# YOUR GUIDE IN THE FIGHT Young Adults & Colorectal Cancer

A F!GHT COLORECTAL CANCER" Resource

for all stages of colorectal cancer

# Colorectal Cancer Under 50 Sucks: But You're Not Alone

Whether you're 18 or 45, a colorectal cancer diagnosis is earth shattering and feels terribly isolating and lonely. But for what it's worth: You're not alone. In fact, you're part of an alarming trend and a growing population of people younger than 50 facing this disease.

It's important that you advocate for yourself, starting right now. We're here to help.

#### No One Fights Alone

Nearly half of all cancer survivors report significant emotional distress. If you or a loved one needs to talk, call the Cancer Support Community Helpline at 888-793-9355, or call or text the Suicide & Crisis Lifeline at 988.

# How Do I **Respond to That?**

- "Wow, you're awfully young for colorectal cancer!"
  - I know, but it's also on the rise. More than one-third of colorectal cancers diagnosed in patients under age 35 are hereditary. If cancer runs in your family, you might consider genetic testing; it's a simple blood test."
- "What did you do to get colorectal cancer?"
  - I didn't do anything, and I had no control over this. My cancer could be genetic; it could be environmental; or it could be an unknown cause or a combination of things. I'm not the only one this is happening to, and researchers are trying to figure out what's going on."
- "What can I do to help you?"
  - "Here are some ways you can help me: I could use help with meals, childcare, emotional support, for example. Also, continue to invite me even if I can't always come, and keep me in the loop about your life too. That will go a long way in helping me feel better and maintain normalcy."



The Colon Club raises awareness, educates, and supports those with colorectal cancer, especially people diagnosed between 15 and 39. Colon Camp, an annual retreat, brings survivors and caregivers together to heal, learn, and share their experiences in a safe and supportive environment. Learn more at ColonClub.com.













# Facing **Treatment**

Being a young person with cancer can feel isolating. While everyone facing cancer is fighting for their lives, studies show that young people with colorectal cancer tend to be diagnosed in the later stages of the disease (stage III or IV), which concerns doctors.

If you are a young patient, you may be advised to start treatment or have surgery promptly, and it's crucial not to delay.

However, you should also take important steps, such as asking questions that may impact your treatment and quality of life.

#### Here's what we mean:

#### Preparing for chemotherapy or targeted therapies?

Ask your doctor how long the treatment sessions will last, so you can plan for time off work or work-from-home options. Also, learn how to stay safe when you have a weakened immune system. You can prepare by finding virtual ways to socialize, such as online games and setting up text chains. Ask your doctor about common side effects of your specific treatment, if there is anything you can do in advance to prevent them, and how to manage or reduce them.

#### **Preparing for radiation?**

Brace yourself for the possibility of skin burns and urinary dysfunction, which may limit your mobility and daily activities. Look for ways to move that won't cause pain, and ask your doctor and members of the community for tips. Be aware that radiation can also cause sexual dysfunction, so read up to determine how other patients have dealt with this issue. Have a strong support system in place, as daily treatments and side effects for a full month can dominate your schedule.

#### Preparing for surgery?

You may need a stoma/ostomy (permanent or temporary), so it's important to educate yourself on stoma and ostomy care, and insurance coverage. You'll need to avoid lifting anything over 10 pounds for six weeks after surgery, so plan accordingly if you have children or need to make adjustments to your home. Additionally, you may have dietary restrictions, so learn how to maintain proper nutrition and hydration during this time.

In all of these scenarios, topics like fertility, career, mental health, and finances must be addressed—in addition to the specifics of your treatment plan and the effects treatment will have on your body.

#### **Support Team Checklist:**

- \* Medical team: doctors, pharmacists, nurses, nurse practitioners, physical therapists, and navigators
- \* Social support team: social workers, psychologists, counselors, nutritionists, dietitians, and trainers
- \* Family and friends: neighbors. coworkers
- \* Online communities: Community of Champions, Resource Meetups, and Colon Talk
- \* Lawyers, accountants, and financial advisors: for legal advice, medical tax deductions, and financial planning



### Questions to Ask to Self-Advocate:

- \* Will I have genetic testing?
- \* Can I consider clinical trials? \* Will I have biomarker testing?
  - \* Can I meet with a nurse navigator?

# **Survivorship** Care Plans

Once you finish treatment, it can feel like your safety net is gone. But don't worry, that's normal and things will improve. Ask your oncologist's office for a Survivorship Care Plan (SCP) so you are prepared going forward.

Some offices may not offer it automatically, so don't be afraid to speak up and ask for one. An SCP is a great way to make sure you're getting the best ongoing care, especially if you're young. Plus, if your doctors retire, move, or sell their practice, you'll still have the SCP to refer to. You can access it online or get a printed copy. Having a plan is empowering and feels comforting as you forge ahead.

#### **Your Survivorship Care Plan should include:**

- ▶ Medical history: A record of your cancer diagnosis, pathology, bloodwork, biomarkers, genetic testing results, surgeries, and treatment history. Detail the treatments you received, the dosages, the dates, the administering doctor, and facility. Also note any toxicities, allergies, or intolerances.
- **Follow-up care:** A schedule for checkups and follow-up tests, scans, and bloodwork.
- > Symptoms to watch for: A list of possible side effects from your treatments. This includes everything from signs of recurrence to things like skin cancer risks and potential dental concerns. Some treatments will put you at a higher risk for other cancers in the future.
- ▶ Lifestyle tips: Ideas for ways to stay healthy everything from diet to exercise.

# Thinking About Your Future

When you're a young patient with cancer, saving your life is the goal of your oncology team. They may not have thought about preserving your fertility.

However, as a young patient, it is important to ask questions about preserving your fertility if you think you might want kids in the future, because this may factor in additional procedures that need to be done. You may be at an age where having children is not something you've considered yet, but be sure to talk to your care team if you think it's a possibility in your future.

Oncofertility is a medical field that helps people who have or had cancer potentially preserve the ability to have children in the future. All forms of cancer treatments threaten your ability to conceive and bear children. Infertility is a side effect for some — but not all — young survivors.

Some women experience problems with eggs, ovaries, or begin early menopause. Some men experience low sperm production and testosterone levels. You can take steps to preserve your fertility. Ask!

If you did not discuss fertility or undergo any preservation steps prior to cancer treatments, there are still several family planning options, such as IVF treatments; egg, sperm, and embryo donors; surrogacy; or adoption.



Can you still have sex if you have colorectal cancer? Yes, but it may look and feel different for you and your partner. Body image issues may challenge intimacy, and surgeries and treatments may bring pain and/or force you to find new ways to be intimate comfortably.

Although colorectal cancer isn't sexy, you still are. Even if you don't feel that way. Getting back to intimacy doesn't necessarily equal getting back to sex, so it's OK to start back slowly by making it a priority to start setting aside time as a couple.

Talking about sexual health with your doctor or nurse can be awkward, but power through. It's an important

part of your life, so find the person on your treatment team you feel most comfortable with and start the conversation with them.

Sex therapy (as an individual and as a couple) can help you rediscover intimacy and reduce anxiety. It also can help you cope with both physical and mental challenges of a colorectal cancer diagnosis and treatment.

Talk about sexual health with your partner. Emotional intimacy can help you and your partner achieve physical intimacy. Talk about how cancer has impacted your relationship and what each of you needs in the bedroom. Turn back to each other as a couple.

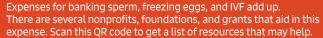
# Sex Tips

- \* For men, depending on treatment plans, explore penile stimulation.
- \* For women, after radiation, ask about vaginal dilators, over-the-counter and prescription lubricants, and pelvic floor physical therapy.
- \* Wearing a shirt over your ostomy during sex may help you explore new positions. OSTOmysecrets® sells products to help you feel more comfortable and confident.

- \* Consider bringing toys or fun into the bedroom. Try something new.
- \* Be patient with each other and offer lots of grace and no shame.
- \* **REMEMBER:** There are many ways to be intimate and show affection.



#### Can I Afford This?







# **Adulting**

#### Bills, Bills, Bills

Cancer isn't cheap. Financial toxicity refers to the stress of paying for your care, from high medical bills, loss of income, and other expenses.

If you have health insurance, try to understand what is and isn't covered in advance to decrease the chances of having unexpected surprises.

Ask your health care team if there is a financial navigator who can assist you. If you're feeling overwhelmed, there are resources that can help.



Scan here for ideas and ways to get help, or visit FightCRC.org/PaymentOptions

# Am I Going Crazy?

No, you are not going crazy, and you are not alone. A cancer diagnosis is overwhelming, and it will impact every aspect of your life, including your emotional, mental, and spiritual health. Facing cancer is traumatic, so feeling sad, angry, scared, or depressed is completely normal and understandable.

You're going to experience a lot of emotions as you go through this. Be kind and gentle with yourself. Don't underestimate the support a therapist can provide during difficult times. Reach out for help when you need it. The broader your support system, the better!

#### **Know Your Rights**

Many patients have to navigate their careers, their educations, or both while undergoing treatment. Your medical diagnosis is private and does not have to be disclosed to your employer or educational institution.

You have legal rights under the Americans with Disabilities Act (ADA). Employers must provide reasonable accommodations, such as accessible parking or a flexible schedule. Beyond paid time off, you may also be eligible

for short-term disability, long-term disability, and family and medical leave coverages. Short-term and long-term disability provides income during time off, while family and medical leave offers job protection. Get the support you need to succeed—inquire about your options sooner rather than later.

If you're having trouble getting dressed and traveling to school or work, having the option to work remotely or attend classes virtually can be helpful.

#### Checklist for Coping with Depression:

- Ask your health care team about treatments that can help (which may include antidepressants, acupuncture, massage, cannabis, for example).
- Take time each day for deep breathing and relaxation.
- Make plans with a supportive family member or friend to do something you enjoy or to experience a new activity.
- Avoid alcohol and tobacco products.
- Do not ignore signs of depression and anxiety—the first step in treating these conditions is through acknowledgment. Depressive disorders, anxiety, and cancer-related PTSD add excess stress to the body, which is trying to heal and fight cancer.

For more mental health and support resources visit FightCRC.org/FindSupport

# How Do I Tell My Kids?

Here's some encouragement: You know your children best. How you choose to talk to your kids about your cancer is up to you.

Here are a few tips:

- \* It's important to talk to your kids about what's happening. Tell them when you are ready. You need to be prepared emotionally first.
- \* Let your kids know they can always talk to you. Designate another adult you trust, so your kids can ask them guestions about your cancer diagnosis or treatment.
- \* Tell their teachers about your diagnosis. Their teachers can help keep you posted if your child's behavior changes at school, or if they see your child struggling.

# What if I **Don't Survive?**

It's never easy to think about end-of-life care. But it's important to fill out the following two key documents when you are ready, and as early as possible, even if you feel you won't need them:

#### **Advance Directive**

I'M SURE YOU'RE FINE

This legal document outlines your wishes regarding medical treatment and end-of-life care if you become unable to make decisions. It allows you to appoint a health care proxy or power of attorney to make medical decisions on your behalf.

#### **Living Will**

This outlines your wishes regarding medical treatment if you are unable to communicate. It typically includes instructions on life-sustaining treatments, such as artificial respiration, hydration, and nutrition.



#### **WORK TIP:**

Ask human resources about your company's sick leave policy so you are informed of your benefits.



# SCHOOL TIP:

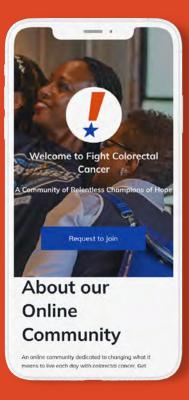
Contact your institution's student disability services or human resources for academic accommodations, such as extra time or lecture notes.

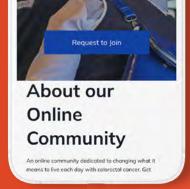


#### LIFE TIP:

Learn how to name your feelings. Being able to accurately express yourself can help others understand how you feel. Engage in journaling, art, exercise, cooking, and other ways to express and release them.









# COMMUNITY of **Champions**

Many young survivors find that online communities of support fit their needs better than support groups at their local hospitals. There are a lot of young colorectal cancer survivors online, and in Fight CRC's community, who are ready to meet and walk through this with you.



Search at community.FightCRC.org





or visit FightCRC.org/Donate



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