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2nd Edition

UNDERSTANDING COLORECTAL CANCER

A Guide for Patients and their Families



*Discovering
strength
in support*



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COLORECTAL CANCER



If you've been diagnosed with colorectal cancer, disease management needs to be top of mind. In this fight, it's important to arm yourself with as much information as you can about the treatment options available to you! Knowing your colorectal cancer biomarkers can help your doctor identify the best disease management plan for YOUR cancer.

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2nd Edition

UNDERSTANDING COLORECTAL CANCER

IN THIS GUIDE

- 2 **Overview:** Support is the cornerstone of managing a colorectal cancer diagnosis
- 3 **Staging:** Staging is the foundation of your disease management plan
- 4 **Genomic and Genetic Testing**
- 6 **Colon Cancer Survivor Perspective:** Jeremy Echols
- 7 **Treatment Options:** Learn about the types of treatments that may be available
- 8 **Caring for an Ostomy**
- 9 **Rectal Cancer Survivor Perspective:** Marra Lashbrook Rodriguez
- 10 **Supportive Care:** Plan with your doctor for physical and emotional side effects
- 12 **Clinical Trials:** Learn about clinical trials and how to find them
- 13 **Financial Considerations:** Planning and organizing may help you manage cancer-related costs
- 14 **Nutrition:** Understanding the role of nutrition
- 15 **Maintaining Care:** Follow-up planning can help you move forward confidently
- 16 **Assistance:** Support available for you
- 17 **Notes**



"You will have good days and bad days, but remember that a healthy mindset is essential. Be sure to find what helps you."

~Jeremy Echols, page 6



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Support is the cornerstone of managing a colorectal cancer diagnosis

Learning you have colorectal cancer can be life-changing. Suddenly you are faced with many decisions, some that must be made soon. It is important to know that you are not alone. You are now part of a close-knit cancer community made up of survivors, families, health care professionals and advocates. They range in ages and cultures. Some have had colorectal cancer; others are dedicated to ensuring you have the resources you need to manage it. You are encouraged to get to know them, and learn from their experiences. They are here for you.

HOW TO GET STARTED

Begin by learning as much as you can about colorectal cancer and then about your specific diagnosis. If you are not sure what it is, ask your doctor to write it down for you. All colorectal cancer diagnoses are not the same and can respond differently to treatments. This is true for many reasons, such as where it is located in your body and if biomarkers are present in the tumor. Ongoing research focusing on biomarkers, early detection and more are helping improve the ways colorectal cancer is treated, so it is important to be aware of your options.

Use reputable sources such as those included in the *Assistance* section on page 16, and ask your health care team for additional resources. The more informed you are, the better prepared you will be to make the decisions ahead.

UNDERSTANDING COLORECTAL CANCER

Cancer that begins in the colon or rectum is referred to as colorectal cancer. You may hear “colon cancer” and “rectal cancer.” Both are correct depending on where in the body the cancer started.

Part of the digestive system, the colon makes up about the first six feet of the large intestine, and the rectum and anal canal are about the last six inches (see Figure 1). Colorectal cancers typically begin as benign polyps that may become cancerous. During a screening procedure called a colonoscopy, polyps are removed (polypectomy). A similar

procedure (local excision) may be done during a colonoscopy to remove small tumors.

If you or a loved one has already received a colorectal cancer diagnosis, you may think this information isn’t helpful. Not so. One of the top reasons for recurrence may be lack of follow-up screening. Staying up to date with colorectal cancer follow-ups and regular screenings for other conditions is very important.

ASSEMBLE YOUR MULTIDISCIPLINARY TEAM

Support is available in many forms. Your team may include many of the following specialists, as well as other health care professionals. Their responsibilities can vary based on where you receive care.

Advanced practice providers (oncology nurse practitioners and physician assistants) work closely with the oncologist and other team members to help oversee an individual’s care and evaluations. They also specialize in managing the physical and psychological needs of cancer patients and their loved ones.

Case managers may be social workers, trained financial counselors, nurses or a combination of these experts who ensure you receive quality services, from screening and assessment to care coordination and discharge planning.

Colorectal surgeons specialize in surgeries of the digestive tract.

Counselors are mental health professionals, such as psychologists, psychiatrists or social workers, who are trained to help you manage your feelings, worries and concerns.

Enterostomal therapists are health professionals trained in the care of persons with stomas, such as colostomies. They may also be known as ostomy nurses.

Gastroenterologists have special training in diagnosing and treating disorders of the colon and rectum.

Nurse navigators, also called patient navigators, guide patients through the health care system, from screening and diagnosis to treatment and follow-up. They help patients com-

municate with their health care providers; set up appointments for medical visits and tests; and provide information on where patients can get financial, legal and social support. Nurse navigators may also help patients find information on how to discuss their medical situation with employers.

Oncologists are trained to diagnose and treat cancer using medicines. Some oncologists specialize in a particular type of cancer treatment.

Palliative care specialists offer physical and emotional support for cancer symptoms, pain management, treatment-related side effects and more.

Pathologists specialize in diagnosing disease by studying cells and tissues under a microscope and help interpret laboratory tests including molecular and genomic analyses.

Pharmacists prepare and dispense prescriptions, ensure medicines and doses are correct, and prevent harmful drug interactions. They also counsel patients on the safe and appropriate use of their medications.

Radiation oncologists are specially trained to use radiation to treat cancer.

Radiologists are trained in creating and interpreting pictures of areas inside the body. The pictures are made with X-rays, sound waves or other types of energy.

Social workers may help with various tasks, such as finding services or working with insurance companies, as well as providing counseling for patients and families.

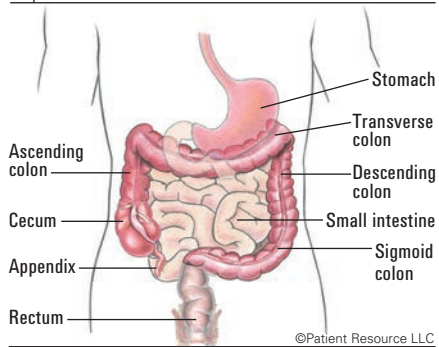
Surgical oncologists are specialists who treat cancer using surgical procedures.

Caregivers can assist you with the tasks of daily living that you may not be able to perform by yourself. This may include going to medical appointments, shopping, bathing, getting dressed, eating and helping with your ostomy (if applicable). It’s a good idea to identify more than one person to help with these tasks. Hospitals and home-care agencies can provide skilled nursing care or arrange for someone to help with this role when family and friends cannot.

Support groups and advocacy groups offer you the chance to talk with others who are facing the same challenges and share knowledge. Groups may be local or online.

Many of these groups offer peer-to-peer support through programs that match the patient with a person who has had a similar diagnosis. Being able to talk with someone who knows what you’re going through is extremely helpful. ■

FIGURE 1
COLORECTAL ANATOMY



Staging is the foundation of your disease management plan

Doctors rely on many tests to diagnose colorectal cancer. Some tests, including laboratory studies and imaging studies such as computed tomography (CT), help doctors assign an initial stage to your cancer. This initial stage is known as the clinical stage because it is based on clinical findings. The final stage is assigned by the pathologist who examined the colon or rectal tumor and lymph nodes that were removed. This final stage is known as the pathologic stage. The stage provides important information for selecting appropriate treatment options and for understanding the prognosis (outcome).



Colorectal cancer is classified according to the tumor, node, metastasis (TNM) system developed by the American Joint Committee on Cancer (AJCC). For many cancers, the size and location of the tumor is of critical importance, but for colorectal cancer, how deeply the tumor penetrates the intestinal or rectal layers is an important prognostic feature of the tumor. The T category is used to describe this depth; the N category is used to describe how many nearby lymph nodes are involved (contain cancer cells); and the M category is used to note whether cancer has metastasized (spread to other parts of the body) (see Table 1).

Once a colorectal cancer has been classified with the AJCC TNM system, a prognostic stage group is assigned (see Table 2). Stages 0

to IV are further subdivided, grouping tumors that are associated with similar prognoses. This grouping enables doctors to recommend the most appropriate disease management plan for a particular stage.

The stage of your colorectal cancer and other characteristics of the tumor are documented on a pathology report. A pathology report is prepared by a pathologist after he or she has examined the specimen with and without a microscope, documenting its size, describing its location and appearance, and performing special testing. Results from testing the tumor sample for mutations, also known as molecular testing, may be on the initial pathology report or reported later in a separate document. These results are important because they can help guide ad-

ditional treatment decisions, such as which drug therapies to use, and identify people who need testing for Lynch syndrome, an inherited condition that results in a risk of developing colorectal and other cancers. Some commonly tested mutations in colorectal cancer are *BRAF* (pronounced BEE-raff) and *RAS* (pronounced Rass), which includes *KRAS* (pronounced KAY-rass) and *NRAS* (pronounced EN-rass), and *EpcAM*. Microsatellite instability (MSI) and deficient mismatch repair (dMMR) testing will likely be done, among others (see *Genomic and Genetic Testing*, page 4). If *KRAS*/*NRAS* or *BRAF* mutations are not present, testing for *HER2* overexpression may be recommended for patients with Stage IV colon cancer.

Other important information about the tumor that is included on the pathology report includes its histologic grade and the status of the surgical margins. The histologic grade indicates how closely the tumor cells resemble healthy cells. Grade 1 cells look similar to healthy cells, and the tumor is likely to grow slowly; in contrast, Grade 4 cells look very different from healthy

TABLE 1
AJCC TNM SYSTEM FOR CLASSIFYING COLORECTAL CANCER

Classification	Definition
Tumor (T)	
TX	Primary tumor cannot be assessed.
T0	No evidence of primary tumor.
Tis	Carcinoma in situ, intramucosal carcinoma (involvement of lamina propria with no extension through muscularis mucosae).
T1	Tumor invades submucosa (second layer of tissue in the colon or rectum) (through the muscularis mucosa [first layer of tissue in the colon or rectum] but not into the muscularis propria [third layer of tissue in the colon or rectum]).
T2	Tumor invades the muscularis propria (third layer of tissue in the colon or rectum).
T3	Tumor invades through the muscularis propria (third layer of tissue in the colon or rectum) into pericolorectal tissues (tissues around the colon or rectum).
T4	Tumor invades the visceral peritoneum (outer lining of colon or rectum) or invades or adheres to adjacent organ or structure.
T4a	Tumor invades through the visceral peritoneum (outer lining of colon or rectum) (including gross perforation of the bowel through tumor and continuous invasion of tumor through areas of inflammation to the surface of the visceral peritoneum).
T4b	Tumor directly invades or adheres to adjacent organs or structures.
Node (N)	
NX	Regional lymph nodes cannot be assessed.
N0	No regional lymph node metastasis.
N1	One to three regional lymph nodes are positive (tumor in lymph nodes measuring greater than or equal to 0.2 mm), or any number of tumor deposits are present and all identifiable lymph nodes are negative.
N1a	One regional lymph node is positive.
N1b	Two or three regional lymph nodes are positive.
N1c	No regional lymph nodes are positive, but there are tumor deposits in the subserosa, mesentery or nonperitonealized pericolic, or perirectal/mesorectal tissues (nearby tissues).
N2	Four or more regional nodes are positive.
N2a	Four to six regional lymph nodes are positive.
N2b	Seven or more regional lymph nodes are positive.
Metastasis (M)	
M0	No distant metastasis by imaging, etc.: no evidence of tumor in distant sites or organs.
M1	Metastasis to one or more distant sites or organs or peritoneal (membrane that lines the abdominal cavity) metastasis is identified.
M1a	Metastasis to one site or organ is identified without peritoneal (membrane that lines the abdominal cavity) metastasis.
M1b	Metastasis to two or more sites or organs is identified without peritoneal (membrane that lines the abdominal cavity) metastasis.
M1c	Metastasis to the peritoneal (membrane that lines the abdominal cavity) surface is identified alone or with other site or organ metastases.

TABLE 2
STAGES OF COLORECTAL CANCER

Stage	T	N	M
0	Tis	N0	M0
I	T1	N0	M0
	T2	N0	M0
IIA	T3	N0	M0
IIB	T4a	N0	M0
IIC	T4b	N0	M0
IIIA	T1-T2	N1/N1c	M0
	T1	N2a	M0
IIIB	T3-T4a	N1/N1c	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
IVC	Any T	Any N	M1c

Used with permission of the American Joint Committee on Cancer (AJCC), Chicago, Illinois. The original and primary source for this information is the AJCC Cancer Staging Manual, Eighth Edition (2017) published by Springer Science+Business Media.

cells, and the tumor is likely to grow quickly. The surgical margin is the area of healthy tissue around the tumor. The pathologist will examine the margin to see if it contains cancer cells. If cancer cells are present in the margins, additional treatment may be needed.

An accurate diagnosis is crucial to receiving an appropriate disease management plan. To gain more information, consider seeking a second opinion or advice from another doctor or group of doctors who specialize in treating colorectal cancer. Some doctors may prefer one treatment approach, while others might suggest a different combination of treatments. You need to learn about all your treatment options. There is often collective wisdom gained from the experience and opinions of different oncology specialists who are experts in your type of cancer. A second opinion is also a way to help confirm your pathology, diagnosis and staging are accurate and that you are aware of clinical trials that you might want to discuss with your oncologist. ■

Genomic and Genetic Testing

Many cancers are caused by mutations (changes) in a cell's DNA, and some of those mutations can be tested for and used to develop a disease management plan.

Genomic Testing

Genomic testing is a type of molecular testing that looks at the DNA of a tumor. It may include testing for specific genes, proteins or molecules of the tumor and may be used to determine whether genetic mutations are present within the tumor. It is typically performed on the initial biopsy material and is repeated if the cancer recurs. It may also be used to detect biomarkers, which are substances such as genes or molecules that can be measured in the blood, plasma, urine, cerebrospinal fluid or other body fluids or tissues. Biomarkers are produced by cancer cells or other cells of the body in response to cancer.

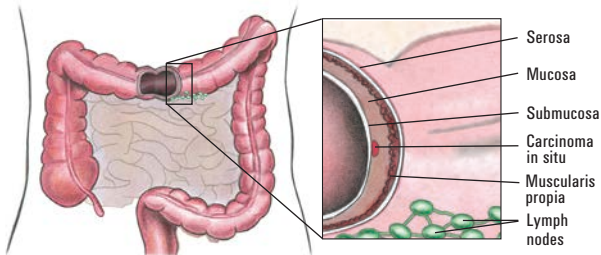
Molecular testing results can also indicate the cancer's behavior, how aggressive it might be and whether it may metastasize (spread). This information can lead to a more precise diagnosis and an appropriate disease management plan for your cancer.

The results of genomic testing help doctors determine whether a person qualifies for specific types of therapy. Many mutations are treated by targeted therapies, a type of systemic therapy that targets specific genes, proteins, enzymes and other molecules involved in the development and growth of cancer (see *Treatment Options*, page 7). Targeted therapies work in different ways and target various molecules or cellular functions. They can reduce growth signals and help destroy cells, including cancer cells.

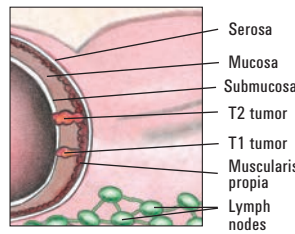
In addition to testing for *BRAF*, *RAS*, *NRAS*, *KRAS* and *HER2* to determine eligibility for targeted therapies, your doctor will also look specifically for regions of high DNA errors caused by high microsatellite instability (MSI-H) and deficient mismatch repair (dMMR) to determine eligibility for immunotherapy, an approach that uses the immune system to treat cancer.

STAGES OF COLON CANCER

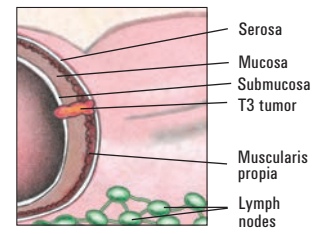
Stage 0 A cluster of malignant cells, known as carcinoma in situ, that has not spread into surrounding tissue or elsewhere.



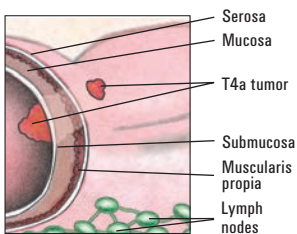
Stage I The tumor has spread to the submucosa or the muscularis propia, but has not spread to regional lymph nodes.



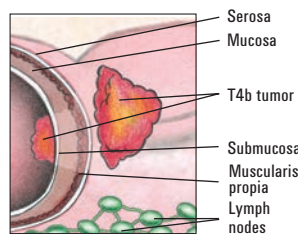
Stage IIA The tumor has spread through the muscularis propia into other colorectal tissues, but has not spread to regional lymph nodes.



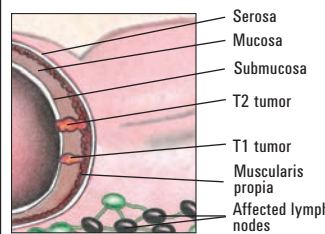
Stage IIB The tumor has spread through the inner layer of the abdominal membrane, but has not spread to regional lymph nodes.



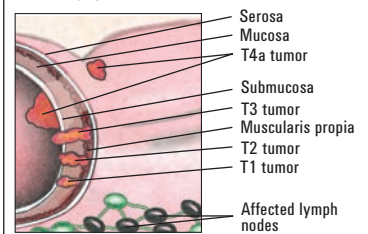
Stage IIC The tumor has spread to or adhered to surrounding organs or structures, but has not spread to regional lymph nodes.



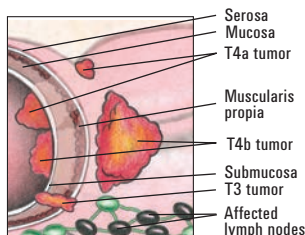
Stage IIIA The tumor has spread to the submucosa or the muscularis propia, and has spread to regional lymph nodes or fatty areas near the lymph nodes.



Stage IIIB The tumor has spread into the submucosa, the muscularis propia or the subserosa, or through the inner layer of the abdominal membrane, and has spread to regional lymph nodes or fatty areas near the lymph nodes.



Stage IIIC The tumor has spread into the subserosa or through the inner layer of the abdominal membrane, or has spread to nearby tissues or organs, and has spread to regional lymph nodes or fatty areas near the lymph nodes.

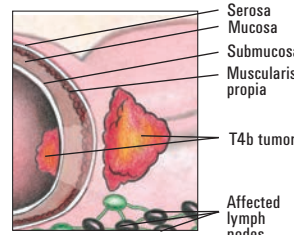


Stages IVA, IVB, IVC

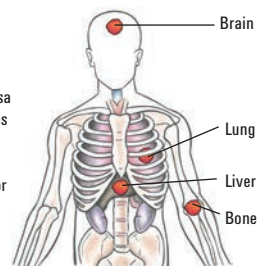
Stage IVA: The tumor may be any size and in any location in the colon, may have spread to regional lymph nodes, and has spread to one organ or site.

Stage IVB: The tumor may be any size and in any location in the colon, may have spread to regional lymph nodes, and has spread to two or more organs or sites.

Stage IVC: The tumor may be any size and in any location in the colon, may have spread to regional lymph nodes, and has spread to the inner layer of the abdominal membrane alone or with spread to other sites or organs.



Metastasis



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The biomarkers tested to determine if you could be a candidate for immunotherapy include the following:

- **Tumor mutational burden (TMB).** This is an assessment of the number of genetic mutations in a tumor. Tumors determined to be TMB-high are candidates for immunotherapy.
- **Microsatellite instability-high (MSI-H) or deficient mismatch repair (dMMR).** MSI-H indicates an abnormality in the sequence of DNA in microsatellites, which are short, repeated sequences of DNA. dMMR occurs when a cell loses its ability to correct errors made when DNA is copied during cell division. These mutations may qualify you for some types of immunotherapy.

Identifying your cancer’s biomarkers can help your doctor choose the most appropriate treatment option for you.

Genetic Testing

Identifying hereditary cancers allows people at an increased risk to be monitored more closely for the development of cancer. A family history of a certain cancer may prompt you to be tested to see if you carry the gene. Having an inherited mutation doesn’t mean you will automatically develop cancer; it only means the risk is increased. Lynch syndrome, also known as hereditary non-polyposis colorectal cancer, is the most common inherited disorder that increases your risk of colorectal cancer. Lynch syndrome also increases the risk for other types of cancer.

Genetic tests are generally ordered by a doctor or another health care provider if there is concern you may have an inherited risk of cancer. Doctors may test for one gene or a small number of genes, which is called single/limited gene panel testing, or many genes,

which is called multi-gene panel testing. Typically, a blood or saliva sample is collected and sent to a laboratory for testing.

When a multi-gene panel is necessary, next-generation sequencing (NGS) is used to define the DNA sequence of these genes. This technique is capable of processing multiple DNA sequences simultaneously with more speed than single-gene tests. DNA sequencing determines the order of the four building blocks of DNA. NGS can be performed on both tumor tissue and on DNA in the blood and, at present, can detect abnormalities that may be treated with specific therapies.

Although some direct-to-consumer genetic tests are available, they are not recommended for a person who has cancer. If you want to learn more about genetic testing, ask your doctor or request a referral to a genetic counselor. ■



STAGES OF RECTAL CANCER

<p>Stage 0 A cluster of malignant cells, known as carcinoma in situ, that has not spread into surrounding tissue or elsewhere.</p> <p>Labels: Transverse colon, Sigmoid colon, Rectum, Anus, Mucosa, Submucosa, Serosa, Muscularis propria.</p>	<p>Stage I The tumor has spread to the submucosa or the tumor has spread to the muscularis propria.</p> <p>Labels: Sigmoid colon, T1 tumor, T2 tumor, Rectum, Anus, Mucosa, Submucosa, Serosa, Muscularis propria.</p>	<p>Stage IIA The tumor has spread through the muscularis propria into other colorectal tissues.</p> <p>Labels: Sigmoid colon, T3 tumor, Rectum, Anus, Mucosa, Submucosa, Serosa, Muscularis propria.</p>	<p>Stage IIB The tumor has spread through the inner layer of the abdominal membrane.</p> <p>Labels: Sigmoid colon, T4a tumor, Rectum, Anus, Mucosa, Submucosa, Serosa, Muscularis propria.</p>
<p>Stage IIC The tumor has spread to or adhered to surrounding organs or structures.</p> <p>Labels: Sigmoid colon, T4b tumor, Mucosa, Submucosa, Serosa, Muscularis propria, Rectum, Anus.</p>	<p>Stage IIIA The tumor has spread to the submucosa or to the muscularis propria and has spread to one to three regional lymph nodes or fatty areas near the lymph nodes. Or, the tumor has spread to the submucosa and has spread to four to six regional lymph nodes.</p> <p>Labels: Sigmoid colon, T4b tumor, T4b tumor, Affected lymph nodes, Rectum, Anus, Mucosa, Submucosa, Serosa, Muscularis propria.</p>	<p>Stage IIIB The tumor has spread through the muscularis propria into other colorectal tissues or has spread through the inner layer of the abdominal membrane and has spread to one to three regional lymph nodes or fatty areas near the lymph nodes. Or, the tumor has spread to the muscularis propria or spread through the muscularis propria into other colorectal tissues and has spread to four to six regional lymph nodes. Or, the tumor has spread to the submucosa or to the muscularis propria and has spread to seven or more regional lymph nodes.</p> <p>Labels: Sigmoid colon, T1 tumor, T2 tumor, T3 tumor, T4a tumor, Affected lymph nodes, Rectum, Anus, Mucosa, Submucosa, Serosa, Muscularis propria.</p>	
<p>Stage IIIC The tumor has spread through the inner layer of the abdominal membrane and has spread to four to six regional lymph nodes. Or, the tumor has spread through the muscularis propria into other colorectal tissues or has spread through the inner layer of the abdominal membrane and has spread to seven or more regional lymph nodes. Or, the tumor has spread to or adhered to surrounding organs or structures and has spread to regional lymph nodes or fatty areas near the lymph nodes.</p> <p>Labels: Sigmoid colon, T3 tumor, T4a tumor, Affected lymph nodes, Rectum, Anus, T4b tumor, Mucosa, Submucosa, Serosa, Muscularis propria.</p>	<p>Stages IVA, IVB, IVC</p> <p>Stage IVA: The tumor may be any size and in any location in the rectum, may have spread to regional lymph nodes and has spread to one organ or site.</p> <p>Stage IVB: The tumor may be any size and in any location in the rectum, may have spread to regional lymph nodes and has spread to two or more organs or sites.</p> <p>Stage IVC: The tumor may be any size and in any location in the rectum, may have spread to regional lymph nodes and has spread to the surface of the inner layer of the abdominal membrane alone or with other organs or sites.</p> <p>Labels: Sigmoid colon, T4b tumor, Mucosa, Submucosa, Serosa, Muscularis propria, Rectum, Anus, Affected lymph nodes.</p> <p>Metastasis</p> <p>Labels: Brain, Lung, Liver, Bone.</p>		

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Diagnosed with Stage IV colon cancer at just 33 years old, Jeremy Echols strives to keep a healthy mindset. He encourages others who are facing the disease to surround themselves with a solid support system.

Support and perspective guide this young cancer survivor

Consistent abdominal pain was my first symptom. A month later I started noticing blood in my stool, so right away I booked an appointment with a colorectal surgeon. I was 33 years old and in great physical condition. I practically lived at the gym, followed a strict meal plan, never smoked and was not a heavy drinker. We had no reason to believe it would be anything serious, but the surgeon scheduled a colonoscopy “to be sure.” I’m so grateful he did.

I had the colonoscopy, and the surgeon found a mass. He wasn’t sure what it was but said he’d know after results came back from the biopsy.

A week later I received a voicemail while I was at work. Typically I don’t listen to voicemails, especially at work, but for some reason I listened to this one. It was from a cancer center calling to schedule a new patient appointment. That’s how I found out I had cancer — through a voicemail. I found an empty conference room and just cried.

The first person I called was my Dad. He had been diagnosed with stomach cancer just three months before. He was my strength throughout the entire process.

I met with an oncologist who told me the cancer was Stage I and that my prognosis was really good. Fortunately for me, my wife is a pharmacist with knowledge and experience with cancer drugs. Having her with me to ask questions and eventually agree with the treatment plan made me comfortable. I also met with a cancer genetic counselor and had testing. Results came back negative for any gene that would predispose me to colon cancer.

I was scheduled for surgery the next month. They said that depending on how it went, I MIGHT have a few cautionary rounds of chemotherapy. I had a 7-hour laparoscopic procedure to remove a section of my colon. My hospital stay was four days followed by about six weeks of recovery.

During my recovery, I had a PET and expected to hear “you look great and don’t need chemo.” Unfortunately, my oncologist said the results showed evidence of disease in my liver and aorta. My diagnosis was upgraded to Stage IV, and I needed full chemotherapy.

That was the moment I just knew I was dying. My friend came with me to that appointment and he said, “God is going to take care of you.” I replayed those eight words continuously during treatment.

There is no special formula for chemotherapy. The physical side effects were rough, especially in the beginning. I actually thought I wouldn’t have any. I was wrong. One thing that helped was keeping a treatment journal. I wrote down what and when I ate and what time I started experiencing different side effects. That really helped me anticipate how future rounds of treatment would go. It got “better” as treatment progressed because I knew what was coming.

I became much more concerned about the mental battle I was facing. One of the first things I did after starting chemotherapy was schedule sessions with a therapist. I wanted to face everything head on and not bury my emotions.

After 12 rounds of chemotherapy, I received the news that my scans were “stable” and treatment would end. As great as that was to hear, it was also the same day that my Dad passed away.

I continue to have follow-ups every three months. I still get anxious but I have learned how to identify anxiety early and not let it spiral out of control. I also had genomic testing for the first time at my last follow-up and am awaiting the results.

One thing I wish I had known was how to redefine normal. I put a lot of pressure on myself to hurry back to my old self (even while I was still going through treatment) and that only led to disappointment. Be patient with yourself and take everything a day at a time. It took a while but I’m happy to be getting active again. The path will be challenging but I just keep putting one foot in front of the other.

It’s important to surround yourself with a strong support system. I had a couple of friends (as young as I am) who were diagnosed with breast cancer. They encouraged me when I needed it. It made me realize that sharing not only gave me an outlet, it helped others know they aren’t alone. That’s been my goal. I’ve been able to meet some awesome people and connect with great organizations like Fight Colorectal Cancer since I started sharing my story.

You will have good and bad days. It’s okay to be down at times, but try not to stay there. A healthy mindset is essential. I wouldn’t say I’m strong, but rather I keep a proper perspective. My faith and family are what help me with that. Be sure to find what helps you. ■



Learn about the types of treatments that may be available

Your doctor will create a **treatment plan** for you. It will be based on many factors: diagnostic test results, including imaging, bloodwork, genetic tests and biopsies; your age and general health; and tumor size and biomarkers. Each treatment type has risks and benefits; learning about them can help you decide which treatment may be appropriate for you. As you discuss the available options with your doctor, it is very important that you share your expectations.

Your primary treatment is administered with the goal of achieving No Evidence of Disease (NED) and preventing recurrence. It is sometimes referred to as standard of care, first line or second line. Standard of care refers to a guideline for the appropriate treatment of a condition. First-line therapy is the first treatment given. Second-line therapy is given when the first-line therapy doesn't work, is no longer effective or has side effects that are not tolerated.

In some cases, your treatment plan may also include neoadjuvant or adjuvant therapy. Neoadjuvant therapy is given before the main treatment, which is usually surgery, to help shrink a tumor, often in an effort to make it easier to remove surgically. Adjuvant therapy is given after that initial treatment to destroy any cancer cells that may remain or that may be too small for laboratory testing or imaging studies to detect. This follow-up treatment may decrease your risk of your cancer recurring (coming back).

Your treatment plan may include surgery, drug therapy (targeted therapy, chemotherapy or immunotherapy) or radiation therapy, or a combination of them.

You can also talk to your doctor about whether you may be a candidate for a clinical trial.

SURGERY

Surgery is the most common treatment for all stages of colorectal cancer. Depending on the tumor's size, stage and location, different procedures are used to remove the part of the colon or rectum containing the tumor and to reattach the ends. Nearby lymph nodes may also be removed (lymphadenectomy) to allow a pathologist to determine if the cancer has spread, and if so, how far.

Several different types of surgical procedures may be done. Open surgery involves operating through a large incision in the abdomen. Laparoscopic surgery allows the surgeon to operate through a few small incisions in the abdomen, guided by a laparoscope (a special lighted instrument with a tiny video camera attached). The smaller incisions typically result in shorter recovery time. In robotic-assisted laparoscopic surgery, a surgeon with specific training and

experience controls robotic arms that operate the surgical tools.

Your surgeon will try to preserve normal bowel function whenever possible. However, sometimes a different pathway for bowel function must be created. The surgeon attaches one end of the small intestine or colon to an opening created in the abdomen called a stoma. A pouch is attached to the stoma to collect waste. This procedure is called a colostomy, ileostomy or simply an ostomy, depending on the part of the intestine used to form the stoma.

Surgeries for colon cancers

Polypectomy removes a polyp, which is a growth that protrudes from the colon wall. This surgery is typically performed during a colonoscopy, which is the examination of the inside of the colon using a colonoscope that is inserted into the rectum.

A **local excision** may be used for very early-stage colon cancers. Instead of making an incision in the abdominal wall, a tube with a cutting tool is inserted through the rectum into the colon to remove the cancer.

A **resection** may be used to remove large tumors in the colon. This surgery may also include a colostomy or ileostomy depending on the location in the intestines.

Lymphadenectomy removes lymph nodes. For a regional lymphadenectomy, some of the lymph nodes in the tumor area are removed; for a radical lymphadenectomy, most or all of the lymph nodes are removed from the tumor area.

Colectomy surgically removes all or part of the colon. When only part of the colon is removed, it is called a partial colectomy, hemicolectomy or segmental resection. A partial colectomy will remove the tumor and a portion of healthy tissue around it. After part of the colon is removed, the doctor may perform an anastomosis, which is a procedure to connect healthy sections of the colon.

In an open colectomy, one long incision is made in the wall of the abdomen and doctors can see the colon directly. In a laparoscopic-assisted colectomy, several small incisions are made and a thin, lighted tube attached to a video camera is inserted through one opening to guide the surgery. Surgical instruments are inserted through the other openings to perform the surgery.

Ostomy is a surgery that creates a stoma, or opening in the abdomen, and connects the end of the colon or small intestine to the opening. An ostomy provides a new path for stool (body waste) to exit the body. The procedure is known as a colostomy when the colon is attached to the stoma and an ileostomy when the end of the small intestine is attached to the stoma (to bypass the entire colon).

An ostomy can be temporary or permanent. With a temporary ostomy, the intestine can be reconnected after healing. Having an ostomy can be a physically and emotionally challenging adjustment. Working with a trained ostomy nurse can help make the transition easier.

Surgeries for rectal cancers

Polypectomy removes a polyp, which is a growth that protrudes from the rectal wall. This surgery is typically performed during a colonoscopy, which is the examination of the inside of the colon.

A **local excision** may be used for cancers found on the inside surface of the rectum.

Resection may be performed for cancers that have spread to the rectal wall.

Proctectomy is surgery to remove all or part of the rectum.

A **coloanal anastomosis** may be performed to connect the colon to the anus so that stool passes normally.

Transanal surgery, also known as a transanal excision (TAE), may be used to treat small rectal cancers. This procedure removes the tumor through the anus and may involve the entire rectal wall and surrounding tissues. Other types of transrectal surgeries include transanal local excision and transanal endoscopic microsurgery, which remove tumors in the middle or upper rectum.

Transanal endoscopic microsurgery (TEM) is a minimally invasive surgery to remove early stage rectal cancers. This surgery requires special equipment and specially trained surgeons and is not offered in all cancer centers.

Transabdominal surgery involves making an incision in the abdomen to reach the cancerous tissue. It may be done as open surgery or minimally invasive surgery, which is only used under certain conditions.

Total mesorectal excision (TME) is a common surgery to remove tumors in the rectum along with lymph nodes and nearby fat.

Low anterior resection (LAR) removes tumors in the upper rectum and includes a TME. Part of the sigmoid colon may also be removed.

Abdominoperineal resection (APR) removes tumors in the lower part of the rectum that may have grown into the anus or nearby muscle. It includes an incision into the perineum, which is the skin between your anus and genitals.

Pelvic exenteration is surgery to remove the lower colon, rectum and bladder, and create stomata (openings) through which urine and stool are passed out of the body. In women, the cervix, vagina, ovaries and nearby lymph nodes are also removed.

DRUG THERAPIES

These treatments involve drugs that may be given orally or intravenously (IV) through a vein in your arm or a port. They are systemic therapies that travel throughout your body.

Chemotherapy may include two or more drugs

that are used alone or combined with other therapies. Chemotherapy can be given before surgery (neoadjuvant) to shrink a tumor for easier removal and/or after surgery (adjuvant) to kill any remaining cancer cells. It may also be given for metastatic disease.

Hepatic arterial infusion (HAI) may be used when colon or rectal cancer has spread to the liver. It is chemotherapy delivered directly into the liver through its main blood vessel, the hepatic artery.

Targeted therapy drugs can help slow the growth and progression of cancer by interfering with specific molecules involved in tumor growth and progression. These agents interact with or modify the molecules on or inside cancer cells that alter signaling pathways, which are complex systems that direct basic

CARING FOR AN OSTOMY

An ostomy is a surgical procedure to create an opening (a stoma) from an area inside the body to the outside. Some people with colorectal cancer may have a colostomy or ileostomy as a way to eliminate waste depending on the part of the intestine that is involved.

A stoma may be temporary or permanent. It will need to be cared for to prevent infection, and you will need to learn how to change the pouch. Follow all the instructions provided by your health care team for caring for an ostomy. They may recommend the following.

Cleaning

To clean the skin around your stoma, water is recommended. Soap will not hurt the stoma, but you must rinse the area around it well. Before putting on the skin barrier or pouch, dry your skin completely. Cleaning around the stoma may cause some bleeding but it should stop quickly. If it doesn't, call your ostomy nurse or doctor.

Allergies and sensitivities

It is possible to become allergic or sensitive to the adhesive, skin barrier, tape or pouch material at any time or even weeks, months or years after using it. Consult with an ostomy nurse if you have allergic symptoms.

Colostomy irrigation

This is only used for descending and sigmoid colostomies to help move stool through the colon. It is not used as often now that pouch systems have improved. Ask your doctor or ostomy nurse if irrigation is right for you.

Emptying and changing the pouch

Before you leave the hospital, you will be shown how to empty and change the pouch. It is recommended to empty the pouch when it reaches a third to half full to prevent leaking. Having a regular

changing schedule may be helpful. The pouch will need to stick to your skin, and the length of time it stays may depend on the weather, skin condition, weight changes, activity and the type of waste. Because the pouch needs to seal to the skin, you may need to shave the area around the stoma. Rinse well, and let the skin dry before applying the pouch.

Common challenges

- Gas can be a problem right after surgery or because of certain foods. Eat regular, smaller meals, and don't skip meals. Odor-resistant pouches are available. Medicines may also help, so ask your doctor or ostomy nurse.
- Some medicine capsules may come out into the pouch. This may indicate you didn't receive an adequate dose of the medicine. Call your doctor or pharmacist to see if a liquid medication that is easier to digest may be available.
- If large areas of skin become red and sore, you will not have a good seal around the stoma. If the irritation gets worse, call your doctor.
- There may be times when there is little to no output. If you develop cramps, pain and/or nausea and your stoma has not been active for four to six hours, contact your doctor right away.
- Diarrhea is an indication that something isn't right. It occurs when food moves too quickly through the small intestine for fluids to be absorbed. As a result, fluid and electrolytes may need to be replaced to avoid other problems. It may also be caused by eating certain foods, emotional stress, an intestinal infection or food poisoning, antibiotics or a partial blockage.
- Dehydration could be a serious problem. It can cause an electrolyte imbalance. Make sure you are drinking enough fluids.
- Phantom rectum can occur after rectal surgery. Your brain may treat your surgical site as if the rectum were still present. This is similar to the feeling of having a limb after the limb is removed. This can be temporary or can linger for a long time. Some people who have experienced it say sitting on the toilet helps.
- Short bowel syndrome may occur when a large portion of the small intestine is removed. There may not be enough intestine to absorb nutrients and you will need to be under medical supervision.



“I recommend you have an ostomy nurse walk you through the experience and guide you in finding the right supplies for you.”

Marra Lashbrook Rodriguez

cell functions, such as cell division and death.

Some targeted therapy drugs are oral medications, and some may be given in combination with other drug therapies.

To determine if certain targeted therapy treatments are appropriate for you, testing is performed on a biopsy sample of tissue. A pathologist will examine the tissue under a microscope and perform genomic tests to determine if mutations are present in the tumor (see *Genomic and Genetic Testing*, page 4). These include *BRAF* (pronounced BEE-raff) and *RAS* (pronounced Rass), which includes (*NRAS* [pronounced EN-rass] and *KRAS* [pronounced KAY-rass]). Tumors that do not have a *RAS* or *BRAF* mutation may also be tested for *HER2* expression.

Monoclonal antibody therapies block the activity of epidermal growth factor receptor (*EGFR*) or vascular endothelial growth factor (*VEGF*, pronounced vej-EFF) receptor. *VEGF* is a protein that is essential for creating blood vessels.

The growth of new blood vessels is a process called angiogenesis. When an angiogenesis inhibitor is administered, there may be less vessel formation to supply blood and the tumor eventually “starves” and dies. Angiogenesis inhibitors are often given in combination with chemotherapy.

Targeted therapies approved to treat colorectal cancer either reduce *VEGF* activity, target the neurotrophic tyrosine receptor kinase (*NTRK*, pronounced EN-track) gene fusion, inhibit mutant *BRAF* activity or block *EGFR*. Before recommending an *EGFR* inhibitor, your doctor should test your tumor for *RAS* gene mutations that may prevent the drug from working.

A kinase inhibitor is a substance that targets a type of enzyme called a kinase. Kinase inhibitors may slow the growth and progression of tumors.

Immunotherapy uses the immune system to attack cancer. The types of immunotherapy approved for colorectal cancer are immune checkpoint inhibitors, which work by blocking specific proteins and receptors that can trigger an immune system slowdown. This allows the immune system to continue fighting the cancer.

Some immunotherapy drugs can be used for certain children and adults who have microsatellite instability-high (MSI-H) or mismatch repair deficient (dMMR) colorectal tumors as tested by a pathologist (see *Genomic and Genetic Testing*, page 4).

RADIATION THERAPY

Radiation therapy uses high-energy particles or waves, such as X-rays, electron beams or protons, to kill cells, including cancer cells, and help shrink tumors. It may also be used to manage symptoms from specific areas of cancer involvement, such as bone or brain metastases. This is typically called palliative radiation therapy.

External-beam radiation therapy (EBRT) is the most common form of radiation therapy given for colorectal cancer. It is similar to a conventional X-ray, except the radiation beams are strong enough to kill cells, including cancer cells.

Stereotactic radiation therapy is a type of EBRT that uses special equipment to position the patient and more precisely deliver radiation to a tumor. The total dose of radiation is often divided into smaller doses given over several days or more.

3D-conformal radiation therapy (3D-CRT) delivers radiation at different angles directly to the tumor.

Intraoperative radiation therapy is aimed directly at a tumor during surgery.

Brachytherapy is internal radiation therapy. This type of therapy involves the placement of radioactive “seeds” through a catheter inserted near the tumor to deliver radiation directly to the area where the tumor was removed.

Chemoradiation is often used for rectal cancer before surgery. It combines chemotherapy with radiation therapy and is also known as chemoradiotherapy.

OTHER THERAPIES

Radiofrequency ablation (RFA), **microwave ablation** (MWA) or **cryoablation** may be used to treat colorectal cancer that has spread to the liver. RFA uses radiofrequency waves to heat the tumor; MWA uses microwave energy to heat the tumor; and cryoablation freezes the tumor.

CLINICAL TRIALS

Depending on your type of cancer and open clinical trials, one may be an option for you. Ask your doctor if a clinical trial is right for you. ■

▲ RECTAL CANCER SURVIVOR PERSPECTIVE

Introvert to advocate



Marra Lashbrook Rodriguez

➔ Unexpected rectal bleeding prompted Marra Lashbrook Rodriguez to get a colonoscopy. To her surprise, the results showed she had Stage IIIB rectal cancer at only 39 years old.

Her first reaction was devastation. With sons ages 5 and 7, she was fearful of them growing up without their mother.

She was considered fairly young to be diagnosed with rectal cancer so her oncologist did genetic testing and ruled out genetics as the cause.

She had chemotherapy and radiation therapy, and surgery to remove her rectum and colon as well as create a temporary ileostomy.

She learned to advocate for herself, seeking multiple opinions and finding the right care team for her. She asked her doctors about specifics such as biomarkers, treatment options and where to learn more. In this quest for information, she found Fight Colorectal Cancer and read all of their educational resources.

Marra is not afraid of the cancer returning, but she is realistic and vigilant about the possibility of recurrence or secondary cancers. She pays attention to her body and monitors it accordingly. She faces the reality of recurrence with education, faith and hope. She offers that same hope to others fighting this disease as an ambassador for Fight Colorectal Cancer.

She helps patients find joy in the darkest hours, just like she did. She encourages them to find milestones, small wins and reasons to celebrate.

Marra was previously introverted but is now outspoken. She works to bring awareness to the public, sharing her perspective with lawmakers for policy changes and getting resources into the hands of patients.

Through her faith and the support of her husband and two sons, she is living life to the fullest. ■

Plan with your doctor for physical and emotional side effects

Many parts of a colorectal cancer diagnosis and treatment can feel overwhelming. Support for physical and emotional challenges is available from your multidisciplinary team and through a wide range of services known as supportive care. This set of services can help with some of the physical, emotional as well as the practical, spiritual, financial and family-related challenges you may experience.

A primary focus is to help you recognize and understand side effects from the time you are diagnosed through treatment and survivorship.

Also called palliative care, supportive care services are often confused with hospice care. These services can benefit anyone with a serious or life-threatening illness. It is available at any time, whereas hospice care is reserved for end-of-life care.

Supportive care services are often financially covered by individual insurance plans, Medicare or Medicaid. To learn more, you can talk with the hospital's social worker, financial counselor or your health insurance representative.

Recognizing the following symptoms and side effects is important. Talk to your health care team with any questions.

POTENTIALLY SEVERE PHYSICAL SIDE EFFECTS

Severe side effects can occur with treatment. Ask your doctor whether you are at risk, how to identify the symptoms and when to seek emergency care. Report symptoms to your health care team immediately if they occur.

Though not a complete list, possible severe side effects include the following:

- **Cytokine release syndrome** can occur if immune cells affected by treatment rapidly release large amounts of cytokines into the bloodstream. Cytokines are a type of protein made by certain immune and non-immune cells that can stimulate or slow down the immune system. Symptoms may include headache, fever, nausea, rash, low blood pressure, rapid heartbeat and difficulty breathing.
- **Immune-related adverse events** (irAEs) may occur with certain drugs. They can occur if the immune system becomes overstimulated by treatment and causes inflam-

mation in one or more organs or systems in the body. Some irAEs can develop rapidly, becoming severe and even life-threatening without swift medical attention. Before beginning immunotherapy, talk with your doctor about your risk for irAEs and learn the symptoms.

- **Infection** can occur as a result of a low white blood cell count (neutropenia) or other factors.

Contact your doctor immediately – do not wait until the next day – if you have any of these symptoms: oral temperature over 100.4°F, chills or sweating; body aches, chills and fatigue with or without fever; coughing, shortness of breath or painful breathing; abdominal pain; sore throat; mouth sores; painful, swollen or reddened skin; pain or burning during urination; pain or sores around the anus; or vaginal discharge or itching.

- **Infusion-related reactions** most frequently occur with treatment given intravenously (IV) through a vein in your arm, usually soon after exposure to the drug. Reactions are generally mild, such as itching, rash or fever. Ask your doctor about more serious symptoms to watch for.

COMMON PHYSICAL SIDE EFFECTS

Though most cancer treatments do have side effects, keep in mind that you may not experience all of them. Every person responds differently, even to the same type of treatment.

There are varying degrees of side effects. It is critical that you and your doctor discuss ahead of time what you should watch for and what to do if any occur (see sidebar, opposite page).

LATE EFFECTS

Be alert for side effects that may develop long after treatment ends. These are known as “late effects.” Late effects and other medical conditions can develop months or years after treatment has ended and should be discussed with your doctor.

EMOTIONAL SIDE EFFECTS

Cancer can affect you emotionally as well as physically. It's common to experience anger, fear, guilt, insecurity, loneliness and other emotions. Taking care of your well-being may help you better cope with cancer-related issues, including physical side effects. Supportive care services can connect you with resources to manage these feelings.

It is also important to recognize the effect that physical changes from treatment can have on your self-esteem and body image. Treatments may leave scars, discoloration of the skin, hair loss, lymphedema and other conditions. An ostomy may add other challenges. These can affect your mood, self-image and sense of desirability. All of these feelings are completely normal, and it is important to address them.

Support is available through a number of sources, from online and in-person support groups to counselors, psychologists, psychiatrists and other specialists. Contact your doctor about excessive crying or continued feelings of hopelessness or despair. Get immediate medical attention for thoughts of suicide or death.

WHAT OTHER TYPES OF SUPPORT ARE AVAILABLE?

Ask your health care team how to access these important services.

Social support is available in many forms. One-on-one buddy programs can pair you with another person who has the same type of cancer as you. Talking with someone who has gone through a similar experience can be extremely helpful. In addition, telephone and email cancer helplines, advocacy groups, national organizations and wish-fulfillment organizations are available.

HAND WASHING FOR PATIENT SAFETY

1 Wet your hands

2 Soap

3 Lather and scrub **20 sec**

4 Rinse **10 sec**

5 Dry your hands

6 Turn off tap

Don't forget to wash

- Between your fingers
- Under your nails
- The tops of your hands

→ For a printable copy, go to: PatientResource.com/HandWashing.aspx

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Some common physical side effects of colorectal cancer treatment

Contact your doctor if you experience any side effects.

Abdominal pain: typically occurs in the stomach and may include cramping and aches, which can range from dull to severe and debilitating

Anemia: abnormally low red blood cell count

Bleeding problems (hemorrhages) and bruising: If you experience any of these symptoms, contact your doctor immediately: blood in your stools or black stools (looks like tar); pink or brown urine; unexpected bleeding or severe bleeding that you cannot control; vomit that looks like coffee grounds; coughing up blood or blood clots; increased bruising, dizziness, weakness or confusion; changes in speech; or a headache that lasts a long time.

Chemo brain (cognitive dysfunction): brain fog, confusion and/or memory problems

Constipation: difficulty passing stools or less frequent bowel movements compared to your usual bowel habits

Diarrhea: frequent loose or watery bowel movements that are commonly an inconvenience but can become serious if left untreated

Fatigue: tiredness that is much stronger and harder to relieve than the fatigue an otherwise healthy person feels

Hair loss (alopecia): hair loss on the head, face and body

Hand-foot syndrome: also known as Palmar-Plantar Erythrodysesthesia. It is characterized by pain, swelling, tightness and redness on the palms of the hands or the soles of the feet. It can also cause painful blisters or calluses.

Infertility: the inability to become or stay pregnant or to father a child

Lymphedema: fluid buildup from lymph node removal that causes swelling

Mouth sores: small cuts or ulcers that can affect the gums, tongue, roof of the mouth or lips; may be caused by chemotherapy

Nausea and vomiting: a feeling of sickness with an inclination to vomit

Neuropathy: numbness, pain, burning sensations and tingling, usually in the hands or feet at first

Neutropenia: low white blood cell count that increases the risk of infection

Sexuality issues: reduced desire or feeling less desirable

Skin reactions: rash, redness and irritation or dry, flaky or peeling skin that may itch

Thrombocytopenia: low number of platelets in the blood, which can lead to bruising, bleeding and clotting problems

Mental support may include exercise, counseling, meditation and medication as appropriate. Don't hesitate to ask your doctor about ways to improve your mental health.

Spiritual support is available from a spiritual care advisor at your treatment center or from your religious community. Many hospitals offer a chaplain who is trained to talk about spiritual concerns such as life and death, regardless of your faith. A spiritual advisor can help you find meaning in life and create legacy plans, and will also work with your social worker to help you with practical, social and emotional issues. Spiritual support is available to you even if you do not consider yourself a religious person.

Financial support is available from a social worker or financial counselor. The stress and anxiety of paying for treatment and other related expenses can negatively affect your well-being. Expenses may include traveling for treatment, daycare and medications. They can also help you apply for medical leave or disability payments if you are unable to work for a period of time.

Ostomy support is available for people who've had a colostomy or an ileostomy. Your doctor, a nurse or an enterostomal therapist who specializes in colostomy management will help teach you how to care for, clean and maintain an ostomy. You may consider reaching out to an ostomy support group that includes people who live with ostomies because they can offer first-hand experience.



Rehabilitation support is most often given after cancer treatment, but it can also be given before. When it's given before treatment, the rehabilitation team can help you build strength so your body is better prepared to handle treatment.

After cancer treatment, the rehabilitation team will teach you exercises that will help your body recover from surgery or improve the function of muscles and tissues damaged by radiation treatment or drug therapy. These exercises may cause some discomfort in the beginning, but over time, your body will become stronger and this discomfort may lessen. Gaining muscle strength can also help control other cancer-related pain.

Dietary support may be necessary after colorectal cancer treatment. Your dietary needs

may change and certain foods may be recommended or avoided (see *Nutrition*, page 14). A dietitian can work with you and your caregiver to develop a nutrition plan for you. Your dietitian may also function as a liaison between you and your medical team, helping to relay or explain information, and serve as an advocate for you. Ideally, you will meet with one very soon after diagnosis.

In some cases you may need enteral (EN-teh-rul) nutrition, also called tube feeding. This may be your single source of nutrients, or it may be used to add them until you can eat enough by mouth. It may be a temporary or permanent solution. A tube may be placed through the abdomen and into the stomach or intestine to deliver a liquid mixture. It can be given as several "meals" throughout the day (also called bolus feeding), or a specific amount can be delivered over a certain amount of time through the use of a special pump. In the hospital, your health care team will manage this for you. If you need to continue (or begin) this type of feeding at home, you will be trained on the process. ■

[KEY TAKEAWAYS]

- ▶ Supportive care services provide help for physical, emotional, practical, spiritual, financial and family-related challenges associated with a cancer diagnosis.
- ▶ Ask your doctor about potential side effects and what to do if you develop them.
- ▶ Many forms of support are available to assist you.

Learn about clinical trials and how to find them

As medical and scientific teams continue to learn more about how colorectal cancer begins and spreads, they continue to test potential treatments by conducting clinical trials. Advances made as a result of these research studies can bring more hope to people whose lives are affected by colorectal cancer.

Clinical trials evaluate new methods for cancer care. Many research studies are underway for all stages of colorectal cancer. Some are identifying drug therapies to treat genetic mutations. Others are focused on better screening methods for prevention and early detection. Still others are evaluating the benefits of certain drug therapies used alone, in combination with other therapies or in a different order.

Receiving your cancer treatment through a clinical trial may offer the following:

- Access to cancer treatment that is not available outside a clinical trial.
- Monitoring by the clinical trial's medical team in addition to your regular doctor.

- A role in advancing cancer research for future patients.

Clinical trials are carefully planned, structured and highly regulated for the safety of all participants. Cancer treatments, including those being tested in clinical trials, presents potential risks and side effects. They may require more tests and/or medical appointments than you would ordinarily have scheduled. Ask in advance to make sure you'll be able to rearrange your schedule of work, school, family commitments and other obligations to accommodate the appointments required to meet the trial's protocol.

As you and your doctor discuss the potential treatment option of a clinical trial, keep in mind that ongoing clinical trials take place in a variety of locations. It takes research to find clinical trials, and that's where you come in. While your health care team is exploring potential trials, you can look for them, too. Start by educating yourself about clinical trials using trusted resources such as this guide. Then, from the comfort of your home, look for clinical trials you may qualify for using online clinical trial search sites (see below).

Navigating some search sites can be confusing. To help prepare you, we've created mock screens below to show you what you may see as you look for a trial that may apply to you.

When you find a clinical trial that you may qualify for, print out the information and talk with your doctor about it. ■

» HOW TO SEARCH FOR A CLINICAL TRIAL

► Before you begin, have your exact diagnosis, pathology report and details of your previous cancer treatments on hand to help determine if you meet the basic eligibility criteria. Then, start by using the list of clinical trial sites below. Your doctor may recommend additional sites.

[STEP 1] FILL IN YOUR INFORMATION

Enter Your Diagnosis

For example, enter "colorectal cancer." To further customize the search, select applicable eligibility criteria, such as age and gender, on the results screen.

Desired Location

If you prefer a clinical trial close to home, enter your home address. Enter additional locations if you're willing and able to travel for treatment.



Other Terms

You can refine your search even more by adding a particular treatment type or genomic mutation. You can also add a National Clinical Trial identifier, which is a unique eight-digit code preceded by "NCT" that is assigned to each trial.

[STEP 2] READ YOUR SEARCH RESULTS

Recruitment Status

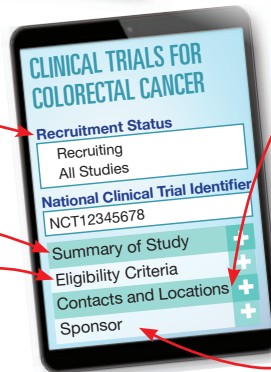
This indicates whether the trial is actively seeking patients, not yet recruiting or otherwise inactive. The status will change, so check often for updates.

Summary of Study

Here you'll find details about the purpose of the clinical trial and the treatment being studied. This section is usually written for health care providers, so it may be difficult to interpret. In that case, print out the information to discuss with your doctor.

Eligibility Criteria

This outlines the criteria you must meet to be eligible for the trial, such as the stage of disease, sites of metastasis, overall health requirements and previous treatments. Discuss any questions you may have about qualifying for clinical trials.



Contacts and Locations

This may contain contact information for the clinical trial investigators, staff or sponsors, who may be able to provide more details about the study.

Sponsor

This is the entity responsible for the clinical trial. It may be a pharmaceutical or biotechnology company, a university, the National Cancer Institute or others.

Planning and organizing may help you manage cancer-related costs

When you find out you have cancer, you first need to spend your energy on learning about your disease and working with your doctor to make a disease management plan. However, you may also find yourself quickly worrying about costs. The financial aspect of cancer can have a huge impact on your overall health, happiness and well-being, and feeling confident about your finances can help you tackle your treatment wholeheartedly.

The cancer-related expenses you incur can vary, depending on your diagnosis, recommended treatment plan, follow-up care and level of insurance coverage. Understanding your insurance, planning a budget and seeking financial assistance may help you take control of your financial situation right from the start.

TYPES OF CANCER-RELATED COSTS

Cancer-related costs can be grouped into two types of expenses: medical and lifestyle. The medical expenses, including medical office visits, tests, treatments, drugs and caregiving, are the most obvious additions to your spending.

Less obvious are the increases in your routine living expenses because of new, cancer-related costs. After a cancer diagnosis, you may spend more money on transportation and travel, legal help and financial services. You may also need to hire help for child or elder care, meal preparation or housecleaning. These additional expenses are a heavy burden on their own but are even more substantial when combined with the possibility that your income may be reduced if you

and/or your significant other are unable to work the same number of hours during your treatment.

Unfortunately, your cancer-related costs won't end when treatment does. You will need to budget for follow-up care, frequent screenings and checkups. You might have to adjust to a permanently reduced income if you aren't able to return to your regular work hours.

TALK TO YOUR HEALTH CARE TEAM

The costs can add up quickly, so it's vital to talk to the members of your health care team about the cost of your cancer care. They understand that treatment can be expensive and may create financial hardship, so don't be embarrassed to bring it up.

Many people are hesitant to ask about cutting costs because they fear their treatment will suffer. However, depending on your specific insurance coverage and treatment plan, your doctor may be able to prescribe alternative treatment options that are better covered by your insurance and also work for your type of cancer.



SEEK FINANCIAL ASSISTANCE

Before you become totally overwhelmed, know that there are hundreds of resources that provide financial assistance in a variety of categories, including child care, personal items (wigs, ostomy supplies, etc.), counseling services, legal help, wish fulfillment and transportation.

Social workers, advocates, financial counselors and patient navigators at your medical facility can refer you to organizations that can help, and many advocacy groups and other nonprofit organizations will also point you toward sources of financial assistance. Depending on your situation, federal laws may offer benefits, protect you from the loss of health insurance and guard against discrimination on the basis of your health. And don't forget your family and friends. They can help you search for financial assistance and offer advice about what could be most helpful for you. ■

10 HELPFUL STEPS

1 Review your income and expenses. Gather your current bills and check stubs to gain a better understanding of how much money you currently have coming in and going out. Next, review your health insurance policy to determine your deductibles, co-payments and covered services, and then use that information to help estimate your out-of-pocket medical expenses. Finally, list any savings or other assets (life insurance plan, property, investments) that you can use to get cash if you need to, and talk to your family about ways you can all cut back on expenses.

2 Complete a budget worksheet. List your income and expenses (some of which will be estimates) on a budget worksheet. Complete a new worksheet each month to track your finances and become better prepared for your expenses.

Download a budget worksheet template at PatientResource.com/budget.aspx

3 Talk to your health care team. Most medical facilities have social workers, financial counselors and patient navigators who can help you with financial issues. Special payment arrangements may be possible.

4 Get the most out of your insurance. File claims for reimbursement immediately and review any denials. Always review your policy, ask for help from your doctor's office and talk to them about whether an appeal is appropriate.

5 Find ways to reduce the cost of drugs. Look for a pharmacy in your area that offers low prices on generic drugs. Your anti-cancer drugs may not be included in low-cost lists, but other drugs, such as those prescribed to help you manage side effects, are sometimes available in a generic form. Also, check to see if the manufacturer of your anti-cancer drug has a financial assistance program. If you have Medicare coverage with a Part D prescription drug plan, see if another Part D plan covers more of your cancer-related drugs. Finally, find out if your insurance offers a mail-order prescription program, as the cost may be lower than getting drugs from a local pharmacy.

6 Search for financial assistance. Many national and local advocacy groups and other nonprofit organizations can help you find financial assistance. See page 16 for some resources you can start with.

7 Learn about possible benefits and protections. Review federal laws, including COBRA, FMLA and HIPAA, to see if you are eligible for any benefits and/or protections related to your health care and employment. A social worker can assist, and several organizations can help you determine whether these laws apply to you.

8 Tell creditors about your situation. If your budget shows that your expenses exceed your income, get in front of the problem by talking to your creditors. It may be possible to negotiate payments. A nonprofit credit counseling service may also be able to help you work with your creditors. Communicate as needed.

9 Take care of estate planning. Give yourself peace of mind and a sense of security by preparing and documenting a plan of how to divide your property before and after death.

10 Keep your paperwork organized. Being organized is integral to handling financial matters. Set up a system early, and stay organized so you never have to scramble for a document.

Understanding the role of nutrition

Colorectal cancer – as well as its treatments and side effects – may make it harder to get all the nutrients your body needs. Your body may not digest food the way it normally does, or mouth sores may make eating uncomfortable. Talk with your doctor about your nutritional goals and how best to achieve them.

IF YOU'VE HAD SURGERY

While you are recovering, your medical team will provide guidance about what to eat and what to avoid. Their suggestions may include:

- Drink clear liquids such as tea, water, popsicles, broth and juice without pulp.
- Move gradually to other types of liquids.
- Avoid high-fiber foods.
- Avoid fried foods, tough meats, sausage or hot dogs.
- Introduce foods one at a time in small portions. Wait 1 to 2 hours to see how your body responds before trying more.

Your medical team will tell you what foods could be appropriate for you. If you have an ostomy, your registered dietitian can help you manage your diet. A key thing to remember is to chew your food thoroughly.



“Focusing on wellness for myself and others is my passion – one part is teaching a free “Yoga for Cancer Survivors” class.”

Jean diCarlo Wagner, colon cancer survivor

TREATMENT AND NUTRITION

Some symptoms from colorectal cancer and its treatment can be impacted by nutrition. For example, drinking plenty of water may ease dry mouth and replace lost fluids from diarrhea.

Mouth, tongue or throat soreness may occur if you have chemotherapy, which can make it harder to eat, drink and swallow. Blend or cut

food into smaller pieces. Cook food until it is tender. Talk to your doctor about softer, blander foods such as clear soups and broths.

If you're having trouble swallowing, try the following:

- Suck on ice chips.
- Drink liquids with your meals.
- Sip cool drinks between meals.
- Use a straw.

Avoid hot foods or those that make mouth sores worse, such as:

- Salty, spicy or acidic foods such as tomatoes and citrus fruits
- Carbonated or caffeinated drinks
- Alcohol

Appetite loss can occur during and after cancer treatment. Talk to your doctor about the most appropriate ways to maintain a healthy weight.

What if you lose too much weight or have trouble meeting all your nutritional needs with food? In that case, your doctor may decide that tube feedings through your esophagus or abdomen (enteral nutrition) can supplement or replace eating. If you can't accept food by mouth, need bowel rest or are not absorbing nutrients well, intravenous (IV) feeding can also help.

EATING TO STAY HEALTHIER

What you put into your body may play a role in your energy level and your overall health. Talk to your doctor about your specific needs. You could consider talking to your doctor about:

- Eating a variety of colorful fruits and vegetables.
- Microwaving or steaming vegetables when cooking to preserve the most nutrients.
- Washing all fruits and vegetables well.
- Limiting your intake of red meat and processed meat.
- Avoiding saturated fats and fried foods.
- Limiting alcohol.
- Doing your best to maintain a healthy weight. ■

KEY TAKEAWAYS

- ▶ Learn how to choose and prepare appropriate foods.
- ▶ Do your best to maintain a healthy weight — not overweight or underweight.
- ▶ Eat to maintain your energy, maximize nutrition and stay healthy overall.



Follow-up planning can help you move forward confidently

For those who have moved past active treatment, it is important to continue to be proactive about your health, including making and keeping regular follow-up appointments. Regular monitoring will help your doctor detect warning signs of a recurrence or a second cancer so early treatment is possible. These appointments also give you the opportunity to keep the lines of communication with your doctor open.



Your doctor or nurse will work with you to develop a customized follow-up care plan that may include the following:

- Follow-up appointment schedule for ongoing monitoring.
- Ongoing medications or therapies, including type, dosage, frequency and duration.
- Referral(s) for cancer rehabilitation services, such as physical or occupational therapy, a lymphedema specialist or others.
- Information about your risk of a recurrence, a second cancer, long-term treatment-related side effects and late effects.
- Recommended screening guidelines for other types of cancer.
- What you can do to stay healthy.

FOLLOW-UP DOCTOR APPOINTMENTS

After treatment is complete, you may still see your doctors for follow-up care. How often you see your doctor depends, in part, on the stage of your cancer and its chance of coming back. It also depends on your overall health.

Regular visits are important. Your doctor can take a history, conduct exams and tests, care for any chronic medical conditions, check for signs or symptoms of recurrence and help you better manage any side effects. Continue to keep copies of your medical records. That is especially helpful if you see a new doctor.

Follow-up is most important the first 5 years after treatment. That is when cancer is most likely to return.

If you have no signs of cancer, your doctor may suggest a physical exam and certain tests every 3 to 6 months for 2 years after treatment. Then, your appointments may change to every 6 months or so for the next few years. If you had an early-stage cancer, follow-up may be less frequent. If your cancer has spread (metastasized) or you are diagnosed with hereditary colorectal cancer, talk to your doctor about the plan for follow-up.

ONGOING MONITORING: TESTS YOU MAY NEED

Testing after treatment varies, but your doctor may recommend the following:

- A **colonoscopy** about 1 year after surgery and 3 years later if results are normal. Depending upon your test results, future exams will be less or more frequent but should typically occur every 5 years if normal.
- **Proctoscopy** every 3 to 6 months for 2 years, and then every 6 months for a few years, if a surgeon removed rectal cancer through your anus.
- **Imaging tests** such as a CT scan every 6 months to a year if you are at high risk for cancer recurrence. If you had tumors in your liver or lungs, you may receive scans more often.
- **Blood tests** about every 3 to 6 months for 2 years and then every 6 months for a few years. These tests check for substances called biomarkers, which may show up in your blood if you've had colorectal cancer. If levels go down with treatment and then go back up after treatment, this may be a sign that cancer has returned.

Guidelines may change if studies show that testing is needed less or more often, and your situation may impact what your doctor recommends.

Colorectal cancer can run in families. Consider talking to family members about getting genetic testing to see if they are at higher risk (see *Genomic and Genetic Testing*, page 4).

LATE EFFECTS

After treatment, some side effects go away. In

some cases, though, you may have side effects that last a long time or that show up much later. These are called late effects. Discuss any side effects with your health care team. Some of these side effects may include:

- Chronic diarrhea
- The need to go to the bathroom often
- Trouble holding your stool
- Urinary symptoms
- Numbness or tingling in fingers or toes (neuropathy) from chemotherapy

HEALTH, WELLNESS AND LIFESTYLE RECOMMENDATIONS

Talk to your health care team about steps you can take to help you stay healthy.

- Do your best to maintain a healthy weight.
- Get regular physical activity. Even a short daily walk can energize you and offer multiple health benefits. Physical activity is also a great way to reduce stress, which is important to your overall health. Before you begin any new exercise program, discuss it with your doctor.
- Talk to your doctor about eating a balanced diet. Aim for a diet rich in vegetables, fruit, lean meat and fish. Avoid refined sugars, fats and red or processed meats (see *Nutrition*, page 14).
- Ask your doctor or dietitian about supplements you may need.
- Avoid alcohol, which is linked to an increased risk of colorectal cancer, especially in men.
- If you smoke, quit. Research shows that smokers are more likely to have a worse prognosis than non-smokers.

Pay attention to how you're feeling mentally and emotionally, and know that support is available — whether from family and friends or more formal support groups and professional counseling. Don't forget to bring up emotional issues with your doctor, too. ■

[KEY TAKEAWAYS]

- ▶ **Discuss your ongoing care plan with your doctor to understand what lies ahead.**
- ▶ **Regular monitoring will help your doctor detect warning signs of a recurrence or a second cancer so early treatment is possible. Take steps to stay as healthy as you can — both physically and mentally.**

Support available for you

CANCER EDUCATION

Centers for Disease Control and Prevention (CDC)..... www.cdc.gov
 National Cancer Institute..... www.cancer.gov
 U.S. National Library of Medicine www.nlm.nih.gov

CLINICAL TRIALS

ClinicalTrials.gov www.clinicaltrials.gov
 Fight Colorectal Cancer..... http://trialfinder.fightcrrc.org
 National Cancer Institute..... www.cancer.gov/clinicaltrials
 NCI Contact Center (cancer information service) 800-422-6237

GOVERNMENT ASSISTANCE

Benefits.gov www.benefits.gov
 Centers for Medicare & Medicaid Services www.cms.gov
 Hill-Burton Program..... www.hrsa.gov/get-health-care/affordable/hill-burton, 800-638-0742
 InsureKidsNow.gov www.insurekidsnow.gov, 877-543-7669
 Legal Services Corporation www.lsc.gov, 202-295-1500
 Medicare www.medicare.gov
 Social Security Administration www.ssa.gov, 800-772-1213
 U.S. Department of Veterans Affairs www.va.gov/health

MENTAL HEALTH SERVICES

American Psychosocial Oncology Society Helpline 866-276-7443

REIMBURSEMENT & PATIENT ASSISTANCE PROGRAMS

myAbbVie Assist www.abbviepaf.org, 800-222-6885
 Amgen Assist 360 amgenassist360.com/patient, 888-427-7478
 Amgen Safety Net Foundation..... amgensafetynetfoundation.com
 Astellas Pharma Support Solutions ... astellaspharmassupportsolutions.com/patient, 800-477-6472
 AstraZeneca Access 360..... myaccess360.com/patient, 844-275-2360
 AstraZeneca Patient Savings Programs For Specialty Products astrazenecaspecialtysavings.com, 844-275-2360
 AstraZeneca Prescription Savings Program (AZ&ME)..... azandmeapp.com, 800-292-6363
 Bausch Health Patient Assistance Program bauschhealthpap.com, 833-862-8727
 Bayer US Patient Assistance Foundation patientassistance.bayer.us, 866-228-7723

BI Cares Patient Assistance Program www.boehringer-ingenheim.us/our-responsibility/patient-assistance-program, 800-556-8317
 Bristol-Myers Squibb bms.com/patient-and-caregivers/get-help-paying-for-your-medicines, 800-721-8909
 Bristol-Myers Squibb Access Support bmsaccesssupport.bmscustomerconnect.com/patient, 800-861-0048
 Bristol-Myers Squibb Patient Assistance Foundation bmspaf.org, 800-736-0003
 Celgene Patient Support www.celgenepatientsupport.com, 800-931-8691, ext 4082
 Genentech gene.com/patients/financial-support
 Genentech Access Solutions genentech-access.com/patient, 877-436-3683
 Genentech BioOncology Co-pay Assistance Program copayassistancenow.com, 855-692-6729
 Genentech Patient Foundation..... gene.com/patients/patient-foundation, 888-941-3331
 GSK For You..... www.gskforyou.com, 888-825-5249
 Helsinn Cares..... helsinnreimbursement.com, 844-357-4668, select prompt 2
 Ipsen Cares..... www.ipsecares.com, 866-435-5677
 Lilly Cares Foundation Patient Assistance Program lillycares.com, 800-545-6962
 Lilly Oncology Support Center..... lillyoncologysupport.com, 866-472-8663
 Merck Access Program merckaccessprogram.com/hcc/
 Merck Helps merckhelps.com, 800-727-5400
 Novartis Oncology Universal Co-pay Program..... copay.novartisoncology.com, 877-577-7756
 Novartis Patient Assistance Foundation..... pap.novartis.com, 800-277-2254
 Novartis Patient Assistance NOW patientassistancenow.com, 800-245-5356
 Pfizer Oncology Together pfizeroncologytogether.com/patient, 877-744-5675
 Pfizer RxPathways..... pfizerrxpathways.com, 844-989-7284
 Sancuso Patient Assistance..... sancuso.com/patient/patient-assistance, 800-726-2876
 Sanofi Genzyme CareASSIST..... www.sanoficareassist.com, 833-930-2273
 Sanofi Genzyme Patient Support Services sanofigenzyme.com/en/patient-support/patient-services
 Sanofi Patient Connection sanofipatientconnection.com, 888-847-4877
 Taiho Oncology Patient Support..... www.taihopatientsupport.com, 844-824-4648
 Teva Cares Foundation Patient Assistance Programs tevacares.org, 877-237-4881
 Teva CORE tevacore.com, 888-587-3263

➔ For more resources, go to PatientResource.com



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