# What You Need to Know When Diagnosed with Colorectal Cancer

The colorectal cancer journey is different for everyone, there is no single road map to follow. Whether you just received a diagnosis, or you are a caregiver, these tips will help you through.

#### 1. Learn as much as you can about your diagnosis.

- The Colorectal Cancer Alliance provides information and education about your specific diagnosis. Patients, caregivers, and family members can visit <a href="mailto:ccalliance.org/journey">ccalliance.org/journey</a> to get personalized resources.
- Ask questions and get the facts about your diagnosis. Write questions prior to your office visit. Bring someone to take notes during office visits, or record them to listen later.
   Questions may come to you any time, so keep a notebook nearby and write them down.
- Expect the unexpected. Your medical team will tell you what to expect during treatment. But it's normal to face changes and challenges.

# 2. Put together the right medical team and coordinate frequently.

- Your treatment may need specialized experts. A surgeon, oncologist, pain specialist, social
  worker, and others may work together on your <u>cancer care team</u>. Your doctor can help you
  build the right one. The Colorectal Cancer Alliance's <u>Helpline at 877-422-2030</u> or Cancer
  Support Community's <u>Helpline at 888-793-9355</u> can also guide you through the process.
- If <u>surgery</u> is needed, always seek an opinion from a board-certified colorectal surgeon. They are experts and have extensive training in colorectal surgery.
- If you want to have children, ask questions about <u>preserving your fertility</u> before treatment begins.
- Let your care team know how you feel. Work with them to make decisions that balance treatment risks and benefits with your preferences and values.

# 3. Improve your treatment options with testing.

- Ask your doctor for <u>biomarker testing</u>. Your biomarker test results can help you and your doctor choose the best treatment for you. Biomarkers in colorectal cancer are used for diagnosis, progression, prognosis, and treatment.
- Stage III and IV patients can use the Alliance's free <u>Personalized Treatment Program</u>. Using your biomarker test results, the program provides an in-depth report about your tumor and personalized treatment options.

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- Use the Alliance's <u>Clinical Trial Finder</u> to explore your options. The tool provides a list of trials to review with your doctor. Specialized navigators can walk you through the process.
- Talk to your doctor about genetic testing for an inherited mutation. Ask if you are at risk
  for <a href="hereditary conditions">hereditary conditions</a> like familial adenomatous polyposis (FAP) or Lynch syndrome. A
  simple blood test can determine if you carry these conditions, which may put you or your
  family at greater risk of colorectal cancer.

# 4. Always seek a second opinion.

- The more you know, the more prepared you are to make informed decisions about your treatment.
- Seek opinions from experts who take a multidisciplinary approach to treatment. For
  example, if you are a stage III or IV patient, a tumor board, surgeon, and oncologist will all
  review your case before treatment starts. Find these experts at teaching hospitals or the
  National Cancer Institute.

# 5. Get support as a caregiver (or for your caregiver).

- <u>Caregivers</u> receive a lot of information, and it can be overwhelming. Being under stress can make remembering critical details even harder. Use a calendar and a notebook to keep important dates and information.
- Allow yourself guilt-free time to learn new ways of resting, processing, and finding peace.
- Helpful ways to reduce stress usually include daily journaling, meditation, watching funny movies, engaging in creative hobbies, and talking to a trusted friend.
- Talk to your human resources personnel about the Family Medical Leave Act, job accommodations, and other ways that your caregiving role can be supported while staying employed.

#### 6. Ask for help.

- Coping with life while you are going through colorectal cancer treatment can be hard. Accept help when you can, and don't be afraid to ask for the specific help you want and need.
- Give your friends and family a chance to feel good by accepting their help.
- If you experience insomnia or anxiety longer than one month, a mental health professional could help.
- Use Cancer Support Community's <u>MyLifeLine</u> to create a private website to document your cancer journey. Friends and family can use the site to plan support, like delivering meals or giving rides to treatment.

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#### 7. Reach out for support.

- The Colorectal Cancer Alliance's certified <u>patient & family support navigators</u> guide you through your treatment and survivorship journey. They not only understand the system, many have been in your shoes. They exist to help you.
- Peers can help you feel supported and give you tips on how to overcome unique challenges. The <u>Colorectal Cancer Alliance's Buddy Program</u> matches you with peers who have had similar experiences.
- Speak to a navigator or resource specialist through <u>Cancer Support Community's Helpline</u> or Live Web Chat for support, coaching, resources, and to talk about your cancer experience.

# 8. Find your community.

- A new cancer diagnosis can feel isolating. Loss of hope, loneliness, and worry are some of the challenges of living with colorectal cancer. To connect with the following programs, call the Alliance Helpline at 877-422-2030 or visit ccalliance.org.
  - » Find the critical answers and support you need in <u>Ally to Ally</u>, a secure, private website for community sharing, discussion, and service.
  - » <u>Blue Hope Nation</u> is a private Facebook group of survivors, caregivers, friends, and family members from across the world. They know exactly what you're going through.
  - » Patient & Family Support Group Chat is an online community where you can connect with other patients, family members, and caregivers for support.
- To connect with the following programs, call the <u>Cancer Support Community Helpline</u> at 888-793-9355 or visit <u>cancersupportcommunity.org</u>.
  - » <u>MyLifeLine</u> is an online community with discussion boards to connect with others like you. Share your unique cancer experiences and offer insights, coping strategies, and inspiration.
  - » Connect with your local <u>Cancer Support Community or Gilda's Club</u> for in-person and virtual support groups, yoga classes, educational workshops, and more.

# 9. Manage stress and lifestyle.

- Manage stress by meditating, listening to music, talking with friends, or taking a walk. Take a portion of each day to do your favorite things.
- Maintain a balanced diet and get regular exercise to gain control, an emotional uplift, boost your energy, and reduce stress.
- Find something you like to do and set reasonable goals to help you make exercise a part of everyday living.
- Don't let the cancer-related thoughts consume you. Allow yourself to take time away from the disease.

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# 10. Insurance, employment & financial resources.

- Learn about your insurance plan and its benefits. Ensure you have adequate coverage in place to minimize out-of-pocket expenses.
- Check your prescription drug coverage, as many cancer drugs are considered specialty medications.
- Find out how your <u>employer</u> will handle your <u>time away from work during treatment</u>, including work accommodations and disability options.
- File medical bills. Get a multi-pocket expanding file folder to separate each bill by provider. Attach your 'Explanation of Benefits' from the health insurance provider to these bills and make sure the amounts due match.
- Learn about ways to <u>manage the costs of cancer care</u>, such as finding a financial counselor and reaching out to foundations or patient assistance programs.
- For more resources visit the Colorectal Cancer Alliance's
   Support & Financial Resource Guide and financial assistance programs.

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ccalliance.org | Helpline: (877) 422-2030

The Colorectal Cancer Alliance is a national organization committed to ending colorectal cancer within our lifetime. We are your allies — a national network of passionate survivors, caregivers and advocates dedicated to helping you and your family navigate all aspects of the disease, from diagnosis and treatment to a lifetime of progression-free survival. We are a community of people eager to share experiences, address your concerns, and answer your questions. We understand the different stages of the colon cancer journey because we've been there. We are here for you when you need us because we believe tomorrow can't wait.



www.CancerSupportCommunity.org Helpline: (888) 793-9355

