

Colorectal Cancer Among Young Adults

Receiving a cancer diagnosis at any point in life can feel overwhelming. When this happens at a younger age, the impact may feel more difficult to manage or come as a surprise. You may have full-time responsibilities such as work, school, and/or caregiving. You may be navigating other life plans such as starting a career, making a move to another area, or dating.

Colorectal cancer (CRC) has become a common cancer among young adults, those younger than 50 years old. Managing appointments and treatment for colorectal cancer while trying to meet other demands can feel difficult. Experiencing a CRC diagnosis at a younger age can bring on a variety of emotions. You may feel that your future goals are now hindered and need to shift focus on navigating a cancer diagnosis. Seeking the help you need is important as you navigate this new life challenge.

Know that you are not alone.

This fact sheet will discuss the unique challenges for a young adult diagnosed with colorectal cancer. It will provide you resources and ways to maintain your quality of life throughout treatment and into survivorship.



For more information and resources on colorectal cancer, please visit www.CancerSupportCommunity.org/Colorectal-Cancer



UNDERSTANDING YOUNG ONSET OF COLORECTAL CANCER

Colorectal Cancer includes cancers in any part of the colon and rectum. As with many cancer types, the causes of CRC can vary. Common symptoms of CRC are blood in the stool, change in bowel habits, and persistent abdominal discomfort. Risk factors include having a sedentary lifestyle, consuming poor-quality foods, and some chronic conditions. This includes Crohn's Disease and Irritable Bowel Syndrome (IBS). There are multiple factors that can lead to CRC. Unfortunately, there is not one factor that contributes to it occurring in younger patients.

Genetic and Tumor Testing

About 5 to 10 percent of colorectal cancers are hereditary. Patients with a strong family history may be more likely to be diagnosed with CRC at a younger age. However, some may not test positive for a genetic marker. Genetic testing may use a saliva or blood sample. This testing may be ordered by your oncologist, primary care doctor, or genetic counselor. Lynch Syndrome and Familial Adenomatous Polyposis (FAP) are inherited conditions associated with colorectal cancer. Genetic testing can help determine treatment options and guidance for survivorship and future follow-up.

Tumor testing are tests that look for specific markers on the cancer tumor. Some that are linked to colorectal cancer include KRAS, HER2, MSI, BRAF, and NRAS. Completing tumor testing early is important as it may lead to additional treatment options. Ask your care team about tumor testing options that are available for your specific diagnosis.

MAINTAINING QUALITY OF LIFE

Navigating a CRC diagnosis and its treatment as a young adult can come with unexpected challenges. Some of these unique challenges may not exist with people diagnosed at an older age. You may need to figure out how to balance obligations to your full-time or part-time job or to your family. Depending on your personal goals, you may feel discouraged about how cancer will affect your life plans. This may include creating a new or expanded family, advancing your career, or your relationship with others. Although it may feel difficult at times, try to have dedicated moments to reflect on your personal goals. Speak to your care team about these goals and discuss with them how you want to achieve them. **You play an important role in your care.**

Ask your care team about resources to help you navigate each of these important factors of your well-being. Below are some areas that are important for your care as you manage your CRC diagnosis and treatment.

It is important for you to feel empowered in your treatment. Your care team should allow you to choose the treatments that will help you reach your personal goals. Refer to Cancer Support Community's page on how to learn more about making treatment decisions:
www.CancerSupportCommunity.org/Decisions



SOCIAL AND PSYCHOSOCIAL

Cancer is a major life challenge. You may need to learn how to balance your social and mental well-being with the needs of your CRC treatment. You may not know how to talk to your friends, family, and/or child(ren) about your diagnosis. You may experience stigma from others about having colorectal cancer at a young age. **It is important to know that you did not cause cancer to develop at a young age.** Prioritizing your mental health throughout your experience is crucial. Speak to your care team about any new symptoms or emotions you experience. They can provide the best care for you when they are aware of how you are feeling.

Share your mental health concerns with your care team just as you would with your physical side effects from treatment. There are many support resources available to help with feelings of anxiety and depression.

If you are experiencing feelings of suicidality or extreme emotional distress, call or text the National Suicide Prevention Lifeline at 988.

Visit our page for more information on mental health and how to speak to your care team about your mental wellness: www.CancerSupportCommunity.org/Coping-Mental-Health-Concerns

ACTIONS TO CONSIDER:



Speak to your care team early and often about any physical and emotional side effects that you experience.



Establish the person(s) in your life to serve as your trusted support system. They can be the people you go to first with any questions, concerns, or other challenges you are facing. This may include a nurse or social worker on your care team and/or a trusted family member or friend.



Coordinate with your family members and/or friends to assist with sharing responsibility of other needs. This may include childcare, transportation, cooking meals, or coming to appointments with you.



Ask your care team for resources that can support your mental health. This may be referrals to a counselor or therapist, or to local support groups.



Share with your care team any important events or goals that you have for yourself, even those unrelated to your care. They may be able to help with scheduling appointments for your treatment so that you can attend these events.

WORK, SCHOOL, AND FINANCIAL

A cancer diagnosis can lead to financial toxicity. Financial toxicity is the cost-related distress that cancer patients face because of their care. Undergoing cancer treatment can be very expensive, even with insurance. This can lead to feeling distressed. You may have full-time duties that would not allow you to earn a traditional income or have insurance coverage. If you have a job, it may feel difficult to pay for treatment if you have to take time off work because of the demands of treatment. Regardless of your situation, fitting in your medical appointments and knowing how to pay for them, can feel very overwhelming. Be open to seeking and accepting support that is available to help you navigate these concerns. **Advocate for yourself! Ask multiple people your questions in order to receive the support you need.**



The Financial Navigators at Cancer Support Community's FREE Helpline are up to date on financial assistance options. They can offer support regardless of where you live or are receiving care.

They are available Monday-Thursday 11am-8pm ET and Friday 11am-6pm ET. Call 888-793-9355.

ACTIONS TO CONSIDER:

Speak to your employer or school instructors about your diagnosis when you are comfortable. Ask about leave of absence options to maintain your employment/school enrollment status. See if they can be flexible in work options, such as remote work or adjusting your schedule.

Speak to your care team to explore financial resources. There may be financial assistance programs that can help with the costs of your care. Insurance programs or other organizations may help with everyday costs such as rent, food, and transportation. Social workers and patient navigators are knowledgeable about these options and can help you.

Find the contact information of your insurance provider. Call them and ask about how your insurance coverage will help pay for your treatment. Ask them for any alternative treatments/medications that may be as effective but cost less. Ask your social worker or financial navigator to help you navigate your insurance and cost of care.

Visit our webpage for more information and helpful resources about how to navigate the costs of your care:
www.CancerSupportCommunity.org/Help-Managing-Cancer-Costs





Sexual Wellness and Fertility

Treatment for colorectal cancer, such as radiation and specific surgeries, can affect fertility and sexual wellness. Because of this, decisions on fertility preservation may need to happen before treatment begins. Whether you are dating, married, or single, it is important to have conversations with your care team about family planning or fertility preservation. Even if family planning was not on your mind before your diagnosis, it is worth considering your options. You may feel like you have to make this decision quickly in order to begin treating your cancer. However, you are an important member of the decision-making for your care. Take the time you need to feel confident in your decision.

Treatment can impact your sexual wellness and intimacy. You may experience symptoms such as dryness or changes in sexual desire. These physical side effects may lead to feeling decreased connectedness to your partner or a lack of comfort with intimacy.

ACTIONS TO CONSIDER:

- Ask your care team about your options for fertility preservation. You can work with your care team on the best plan for you based on your genetic testing results and treatment plan.
- Share your side effects with your partner. Have open and honest conversations with them. Consider meeting with a therapist or physician that specializes in sexual intimacy concerns.
- Speak with your care team about how you can remain intimate with your partner while receiving cancer treatment. Ask about medications or other options that can help alleviate any sexual health side effects you are experiencing.

Visit our page on intimacy, sex and fertility issues for more information and support options:
www.CancerSupportCommunity.org/Article/Intimacy-Sex-and-Fertility-Issues



SURVIVORSHIP CONSIDERATIONS

Survivorship for colorectal cancer can look different for everyone. Some define survivorship beginning at diagnosis or not until your active treatment (radiation, chemotherapy, and/or surgery) is complete. Since each colorectal cancer experience is unique, every patient will have different needs during survivorship.

If your CRC diagnosis is in an earlier stage, you may be treated for a shorter period of time, with an increased chance for successful treatment. Your survivorship goal in this case may be to recover from the emotional and physical side effects of your treatment. Creating a network of loved ones to help support your unique needs is important. For advanced or metastatic CRC, survivorship may focus on maintaining your quality of life through services such as palliative care. Palliative care helps manage symptoms such as nausea, fatigue, and pain. The palliative care team can also support you and your loved ones through difficult decision making. **It is important to know that palliative care can be received at any time throughout treatment regardless of the diagnosis.**

You may commonly hear that patients need to figure out their “new normal.” Similar to survivorship, this will also look different for everyone. You may have seen your care team regularly for treatment. While in survivorship, you may see them less often for follow-up appointments. This transition can bring on different challenges and concerns. You may feel overwhelmed with emotions while reflecting upon your experience. You may have questions about how to care for yourself moving forward. Your care team may recommend seeking out additional care during this time. This may include screening for other cancers or complete tests to monitor for any changes in your health status.

Discovering your “new normal” may feel exciting at times but may also bring on feelings of worry. Being able to feel at peace with your “new normal” may take time, and that is okay! Everyone navigates this new phase in their own way and it should be done in a way that works best for you. It is important throughout survivorship to keep in touch with your physical and mental health. Continue to communicate with your care team. They can continue to help you find the support you need to improve your quality of life and reach your goals.



ACTIONS TO CONSIDER:

- Whether your CRC diagnosis is early-stage or more advanced, don't lose hope. Continue to ask your care team about all the treatment options available to you. Treatment for CRC continues to advance with new options becoming available.
- Always communicate your personal and treatment goals with your care team. Your opinions matter and you need to be part of the decision-making process. It is okay if these goals change over time. Keep your team in the loop as your needs and goals change.
- Be open to seeking a second or third opinion with other doctors at different cancer centers. Other hospitals or cancer centers may have access to additional treatments, such as clinical trials.

Receiving a colorectal cancer diagnosis or experiencing it as a loved one can bring on a variety of new emotions. You may wonder why this happened at such a young age and have a lot of questions about how to move forward. There are many resources available to help with your needs at any given time. Do not give up if the first few options are not a good fit.

Colorectal cancer and its treatment can cause side effects that may impact your physical, mental, sexual, and social health. Share with your care team and other people in your support system about how you are feeling. Your health and the health of your loved ones are important and should be prioritized and addressed every step of the way. As you navigate your colorectal cancer diagnosis and treatment, remember that you're not alone. Ask all your questions to your care team and advocate for yourself to ensure that all your needs are met.

RESOURCES

YOUNG ADULT CANCER RESOURCES

Stupid Cancer

<https://stupidcancer.org/>

Elephants and Tea

<https://elephantsandtea.org/>

Ulman Foundation

<https://ulmanfoundation.org/>

COLORECTAL CANCER RESOURCES

Colorectal Cancer- Cancer Support Community

1-888-793-9355

www.CancerSupportCommunity.org/Colorectal-Cancer

Colorectal Cancer Alliance

1-877-422-2030

www.CCAlliance.org

American Cancer Society

800-227-2345

www.Cancer.org/Cancer/Colon-Rectal-Cancer

Fight Colorectal Cancer

1-877-427-2111

www.FightColorectalCancer.org

Colon Club

www.ColonClub.com

Colontown

www.Colontown.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-Thurs 11am-8pm ET and Fri 11am-6pm 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 nearly 200 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:
www.CancerSupportCommunity.org/Find-Location-Near-You

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

MyLifeLine® — CSC's secure, online community welcomes anyone impacted by cancer to easily connect with community to reduce stress, anxiety, and isolation. Create a personal network site and invite friends & family to follow your journey. And participate in our discussion forums any time of day to meet others like you who understand what you are experiencing. Join now 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.

This publication is available to download and print yourself at www.CancerSupportCommunity.org/Colorectal-Cancer.

For print copies of this publication or other information about coping with cancer, visit www.Orders.CancerSupportCommunity.org.

**Frankly Speaking About Cancer:
Colorectal Cancer Program Partner:**



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