



YOUR GUIDE IN THE FIGHT



DISCLAIMER STATEMENT

The information and services provided by Fight Colorectal Cancer are for general informational purposes only, 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.

MADE POSSIBLE

All medically-reviewed content was written and edited by Fight Colorectal Cancer.

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



Bristol-Myers Squibb

Genentech

A Member of the Roche Group



MERCK

Be well

SANOFI



FIGHT COLORECTAL CANCER

We are here for you

A cancer diagnosis is overwhelming, so be patient. Give yourself time to feel whatever you need to: anger, depression, fear. You won't feel that way forever. Try to take one day at a time, and when that's too much, take one hour or one minute at a time. It is not only important to learn all that you can about your recent diagnosis, but allow yourself to feel the emotional effects that come with a cancer diagnosis.

YOUR GUIDE IN THE FIGHT

If you have recently been diagnosed with Stage III or IV colorectal cancer, 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 for your path ahead. We'd like to help you understand how to cope with colorectal cancer proactively. You have options and we hope this Guide will help you navigate the many decisions you will make along the way.

We've designed this resource to empower you and point you in the right direction to trusted and credible resources, with a useful "toolbox" full of worksheets at the end. You can track your health history and course of treatment, and maintain control.



This roadmap, or as we like to call it: Your Guide in the Fight, offers information, tips and tools to:

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

TABLE OF CONTENTS

4 | What is stage III and stage IV colorectal cancer?

5 | Step 1: Understanding Your Diagnosis

7 | Step 2: Talking to the Right People

Key members of your treatment team

Get a second opinion

10 | Step 3: Interpreting Medical Information on the Web

How to read survival statistics

13 | Step 4: Understanding Your Treatment Options

General treatment options by treatment type

Treatment options by diagnosis

27 | Step 5: Managing Treatment Side Effects

34 | Step 6: Asking For Help

Patient support programs

Financial assistance programs

38 | Step 7: Staying Strong through the Fight

Nutrition & exercise

Sex & intimacy

41 | Step 8: Post-Treatment Follow-up

Lifestyle changes

44 | Step 9: End of Life Issues

Palliative & hospice care

Advance directives

48 | Step 10: Moving Down the Road to Survivorship

Taking care of you

Strength from other survivors

55 | TOOLBOX: Forms & worksheets





WHAT IS STAGE III AND STAGE IV COLORECTAL CANCER?

Colorectal cancer occurs when abnormal cells form tumors in normal 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, causing 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 (sometimes called late-stage 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.

V O C A B U L A R Y

- **Colon Cancer** is cancer that forms in the tissues of the colon (the longest part of the large intestine)
- **Rectal Cancer** is cancer that forms in the tissues of the rectum (the last 5-6 inches of the large intestine closest to the anus)
- **Recurrent Cancer** is cancer that returned after being diagnosed and treated
- **Metastatic Cancer** is cancer that spread beyond its original location in the colon or rectum.
- **Lymph nodes** are small, bean-shaped structures found throughout the body that filter substances in a fluid called lymph and help fight infection and disease

V O C A B U L A R Y

Stage III - cancer has spread to lymph nodes

Stage IV - cancer has spread to form tumors in other areas of the body, like liver and lungs

StepOne

UNDERSTANDING YOUR DIAGNOSIS

Discovering you have cancer, you may be feeling a range of emotions. You may be feeling anxious to begin treatment right away, but know there are steps that you and your doctor must take before you can begin treatment.

Staging is an important part of a patient's diagnosis, prognosis and treatment planning. Once established, your cancer stage will stay the same, even if the cancer progresses, recurs (comes back), or is in remission (no evidence of disease "NED").

- First you will have blood tests and diagnostic scans, such as CT and PET scans. Blood tests will look for certain enzymes; diagnostic scans will show where the cancer is located. Your doctor will assign a clinical stage to your cancer based on these tests and scans, as well as your physical history and physical exam.
- Surgery may be the next step. Doctors may want to conduct a biopsy to remove cells from the tumor and have a pathologist examine them to determine whether they appear normal (called cell differentiation). This process will determine the pathologic stage. Tumors with a large number of highly abnormal cells are called high grade, and are considered to be more aggressive (they reproduce and spread faster) than cells in low grade tumors.

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

T—for **Tumor**: How far the tumor extends from the inner lining of the colon or rectum through the layers of its walls

N—for **Nodes**: Whether cancer cells are found in the lymph nodes by the colon

M—for **Metastasis**: Whether cancer has spread beyond the colon and its adjacent tissues to organs like the lungs or liver

Once doctors classify a tumor with the TNM system, an overall stage is assigned, ranging from stage 0 (no cancer was found) to stage IV (cancer spread to other organs beyond the colon or rectum).

If you have stage II, III or IV cancer, you may receive an even further classification such as A, B or C. This helps your treatment team determine the best treatment for your particular diagnosis.

Learn more about the TMN Classification System for Colorectal Cancer
at [FightColorectalCancer.org/GuideintheFight](https://fightcolorectalcancer.org/GuideintheFight)

Stages of Colorectal Cancer based on the
TNM Classification System

Stage	TNM Classification
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

Primary Tumor (T)

TX: Primary tumor cannot be evaluated

T0: No evidence of primary tumor

Tis: "Carcinoma in situ" or CIS (abnormal cells are present but are not yet cancer)

T1, T2, T3, T4: 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.

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

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 CRC survivor



FOR MORE INFORMATION VISIT:

Fight Colorectal Cancer:

www.FightColorectalCancer.org

National Cancer Institute:

www.Cancer.gov

StepTwo

TALKING TO THE RIGHT PEOPLE

After you are diagnosed with colorectal cancer, you need to work with a healthcare team that you can rely on. You should find doctors that you respect and can talk with, who don't make you feel rushed, who answer your questions, and who help you gather information to make thoughtful treatment decisions.

This is a time in your life where there will be lots of information to digest, and sometimes there aren't clear-cut solutions for you. Your healthcare team can play a valuable role in maintaining and improving your quality of life. Finding the right people may take time, and that's okay. Remember that you're hiring each specialist for a very important job, so hire people you want to work with.

Find people you *trust* that make you feel comfortable. You can meet with more than one doctor to ensure that you're working with a team that suits your needs.

KEY MEMBERS OF YOUR TREATMENT TEAM

A cancer diagnosis requires multiple doctors and specialties. You will be working with a multidisciplinary team (different healthcare professionals with specialized skills and expertise). Effective teamwork requires collaboration and communication – especially when it comes to your treatment recommendations for comprehensive and high-quality care. Making sure all of your treatment providers are communicating with one another is important.

SURGEON OR SURGICAL ONCOLOGIST: Look for a surgeon experienced with colon and rectal cancer (experience is especially important for rectal cancers). This specialist will want to biopsy your tumor and then surgically remove it (as well as any affected tissue or lymph nodes). If you are considering liver or lung surgery, find a specialist experienced with colorectal cancer metastasis.

- For a referral, contact the American Society of Colon and Rectal Surgeons (www.fascrs.org under “Patients and Public” or call **800.791.0001**)

MEDICAL ONCOLOGIST: This doctor specializes in the general diagnosis and treatment of cancer. Oncologists are experts in using medications such as chemotherapy or targeted therapies to treat cancer.

- For a medical oncologist, contact the American Society of Clinical Oncology (search for a medical oncologist through www.cancer.net or **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 with rectal cancers.

- For a radiation oncologist, contact the American Society of Clinical Oncology (search for a radiation oncologist through www.cancer.net or **888.651.3038**)

ONCOLOGY NURSE: This nurse specializes in treating the side effects you may experience from colorectal cancer treatment. An oncology nurse will likely be the person administering your treatment, and can be a key resource for information and support.

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

PALLIATIVE CARE DOCTOR/NURSE: This specialist can work with your treatment team to relieve pain from uncomfortable symptoms. Palliative care can begin at the time of diagnosis and can continue throughout treatment. Working with a palliative care specialist can help make you more comfortable throughout the treatment process.

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

COMMUNICATING WITH YOUR HEALTHCARE TEAM

To help ensure you and your caregiver have productive conversations with your healthcare team at every appointment, here are some tips on how to stay organized during and after treatment:

CARRY A NOTEBOOK. Keep track of what you learn along the way. Make notes about:

Questions: Anytime a question comes to mind – write it down. When you get answers, write those down too. You'll likely have questions about anything from treatment reactions to follow-up plans and logistics.

Side effects: Keep track of the symptoms or side effects that make you uncomfortable or stop you from doing things you enjoy. This will remind you to ask about relieving those problems and help you to remember strategies that did or didn't work. (See the Side Effects Management tool on **page 61**.)

Medications & Supplements: It is important to tell your physician about all supplements or over-the-counter (OTC) medications you are taking. Each physician will need to know this information because some can adversely affect your treatment or react badly with certain cancer drugs. Keeping your list in one place will not only help you, it can help your caregiver, family members, and doctors keep track of your complete medical care (including medication for diabetes, cholesterol, or anything else (See the Medications Management tool on **page 60**.)

Your “to do” list: It's always helpful to stay organized by keeping your to-do list with your calendar. It will help you remember what medications to take and when, remind you of your next medical appointment and help you keep track of when you need help to get something done with work, family or other responsibilities. This can be done on paper (see sample on **page 62**) or with organizing apps for your smart phone or tablet like “My Cancer Circle,” a free app by Lotsa Helping Hands (www.rci.lotsahelpinghands.com).

BRING SOMEONE WITH YOU TO APPOINTMENTS. It's okay to ask for help. It is hard to manage all of the information and emotions that accompany a colorectal cancer diagnosis. A second set of ears can be very helpful at medical appointments. A friend or family member can help you remember things you might forget, take notes and discuss what you heard.

USE AN ONLINE SCHEDULER/PLANNER. The added complexity of managing colorectal cancer treatment thrown into an already busy life can feel overwhelming without organization.

An online planner can be used to recruit and coordinate help when you need it. This can help friends and family see how they can help you and offer assistance with everyday tasks like driving you to medical appointments, preparing dinner, watching kids or making phone calls.

GET HELP WHEN YOU NEED IT. Consider resources like:

- Lotsa Helping Hands (www.rci.lotsahelpinghands.com)
web-based caregiving coordination service
- My Lifeline (www.mylifeline.org)
create a patient website to update family and friends and post requests

GET A SECOND OPINION

Always know that you are entitled to get a second opinion at any point throughout your diagnosis and treatment. In fact, most doctors and specialists encourage it! A good health care professional wants you to feel comfortable with the treatment you are receiving, so don't be afraid to ask for another opinion to be sure you are getting the right care. Consider a second opinion if you would like to learn more about clinical trials or if you want to feel certain that you're on the right track. If the second opinion is the same as the first, great. If it's different, you may want to check with a third expert to help you make your decision

To prepare for conversations with other doctors or medical experts, gather copies of your labs, scans and surgical test results, and if possible, share this information with the second opinion expert before your appointment with him/her. So, if possible try to schedule your second opinion **before you start treatment**.

FINDING TREATMENT SERVICES

Investigate your options. Look to see if there are a variety of hospitals or medical facilities in your town or city, as this may help you to better understand the services available to you. This is especially important if you have metastatic CRC, because some treatment options are not available in a community clinic. You may need to look into other cities.

For a complete list of National Comprehensive Cancer Network institutions, also with a full range of experienced staff, contact the National Comprehensive Cancer Network (www.nccn.org).

For a complete list of Comprehensive Cancer Center locations with a full range of experienced staff, search the National Cancer Institute (www.cancer.gov or call **800.422.6237**).



TIPS

If you have any concerns about your pathology results, you can request a second pathologist to review your tumor biopsy. Pathology results are a piece of information that physicians use to base treatment recommendations.

StepThree

INTERPRETING MEDICAL INFORMATION ON THE WEB

Your treatment team is your best resource for information. But, it's also easy to lean on "Dr. Google" and search online for information about treatment options, facilities and survival rates. If you research through the Internet, take care to obtain information that is reliable and appropriate for your particular diagnosis.

There are many websites that offer information about colorectal cancer and how to treat it. Before you believe everything you read, pay attention to the source of information. Start with some credible sources like the National Cancer Institute (cancer.gov); patient organizations like Fight Colorectal Cancer (FightColorectalCancer.org) or the American Cancer Society (cancer.org); or information on safe websites like Comprehensive Cancer Centers (cancercenters.cancer.gov).

Be cautious. Remember: not all online health information is accurate.

OUR TOP FOUR SITES FOR RELIABLE INFORMATION:

- <http://www.nlm.nih.gov/medlineplus> (health information)
- <http://healthfinder.gov> (healthy living, personalized health advice)
- <http://www.ncbi.nlm.nih.gov/pubmed> (scientific journal articles)
- <http://www.uptodate.com> (peer reviewed, evidence-based medicine)

From websites to social networking sites, such as Facebook or Twitter, we can't overemphasize how important it is for you to be critical about the health information you read. The same online tips apply to social media. It's important to find sources you can trust.

TIPS

WHEN SEARCHING FOR AND FINDING INFORMATION ONLINE:

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



GET STARTED ONLINE...

Our organization is committed to providing patients and their caregivers with reliable and relevant information about colorectal cancer. We provide fact sheets, webinars and blogs that cover a range of topics from treatment options to survivorship.

- Bookmark our website: www.FightColorectalCancer.org
- Friend us on Facebook.com/FightCRC
- Follow us on Twitter.com/FightCRC

HOW TO READ SURVIVAL STATISTICS

One of the first questions that most patients ask after being diagnosed is “How long do I have?” Whether we want to ask the question or not, worrying about dying from colorectal cancer is always in the back of the minds of patients and caregivers.

Don't be surprised if your doctor doesn't give you a firm answer about how long you have to live. Survival, even when cancer has spread and is advanced, is remarkably individual. Your doctor can share average statistics for people with diagnoses similar to yours, but the truth is that every case is unique and your case is your own!

Doctors use different types of statistics and terms when talking about survival. Based on the type of survival statistic, you might run across differences in what you're told. If you ask, they may say, “five-year average survival” for the general stage of your cancer.

TYPES OF SURVIVAL STATISTICS:

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

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

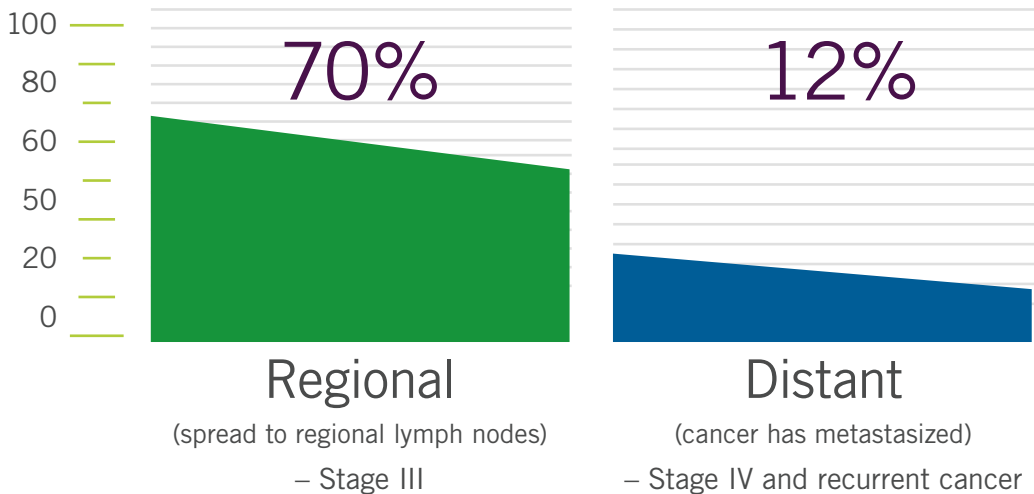
Median Overall Survival: the time at which 50 percent of patients are still alive after a diagnosis or particular treatment

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

Recurrence: A return of cancer after it has been initially treated (for example, a person with stage II disease whose cancer comes back after treatment is said to have a ‘recurrence’).

Doctors give survival statistics based on historical information, so the numbers do not reflect the current standards of care or recent improvements in chemotherapy, surgery and radiation therapy. Improvement of the treatments you get today recently increased the relative survival for people diagnosed at stage III, and the length of time that people with metastatic cancer will live. Remember: survival statistics may not predict the outcome of your case!

Five-Year Relative Survival by Stage at Diagnosis for **2003-2009**
All Races, Both Sexes



Source: <http://seer.cancer.gov/statfacts/html/colorect.html#survival>

This survival chart offers one example of why survival statistics don’t always predict your case or display the most recent information. The chart shows that 70 percent of the people diagnosed with stage III CRC from 2003-2009 were alive after five years. This is significant because cancer recurrence is most common within three years of diagnosis – so most of the people who survived are probably cancer-free. Additionally, while there are no cures for metastatic cancer, new treatments have increased the time people live with advanced disease – and this chart does not show that information. In 1999, the average survival after a diagnosis of metastatic cancer was nine months, while today it is almost three years. Unhappily, we don’t yet have a cure for all metastatic CRC patients, although some stage IV patients have been cured, particularly those with surgically removable metastases only to the liver.

T I P

For more information about interpreting survival statistics, Dr. Stephen Gould explains the challenge of applying “average” statistics to an individual patient in his essay *The Median Is Not The Message*.

http://www.cancerguide.org/median_not_msg.html

StepFour

UNDERSTANDING YOUR TREATMENT OPTIONS

Your treatment will often include combinations of surgery, chemotherapy and radiation. You may receive a standard treatment regimen (combinations that other patients received that proved to offer the best results) or be offered an experimental treatment in a clinical trial (see **page 19** for more information about clinical trials). Ideally, you can

work with a multidisciplinary team to discuss all of your treatment options and possible combinations.

Building a treatment plan can take time, especially if you have metastatic disease. This is where a second opinion from a major cancer center can be very helpful as you decide which course of treatment to take.

VOCABULARY

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

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 elsewhere in the body)
- 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
- The specific tumor type, defined by biomarkers* (stage IV only)

*Note: If you have stage IV CRC, you should have a biomarker test. Results from this test will help your doctors personalize your treatment plan. Do this before you make treatment decisions. (See **page 15** for more information about biomarkers).

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

If you have...	Your personal preference might be to...	So your doctor may suggest...
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

Understanding your treatment options is an essential step. This section of our Guide will explain what each type of treatment means and dive deeper into how combined treatments are used for stage III, stage IV and recurrent CRC.

GENERAL TREATMENT OPTIONS

SURGERY

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

WHAT TO EXPECT BEFORE AND AFTER INITIAL SURGERY WITH:

Before surgery, your blood counts will be measured, your blood chemistry and CEA levels will be evaluated, and you will have a CT scan of the chest, abdomen and pelvis, or a PET scan, to determine exactly where the cancer is located. These tests are frequently done after surgery as well to compare results.

Because surgery alone is not enough to fight stage III or stage IV CRC, you will undergo additional treatment. More information about chemotherapy, radiation, and other treatments follow.

QUESTIONS TO ASK BEFORE YOUR INITIAL SURGERY:

- What stage of cancer do my pre-surgical diagnostic tests indicate I have?
- 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 a minimum of 12 operations on your type of cancer per year).
- Is the specialist a certified colorectal surgeon? (This training is especially important for the treatment of rectal cancer).
- Will a temporary or permanent ostomy be necessary?
- Do I need chemotherapy and/or radiation therapy before surgery? After surgery?
- How many lymph nodes will be removed during surgery? (A minimum of 12 should be removed).

QUESTIONS TO ASK AFTER YOUR INITIAL SURGERY:

- What is my post-surgical diagnosis? What is the stage of my cancer?
- What additional tests should be done to increase the accuracy of my diagnosis and determine my need for additional treatment?
- What can I do to help recover from surgery?

If stage IV or recurrent:

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

OSTOMY

You may be faced with needing a colostomy as part of your surgical treatment of colon or rectal cancer. Whether temporary or permanent, an ostomy creates a new path for your body's waste through a stoma (leading your colon directly through an opening in your abdomen). An ostomy pouch fastens to the skin to collect waste. Whether the ostomy is temporary or permanent, people with ostomies can learn to live as fully as everyone else.

TIPS

FOR LIVING WITH AN OSTOMY:

- Ask if there's an ostomy nurse who can help you at home after surgery
- Ask how to recognize potential problems before they occur
- If your pouch is uncomfortable, ask about alternative pouching systems
- For extra support and information, contact a local ostomy organization:

The United Ostomy Association of America

www.ostomy.org

Shaz's Ostomy Pages

www.ostomates.org

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 and let you know which problems deserve a call to your doctor. Be patient if it takes time to get used to dealing with your pouch, or if you need to try a few different kinds until you find the one that works for you.

BIOMARKER TESTS

You need to be tested for certain biomarkers before you receive certain types of chemotherapy treatment. Your results can help your healthcare team determine which drug may or may not be right for you. Some (not all) chemotherapy drugs will not work if your tumor has a certain genetic mutation. Biomarkers are specific characteristics of cancer cells that can be identified with special tests. These tests can identify whether a specific gene in a cell is mutated. For example, in CRC, genes such as KRAS, NRAS and BRAF indicate gene



mutations from metastatic cancer. Testing positive for these gene mutations will show your doctors which treatments to avoid.

COMMON BIOMARKER TESTS:

- **KRAS and NRAS 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 an NRAS mutation, then drugs that target EGFR may not benefit that patient. This test is typically for stage IV patients, and sometimes for stage III recurrence.
- **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 for stage IV patients only, although sometimes with stage III recurrence.
- **Carcinoembryonic antigen (CEA):** CEA is a protein that may be higher in CRC patients. High levels of CEA may indicate that cancer is growing while low levels may indicate that treatment is working.

VOCABULARY

- Prognostic markers are used to describe a patient's outcomes, but don't predict a response to treatment
- Predictive biomarkers determine whether or not a patient may respond well to a particular targeted treatment

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. Talk with your healthcare team to see if these tests are appropriate for you.

CHEMOTHERAPY

If you have stage III or stage IV CRC, it is very likely you will need some form of chemotherapy during the course of treatment. Chemotherapy may be used alone, or in combination with other targeted therapies.

Chemotherapy is the use of drugs to stop or limit the growth of rapidly dividing cancer cells. Chemotherapy can be taken by mouth (oral chemotherapy) or injected into a vein (intravenous chemotherapy) to reach cancer cells throughout the body (systemically). When chemotherapy is placed directly into the abdomen, the drugs mostly affect cancer cells in that area (regional chemotherapy).

Your side effects will depend on how your chemotherapy is given and the type of 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 feel side effects in your mouth, hair and stomach, for example. (See **page 27** for information on side effect management.)

ORAL CHEMOTHERAPY

Chemotherapy the stomach absorbs is offered orally, as a tablet or capsule, and can be swallowed at home. It is equally 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 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. Taking your pills exactly as prescribed (treatment adherence) is very important. Talk with your doctor or nurse about the importance of taking your medication on time and as directed.

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

TARGETED THERAPY

Targeted therapies are drugs that block the growth of cancer by interfering with the molecules involved in tumor growth and spread. Most targeted therapies are either small-molecule drugs (drugs that attack proteins inside cancer cells) or monoclonal antibodies (drugs that attack proteins outside of cancer cells or on cell surface).

More information on targeted therapies on **page 25**.
Also, visit: <http://www.cancer.gov/cancertopics/factsheet/Therapy/targeted>

CHEMOTHERAPY AND TARGETED THERAPY BRAND & TRADE (GENERIC) NAMES:

BRAND NAMES	=	GENERIC NAMES
Avastin®	→	Bevacizumab
Erbix™	→	Cetuximab
Vectibix®	→	Panitumumab
Eloxatin®	→	Oxaliplatin
Campostar™	→	Irinotecan
Xeloda®	→	Capecitabine
Stivarga®	→	Regorafenib
Zaltrap®	→	Ziv-Aflibercept
Leucovorin™	→	Folinic Acid
Efudex™	→	5-FU or fluorouracil

RADIATION THERAPY

If you have stage III or stage IV rectal cancer, it's likely that radiation therapy will be discussed. Radiation therapy is not often used to treat colon cancer, and more commonly used to treat rectal cancer. When used in colon cancer, it is used most often in the treatment of tumors that have grown next to or into other organs. Radiation therapy may sometimes be used to relieve symptoms and improve quality of life.

Radiation uses high-energy x-rays or other types of radiation to kill cancer cells or keep them from growing. 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 is used when a tumor cannot be surgically removed. It generally involves no large incisions, less risk, less pain and shorter recovery times.

TYPES OF RADIATION TREATMENT:

- External beam radiotherapy (EBRT) uses a machine outside of the body to direct radiation toward the cancer. This is the approach most commonly used
- 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, using small beams of varying intensity
- Selective Internal Radiation (SIR-Spheres Microspheres or Theraspheres) are tiny beads covered with radioactive material, and are injected into your liver to target liver metastases. They are a permanent implant for single-use only, providing a high-energy isotope to kill cancer cells in the liver from metastasized colorectal cancer
- Intraoperative-radiotherapy (IORT) is another radiation option, 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) for patients whose tumors can't be removed by surgery
- Radio surgery delivers a single high dose fraction of radiation, stereotactically directed to the liver

CLINICAL TRIALS

It's always a good idea to talk with your healthcare team to learn if you're eligible for any clinical trials. Clinical trials test new treatments for CRC or other cancers – this can include drug therapy, surgery, radiation, and combination procedures. There are also clinical trials that test new ways to stop cancer from recurring or reduce the side effects of cancer treatment.

All treatments go through the clinical trial process before the Federal Food and Drug Administration (FDA) approves them for public use. These studies are designed to protect participants while producing data 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 and help find cures. Most 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 with very clear information about the study before you decide to participate. 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. Ask your treatment team if you would qualify for any available clinical trials.

QUESTIONS TO ASK REGARDING CLINICAL TRIALS:

- Am I eligible for a clinical trial? If yes, do you feel that would be a good choice for me?
- How do the possible risks and benefits of the new treatment compare with my other treatment options?
- Are there extra procedures or visits in the trial compared with standard care?
- Who will pay for what in the trial?
- What is the standard treatment for someone in my situation? What do you recommend?
- What will my treatment schedule look like?
- What are the short- and long-term side effects of the treatment you are recommending?
- How will my health be monitored during treatment?

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.

For further information about clinical trials, please visit

- Fight Colorectal Cancer's Clinical Trials Matching Service: [FightColorectalCancer.org/ClinicalTrials](https://fightcolorectalcancer.org/ClinicalTrials)
 - Provides all available trials for colorectal cancer, offering search features to find relevant and specific offerings.
- The National Institutes of Health Clinical Trials Matching Service: 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 industry and university-sponsored trials. For specific results, refine your search by location, the type of trial or treatment, or by a specific drug name.

TREATMENT OPTIONS BY DIAGNOSIS

It is important to understand the treatment options specifically available to you. Ask about possible side effects. The treatments listed here offer general guidance 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 part of the colon is removed. In this procedure, a stoma (an 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 (**page 15**). A colostomy can be temporary and reversed, or be permanent.
 - ◇ **Temporary Ostomy & Reversal Surgery:** a colostomy reversal is possible if the colon can heal after the initial resection surgery. When healing is complete (after a few months to 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, allowing 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).

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 is recommended. Radiation is not, however, 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. (If an ostomy is recommended, refer back to **page 15** for additional information on ostomies).

- Low anterior resection (LAR): the tumor and part of the rectum is removed without affecting the anus. The colon is then attached to the remaining part of the rectum so that after the surgery, your bowels can be used in the usual way.
- Abdominoperineal resection (APR): one incision is made in the abdomen and another in the perineal area 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.

CHEMOTHERAPY COMBINATIONS

For stage III rectal cancer patients who are medically fit and can tolerate combined methods of therapy, treatment can consist of chemoradiation (chemotherapy and radiation) before surgery, abdominal surgery, and/or adjuvant chemotherapy after surgery.

Patients who cannot tolerate chemoradiation at first may go directly to surgery with no additional treatment and then onto adjuvant chemotherapy and/or chemoradiation after surgery.

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
- Bolus 5-FU and external beam radiation (Less often recommended)
- 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 IV METASTATIC CANCER OR RECURRENT CRC

Even though you may be terrified when you're first told that your cancer has spread beyond your colon or rectum and is metastatic, you can take time to get the very best information and advice possible from a multidisciplinary team. This process is vitally important.

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

Make sure to 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
- One or more clinical trials

SURGERY

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

- Partial hepatectomy: the part of the liver with metastases is surgically removed
- 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: 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 is now approved for patients whose cancer has progressed during or after treatment with first line therapies (typically FOLFOX and bevacizumab (Avastin®).

Patients who are not able to 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 capectiabine (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®)

For more information on the wide variety of drug combinations for patients who have a cancer recurrence or when the first line of chemotherapy treatment doesn't stop the growth of cancer, please visit:

[FightColorectalCancer.org/GuideInTheFight](https://fightcolorectalcancer.org/GuideInTheFight)

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 helpful in patients with stage IV CRC, but not in patients with stage III CRC.

Most targeted therapies are either small-molecule drugs or monoclonal antibodies. Small-molecule drugs pass into cancer cells and attack proteins that are inside the cell. Most monoclonal antibodies aim at targets that are outside cancer cells or on the cell surface.

- Bevacizumab (Avastin®) a monoclonal antibody used to block the growth and development of blood vessels
- Ziv-aflibercept (Zaltrap®) a recombinant fusion protein used to block blood vessel development
- Cetuximab (Erbix®) a monoclonal antibody to inhibit cell growth for patients without a KRAS or NRAS mutation
- Panitumumab (Vectibix®) a monoclonal antibody to inhibit cell growth for patients without a KRAS or NRAS mutation
- Regorafenib (Stivarga®) a small molecule drug to inhibit cell growth by interfering with the internal workings of the cell
- Ramucirumab (Cyramza®) a monoclonal antibody used to block the growth and development of blood vessels

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.

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.

- What is the standard treatment for someone in my situation? What do you recommend?
- What will my treatment schedule look like?
- Am I eligible for a clinical trial? If yes, do you feel that would be a good choice for me?
- What can be done to remove or treat my metastatic tumors?
- Is there a way to determine whether specific drugs will be effective in treating my cancer? Should my tumor be genetically tested?
- How long will I receive this treatment?
- What are the short- and long-term side effects of the treatment you are recommending? What can we do to minimize my side effects?
- When I am in treatment and experiencing side effects, what side effects should trigger a call to your office (for example, a fever > 101, diarrhea > 4 times/day) and which can wait for my next visit?

- How will my health be monitored during treatment? When will we know if the treatment is working?
- If this treatment stops working for me, what's the next option?
- Do you have any recommendations for support groups?

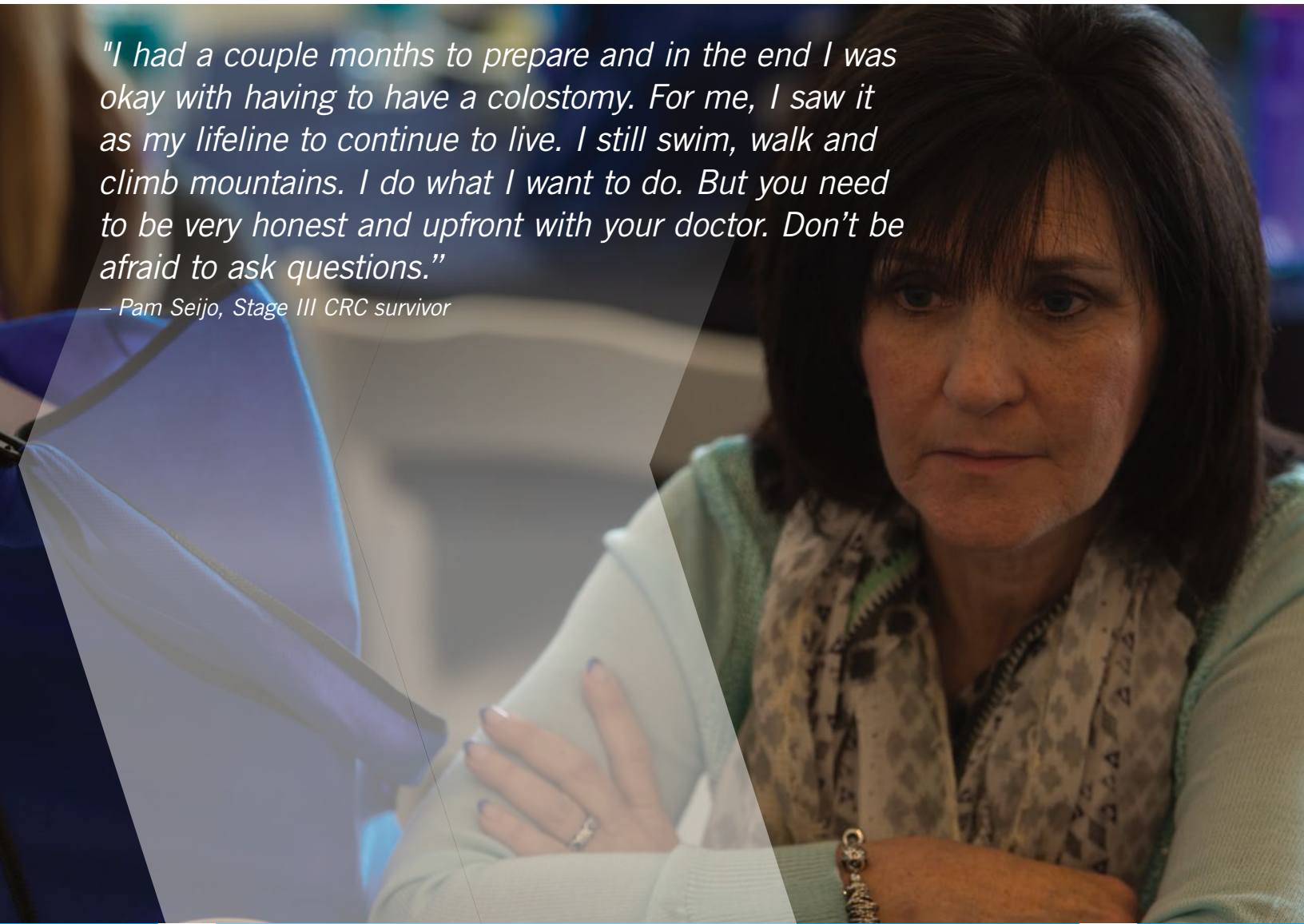
For additional information - National Comprehensive Cancer Network (NCCN) Guidelines for Patients:

The NCCN maintains a library of guidelines for both doctors and patients, based on currently published clinical trials results. Many institutions and physicians follow the approach laid out by these guidelines, and adjust them as appropriate for patients. It is worth looking at the NCCN patient guideline to further understand your diagnosis, treatment and side effects. Contact Fight Colorectal Cancer and ask about our free resources or printed copies of patient materials.

Keep track of your treatment history, see forms beginning on **page 55**

FREE PATIENT WEBINARS

We host patient webinars each month. Our speakers are leading experts from across the country. Don't forget to visit our website to see what we have scheduled, [FightColorectalCancer.org/Webinars](https://fightcolorectalcancer.org/Webinars).



"I had a couple months to prepare and in the end I was okay with having to have a 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 CRC survivor

StepFive

MANAGING SIDE EFFECTS

Talk with your healthcare team about possible side effects. Be prepared and know what to look for and how to manage problems with your healthcare team. In this section of our Guide, we share information about the most common side effects experienced by CRC patients, and practical tips for handling them. Not everyone experiences the same side effects, nor do they experience them in the same way.

TIPS

TO MANAGE FATIGUE:

- Keep your goals simple until you feel able to do more
- Plan your activities to maintain the energy you do have
- Even small daily walks or upper body strength exercises can do wonders for your energy level. Your doctor can help you establish a beneficial exercise plan
- Take short naps during the day when you need them (but not in the late afternoon)
- Aim to sleep at least 8 hours each night. Avoid caffeine for at least 8 hours before bedtime
- Eat healthy foods
- Try relaxation techniques like meditation, yoga, or other activities to decrease stress
- Make sure your treatment team is checking your blood counts for anemia

FATIGUE

Fatigue is the most common side effect experienced by people who undergo cancer treatment. The good news is that fatigue usually goes away after you've completed treatment. Still, if you feel extremely tired, weary, exhausted or worn out – there are things you can do to regain energy.

Tell your doctor about your fatigue. It's important to have your blood levels checked in case anemia is the cause. Believe it or not, exercise has been shown to help fight treatment-related fatigue.

TIPS

TO PREVENT INFECTION:

- Wash your hands frequently
- Avoid being near people who are sick
- Stay out of crowds
- Be careful and 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

INCREASED RISK OF INFECTION / FEVER

Chemotherapy can decrease your white blood cell count, which puts you at risk for getting an infection - a serious side effect. Serious infections can land you in the hospital, and may even be life-threatening. A fever is sign of infection. Take your temperature anytime you feel warm and contact your healthcare team if your temperature is above 101 F so they can evaluate your need for antibiotics. Your body needs white blood cells to fight infection. If your white blood count is too low,

you might need to take time off before your next treatment so your body can get stronger.

DIARRHEA

TIPS

TO MANAGE DIARRHEA:

- Sip warm liquids slowly throughout the day. Avoid large quantities at once. Avoid alcohol and caffeine
- 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.)
- Avoid hard-to-digest foods like popcorn, raw vegetables and “gassy” vegetables. Avoid spicy, greasy and high-sugar foods
- Lie down immediately after eating
- Discuss anti-diarrhea medications with your doctor.
- Discuss a diet plan with a Registered Dietitian (RD)
- A fiber supplement like Metamucil can help

You know you have diarrhea when you have frequent bowel movements that are soft, loose or watery. It can result from chemotherapy treatments, colon surgery and radiation treatment, or because of your diet. If you are experiencing diarrhea, tell your doctor. Medications can be prescribed and other strategies can help.

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 diarrhea, common with irinotecan (Camptosar®) treatment,

include seven or more loose or watery stools a day, abdominal cramping, nausea and vomiting, fever, bleeding, or dehydration. Patients may also feel weak or dizzy when they stand. Abdominal cramping is an early sign that diarrhea is complicated and needs aggressive treatment, requiring you to contact your doctor immediately. Also, if diarrhea doesn't improve after 24 to 48 hours or gets worse, it is very important to contact your doctor.

NEUROPATHY OR NERVE CHANGES

Neuropathy is common among those receiving chemotherapy. You might feel a numbness or tingling in your hands and feet, a loss of sensation, shooting pain, a loss of balance, aching muscles, problems with finger dexterity and forgetfulness. A unique symptom that many CRC patients experience with neuropathy is an extreme sensitivity to cold. The good news is that neuropathy often goes away when you've completed treatment, but sometimes this type of nerve damage can linger.

TIPS

TO MANAGE NEUROPATHY:

- Use gloves and warm socks
- Wear scarves or face masks outdoors in cold weather if you must go outside
- Avoid eating or drinking cold or even cool foods. Eat food that is room temperature
- Avoid excessive air-conditioning
- Take care to use handrails and avoid clutter that may cause you to stumble or trip

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 with the drug ends, but it may take 18 months to 2 years to go away completely.

Types of Neuropathy:

- **Acute oxaliplatin-induced neuropathy** - often begins shortly after an infusion of oxaliplatin and gets

better within a few days. It is 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. Others may feel like their throat is closing and they cannot breathe, although breathing isn't really 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. Some patients start with feeling pins and needles, others may go on to have numbness and find it difficult to do small tasks with their fingers. In some cases, neuropathy can cause pain and difficulty with daily life, including walking. It is very important to let your doctor know if symptoms last beyond a few days after treatment. Use a notebook to track how you feel and let your doctor know if neuropathy gets worse.

It helps to 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 and regorafenib, you may experience high blood pressure, which is routinely treated with appropriate medication. Treatment may be paused or halted if blood pressure increases too much.



You never need to feel that you have to go through this alone. You can connect with other survivors, friends and family. Different people fill different needs. And when you're ready, and you will be ready, you can reach out to help others (and help yourself in the process).

- Belle Piazza, stage IV CRC survivor

MOUTH SORES (MUCOSITIS)

Mouth sores are a common side effect of 5-FU. They are painful and can make eating or swallowing difficult or impossible. Cooling the tissues of the mouth and throat with ice chips before and during administration of chemo helps to prevent mouth sores. Popsicles can help too. However, avoid ice if your treatment includes oxaliplatin.

There are several “magic” mouthwashes that can help with pain and healing if sores do develop. However, it is unclear how effective these are in treating mucositis. If it is determined by your doctor that these mouthwashes may help you, they will write out the recommended ingredients, along with the amount of each ingredient for you. Antibiotics may be required if sores become infected.

T I P S

TO MANAGE HAND-FOOT SYNDROME:

- 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 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

HAND-FOOT SYNDROME

Hand-foot syndrome refers to red, cracked, or peeling skin that develops in some patients taking 5-FU, capecitabine or regorafenib. 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. A few small studies have indicated that vitamin B6 (pyroxidine) may help.

RASHES

Targeted therapies tend to cause itchy, painful rashes that look similar to acne.

- Treatment with cetuximab or panitumumab can cause an acne-like rash. The rash, which commonly occurs on the face and chest, can be painful and itchy. The rash gradually occurs in four to six weeks. Your doctor may prescribe a medicated cream to control itching and ease discomfort, or an antibiotic if infection becomes a concern. You may also be referred to a dermatologist. You may pause treatment if the rash becomes intolerable.
- Never stop taking or reduce your medication without your doctor’s approval. If you are experiencing skin rashes that are severe, talk to your doctor about ways to manage the rash.
- Rash related to oral targeted therapy - Regorafenib may cause an itchy rash. Talk with your doctor if this happens to see if specific creams or lotions can help.

T I P S

ON MOISTURIZING CREAMS AND LOTIONS:

- Aveeno Moisturizing Bar
- Lubriderm Daily Moisture Lotion
- Dermal Therapy

WOUND HEALING

Bevacizumab, aflibercept and regorafenib can slow down the healing of wounds, so these drugs will be stopped at least two weeks before surgery.

FECAL INCONTINENCE, ADHESIONS (RECTAL CANCER)

Unfortunately, even though radiation treatments are carefully planned to target the tumor and surrounding rectum, it is almost impossible to avoid damaging healthy tissue. If you experience redness and skin irritation, ask your radiation oncologist for creams to soothe burns.

If you have more serious irritation of rectal tissues that causes diarrhea, rectal bleeding, painful bowel movements, incontinence, or bladder irritation causing frequent urination, blood in the urine, or burning during urination, consult your doctor for relief. There are medical and lifestyle options that can minimize the impact of fecal incontinence and adhesions. Talking with your treatment team is vitally important.

CHEMO-BRAIN

It is estimated that one in five people who take chemotherapy for cancer experience what's called "chemo-brain." This is a hazy experience where symptoms such as forgetfulness, difficulty finding the right words and difficulty multi-tasking or concentrating have been described as a side effect. Some people regain mental clarity over time, others remain a bit less sharp.

V O C A B U L A R Y

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

If you experience chemo-brain, it's useful to practice compensation techniques to help you remember things and stay on task. For more information on combating chemo-brain,

visit websites like: American Cancer Society - www.cancer.org, The National Cancer Institute - www.cancer.gov and/or CancerCare - www.cancercare.org.

T I P S

AND TRICKS TO HELP WITH YOUR MEMORY:

- Write lists & keep your notebook handy
- Schedule appointments and medications into your calendar (ideally in a phone with a calendar alarm)
- Keep consistent habits (such as placing 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

COMPLEMENTARY AND ALTERNATIVE APPROACHES

If you are interested in complementary and alternative medicine (CAM) treatments, you're not alone. Many patients look for approaches to "add to" or "complement" treatment for CRC, especially when looking for ways to feel better. Many cancer centers now have health care providers who specialize in CAM and offer services like acupuncture to help manage side effects.


Before you begin any of these alternative treatments, you need to understand how they are different, and how they might affect your treatment. If you are considering complementary or alternative approaches, be sure to discuss this first with your doctor.

For tips on talking to your doctor about CAM, visit <http://www.cancer.gov/publications/patient-education/thinking-about-cam>

CAM approaches, especially supplements or pills, are not recommended to treat colon or rectal cancer since, 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.

V O C A B U L A R Y

- Complementary medicine is used together with conventional medicine. An example of a complementary therapy is using aromatherapy to help lessen a patient's 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.



get behind a cure.

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 stress reduction
 - ◇ 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 your chemotherapy

TIPS

ON DETERMINING IF CAM IS RIGHT FOR YOU

- Is it safe? How do you know it's safe?
- Is there any evidence that it is effective for your purpose?
- What's the evidence? Is it a clinical trial or simply anecdotal stories? Is clinical evidence based on human tests?
- Are you certain that what is listed on the label is actually what is in the bottle?
- Always discuss your plan with your doctor!

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: Such as art, music, or dance

StepSix

ASKING FOR HELP

It requires a good deal of patience and organization to stay on track with cancer treatment while also balancing your work and home life. Here are some practical tools to help so you can focus less on your medical to-do list and more on enjoying the rest of your life!

Asking for help is a great thing. So is accepting help when it's offered. Lots of people will ask how they can help, so think about ways to give them the gift of helping you.

Break down your needs into small, manageable parts so that if someone says, "How can I help?" you can say, "Can I give you a small list of things I need from the store?" or, "Can you pick up my dry cleaning next week?" Plus, you'll feel less overwhelmed and more in control over your to-do list. There are several websites and planning tools available to recruit friends and family to help, but you can also begin by simply writing down the things you'd like help with and thinking about who you might like to ask for support.

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)

Your first call for support can always be to your nurse or the hospital social worker who will know about local resources. For example, the American Cancer Society has a program that helps find drivers to get people to treatment. Reach out to family and friends for their help with manageable requests and if you need additional assistance.

CANCER SUPPORT ORGANIZATIONS

- American Cancer Society: www.cancer.org or call **1.800.227.2345** (local & national support services)
- Advocacy Connector: www.advocacyconnector.com (find the type of help you need)
- CancerCare: www.cancercare.org (counseling, support groups, education & financial assistance)
- Cancer Support Community: www.cancersupportcommunity.org (local & national support services)
- LIVESTRONG: www.LiveStrong.org or call **1.855.220.7777** (several programs to help patients)
- Stupid Cancer: www.StupidCancer.org (young adults facing cancer)

COLORECTAL CANCER SUPPORT

- Fight Colorectal Cancer's message boards or Patient Resource Facebook Groups: www.FightCRC.org
- Chris4Life: www.chris4life.org
- Colon Cancer Alliance: www.ccalliance.org
- Colon Cancer Coalition/GYRIG: www.coloncancercoalition.org
- ColonTown: www.ColonTown.org
- Colon Club (esp. for young adults): www.ColonClub.org
- Colorectal Cancer Line: www.ColorectalCareLine.org or call **1.866.657.8634**
- Michael's Mission: www.MichaelsMission.org

MANAGING MEDICAL COSTS

Cancer care can cost a lot! We don't often think twice about going to the doctor and paying for it when it's covered by insurance. However, an illness like colorectal cancer means you'll be visiting the doctor a lot and taking several medications. Don't be surprised by un-covered costs.

Stay on top of your medical bills and insurance payments so you know where things stand. If you don't have insurance or if you have a lot of out-of-pocket expenses like co-pays, there are groups listed below who can help.

GENERAL QUESTIONS ABOUT THE COST OF CARE:

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

COPING WITH THE COST OF CARE

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

A free publication by the Cancer Support Community that can help guide you through the financial impact of cancer care. www.cancersupportcommunity.org

- **The Patient Advocate Foundation**

Offers free publications such as the Co-Pay Relief Program Brochure or their Colorectal CareLine Brochure, or one-on-one assistance through their hotline: **800.532.5274**. They also provide co-payment assistance, help find care for people who are un- or under-insured, and assist with insurance appeals (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 “PAP programs” provide discounted or free medications to people 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.

MANUFACTURER DRUG ASSISTANCE PROGRAMS, BY DRUG TYPE:

- Camptosar® (Irinotecan) www.pfizerhelpfulanswers.com or call **1.866.706.2400**
- Eloxatin® (Oxaliplatin) www.visitspconline.com or call **1.888.847.4877**
- Avastin® (Bevacizumab) www.genentech-access.com or call **1.866.422.2377**
- Erbitux® (Cetuximab) www.lillytruassist.com or call **1.855.559.8783**
www.bmspaf.org or call **1.800.736.0003**
- Vectibix® (Panitumumab), Aranesp® (Darbepoetin), Neulasta® (Pegfilgrastim)
www.amgenassist.com or call **1.888.427.7478**
- Stivarga® (Regorafenib) www.stivarga-us.com or call **1.866.639.2827**
- Zaltrap® (Ziv-Aflibercept) www.zaltrap.com or call **1.855.925.8727**
- Oncotype DX® www.oncotypedx.com or call **1.866.662.6897**
- Procrit® www.janssenaccessone.com or call **1.800.553.3851**

NONPROFIT FINANCIAL ASSISTANCE PROGRAMS

- Advocacy Connector www.advocacyconnector.com
- Cancer Care Financial Assistance www.cancercare.org or call **1.800.813.4673**
- Cancer Care Co Pay Assistance www.cancercarecopay.org or call **1.866.552.6729**
- Chronic Disease Foundation www.cdfund.org or call **1.877.968.7233**
- HealthWell Foundation www.healthwellfoundation.org or call **1.800.675.8416**
- Needy Meds www.needymeds.org or call **1.800.503.6897**
- Partnership for Prescription Assistance www.pparx.org or call **1.888.447.2669**
- Patient Advocate Foundation www.patientadvocate.org or call **1.800.532.5274**

This is not an all-inclusive list of manufacturing and non-profit organizations offering financial assistance. There may be local organizations in your area who offer assistance as well.

TRACKING MEDICAL COSTS & INSURANCE PAYMENTS

Often medical bills are confusing because one visit to the doctor may include separate bills from the doctor, the lab, a specialist, and medications prescribed, for example. It's often difficult to keep track of everything and get a good sense of your out-of-pocket costs.

Try to keep your receipts and Explanation of Benefits (EOBs) in one place and consider keeping a notebook or binder to store notes and pertinent information about health care bills. Perhaps you can pick one day each month to be “health care bill day” when you can focus on keeping your budget and bills organized.

If you use a health savings account (HSA) through your work, remember to take advantage of the benefits it provides.

Staying financially organized is difficult for most everyone. We provide a sample “Medical Costs Tracking” tool on **page 63**, however, we realize that this tool may not work for everyone. Use it for ideas that can help you most directly.



StepSeven

STAYING STRONG THROUGH THE FIGHT

No one expects to get 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?” In addition, you may have financial concerns or problems dealing with the medical system or insurance. With all of this stress, most patients and their loved ones experience real feelings of depression or anxiety after a diagnosis. Who wouldn’t?

TIPS

TO COPING WITH CANCER:

- Tell your health care team that you need help, and ask for a referral to a counselor and support services
- Check out the Cancer Support Community (www.CancerSupportCommunity.org) or CancerCare (www.CancerCare.org). Both organizations have phone lines staffed with trained mental health professionals who can help you find the support and services you need.
- Contact a social worker experienced with oncology
- Contact the Patient Advocate Foundation (www.patientadvocate.org) for help if you need co-pay assistance or if you can’t afford medical care. They will do their best to help you through the system
- Join a support group, perhaps online
- Ask your doctor about medications that can help
- Focus on living in the moment
- Use relaxation techniques such as deep breathing when you feel panic
- Reach out to CRC specific-support organizations

Research shows that early identification of emotional distress and follow-up treatment (counseling and support services) helps everyone involved. It’s important to find help if you need it. There are organizations that can help with emotional stress from the diagnosis, insurance hassles or financial assistance, and even with getting to and from your doctor appointments if that’s a problem.

FOOD AND DRINK

As you move from diagnosis to treatment and surgery, your dietary needs will change. After surgery, you will be on a “low residue” diet which means a diet low in fiber to minimize the amount of work your colon and rectum do. Think white bread, not whole wheat! It might take your colon several weeks or longer to start working normally. It’s not uncommon to experience problems with diarrhea as your body heals.

TIPS

FOR EATING AFTER SURGERY:

- Talk to your nurse before you leave the hospital and get a list of what you can eat
- Ask about a consultation with the hospital's nutrition team
- 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 great list of foods to eat and foods to avoid
- Don't be shy about talking with your care team about problems with diarrhea

During treatment, you may not feel like eating or drinking, but you need to stay strong. Foods may taste different, and side effects like mouth sores or cold sensitivity might make it hard to eat. Drinking enough fluids is critical to help your body work efficiently. If you're not taking in enough fluids, or if

you have problems with vomiting and diarrhea, you're at increased risk for dehydration. Dehydration is serious, so pay attention to how you feel and if you're concerned, call your health care team.

TIPS

FOR EATING WHEN YOU DON'T WANT TO:

- Eat small meals
- If you're not on FOLFOX, 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
- Try different things. If you get an urge for a certain food, go for it

SYMPTOMS OF DEHYDRATION:

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

For personal help or advice, get a referral to a nutritionist, or find a Registered Dietitian who has worked with cancer patients To find a Registered Dietitian with certification in Oncology, search the Academy of Nutrition and Dietetics at: www.eatright.org

EXERCISE

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. It maintains weight, muscle tone and overall health. It reduces stress and gives you energy to face the next challenge with vigor. This can be true both during and after treatment.

Talk with your doctor about what's feasible for you. Try to build exercise into your life as a priority. Start with 10-15 minutes each day (or 10 minutes a few times a day) and try to build yourself up to more (ideally 30 minutes per

day on most days of the week.) Don't feel badly if you're too exhausted to do much at tough times during your treatment, it can be a goal for when you feel better. If it helps, recruit friends to keep you active and motivated.

SEX AND INTIMACY

Treatment for colorectal cancer (especially radiation for rectal cancer) can make intercourse difficult, painful, and undesirable - or in some cases, impossible. You might be too anxious to think about intimacy, or just too tired. Most often, issues around sex are not automatically discussed by your healthcare team, so if you have concerns, remember to ask. Remember that sexuality is about more than intercourse. It is about everything associated with the intimacy of loving someone. Because of the power of intimacy, feeling sexually satisfied can involve something as simple as a kiss or caress.

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 other ways to manage sexual side effects
- Try alternative ideas for intimate contact if intercourse is uncomfortable or impossible
- Review information in the American Cancer Society's web pages titled "Keeping Your Sex Life Going Despite Cancer Treatment"
- Don't feel bad about yourself

StepEight

P O S T - T R E A T M E N T F O L L O W - U P

After treatment ends, make sure to celebrate! It's a huge accomplishment and a victory! Your doctor will want to continue seeing you for follow-up surveillance and care. Colorectal cancer recurrence is most common within the first five years after treatment, so follow-up visits will be more frequent during this time.

Your medical oncologist doctor will request physical examinations, blood work, scans and colonoscopies based on your cancer type (colon or rectal cancer), your individual risk for recurrence and the time from diagnosis.

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 Colorectal Cancer

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 6 months	Every 6 months	Every 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 patients)	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 one 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				
CT of the abdomen and pelvis (colon cancer) and of the chest (rectal cancer)	Annual	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 health care provider may be the doctor who knows the most about your complete medical history and your follow-up care. 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.

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

Questions to ask when leaving your oncology healthcare team:

- Can I have a written comprehensive care summary?
- What tests were done to diagnosis my colon or rectal cancer, including their results and when and where they were done?
- What was my diagnosis? What was the stage, location of tumors, and levels of markers such as CEA (see page on biomarkers)?
- What family or personal medical history is important to my diagnosis, treatment, and follow-up?
- What surgeries, chemotherapy, and radiotherapy did I receive, including dates, dosages and reactions?
- What clinical trials was I part of?
- What other services did I receive — nutrition, psychological support, home health care, genetic counseling?
- What is the full contact information for the places I received treatment and key providers?
- Who is the key person who will coordinate my follow-up care and how will I contact that person?



LIFESTYLE CHANGES

Research shows that a healthy lifestyle can decrease the risk of recurrence. Components of a healthy lifestyle include:

- Limiting sun exposure
- Maintaining a healthy weight
- Adopting a physically active lifestyle (30 minutes of moderate to vigorous activity at least 5 days a week)
- Reducing alcohol use
- Quitting smoking
- Eating a healthy diet (low in red meat and processed foods) that emphasizes plant sources

Talk with your doctor and partner with your family or a friend to help you stick with a healthy lifestyle plan that works for you.

Questions for your primary care doctor when you are done with treatment:

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

StepNine

END OF LIFE ISSUES

If there comes a time when you've run out of treatment options, deciding how you will live out the rest of your life is important, for both yourself and for your family. Thinking about the end of life can be tough. Thinking about death, and planning how you will handle it *is* tough. You may feel that planning is “giving up.” You may feel that you need to focus only on staying well. Your family and loved ones may not be comfortable thinking or talking about it. But it is important.

All of this is understandable. At the same time, planning can be empowering. There are resources, experts, and support people to help you — especially 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 simply planning — and chances are you'll be glad you did it.

Planning helps you regain a sense of control over life's rollercoaster — including the ups and downs of cancer. You'll realize how much excellent help is available for all stages of life, including those at life's end.

It's important to find your own way to deal with this. Remember you have to make the time to think things through ahead of time.

Getting your affairs in order can give you a sense of relief, and free up your energy for more immediate challenges.

Hospitals now require clear directions about your personal wishes and who can make decisions for you if you are admitted to the hospital but are unable to make decisions for yourself.



Planning for what you want during both treatment and as the end of your life approaches 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. Remember, 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 all 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 after your death
- **Spiritual support including your clergy.** 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)

PALLIATIVE CARE

Palliative care is a system of medical, physical and emotional support provided by a team of specialists for people with advanced illness who need relief from symptoms, pain and stress. Palliative care provides ongoing support throughout your treatment and after it ends. It focuses on providing relief for symptoms such as pain, shortness of breath, fatigue, constipation, nausea, loss of appetite, difficulty sleeping and depression. Palliative care also supports the caregiver.

Unlike hospice care (which is specifically for end-of-life situations), palliative care is for those with advanced disease. It's designed to help you and your family, with the goal of improving the quality of life for everyone affected. It also helps cancer survivors gain strength to carry on with daily life, improves their sense of control and can help tolerate treatments. Ask if your hospitals, cancer centers, or long-term care facility provides palliative care. You might even be able to receive it at home.

HOSPICE CARE

Hospice professionals focus on providing the best possible quality of life — hour by hour, minute by minute — to an individual at the end of their life and support their loved ones.

When do you use hospice?

Hospice care is provided to people who have a limited life expectancy, usually no more than six months. However, care can be extended beyond six months. Patients may also choose to leave hospice services and return to a different form of medical treatment if they choose.

The hospice philosophy is that death is the final stage of life, affirming life while allowing death to take its course.

Hospice care treats the person rather than the disease, working to manage symptoms so that a person's last days may be spent with dignity and quality, surrounded by their loved ones. It is a family-centered service that includes the patient and the family in making decisions.

Hospice care is provided by an interdisciplinary team that includes:

- Hospice physician or medical director who may take over the patient's medical care or may work closely with the patient's chosen physician
- A nurse who makes regular visits to assess the patient's condition, provide pain relief, help deal with other uncomfortable symptoms, and help the family provide care. Hospice nurses are available 24 hours a day, 7 days a week to manage crises or answer family questions
- Home health aides who provide practical personal care for the patient
- A social worker who coordinates community services and financial needs and provides support and emotional counseling for the family
- Trained volunteers who can provide respite care or other support for the patient and family and
- 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 and needs, while always putting 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 and find out what is available to you. Hospice staff can work with your medical team to receive a referral or you can make a request to your doctors office to receive a referral when you are ready.

For additional information about hospice and palliative care, see

<http://www.cancer.gov/cancertopics/factsheet/Support/hospice>

ADVANCED DIRECTIVES

Advance directives allow you to document your personal wishes and goals for medical treatment at end of life. You also pick people who can act for you if you are unable to make decisions, so that your wishes can be carried out the way you want.

Advance Directives are legal documents which may vary from state to state. Advance directives are not just for people with cancer or people who are dying. Everyone should have them in place so that good decisions can be made 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 health care, health care agent, or health care 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 provides information about how a person wants to be treated medically if the person cannot speak for himself or herself. It may also be referred to as a directive to physicians, healthcare declaration, or medical directive. Living wills tell families and health care staff what kind of life-sustaining care the person wishes to have such as cardiopulmonary resuscitation, mechanical ventilation, artificial nutrition and hydration, or dialysis
- DNR or Do-Not-Resuscitate orders must be written by a physician, although they can be written at the request of patient or family. A person with a valid DNR will not be given cardiopulmonary resuscitation (CPR) if their heart or breathing stops. DNR orders can be written for hospital care or for patients who are being cared for at home

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

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

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

StepTen

MOVING DOWN THE ROAD TO SURVIVORSHIP

TAKING CARE OF YOU

During and after treatment, or during treatment breaks, life goes on. You still need to check in with your primary care provider, your dentist and any other medical professionals who are involved with your ongoing health. Survivorship care plans can give you a structure to help you take care of your whole self.

Some of the best tools for Survivorship Care planning are offered online. They can be used by you, in partnership with your doctors. Some popular ones include:

Journey Forward: www.journeyforward.org

The LIVESTRONG Care Plan: www.livestrongcareplan.org

NCCN's survivorship plan: www.nccn.org/patients

Questions to ask about your survivorship care plan:

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

“ You become a survivor the moment you decide to fight. ”

– Tonya Floyd, Stage III CRC survivor

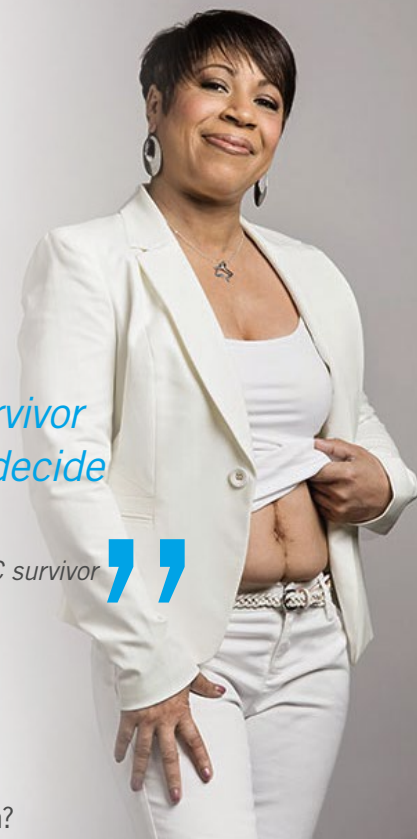


Photo courtesy of Mark McCarty, The Colon Club

STRENGTH FROM OTHERS

It feels good to talk with and learn from others who share what you're going through. When you talk to other survivors, you'll quickly realize that 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 (even if they're different from your own) and answer questions.

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

To feel inspired by other colorectal cancer survivors, start by reading some of the personal stories on Fight Colorectal Cancer's blog at [FightColorectalCancer.org/blog](https://fightcolorectalcancer.org/blog) or join us on Facebook at Facebook.com/FightCRC.

Gain a New Perspective on Strength & Life

Having a potentially life-threatening disease often leads people to examine their lives and look for meaning. The fear of death often leads us to think about what we value and want for our lives. 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 one-year and five-year cancer-free milestones. Others celebrate milestones and anniversary dates such as the end of chemotherapy or the anniversary of surgery to treat your cancer, or the completion of each follow-up visit.

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 the treatments stop and scars heal. Survivorship is a journey. As a survivor, caregiver or family member, you can raise awareness and support finding a cure for colon and rectal cancers.

Inspired by the over ONE MILLION colorectal cancer survivors, One Million Strong is a campaign that raises awareness about colorectal cancer - the second-leading cause of cancer deaths in the U.S. Our goal is to empower survivors, caregivers and others who've been touched by the disease to share their stories and raise awareness about this disease.

Each March, Fight Colorectal Cancer hosts Call-on Congress. It is a three-day educational event open to survivors, caregivers and their 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. We train advocates on how to share their stories and build relationships with members of Congress. And then we put them into Congressional offices on "Hill Day." Advocates leave D.C. with a better understanding of how to push for policies that impact colorectal cancer, determined to return year after year.

If you've been touched by colorectal cancer, we invite you to join us.
Learn about how to fight with us at FightColorectalCancer.org.



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 a while 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

FIGHT COLORECTAL CANCER'S MEDICAL ADVISORY BOARD 2015

Dennis Ahnen, MD
University of Colorado Cancer Center

Nancy Baxter, MD, FRCSC
St. Michael's Hospital, University of Toronto

Al B. Benson III, MD FACP
Northwestern University

Dan Dixon, PhD
University of Kansas Cancer Center

Richard M. Goldberg, MD
The Ohio State University Medical Center

Carolyn Grande, CRNP, AOCNP
University of Pennsylvania

David Greenwald, MD
Montefiore Medical Center

Axel Grothey, MD
Mayo Clinic College of Medicine

Heather Hampel, MS, CGC
The Ohio State University Medical Center

Heinz-Joseph Lenz, MD, FACP
University of Southern California

Paul Limburg, MD, MPH
Mayo Clinic

John Marshall, MD
Georgetown University Medical Center

Howard McLeod, PharmD
Moffitt Cancer Center

Neal J. Meropol, MD
**University Hospitals Seidman Cancer Center and
Case Western Reserve University**

Edith Mitchell, MD
Thomas Jefferson University

Nicholas Petrelli, MD
Christiana Care Health System

Leonard Saltz, MD
**Weill Medical College of Cornell University and
Memorial Sloan-Kettering Cancer Center**

Daniel J. Sargent, PhD
Mayo Clinic College of Medicine

Joel E. Tepper, MD
University of North Carolina School of Medicine

WRITERS:

Erica Weiss, MPH, MSUP
Plain Language Health Writer

Nancy Roach
Founder and Chair, Fight Colorectal Cancer

Anjee Davis, MPPA
President, Fight Colorectal Cancer

Kim Ryan
**Director of Patient Information Services,
Fight Colorectal Cancer**

Danielle Burgess
Director of Communications, Fight Colorectal Cancer

ADDITIONAL REVIEWERS:

Sarah Leonard, RN, BSN, OCN
John Muir Cancer Institute

Laura Porter, MD
Colon Cancer Alliance

RESOURCES

Advocates Facebook Group

www.facebook.com/groups/AdvocatesFightCRC

Advocacy Connector

www.advocacyconnector.com

American Society of Colon and Rectal Surgeons

www.fascrs.org

American Society of Clinical Oncology

www.cancer.net

CancerCare

www.cancercare.org

Cancer Support Community

www.cancersupportcommunity.org

Chris4Life

www.chris4life.org

Colon Cancer Alliance

www.ccalliance.org

Colon Cancer Coalition/GYRIG

www.coloncancercoalition.org

ColonTown

www.ColonTown.org

Colon Club

www.ColonClub.org

Colorectal CareLine

www.ColorectalCareLine.org

Comprehensive Cancer Centers

cancercenters.cancer.gov

Fight Colorectal Cancer

www.FightColorectalCancer.org

Fight Colorectal Cancer's Clinical Trials

<http://FightColorectalCancer.org/ClinicalTrials>

Health Information

<http://www.nlm.nih.gov/medlineplus>

Healthy Living, Personalized Health Advice

<http://healthfinder.gov>

Helping Hands

www.rci.lotsahelpinghands.com

LIVESTRONG

www.LiveStrong.org

Michael's Mission

www.MichaelsMission.org

My Lifeline

www.mylifeline.org

National Comprehensive Cancer Network

www.nccn.org

National Cancer Institute

www.cancer.gov

National Cancer Institute

www.Cancer.gov

Peer Reviewed, Evidence-Based Medicine

<http://www.uptodate.com>

Scientific Journal Articles

<http://www.ncbi.nlm.nih.gov/pubmed>

Stupid Cancer

www.StupidCancer.org

The National Institutes of Health Clinical Trials

<http://www.clinicaltrials.gov>

PATIENT ASSISTANCE PROGRAMS

Avastin® (Bevacizumab)
www.genentech-access.com

Camptosar® (Irinotecan)
www.pfizerhelpfulanswers.com

Cancer Care Co Pay Assistance
www.cancercarecopay.org

Cancer Survivors Network (CSN)
Available by phone at 1-877-333-HOPE
www.csn.cancer.org

Chronic Disease Foundation
www.cdfund.org

Eloxatin® (Oxaliplatin)
www.visitspconline.com

Erbitux® (Cetuximab)
www.lillytruassist.com | www.bmspaf.org

HealthWell Foundation
www.healthwellfoundation.org

Journey Forward
www.journeyforward.org

Needy Meds
www.needymeds.org

Nutrition and Dietetics
www.eatright.org

Oncotype DX®
www.oncotypedx.com

Partnership for Prescription Assistance
www.pparx.org

Procrit®
www.janssenaccessone.com

Stivarga® (Regorafenib)
www.stivarga-us.com

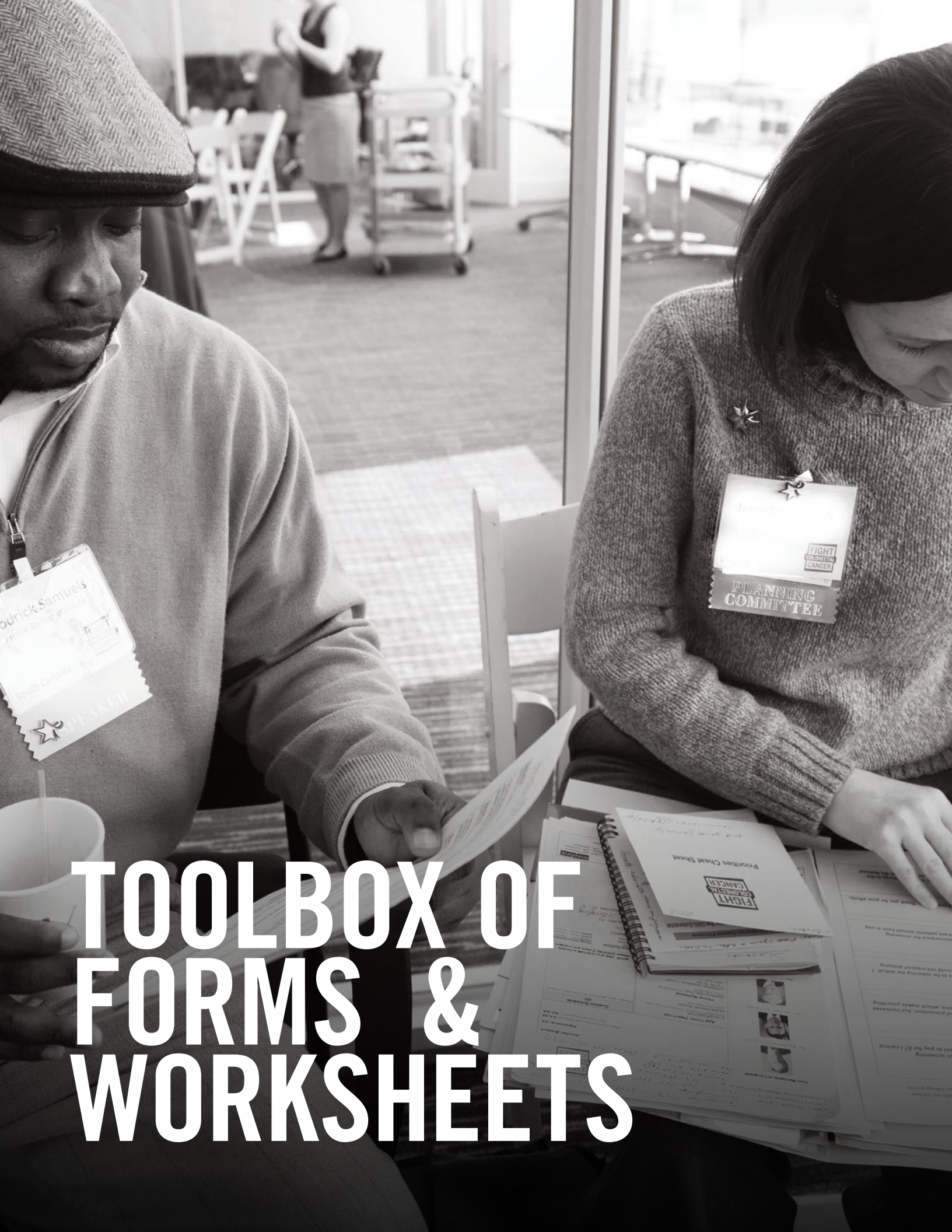
The LIVESTRONG Care Plan
www.livestrongcareplan.org

The American Cancer Society (ACS)
Available 24 hours a day at 1-800-ACS-2345
www.cancer.org

The National Cancer Institute Database
www.cancer.gov/cancertopics/pdq/cancerdatabase

Vectibix® (Panitumumab), Aranesp® (Darbepoetin),
Neulasta® (Pegfilgrastim)
www.amgenassist.com

Zaltrap® (Ziv-Aflibercept)
www.zaltrap.com



TOOLBOX OF FORMS & WORKSHEETS

PERSONAL INFORMATION & MEDICAL HISTORY

Name: _____ Cell: _____ Work: _____

Emergency Contact: _____ Phone: _____

Primary Care Physician: _____ Phone: _____

Primary Insurance: _____ Policy #: _____

Insured Name: _____ Group#: _____ Phone: _____

Secondary Insurance: _____ Phone: _____

Insured Name: _____ Group#: _____ Policy #: _____

Do you have a living will or an advance directive? _____

Do you have a healthcare proxy? _____

Primary Support Person (Caregiver)

Name: _____ Relationship: _____

Cell: _____ Work: _____

Past Cancer History

Type of Cancer: _____ Date diagnosed: _____

Doctors' names: _____ Facility: _____

Address: _____ Phone: _____ Fax: _____

Past Treatment

Details:

- ☐ Chemotherapy
- ☐ Surgery
- ☐ Radiation
- ☐ Hormone
- ☐ Others

MEDICAL HISTORY (PLEASE CHECK ALL THAT APPLY)

- | | | |
|---|--|---|
| <input type="radio"/> Arthritis | <input type="radio"/> Gynecological problems | <input type="radio"/> Prostate problems |
| <input type="radio"/> Asthma | <input type="radio"/> Heart problems | <input type="radio"/> Seizures/epilepsy |
| <input type="radio"/> Blood disorder | <input type="radio"/> Hepatitis | <input type="radio"/> Skin disorders |
| <input type="radio"/> Circulation problems | <input type="radio"/> High blood pressure | <input type="radio"/> Shingles |
| <input type="radio"/> Depression/anxiety | <input type="radio"/> HIV/AIDS | <input type="radio"/> Stroke |
| <input type="radio"/> Diabetes | <input type="radio"/> Kidney/urine problems | <input type="radio"/> Thyroid problems |
| <input type="radio"/> Frequent infections | <input type="radio"/> Liver problems | <input type="radio"/> Tuberculosis |
| <input type="radio"/> Gastrointestinal problems | <input type="radio"/> Lung problems | <input type="radio"/> Ulcers |

Please provide detailed information on the boxes checked.

Please list past surgeries and note date of surgery. (Make more copies if needed.)

Family history (Please note any of your relatives who have had a chronic illness for example, cancer, heart disease, diabetes).

- | | | |
|---|--|--|
| <input type="radio"/> Biological mother | <input type="radio"/> Maternal grandmother | <input type="radio"/> Maternal grandfather |
| <input type="radio"/> Biological father | <input type="radio"/> Paternal grandmother | <input type="radio"/> Paternal grandfather |
| <input type="radio"/> Sibling | <input type="radio"/> Sibling | <input type="radio"/> Sibling |
| <input type="radio"/> Aunt | <input type="radio"/> Uncle | <input type="radio"/> Other |

Please provide detailed information on the boxes checked.

MY MEDICAL TEAM – CONTACT LIST & BUSINESS CARDS

Physician name Specialty Phone Email/Website	
Physician name Specialty Phone Email/Website	
Physician name Specialty Phone Email/Website	
Physician name Specialty Phone Email/Website	
Physician name Specialty Phone Email/Website	
Physician name Specialty Phone Email	

SECOND OPINION REFERRALS

Specialty	Physician's name	Phone number	Address	Notes

Date	My questions	Answers / Follow-up Notes / Recommendations	Other

DETAILED TREATMENT HISTORY

Date	Type of surgery	Physician	Notes

Date	Chemotherapy / Targeted Therapy / Radiation	Physician	Notes / Side Effects

MEDICATION MANAGEMENT CHART

Name: _____ Date of Birth _____

Pharmacy Name and Phone Number _____

Insurance _____

RX allergies/ Reactions _____

[illegible]

SIDE EFFECTS MANAGEMENT CHART

You can keep track of your treatment schedule here.

Note any symptoms to discuss with your doctor (chills, fever, cough, pain, pale skin, bleeding, loss of appetite, rapid heartbeat, trouble breathing, fatigue, dizziness, diarrhea, numbness...anything.)

In your plan of action, list medical and non-medical solutions. Note things that work well for you, and things that don't work.

Date Time Treatment	Side effects or symptoms	Plan of Action
Date Time Treatment	Side effects or symptoms	Plan of Action
Date Time Treatment	Side effects or symptoms	Plan of Action
Date Time Treatment	Side effects or symptoms	Plan of Action
Date Time Treatment	Side effects or symptoms	Plan of Action
Date Time Treatment	Side effects or symptoms	Plan of Action
Date Time Treatment	Side effects or symptoms	Plan of Action
Date Time Treatment	Side effects or symptoms	Plan of Action

THE HELP I NEED

What help do I need?	Help is on the way (name)	Contact information (email or phone)
Home Care Support		
Medical Support		
Practical Support		
Emotional Support		
General		

MANAGING MEDICAL COSTS

Insurance company name _____

Telephone number _____

Contact _____

Details	Charges	Payment Info
Date MD name Purpose of visit: Lab Scan Medication/treatment Doctor Visit Other	Date of bill Amount	Date Bill Paid Pay by: Insurance Check Credit Card Other
Date MD name Purpose of visit: Lab Scan Medication/treatment Doctor Visit Other	Date of bill Amount	Date Bill Paid Pay by: Insurance Check Credit Card Other
Date MD name Purpose of visit: Lab Scan Medication/treatment Doctor Visit Other	Date of bill Amount	Date Bill Paid Pay by: Insurance Check Credit Card Other

FOLLOW-UP CARE PLAN

My Recommended Plan:

Test	Year 1	Year 2	Year 3	Year 5
Physical	Date: Notes:			
Colonoscopy	Date: Notes:			
Chest, abdominal and pelvic CT	Date: Notes:			
Blood tests	Date: Notes:			
PET-CT Scan	Date: Notes:			
Other	Date: Notes:			
Other	Date: Notes:			

Prescribing Doctor _____ Phone _____

Primary Care Physician _____ Phone _____

YOUR GUIDE IN THE FIGHT

STAGE III AND STAGE IV COLORECTAL CANCER

To download a digital copy of this book,
visit FightColorectalCancer.org/GuideInTheFight

For media, extra copies and reprint information, please contact:

Fight Colorectal Cancer
1414 Prince Street, Suite 204
Alexandria, VA 22314
(703) 548-1225

FightColorectalCancer.org

Info@FightCRC.org

Your Guide in the Fight

Copyright ©2015 Fight Colorectal Cancer