

Wellness Throughout Your Journey

Your body will undergo many changes and stresses during your treatment and recovery period. Leading a healthy lifestyle before, during and after cancer treatment, will help make your journey easier. Ask questions and learn about the next steps of your care. Knowledge will help you prepare mentally and may reduce some stress.

Nutrition

Good nutrition is a vital part of cancer treatment and survivorship. Healthy eating can improve your strength and energy levels, increase tolerance of side effects, help to maintain a healthy weight, decrease risk of infection, promote healing and lower cancer risk. Certain cancers, including colon cancer, have been linked to obesity and to inactivity. These are two risk factors you can control to help reduce the risk of developing new cancers and live a healthy life. Eating the right foods before, during and after treatment is important for recovery. Be aware that your treatment plan may affect your appetite.

Basic Dietary Guidelines

- **Eat fruits, vegetables and whole grains:** Fruits, vegetables and whole grains are known to contain phytochemicals with antioxidant, antiestrogen and chemopreventative properties. Phytochemicals are compounds produced by plants such as flavonoids, catechins, carotenoids and polyphenols. Fruits and vegetables which have vibrant color or belong to the cruciferous vegetable group (cauliflower, broccoli, kale, etc.) are especially high in phytochemicals. During treatment, soups and smoothies are a great and appealing way to get these nutrients. Strive for 8 to 10 fruits and vegetables daily.
- **Choose whole grains:** They are minimally processed and are high in complex carbohydrates, fiber, vitamins, minerals and phytochemicals.

- **Eat protein:** Protein is needed for many different functions like making genes, blood, tissue, muscle, collagen, skin, hair, nails, hormones, enzymes, nutrient carriers, infection-fighting antibodies, neurotransmitters and other chemical messengers. During cancer treatment (chemotherapy, surgery and radiation), having enough protein is needed for:
 - Repair and recovery
 - Maintaining muscle
 - Helping to restore the gastrointestinal tract
 - Boosting blood counts
 - Healing tissues
 - Boosting the immune system
 - Reducing fatigue

The best protein sources are eggs, fish (wild), poultry, red meat, dairy, legumes, nuts, seeds and whey protein. Avoid processed meats. It is best to find locally sourced and grass fed animal protein.



- **Choose healthy fats:** Fats are essential to health, but it is important to select them wisely. Avoid trans fats (which are created during the manufacturing process; often called hydrogenated oil or partially hydrogenated). Highly processed oils like canola oil, corn oil, soybean oil, vegetable oil, peanut oil, sunflower oil and margarines should be replaced by healthy fats like olive oil, coconut oil, avocado oil, ghee, butter, flax oil, avocados, wild caught fish, olives or nutbutters.

- **Eat fiber rich foods:** Fiber is the part of food that cannot be digested and is found in fruits, vegetables, whole grains and legumes. Start with vegetables first. You should aim to eat 30 to 35 grams of fiber per day. Increase your fiber intake slowly and make sure to increase your fluid intake too.
- **Avoid processed foods and those high in sugar:** Eat whole foods that are minimally processed like a piece of fruit, carrot sticks, or plain yogurt with fresh fruit. Avoid foods that are processed like packaged cookies, snack foods and sweetened soda. Processed foods typically are high in refined sugar, unhealthy fats and calories and are low in fiber and phytochemicals. Processed foods have been shown to be harmful to your beneficial gut bacteria and may put you at greater risk for cancer.
- **Be mindful of your portions:** During treatment it is important to maintain your weight (if you are overweight discuss whether gradual weight loss is appropriate during treatment). After treatment it is very important to achieve and maintain a healthy weight; you should aim for the lower end of a normal BMI. If you are underweight, you may want to increase your portions of healthy foods to gain weight gradually.

Additional Thoughts

- **Organic foods:** There is a great deal of confusion regarding eating organic food. “Organic” is used for foods grown without synthetic pesticides and genetic modifications (GMO). It is also used for meat, poultry, eggs and dairy products that come from animals that are not given antibiotics or growth hormones. The Environmental Working Group (ewg.org) produces an annual list of foods that have higher and lower pesticide residue (the “Dirty Dozen” and “Clean Fifteen”) which can help you focus on which foods to buy organic and which are appropriate to buy conventional.
- **Non-GMO:** GMO products are products that have been produced by modifying its genetic make-up in unnaturally occurring ways. There are many health concerns about consuming GMO products. In fact, over 60 countries in the world do not rate them as safe. In the United States and Canada, GMO products are not allowed in food products that are certified organic. So, the best way to avoid GMO foods is to buy organic or products verified by the “Non-GMO Project”. More information can be found at nongmoproject.org.
- **Soy:** Soy is an excellent source of plant based protein and contains healthful nutrients such as B-vitamins, iron, calcium and isoflavones. Current research suggests that eating several servings of soy a week is safe if the soy comes from whole foods such as soy beans (edamame), tofu and soy milk. Soy products should be organic and non-GMO. You should avoid soy protein powders which are highly concentrated forms of processed soy.
- **Keep hydrated by drinking plenty of water:** Staying hydrated is important since water carries nutrients and waste products in the body, keeps your joints moving smoothly, and aids in body temperature regulation. It is important to increase your fluids when you increase the fiber in your diet. Water is the best way to hydrate your body. Herbal and green tea, non-fat milk and water infused with fresh fruit or cucumber are other options. Limit the amount of high sugar drinks such as soda and fruit juice as well as alcoholic beverages.

Do not hesitate to ask to meet with a dietician to learn more about good nutrition and how to tailor these suggestions to your needs and lifestyle.

Exercise

There is a new concept called “prehabilitation” which is when you focus on making yourself healthier before starting cancer treatment. Research shows that doing this helps with possible side effects as well as emotional and mental balance during and after treatment. Prehabilitation includes nutrition and stress reduction. It also includes exercise.

The benefits of exercise in helping people deal with fatigue, mood swings and other side effects during and after treatment are well-documented. Significant evidence also suggests that exercise may reduce the risk of cancer recurring and make a real difference in survival.

Exercise can take many forms. It can be a special tool at your disposal to empower you. It enhances well-being and makes you feel good. It is a tonic for the mind and body and can help you avoid or reverse weight gain. Even moderate amounts of regular exercise – a half-hour walk every day, a few laps in the pool, yoga or stretching – can make a difference to your physical and emotional health. Research shows that strength training can also be a powerful way to promote your health.

Exercise Tips

- Consult with your health care provider before starting an exercise program.
- Any form of exercise should initially be supervised by a certified trainer or instructor; look for credible exercise programs with licensed professionals in your community who have experience and training in working with people who have cancer.
- Exercise for at least two, but preferably four, hours a week. You can start with 20 minutes of walking, biking, swimming or using a treadmill. These are continuous movement aerobic exercises that improve mood, reduce hot flashes, prevent constipation, improve cardiovascular fitness and promote sleep.



- Carry a water bottle when exercising and drink plenty of water. Wear comfortable shoes and be aware of posture and breathing. Start slowly and gradually build up your duration and intensity.

Mindfulness Meditation

Although there are many different types of meditation practices. Mindfulness meditation has become widely known because of its simple and effective techniques. It is helpful in reducing stress, improving health and in living more fully in the present. Studies show that mindfulness is effective in relieving physical and psychological conditions and in enhancing healing.

In mindfulness meditation we bring attention to our experience in the present moment. We focus on breathing, physical sensations, feelings and thoughts.

It is best to learn mindfulness and other meditation techniques from experienced teachers. Meditation is simple yet difficult because it contradicts our habits of busyness, distraction and being lost in thought. Attending a class, a weekly sitting group or a day-long retreat are useful ways to begin meditation practice.

For general relaxation and exploration of meditation, there are also Apps for your smartphone or tablet that may be helpful.

Returning to Work

Returning to work after cancer treatment can help restore some normalcy to your life. You may feel more productive, more in control of your life, get a self-esteem boost and a boost to your income. However, returning to work can also be challenging with important considerations and details to attend to. Here are some tips and resources that may help with this part of your experience:

- Plan for your return to work. Talk to your doctor about your plans. Ask when it would be medically advisable to do so.
- Call your human resources department and/or your supervisor to discuss the timing of your return and what your schedule might be like. Be proactive about what you need.
- *You might ask about:*
 - Part time hours at first
 - Flex time (to allow for medical appointments)
 - Working from home
 - Job sharing
 - Family and Medical Leave Act
 - Reasonable accommodations under the American With Disabilities Act.



- *Develop a self-care plan for returning to work:*
 - Make sure to build work breaks into your schedule.
 - Stay in touch with body signals of stress and fatigue.
 - Be mindful of good nutrition.
 - Consider trying breathing exercises, guided imagery or meditation to reduce any stress you may have.
- Prioritize your tasks by scheduling important things early in the day. Set alarms, keep lists and set reminders. Use the tools you need to keep you on track.
- Consider what you tell your co-workers about your cancer experience. If you have a supportive team, sharing your experience may be very helpful. Alternatively, it is ok to separate your medical life from your work life.
- Know that co-workers may respond differently. Some may be supportive and understanding, whereas others may treat you differently or not know what to say.
- There will probably be a time of co-worker adjustment. *Be patient with yourself and them!*

The following is a list of organizations that may be helpful when returning to work (current as of September 2019):

- **The American Cancer Society** (www.cancer.org)

- **Job Accommodation Network** (<http://askjan.org>)

“This free service from the US Department of Labor, Office of Disability Employment Policy has information about job accommodations for people with limitations, accommodation ideas, and tips on how to approach employers and ask for accommodations.”

Toll free: 800-526-7234 • TTY: 877-781-9403

- **American with Disabilities Act (ADA) Technical Assistance** (www.ada.gov)

“For general information about the ADA, answers to specific questions, free ADA materials, or information about filing a complaint.”

Toll free: 800-514-0301 • TTY: 800-514-0383

- **US Equal Employment Opportunity Commission (EEOC)** (www.eeoc.gov/laws/types/cancer.cfm)

“Offers information on your rights and the laws that apply to your state, including filing charges for discrimination. Also has special information for people with cancer, ‘Questions and Answers About Cancer in the Workplace and the Americans with Disabilities Act (ADA)’ which can be found on the EEOC website.

Toll free: 800-669-4000 • TTY: 800-669-6820

- **Cancer Legal Resource Center (CLRC)** (www.cancerlegalresources.org)

“Offers free, confidential information and resources on cancer-related legal issues to cancer survivors, their families, friends, employers, and others coping with cancer.”

Toll free: 866-843-2572 • TTY: 213-736-8310

- **Cancer and Careers** (www.cancerandcareers.org)

“For information on dealing with the potential impact cancer may have on your career, creating an action plan, sharing your diagnosis with employers and co-workers, legal issues, and insurance issues.”

- **National Coalition for Cancer Survivorship** (<https://www.canceradvocacy.org>)

The NCCS “Advocates for changes in how the nation researches, regulates, finances and delivers quality cancer care, empowers cancer survivors through its publications and programs, which provide tools for self-advocacy, and convenes other cancer organizations to address nationwide public policy issues affecting cancer survivors.”

- **Triage Cancer** (www.triagecancer.org) is an incredible resource for those with cancer.

They have a wonderful video and a webinar series. You can only link to them from <https://triagecancer.org/employment> but they cover the following topics:

- Dealing With Side Effects at Work
- Employment Rights After a Cancer Diagnosis
- Taking Time Off and Paying For It
- “Chemo Brain” & Accommodations at Work & at School

They also link to other valuable video content.

See the “Resources” section of this binder for additional information.

Survivorship Care Plan

One resource that may help you is a Survivorship Care Plan or Treatment Plan. This document may be given to you after your treatments are finished. The Survivorship Care Plan/Treatment Plan will have information on your cancer, diagnosis date, surgery and treatments. It will also give you information on follow-up care including a recommended schedule of doctor visits and tests, a review of signs and symptoms to be aware of for cancer recurrence and information on late and long-term side effects. Use this tool to talk to your doctors, including your primary care physician.

For an example of what a Survivorship Care Plan may look like, see the end of this chapter.



Follow-up Care

- It is very important to go to all scheduled follow-up appointments once your treatment is complete. Your doctor will perform a physical exam, ask you about any problems or symptoms and order laboratory or imaging tests as needed.
- You should never hesitate to tell your doctor about any symptoms or side effects you have, especially those that concern you.
- Your follow-up appointments will probably be scheduled for every four to six months in the beginning. The longer you are cancer free, the fewer appointments you need. After five years of being cancer free, you will probably see your oncologist only once a year.
- You will need yearly colonoscopies to protect your remaining colon and check for return of cancer. Small cancers in the colon are treatable at the time of colonoscopy.
- Blood tumor markers, liver function tests, bone scans and chest x-rays are usually not needed unless your symptoms or a physical exam suggest something unusual.
- You may need to have your heart function monitored if you are on targeted therapy. Your oncologist will let you know how often testing needs to be done.

Long-Term Side Effects

Cancer treatments may cause late or long-term side effects. Long-term side effects are the physical and physiological changes that last for months to years after treatment ends. Long-term side effects include things like neuropathy, chemo brain, heart problems and skin changes. Late-term side effects are physical and physiological changes that may not occur for months or years after treatment. Late and long-term side effects are specific to the treatment you received.

Colon and Rectal

Some late and long-term side effects from surgery, chemo/immunotherapy, hormonal therapy and/or radiation therapy include:

- Bowel dysfunction like chronic diarrhea, abdominal pain, increased bowel frequency
- Fatigue
- Sleep difficulty
- Fear of recurrence
- Anxiety
- Depression
- Pain and numbness (peripheral neuropathy)
- Urinary incontinence (loss of bladder control)
- Sexual dysfunction
- Early menopause for premenopausal women
- Heart problems
- Increased risk of other cancers
- Infertility
- Liver problems
- Lung disease
- Nerve damage
- Osteoporosis (weakening of the bones)
- Reduced lung capacity
- Intestinal problems
- Lymphedema (swelling in the limbs)
- Memory problems
- Skin changes

These any many other side effects are common, but should be evaluated by your oncologist.

Cancer treatment side effects can happen months or years after completing your treatment. It is important to continue to communicate with your medical team about any symptoms you are experiencing so they can be addressed.

Anal

Some late and long-term side effects from surgery, chemo/immunotherapy, hormonal therapy and/or radiation include:

- Damage to the anal tissue and formation of scar tissue
- Anal stenosis (narrowing of the anus) requiring dilation
- Incontinence due to weak muscles in the anus
- Frequent bowel movements
- Passing urine more frequently
- Difficulty passing urine
- Bleeding from urine and stools
- For women, dryness and shrinking of the vagina, making sex uncomfortable (use of vaginal dilators after treatment may help keep this to a minimum)
- For men, difficulty getting an erection
- Loss of fertility for men and women
- For women, early menopause
- Chronic diarrhea and weight loss
- Weak pelvic bones, increasing risk of hip or pelvic fractures
- Abnormal swelling in the legs, called lymphedema

These any many other side effects are common, but should be evaluated by your oncologist.

When completing treatment, many people become fearful of their cancer coming back. Symptoms that should be brought to the attention of your provider include:

- Anything that represents a brand new symptom
- Anything that represents a persistent or on-going symptom
- Anything you are worried about that might be related to the cancer coming back



In addition, here are some symptoms that may be associated with cancer recurrence:

- Skin inflammation or area of redness, pain, heat, and swelling
- Bleeding
- Bloating
- Abdominal cramping
- Persistent diarrhea or diarrhea that is severe with more than 5 bouts of diarrhea daily
- Dark urine that may indicate dehydration
- Persistent and worsening pain, such as chest or bone pain
- Persistent cough
- Difficulty breathing
- Loss of appetite
- Weight loss
- Severe headaches
- Seizures
- Any other new, unusual and/or persistent symptoms

If any of these occur, see your oncologist for further evaluation.

The information in this section is not meant to replace the individual attention, advice, and treatment plan of your oncologist and medical team.

Completing Your Cancer Treatment

You may start to feel excited as your cancer treatments come to an end. You have probably spent months scheduling appointments, figuring out which foods taste good, altering your exercise routine, figuring out when your good and bad days will fall, fitting work into your treatment schedule, accepting help when you otherwise would not and learning to accept you cannot always control the bumps along the road. You may be planning a celebration, thinking of vacation spots, thankful you have more free time or just happy you don't have to see your healthcare team as often. The last thing you may imagine is feeling an unexpected range of emotions like fear, sadness, anxiety and loss.

The transition to "post-acute survivorship" (after diagnosis and treatment) may bring up similar feelings you felt as you transitioned from a new diagnosis to surgery, from surgery to chemo/biotherapy or from chemo/biotherapy to radiation therapy. You may remember feeling anxious each time you started a new phase of treatment. Moving from active treatment to completing treatment is another phase of the cancer journey.

You may have spent months or years focusing on your cancer treatment and once completed, you may feel at a loss. You may start to wonder:

- How do I know my cancer is gone?
- What do I need to do to prevent my cancer from coming back?
- I am sure my cancer has come back because this pain is new.
- I feel lost without the routine I've been used to.
- I miss the security of seeing my nurses and doctors so frequently.

You may feel that you have been personally changed by the experience of being diagnosed with cancer and going through treatment. Going back to "the way everything was before" can be challenging because your personal goals and identity may have changed. Therefore, your everyday life, including relationships with co-workers, family, friends and significant others may need to be adjusted to fit the "new you". It is normal to feel surprised, anxious or even depressed. Many people feel like they are on unsure footing during this phase. Please make sure you talk about this to your health care team. We are here to support you.

Make sure you seek out information from a reputable source. Plan to talk to your doctor or nurses about the treatment you have had, follow-up visits and tests, late and long-term side effects, eating healthy, proper exercise and when to call if you notice anything new. There are physical and online support groups, peer navigation, counselors, legal organizations and other resources available.

It may be difficult to think about, but take time to make plans for a good death. This is something that everyone should consider, not just cancer survivors. This will give you some control over the end of your life and also help make it less painful, while being more supported and dignified. It is easier to do this when you have the luxury of time. It is important to talk to your family and let them know what your wishes are should you not be able to make your own decisions. Get your affairs in order. If possible, talk to an estate planner about a will or trust. Have an advanced directive form filled out. Make arrangements for your burial or cremation. Spend time getting your emotional affairs in order. Spend time with your family and friends. Cross items off your bucket list. Prioritize what is important to you.

Survivorship Care Plan

As mentioned earlier in this chapter, when you complete your cancer treatment(s) you may receive a Survivorship Care Plan (also known as an After-Treatment Plan, Post-Treatment Care Plan, or Oncology Care Plan).

The care plan will include information on your surgery, systemic therapy (e.g. chemotherapy or immunotherapy), and radiation therapy. It will also provide general follow-up information including recommended timing for doctor visits and tests, possible late and long-term side effects and other topics important for your life after cancer treatment.

It is important to understand the follow-up information can change depending on your health, updates in recommended guidelines, or if you have any new concerns. Please ask your oncologist for your care plan if you don't receive one after your first follow-up visit.

Please see the following pages for an example of what your Survivorship Care Plan may look like.

Treatment Summary and Survivorship Care Plan for Colorectal Cancer

General Information	
Patient Name:	
Patient ID:	
Phone:	
Date of Birth:	
Health Care Providers	
Medical Oncologist:	
Surgeon:	
Radiation Oncologist:	
Primary Care Physician:	
Gastroenterologist:	
Cancer Diagnosis Information	
Tumor Type/Histology/Grade:	
Diagnosis Date:	
Staging Information:	
Cancer-Related History:	
Genetic Information:	
Recurrence Score:	
Tobacco Use:	
Alcohol/Drug Use:	
Treatment Summary	
Surgery:	
Chemotherapy:	
Radiation Therapy:	
Persistent symptoms or side effects at completion of treatment:	

† A colonoscopy should be done around the time of surgery. If the examination shows no signs of a recurrent tumor or polyps, a colonoscopy should be done at 3 years, and if normal, every 5 years thereafter.

Scientific evidence for the routine use of the following tests is lacking and they are not recommended for follow-up care:

- A complete blood count (CBC) test or liver function tests
- A fecal occult blood test to look for blood in the stool

Colon Cancer Follow-up Sheet

Colon Cancer Follow-up Sheet					
Date of Surgery					
Estimated Target Dates	Dates Completed				
DOS <i>plus</i>	Actual Dates	CEA ¹ (Date/Value)	Counseling Visit ²	CT Scanning	Colonoscopy ³
+ 0 years / 3 months					
+ 0 years / 6 months					
+ 0 years / 9 months					
+ 1 years / 0 months					
+ 1 years / 3 months					
+ 1 years / 6 months					
+ 1 years / 9 months					
+ 2 years / 0 months					
+ 2 years / 3 months					
+ 2 years / 6 months					
+ 2 years / 9 months					
+ 3 years / 0 months					
+ 3 years / 6 months					
+ 4 years / 0 months					
+ 4 years / 6 months					
+ 5 years / 0 months					
Comments / Evidence of Recurrence:					

¹Carcinoembryonic antigen (CEA) testing is not recommended during the administration of adjuvant chemotherapy.

² As guidelines suggest 3 to 6 months for counseling visits, optional dates are marked with (opt).

³ Acceptable to wait 3 years for follow-up if the pre or perioperative colonoscopy examined the entire colon.

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Important caution: this is a summary document whose purpose is to review the highlights of the cancer treatment for this patient. This does not replace information available in the medical record, a complete medical history provided by the patient, examination and diagnostic information, or educational materials that describe strategies for coping with cancer and cancer therapies in detail. Both medical science and an individuals health care needs change, and therefore this document is current only as of the date of preparation. This summary document does not prescribe or recommend any particular medical treatment or care for cancer or any other disease and does not substitute for the independent medical judgment of the treating professional.