

Volume 19, Issue 2 Fall 2024 Letter from the **EDITOR** 

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he other day, my 13 year old experienced a "first," and it was so monumental, I almost added it to her baby book: She deep cleaned her room on her own. Now for the parents with organized teenagers who make their beds every morning, load dirty dishes into the dishwasher, and pick up after themselves without prompts or threats—this may seem silly. But for those with teens like mine, you know this was huge.

While this situation was big for me as her mom (and the homeowner), it was even more impactful for her. Reorganizing, donating unwanted items, tossing unusable ones, and using her allowance to buy new decor gave her a sense of control and empowerment. She was smiling for days after the cleanout, and it's evident that she created a more fun and relaxing space.

As patients and caregivers, it does us good to consider going through a similar experience when it comes to our health. We need to take inventory of what we have and know right now, realize what's outdated and needs to go, and perhaps add in something new. This can apply to everything from reviewing who is on your team to ensuring you have the right supports in place, from asking about going on a clinical trial to getting help for a side effect, from trashing old brochures to updating documents in your estate planning files.

Cancer can be so disempowering, but getting organized is one way to feel like you've regained some control.

We're not preaching to the choir on this, as we've been working on deep cleaning our resources at Fight CRC. We're updating what's old, and reorganizing and recategorizing what's new, so you have up-to-date, medically reviewed, dependable information. We want to provide you with relevant, reliable, and relatable resources that address topics that come up every step of the way-from diagnosis through end of life and/or survivorship care.

This thought is what's behind this issue of Beyond Blue, and it's why the magazine looks a little different. But the quick-and-easy tips, resources, and stories that you love and look forward to are all still here. We've just "cleaned house" a bit to make this an even more helpful and hopeful space as we help guide you through the fight.

STAY STRONG,

Danulle Ripley-Burgess

**DANIELLE RIPLEY-BURGESS VP OF DISEASE AWARENESS** 



### **FOLLOW DANIELLE!**

@DanielleisB



#### **ABOUT THE EDITOR**

Danielle Ripley-Burgess is a 23-year colorectal cancer survivor first diagnosed at age 17. Today, she's in remission. Danielle is an award-winning communications professional and author of Blush: How I Barely Survived 17.

Learn more at FightCRC.org

Join the Fight at FIGHTCRC.ORG

We fight to cure colorectal cancer and serve as relentless champions of hope for all affected by this disease through informed patient support, impactful policy change, and breakthrough research endeavors.





Years ago, the idea of ditching razors and clippers during November became a global phenomenon. Teams, organizations, news crews, police forces, and more rallied together to grow out their hair and raise awareness and money for important causes.

A key organization spearheading this effort has been No-Shave November.

### **Meeting The Hill Family**

No-Shave November was started by the Hill Family of Chicagoland, who lost their father, Matthew Hill, to colorectal cancer in 2007. Matthew was a husband, a father to eight children, and according to his friends and family, an "all-around amazing quv."

In 2009, his children started No-Shave November to raise awareness and money in his memory.

As Christine Hill told the TODAY show, "A lot of cancer patients undergo chemo and they lose hair. So we grow our hair for those that are losing it. And then, the money that you would have spent on hair removal is donated to the cause."

What began as a unique fundraising effort for No-Shave November quickly grew into an international movement celebrated by participants all over the world.

Throughout its growth, No-Shave November has raised millions of dollars and supported several cancer nonprofits. Fight CRC has received support every year in honor of Matthew's legacy, and hundreds of men and women have supported the cause. Over the years, No-Shave November has donated more than \$2 million to Fight CRC.

### **A New Chapter**

In 2024, the Hill family made the decision to shift the administration and management of No-Shave November to Fight CRC.

Fight CRC is excited to keep this movement going so men, women, and children can get involved in such a critical cause! The No-Shave November movement will continue, now powered by Fight CRC. Donations given toward the cause will continue to support cancer awareness and research.





Matthew Hill (center) with his family, who started No-Shave November in his memory.









### **GET INVOLVED!**

We hope you'll join us! Here's a few ways to engage:

- Ditch the razor and donate the cost of what you'd spend on products. (Both men and women can participate!)
- Go to gethairy.no-shave.org and sign up to fundraise as individual or team members.
- If you're letting it grow, take pictures of your progress! Post with the hashtag #noshavenovember.



### This is a Colon

hile the general public often thinks about the colon as one, big organ, when you're facing a colorectal cancer diagnosis, it's important to understand a little more about the anatomy of the colon and rectum, and how it works.

The colon has two sides, five sections, and two colic flexures (also known as curves).

### The RIGHT side of your colon accounts for your:

- Cecum
- Ascending colon
- Hepatic flexure
- Transverse colon (right half)

### The LEFT side of your colon accounts for your:

- Transverse colon (left half)
- Splenic flexure
- Descending colon

- Sigmoid colon

Although not technically the colon, vour rectum is considered left side.

Understanding which side of the colon (right or left) colorectal cancer first originated, and the section of colon as well, is important information because it can impact surgery, post-surgery side effects, and treatment planning.



### DAAD ABIGHANEM

Stage IV Survivor

"It's the hope that gets you," I repeated to myself when I learned that my stage II rectal cancer was upstaged. Surgery, then, was not the end of the road. I told myself I must undergo chemotherapy and endure countless blood tests and scans. This knowledge devastated me more than the original diagnosis. Restlessness, panic, and visceral fear set in. My family and friends didn't know how to comfort me without repeating platitudes. The scientist in me obsessed over side effects and survival rates, taking me down rabbit holes of data and scientific articles.

During one such excursion, I discovered Fight CRC's website, with its trove of information and resources. I signed up for my first Meetup and walked in nervously and without expectations. I tried to make myself small, but Carole,

the facilitator, wouldn't let me. She and the other group members, many of whom were long-time survivors, made me feel safe, heard, and less alone. They validated my feelings and nodded their understanding as I talked about nausea, cold sensitivity, and "scanxiety." They listened without judgment, refrained from comparing my illness to theirs, offered helpful tips and solutions, and encouraged me to always advocate for myself. They taught me it was ok to feel hopeful, angry, sad, grateful, or any combination

Almost two years later, I still look forward to Fight CRC's Meetups, and hope that I, too, can offer a measure of comfort to anyone living with colorectal cancer.

We host Meetups so patients and caregivers can connect with one another and get resources and support. Find the next meetup and sign up at FightCRC.org/Meetups.

# **Pro Tips**

Building your team



### **JESSICA ACOSTA**

Stage III Survivor

"While this has been a team effort from my wife, family, friends, and medical team, I couldn't imagine doing this without my oncologist. She always goes the extra mile. She constantly advocates for me to insurance companies and throughout the hospital. When my insurance company denies scans, she and her team sort it out for me. She has helped me strengthen my ability to advocate for myself!"

### **WENDY HARPP**

Stage III Survivor

"Thank goodness for the amazing ileostomy nurses, who I had to see weekly for months when finding the right bag to fit. They were angels and my saviors over those six months. The little tricks they taught me and ways to reduce the burn on my skin: I'll forever be grateful to them. If I were starting a new career, I would be an ileostomy nurse, because they were such a huge part of my team."



### **SCOTT HANCOCK**

Stage IV Survivor

"I don't think I would be alive today if it wasn't for my wife, Sharon. She has been amazing on our 6-year journey. She is always thinking through treatments, side effects, meds, and more for me. I can miss things, but she has stayed on top of everything, especially when my chemo brain kicks in."



### JENNA ALARCON MCELWAN

Caregiver

"My brother, Lance, was diagnosed with stage III colon cancer in 2021. I was one of his caregivers, and to me, the most critical person for our team was a good medical professional (one who is honest and straightforward, and also advocates for the best possible outcome). Additionally, spiritual support was extremely helpful to Lance, and it helped our family heal after his passing."



### **LAKEN DILDAY**

Caregiver

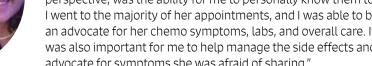
"Something critical for my mom's cancer team, from a caregiver perspective, was the ability for me to personally know them too. I went to the majority of her appointments, and I was able to be an advocate for her chemo symptoms, labs, and overall care. It was also important for me to help manage the side effects and advocate for symptoms she was afraid of sharing."



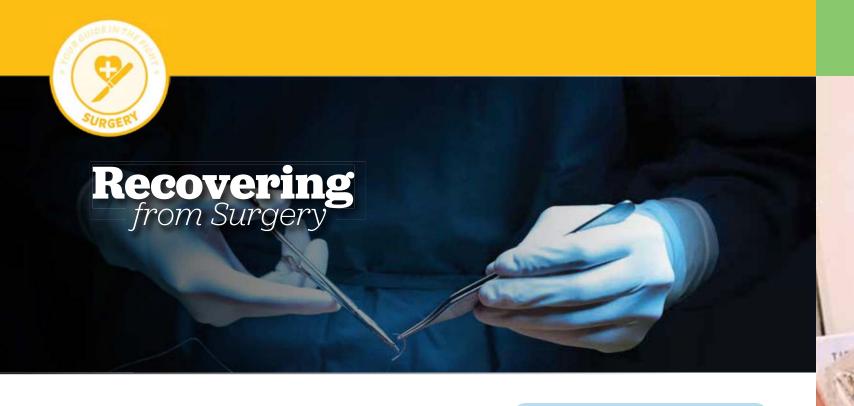
Nothing is harder than feeling alone when you already feel isolated by cancer. That's why we've created several groups within our Community of Champions. Come find your people and get support.

Community.FightCRC.org





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## **Biomarkers**

Biomarkers bring gamechanging information and can significantly impact the decisions being made about a patient's treatment plan.

# Surgical options will depend on the stage of cancer and if it's colon cancer or rectal cancer. Not all patients will undergo surgery.

But if colorectal surgery is needed, it's important to be prepared for recovery. Regardless of the type of surgery and surgical technique used, movement is key.

Get up and walk as much as you're able. Don't push it though, even a slow walk around the hospital halls or your house will help.

#### DIET

Diet will progress as the body recovers. Patients who had colorectal surgery will be on "nothing by mouth" (NPO) immediately following surgery, but progress to ice chips and clear liquids once the body is ready. The doctor will indicate when it's time. If ice and clear liquids are well tolerated, you'll move to full liquids. Tolerating full liquids will lead to more food choices, although stick with mild, soft foods without fiber.

### A low-residue diet will likely be advised for several weeks as you're recovering.

A low-residue diet is low in fiber, which minimizes the amount of work for your colon and rectum.

Think "white bread and white rice, not whole grain bread and brown rice," and avoid foods like raw vegetables, nuts and seeds, whole grain products, beans, and fried meats.

### PREPARING THE HOUSE

Many patients spend most of their recovery time at home. A few things to line up as you plan for recovery:

- Mobility around the house make sure you have a bed and chair that you can get to easily.
- Groceries—have someone stock your kitchen with foods you'll need after surgery.
- Transportation—your doctor will let you know when you're cleared to drive. Have rides lined up until you can drive again.

The days and weeks after surgery can be challenging, but patience and adherence to your doctor's instructions will help you recover more quickly.

# Quick Guide: Surgery Techniques

There are several surgery techniques; ask your surgeon which option(s) apply to you and why. Your past surgeries and current health will play a role in the decision.

- Open surgery: involves a long cut (incision) down the middle of the abdomen to access the area where the surgery needs to be done.
- Laparoscopic surgery: uses multiple small incisions instead of one long cut. The doctor inserts a tiny camera and small tools into the cuts to remove the cancer.
- Robotic-assisted surgery: It is like laparoscopic surgery, but the doctor uses a console in the operating room to control tools held by a robotic machine.



What kind of foods are part of a low-residue diet?

\*ChatCRC is Fight CRC's chatbot that provides instant information about colorectal cancer resources & support. Start chatting by visiting Chatbot.FightCRC.org or text 318-242-8272 (318-CHATCRC).

### **Kayla Campbell**

Stage IV Survivor

My biomarkers are **G12D KRAS-positive** and **MSI-Stable (MSS)**.

This affects my treatment options by letting me know what clinical trials I qualify for.

Having the KRAS G12 has led me to some clinical trials that are specific to my gene markers.

My doctor ordered a biomarkers test, and it came back and showed us what is going on with my tumor. It's in my medical files, and he also gave me a copy of the report.

Always ask for a copy of your results for your personal records!

# WHAT ARE MY BIOMARKERS?!

All colorectal cancer patients need biomarker testing; however, not all patients need the same biomarker tests. To find out about when you need testing and what the different biomarkers mean, visit **FightCRC.org/Biomarkers** or scan the QR code below.



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**Brand** name

### **Oral Treatment**

f you've been encouraged to undergo chemotherapy or targeted therapy, it's important to know that not all drugs are the same. You may have options when it comes to how you receive treatment. Some treatment options come in pill form instead of IV.

Brand name (generic) Drug type	Dosage	When It's Prescribed
Xeloda° (capecitabine) Chemotherapy	Comes in 150 mg and 500 mg tablets. Dosage is determined by your doctor and is based on body size.	For stage II, III, and IV patients either before (neoadjuvant) or after (adjuvant) surgery to remove the primary tumor and/or any metastases.
Lonsurf® (trifluridine & tipiracil) Combination drug Chemotherapy	Comes in 15 mg and 20 mg tablets, specific dosage will be determined by your doctor.	For those whose cancer has spread to other parts of the body (stage IV).
Fruzaqla® (fruquintinib) Targeted therapy	Available in 5 mg and 1 mg tablets, specific dosage will be determined by your doctor.	For stage IV patients who have previously received treatment with a fluoropyrimidine, oxaliplatin, irinotecan HCL, and an anti-VEGF therapy.
Braftovi® (encorafenib) Targeted therapy	Recommended dose of 300 mg once daily in combination with IV infusion cetuximab.	For stage IV patients with a specific mutation of BRAF V600E.
Stivarga® (regorafenib) Targeted therapy	Comes in 40 mg tablets. Your specific dose will be determined by your doctor.	For stage IV patients who have not responded to prior treatments.
Krazati° (adagrasib) Targeted therapy	Recommended dosage of 600 mg twice daily, your doctor will determine your specific dose. Adagrasib comes in 200 mg tablets. It may be used with IV cetuximab.	For stage IV patients with the KRAS G12C mutation who have already received a fluoropyrimidine, oxaliplatin, and irinotecan HCL.
Lumakras® (sotorasib) Targeted therapy	Comes in 320 mg and 120 mg tablets. Dosage will be determined by your doctor. May be administered with IV cetuximab.	Sotorasib is not currently approved for CRC treatment, but may be prescribed off-label. It targets a specific mutation of the KRAS gene.
Retevmo® (selpercatinib) Targeted therapy	Comes in 40 mg and 80 mg capsules. Specific dosage will be determined by your doctor.	For stage IV patients that possess a RET gene fusion and did not respond to other therapies.
Vitrakvi® (larotrectinib) Targeted therapy	Comes in 25 mg or 100 mg capsules, or a 20 mg/mL oral solution.	For stage IV patients with an NTRK gene fusion that has gotten worse after other treatment, or cannot be treated with other therapies.
Rozlytrek® (entrectinib) Targeted therapy	Comes in 100 mg and 200 mg capsules. Specific dosage will be determined by your doctor.	For stage IV patients with a NTRK gene fusion that has gotten worse after other treatment, or cannot be treated with other therapies.
Tukysa° (tucatinib) Targeted therapy	Comes in 50 mg and 150 mg tablets. Recommended dosage for CRC is 300 mg twice daily, in combination with trastuzumab. Your specific dosage will be determined by your doctor.	For stage IV patients with an unmutated RAS gene, who have already been treated with a fluoropyrimidine, oxaliplatin, and irinotecan HCL. Tucatinib targets the HER2 protein.
Tykerb° (lapatinib) Targeted therapy	Comes in 250 mg tablets, often administered with trastuzumab.	Lapatinib is not specifically approved to treat CRC, but may be prescribed off-label. Targets the HER2 protein.

### **Oral Treatment Options**

To learn more about oral treatment options and get patient tips, scan this QR code.





linical trials are research studies intended to help people live longer, healthier lives. They are carefully designed by researchers who enroll volunteers willing to help find better treatments for a given disease.

Clinical trials are performed to test new medications, procedures, protocols, interventions, and devices to see if they are safe and effective. They are performed for many diseases within different groups of people (age, ethnicity, sex).

Clinical trials may also be performed with the goal of addressing side effects secondary to a primary illness, such as cachexia or skin toxicity, that may accompany cancer treatments. They may be performed to see if a new treatment option is safer or more effective than an existing option. Clinical trials also address quality of life and symptom management, genetics and personalized medicine, and survivorship and long-term outcomes.

### TRIALS ARE VOLUNTARY

Participation in clinical trials is voluntary. You may choose to stop at any time for any reason. Clinical trials involve informed consent, where you are given important information about benefits and risks, and you are educated every step of the way.

You will not be a "guinea pig" while participating in a clinical trial. At a minimum, participants receive all treatments they would receive if they were not participating in a clinical trial.

#### **NOT A LAST RESORT**

Clinical trials are not a last resort; they are not only for those who have run out of other options; and they are not only for those with stage IV (metastatic) colorectal cancer or advanced disease.

### **NEW THERAPIES**

Every drug available in the United States has undergone testing within a clinical trial. There are no new therapies without clinical trials, and there are no clinical trials without participants!

It is important to view clinical trials as a potential option at every stage of your treatment, as they may offer you access to treatments you might not otherwise be able to receive.

And, don't forget (we're talking to you too, caregivers!): You can also enroll in clinical trials studying prevention and early detection techniques. People are needed to enroll in trials that are designed to stop or catch cancer when it's most curable.

PHUONG GALLAGHER
Stage IV Survivor

"Clinical trials are not a last-ditch effort for various treatments. At all phases of the journey, you should be aware of your options. You might get better treatment for your case on a clinical trial than standard of care. You're always informed of everything going on in the trial, and you can withdraw consent at any time. It's really easy to withdraw, but it's not easy to get on. There are a lot of moving parts. Gather your information. Know your biomarkers because that does make a difference on what you can join."





Our clinical trial finder is a one-stop shop to find and learn more about high-impact research studies inclusive of late-stage colorectal cancer. Our trial finder is carefully curated by trained research advocates who review trials found on clinicaltrials.gov. It's for patients with both MSI-H and MSS biomarkers. Start searching at **TrialFinder.FightCRC.org**.

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# **Pro Tips**

Managing side effects



**PHILLIP DAWSON** 

Stage IV Survivor

"I am presently receiving immunotherapy. Prior to this, I received chemotherapy from 2020-2024. I am presently on Fruzaqla®/fruquintinib. I struggled heavily after days 14-17. I started to experience neuropathy in my hands, which is a side effect I NEVER experienced during my 63 previous rounds of IV chemotherapy. My fingers would blister and turn beet red, then peel. Because I use my hands at work, I quickly had to refrain from taking the medication until my hands healed. During a follow up with my oncologist, he insisted we were making progress, so the compromise was taking the medication 7 days on, then 7 days off. The neuropathy I previously experienced has not returned. We do believe that reaching past 14+ days was the culprit to my negative side effects. We have had continuous success since then. I've also received a Urea cream prescription which suppresses the pain in my hands and feet. As long as I use the cream at least twice a day, my symptoms have been kept at bay."

### **ANGELA TRIPIDO**

Stage IV Survivor

"A side effect from my FOLFOX treatment last year was neuropathy. The tingling, pain, and discomfort were always worse while I was on my portable pack and for about four days after. Wearing thin Isotoner® gloves helped my hands a lot. I tried to do hand- and feet-focused exercises, too. I also used tons of lotion and Aquaphor® to keep my hands (especially my cuticles) from drying and cracking. I'd do the same on my feet (particularly my heels), and then I'd put them in thick wool socks. I also invested in a better pair of walking sneakers to help make walking more comfortable. I was lucky that the tingling and pain didn't last. When my skin (around my fingernail or toenail) cracked for no reason, I would soak it in warm, salty water for about 10 minutes several times a day."





**BETH CVRKEL** 

Stage III Survivor

"My experience with LARS has been urgency, frequency, and clustering. A few things that have helped me: loperamide (an over-the-counter medicine), diet (beginning with low fodmap and slowly adding foods), pelvic floor physical therapy (this is more than kegels), bidets, mindfulness (meditation, acupuncture, yoga, massage), irrigation (ask your doctor about Coloplast's Peristeen® Plus), products like Aquaphor®, and B-Sure® absorbent pads."

### **CINDY WRIGHT**

Stage III Survivor

"I really did not lose much hair or have peripheral neuropathy until about four weeks after treatment completion (My surgery was in October 2023. Chemo started in November and was completed in February. I had two cycles of CAPOX, then three cycles of FOLFOX due to severe GI toxicity on CAPOX.) I ended up losing about 60% of my hair, even though I had been babying it all along with products just for that purpose. I chopped off the length, keep it in a ponytail most of the time until those baby hairs fill out, and take biotin. For the neuropathy, I take Alpha-lipoic acid (ALA), pyridoxal 5-phosphate (P5P), B12, walk a lot, stretch, do dry brushing, massage, and detox baths. It has been almost five months, and the neuropathy is improving a lot. Never give up!"





MICHAEL HOLTZ

Stage III Survivor

"I received 28 rounds of radiation to my rectum. The side effects I experienced included anal leakage and blistering along my "gluteal crease." While I knew blistering was a possibility and could be treated with A&D® ointment, I wasn't told about the leakage. When I asked, the radiation tech told me leakage was normal. Adult diapers saved me."

# **Getting Help**

Many patients and caregivers say mental health is one aspect of cancer they wish was talked more about. Here are a few stories from survivors who sought out mental health support.



BILL PHILLIPS
Stage III Survivor

"At diagnosis, I started meeting with a licensed clinical social worker (LCSW) in the oncology department who was excellent, but I needed more. She even met with my family and helped refer my wife to mental health counseling for anxiety and depression. My own mental health journey took flight when I was introduced to a life coach by a mutual friend about halfway through treatment. We began by focusing on myself and the mental-physical connections between early/existing trauma and CRC. He also introduced me to breath work and plant medicine, which then led to my serious yoga practice, meditation, journaling and playing music again. I've now reached post-reversal surgery, and I'm the strongest I've ever felt mentally, and I'm working hard on physical healing. I started calling the compendium of activities, aggressive healing. I recently started a course to become a certified life coach and plan to give back by teaching the methods that worked so well for me".



ALECIA MANDAL
Stage IV Survivor

"I was diagnosed in August 2020 and thought I had everything handled. One night, I was out with one of my friends who had been diagnosed with stage Il breast cancer, I'm not sure what was even said about our kids, but I completely broke down and started sobbing! Literally. My friend gave me her therapist's name and I started seeing her five days later. That same night, I texted my oncologist and asked for medication to help me cope. Having stage IV cancer, no matter how well you are doing, means you are always waiting for the other shoe to drop. You get scared to make future plans because vou're not sure if vou're going to be around. I am now on Zoloft®. and I see a weekly therapist. Both things have helped me not 'lose it' and allow me to live this life one day at a time. I used to think of meds and therapy as a sign of weakness. Not anymore. Best decisions I have ever made!"



KIMBERLY HOLIDAY-COLEMAN

Stage III Survivor

"I started with art therapy for cancer patients and survivors. This helped me so much. I realized we are all working through our unique challenges. Adding my family to the therapy mix was healing for all of us. Cancer therapy for my hubby and children was a game changer for bonding us in a healthy way during and beyond the cancer journey. Many people think healing from cancer is just physical. However, after my journey, it seems the strongest support we can have during the cancer journey is for our mental health."



### **FIND GRATITUDE**

A good first step toward improving mental health is beginning a practice of gratitude. Finding gratitude can help lower anxiety and calm nerves. Fight CRC publishes a 30-day Gratitude Journal. For a free copy, visit *FightCRC.org/Gratitude*.

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## CRAP

### Sugar is the leading cause of cancer.

Tobacco and obesity/being overweight are the leading causes of cancer. Someone may have never eaten sugar in their lifetime, and they can still get cancer. The cells in our body use sugar (glucose) for energy. Cancer cells grow faster than healthy cells, which requires a lot of energy, leading to a belief that sugar "feeds" cancer cells.

There is not strong evidence that cutting sugar out of your diet will prevent cancer or stop cancer cell growth. However, too much sugary foods or drinks can cause weight gain or obesity, which can contribute to cancer risk. But sugar by and of itself does not cause cancer.

#### What to do?

Focus on maintaining a healthy weight by obtaining nutrients from all sources available to fuel healthy cells. Physical exercise will help. Your healthy cells will stay with you once cancer is gone. Your job is to keep those cells healthy and strong as you fight cancer. Have those treats (in moderation!). But also get sugars through fruit, vegetables, lean proteins, lean dairy, whole grains, beans, legumes, nuts, and seeds.

### **Download**

### **Fact or Crap Food Guide**

**DEVELOPED IN PARTNERSHIP** WITH ONCOLOGY NUTRITIONIST **NICHOLE ANDREWS** 





### Red meat is a good source of protein.

Protein is needed for body's maintenance, growth, and repair. Your body needs an increase in protein while undergoing treatment or following surgery. If you are getting your protein through a steak. that's OK. Get your protein through your food, and from whatever is appetizing and nourishes vou.

High levels of red meat consumption have been associated with colorectal cancer, however most people do not eat a steak for dinner every night. You can have red meat, in fact, you can have a serving-size steak three times a week and not reach 18 oz. Keep in mind that there are less inflammatory options for protein, such as poultry, fish, eggs, and some dairy products. Plant sources of protein include nuts, seeds, tofu, legumes, and grains. Some vegetables contain a small amount of protein. Fruits and fats don't provide any protein.



# SHOULD YOU BE WORKING?

Many patients diagnosed with cancer have not yet reached retirement age, and they face the dilemma of work. Some continue working following a diagnosis, and others find that making some type of a career change, or ending employment, is necessary.

Someone's job can be a key piece of their identity; how often do you meet someone and ask, "What do you do?" to get to know them? A lot. That's why making decisions about work needs to be done carefully. We suggest having a conversation with members of your health care team about this.

#### ASK:

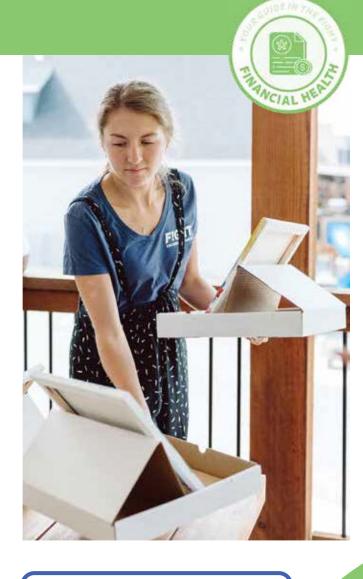
- When and how often will I need treatment?
- If surgery is needed: What is the estimated recovery time and are there any physical limitations for an extended amount of time?
- When are side effects likely to kick in? What are those side
- Do you think my immune system can handle working? (Describe vour daily responsibilities in detail and if you use mass transit to get to/from work.)
- If I do choose to keep working, what are the risks?
- What are signs that I should consider either not working, or finding a different role?

#### **MAKING YOUR DECISION**

The choice to work is up to you, and there are many variables to consider. Here's a few things to talk through with your friends and family:

- Accommodations: Does your employer offer the option of a flexible schedule that could work around your treatment plan? Are there any opportunities to work virtually, eliminating a need for travel and possible germ exposure? Are there any other reasonable accommodations to request in order to continue workina?
- Financial Review: Do you have insurance through your employer? What is your company policy on sick time? If you cannot perform your current role, is there another role that you could take on that's more suitable to your needs?
- Self-Assessment: Ask yourself hard questions before making a decision. What do I want to give my energy toward? What do I need to feel fulfilled? Is work going to help or hinder my physical and mental health? Will quitting my job lead me to an identity crisis, or will it give me freedom? What are my career priorities now that I've been diagnosed with cancer? What are my financial needs? Am I responding or reacting? (Tip: Don't react)

Whether you choose to work or not, make sure you have people and activities in your life that will both give you the support you need, but also offer ways for you to contribute and help others.



### **Ouick Guide: Employment** and Legal **Acronyms**

A discussion about work often brings up legal rights and responsibilities. As you're exploring your options, these programs may come up.

ADA: Americans with Disabilities Act

FMLA: Family Medical Leave Act

**SSDI:** Social Security Disability Insurance

In addition to speaking with HR, you can ask a social worker at the hospital for assistance. Our partners at Triage Cancer (triagecancer.org) and Cancer & Careers (cancerandcareers.org) also have a wealth of resources for you.

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# **Pro Tips**

End-of-life planning



### **KRYSTAL GURNELL**

Caregiver

"A caregiver should respect the patient's wishes, whether those are communicated verbally or through other means, like through a living will or a medical power of attorney. My mother shared her detailed wishes for care with my father in person. That allowed us to advocate effectively for her in a united front when she received medical care. We also reminded the medical staff to respect her privacy and stay HIPAA compliant."

#### **JEN FRENCH**

Caregiver

"I know when you're initially diagnosed, you're not trying to think like this, but it's important to plan, especially if you have a stage IV diagnosis: family planning, personal planning. It's important to not wait until it's a little too late. My wife and I didn't want to have these conversations, but it was important to discuss these things in our relationship."





#### TAMI PANGELINA

Caregiver

"It's very important to have clear and open conversations about your loved one's wishes regarding medical treatment and care. This includes discussing advanced directives, such as living wills and health care power of attorney, which outline the patient's desires for medical treatment if they become unable to communicate their decisions—which is what happened to my nephew Daniel at the end. It is a very hard and difficult task, and I have to relive that all the time. Additionally, understanding their preferences for pain management, hospice care, and emotional and spiritual support can ensure their end-of-life experience aligns with their values and desires. It was essential to document his decisions and to share them with all relevant parties to avoid confusion."

#### **ZAKELA MICKENS**

Caregiver

"I was my brother's caregiver. At the time, it was something so new to us. We didn't know anyone with a direct connection to colorectal cancer at the time. My brother was really young, and in his mind, you get chemo, and then cancer's over. I was not prepared for the mental rollercoaster he would go on. I didn't know what he was dealing with. I saw his mental health really decline before he came to grips with what was happening to him. I was saying cliche things. Once the disease progressed, I was not prepared for what happened to him mentally. For the most part, providers didn't explain it. I had to call family to come help me."





### **ERIC HAUSMANN**

Caregiver

"The biggest issue for me as a caregiver was denial. I thought I was mentally prepared for my wife Rose's death, but I really wasn't. She had such energy that I guess I thought, 'We don't need to talk about this right now,' when I should have talked to her about it well before her death. I believe she was mentally prepared, but I wasn't. When it happened, people were asking if she wanted to be buried or cremated, and I did not know. I know she told me, I just thought, 'we do not need to be discussing that now' when we talked about it. So as a caregiver, we need to listen to the patient more even though we might not want to hear it. These issues must be talked about and written down if possible."



Can you give me a checklist of what I need to pull together to have my affairs in order?

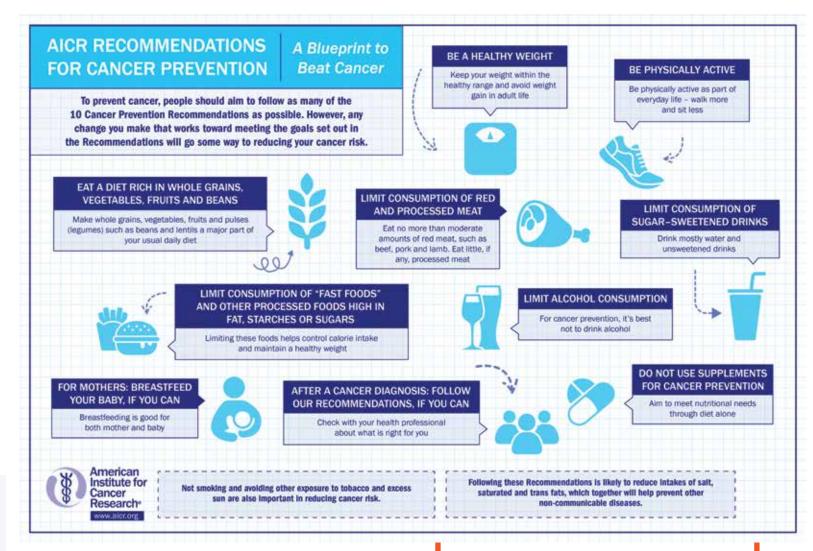
\*ChatCRC is Fight CRC's chatbot that provides instant information about colorectal cancer resources & support. Start chatting by visiting Chatbot.FightCRC.org



In a study that tracked the lifestyles and quality of life of nearly 1,100 people over 10 years, researchers at the American Institute for Cancer Research (AICR) found that colorectal cancer survivors who closely followed the Cancer Prevention Recommendations were more likely to have a better quality of life compared to those who did not follow them.

Survivors who followed the recommendations had overall health and cognitive function and less fatigue. Physical activity had the strongest influence on their scores.

AICR and the World Cancer Research Fund International (WCRF) have packaged the following recommendations.





Does your team or this health system offer any resources that can help me stick to a lifestyle focused on cancer prevention?

Join the Fight at FIGHTCRC.ORG

Join the FIGHT Get RESOURCES

## **BE A CHAMPION**

Are you ready to become a relentless champion alongside Fight CRC? We have many ways for you to get involved!



### **Volunteer**

From serving on our Gratitude Team, delivering education as a Resource Champion, or working in-person events and representing Fight CRC, volunteers carry our heart and soul. To get started, fill out a volunteer application at FightCRC.org/Volunteer



### **Fundraise**

Celebrate your birthday by raising money, or rally your loved ones to support Fight CRC! As a nonprofit organization, we depend on the generosity of people ready to invest in the cause. To see all the ways you can give and fundraise, go to FightCRC.org/Fundraise



### Advocate

As the leading patient advocacy organization in the U.S., we insist Congress hears our voices. In addition to having a full-time presence in Washington, D.C. and hosting our annual Call-on Congress, we send out appeals with requests to email members of Congress. We also train up research advocates who serve as the squeaky wheels when it comes to clinical trial design and the scientific community. Learn more at FightCRC.org/Advocacy

### **Share Your Story**



Thousands of patients and caregivers find their way to Fight CRC each month looking for stories of hope. Our Champion Stories do just that. By sharing your story, you'll help someone realize they're not alone. You'll inspire them to reach out and connect. If you're ready to share your story, submit it at FightCRC.org/Story



ANTONIO DIONIZIO Previvor

"Call-on Congress had a major impact on me and my advocacy. Advocacy impacts me greatly because it helps me express my concerns about the underfunding of colorectal cancer research and helps me to fight for what's right within the CRC community. It's about empowering my voice caregivers, loved ones, etc."

to get what I want as a human. Meeting members of Congress and their staffers has made it easier to talk to others about CRC and tell my story while also hearing other people's stories. It allows me to see how it affects others' lives from survivors,

### **CLINIC RESOURCES**

In addition to *Beyond Blue*, Fight CRC offers a wide library of free resources covering various topics patients and caregivers face, and we offer bulk resources to clinics and volunteers needing supplies for education and awareness events. Print resources are available in English, Spanish, and Chinese.



### THANK YOU TO OUR SPONSORS!







### **SUBSCRIBE TO BEYOND BLUE**

Beyond Blue is written for patients and caregivers—by patients and caregivers. It is published each fall and spring, and is mailed to homes and clinics for FREE.

Scan to subscribe or request free resources, or email Zac Getty at Zac@FightCRC.org.





Join the Fight at FIGHTCRC.ORG BEYONDBLUE



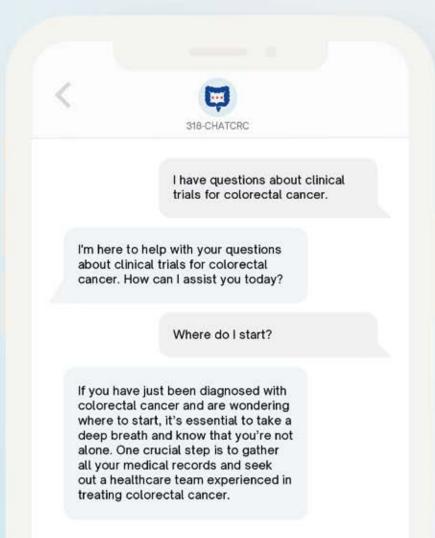
134 PARK CENTRAL SQUARE #210 SPRINGFIELD, MO 65806

# **Got Questions? Text us 24/7.**

(OR VISIT CHATBOT.FIGHTCRC.ORG)

318-242-8272

Text us from anywhere—the doctor's office, your car, or even the toilet. (Yes, seriously).



# Save Our **Number!**



U.S. patents pending.