

Preparing for Your Doctor's Visit

A worksheet for people with Colorectal Cancer

Colorectal cancer develops when cells in the colon or rectum grow out of control. Colon cancer impacts the large intestine or large bowel. Rectal cancer occurs in the rectum. The rectum is the passageway that connects the colon to the anus.

If you have colorectal cancer, this worksheet can help you take control and have better discussions with your health care team after diagnosis. This guide provides a quick overview of treatment options, questions to ask your health care team, a worksheet to help you set your own goals, and resources for information and support.

After diagnosis, things may happen very suddenly. It is normal to feel anxious and overwhelmed. You can learn more about coping and details on treatments in our *Frankly Speaking About Cancer: Colorectal Cancer* booklet (www.CancerSupportCommunity.org/CRC). You can call the Cancer Support Community's Helpline at 888-793-9355 and the Colorectal Cancer Alliance's Helpline at 877-422-2030.

GETTING TO KNOW YOUR HEALTH CARE TEAM

Cancer treatment is complicated and changes all the time with new discoveries. You need a health care team you can trust to take the best care of you. Your team may include a number of health care professionals who work together including:

Physicians: You may see a **medical oncologist, surgical oncologist** or **colorectal surgeon, a radiation oncologist,** and a **gastroenterologist**. Look for doctors who have experience treating colorectal cancer, such as a board-certified colorectal surgeon. Choosing the right surgeon is especially important for both rectal and colon cancer.

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

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

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

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



Palliative care specialist: This person helps patients manage difficult symptoms, pain, and side effects. They focus on improving patients' quality of life during their cancer treatment.

Financial Navigator: This person provides information and resources to help you and your family manage cancer related costs. They can offer referrals and help you enroll in financial assistance programs if available.

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

TALKING ABOUT COLORECTAL CANCER TREATMENT

You will hear many words used to describe colorectal cancer. However, there are some terms that you should become familiar with as you discuss treatment options with your health care team. Some key ones to know are:

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

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

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

CHEMOTHERAPY: Chemotherapy uses drugs to stop the growth of cancer cells, either by killing the cells or by stopping them from dividing.

CHEMORADIATION: You may receive chemotherapy and radiation during the same time period. This may be done before surgery to shrink the size of a tumor.

IMMUNOTHERAPY: Immunotherapy uses the body's natural defenses to find, attack, and kill cancer cells. It may help to think about it as boosting the immune system's response.

TARGETED THERAPY: Targeted therapy aims to more precisely attack cancer cells. These drugs target changes in the genes or proteins of cancer cells that help them grow, divide, and spread. They keep cancer from growing and spreading with less harm to cells that are not cancer.

CLINICAL TRIALS: These studies are done to test new drugs, combinations of drugs, or different ways of doing stem cell transplant.



ASK YOUR HEALTH CARE TEAM

- Talk with your doctor and confirm that the specialists on your health care team have experience treating colorectal cancer.
- Ask about the next steps in your treatment and what tests you will need.
- Ask about symptoms and side effects and which ones you need to know about and report to your team. Ask about side effect management.
- Ask questions until you understand what is being said. You can ask for information in a different language or a drawing if you need it.
- Talk to your health care team about how you are feeling. Ask about a counselor or mental health services if you are feeling overwhelmed or anxious.
- Ask about the latest information on clinical trials.

TIPS FOR TAKING CONTROL

- Take someone with you to appointments, for support and an extra set of eyes and ears. If you go to an appointment alone, bring a recorder or use a cell phone to record your conversation with your doctor. Be sure to ask your doctor if it is OK to record.
- Be proactive. Talk to your health care team or financial navigator about ways to manage treatment costs before you start treatment.
- Write down your questions before each doctor's visit. Keep a journal to take notes or use this worksheet to track your progress over time. This can include information about tests, lab works, and the symptoms and side effects you may be experiencing.
- Be your own advocate. If you don't feel your health care team is addressing your concerns, consider getting a second opinion.
- Learn the words that doctors use to talk about colorectal cancer. This can help you better understand your test results and treatment options.



Below are some of the symptoms and side effects people with colorectal cancer may experience as shared by members of our Cancer Experience Registry. Think about how often they affect you. Talk to your health care team about how best to manage them.

| | Rarely | Sometimes | All the Time |
|---|---------------|------------------|---------------------|
| Fatigue, feeling very tired, or shortness of breath | | | |
| Pain, soreness, or scarring | | | |
| Having trouble sleeping | | | |
| Feeling anxious, overwhelmed, or depressed | | | |
| Feeling tingling or numbness in your hands, arms, feet, or legs | | | |
| Diarrhea, constipation, weight loss, trouble eating, or bloating | | | |
| Fever or chills | | | |
| Headaches, confusion, or blurred vision | | | |
| Edema (swelling) | | | |
| Skin problems (rashes, itching) | | | |
| Others: | | | |
| How often are cancer or side effects interfering with your life? | Rarely | Sometimes | All the Time |
| Work/School/Home (unable to go to work/school or do daily tasks) | | | |
| Unable to do Activities I Normally Enjoy, Such as Traveling | | | |
| Confidence/Self-Image | | | |
| Difficulty Thinking/Brain Fog/Chemo Brain | | | |
| Social Relationships | | | |
| Health Insurance or Other Financial Worries | | | |
| Eating and/or Exercise/Being Active | | | |
| Difficulty Sleeping/Insomnia | | | |
| Others: | | | |



THINK ABOUT TREATMENT AND YOUR PERSONAL GOALS

When you talk to your doctor about your treatment options, ask about the goals of the treatment and how each treatment might affect the goals that you have for your life. Possible goals may be to: live as long and as well as possible, contribute to progress

by taking part in research, make it to a special event/milestone, or find cutting edge treatments. Let your health care team know about your treatment and personal goals. Remember that your goals may change over time.

SETTING YOUR PERSONAL GOALS FOR TREATMENT

| | |
|--|--|
| Physical Health and Well-Being | <i>What do you want to be able to do?</i> |
| Family and Social Relationships | <i>What's going on in the lives of others that is important to you?</i> |
| Work/School | <i>Do you want to continue working? Can you adjust your schedule or responsibilities?</i> |
| Personal and Spiritual Growth | <i>How is your confidence and self-esteem? Are you able to do things you enjoy?</i> |
| Community Involvement | <i>Are you getting the support you need from your community? Are you able to stay active/involved in your community?</i> |
| Other: | <i>What else is important to you?</i> |



PREPARING FOR YOUR NEXT HEALTH CARE VISIT

If you are feeling either better or worse today than at your last appointment, let your health care team know.

Write down your questions before each doctor's visit. Below are some suggested questions and discussion points. Concentrate on the issues that are most important to you.

Can you explain my test results to me?

When should I start treatment? What happens if I don't start treatment now?

Are there any genetic risk factors I should be aware of?

Have I been tested for biomarkers? If so, how will this impact my treatment?

How long will I be on the treatment? What are the common side effects?

The symptoms and side effects that are affecting me the most are: [discuss your answers from page 4].

My symptoms and side effects are interfering with my life in these ways: [discuss your answers from the bottom of page 4].

What can we do to manage my symptoms and side effects?

My top goals for treatment are: [fill in your answers from page 5].

Is the treatment that I am currently on the best treatment for me to meet these goals?

What other treatments are available to me? What are the pros and cons of each option? Are there any new treatments or clinical trials that may be right for me?

Do you have a suggestion for where to go to seek a second opinion?

How can I manage treatment costs? Is there a financial navigator that I can talk with?

Will treatment impact my fertility? Should I see a fertility specialist before I start treatment?



GETTING SUPPORT

Think about people in your life who can help (your spouse or partner, friends, faith community, support group, or co-workers).

- Make a list of things you need (childcare, meal prep, laundry, etc.) and who can help with each task. Consider using **MyLifeLine.org** to help you stay organized and let friends know what you need.
- Ask your health care team about resources for social, emotional, and practical support.
- You can also ask for a mentor or to be matched with another person with colorectal cancer.
- If you search for information online, make sure that you are using trusted websites.
- Turn to the back page of this publication to see a listing of trusted organizations. CSC and many other organizations have helplines, support groups, online discussion boards, and more ways to seek support from others who have colorectal cancer.

FINANCIAL RESOURCES

Even with a health care plan, treatment can be expensive. Keeping up with costs can be overwhelming. However, there are many resources that can help.

- Talk with your health care team and your pharmacist about the cost of your treatment.
- Ask your doctor to refer you to an oncology social worker, financial counselor, or to a nonprofit organization for help managing financial issues and costs.
- Reach out to your health care plan to find out what resources they have that could help you.
- Ask about pharmaceutical assistance programs and what the qualification requirements are.
- If your treatment center is far away, ask if there are assistance programs that can help cover your travel costs.

The more you learn, the more you can help to reduce unexpected costs. To learn more about ways to manage the cost of treatment, visit: **www.CancerSupportCommunity.org/Cost**

FINANCIAL SUPPORT RESOURCES

Cancer and Careers (CAC) · www.CancerandCareers.org

CancerCare · 800-813-4673 · www.CancerCare.org/financial_assistance

Colorectal Cancer Alliance · 877-422-2030 · www.ccalliance.org

Partnership for Prescription Assistance · www.pparx.org

Patient Access Network Foundation · 866-316-7263 · www.panfoundation.org/get-help

Patient Advocate Foundation · 800-532-5274 · www.patientadvocate.org

COLORECTAL CANCER ALLIANCE RESOURCES

Trying to figure out colorectal cancer symptoms, screening, a new diagnosis and treatment options? Call the Colorectal Cancer Alliance's **Helpline at 877-422-2030**.

The Alliance's online communities, Facebook Blue Hope Nation and Ally to Ally, offer a national network of survivors and advocates, find the critical answers and support you need faster than ever. **www.ccalliance.org/patient-family-support/online-community**.



COLORECTAL CANCER INFORMATION AND SUPPORT

Cancer Support Community · 1-888-793-9355 · www.CancerSupportCommunity.org

American Cancer Society · 800-227-2345 · www.Cancer.org

American Cancer Society Colorectal Page · www.Cancer.org/cancer/colon-rectal-cancer

Colorectal Cancer Alliance · 877-422-2030 · www.ccalliance.org

Fight Colorectal Cancer · 877-427-2111 · www.FightColorectalCancer.org

Patient Empowerment Network · www.PowerfulPatients.org/Colon

United Ostomy Associations of America · 800-826-0826 · www.Ostomy.org

CANCER SUPPORT COMMUNITY RESOURCES

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

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

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

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

Cancer Experience Registry® — Help others by sharing your cancer patient or cancer caregiver experience via survey at www.CancerExperienceRegistry.org.

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

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

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

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

This publication was made possible through generous support from:



Frankly Speaking About
Cancer: Colorectal Cancer
PROGRAM PARTNER

