monitored during treatment?
- Q: Is there a placebo?
- Q: If I'm not eligible now, will I be eligible in the future?

## CLINICAL TRIAL PHASES

**Phase I** answers the questions: how much, how safe, how often?

**Phase II** answers the question: does the new treatment do any good?

**Phase III** answers the question: what's better: a new treatment or the standard treatment?

**NOTE: Phase I trials are often not in the large databases. Look on the websites of cancer centers near you to see what they are offering, or call their oncology department.**

 Visit Fight Colorectal Cancer's clinical trials page: [FightCRC.org/ClinicalTrials](https://www.fightcancer.org/clinicaltrials)

 The National Institutes of Health Clinical Trials Matching Service: [ClinicalTrials.gov](https://www.clinicaltrials.gov)

\* All phase III and most phase II trials are required by the FDA to be listed in this website, including all government-sponsored trials and most pharmaceutical and university-sponsored trials. For specific results, refine your search by location, type of trial or treatment, or by specific drug name.



## TREATMENT OPTIONS BY DIAGNOSIS

The treatments listed here offer general information for stage III colon cancer, stage III rectal cancer, and stage IV (metastatic) disease.

### STAGE III COLON CANCER

#### SURGERY

Initial treatment for stage III colon cancer surgically removes the section of colon that contains the tumor and surrounding tissue with its blood vessels and lymph nodes.

- **Colectomy:** removes the cancerous part of the colon and nearby lymph nodes. This surgery can be done through a large incision in your abdomen, or with laparoscopic surgery through a small incision. After the cancerous part of the colon is removed (called a resection), the two ends of the remaining colon are reattached to eliminate waste through the rectum.
- **Colostomy:** creates a way for stool to be removed from the body when the colon cannot function normally. In this procedure, a stoma (opening) is made to the outside of the body and an ostomy pouch is placed around the stoma to collect and remove waste. An ostomy refers to the opening in the body for waste; while the stoma is the actual end of the intestine seen peeking through the abdominal wall. Learning how to care for your ostomy is essential for your wellbeing after this procedure. A colostomy can be temporary or permanent. See page 24.

- **Temporary Ostomy & Reversal Surgery:** a colostomy reversal is possible if the colon can heal after the resection surgery. When healing is complete (after a few months or years), a reverse colostomy surgery (colostomy take-down) is performed so the stoma will no longer be necessary. Reverse colostomy involves reconnecting the healed colon to your digestive tract using sutures that will dissolve. This allows the colon to function normally again.

#### CHEMOTHERAPY

Chemotherapy is generally recommended after surgery for stage III colon cancer patients to improve survival by preventing the cancer from coming back (recurring).

▶ Make sure that you receive biomarker testing that can help to individualize treatment.

**For patients able to tolerate combination chemotherapy that includes oxaliplatin (Eloxatin®):**

- **FOLFOX:** combination treatment of 5-FU, folinic acid, and oxaliplatin
- **FLOX:** combination with bolus dose 5-FU, folinic acid, and oxaliplatin

Severe diarrhea is more common with FLOX than FOLFOX but outcomes are similar.

**For patients who have medical reasons not to use combination chemotherapy:**

- Xeloda® (capecitabine): oral chemotherapy which is converted to 5-FU in the tissues
- 5-FU and leucovorin

Your doctor can discuss the advantages and disadvantages of each chemotherapy regimen or a clinical trial for your individual needs.

**RADIATION**

If the surgeon finds that the tumor has spread outside the colon to the wall of the abdomen or other nearby tissues, follow-up radiation treatment may be recommended. Radiation is not routine for stage III colon cancer.

---

**STAGE III RECTAL CANCER**

**SURGERY**

For rectal cancer, abdominal surgery is often required to remove tumors. You may be treated with radiation and chemotherapy before surgery.

- **Low anterior resection (LAR):** the tumor and part of the rectum is removed without affecting the anus. Then the colon is attached to the remaining part of the rectum so that after the surgery your stool can exit through the anus like it does before surgery. For some, a temporary colostomy is needed.
- **Abdominoperineal resection (APR):** one incision is made in the abdomen and another in the perineal area between the legs to remove the anus and the tissues surrounding it, including the sphincter muscle. This is a more invasive surgery than the LAR because the anus is removed. With an APR you will need a permanent colostomy to allow stool a path out of the body. It is mainly used for large tumors and those arising very close to the anus such that removal

of the tumor requires removal of the muscles that control bowel movements as well as the anus.

**CHEMOTHERAPY COMBINATIONS**

For stage III rectal cancer patients who are medically fit and can tolerate combined methods of therapy, treatment can include chemoradiation (chemotherapy and radiation) before surgery, abdominal surgery, and/or adjuvant chemotherapy after surgery. Patients who cannot tolerate chemoradiation at first may have surgery first, followed by adjuvant chemotherapy, and/or chemoradiation after surgery.

**TOTAL NEOADJUVANT THERAPY (TNT)**

Some institutions are attempting to move all the therapy to pre-surgery, including chemotherapy. This is called Total Neoadjuvant Therapy (TNT). In this case, chemotherapy followed by chemoradiation, followed by surgery, is a potential treatment option. One advantage to this approach is the ability to get more treatment with chemotherapy since the radiation and surgery can compromise the treatment if it is given at the end of the other therapies.

### CHEMORADIATION COMBINATIONS

- Continuous infusion 5-FU and external beam radiation (EBRT). Treatment usually lasts several weeks. The chemotherapy drug is delivered intravenously through a pump carried in a fanny pack to provide a continuous infusion of 5-FU
- Oral capecitabine (Xeloda®) and radiation
- Clinical trial

### ADJUVANT CHEMOTHERAPY OPTIONS

- 5-FU and leucovorin
- FOLFOX (oxaliplatin, leucovorin, continuous infusion 5-FU)
- Oral capecitabine (Xeloda®)
- Clinical trial

### ADJUVANT CHEMORADIATION OPTIONS (A “SANDWICH” OF CHEMO-CHEMORADIATION-CHEMO):

- 5-FU with leucovorin or FOLFOX or capecitabine (Xeloda®)
- Radiotherapy with either continuous infusion 5-FU or capecitabine (Xeloda®)
- Additional 5-FU with leucovorin or FOLFOX or capecitabine (Xeloda®)

### STAGE III COLON OR RECTAL CANCER

Depending on your biomarkers, you may want to discuss targeted therapies, like larotrectinib (Vitrakvi®) and entrectinib (Rozlytrek®), with your doctor.



## STAGE IV METASTATIC CANCER OR RECURRENT CRC

You may be terrified when you're first told that cancer has spread beyond your colon or rectum and is metastatic; however, take time to get the very best information and advice possible from a multidisciplinary team. With your healthcare team, consider whether:

- Your metastatic tumors are limited enough to be removed surgically (resectable) and might be curable
- Your tumors are not resectable now, but with adjuvant treatment might become resectable and converted to a curable situation
- Your cancer is widespread and unlikely to become resectable, and should be treated palliatively with the goal of extending your quality of life for as long as possible

 Learn more about palliative care in **Part 2** of *Your Guide in the Fight*.



Get a second opinion, even if it takes extra time. Work with your doctor to determine how to best integrate your treatment needs with your desire to get a second opinion.

## EXAMPLES OF TREATMENT OPTIONS COMBINED TO TREAT METASTATIC DISEASE OVER TIME:

- Surgery to remove primary colon or rectal tumors
- Drug therapy using a variety of chemotherapy and targeted treatments
- Radiation therapy to shrink or destroy both primary and metastatic tumors
- Radiofrequency ablation to shrink or kill tumors with heat from radio waves
- Surgery to remove metastatic tumors in other areas of the body
- Chemotherapy directly applied to liver metastases (Hepatic Arterial Infusion or HAI)
- Treatment with radioactive beads called Selective Internal Radiation
- Immunotherapy for those who fit specific indications
- One or more clinical trials

**Chemotherapy is used  
to slow or stop the  
growth of cancer.**



## SURGERY

If the liver, lungs, or lining of the abdomen (peritoneum) are affected, you may undergo multiple surgeries to remove metastatic disease. Chemotherapy and radiation are often combined with surgery to shrink tumors. Surgical treatments for metastases are highly specialized procedures requiring an expert team. These are frequently done after the initial surgery is performed on your primary tumor.

- **Partial hepatectomy:** surgical removal of the part of the liver with metastases
- **Pulmonary metastasectomy:** lung metastases are removed by surgery or laser
- **Chemoembolization:** surgery to block the flow of blood to the liver so anti-cancer drugs can flow directly through the liver's arteries to the cancer site
- **Hyperthermic Intraperitoneal Chemotherapy (HIPEC):** peritoneal metastases are removed, then chemotherapy is directed to the abdominal cavity

## CHEMOTHERAPY COMBINATIONS

Chemotherapy is used to slow or stop the growth of cancer. If colon cancer continues to grow after initial chemotherapy treatment, there are many varieties and combinations of anti-cancer drugs that doctors may explore with you.

### CAPOX OR XELOX

- Capecitabine (Xeloda®) plus oxaliplatin (Eloxatin®)
- Capecitabine is an oral drug that works the same way as 5-FU inside the cancer cell

### FOLFOX

- 5-FU, oxaliplatin (Eloxatin®) and leucovorin

### FOLFIRI

- 5-FU, irinotecan (Camptosar®), and leucovorin
- These regimens may be combined with targeted therapies such as bevacizumab (Avastin®), cetuximab (Erbix®) or panitumumab (Vectibix®)

- Ramucirumab with FOLFIRI for patients whose cancer has progressed during or after treatment with first-line therapies (typically FOLFOX and bevacizumab (Avastin®)).

**Patients who cannot tolerate intensive therapy have other options. Doctors may recommend:**

- 5-FU plus leucovorin with or without bevacizumab (Avastin®)
- Capecitabine (Xeloda®) with or without bevacizumab (Avastin®). Treatment with capecitabine (Xeloda®) alone should only be considered a reasonable option for selected patients who are not candidates for more aggressive combination regimens with oxaliplatin (Eloxatin®) or irinotecan (Camptosar®)
- TAS-102 (Lonsurf®)

 For more information on drug combinations for patients who have a cancer recurrence, or when the first line of chemotherapy treatment doesn't stop the growth of cancer, talk with your doctor.

## TARGETED THERAPIES

Targeted therapy attacks specific proteins that occur more frequently on or in cancer cells than normal cells. Targeted therapies have been shown to be beneficial in patients with stage IV CRC.

Most targeted therapies are either small molecule drugs or monoclonal antibodies (biologic drugs. See page 27 for more information). Small molecule drugs pass into cancer cells and attach to proteins that are inside the cell. Most monoclonal antibodies aim at targets that are outside cancer cells or on the cell surface. Many monoclonal antibodies are biologics, which are derived from living organisms, versus chemicals, which are what make small-molecule drugs.

**Biosimilars** are a drug type equal in terms of effectiveness to biologics (meaning, there are not clinically significant differences), but they are not identical because of how they're made. Biologic drugs are derived from living organisms versus chemicals. Learn more about biosimilars in the Fight CRC Biosimilars Mini Magazine.

- Panitumumab (Vectibix®) is a monoclonal antibody used to inhibit cell growth for patients without a KRAS or NRAS mutation. In June 2017 the FDA announced the expanded use of panitumumab to include wild-type RAS metastatic colorectal cancer (mCRC), which is defined as wild-type in both KRAS and NRAS. It can also now be used as first-line treatment in combination with FOLFOX chemotherapy.
- Bevacizumab-awwb; ABP-215 (Mvasi®) is approved to treat adult cancer types, including CRC. It is a biosimilar of bevacizumab. Mvasi® is approved for the following CRC indications:
  - First- or second-line treatment for metastatic CRC (mCRC), in combination with 5-fluorouracil (5-FU) based chemotherapy
  - Second-line treatment for mCRC, in combination with fluoropyrimidine-irinotecan- or fluoropyrimidine-oxaliplatin-based chemo for patients whose cancer progressed on first-line bevacizumab
- Bevacizumab (Avastin®) is a monoclonal antibody used to block the growth and development of blood vessels
- Ziv-aflibercept (Zaltrap®) is a recombinant fusion protein used to block blood vessel development
- Cetuximab (Erbix®) is a monoclonal antibody to inhibit cell growth for patients without a KRAS or NRAS mutation
- Panitumumab (Vectibix®) is a monoclonal antibody to inhibit cell growth for patients without a KRAS or NRAS mutation
- Regorafenib (Stivarga®) is a small molecule drug to inhibit cell growth by interfering with the internal workings of the cell
- Ramucirumab (Cyramza®) is a monoclonal antibody used to block the growth and development of blood vessels
- Larotrectinib (Vitrakvi®) and entrectinib (Rozlytrek®) is indicated for patients who have an NTRK gene fusion. Talk to your doctor about biomarker testing to learn if this is a treatment option for you.
- bevacizumab-bvxx (Zirabev®) is approved for five different cancer types including metastatic colorectal cancer. It is a biosimilar of Avastin®.

Most patients with stage IV colorectal cancer receive a combination of FOLFOX and bevacizumab (Avastin®) as their first-line treatment, but other options exist. FOLFOX or FOLFIRI chemotherapy or cetuximab (Erbix®) or panitumumab (Vectibix®) targeted therapy can be used for patients with non-mutated KRAS or NRAS genes. You and your doctor will work together to determine the best treatment plan for you, which may include a clinical trial.

▶ For information on payment assistance, call The TRAK Assist™ patient support program 1-844-634-TRAK (8725)

## IMMUNOTHERAPIES

ALL CRC PATIENTS SHOULD KNOW THEIR MSI/MMR STATUS!

Immunotherapy for colorectal cancer has been shown to be effective in a small subset of patients with a certain biomarker: microsatellite-instability or mismatch repair deficiency.

- Pembrolizumab (Keytruda®) is an option for patients who have the microsatellite instable-high (MSI-H) or deficient mismatch repair (dMMR) biomarkers. This treatment is indicated for adult and pediatric patients with unresectable or metastatic solid tumors that have been identified as having a biomarker referred to as MSI-H or dMMR, including patients with solid tumors that have progressed following prior treatment and who have no alternative treatment options. About 4% of all patients with metastatic colorectal cancer are MSI-high or dMMR.
- Nivolumab (Opdivo®) is approved for use in microsatellite instability high (MSI-H) or mismatch repair deficient (dMMR) metastatic colorectal cancer (mCRC). Nivolumab has been approved for mCRC patients whose cancer either progressed after being treated with a fluoropyrimidine, oxaliplatin, and irinotecan, or did not respond to those treatments.
- Ipilimumab (Yervoy®) This drug may be used in combination with nivolumab as a treatment option for metastatic colorectal cancer (mCRC) with microsatellite instability-high (MSI-H) or mismatch repair deficient (dMMR) cancer following the progression on a fluoropyrimidine, oxaliplatin, and irinotecan.

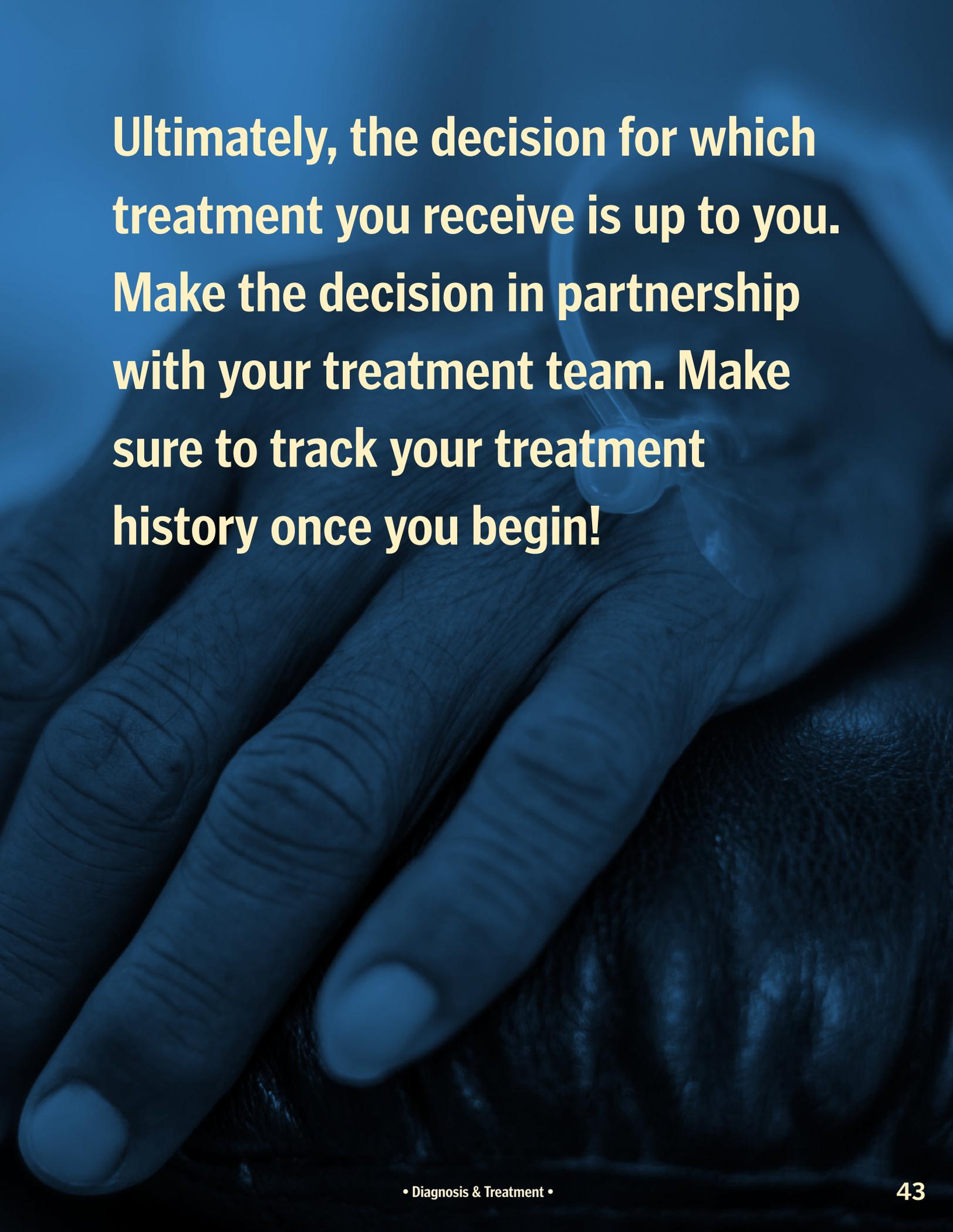


## QUESTIONS TO ASK IF YOU HAVE STAGE IV OR RECURRENT CRC

Treatment for stage IV or recurrent colorectal cancer is complex, and generally requires consultation with medical, surgical, and radiological doctors.

- Q: What is the standard treatment for someone in my situation? What do you recommend?
- Q: Can my tumors be treated surgically or with a locally ablative procedure?
- Q: What will my treatment schedule look like?
- Q: Am I eligible for a clinical trial? If yes, do you feel that would be a good choice for me?
- Q: What can be done to remove or treat my metastatic tumors?
- Q: Is there a way to determine whether specific drugs will be effective in treating my cancer? Should my tumor be genetically tested?
- Q: How long will I receive this treatment?
- Q: What are the short- and long-term side effects of the treatment you are recommending? What can we do to minimize my side effects?
- Q: When I am in treatment and experiencing side effects, what side effects should trigger a call to your office (for example, a fever > 100.5, diarrhea > 4 times/day) and which can wait for my next visit?
- Q: How will my health be monitored during treatment?
- Q: When will we know if the treatment is working?
- Q: If this treatment stops working for me, what's the next option?
- Q: Do you have any recommendations for support groups?

 Ultimately, the decision for which treatment you receive is up to you. Make the decision in partnership with your treatment team. Make sure to track your treatment history once you begin!



**Ultimately, the decision for which treatment you receive is up to you. Make the decision in partnership with your treatment team. Make sure to track your treatment history once you begin!**

## MEDICAL ADVISORY BOARD REVIEWERS

All medically-reviewed content in *Your Guide in the Fight* was written and edited by Fight Colorectal Cancer.

**Dennis J. Ahnen, M.D.**

University of Colorado  
Hereditary Cancer Clinic

**Al B. Benson III, M.D., FACP**

Northwestern University

**Dustin Deming, M.D.**

University of Wisconsin  
Carbone Cancer Center

**Richard M. Goldberg, M.D.**

Ohio State University Medical Center

**Edith Mitchell, M.D., FACP**

Thomas Jefferson University

**Joel E. Tepper, M.D.**

University of North Carolina  
School of Medicine  
Radiation Oncology

View all Medical Advisory Board members at: [FightCRC.org/MAB](https://fightcrc.org/MAB)

## ADDITIONAL REVIEWERS

**Wells Messersmith, M.D.**

Professor and Co-Division Head, Division of  
Medical Oncology University of Colorado

**Christopher Lieu, M.D.**

Assistant Professor, Director Colorectal  
Medical Oncology University of Colorado

**Jessica Martin, Ph.D.**

Fight Colorectal Cancer  
Research Advocate  
Stage IV Fighter

## YOUR GUIDE IN THE FIGHT DEVELOPMENT TEAM

**Will Bryan**

Will Bryan Design

**Anjee Davis, MPPA**

President

**Andrea (Andi) Dwyer**

The Colorado School of Public Health  
University of Colorado Cancer Center

**Elizabeth Fisher, MBA**

Project Manager

**Nancy Levesque**

Director of Communications

**Sam Monica**

Brand Manager

**Nancy Roach**

Founder

**Erica Weiss, MPH, MSUP**

Plain Language Health Writer

**Sharyn Worrall, MPH**

Senior Manager of Education and Research



PHOTO CREDITS: Brett Flashnick, Ryan Hollis, Travis Howard, Brian Threlkeld

# ADDITIONAL RESOURCES



## PATIENT WEBINARS

Fight CRC hosts free patient webinars featuring leading experts from across the country.



## PODCASTS

Fight CRC's educational podcasts put a stop to "taboo-ty" topics and discuss real issues impacting colorectal cancer patients.

View all resources at: [FightCRC.org/Resources](https://FightCRC.org/Resources)



Screening

Skin Toxicity

Biosimilars

Clinical Trials

Genetics

Side Effects

Download or order copies at: [FightCRC.org/Resources](https://FightCRC.org/Resources)

## MADE POSSIBLE

Your Guide in the Fight was made possible thanks to the support of the following organizations:



***RELENTLESS  
CHAMPIONS OF  
HOPE IN THE  
FIGHT AGAINST  
COLORECTAL CANCER***

***F!GHT***  
***COLORECTAL CANCER***

134 Park Central Square, Suite 210 • Springfield, MO 65806

***@F!GHTCRC***   



**STAGE III & STAGE IV COLORECTAL CANCER**

**2**

**TREATMENT, SIDE EFFECTS,  
& SURVIVORSHIP**

**YOUR  
GUIDE  
★ IN THE ★  
FIGHT**

**FIGHT COLORECTAL CANCER**



# YOUR GUIDE ★ IN THE ★ FIGHT

## FIGHT COLORECTAL CANCER

### DISCLAIMER

The information and services provided by Fight Colorectal Cancer are for general informational purposes only and are not intended to be substitutes for professional medical advice, diagnoses, or treatment. If you are ill, or suspect that you are ill, see a doctor immediately. In an emergency, call 911 or go to the nearest emergency room. Fight Colorectal Cancer never recommends or endorses any specific physicians, products, or treatments for any condition.

### FIGHT COLORECTAL CANCER

We FIGHT to cure colorectal cancer and serve as relentless champions of hope for all affected by this disease through informed patient support, impactful policy change, and breakthrough research endeavors.

### YOUR GUIDE IN THE FIGHT

If you have recently been diagnosed with stage III or IV colorectal cancer (CRC), or have a loved one with the disease, this guide will give you invaluable information about how to interpret the diagnosis, realize your treatment options, and plan your path. You have options, and we will help you navigate the many decisions you will need to make.

*Your Guide in the Fight* is a 3-part book designed to empower and point you towards trusted, credible resources.

*Your Guide in the Fight* offers information, tips, and tools to:

- Navigate your cancer treatment
- Help you gather information for treatment
- Provide you with tips to manage symptoms
- Direct you to resources for personal strength, organization, and support
- Help you manage details from diagnosis to survivorship

### LOOK FOR THE ICONS



Tips and Tricks



Additional Resources



More information can be found on another page or part

# TREATMENT SIDE EFFECTS & SURVIVORSHIP

# 2

PAGE • TABLE OF CONTENTS

- 3 • Side Effects
- 15 • Palliative Care
- 17 • Asking for Help
- 21 • Staying Strong Through the Fight
- 26 • Post-Treatment Follow-up & Survivorship
- 32 • Family History and Genetics
- 35 • Strength From Others

WHAT YOU WILL KNOW AFTER READING PART 2

- WHAT SIDE EFFECTS I MAY FACE
- TIPS FOR MANAGING SIDE EFFECTS AND RESOURCES TO HELP
- SURVIVORSHIP CARE PLANNING
- MY SCREENING FOLLOW-UP POST TREATMENT

PHOTO: Dr. Eduard and Lily Quiko | CRC advocates

**Not everyone experiences the same side effects, nor are side effects experienced in the same way.**



Traci Bryan  
CRC Caregiver

Dawn Blatt  
Stage III survivor

# SIDE EFFECTS

# 1

Talk with your healthcare team about possible side effects before beginning treatment and during treatment.

Not everyone experiences the same side effects, nor are side effects experienced in the same way.

**Palliative care** is a way to receive ongoing support and symptom management throughout your treatment, and following treatment completion. It can help you gain strength to carry on with daily life, improve your sense of control, and help you tolerate treatments. There are many ways for you and your care team to manage side effects.

The next few pages outline some of the most common side effects experienced by colorectal cancer patients and survivors.

## MANAGING TREATMENT SIDE EFFECTS

### ► Cancer-Related Fatigue

Cancer-related fatigue (CRF) is common among cancer patients. For many it goes away after treatment is completed, but for some, CRF lasts for months or years after treatment ends.

CRF is more than just being tired. Some people explain it as a sense of heaviness. The impact of this side effect can touch many aspects of your quality of life, including your physical, psychological, and social well-being. It may limit your ability to participate in day-to-day activities and activities you enjoy doing.

Tell your doctor about your fatigue as they may request blood tests, or recommend things you can do to manage it.

💡 See the list of tips on page 4.

🔧 Download Fight CRC's Side Effects Mini Magazine for more information on how to manage treatment

[FightCRC.org/Resources](https://fightcrc.org/Resources)





## TIPS TO MANAGE FATIGUE



- Plan your activities for times of the day when you have the most energy.



- Exercise regularly. Take short walks or do upper body strength exercises. Exercise has been shown to help fight cancer-related fatigue.



- Take short naps during the day when needed. Avoid taking naps in the late afternoon.



- Aim to sleep at least 8 hours at night. Avoid caffeine for 8 hours before bedtime.



- Eat healthy foods - ask your treatment team to connect you with a nutritionist or registered dietician who can help you choose foods to increase your energy.



- Use relaxation techniques like meditation or yoga.



- Make sure your treatment team checks your blood counts for anemia.

- Relax before bed and prepare your body for sleep. Do not watch television or surf the web.

## ► Increased Risk of Infection/Fever

Chemotherapy can decrease your white blood cell count, which increases your risk for infection. Infections can land you in the hospital, and may be life threatening.

A fever is a sign of infection. Take your temperature anytime you feel warm and **contact your healthcare team if your temperature is above 100.5 F** so they can evaluate your need for further medical assistance and, potentially, antibiotics. Unless approved by your doctor, do not take any over the counter medications, such as acetaminophen or ibuprofen, that may mask the fever.

If your white blood count is too low, you may need to wait for it to go up before your next treatment.

## ► Diarrhea

Signs of diarrhea include frequent bowel movements that are soft, loose, or watery. It can result from chemotherapy treatments, colon surgery, radiation treatment, infections, or diet.



## TIPS TO PREVENT INFECTIONS



- Wash your hands frequently
- Do not cut your cuticles



- Avoid being near people who are sick



- Stay out of crowds



- Be careful to prevent cuts. If you do cut yourself, clean the area well and apply an antiseptic



- Avoid raw fish and undercooked meats and eggs. Wash fruits and veggies.



- Avoid community swimming pools and hot tubs



- Avoid community gym equipment or be sure to clean the equipment very well before use





**Exercise has been shown to help fight cancer-related fatigue.**

Ask your doctor to prescribe medications to address diarrhea before it develops. This will ensure you're prepared. Let your doctor know if you experience diarrhea as soon as possible so they can help guide your next steps in how to manage this side effect.

 Before beginning chemotherapy, get a sense of your current pattern of daily stools—number and consistency—to use as a baseline. If you have an ostomy, note the consistency and amount of daily output.

Symptoms of complicated, severe diarrhea (which may result from irinotecan Camptosar® or other treatments) require a call to your doctor. Severe symptoms include:

- 7 or more loose or watery stools a day
- Abdominal cramping
- Nausea and vomiting
- Fever
- Bleeding or blood in the stool
- Dehydration
- Feeling weak or dizzy when standing

Abdominal cramping is an early sign that diarrhea is complicated and needs aggressive treatment. Contact your doctor immediately if you experience abdominal cramping.

**If diarrhea doesn't improve after 24 to 48 hours, or it gets worse, contact your doctor.**

## ► Neuropathy or Nerve Changes

Neuropathy is common when receiving chemotherapy. Symptoms include numbness or tingling in your hands or feet, a loss of sensation, shooting pain, loss of balance, aching muscles, problems with finger dexterity, and forgetfulness.



### TIPS TO MANAGE DIARRHEA



- Sip warm liquids slowly throughout the day. Avoid large quantities at once. Avoid alcohol and caffeine.



- Discuss anti-diarrhea medications with your doctor



- Eat small, frequent meals and snacks. Snack on dry, salty foods like crackers and toast. Eat yogurt with active cultures and foods with soluble fiber (oatmeal, oat bran, bananas, etc.).



- Discuss a diet plan with a registered dietitian (RD)



- A fiber supplement like Metamucil may help



- Avoid hard-to-digest foods like popcorn, raw vegetable, and “gassy” vegetables. Avoid spicy, greasy, and high-sugar foods.



- Lie down immediately after eating



### TIPS TO MANAGE NEUROPATHY



- Wear scarves or face masks outdoors in cold weather



- Wear gloves and warm socks



- Avoid eating or drinking cold foods. Eat room temperature food.



- Avoid excessive air conditioning



- Use handrails and avoid clutter that may cause you to stumble or trip



- Protect your hands when getting items out of the refrigerator

A unique symptom you may experience with neuropathy is an extreme sensitivity to cold.

Oxaliplatin, a drug used in the FOLFOX chemotherapy treatment, is known to cause acute or chronic nerve damage. While acute neuropathy can be managed by avoiding cold things, chronic or peripheral neuropathy gets worse with cumulative doses of oxaliplatin. It tends to fade after treatment when the drug ends, but may take 18 months to 2 years to go away. For some people, these symptoms continue for many years.

## Types of Neuropathy:

### Acute oxaliplatin-induced neuropathy –

- Begins shortly after an infusion of oxaliplatin and gets better within a few days
- Triggered by eating, drinking or touching something cold, or breathing cold air
- Some patients experience sharp pain in their mouth or jaw when they take a bite of cold food
- Some patients feel like their throat is closing and they cannot breathe, although breathing is not actually affected

### Chronic peripheral neuropathy –

- The risk of a longer-lasting sensory neuropathy in your hands and feet increases as the amount of oxaliplatin increases in your body
- Feeling “pins and needles” or numbness
- For some patients, neuropathy can cause pain and difficulty with daily life, including walking or doing small tasks with their fingers like buttoning a shirt



## NEUROPATHY TIPS from Dana Cardinas, Doctor of Podiatric Medicine (DPM), FACFAS and stage IIIc colon cancer survivor

### Things to consider before treatment begins:

- ▶ Understand that cold sensitivity is temporary and although unpleasant, will go away
- ▶ Discuss with your oncologist nerve protective supplements that are safe for you to take during treatment
- ▶ Exercise to tolerance during treatment
- ▶ Keep a log of all your nerve symptoms so you can discuss them during your oncology visits
- ▶ Educate yourself on all the potential nerve symptoms you might experience

### Things to consider when managing neuropathy:

- ▶ If you are experiencing painful neuropathy, combining prescription medications like gabapentin with exercise or devices that increase blood flow to the nerves is more effective than taking a medication alone. If you have numbness and coordination symptoms, then nerve glide exercises and focusing on balance and strength will help you more. The key to improving your neuropathy is movement. The more you can move, the more blood flow to the nerves, the happier your nerves will be.

Keep your doctor and health care team updated on your neuropathy.

 Use a notebook to track how you feel and let your doctor know if neuropathy gets worse.

 Be prepared for your first oxaliplatin treatments by wearing gloves, a shawl or blanket, warm socks, and avoiding cold foods/drinks.

### ▶ High Blood Pressure

If you're taking bevacizumab, aflibercept, ramucirumab, or regorafenib, you may experience high blood pressure. High blood pressure is routinely managed with appropriate medication. Treatment may be paused or halted if blood pressure increases too much.

### ▶ Mouth Sores (Mucositis)

Good dental care is key and regular standard dental visits. Mouth sores are inflammation and ulceration in the mouth as a result of some cancer treatments. This side effect can be very uncomfortable, however, it is important to maintain good dental care and regular standard dental visits while undergoing cancer treatment.

### ▶ Hand-Foot Syndrome

Hand-foot syndrome can occur with some types of chemotherapy, like 5-FU, capecitabine or regorafenib. Signs of it include red, cracked, peeling, or painful skin. This condition is not life threatening and it gets better once you stop taking the drugs. If you experience early signs of hand-foot syndrome, you can reduce the dose of your treatment to stay on schedule.



### TREATING MOUTH SORES

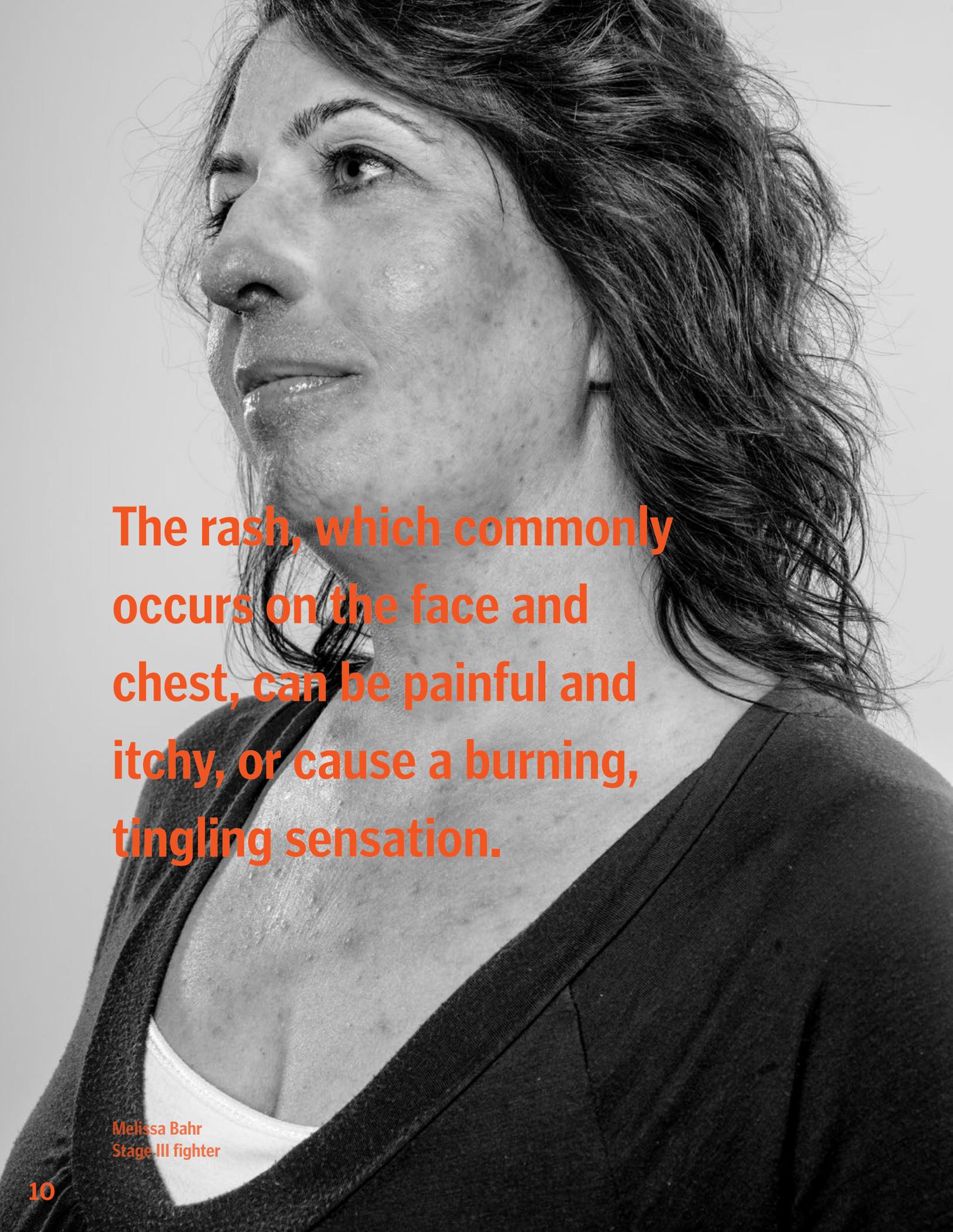
There are several “magic” mouthwashes that can help with pain and healing if sores do develop; however, their effectiveness is unclear. If your doctor suggests these mouthwashes may help, they will write out the recommended ingredients and the amount of each ingredient for you. Antibiotics may be required if sores become infected. Remember that it is important to maintain good dental care while in treatment.



### TIPS TO MANAGE HAND-FOOT SYNDROME

- Heavy emollients are suggested, especially urea based products
- Avoid alcohol based cleansers
- Petroleum jelly, over-the-counter moisturizing creams, or prescription ointments may help healing
- Some patients find relief from petroleum jelly on the skin under white cotton gloves or wearing socks overnight
- If you use petroleum jelly or other moisturizers, be sure to avoid infection by thoroughly cleansing the area the next morning. Leaving thick moisturizers on your skin or on open wounds can lead to infections
- Avoid long exposure of feet and hands to hot water (like washing dishes or long showers)



A black and white close-up portrait of a woman with long, dark, wavy hair. She is looking slightly upwards and to the left. Her skin, particularly on her face and neck, shows signs of a rash, with visible redness and small bumps. She is wearing a dark-colored top over a white undergarment.

**The rash, which commonly occurs on the face and chest, can be painful and itchy, or cause a burning, tingling sensation.**

Melissa Bahr  
Stage III fighter

## ► Rashes and Skin Toxicity

Targeted therapies (drugs that interfere with the growth and spread of cancer) tend to cause skin toxicity. Epidermal growth factor receptor inhibitor drugs (EGFR-i), like cetuximab or panitumumab are types of targeted therapies that can cause this side effect.

The rash commonly occurs on the face and chest, but can also present on other body parts. It can be painful and itchy, or cause a burning, tingling sensation. Your doctor may prescribe a medicated cream to control itching and ease discomfort, or an antibiotic if infection becomes a concern. You might be referred to a dermatologist. If the rash becomes intolerable, you and your doctor may decide to lower your treatment dose.

Never stop taking or reduce your medication without your doctor's approval. If you experience severe skin rashes, talk to your doctor about ways to manage the rash.



### TIPS ON MANAGING EGFR RASH

- Moisturize often and apply topical itch ointments or creams
- Keep nails short and clean
- Wear sunscreen and keep your skin covered
- Opt for fragrance-free products



For more information, and for tips from other patients, check out our Skin Toxicity resources at

[FightCRC.org/SkinTox](https://www.fightcancer.org/skintox)



The oral targeted therapy, regorafenib, may also cause an itchy rash. Talk with your doctor if this happens to see if specific creams or lotions can help.

## ► Wound Healing

Bevacizumab, aflibercept, and regorafenib can slow the healing of wounds. These drugs should be stopped at least two weeks before surgery. Talk to your care team about these medications and how they may affect your healing after surgery.

## ► Fecal Incontinence, Adhesions (Rectal Cancer)

Radiation treatments are carefully planned to target the tumor and surrounding rectum; however, it's almost impossible to avoid damaging healthy tissue. If you experience redness and skin irritation, ask your radiation oncologist for creams to soothe burns.

Serious irritation of rectal tissues can cause diarrhea, rectal bleeding, painful bowel movements, incontinence, or bladder irritation causing frequent urination, blood in the urine, or burning during urination. If you experience these side effects, consult your doctor. There are medical and lifestyle options that can minimize the impact of fecal incontinence and adhesions.



### VOCABULARY

- **Fecal incontinence:** the inability to control your bowel movements
- **Adhesions:** scar tissue. Adhesions in the colon can cause partial or complete blockage of the colon, resulting in abdominal pain and swelling, nausea and vomiting.

## ► Chemo-Brain

It is estimated that 1 in 5 people who take chemotherapy for cancer experience “chemo-brain.” This is described as a hazy experience with symptoms such as forgetfulness, difficulty finding the right word, and difficulty multi-tasking or concentrating. Some people regain mental clarity over time, while others do not.

If you are having more serious side effects like visual loss, change in gait, or unrelenting headache, notify your doctor.

If you experience chemo-brain, there are techniques you can use that may help you remember things and stay on task.



### TIPS AND TRICKS TO HELP WITH YOUR MEMORY

- Keep your notebook handy and write lists
- Schedule appointments and medications into your calendar (ideally in a phone with a calendar alarm)
- Keep consistent habits (for example, place your keys in the same spot each day)
- Ask for help when you need it
- Get plenty of rest
- Contact a social worker for guidance

## ► Depression, Anxiety, Post-Traumatic Stress Disorder, Fear of Recurrence

A cancer diagnosis affects more than the physical body – it can also cause mental health side effects that are important to recognize and treat. Many patients



## WHEN SHOULD I CALL THE DOCTOR?

It’s important to keep your care team up to date on all of your side effects. It’s also important to know when to seek immediate medical attention. Although rare, there are instances when patients develop severe or life-threatening toxicities within the first few days of receiving treatment of 5-FU or capecitabine (Xeloda®).

### Side effects that include the following require a call to the doctor or the ER:

- Altered mental state or coma
- Irregular heartbeat, heart attack or other cardiac symptoms
- Unusually severe gastrointestinal pain and diarrhea
- Inability to eat due to nausea
- Vomiting more than 6 times
- Blood in stool (stool could appear black and tar-like)
- Blood in vomit (vomit could appear very dark in color or look like coffee grounds)
- Severe mucositis (oral and/or anal) that affects daily activity
- Fever over 100.5 degrees F
- Any unusual side effects that your treatment team did not tell you about

The symptoms above differ from the common side effects experienced by CRC patients and can be a sign of early-onset severe toxicity. Early-onset severe toxicity usually occurs during or shortly after the first or second round of treatment. Call your doctor as soon as possible if you experience moderate to severe side effects. If you are experiencing early-onset severe toxicity, uridine triacetate (Vistogard®) is a medication that can reduce further toxicity from occurring if it is administered within 96 hours of your last 5-FU or Xeloda® treatment.

Pay attention to your side effects. Track them diligently and report to your doctor. If you have side effects that are severe or unexpected, call your doctor.

and survivors experience varied levels of depression and anxiety, and many survivors experience Post-Traumatic Stress Disorder (PTSD) and fears of cancer recurrence. Some of the common signs of depression include: persistent sadness, empty feelings, loss of interest in daily activities, fatigue, feelings of guilt, worthlessness, loss of concentration, sleep problems, suicidal thoughts, and hopelessness. These side effects are not

always easy to treat, however, there is help available.

Ask your healthcare team to put you in contact with a mental health professional like a social worker, therapist, or psycho-oncologist.

**If you need help finding a professional in your area, or would like to speak to someone about your concerns, call our toll-free Resource Line: [1-877-427-2111](tel:1-877-427-2111)**

---

## COMPLEMENTARY AND ALTERNATIVE APPROACHES, AND INTEGRATIVE MEDICINE

Many patients look for approaches to “add to” or “complement” treatment for colorectal cancer (CRC), especially when looking for ways to feel better. Complementary and alternative medicine (CAM) approaches are commonly used by patient, as they may increase quality of life. Some examples include yoga, massage therapy, acupuncture, and tai chi.

Many cancer centers now have healthcare providers on staff who have a CAM specialty (like massage or acupuncture, for example), and may even have oncologists or other medical doctors who specialize in integrative medicine.

Some CAM approaches include supplements and pills and are not recommended to treat colon or rectal cancer. So far, no alternative method has been proven either safe or effective by conclusive scientific evidence. CAM approaches may be dangerous or even deadly; some are harmful to patients undergoing standard treatment for cancer. Others may interfere with the action of chemotherapy or drugs used to treat side effects.

Before you begin any alternative treatments, you need to understand how they might affect your current treatment. If you are considering CAM, discuss with your doctor first.

**For tips on talking to your doctor about CAM, visit:**

**[Cancer.gov/About-Cancer/Treatment/CAM](https://www.cancer.gov/About-Cancer/Treatment/CAM)**

- **Complementary medicine** is used together with conventional medicine. An example of a complementary therapy is using aromatherapy to help lessen your discomfort following surgery.
- **Alternative medicine** is used in place of conventional medicine. An example of an alternative therapy is using a special diet to treat cancer instead of undergoing surgery, radiation, or chemotherapy that has been recommended by a conventional doctor.
- **Integrative medicine** combines treatments from conventional medicine and CAM, for which there is some high-quality scientific evidence of safety and effectiveness.

Examples of CAM methods that have proven beneficial vs. harmful:

### BENEFICIAL:

- Acupuncture has been shown to help patients reduce feelings of pain and nausea, and may improve joint mobility
- Meditation and guided imagery can provide comfort and reduce stress
- Tai chi is beneficial for relieving pain and improving the ability to walk and move



### POTENTIALLY HARMFUL:

- St. John's Wort, an herb sometimes taken for depression, can interfere with the cancer treatment irinotecan
- The herbs comfrey and kava can cause serious harm to the liver
- Patients in treatment have been advised to not take fish oil supplements, as this can interfere with the effectiveness of chemotherapy
- Colon hydrotherapy (also known as colon irrigation, colon cleansing, or high enema) uses more than 20 gallons of water inserted through the rectum is used to gently “cleanse” the large intestine. This practice has no scientific credibility and could cause perforation, dehydration, and infection.



### ASK YOURSELF: IS CAM RIGHT FOR ME?

- Is it safe? How do you know it's safe?
- Is there any evidence that it is effective?
- What's the evidence? Is it a clinical trial or simply anecdotal stories? Is evidence based on human tests?
- Am I certain that what is listed on the label is actually what is in the bottle?
- Did I talk to my doctor? Did they support the use of this type of therapy?

Examples of mind-body practices that can reduce stress and anxiety:



**Meditation:** Focused breathing or repetition of words or phrases to quiet the mind



**Hypnosis:** A state of relaxed and focused attention in which the patient concentrates on a certain feeling, idea, or suggestion to aid in healing



**Yoga:** Systems of stretches and poses with special attention given to breathing



**Imagery:** Imagining scenes, pictures or experiences to help the body heal



**Creative outlets:** Art, music, or dance for example

# PALLIATIVE CARE

# 2

## Palliative care is designed to help improve your quality of life.

PALLIATIVE CARE IS A PATIENT- AND family-centered system of medical, physical and emotional support provided by a team of specialists for people with advanced illness who need relief from side effects.

Palliative care provides ongoing support throughout your treatment and following treatment completion. It focuses on providing aggressive symptom management for symptoms such as pain, shortness of breath, fatigue, constipation, nausea, loss of appetite, difficulty sleeping, and depression.

This type of care is for anyone at any stage, and can start at the time of diagnosis. It is designed to help you gain strength to carry on with daily life, improve your sense of control, and allow you to tolerate treatments.

Even if you are still seeking disease-directed treatment, ask if your hospital, cancer center, or long-term care facility provides palliative care. You might even have the option to receive palliative care at home.

### When is the right time to seek palliative care?

The earlier you ask your care team about palliative care, the better. Palliative care is appropriate for any diagnosis, at any stage in a serious disease, and at any age. You may consider talking to your doctor about palliative care if you:

- Visit the hospital or ER regularly
- Have challenging symptoms (physical and/or psychosocial)
- Would like help in making difficult decisions
- Have a hard time taking care of yourself
- Are concerned your caregiver is experiencing distress

Consulting a palliative care expert can help you become more clear about what you need to achieve greater quality of life.

**Palliative care also supports the caregiver.**

## Common Questions About Palliative Care

### 1 WHERE DO I RECEIVE PALLIATIVE CARE?

Palliative care can be provided in the hospital, outpatient clinic, and at home.

### 2 DOES MY INSURANCE PAY FOR PALLIATIVE CARE?

Most insurance plans, including Medicare and Medicaid, cover palliative care.

### 3 HOW DO I KNOW IF PALLIATIVE CARE IS RIGHT FOR ME?

Palliative care may be right for you if you suffer from pain, stress or other symptoms due to a serious illness.

### 4 WHAT CAN I EXPECT FROM PALLIATIVE CARE?

You can expect relief from symptoms such as pain, shortness of breath, fatigue, constipation, nausea, loss of appetite and

difficulty sleeping. Palliative care helps you carry on with your daily life. It improves your ability to go through medical treatments. It helps you better understand your condition and your choices for medical care. In short, you can expect the best possible quality of life

### 5 HOW DOES PALLIATIVE CARE WORK WITH MY OWN DOCTOR?

The palliative care team works in partnership with other doctors to provide an extra layer of support for you and your family.

### 6 HOW DO I GET PALLIATIVE CARE?

You have to ask for it! Just tell your doctors and nurses that you would like to see the palliative care team. You can also visit the Provider Directory on [GetPalliativeCare.org](http://GetPalliativeCare.org).

## QUALITY OF LIFE (QOL)

Simply put, QOL it is your standard of health, overall enjoyment of your life, sense of well-being, and ability to engage in the activities you enjoy. There are four major areas of wellbeing associated with QOL: physical, social, psychological, and spiritual.



# ASKING FOR HELP

# 3

Keeping organized can help you stay on track with cancer treatment, especially while balancing your work and home life.

ASKING FOR HELP IS a great thing, and so is accepting help when it's offered. After your diagnosis, people may ask you how they can help. It may feel strange to accept help - but try to remember that people are asking how they can help because they care about you and they WANT to help. Consider having a list of responses ready beforehand so that when the question arises, you're prepared for the opportunity!

 Break down your needs into small, manageable parts, as this can help you feel less overwhelmed and more in control of your to-do list.

Some examples might include:

- Can I give you a small list of things I need from the store?
- Can you pick up my dry cleaning on Tuesday or Wednesday?
- Can you vacuum my house one day next week?

There are several websites and planning tools available to recruit friends and family to help, but you can also begin by simply writing down things you'd like help with and thinking about who you might ask for support.

Your first call for support can be to your nurse or social worker who will direct you to local resources. You can also

reach out to family and friends for their help with manageable requests and if you need additional assistance.

Examples of the type of help you might need:

**Medical care needs:** driving to doctor's appointments, staying on track with medications, managing side effects

**Home care needs:** meals, cleaning, driving, childcare, home maintenance

**Practical support:** calls to insurance, legal or financial assistance, paying bills

**Emotional support:** coping with depression, finding fun, just talking



**CANCER SUPPORT ORGANIZATIONS**

**American Cancer Society:**  
*Cancer.org*  
or call **1.800.227.2345**  
(local & national support services)

**Advocacy Connector:**  
*AdvocacyConnector.com*  
(find the type of help you need)

**CancerCare:**  
*CancerCare.org*  
(counseling, support groups,  
education & financial assistance)

**Cancer Support Community:**  
*CancerSupportCommunity.org*  
(local & national support services)

**LIVESTRONG:**  
*LiveStrong.org*  
call **1.855.220.7777**  
(several programs to help patients)

**Stupid Cancer:**  
*StupidCancer.org*  
(programs for young adults  
facing cancer)



**COLORECTAL CANCER SUPPORT**

**Fight Colorectal Cancer:**  
*FightCRC.org*

**Fight CRC's Inspire Community:**  
*FightCRC.org/Inspire*

**Colorectal Cancer Alliance:**  
*CCAlliance.org*

**Colon Cancer Coalition/GYRIG:**  
*ColonCancerCoalition.org*

**ColonTown:**  
*ColonTown.org*

**Colon Club:**  
*ColonClub.org*

**Fight CRC Resource Line/  
Community Cancer Support  
Helpline:**

Call **1-877-427-2111** from 9 a.m.  
– 9 p.m. ET Monday through Friday  
to get live assistance. The call line is  
available in more than 200 languages.

**Michael's Mission:**  
*MichaelsMission.org*

NOTES

---

---

---

---



**Asking for help is a great thing,  
and so is accepting help when  
it's offered.**

**Research shows that early identification of emotional distress and follow-up care helps everyone involved.**



Trisha Mouzon  
Stage III survivor

# STAYING STRONG THROUGH THE FIGHT 4

---

## No one expects a cancer diagnosis.

SUDDENLY YOU HAVE to think about things like, “How is this going to impact my family?”, “Will I be able to work during treatment?”, and “Will the cancer kill me?” With all this stress, most patients and their loved ones experience feelings of depression, anxiety, and distress after a diagnosis. Who wouldn’t?

Research shows that early identification of emotional distress and follow-up care (such as counseling and support services) helps everyone involved. Find help if you need it. There are organizations that offer support for emotional stress that results from the diagnosis, insurance or financial assistance, and even transportation to and from appointments.

 Check out the list of resources in the back of **Part 3** for some organizations to get you started.

## DIET AND NUTRITION

As you move from diagnosis to treatment and surgery, your dietary needs will change. During treatment, you may not feel like eating or drinking, but you need to make sure you are getting proper nutrients and combating unwanted weight loss. Foods may taste differently, and side effects like mouth sores or cold sensitivity might make it hard to eat.

After surgery, you will be on a “**low residue**” diet, which means a diet low in fiber to minimize the amount of work for your colon and rectum. Think white bread, not whole wheat! It is common to experience problems with diarrhea as your body heals, and it might take several weeks or longer for your colon to start working normally again. Talk to a nutritionist who can help you plan meals during this time.

### NOTES

---



---



---



---



---



---



---



### TIPS FOR COPING

- If you're feeling overwhelmed, stressed or sad, ask your healthcare team for a referral to a counselor and emotional support service programs
- Contact a social worker experienced with oncology
- Join a support group in person or online
- Ask your doctor about medications that can help
- Focus on living in the moment – on the things in your life you can control. Avoid unhelpful speculation about unknowns
- Use relaxation techniques such as deep breathing when you feel panic
- Write your questions, thoughts, and concerns in a notebook and keep it with you at all times (a smart phone has many options for note-taking too)



### RESOURCES FOR COPING

- Check out the Cancer Support Community ([CancerSupportCommunity.org](https://www.cancersupportcommunity.org)) or CancerCare ([CancerCare.org](https://www.cancercaresupport.org)). They have phone lines staffed with trained mental health professionals who can help you find the support and services you need.
- Contact the Patient Advocate Foundation ([PatientAdvocate.org](https://www.patientadvocate.org)) for help if you need co-pay assistance or if you can't afford medical care.



### TIPS FOR EATING AFTER SURGERY

- Request a consultation with the hospital’s nutrition team or registered dietician
- Talk to your nurse before leaving the hospital and request a list of what you can and cannot eat
- Look at the American Cancer Society’s “Low Residue Diet” information – if you don’t have Internet access, ask a friend or your care team to print a copy. It has a helpful list of foods to eat and foods to avoid
- Don’t be shy about talking with your care team about diarrhea, as sometimes this can be improved by dietary changes



### TIPS FOR EATING AND DRINKING WHEN YOU DON’T WANT TO

- Eat small meals
- If you are not taking FOLFOX (a type of chemotherapy), suck on ice chips or sip fruit smoothies all day long to avoid dehydration. If you are on FOLFOX, stay away from cold drinks and stick to room temperature beverages
- Talk to a nurse if you are too nauseated to eat or drink. Medications to curb your nausea may be available
- If people offer to cook for you, say YES and give them some ideas of what you can eat
- If you get an urge for a certain food, go for it

## STAYING HYDRATED

Staying hydrated is critical to your overall health. If you are having problems with vomiting and diarrhea, or if you are not drinking enough fluids, you are at risk for dehydration, which is a serious concern. Symptoms of dehydration include:

- Dry, sticky mouth
- Sleepiness or tiredness
- Unquenched thirst
- Decreased urine output - 8 hours or more without urination
- Dry skin
- Headache, dizziness, or lightheadedness
- Constipation

To avoid dehydration, suck on ice chips throughout the day and keep room temperature water nearby at all times.

For personal help or advice, get a referral to a nutritionist, or find a registered dietitian who has worked with cancer patients.



Find a registered dietitian with certification in Oncology, search Academy of Nutrition and Dietetics: [EatRight.org](http://EatRight.org)

## EXERCISE AND PHYSICAL ACTIVITY

Even if you feel too exhausted or uncomfortable to think about exercise, do it anyway! Research repeatedly shows that most patients benefit from moderate exercise. Physical activity helps to maintain weight, muscle tone, and overall health. It reduces stress and increases energy. This is true both during and after treatment.

- Talk with your doctor to build an exercise plan—make it a priority.
- Start with 10-15 minutes daily (or 10 minutes a few times a day) and build yourself up to more (ideally 30 minutes per day, most days).
- Don't feel bad if you are too exhausted to do much at tough times during your treatment, it can be a goal for when you feel better.
- Recruit friends to keep you active and motivated. Seek exercises that are fun for you!

 Check out Fight CRC's resources on exercise: [FightCRC.org/Exercise](https://fightcrc.org/Exercise)

## SEX AND INTIMACY

Treatment for colorectal cancer (especially radiation for rectal cancer) can make intercourse difficult, painful, and undesirable—or in some cases, not possible. You may feel too anxious or too tired to think about sex.

It's possible that issues regarding sexual health and intimacy may not be brought up by your healthcare team. Therefore, it is important that you bring it up if you have questions or concerns. Remember that intimacy and sexual health is about more than intercourse. It is about connecting with and showing someone you love them. Because of the power of intimacy, feeling sexually satisfied can involve something as simple as a kiss or hand holding. There are many different ways to improve sexual function for both men and women if changes happen because of treatment.

 For more information check out Fight CRC's resources on sexual intimacy: [FightCRC.org/Intimacy](https://fightcrc.org/Intimacy)

### QUESTIONS TO ASK YOUR DOCTOR ABOUT SEX:

- Q:** Is it OK to have sex while in treatment?  
If not, when can I begin having sex again?
- Q:** Are there any types of sex I should avoid?
- Q:** What type of birth control should I use at this time?
- Q:** What else do I need to know about how my treatment will affect my sex life?



## TIPS TO MANAGE PROBLEMS WITH SEX AND INTIMACY

- Talk to your partner about your concerns, feelings of embarrassment, and fears of sexual dysfunction – relationships and intimacy are often improved when we can share candidly.
- If you have rectal cancer and are receiving radiation, talk with your radiologist about ways to minimize impacts on your sexual organs.
- Ask your doctor about treatments that may improve your sexual desire, performance or both.
- Talk with a counselor or other survivors about ways to manage sexual side effects. There are sexual health medical professionals trained to help you and your partner reclaim sexual vitality after cancer treatment.
- Try alternative ideas for intimate contact if intercourse is uncomfortable or impossible. This may include more hugging and hand holding or enjoying new experiences with your partner.
- Review information in the American Cancer Society’s web pages titled “Keeping Your Sex Life Going Despite Cancer Treatment.”



# POST-TREATMENT FOLLOW-UP AND SURVIVORSHIP

# 5

## After treatment ends, celebrate!

ONCE ACTIVE TREATMENT ends, you may feel a variety of emotions - joy, anger, anxiety, relief. Some may experience emotional distress, and others may not. Either way, finishing treatment is a milestone. If you need to, reach out to your care team for additional support at this

time as you move into survivorship. Colorectal cancer recurrence is most common within the first 5 years after treatment, so follow-up visits will be more frequent during this time.

Your medical oncology team will request physical examinations, blood work, scans, and colonoscopies

based on your cancer type (colon or rectal cancer), your individual risk for recurrence and time from diagnosis.

One of the top reasons for recurrence is lack of follow-up screening. Talk to your healthcare team about screening and stay up to date!



Here’s a general guide on what doctors will recommend for the frequency of follow up visits and testing but remember – each person is unique.

## RECOMMENDED SURVEILLANCE AFTER CURATIVE TREATMENT FOR CRC

Examination Type	Year 1	Year 2	Year 3	Year 4	Year 5
Physical examination and history	Every 3-6 months	Every 3-6 months	Every 3-6 months	Every 3-6 months	Every 3-6 months
CEA (carcinoembryonic antigen) test	Every 3-6 months	Every 3-6 months	Every 6 months	Every 6 months	Every 6 months
Colonoscopy (colon and rectal cancer)	Colonoscopy at 1 year (rectal cancer patients: may be done at 3-6 months if it was not done before surgery). If advanced adenoma found, repeat in 1 year; otherwise repeat in 3 years. If 3-year colonoscopy is clear, repeat every 5 years.				
Sigmoidoscopy (for rectal cancer patients who received LAR)	Every 6 months can be considered				
Abdominal and chest CT scan (colon and rectal cancer) and pelvic CT scan (recommended if primary tumor was located in the rectum)	Yes	Yes	Yes	As determined by your doctor	As determined by your doctor

*\*Adapted from the National Comprehensive Cancer Network treatment guidelines for colon and rectal cancer. These recommendations are guidelines only.*

Your primary care provider may be the doctor who knows the most about your complete medical history and follow-up care. Therefore, your oncologist should give your primary care provider a copy of your comprehensive care summary for their records. Depending on the treatments you received, it may be even more important to have your blood pressure, cholesterol, and glucose levels monitored, and to have evaluations for late effects of treatment.

A history of cancer adds a slight risk for other cancers, so be sure to follow recommended cancer screening for prostate, breast, and cervical cancer, as appropriate. You should also receive flu and pneumonia vaccines annually.

## SURVIVORSHIP CARE PLAN

A survivorship care plan is a detailed plan given to a patient after treatment ends. It includes a summary of all treatments received, along with recommendations for follow-up care. It may include schedules for exams and medical tests to see if the cancer has come back or spread to another body part. A survivorship care plan should also include information and

resources to help manage all psychosocial aspects of care, including emotional, social, legal, and financial needs.

In addition, it should include recommendations for healthy living, diet, and exercise. Talk to your doctor about a survivorship care plan, which can give you a structure to help you take care of your whole self after active treatment ends. Visit [FightCRC.org](https://www.fightcancer.org) for more information and survivorship care planning programs. The list of questions on page 32 and 33 are a great place to start.

Some of the best tools for survivorship care planning are offered online. You can even use them in partnership with your doctors.

Some popular care plans include:

- Journey Forward  
[JourneyForward.org](https://www.journeyforward.org)
- GI Cancers Alliance  
[LiveStrongCarePlan.org](https://www.livestrongcareplan.org)
- The LIVESTRONG Care Plan  
[LiveStrongCarePlan.org](https://www.livestrongcareplan.org)
- NCCN's Survivorship Plan  
[NCCN.org/patients](https://www.nccn.org/patients)

## ? QUESTIONS TO ASK ABOUT YOUR SURVIVORSHIP CARE PLAN

- Q: Who can help me create a full record of my treatment history to date?
- Q: Which doctors should I see for which type of care?
- Q: How often should I have routine visits?
- Q: What's my schedule for post-treatment follow-up tests?
- Q: What problems should I report to which doctor?
- Q: What long-term and late effects can I expect from the treatment I received?
- Q: What can I do to maintain my health and well-being?
- Q: If I need accommodations at work, can you help me with that?
- Q: Can you refer me to a support group or someone to talk to for my emotional health?

A photograph of a woman and a man in a warm, orange-toned setting. The woman, on the left, is smiling and pointing her finger at the back of a man's t-shirt. The man, on the right, is seen from the back, looking slightly to the side. The t-shirt has the words "NEVER GIVE UP NEVER GIVE IN" printed in large, white, block letters. The woman's t-shirt has some text on it, including "Dilts Matter" and "#SP...".

**Survivorship care plans can give you a structure to help you take care of your whole self.**

Jessica Dilts, Stage IV survivor  
and her caregiver Aaron Cash

## QUESTION QUESTIONS TO ASK WHEN LEAVING YOUR ONCOLOGY HEALTHCARE TEAM

Q: Can I have a written comprehensive care summary (also known as treatment summary care plan)?

---



---



---

Q: What tests were done to diagnose my colon or rectal cancer, including their results? When and where were these done?

---



---



---

Q: What was my diagnosis? What was the stage, location of tumors, and levels of markers such as CEA (  More information on these topics in **Part 1**)?

---



---



---

Q: What family or personal medical history is important to my diagnosis, treatment, and follow-up?

---



---



---

Q: What surgeries, chemotherapy, and radiotherapy did I receive? What dates did these occur, what dosages did I get, and what reactions?

---



---



---

Q: What clinical trials was I part of?

---

Q: What other services did I receive — nutrition, psychological support, home healthcare, genetic counseling?

---



---

Q: What is the full contact information for the places I received treatment and who were my key providers?

---



---



---

Q: Who is the main person who will coordinate my follow-up care and how will I contact that person?

---



---



---

## ❓ QUESTIONS FOR YOUR PRIMARY CARE DOCTOR WHEN YOU ARE DONE WITH TREATMENT:

- Q: What follow-up care will I need? \_\_\_\_\_
- Q: What's the schedule for tests and procedures, and who will provide them? \_\_\_\_\_
- Q: What long-term side effects could I expect from treatment? \_\_\_\_\_
- Q: What are signs or symptoms of a possible recurrence or new cancer? \_\_\_\_\_
- Q: When should I call my oncologist rather than my primary care doctor? \_\_\_\_\_
- Q: What lifestyle changes can I make to help prevent recurrence? \_\_\_\_\_
- Q: What symptoms merit a call to the doctor? \_\_\_\_\_
- Q: Are there medicines or nutritional supplements that I should be taking? \_\_\_\_\_
- Q: Do I need referrals to other health services such as a genetic counselor? \_\_\_\_\_

### LIFESTYLE CHANGES

Research shows that a healthy lifestyle can decrease the risk of recurrence. Consider the following lifestyle adjustments to encourage good health:

- Maintain a healthy weight
- Stay physically active. Engage in 30 minutes of moderate to vigorous activity at least five days a week
- Reduce alcohol use

- Quit smoking
- Enjoy a healthy diet rich in plant-based foods and low in red meat and processed foods
- Limit sun exposure
- Maintain a healthy support network



Talk with your doctor and partner with family or friends to help you stick to a healthy lifestyle.

# FAMILY HISTORY AND GENETICS

# 6

You may know that colorectal cancer can sometimes run in families.

AS A COLORECTAL CANCER SURVIVOR, you are in a unique position to help your family members understand what your diagnosis may mean for them. It is important for family members to share their health history with one another to potentially identify inherited cancer risks.

First-degree relatives (father, mother, sister, brother, children) of colorectal cancer survivors are at an increased risk of the disease and need more frequent colonoscopies (every 5-10 years). The screening guidelines for your first-degree relatives may begin at age 40, or younger if you were under age 60 at the time of your diagnosis of colorectal cancer, or if you have additional close relatives with colorectal cancer.

It is important to tell your first-degree relatives that they may be at increased risk of colorectal cancer because of your diagnosis, and that they should discuss

screening with their doctor. According to the American Cancer Society, individuals with a family history of colorectal cancer diagnosed under age 60 should begin screening at age 40 OR 10 years prior to their family member's diagnosis – whichever comes first.

- *For example:* If you were diagnosed at age 45 with colorectal cancer, your first-degree relatives should begin regular screening (e.g. colonoscopy) at age 35 and repeat it every 5 years.

Share your health history and have your family members talk to their doctors about being screened.

 You can find a local cancer genetic counselor at [nsgc.org](https://nsgc.org)

## LYNCH SYNDROME

It is now possible to test colorectal cancers for Lynch syndrome – a characteristic of the most common form of hereditary CRC. The testing can be done on your tumor by the pathology laboratory and may have been performed automatically after your colorectal surgery. Ask your doctor if your tumor had a characteristic known as “defective mismatch repair.” If it did, you may need a referral to a cancer genetic counselor. If it did not, you may still need a

referral to a cancer genetic counselor if you have a strong personal or family history of cancers and/or colorectal polyps.

For more resources on Lynch Syndrome, visit AliveAndKickn, an organization dedicated to improving the lives of individuals and families affected by Lynch Syndrome and associated cancers through research, education, and screening.

<https://aliveandkickn.org/>



David Dubin and family  
CRC survivor with Lynch syndrome  
Founder of AliveAndKickn

About 5-10% of colorectal cancers occur as a result of a hereditary syndrome. These syndromes can be characterized by clustering of colorectal cancers in several members of the family, by multiple cancers in an individual, and by early age of onset of cancers. There are some

short screening tools that can be used to help identify these hereditary syndromes such as the one below. If you answer “yes” to any of the questions, it is recommended that you talk to your doctor about the possibility of a hereditary colorectal cancer syndrome.

	<b>YES</b>	<b>NO</b>
<p><b>1.</b> Do you have a first-degree relative (mother, father, brother, sister, or child) with any of the following conditions diagnosed before age 50?</p> <ul style="list-style-type: none"> <li>• Colon or rectal cancer</li> <li>• Cancer of the uterus, ovary, stomach, small intestine, urinary tract (kidney, ureter, bladder), bile ducts, pancreas, or brain</li> </ul>	<input type="checkbox"/>  <input type="checkbox"/>	<input type="checkbox"/>  <input type="checkbox"/>
<p><b>2.</b> Have you had any of the following conditions diagnosed before age 50:</p> <ul style="list-style-type: none"> <li>• Colon or rectal cancer</li> <li>• Colon or rectal polyps</li> </ul>	<input type="checkbox"/>  <input type="checkbox"/>	<input type="checkbox"/>  <input type="checkbox"/>
<p><b>3.</b> Do you have 3 or more relatives with a history of colon or rectal cancer? (This includes parents, brothers, sisters, children, grandparents, aunts, uncles, and cousins.)</p>		

↓

**YES to any question**

↓

**Refer for additional assessment or genetic evaluation**

*Reprinted with permission from Patel et al. Dig Dis and Sci, 215:60:748-61; originally published by Kastronos et al (ref 1).*

# STRENGTH FROM OTHERS

# 7

It feels good to talk with and learn from others who share similar experiences as what you're going through.

WHEN YOU TALK TO OTHER SURVIVORS, you'll quickly realize you're not alone. Support groups, online message boards, blogs, and advocacy groups can connect you with people who share information, advice, and resources that matter. They can tell you about their own treatment experiences and answer questions.

The connection you feel with others who are also on this journey can make you feel stronger, and the resilience you can learn from others (or give to others) is invaluable in your fight against cancer.

- ✂ Read personal stories on Fight Colorectal Cancer's blog: [FightCRC.org/blog](https://fightcrc.org/blog)
- ✂ Join us on Facebook: [Facebook.com/FightCRC](https://facebook.com/FightCRC)
- ✂ Share your story! [FightCRC.org/ShareYourStory](https://fightcrc.org/ShareYourStory)



- ✂ Download the Fight CRC Genetics Mini Magazine for detailed information on genetics and colorectal cancer, and a list of genetic conditions associated with colorectal cancer. [FightCRC.org/GeneticsMM](https://fightcrc.org/GeneticsMM)



## ► Gain a New Perspective on Strength and Life

Having a potentially life-threatening disease often leads people to examine their lives and look for meaning. The fear of death often leads to thoughts about life's purpose. In fact, this search for meaning may be the aspect of cancer that has the most surprisingly positive influence.



### Change life's priorities to...

- Remember to do things that make you happy
- Spend more positive time with family, friends, and loved ones
- Seek a more meaningful job
- Volunteer to help others (like becoming a colorectal cancer advocate)
- Focus on your health: quit smoking, eat better, exercise more
- Tap into your fighting spirit
- Enjoy each moment

## ► Celebrate Milestones

Recognizing milestones can help you put your cancer experience into perspective, for better or worse. As emotional as it is, it can be an opportunity to celebrate your perseverance and the fact that you are a cancer survivor.

Marking milestones during and after cancer treatment can be done in a variety of ways. Some people find it meaningful to recognize the 1-year and 5-year cancer-free milestones. Others celebrate milestones and anniversary dates such as the end of chemotherapy or the anniversary of surgery.



### What do you want to celebrate?

- The end of the first round of treatment
- Recovery from surgery
- Your first full year after treatment
- Your birthday
- EVERY day

## SUPPORTING THE CAUSE TOGETHER

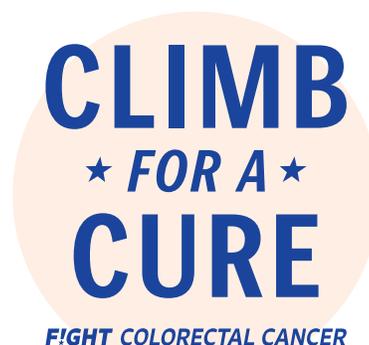
Your fight against colorectal cancer doesn't end once treatments stop and scars heal. Survivorship is an experience. As a survivor, caregiver, family member, or friend, you can raise awareness and support finding a cure for colon and rectal cancers.

Climb for a Cure is a unique event designed to provide an opportunity for colorectal cancer survivors, caregivers, and advocates to commit to a physical and inspiring challenge in honor of those we have lost and those currently fighting. Climbers will find encouragement and camaraderie as they summit a beautiful peak with others who are in the fight. Even if you can't join us in person you can still climb from home. To learn more and get started visit

[FightCRC.org/Climb](https://fightcrc.org/climb)

Each March, Fight Colorectal Cancer hosts Call-on Congress, a three-day educational event open to survivors, caregivers, and their friends and families from across the country. Community leaders, scientists, and medical professionals speak on a range of topics from the federal budget and innovative research, to treatment options and preventative services. Fight CRC trains advocates to share their stories and build relationships with members of Congress. There's also an opportunity to visit congressional offices on "Hill Day." Advocates leave DC with a better understanding of how to push for policies that impact colorectal cancer, determined to return year after year.

Even if you can't attend Call-on Congress, we offer ways to advocate and join the fight all year long from home. To learn more and get started visit [FightCRC.org/SignUp](https://fightcrc.org/signup).



**“I think getting a cancer diagnosis is like being dropped into a foreign country where you don’t understand the language and don’t have a map. It takes awhile to figure out how to get around the new country. I suggest taking a deep breath and finding people who can help navigate while you learn your new language and location.”**

**– Nancy Roach  
Founder • Fight Colorectal Cancer**



## MEDICAL ADVISORY BOARD REVIEWERS

All medically-reviewed content in *Your Guide in the Fight* was written and edited by Fight Colorectal Cancer.

**Dennis J. Ahnen, M.D.**

University of Colorado  
Hereditary Cancer Clinic

**Al B. Benson III, M.D., FACP**

Northwestern University

**Richard M. Goldberg, M.D.**

Ohio State University Medical Center

**Heather Hampel, MS, CGC**

Ohio State University  
Comprehensive Cancer Center

**Jean S. Kutner, M.D., MSPH**

University of Colorado Hospital

**Edith Mitchell, M.D., FACP**

Thomas Jefferson University

View all Medical Advisory Board members at: [FightCRC.org/MAB](https://fightcrc.org/MAB)

## ADDITIONAL REVIEWERS

**Cathy Eng, M.D., FACP, FASCO**

The University of Texas  
MD Anderson Cancer Center  
Professor, Dept of GI Medical Oncology

**Wells Messersmith, M.D.**

Professor and Co-Division Head, Division of  
Medical Oncology University of Colorado

**Christopher Lieu, M.D.**

Assistant Professor, Director Colorectal  
Medical Oncology University of Colorado

**Jessica Martin, Ph.D.**

Fight Colorectal Cancer  
Research Advocate  
Stage IV Fighter

## YOUR GUIDE IN THE FIGHT DEVELOPMENT TEAM

**Will Bryan**

Will Bryan Design

**Anjee Davis, MPPA**

President

**Andrea (Andi) Dwyer**

The Colorado School of Public Health  
University of Colorado Cancer Center

**Elizabeth Fisher, MBA**

Project Manager

**Nancy Levesque**

Director of Communications

**Sam Monica**

Brand Manager

**Nancy Roach**

Founder

**Erica Weiss, MPH, MSUP**

Plain Language Health Writer

**Sharyn Worrall, MPH**

Senior Manager of Education & Research



PHOTO CREDITS: Brett Flashnick, Ryan Hollis, Travis Howard, Brian Threlkeld

# ADDITIONAL RESOURCES



## PATIENT WEBINARS

Fight CRC hosts free patient webinars featuring leading experts from across the country.



## PODCASTS

Fight CRC's educational podcasts put a stop to "taboo-ty" topics and discuss real issues impacting colorectal cancer patients.

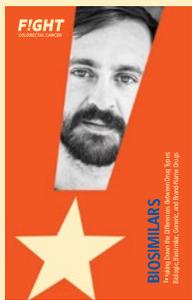
View all resources at: [FightCRC.org/Resources](https://FightCRC.org/Resources)



Screening



Skin Toxicity



Biosimilars



Clinical Trials



Genetics



Side Effects

Download or order copies at: [FightCRC.org/Resources](https://FightCRC.org/Resources)

## MADE POSSIBLE

Your Guide in the Fight was made possible thanks to the support of the following organizations:



***RELENTLESS  
CHAMPIONS OF  
HOPE IN THE  
FIGHT AGAINST  
COLORECTAL CANCER***

***F!GHT***  
★  
***COLORECTAL CANCER***

134 West Park Central Square, Suite 210 • Springfield, MO 65806

***@F!GHTCRC***   



**STAGE III & STAGE IV COLORECTAL CANCER**

**3**

**PRACTICAL ISSUES,  
SUPPORTIVE CARE, & RESOURCES**

**YOUR  
GUIDE  
★ IN THE ★  
FIGHT**

**FIGHT COLORECTAL CANCER**



# YOUR GUIDE ★ IN THE ★ FIGHT

## FIGHT COLORECTAL CANCER

### DISCLAIMER

The information and services provided by Fight Colorectal Cancer are for general informational purposes only and are not intended to be substitutes for professional medical advice, diagnoses, or treatment. If you are ill, or suspect that you are ill, see a doctor immediately. In an emergency, call 911 or go to the nearest emergency room. Fight Colorectal Cancer never recommends or endorses any specific physicians, products, or treatments for any condition.

### FIGHT COLORECTAL CANCER

We FIGHT to cure colorectal cancer and serve as relentless champions of hope for all affected by this disease through informed patient support, impactful policy change, and breakthrough research endeavors.

### YOUR GUIDE IN THE FIGHT

If you have recently been diagnosed with stage III or IV colorectal cancer (CRC), or have a loved one with the disease, this guide will give you invaluable information about how to interpret the diagnosis, realize your treatment options, and plan your path. You have options, and we will help you navigate the many decisions you will need to make.

*Your Guide in the Fight* is a 3-part book designed to empower and point you towards trusted, credible resources.

*Your Guide in the Fight* offers information, tips, and tools to:

- Navigate your cancer treatment
- Help you gather information for treatment
- Provide you with tips to manage symptoms
- Direct you to resources for personal strength, organization, and support
- Help you manage details from diagnosis to survivorship

### LOOK FOR THE ICONS



Tips and Tricks



Additional Resources



More information can be found on another page or part

# PRACTICAL ISSUES, SUPPORTIVE CARE, & RESOURCES

# 3

PAGE • TABLE OF CONTENTS

- 2 • Coping with the Cost of Care
- 5 • Support for Caregivers
- 6 • Advance Directives
- 9 • Tumor Banking
- 10 • Hospice Care
- 12 • End of Life Issues
- 14 • Glossary
- 18 • Resources

## WHAT YOU WILL KNOW AFTER READING PART 3

- TIPS FOR CAREGIVING AND LOVED ONES
- HOW TO SEEK FINANCIAL ADVICE
- HOW TO TALK TO MY KIDS ABOUT CANCER
- WHAT TO ASK MY DOCTOR ABOUT END OF LIFE CARE

# COPING WITH THE COST OF CARE

# 1

## Cancer care can cost a lot.

A COLORECTAL CANCER DIAGNOSIS means you'll be visiting the doctor frequently and will likely be taking several medications. Don't be surprised by costs not covered by insurance. If you don't have insurance, or if you have many out-of-pocket expenses (like co-pays), the groups mentioned in this section may be able to help. It is important to stay on top of your medical bills and insurance payments.

### **Frankly Speaking About Cancer: Coping with the Cost of Care**

This is a free publication by the Cancer Support Community that can help guide you through the financial impact of cancer care. [CancerSupportCommunity.org](http://CancerSupportCommunity.org)

### **Patient Advocate Foundation**

The Patient Advocate Foundation (PAF) is a non-profit organization that provides direct services to patients with chronic, life threatening, and debilitating diseases to help access care and treatment recommended by their doctors. They offer on-on-one assistance through their hotline **800.532.5274**. PAF provides copayment assistance and helps people who are uninsured or underinsured find care. They also provide assistance with insurance appeals. [PatientAdvocate.org](http://PatientAdvocate.org)

## Patient Assistance Programs

Patient Assistance Programs (PAPs) help patients who have difficulty paying for prescription medications. State governments, charitable organizations, and drug companies PAPs that provide discounted or free medications to those who financially and medically qualify. Some also help file appeals to insurance companies who deny coverage for certain medications. Nearly every drug company has a PAP for the products they produce.

### General questions to ask about the cost of care:

- Q:** What will be my treatment expenses based on my insurance?
- Q:** Does my health insurance company need to approve any treatments before I begin?
- Q:** Is the recommended treatment facility part of my health plan's network?
- Q:** If I need to be admitted to the hospital, what is covered under my health insurance?
- Q:** Is there a co-pay for each individual treatment?
- Q:** Who can I talk to when I have billing questions?

## Tracking Medical Costs & Insurance Payments

Medical bills can be confusing because one appointment may include separate bills from the doctor, the lab, a specialist, and prescriptions. It can be difficult to get a good sense of your out-of-pocket costs.

Try to keep your receipts and Explanation of Benefits (EOBs) in one place. Keep a notebook or binder to store notes and pertinent information about healthcare bills. Consider choosing one day each month to be “healthcare bill day” when you can focus on organizing your budget and bills. If you use a health savings account (HSA) through your work, remember to take advantage of the benefits it provides.



### NONPROFIT FINANCIAL ASSISTANCE PROGRAMS

Advocacy Connector  
[AdvocacyConnector.com](http://AdvocacyConnector.com)

Cancer Care Financial Assistance  
[CancerCare.org](http://CancerCare.org)  
or call **1.800.813.4673**

Cancer Care Co-Pay Assistance  
[CancerCareCopay.org](http://CancerCareCopay.org)  
or call **1.866.552.6729**

HealthWell Foundation  
[HealthWellFoundation.org](http://HealthWellFoundation.org)  
or call **1.800.675.8416**

Medicine Assist Tool  
[MedicineAssistTool.org](http://MedicineAssistTool.org)

Needy Meds  
[NeedyMeds.org](http://NeedyMeds.org)  
or call **1.800.503.6897**

Patient Advocate Foundation  
[PatientAdvocate.org](http://PatientAdvocate.org)  
or call **1.800.532.5274**



### MANUFACTURER DRUG ASSISTANCE PROGRAMS BY DRUG TYPE

Camptosar® (Irinotecan)  
[PfizerRXPathways.com](http://PfizerRXPathways.com)  
or call **1.866.706.2400**

Eloxatin® (Oxaliplatin)  
[VisitSPOnline.com](http://VisitSPOnline.com)  
or call **1.888.847.4877**

Avastin® (Bevacizumab)  
[Genentech-Access.com](http://Genentech-Access.com)  
or call **1.866.422.2377**

Erbitux® (Cetuximab)  
[LillyCares.com](http://LillyCares.com)  
or call **1.800.545.6962**

Vectibix® (Panitumumab),  
Aranesp® (Darbepoetin),  
Neulasta® (Peg Igrastim)  
[AmgenAssist.com](http://AmgenAssist.com)  
or call **1.888.427.7478**

Stivarga® (Regorafenib)  
[ReachPatientSupport.com](http://ReachPatientSupport.com)  
or call **1.866.639.2827**

Zaltrap® (Ziv-A ibercept)  
[Zaltrap.com/Resources](http://Zaltrap.com/Resources)  
or call **1.855.925.8727**

Oncotype DX®  
[OncotypeDX.com](http://OncotypeDX.com)  
or call **1.866.662.6897**

Lonsurf® (trifluridine and tipiracil):  
[TaihoPatientSupport.com](http://TaihoPatientSupport.com)

This is not an all-inclusive list of manufacturing and non-profit organizations offering financial assistance. There may be organizations in your area who offer assistance. For more information on financial assistance, visit [FightCRC.org](http://FightCRC.org)



Gailia Walter  
CRC advocate

# SUPPORT FOR CAREGIVERS

# 2

## Caregivers can support their loved one through words and actions.

### WAYS TO SUPPORT YOUR LOVED ONE:

- Attend doctor appointments
- Manage side effects
- Relay health information to friends and family
- Talk through treatment decisions
- Help with medication

As a caregiver, it's easy to put your loved one's needs before your own, but remember that your role can be physically, emotionally, and spiritually challenging. It's important to take good care of yourself and ensure you get the support you need. You may consider talking to a social worker or mental health professional, keeping a journal, and scheduling time each week for you to engage in activities that make you happy and reduce stress.

End of life can be a challenging and stressful experience for caregivers and family members. Finding support – emotional, spiritual and mental – is extremely important. You may notice a variety of feelings and emotions throughout your time as a caregiver, ranging from fear, isolation, anger, guilt, and others. Ask to talk to a social worker or other mental health professional and engage in activities that help you feel calm and centered.

**“It's important to talk about thoughts and feelings with others.”** - Martin Lannon, caregiver to wife Trish, a Stage III survivor

During the end-of-life phase, the caregiver role continues. Caregivers can support their loved one through their words and actions. Here are some

ways caregivers can provide support at the end of life:

- Create a positive and peaceful atmosphere
- Listen to the feelings, needs, thoughts, and fears that your loved one wishes to express
- Relay the news of any physical discomfort experienced by your loved one to his/her medical care team
- Use gentle touch to offer comfort
- Stay present to the needs of your loved one

 For more information, search [Cancer.gov](https://www.cancer.gov) for caregivers

 Visit [Fightcancer.org](https://www.fightcancer.org) for more caregiving information, resources, and stories.

# ADVANCE DIRECTIVES

# 4

Advance directives are legal documents that allow you to transcribe your personal wishes and goals for medical treatment at end of life.

ADVANCE DIRECTIVES are legal documents that allow you to transcribe your personal wishes and goals for medical treatment at end of life. This includes choosing people who can make decisions for you if you're unable, so your wishes are carried out.

Advance directives may vary from state to state. They are not just for people with cancer or people who are dying. Many people have them in place so that their personal decisions can be carried out in medical emergencies.

**MEDICAL POWER OF ATTORNEY** allows another individual to make decisions for someone who is not physically capable

of doing so. This may also be known as durable power of attorney for healthcare, healthcare agent, or healthcare proxy.

**POWER OF ATTORNEY** gives an individual the right to act on behalf of another person in financial or real estate issues.

A **LIVING WILL** holds information about how a person wants to be treated medically if they cannot speak for themselves. Living wills are also called directive to physicians, healthcare declaration, or medical directive. They tell families and healthcare staff what kind of life-sustaining care you wish to have, such as cardiopulmonary

resuscitation (CPR), mechanical ventilation, artificial nutrition, and hydration, or hydration (dialysis).

**DNR OR DO-NOT-RESUSCITATE** orders must be written by a physician, although they can be written at the request of a patient or family member. A person with a valid DNR will not be given CPR if their heart or breathing stops. DNR orders can be written for patients who are being cared for at a hospital or at home.

Legal requirements for completing and changing advance directives vary according to state law. Your state also defines who can witness them



Julienne Gede Edwards  
Stage IV fighter

and whether or not they need to be notarized. Living wills and medical power of attorney (or healthcare proxy) cannot go into effect until a doctor certifies that you are unable to make your own medical decisions. If your condition improves, your healthcare proxy can no longer speak for you. Emergency medical technicians cannot honor living wills or healthcare agents. By law, if they are called, they must stabilize an individual and transport him/her to a healthcare facility.

 If you or your loved one has a DNR signed by a physician, put it where the emergency medical personnel can see it, or where those caring for you can find it quickly and easily.



# TUMOR BANKING

# 5

Tissue banking is the storing of human tissue that was removed during a medical procedure, for example, a biopsy, for scientists and researchers to use to advance science.

MANY PEOPLE CONSIDER TISSUE donations, or tumor banking, throughout treatment and at the end of life. With proper written consent, the tissue is sent and stored at a tissue bank, where it is preserved. Donations could include parts of tumors, cancer cells, bodily fluids, and the whole body.

Patients often ask if their donation will directly benefit them. While colorectal cancer (CRC) research is moving more swiftly than ever, it is unlikely that you will benefit directly. More likely, your donation will help advance research and education for others who are diagnosed with CRC in the future.

If you choose to donate, you will sign a consent form detailing how the tissue bank will prioritize confidentiality laws that protect your medical information,

the intent of the use of tissue donated, and other specifics about the process. You also have options for how much, or how little, personal and medical information you want to share. An institutional review board (IRB) will likely be involved in this process. Even after you have signed a consent form, you have the option to change your mind and decline.

In making the decision to donate tissue, it's always a good idea to talk with your care team and your friends and family first.

 For additional information about tissue banking, visit National Cancer Institute (NCI): [Cancer.gov](https://www.cancer.gov)

# HOSPICE CARE

# 6

## Hospice professionals focus on providing the best quality of life to an individual at the end of their life.

THE PHILOSOPHY of hospice care is to provide assistance and support for people in the final phases of life and to affirm life while allowing death to take its course.

### WHEN DO YOU USE HOSPICE?

Hospice care treats the person, not the disease. It manages symptoms, so a person's last days may be spent with dignity and comfort. It is often a family-centered service that includes the patient and the family in making decisions.

Hospice care may be provided if you have a limited life expectancy, usually no more than six months, although for some, care may extend

beyond six months. If you are on hospice care, you may choose to return to a different form of medical treatment at any time. Depending on your needs, hospice care may be provided in the comfort of home or at an inpatient facility.

### Hospice care is provided by an interdisciplinary team that includes the following:

- A specially trained hospice physician or medical director who may take over your medical care or work closely with your chosen physician
- A nurse who makes regular visits to assess your condition, provide pain relief, help manage other uncomfortable symptoms, and help others who are providing care. Hospice nurses are available 24 hours a day, seven days a week to manage crises or answer questions.
- Home health aides provide practical help for patients. For example help with getting in and out of the bath, getting dressed, and meal preparation.
- A social worker who coordinates community services and financial needs, and provides support and emotional counseling for the family
- A chaplain who helps with spiritual needs and communicates with family clergy or church support

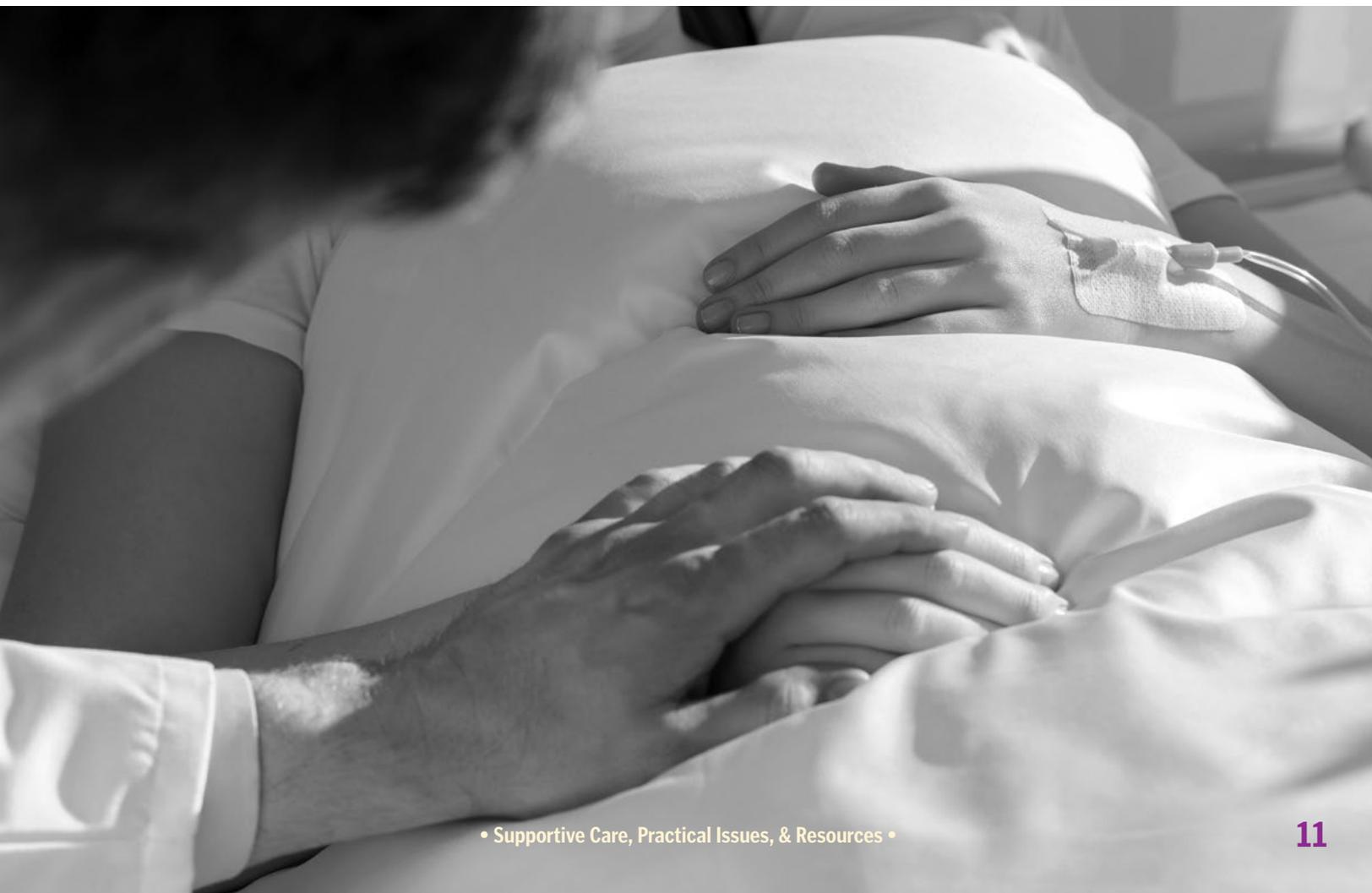
Hospice doctors, nurses, social workers, psychologists and clergy are trained to help with family dynamics. They put the needs and desires of the patient first.

**PAYING FOR HOSPICE.** Hospice care is provided through the Medicare Hospice Benefit or private insurance. Hospice helps arrange payment for patients who are not eligible for Medicare and are uninsured.

**HOW DOES HOSPICE BEGIN?** You will need a referral for hospice, but you don't need to wait for your doctor to contact a hospice program to find out what is available. Hospice staff can work with your medical team to receive a referral, or you can make a request to your doctor's office to receive a referral when you are ready.

① For information on Medicare and Hospice Benefits, visit: [Medicare.gov](https://www.medicare.gov)

① For additional information, see [Cancer.gov](https://www.cancer.gov)



# END OF LIFE ISSUES

# 7

There may come a time when you run out of treatment options, or reach a point where you no longer want to continue treatment.

AT THAT POINT, making decisions about how you want to live the rest of your life is important, for you and your loved ones. Thinking about the end of life can be difficult, uncomfortable, and frightening. You may feel that planning for the end of life is “giving up” and that you should focus only on getting well – but it is important to do what’s right for you. Even if your family and loved ones aren’t comfortable talking about it, it is important to address end-of-life issues.

Planning can be empowering and should not be viewed as “giving up,” rather, “taking action.” There are resources, experts, and people to help you if you’re

facing late-stage or end-of-life issues. It is not an admission of weakness, loss of hope, or lack of faith in your ability to fight cancer. It’s planning. You’re fighting for your **best quality of life** – to complete your journey on your terms.

It’s important to find your own way to manage end-of-life issues, as you have to think things through ahead of time. Getting your affairs in order can give you a sense of relief and free up energy.

Hospitals require clear directions about your personal wishes and who can make decisions for you, should you be unable to make decisions for yourself.

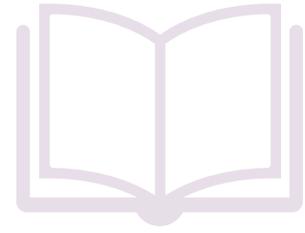
Planning for what you want during treatment and at the end of life requires a team. You'll want to include:

- Family members and friends. Talking over your thoughts and wishes can help clarify your own ideas and let your loved ones know what you need and want. At least one trusted family member or friend needs to know where you keep legal, financial, and medical directive information.
- Your health care team, especially the doctor who coordinates your various specialty caregivers.
- An attorney. You may need help with your will, advance directive, or other legal documents.
- A financial planner, if applicable.
- Social workers. They can talk with both you and your family about your fears, concerns, and needs.
- Hospice staff. You can talk to hospice about their services and requirements before being enrolled. If you have several hospice organizations in your community, see which best fits your needs.
- Insurance professionals. They can clarify what coverage you have for care and help with paperwork that may be needed at the end of life.
- Spiritual support. Some cancer patients are strengthened by planning a funeral or burial place. Once done, they are free to continue with cancer care (pastoral care is included in hospice services).



# Planning is important to you and your loved ones.

# GLOSSARY



**abdominoperineal resection:** the surgical removal of the anus, rectum and sigmoid colon, resulting in the need for a permanent colostomy.

**acupuncture:** Traditional Chinese Medicine (TCM) that involves the insertion of small needles into specific points on the skin. Used to alleviate pain and to treat various physical, mental, and emotional conditions.

**acute:** abrupt onset that usually is severe; happens for a short period of time.

**adenoma:** non-cancerous polyp. Considered the first step toward colon and rectal cancer.

**adjuvant therapy:** treatment used after primary treatment (such as surgery or radiation), generally done to reduce the risk of the cancer returning.

**advance directive:** a legal document stating the treatment or care a person wishes to receive, or not receive, if he/she becomes unable to make medical decisions.

**adverse effect:** a negative or harmful effect.

**antigens:** substances that provoke an immune response in the body. The body produces antibodies to fight antigens, or harmful substances, to try to eliminate them.

**anus:** the opening of the rectum positioned in the fold between the buttocks. At the end of the digestive tract where waste is expelled.

**asymptomatic:** no symptoms; no clear evidence that disease is present.

**benign tumor:** noncancerous tumor that does not invade nearby tissue or spread to other parts of the body the way cancer can.

**biological therapy:** a type of treatment made of substances from living organisms to treat disease. These substances may occur naturally in the body or may be made in a laboratory. Types of biological therapy include immunotherapy (such as vaccines, cytokines, and some antibodies), gene therapy, and some targeted therapies.

**biomarkers:** a biological molecule found in blood, other body fluids, or tissues. Biomarkers appear in tumors, too. Testing your tumor for biomarkers (AKA knowing your tumor type) can help you understand if there are abnormal functions of your body's organs and systems. Biomarkers can come in the form of genetic mutations (genes), proteins, and DNA abnormalities.

**biopsy:** the removal of cells or tissues for examination by a pathologist. The pathologist may study the tissue under a microscope or perform other tests on the cells or tissue. The most common types include (1) incisional biopsy, in which a sample of tissue is removed; (2) excisional biopsy, in which an entire lump or suspicious area is removed; and (3) needle biopsy, in which a sample of tissue or fluid is removed with a needle.

**cancer:** term for diseases in which abnormal cells divide without control and can invade nearby tissues.

**cancer survivor:** anyone who has been diagnosed with cancer – from the time of diagnosis and for the balance of his or her life.

**carcinoma in situ:** a group of abnormal cells that remain in the place where they first formed. Also called stage 0 disease.

**chemotherapy:** treatment that uses drugs to stop the growth of cancer cells, either by killing the cells or by stopping them from dividing. Chemotherapy may be given by mouth, injection, or infusion, or on the skin, depending on the type and stage of the cancer being treated.

**clinical trial:** research study that tests safety and effectiveness of new medical approaches and treatments.

**colectomy:** surgical procedure to remove all or part of the patient's colon. A partial colectomy is when only part of the colon is removed. An open colectomy is when one long incision is made in the wall of the abdomen and doctors can see the colon directly. A laparoscopic-assisted colectomy is when several small incisions are made and a thin, lighted tube attached to a video camera is inserted through one opening to guide the surgery.

**colorectal Cancer (CRC):** the term referring to rectal cancer (cancer located in the rectum) and colon cancer (cancer located in the rest of the colon).

**colostomy:** surgical operation where a piece of the colon is diverted to an artificial opening in the abdominal wall.

**complementary and alternative medicine (CAM):** treatment used in addition to (complementary) or instead of (alternative) standard treatments. CAM may include dietary supplements, vitamins, herbs, teas, acupuncture, massage therapy, or spiritual healing.

**distress screening:** a screening tool to identify stressors to be addressed throughout treatment. Can work like a pain scale to learn about problems and concerns such as housing, insurance and transportation, in addition to psychosocial and emotional challenges.

**DPD deficiency:** A metabolic disorder in which there is a low level of the enzyme dihydropyrimidine dehydrogenase (DPD). DPD is an enzyme needed to help the body break down 5-FU and capecitabine.

**endoscopy:** an examination using a lighted, flexible instrument that allows a physician to see the inside the digestive tract. The endoscope can be passed through the mouth or through the anus.

**explanation of benefits (EOB):** summary of medical treatment costs or healthcare service that an insurance company may send to a patient following the service.

**familial adenomatous polyposis (FAP):** a syndrome where a gene mutation influences the development of colorectal cancer. People with FAP usually develop hundreds, and sometimes thousands, of pre-cancerous polyps, or growths at a young age.

**family history:** a record of a person's relatives along with the relative's medical history to include current and past illnesses. A family history may show a pattern of certain diseases in a family.

**fecal diversion:** a surgical opening of part of the colon (colostomy) or small intestine (ileostomy) to the surface of the skin that provides a passageway for stool to exit the body.

**FIT:** the fecal immunochemical test (FIT) is a screening test for colorectal cancer that tests for blood in the stool (originating from the lower intestines), an early sign of cancer.

**follow up:** follow-up care involves regular medical checkups, which may include a physical exam, blood tests and imaging tests.

**genetics:** the study of heredity and how the characteristics of living things are transmitted from one generation to the next.

**genomics:** the branch of molecular biology concerned with the structure, function, evolution, and mapping of genomes.

**immunotherapy:** a treatment that uses certain parts of a person's immune system to fight diseases such as cancer, either by stimulating the person's own immune system to work harder or smarter to attack cancer cells, or by giving the person immune system components, such as man-made immune system proteins.

**integrative medicine:** A patient approach to medicine that involves both standard treatment and complimentary therapies like massage and acupuncture.

**interdisciplinary team:** A coordinated group of healthcare professionals from diverse fields who work together toward a common goal for the patient. Also called multidisciplinary team.

**late effects:** Health problems that occur months or years after a disease is diagnosed or after treatment has ended.

**localized:** Localized cancer is usually found only in the tissue or organ where it began, and has not spread to nearby lymph nodes or to other parts of the body.

**low residue diet:** a low-fiber diet that includes restrictions on foods that increase bowel activity (like dairy and prune juice). Fruit and vegetable intake is reduced to limited amounts of well-cooked vegetables and cooked or very ripe fruits. Whole-grain breads and cereals are replaced with refined products. Legumes, seeds and nuts are omitted entirely.

**Lynch syndrome:** an inherited disorder in which affected individuals have a higher-than-normal chance of developing colorectal cancer and certain other types of cancer, often before the age of 50 (also called hereditary nonpolyposis colorectal cancer).

**metastasis:** the spread of cancer cells from the place where they first formed to another part of the body. In metastasis, cancer cells break away from the original (primary) tumor, travel through the blood or lymph system, and form a new tumor in other organs or tissues of the body. The new, metastatic tumor is the same type of cancer as the primary tumor.

**mortality:** the number of deaths occurring in a given period in a specified population. It can be expressed as an absolute number of deaths per year, or as a number per 100,000 persons per year.

**multidisciplinary team:** A group of different healthcare professionals who are members of different disciplines with their own specialized skills and expertise.

**NCI-designated cancer center:** cancer research institutions in the US supported by National Cancer Institute. These institutions form the backbone of NCI's programs for studying and controlling cancer.

**neoadjuvant therapy:** treatment given as a first step to shrink a tumor before the main treatment, which is usually surgery, is given.

**oncologist:** doctor with special training in diagnosing and treating cancer. Some oncologists specialize in a particular type of cancer treatment.

**oncology:** branch of medicine that specializes in the diagnosis and treatment of cancer. It includes medical oncology (the use of chemotherapy, hormone therapy, and other drugs), radiation oncology (the use of radiation therapy), and surgical oncology (the use of surgery and other procedures).

**pathologist:** doctor with training in identifying diseases by studying cells and tissues under a microscope.

**primary care:** primary care includes physical exams, treatment of common medical conditions, and preventive care, such as immunizations and screenings. A primary care doctor is usually the first healthcare professional a patient sees for medical care.

**polyp:** a growth on the inner surface of the colon, some of which can progress into cancer; may be scattered throughout the colon and vary in size from a few millimeters to several centimeters; flat or raised appearance.

**prognosis:** the likely outcome or course of a disease; the chance of recovery or recurrence.

**psychosocial:** the psychological, emotional, and social parts of a disease and its treatment; can include feelings, moods, beliefs, the way people cope, and relationships with others.

**recurrence:** return of cancer after treatment and after a period of time during which cancer cannot be detected; the same cancer may return where it started or somewhere else in the body.

**small intestine:** the portion of the digestive tract that first gets food from the stomach. It's divided into the duodenum, the jejunum, and the ileum.

**stoma:** A surgically-created opening from an area inside the body to the outside.

**treatment adherence:** following treatment regimens; a patient's willingness to start treatment and the ability to take medications exactly as prescribed.

**tumor:** nonspecific term that simply refers to a mass; can refer to benign or malignant growths.

# RESOURCES



## Fight Colorectal Cancer

Fight Colorectal Cancer (Fight CRC) is a nonprofit organization and the leading national colorectal cancer advocacy group. We FIGHT to cure colorectal cancer and serve as relentless champions of hope for all affected by this disease through informed patient support, impactful policy change, and breakthrough research endeavors. Additionally, we lead efforts to increase and improve colorectal cancer research for all stages and throughout the cancer continuum from prevention, early detection and diagnosis, therapeutic intervention, post treatment follow-up, and survivorship.  
[www.FightColorectalCancer.org](http://www.FightColorectalCancer.org)

## Fight Colorectal Cancer's Clinical Trials Info

Fight CRC Trial Finder: A Curated List Powered by Patients. This trial finder is a one-stop place to find and learn more about high-impact clinical trials for CRC patients. The Late Stage MSS-CRC Trial Finder is a place you can search for clinical trials that are open in your geography, and for which you may be eligible. The current data are limited to MSS (microsatellite-stable) and stage IV CRC patients. The list of trials curated here is sourced from the [ClinicalTrials.gov](http://ClinicalTrials.gov) website.  
[www.FightCRC.org/ClinicalTrials](http://www.FightCRC.org/ClinicalTrials)

## Advocates Facebook Group

This Facebook group is where advocates can connect with other survivors and caregivers in the fight against colorectal cancer. Focused primarily on policy change, this group is perfect for those looking to get more involved with political advocacy at Fight CRC.  
[www.facebook.com/groups/AdvocatesFightCRC](http://www.facebook.com/groups/AdvocatesFightCRC)

## AliveAndKickn

An organization dedicated to improving the lives of individuals and families affected by Lynch Syndrome and associated cancers through research, education, and screening.  
[www.aliveandkickn.org](http://www.aliveandkickn.org)

American Society of Colon and Rectal Surgeons  
[www.fascrs.org](http://www.fascrs.org)

American Society of Clinical Oncology  
[www.cancer.net](http://www.cancer.net)

## Camp Kesem

An organization offering recreational summer camp for children whose parent(s) have been diagnosed with cancer.  
[www.CampKesem.org](http://www.CampKesem.org)

CancerCare  
[www.CancerCare.org](http://www.CancerCare.org)

Cancer Support Community  
[www.CancerSupportCommunity.org](http://www.CancerSupportCommunity.org)

Caring Bridge  
[www.CaringBridge.org](http://www.CaringBridge.org)

**Colorectal Cancer Alliance**

Colorectal Cancer Alliance's mission is to empower a nation of allies who work with us to provide support for patients and families, caregivers, and survivors; to raise awareness of preventative measures; and inspire efforts to fund critical research.

[www.CCAlliance.org](http://www.CCAlliance.org)

**Colon Cancer Challenge**

a 501(c)3 non-profit organization dedicated to a World Without Colorectal Cancer through awareness, prevention, screening, and research.

[www.ColonCancerChallenge.org](http://www.ColonCancerChallenge.org)

**Colon Cancer Coalition/GYRIG**

Non-profit organization dedicated to encouraging screening and raising awareness of colorectal cancer. Their signature Get Your Rear in Gear® and Tour de Tush® event series are volunteer-driven in communities throughout the United States.

[www.ColonCancerCoalition.org](http://www.ColonCancerCoalition.org)

**Colon Club**

The Colon Club connects young adults diagnosed with colorectal cancer so they never have to feel alone. Our mission is to talk “poo” to as many people as possible, specifically young adults, educating about the risk factors, genetic precursors, and symptoms of CRC and to demand a COLONOSCOPY when it is appropriate for THEM!

**Colontown**

A Paltown, Peer-Curated Community: This is a group of online communities on Facebook dedicated to colorectal cancer.

[www.Colontown.org](http://www.Colontown.org)

**Colorectal CareLine**

[www.ColorectalCareLine.org](http://www.ColorectalCareLine.org)

**Comprehensive Cancer Centers**

[CancerCenters.cancer.gov](http://CancerCenters.cancer.gov)

**Health Information**

[www.MedlinePlus.gov](http://www.MedlinePlus.gov)

**Healthy Living, Personalized Health Advice**

[www.HealthFinder.gov](http://www.HealthFinder.gov)

**Helping Hands**

[www.rci.LotsaHelpingHands.com](http://www.rci.LotsaHelpingHands.com)

**Imerman Angels**

Providing personalized connections that enable one-on-one support among cancer fighters, survivors and caregivers.

[www.ImermanAngels.org](http://www.ImermanAngels.org)

**Inspire**

Inspire is a safe, privacy-protected place where you can connect with people who share your health concerns, obtain support, and find information about colorectal cancer.

[FightCRC.org/Inspire](http://FightCRC.org/Inspire)

**LIVESTRONG**

[www.LiveStrong.org](http://www.LiveStrong.org)

**Michael's Mission**

Michael's Mission is focused on improving the quality of life and treatment options for those suffering from colorectal cancer through education, research and patient support.

[www.MichaelsMission.org](http://www.MichaelsMission.org)

**My Lifeline**

[www.MyLifeLine.org](http://www.MyLifeLine.org)

**My Pearl Point**

Help with nutrition guidance and tips for managing side effects. Free advice and support for living with and beyond cancer.

(877) 467-1936 X 101

[www.pearlpoint.org](http://www.pearlpoint.org)

**National Comprehensive Cancer Network**

Colon and Rectal Patient's Guide: Patient resources published by the National Comprehensive Cancer Network® (NCCN®) that detail the best treatment options. They also include patient-friendly tools, such as questions to ask your doctor, a glossary of terms, medical illustrations of anatomy, and more <https://www.nccn.org/patients/guidelines/cancers.aspx>  
[www.nccn.org](http://www.nccn.org)

**National Cancer Institute**

[www.cancer.gov](http://www.cancer.gov)

**Peer-Reviewed, Evidence-Based Medicine**

[www.UpToDate.com](http://www.UpToDate.com)

**Scientific Journal Articles**

[www.ncbi.nlm.nih.gov/pubmed](http://www.ncbi.nlm.nih.gov/pubmed)

**Store My Tumor**

Specializes in collecting, processing, and storing viable tumor for all types of cancers.  
[www.storemytumor.com](http://www.storemytumor.com)

**Stupid Cancer**

[www.StupidCancer.org](http://www.StupidCancer.org)

**The National Institutes of Health Clinical Trials**

[www.ClinicalTrials.gov](http://www.ClinicalTrials.gov)

**United Ostomy Associations of America (UOAA)**

800-826-0826

[www.ostomy.org](http://www.ostomy.org)

**GENERAL INFORMATION ON FINANCIAL ISSUES AND INSURANCE**

**Agency for Healthcare Research and Quality (U.S. Department of Health and Human Services)**

Provides information on choosing a health plan.  
[www.ahc.gov/consumer](http://www.ahc.gov/consumer)

**America's Health Insurance Plans**

National directory of health insurance plans and information on types of coverage.  
[www.ahip.org](http://www.ahip.org)

**American Association of Retired Persons (AARP)**

Find detailed information on Medicare and other health insurance programs for people over 50.  
888-OUR-AARP (888-687-2277)  
[www.aarp.org/health](http://www.aarp.org/health)

**American Cancer Society - Taking Charge of Money Matters Workshop**

Offers a series of booklets on financial topics for people living with cancer.  
800-ACS-2345 (800-227-2345)  
[www.cancer.org](http://www.cancer.org)

**Department of Health and Human Services**

Learn about the Affordable Care Act (health care reform).  
[www.healthcare.gov](http://www.healthcare.gov)

**Healthcare Blue Book**

Provides healthcare consumers with information on cost of medical services based on where you live.  
[www.HealthcareBlueBook.com](http://www.HealthcareBlueBook.com)

**Medicare**

(U.S. Department of Health and Human Services)  
Find information on the Medicare health insurance program, including prescription drug plans.  
[www.medicare.gov](http://www.medicare.gov)

**Medicaid**

Find your state's Medicaid toll-free hotline.  
[www.medicaid.gov](http://www.medicaid.gov)

**National Association of Insurance Commissioners**

Find your state's insurance commissioner.  
[www.naic.org](http://www.naic.org)

**National Cancer Legal Services Network (NCLSN)**

Find a directory of organizations that provide free legal help for people and families affected by cancer.  
[www.nclsn.org](http://www.nclsn.org)

**National Coalition for Cancer Survivorship**

Publishes the booklets “Working It Out: Your Employment Rights as a Cancer Survivor” and “What Cancer Survivors Need to Know About Health Insurance.”

877-NCCS-YES (877-622-7937)

[www.CancerAdvocacy.org](http://www.CancerAdvocacy.org)

**Patient Advocate Foundation**

Offers legal and advocacy help when disputing insurance claim denials and provides financial assistance information.

800-532-5274

[www.PatientAdvocate.org](http://www.PatientAdvocate.org)

**Patient Advocate Foundation –  
National Underinsured Resource Directory**

Offers an online tool and a smartphone app to help find local, state and national resources for people who are underinsured and looking for insurance coverage options or other types of financial assistance.

800-532-5274

[www.PatientAdvocate.org/help4u.php](http://www.PatientAdvocate.org/help4u.php)

**NeedyMeds.com**

Provides information on how to find pharmaceutical manufacturer assistance programs.

[www.NeedyMeds.com](http://www.NeedyMeds.com)

**Patient Access Network (PAN) Foundation**

Focused on ensuring underinsured patients living with life-threatening, chronic and rare diseases get the financial assistance they need so they can start focusing on what matters most: their health.

1-866-316-7263

[www.PanFoundation.org](http://www.PanFoundation.org)

**Patient Advocate Foundation –  
Co-Pay Relief Program**

Provides financial assistance for prescription drug co-payments to patients who qualify.

866-512-3861

[www.copays.org](http://www.copays.org)

**Partnership for Prescription Assistance (PPA)**

Offers low-cost and free prescription drug programs for those with limited income  
888-4PPA-NOW (888-477-2669)

[www.pparx.org](http://www.pparx.org)

**Social Security Administration**

Find your local social security office.

[www.ssa.gov](http://www.ssa.gov)

**TRANSPORTATION ASSISTANCE  
LOCAL TRANSPORTATION****American Cancer Society – Road to Recovery**

Provides local transportation to and from cancer treatments.

800-ACS-2345 (800-227-2345)

[www.cancer.org](http://www.cancer.org)

**Patient Advocate Foundation –  
Financial Aid Fund**

Provides financial assistance for transportation to and from treatment.

800-532-5274

[www.PatientAdvocate.org](http://www.PatientAdvocate.org)

**LONG-DISTANCE TRANSPORTATION****Air Charity Network**

Offers air travel to treatment centers for cancer patients and their caregivers.

877-621-7177

[www.AirCharityNetwork.org](http://www.AirCharityNetwork.org)

**Corporate Angel Network**

Uses empty seats on corporate aircraft to help cancer patients reach treatment centers.

914-328-1313

[www.CorpAngelNetwork.org](http://www.CorpAngelNetwork.org)

**Lifeline Pilots**

Offers air travel to treatment centers for cancer patients and their caregivers.

800-822-7972

[www.LifelinePilots.org](http://www.LifelinePilots.org)

### **Mercy Medical Airlift**

Offers air travel to treatment centers for cancer patients and their caregivers.

888-675-1405

[www.MercyMedical.org](http://www.MercyMedical.org)

### **National Patient Travel Center**

Offers air travel to treatment centers for cancer patients and their caregivers.

800-296-1217

[www.PatientTravel.org](http://www.PatientTravel.org)

### **Raquel's Wings for Life**

Offers air travel to treatment centers for cancer patients and their caregivers.

940-627-1050

[www.RaquelsWingsForLife.com](http://www.RaquelsWingsForLife.com)

## **LODGING ASSISTANCE**

### **American Cancer Society – Hope Lodge**

Provides lodging for families during cancer treatment.

800-ACS-2345

(800-227-2345)

[www.cancer.org](http://www.cancer.org)

### **AirBNB**

Through a collaboration with the Cancer Support Community, the Airbnb community will provide free housing for cancer patients and caregivers, provided they meet certain geographic and income criteria.

877-793-0498

[www.CancerSupportCommunity.org/AirBNB](http://www.CancerSupportCommunity.org/AirBNB)

## **CLINICAL TRIAL COSTS**

### **National Cancer Institute – Insurance Coverage and Clinical Trials**

Find information on insurance coverage of clinical trial costs.

<http://www.cancer.gov/clinicaltrials/learningabout/payingfor/insurance-coverage>

## **YOUNG ADULT**

### **Allyson Whitney Foundation, Inc.**

Assisting young adults with rare cancers with “Life Interrupted” Grants™. Allowing them to focus on healing rather than financial concerns.

[www.AllysonWhitney.org](http://www.AllysonWhitney.org)

### **Brenda Mehling Cancer Fund**

Supporting patients 18-40 currently undergoing cancer treatment by covering services to meet daily needs, such as co-payments, health expenses, rent, insurance, and more.

[www.bmcf.net](http://www.bmcf.net)

### **Cancer For College**

Provides hope and inspiration by awarding college scholarships to cancer patients and cancer survivors attending an accredited school or university in the US during the award period. High school seniors and current college students eligible to apply. Applications accepted October 1 through January 31.

[www.CancerForCollege.org](http://www.CancerForCollege.org)

### **Legacy**

Legacy provides men with a convenient and affordable at-home solution to preserve their fertility before undergoing potentially harmful cancer treatment.

[www.GiveLegacy.com](http://www.GiveLegacy.com)

### **Samfund**

Through direct financial assistance and free online support and education, help young adults survive and move forward with their lives after cancer.

[www.TheSamfund.org](http://www.TheSamfund.org)

### **Sy's Fund**

Provides funding for meaningful gifts and integrative therapies for young adults ages 18 through 39 with cancer or ongoing medical issues related to cancer or cancer treatment.

[www.SysFund.org](http://www.SysFund.org)

### **Thrive Cancer Fertility Network**

Provides financial aid to individuals 18-40 whose fertility may be compromised and connect those affected by a cancer diagnosis with community support.

[www.CaporalAssistance.org](http://www.CaporalAssistance.org)

### **Ulman Cancer Fund For Young Adults**

Supporting, educating and connecting young adults affected by cancer through online resources, college scholarships, advocacy, and awareness.

[www.UlmanFund.org](http://www.UlmanFund.org)



## MEDICAL ADVISORY BOARD REVIEWERS

All medically-reviewed content in *Your Guide in the Fight* was written and edited by Fight Colorectal Cancer.

**Dennis J. Ahnen, M.D.**

University of Colorado  
Hereditary Cancer Clinic

**Al B. Benson III, M.D., FACP**  
Northwestern University

**Dustin Deming, M.D.**  
University of Wisconsin  
Carbone Cancer Center

**Richard M. Goldberg, M.D.**

Ohio State University Medical Center

**Jean S. Kutner, M.D., MSPH**  
University of Colorado Hospital

**Edith Mitchell, M.D., FACP**  
Thomas Jefferson University

View all Medical Advisory Board members at: [FightCRC.org/MAB](https://fightcrc.org/MAB)

## ADDITIONAL REVIEWERS

**Wells Messersmith, M.D.**

Professor and Co-Division Head, Division of  
Medical Oncology University of Colorado

**Christopher Lieu, M.D.**

Assistant Professor, Director Colorectal  
Medical Oncology University of Colorado

**Jessica Martin, Ph.D.**

Fight Colorectal Cancer  
Research Advocate  
Stage IV Fighter

## YOUR GUIDE IN THE FIGHT DEVELOPMENT TEAM

**Will Bryan**

Will Bryan Design

**Anjee Davis, MPPA**

President

**Andrea (Andi) Dwyer**

The Colorado School of Public Health  
University of Colorado Cancer Center

**Elizabeth Fisher, MBA**

Project Manager

**Nancy Levesque**

Director of Communications

**Sam Monica**

Brand Manager

**Nancy Roach**

Founder

**Erica Weiss, MPH, MSUP**

Plain Language Health Writer

**Sharyn Worrall, MPH**

Senior Manager of Education & Research



PHOTO CREDITS: Brett Flashnick, Ryan Hollis, Travis Howard, Brian Threlkeld

## ADDITIONAL RESOURCES



### PATIENT WEBINARS

Fight CRC hosts free patient webinars featuring leading experts from across the country.



### PODCASTS

Fight CRC's educational podcasts put a stop to "taboo-ty" topics and discuss real issues impacting colorectal cancer patients.

View all resources at: [FightCRC.org/Resources](https://FightCRC.org/Resources)



Screening

Skin Toxicity

Biosimilars

Clinical Trials

Genetics

Side Effects

Download or order copies at: [FightCRC.org/Resources](https://FightCRC.org/Resources)

## MADE POSSIBLE

Your Guide in the Fight was made possible thanks to the support of the following organizations:



***RELENTLESS  
CHAMPIONS OF  
HOPE IN THE  
FIGHT AGAINST  
COLORECTAL CANCER***

***F!GHT***  
★  
***COLORECTAL CANCER***

134 Park Central Square, Suite 210 • Springfield, MO 65806

***@F!GHTCRC***   