

F!GHT
★
COLORECTAL CANCER



SIDE EFFECTS

Managing Side Effects of Colorectal Cancer Treatment

SIDE EFFECTS

The purpose of this resource is to help you learn about the potential side effects of colorectal cancer treatment. In this magazine, you will read about a variety of side effects, why they happen, and tips for how to manage them.

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COVER:
Helen Norris
Stage IV survivor

FIGHT CRC

ABOUT FIGHT COLORECTAL CANCER

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.

MEDICAL DISCLAIMER

The information and services provided by Fight Colorectal Cancer are for general informational purposes only and are not intended to be substitutes for professional medical advice, diagnoses, or treatment. If you are ill, or suspect that you are ill, see a doctor immediately. In an emergency, call 911 or go to the nearest emergency room. Fight Colorectal Cancer never recommends or endorses any specific physicians, products, or treatments for any condition. This mini magazine does not serve as an advertisement or endorsement for any products or sponsors mentioned.



LOOK FOR THE ICONS



Try This at Home



Things to Avoid



Prescription Help



Write this Down



Over-the-Counter Help



Call Your Doctor

SIDE EFFECTS BY COMMON TREATMENT TYPE

ON THE NEXT FEW PAGES, you'll find brief information about general side effects caused by certain treatment types. Later in this magazine, you'll find specific information about side effects and how to manage them.

CHEMOTHERAPY

Chemotherapy attacks all rapidly dividing cells. This means healthy cells from all over the body may be affected, sometimes resulting in unpleasant side effects.

Side effects will depend on how your chemotherapy is given and the type of chemotherapy drug(s) you receive. Symptoms vary from person to person and from infusion to infusion.



Pay attention to your reactions to treatment and record when they occur.

Common side effects of chemotherapy include:

- Low red or white blood cells
- Low platelet count
- Mild-to-moderate diarrhea
- Mild-to-moderate nausea and vomiting
- Mouth sores
- Sensitivity to light
- Hand-foot syndrome
- Cancer-related fatigue

Rare side effects of chemotherapy include:

- Skin and nail changes
- Hair loss
- Liver and kidney damage
- Early menopause
- Secondary cancers

While it's uncommon, a small number of the population (about 2-8%) have Dihydropyrimidine dehydrogenase deficiency (DPD deficiency), which makes their bodies unable to metabolize, or break down, 5-FU or capecitabine (Xeloda®). This inability to break down these drugs can cause them to build up in the body, reaching toxic levels and leading to serious side effects like organ failure, septic shock, or death. If you experience moderate-to-severe side effects, even if it's on your first or second chemotherapy treatment, call your healthcare provider as soon as possible.

Here are some side effects that could be a sign of Early-Onset Severe Toxicity:

- Severe nausea - prevents you from eating or drinking
- Severe vomiting - 6+ times daily
- Diarrhea/incontinence - loose, watery, and more-frequent or uncontrolled bowel movements
- Mucositis - oral and/or anal that interferes with eating and drinking
- Stools that are tarry and black, or vomit that is black
- Severe hand-foot syndrome that interferes with daily activities
- Irregular heart beat, chest pain or heart attack, acute pulmonary edema, congestive heart failure, cardiac arrest
- Dizziness, disorientation, seizures, coma

To reduce further toxicity from occurring, uridine triacetate (Vistogard®) may be administered within 96 hours of your last 5-FU or Xeloda® treatment.

SURGERY

Surgery is often the main treatment for earlier-stage colon cancers, and is often the main treatment for rectal cancers. It's important to plan ahead for surgery:

- Let you employer know. Take off time as needed.
- Schedule childcare and discuss any needs they may have and how you can plan for them.
- Set up care for your pet(s).
- Talk to your doctor about “pre-hab” or a pre-rehabilitation program to help your post surgery recovery.

• Side Effects •



Be on alert for anything unusual that your doctor didn't warn you about.

NEVER hesitate to call your treatment team. Be extremely vigilant in reporting ALL side effects, especially if the drugs you are taking to manage a side effect are not working.



Victor Menoscal, Stage IV survivor

Surgery side effects could include:

- Feeling tired or weak; Cancer-related fatigue
- Bowel irregularities
- Changes in sexual function and/or fertility
- Pain
- Scarring
- Infection
- LARS (more information on page 15)

RADIATION

Radiation is used to destroy cancer cells, but it can also damage healthy cells and tissues near the treatment area. Side effects should subside after your treatment ends. Contact your doctor if any symptoms persist or become uncomfortable.

Side effects could include:

- Fatigue
- Skin irritation including redness, peeling, burning, scarring
- Joint stiffness caused by hardening of the muscle and ligaments
- Infertility
- Secondary cancers
- Bowel irregularities
- Feeling like you have to urinate often
- Nausea

IMMUNOTHERAPY

Immunotherapy has only been shown to be effective in a small subset of colorectal cancer patients. Specifically, patients with certain biomarkers (microsatellite-instability or mismatch repair deficiency).

Side effects of these drugs can include fatigue, cough, nausea, itching, skin rash, decreased appetite, constipation, joint pain, and diarrhea. Other rare but serious potential side effects are cardiac toxicity (heart damage) and Graft-Versus-Host Disease (which occurs when the body's immune system begins to fight itself).



John MacLeod, Stage IV fighter

WHEN TO CALL YOUR DOCTOR

Don't hesitate to call your doctor at any point during cancer treatment.



Contact your medical team or go to the ER if:

- Your temperature is higher than 100.5 °F
- You have signs of an infection (e.g.: sore throat, chills, painful urination)
- You feel incoherent or have changes in consciousness
- You have unusually severe digestive side effects
- You have pain in the chest or develop an irregular heartbeat
- You see unusual or severe skin peeling that begins earlier than expected

Call your doctor if you have blood in your vomit or stool. If you are dizzy, lose consciousness, or are unable to keep fluids down due

to nausea and vomiting, call 911 or head to the closest emergency room. Upon arrival, inform staff that you are a cancer patient undergoing treatment and need to be seen immediately.

CLASSIFICATION OF SIDE EFFECTS

You may hear your doctor refer to “grades” as it relates to side effects. This is in reference to the National Institutes of Health (NIH) Common Terminology Criteria for Adverse Effects (AE) that was developed as a way to accurately report side effects of drugs used in cancer treatment. In this criteria, a grading system is used. The chart below will help you understand those terms.

GRADE	DESCRIPTION
Grade 1	Asymptomatic (no symptoms), mild, clinical, or diagnostic observations only; intervention not needed
Grade 2	Moderate or minimal; local or noninvasive intervention needed
Grade 3	Severe or medically significant, but not immediately life threatening; hospitalization may be needed. Disables or limits self-care and daily activities
Grade 4	Life-threatening consequences or urgent intervention needed
Grade 5	Death related to adverse effect



SIDE EFFECTS 101

THERE ARE OVER ONE MILLION COLORECTAL CANCER (CRC) survivors in the United States. A cancer survivor is anyone who has been diagnosed with cancer – from the time of diagnosis and for the balance of his or her life.

If you're reading this, it's likely you've been impacted by cancer.

Most people diagnosed with CRC receive a combination of treatments to tackle the disease. Standard treatments have gone through clinical trials to test their effectiveness as well as safety, and to monitor and track side effects (also called adverse events).

Side effects can appear during treatment, after treatment, or years later. The National Institutes of Health describe them as “any unfavorable and unintended sign, symptom, or disease temporally associated with the use of a medical treatment or procedure that may or may not be considered related to the medical treatment or procedure.”

Although everyone experiences side effects differently, side effects can cause challenges to activities of daily living and reduce quality of life.

This magazine focuses on the common side effects CRC patients and survivors face, and provides useful tips for how to manage them. For more information, visit www.FightCRC.org

This magazine is not intended to replace medical advice. If you are experiencing side effects, it is imperative to talk to your treatment team.

TIPS TO GET STARTED:

1 Ask your medical team what side effects you should expect during and after treatment.

2 Talk to your doctor about adding a palliative care expert to your team. Palliative care is for any patient who finds that the side effects and stresses of their cancer are having a significant negative impact on their quality of life. It doesn't matter what the cancer stage



Side effects, also known as adverse events, can appear during treatment, after treatment, or years later.

Lindsay Norris, Stage III survivor

is. The earlier a patient with colorectal cancer can get palliative care, the better. Ask your cancer team for a referral.

3 Tell your medical team whenever you have a side effect so they can monitor and help manage symptoms.

If something is out of the norm, wasn't described to you as a possible side effect, or is severe, contact your medical team immediately or call 911.

4 Keep a notebook where you can track your side effects and the things that help you manage them.

5 Remember, you're not alone.

Reach out for support from family, friends, support groups, or online.

To find resources, visit [FightCRC.org](https://www.fightcrc.org) or call the Fight CRC Resource Line at **1-877-427-2111**.

What is Quality of Life (QOL)?

Simply put, QOL is your standard of health, overall enjoyment of life, sense of well-being and ability to engage in the activities you enjoy. There are four major areas of wellbeing associated with QOL: physical, social, psychological, and spiritual.



Rev. Roland Cooper, Stage II fighter

CANCER-RELATED FATIGUE

CANCER-RELATED FATIGUE (CRF) is different from “normal” fatigue. Here’s how:

- It doesn’t get better with rest
- It lasts longer (from months to years)
- It’s unpredictable
- It does not go away with a cup of coffee
- It comes on suddenly with a feeling of being totally wiped out

There are many reasons for cancer-related fatigue including but not limited to: infection, dehydration, depression, anemia, poor diet, and loss of muscle mass. It’s important to let your doctor know what symptoms you experience so they can consider if any additional testing or treatments are necessary.

After cancer treatment ends, be patient. Regaining energy levels to what you consider “normal” can take time.

SIGNS AND SYMPTOMS

YOU FEEL:

- Tired/sleepy (and it doesn't go away with rest)
- Slow, weak or out of energy
- A sense of heaviness
- Restless and have a hard time sleeping
- Irritable

YOU SPEND:

- More time in bed
- Less energy on your appearance
- You have a hard time focusing, concentrating, remembering things

7 TIPS TO MANAGE CANCER-RELATED FATIGUE:

1 EXERCISE – One of the most effective ways to increase energy is exercise. You might feel like you don't have the energy to work out, and that's okay. Start small, with a short walk around the block. Exercise can truly help. Talk to your doctor to create a healthy exercise plan, then grab a friend or family member to exercise with you!

2 CONSERVE YOUR ENERGY – Prioritize activities most important to you.

3 RELAX OR NAP – Try meditation or deep breathing. Take short naps in the late morning or early afternoon (no later than 3 pm or you may affect your night's sleep.)



4 GET RESTFUL SLEEP – Make adjustments to your sleep routine try to improve your sleep as small changes might help you get a better night of sleep. Below are some tips:

- Relax before bed with no television or device (smartphone, tablet, or computer) surfing to prepare your body for sleep.
- Try not to look at the time in the middle of the night as this may make you feel restless.
- Avoid caffeine and alcohol in the afternoon.
- Exercise, but not too close to bedtime.

5 EAT WELL – Get a referral to see a registered dietician who will help you choose foods to increase energy.

6 TALK – Stay socially connected with friends and family members.

7 INVOLVE YOUR SENSES – Start the day with enough light to tell your biological clock that it's time to wake up. Open the blinds, turn on some lights. Throughout the day, get some fresh air to improve your energy.



BOWEL IRREGULARITIES

IF YOU'VE BEEN DIAGNOSED WITH COLORECTAL CANCER, you know that talking about poop (#2, bowel movements, s#!t, etc.) comes with the territory.

Before beginning treatment, get to know your current pattern of daily stools (i.e. how many per day and consistency) to use as a baseline. If you have an ostomy, track the consistency and output. This will help you know if something changes with your bowel habits during or after treatment.

CONSTIPATION

SIGNS AND SYMPTOMS

- Passing fewer than three stools per week
- Having very hard stools or blockage
- Symptoms lasting more than 3 months are considered chronic

5 THINGS THAT COULD LEAD TO CONSTIPATION:

BLOCKAGE – something physically prevents stool from leaving body (like a tumor)

DEHYDRATION – makes stool hard to pass

RECENT SURGERY – the body needs time for “normal” bowel function to return

MEDICATIONS – Some anti-nausea and vomiting medication can lead to constipation. Additionally constipation is a common side effect of opioids used to manage pain.

OTHER REASONS – nerves, hormonal imbalances, age, diet, lack of activity

Managing constipation is often a combination of lifestyle changes and medication, such as a laxative or stool softener.



HERE ARE SOME THINGS TO DISCUSS WITH YOUR DOCTOR:



OVER THE COUNTER:

- Osmotic laxatives, like MiraLax®
- Stimulant laxative, like Senna
- Stool softener, like Colace®
- Bulk-forming agents, like Metamucil®
- Your doctor may recommend an enema. Talk to your oncology team or primary care provider about manual fecal evaluation.



DIET AND LIFESTYLE:

- Prunes and prune juice
- Exercise
- Insoluble fiber (like rice and barley)
- Stay hydrated



PRESCRIPTION:

Opioid-induced constipation may be treated cautiously with a prescribed medication.

DIARRHEA

Diarrhea is extremely common. Chronic diarrhea affects 13-50% of survivors up to 10 years after treatment. Chemotherapy can disrupt the gastrointestinal mucosa, making it hard for the body to “bulk” stool. Radiation inflames the mucosa, causing a similar effect.



If you're experiencing diarrhea, you're not alone.



SIGNS AND SYMPTOMS:

- 7+ loose or watery stools a day
- Abdominal cramping
- Nausea and vomiting
- Dehydration
- Feeling weak or dizzy upon standing

CALL YOUR DOCTOR IF YOU HAVE THE FOLLOWING:

- Abdominal cramping
- Diarrhea gets worse or doesn't improve after two days
- Dehydration (see page 15)
- Diarrhea every hour
- Fever of 100.5 °F
- Black, bloody, or bright red stool

TIPS FOR MANAGING DIARRHEA:



OVER THE COUNTER:

- IMODIUM® (loperamide) or other anti-diarrheal medications
- Fiber supplement like Metamucil® (talk to your doctor first)
- Probiotics



PRESCRIPTION:

- Sandostatin® (octreotide)
- Diphenoxylate-atropine (Lomotil)

Talk to a registered dietician (RD) or a board-certified specialist in oncology (CSO). To find one, reach out to your cancer treatment hospital or cancer center.

DIETARY TIPS FOR MANAGING DIARRHEA:

- Choose beverages with sodium and potassium to replace lost minerals
- Tell your RD if you're taking herbs or dietary supplements (some cause diarrhea)
- Sip warm liquids slowly throughout the day
- Eat small meals and snacks regularly to avoid giving your digestive tract too much food at once
- Snack on dry, salty foods like saltine crackers or dry toast
- Eat well-cooked, peeled fruits and vegetables. You can add

them to soups or smoothies to break down insoluble fiber for easy digestion

- Eat plain yogurt with live active cultures – avoid other dairy products
- Eat more soluble fiber, like oatmeal or oat bran, bananas, and applesauce (avoid beans – they can worsen symptoms)

FOOD TO AVOID:

- Hard-to-digest foods like popcorn, corn, raw vegetables, and “gassy” vegetables (broccoli, cauliflower, cabbage, Brussels sprouts, leeks, etc.)
- Spicy foods
- greasy foods
- alcohol
- caffeine
- sugary foods/drinks

FECAL INCONTINENCE

Fecal incontinence is the inability to control your bowel movements.

You may have problems regaining control of your bowels during and after treatment – especially if you’ve had an ostomy reversal or radiation to treat rectal cancer.

SURGERY – Your pelvic floor muscles and rectum haven’t been put to use for awhile. Like any muscle, exercise can make it stronger. Talk to your doctor to learn about pelvic exercises to regain bowel control.

RADIATION – Doctors are diligent to target only the tumor and surrounding rectum with radiation; however, it’s nearly impossible to avoid damaging healthy tissue.

Try the same tips and tricks for diarrhea, as these could help manage fecal incontinence.



Rachell Allen, Stage IV survivor

Eat small meals and snacks regularly to avoid giving your digestive tract too much food at once.

LOW ANTERIOR RESECTION SYNDROME

LOW ANTERIOR RESECTION SYNDROME (LARS) IS A GROUP OF symptoms that occur following low anterior resection of the rectum. This is a type of surgery involving the resection or removal of part of, or the entire, rectum (last 6-8 inches of the large intestine with an anastomosis or “hook up” of the colon low in the rectum). Anastomosis means that the two remaining ends of the large intestine and the rectum are sewn or stapled back together.

SIGNS AND SYMPTOMS OF LARS:

- Frequency or urgency of stools, largely due to the fact you have less space to store stool after removing part of the rectum
- Clustering of stools (many bowel movements during a few hours)
- Fecal incontinence (lack of control over bowel movements)
- Constipation for more than a few days, followed by multiple bowel movements a few days later
- Increased gas
- Abdominal pain
- Small risk of urinary and/or sexual function due to nerve damage
- Dietary changes: to help with urgency and incontinence (Eating small, frequent meals and staying away from gas-causing foods like cabbage, beans and fried foods).
- Use of medications and over-the-counter drugs: to help with incontinence (Imodium for clustering, Metamucil® as a fiber supplement, for example).
- Counseling: For some, talking about the challenges that result from LARS can really help ease stress and shift the focus to other things in life.
- Stool training and biofeedback: These are non-surgical therapies that can retrain your muscles to manage bowel dysfunction like fecal incontinence and constipation. Essentially, you learn through reinforcement how to train the muscles in your bowel to normalize function. A physical therapist can help you with these practices.

Managing the symptoms of LARS can be difficult, and everyone experiences the symptoms differently. Symptoms for some can last many years. **Here are some ways many patients are managing LARS:**

- Kegel exercises: to help to strengthen muscles. (To do this, tighten your muscles like you are trying to hold back a bowel movement. Hold this position for 5 to 10 seconds. Release and rest. Repeat.)
- Carrying a survival pack: because you never know when you might need one! You may consider including flushable wipes, clean underwear, plastic bag, hand sanitizer, etc.

CHEMOTHERAPY-INDUCED NAUSEA AND VOMITING (CINV)

ALTHOUGH it may feel like motion sickness, CINV isn't triggered by motion changes. It's activated by the gastrointestinal (GI) tract that sends a message to the brain – leading to the uneasy, queasy feeling. If left untreated, vomiting can lead to dehydration, or even reopening of surgical wounds.

TYPES OF NAUSEA AND VOMITING

Acute	Starts within 24 hours after a chemotherapy treatment
Delayed	Starts more than 24 hours after a chemotherapy treatment
Anticipatory	Starts before chemotherapy begins; triggered by smells, sounds, and reminders of previous chemo rounds
Breakthrough	Starts even if medication is taken to prevent it
Refractory	Nausea and vomiting that doesn't respond to drugs
Chronic	Ongoing



Dopamine receptor antagonists, like haloperidol (Haldol®)

- 5-Hydroxytryptamine₃ (5-HT₃) serotonin receptor antagonists, like ondansetron (Zofran®)
- Benzodiazepines (lorazepam (Ativan)), taken before chemotherapy treatment to reduce anticipatory nausea
- Dronabinol (Marinol®) or nabilone (Cesamet®) are cannabinoids that may be used (see note about medical marijuana on page XX)



Antihistamines like hydroxyzine (Atarax®, Vistaril®), diphenhydramine (Benadryl®)



Add ginger to your diet, but only the real stuff (not artificially flavored). Try ginger tea (you can make your own with fresh ginger) or dried ginger candies

- Use acupressure bands, which stimulate points on the wrist to reduce nausea
- Follow the BRATT diet: bananas, rice, apple, tea, toast
- Stay hydrated
- Suck on peppermint candies
- Drink fennel tea
- Sip on a cold, carbonated beverage (non-alcoholic)
- Try acupuncture
- Use aromatherapy – try ginger, nutmeg, or peppermint

Call your doctor if you become dehydrated or symptoms do not go away or improve within 24 hours of taking anti-emetics (drugs used to treat nausea and vomiting).

DEHYDRATION

BE MINDFUL OF YOUR FLUID INTAKE! Drink water throughout the day and eat foods with high water content. If not monitored, dehydration can be life threatening.

SIGNS AND SYMPTOMS:

- Extreme thirst
- Fever
- Rapid heartbeat
- 8 hours or more without urination
- Very concentrated urine/small volume
- Sunken eyes
- Low blood pressure
- Disorientation or confusion

TIPS TO AVOID DEHYDRATION:

- Drink a glass of water first thing in the morning
- Carry a water bottle with you throughout the day
- Drink coconut water or an electrolyte drink (like Gatorade or an electrolyte enhanced water)
- Suck on ice chips or popsicles if you have trouble drinking or eating
- Eat foods with high water content: soup, watermelon, tomato sauce
- Use moisturizer for cracked lips
- Ask your doctor about sodium supplements which help the body retain water

*Your doctor may recommend an oral rehydration solution if you're not vomiting or experiencing diarrhea.

*Severe dehydration may require fluids to be given intravenously by your treatment team.



Carry a water bottle with you throughout the day!





PAIN

THERE ARE MANY TYPES OF CANCER PAIN AND MANY ways to manage it. Pain can result from therapies, surgery, and even the cancer itself.

Discovering a pain management plan that works for you might take time. Don't get discouraged. Not all patients get relief from the same treatments, but your medical care team will do their best to get you comfortable by trying a variety of approaches until one works for you.



When you begin to experience pain, track the following to update your medical team:

- Did the pain begin after chemotherapy, radiation, surgery?
- What makes it better or worse?
- What time of day is it better or worse?
- What have you tried to ease the symptoms? (When you move a certain way, does it get better?)
- Does it prevent you from your daily activities?
- Is this pain that existed prior to your cancer diagnosis?

SYMPTOMS OF PAIN

COMMON PRESCRIPTION TREATMENT OPTIONS

Neuropathic Pain

(see neuropathy on page 23) Nerve pain that is described as sharp, burning, very sensitive, annoying, painful, itching



Antidepressants are often used in smaller doses than when used to treat depression



Anticonvulsants while primarily used to control seizures, some anticonvulsants have effects on the nervous system that could also help lessen pain.



Sodium channel blockers, like lidocaine packs, work by stopping nerves from sending pain signals.



Opioids may be used to manage severe pain



Cannabis and cannabinoids (medical marijuana) may help ease pain

Somatic Pain

Muscle, tissues, or bone pain; stabbing, aching, throbbing



Anti-inflammatories like aspirin, ibuprofen, and Celebrex®. Talk to your doctor before taking an anti-inflammatory, as they can cause negative reactions with some prescription drugs.



Steroids, such as dexamethasone (Decadron®), prednisone



Opioids, such as for severe pain



Cannabis and cannabinoids, such as medical marijuana

Visceral Pain

Pain within the organs of the body



Opioids, such as for severe pain



Cannabis and cannabinoids, such as medical marijuana

Talk to your doctor about side effects that may arise as a result of your pain medications. This could include anything from dry mouth and drowsiness, to more severe effects like changes in blood pressure and liver problems.



NON-PRESCRIPTION WAYS TO TREAT PAIN:

Many CRC patients seek complimentary methods of addressing pain. According to the American Society of Clinical Oncology, “integrative medicine is a combination of medical treatments for cancer and complementary therapies to cope with the

symptoms and side effects.

You may sometimes hear integrative medicine called complementary and alternative medicine (CAM).”

Talk to your doctor before seeking CAM. Make sure the professionals you work with (acupuncturist, massage therapist, etc.) have had plenty of experience working with cancer patients.

Not all patients get relief from the same treatments, but your medical care team will do their best to get you comfortable by trying a variety of approaches until one works for you.

COMMON CAM THERAPIES THAT COULD HELP MANAGE PAIN

Relaxation Techniques	Guided imagery, meditation, hypnosis, and biofeedback can help to redirect the mind from pain and discomfort.
Massage	For cancer patients, massage is aimed at relieving nausea, pain, neuropathy, stress, or anxiety and typically uses a gentler approach.
Heat	Topicals like menthol or capsaicin are available as lotions and creams to reduce pain. They increase blood circulation, causing a warm feeling. If it is uncomfortable, stop use. Keep away from eyes, mouth, and rectum, and steer clear of broken skin or rash.
Cold	A frozen gel pack or bag of frozen peas may ease pain. Be sure to wrap the frozen gel pack or frozen peas in a towel so it doesn't touch the skin directly, and don't use for more than 5-10 minutes at a time. Stop use if you begin to shiver or feel uncomfortable.
Acupuncture	Acupuncture applies tiny needles and pressure on strategic points on the skin. Studies suggest that acupuncture can reduce pain, stress, and anxiety.

A Special Note About Opioids:

Cancer pain may be relieved in 90% of patients with an opioid-based analgesic regimen, following specific guidelines described by the World Health Organization. For first-line opioids for cancer pain, many doctors will prescribe oxycodone or hydromorphone.



If you are prescribed an opioid containing acetaminophen, aspirin or ibuprofen, talk with your doctor or pharmacist before taking these in addition to your opioid prescription.

**This includes most cold medicines and medications to relieve menstrual cramps.*

People who take opioids long term may become physically dependent on them; however, studies show that a cancer patient becoming addicted to opioids after treatment is not

very common. When prescribed an opiate, your doctor will discuss your dosage, duration, follow up and discontinuation of the prescription. If you have a history of substance abuse, tell your doctor to ensure you receive additional counseling.

Special Note About Cannabis and Cannabinoids:

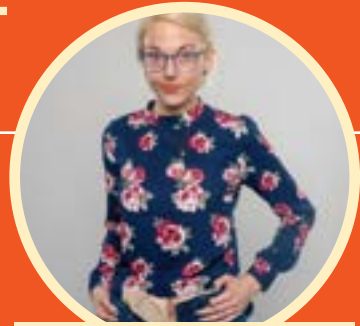
While the benefits of medical marijuana have been well documented among cancer patients and survivors facing treatment side effects, there are some states where it is illegal to obtain and utilize medical marijuana. Talk to your doctor about whether or not this is an option for you. Even in states where marijuana is legal, it is recommended to discuss first with your doctor.

ROBYN'S BATTLE WITH PAIN

Before diagnosis, I was a seemingly healthy young woman with tummy issues. I saw specialist after specialist and was told my symptoms were normal, so I learned to disassociate from the excruciatingly painful rocks in my stomach that rolled around after every meal. I lived with such extreme pain, thinking it was normal.

After diagnosis, it quickly became clear that I needed to tap back into that pain so I could communicate it properly to my medical team. My ability to disassociate from pain was not a super strength in this context, but instead it was confusing both me and my doctors. For some time, I had been rating my pain at a 3 or 4, when in reality, it was more like a 10 or more. I used to be the kind of person who would resist ibuprofen when I had a headache. But these heavy duty medications, I finally accepted, were developed for patients just like me who are in serious pain.

Pain management is not a time for humility – it's a time for honesty. I learned to listen to my body. Admittedly, there was a bit of a learning curve, but now I know when a drug will make me overly nauseous, which ones make me anxious, and my preferred breakthrough medication.



“Pain management is not a time for humility – it’s time for honesty.”

Listen to your body. Pay attention to side effects caused by the pain medication. If one drug leaves you feeling anxious, consider other medications ASAP!

Talk to your doctor about a plan for breakthrough pain. There are times when chronic pain can peak and you may need something to take as needed to knock it back. When you go off pain medications, you may experience withdrawal. Talk to your doctor.

Consider alternative therapies like meditation or acupuncture. I was suspect at first, but I found it so effective for body aches and nausea caused by treatment. Plus, it feels good to pamper your body and mind and just be still for a moment!

- Robyn Schmid Tiffie, Stage IV fighter



NEUROPATHY

NEUROPATHY IS A COMMON SIDE EFFECT FOR THOSE who have received or are currently receiving chemotherapy, specifically oxaliplatin. It is a result of nerve damage and is a notorious chemo side effect. Neuropathy is often felt in the feet first, then the hands. Nerves may regenerate after treatment ends, but it takes time and is dependent on how much nerve damage has been done.

SIGNS AND SYMPTOMS:

- Pain, burning, tingling sensations, “pins and needles”
 - Numbness or sensitivity to cold temperatures
 - Trouble holding onto things with your hands, notably weaker pincer grasp
 - Trouble buttoning shirts
 - Balance problems
 - Weak muscles
 - Trouble swallowing
 - Constipation (see page 12)
- See the table on page 20 for some neuropathy treatment options. Here are additional ideas for managing neuropathy:
- Eat foods at room temperature
 - Use caution when handling scissors, knives, and sharp objects
 - Use caution when handling hot items (like dishes and cooking racks)
 - Wear gloves when grabbing food from the fridge

ACUTE VS. CHRONIC

Acute Oxaliplatin-Induced Neuropathy

- Begins shortly after an infusion
- Gets better within a few days
- Triggered by eating, drinking, or touching something cold, or breathing cold air
- Sharp pain in the mouth or jaw when biting into cold food
- Some patients feel like their throat is closing and they cannot breathe (although breathing isn't actually affected)

Chronic Peripheral Neuropathy

- Risk of long-lasting neuropathy increases as the amount of chemotherapy increases in your body
- Feeling “pins and needles” and/or numbness
- Difficulty doing small tasks with fingers (like buttoning a shirt or tying shoelaces)
- For some, neuropathy causes pain and difficulty with daily life, including walking

- Wear socks, gloves, and blankets in air conditioned rooms
- Find support when walking, use handrails, and sit down when you can
- Wear comfortable, supportive shoes
- Vitamin E, calcium, and magnesium may help

Ask your provider for a recommendation to see an occupational therapist (OT). OTs will help you with daily life activities like taking a shower to avoid slipping) and getting dressed (finger dexterity).

Ask your provider for a recommendation to see a physical therapist (PT). A PT may help you regain function through a variety of exercises and activities.



Nerves may regenerate after chemo treatment ends, but **it takes time** and is dependent on how much nerve damage has been done.

Visit [FightCRC.com](https://www.fightcrc.com) for podcasts, webinars, and blogs with extensive tips and advice for how to manage CIPN!

HAND-FOOT SYNDROME & HAND FOOT SKIN REACTION (HFSR)

Hand Foot Skin Reaction Caused by regorafenib (Stivarga®)

THESE ARE TREATMENT SIDE EFFECTS that show up on the skin on the palms of your hands and the soles of your feet.

SIGNS AND SYMPTOMS:

- Redness
- Swelling
- Blistering
- Stinging, tingling, or burning in fingertips and toes
- Dry, cracked, peeling skin
- Thickened, callused skin

Symptoms usually go away when your treatment dose is lowered or stopped.

TIPS TO MANAGE:

- Use over-the-counter moisturizing creams, or prescription ointments (Eucerin®, Aquaphor®, Udder Cream). Avoid any lotions or creams that include alcohol or fragrances.
- Some patients find relief from petroleum jelly on the skin under white cotton gloves or socks overnight
- Take cool showers, not hot
- Avoid friction, excessive rubbing, scratching and itching of the affected area
- Vitamin B6 (pyridoxine) may help



Sarah DeBord, Stage IV survivor

Leaving thick moisturizers on your skin or open wounds can lead to infections – so clean the area well in the morning.

EPIDERMAL GROWTH FACTOR RECEPTOR (EGFR) RASH

Caused by: EGFR inhibitors like cetuximab (Erbix[®]) and panitumumab (Vectibix[®])

IF YOU'RE ON AN EGFR INHIBITOR, a rash may appear on your face, neck, chest, and/or back. The rash can appear pimple-like and can feel uncomfortable, itchy, and painful.

You may also experience severely dry skin on other parts of your body. Some doctors will prescribe antibiotics for you to take while undergoing this treatment to help minimize the rash and its side effects. Other doctors may suggest you see a dermatologist

while taking an EGFR medication. A dermatologist may recommend prescription creams containing clindamycin or steroids, or a course of oral antibiotics.

If your rash gets really bad (as determined by your doctor) your treatment dose may be reduced. This is because a severe rash can increase your risk of infection.

There are many “do’s and don’ts” that can help you manage EGFR rash. For a detailed list, in addition to more information on this side effect, read the Fight CRC Skin Toxicity Mini Magazine and view the Fight CRC videos about side effects of the skin: FightCRC.org/SkinTox

If your rash gets really bad your treatment dose may be reduced. This is because a severe rash can increase your risk of infection.

HIGH BLOOD PRESSURE

If you're taking bevacizumab, aflibercept, or regorafenib, you may experience high blood pressure. Your doctor will treat this with appropriate medication and may pause your treatment if necessary.



INFECTION



CHEMOTHERAPY CAN DECREASE YOUR WHITE BLOOD cell count (WBC). This complication is called leukopenia.

Your body needs white blood cells to fight infections. Since chemotherapy can decrease your white blood cells, you'r immunity to illnesses and infections is compromised. This can lead to serious, life threatening events.

If your WBC is too low, you may need to wait for it to rise again before your next treatment.

SIGNS AND SYMPTOMS:

- Fever – take your temperature anytime you feel warm or feverish. Contact your healthcare team immediately if your temperature is above 100.5 °F.
- Shaking, chills
- Body aches
- Sore throat
- Shortness of breath
- White coating on your tongue

DO NOT take acetaminophen (Tylenol®), ibuprofen (Advil®, Motrin®) or aspirin to manage a fever or infection without checking with your doctor first.

TIPS TO PREVENT INFECTION:

- Wash your hands frequently
- Avoid being near people who are sick
- Stay out of crowds



Have a conversation with friends and co-workers letting them know that if you/they are sick, you need to make alternative plans to avoid direct exposure.

- Do your best to prevent cuts. If you do cut yourself, clean the area well and apply an antiseptic.
- Avoid raw fish and undercooked meats and eggs. Wash fruits and veggies.
- Avoid community swimming pools, hot tubs, and gyms
- Remind your friends and family to get their annual flu shot.



MOUTH SORES (MUCOSITIS)

MUCOSITIS TYPICALLY PRESENTS 5-10 DAYS AFTER starting chemo and lasts for 7-14 days. It occurs when the mucosal lining of the mouth forms sores.

TO MANAGE MUCOSITIS:



THINGS TO TRY AT HOME

- Cooling the tissues of the mouth and throat with ice chips before and during administration of chemo helps prevent mouth sores. Popsicles can help too. Avoid ice if you're receiving oxaliplatin.
- Keep your mouth moist and clean
- "Magic" mouthwashes can help with pain and healing if sores develop. If your doctor thinks it may work, they will write out the ingredients along with the amount of each ingredient for you.
- Use lip moisturizer
- Use a soft-bristle toothbrush

- Use un-waxed floss
- Apply Vitamin E to open areas
- Eat soft, high protein, calorie-dense foods



AVOID

- Spicy, coarse, rough foods
- Very hot or very cold foods
- Citrus (like tomatoes, lemon, oranges)
- Alcohol and tobacco
- Listerine and similar mouthwashes, especially if you have open sores



PRESCRIPTIONS

- Antibiotics may be prescribed if sores become infected
- Pain killers and antifungals may be prescribed if needed



DRY MOUTH

Caused by: chemotherapy, painkillers, antidepressants, dehydration

DRY MOUTH USUALLY GOES AWAY 2-8 WEEKS AFTER treatment ends; however, the lack of saliva can sometimes lead to dental problems. Try the following tips to avoid dental issues and to improve comfort levels.

TO RELIEVE SYMPTOMS:

- Stay hydrated. Sip water throughout the day.
- Avoid toothpaste and mouthwashes that contain alcohol, which cause more dryness and considerable pain
- Consider using the Biotene® line of products (toothpaste, oral spray, mouthwash, etc.), which are formulated to relieve dry mouth symptoms
- Suck on ice cubes and hard candies, or chew gum to increase saliva
- Acupuncture
- Ask your doctor about medications that stimulate the salivary glands
- Do not smoke or use tobacco
- If you're having a hard time eating due to dry mouth, eat foods that are soft, moist, and room temperature
- Keep your tongue moist

***Before beginning chemotherapy, visit your dentist for additional tips.**

CHANGES IN TASTE



TASTE CHANGES CAN BE ANNOYING AND DISAPPOINTING. Sitting down to your favorite meal, only to have it taste bitter or metallic, can put a damper on dining. In most cases, your taste preferences will return to normal once you've finished treatment.

TIPS:

- Suck on mint or lemon candies before eating a meal
- Eat with plastic or wooden forks or spoons
- If foods taste too sweet, try adding some salt, or try more acidic foods
- Eat foods that smell good – even if you've never tried them before
- Add herbs and seasonings to increase flavor of foods that seem bland, like oregano, basil or cinnamon
- Eat freshly cooked foods rather than canned
- Go for already mild foods like crackers, toast, steamed rice, and yogurt
- Rinse your mouth with a 50/50 baking soda-salt mixture before eating, it might help neutralize the bad tastes
- Substitute eggs, fish, or beans for red meats that tend to taste like metal
- Call your doctor if you've lost weight because you're not eating

FIRST BITE SYNDROME

THIS SYMPTOM IS SOMEWHAT rare but very disconcerting! It's a sharp pain radiating from the salivary glands in the back of the mouth at the first bite of any/all foods; sometimes, it also feels like the jaw is locking up. The symptoms subside after the first few bites. This condition almost always disappears after treatment ends.

TIPS:

- Avoid very hot, very cold, or very sour food or drink which can exacerbate the problem
- Remind yourself of the syndrome before eating or drinking and remember that it will subside very quickly
- A cool cloth over the eyes may help alleviate tear duct pain or discomfort



MOOD CHANGES

MANY PEOPLE WHO ARE DIAGNOSED WITH COLORECTAL cancer experience a range of emotions like sadness and grief that ebb and flow throughout their cancer experience. Cancer treatments, in addition to the cancer diagnosis, can lead to mood changes and mental health side effects, like anxiety and depression, that are important to take note of and bring up with your doctor.

According to the National Comprehensive Cancer Network, Symptoms of mood changes include:

- Feeling down or depressed
- Difficulty concentrating and remembering
- Loss of sexual interest or problems with sexual performance
- Irritability
- Changeable emotions (sudden crying or anger)
- Loss of interest in activities, social events, and socializing
- Changes in sleep (insomnia or excessive sleeping)
- Changes in appetite (overeating or loss of appetite)
- Loss of energy and motivation
- Fatigue
- Feelings of hopelessness or worthlessness
- A feeling that life is not worth living; suicidal thoughts.
- Anxiety
- Increasing interest in alcohol
- Frequent or excessive worry, unease, or fear
- Upset stomach or other physical symptoms
- Panic attacks

Do not ignore feelings and changes in mood and behavior. The first step in treating these conditions is through acknowledgment.

TAKE ACTION

If you're noticing a change in your mental health, there are some things you can do:

- Talk to a mental health professional like a social worker or psychologist. Ask your doctor for a referral if you don't have a mental health professional on your care team already.
- Reach out to family members and friends.
- Ask your health care team about treatments that can help (this may include antidepressants, acupuncture, massage, cannabis and more).
- Call the Fight CRC resources line for short-term counseling and emotional support **1-877-427-2111**
- Join a group (in person, or virtual – Inspire) to talk with others going through similar experiences.
- Take time in the day for deep breathing and relaxation.
- Make plans with a supportive family member or friend to do something you enjoy or experience a new activity
- Avoid alcohol and tobacco products



CHEMO BRAIN

The term chemo brain, also called chemo fog, cancer related cognitive impairment or dysfunction, is used to describe thinking and memory problems that can occur during and after treatment.

SIGNS AND SYMPTOMS OF CHEMO BRAIN MIGHT INCLUDE:

- Being unusually disorganized
- Confusion
- Difficulty concentrating and/or multitasking
- Difficulty finding the right word and/or learning new things
- Feeling of mental fogginess
- Short attention span and short-term memory problems
- Taking longer than usual to complete routine tasks
- Trouble with memory, including remembering conversations



JESSICA'S STORY



I've been living with a stage IV diagnosis since the spring of 2013, so I've been subjected to a wide variety of treatments. Some of them have made it difficult to eat anything at all. But without food, the whole system really breaks down: my stomach gets more upset than ever, I'm irritable and crabby, I sleep a lot more (but the quality of my sleep is poor), I don't feel like exercising... and then I just sink deeper into the emotional and physiological troubles of living with cancer. So, I've found that the best approach for me is to try and eat small amounts of food throughout the day.

First thing in the morning, sometimes before I even get out of bed, I eat something small, reliable, and nutritious. Some days, that means a multigrain toast with avocado or a scrambled egg on top; other days, I reach for oatmeal with a handful of nuts and dried fruit. And yes, many mornings it's a protein bar or protein shake. I try to take at least five bites of this food. And then I repeat the process every two to three hours across the day: just a few bites of something that includes protein, complex carbs and fats. I don't reprimand myself if I

“There are days and weeks when eating large quantities of raw fruits and vegetables just isn't possible — and for some patients it's not possible at all!”

can't finish something or if I'm not eating an optimal diet every single day.

So do what you can to set yourself up for success: find or prep items that you can reach for with little trouble throughout the day. Make eating as easy on yourself as possible. Those little bites will add up and make all the difference, helping to keep you strong as you move through treatments!

- Jessica Martin (left), Stage IV fighter

Fight Colorectal Cancer is a trusted, nonprofit advocacy organization dedicated to empowering patients to be their own health advocates.

RESEARCH

At Fight CRC, we fight to make breakthrough research a reality. We fund innovative research grants, convene meetings with national and global experts on the biggest issues in CRC, and we train survivors and caregivers to be a part of the scientific discussions. To get involved in research and stay up to date on the latest scientific breakthroughs, follow [@FightCRC](#) on Twitter, or visit us at [FightCRC.org/research](#).

ADVOCACY

Are you ready to turn your pain into purpose? By sharing your story and raising awareness, you can help change policy around colorectal cancer. That's what the Fight CRC Advocacy Program is all about! We advocate on Capitol Hill. We engage and teach grassroots advocates like you to get involved in your communities. To learn more about how to raise your voice for CRC advocacy, visit [FightCRC.org/action-center](#).

MEDICAL REVIEWERS

Ashley Glode, PharmD, BCOP
University of Colorado
Skaggs School of Pharmacy
and Pharmaceutical Sciences

CONTRIBUTORS

Jessica Martin, Ph.D.
Fight CRC Research Advocate

Robyn Schmid Tiffie
Fight CRC Research Advocate

DEVELOPMENT TEAMS

Sharyn Worrall, MPH
Andrea (Andi) Dwyer
The Colorado School of Public Health
University of Colorado Cancer Center

Anjee Davis, MPPA

CONTENT

LAYOUT AND DESIGN

Elizabeth Fisher, MBA
Andrew Wortmann
Danielle Burgess
Will Bryan

COVER PHOTOGRAPHY

Travis Howard

RESOURCES

To download or request print materials, go to:
[FightCRC.org/Resources](#)

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134 Park Central Square, Suite 210 • Springfield, MO 65806

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