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Organizing Your Care



Learning you have cancer can trigger a wide range of emotions including shock, fear, numbness, sadness, anger and even betrayal. You may feel overwhelmed by your emotions or the numerous decisions about your care. You may find it difficult to absorb so much new and often confusing information.

You are not alone.

Approximately one in 22 men and one in 24 women will be diagnosed with colon or rectal cancer (CRC) in their lifetime. You may even know someone with cancer who has experienced what you are going through now. Many people go on to lead active, healthy lives.

It is important to understand not all cancers and treatments are the same. There are many factors that may make your journey different than those you have witnessed or heard about. These include

information about your specific cancer (e.g. type, size, location) as well personal factors such as your age, health condition, family cancer history, lifestyle and support system. The more you learn about cancer and the available treatment options,

the better prepared you will be to handle the challenges ahead and make informed decisions about what is right for you.

Don't be afraid to reach out to others during this difficult time. Your family, friends, doctors, nurses, health care team, local cancer support groups and other organizations can provide much needed support and

encouragement and play a vital role in your recovery. The information in this section will help you plan and prepare for your treatment. ***However, it is not meant to replace the individual attention, advice, and treatment plan of your oncologist and medical team.***

Sutter Health's cancer nursing experts created this notebook to provide you with the tools and information you need to take an active role in your care.

Organizing Tips

- Keep a list of all of your doctors and other health care providers.
- If available, take advantage of “My Health Online” (Sutter Health’s electronic health record system) where you can access all of your appointments, lab and test results and can email your doctors. To sign up, ask your doctor’s office, or go to <https://mho.sutterhealth.org/>. *If you need help, ask your nurse or Medical Assistant. If someone close to you would like access to your record, ask about “proxy” access.*
- You may want to keep a small notebook with you to keep an ongoing record of all your visits (doctor, laboratory, X-ray, etc). *Include:*
 - who you spoke with
 - the date and time
 - your questions and the answers you received
 - questions about your medications or any reactions or unusual symptoms that you should report to your doctor.
- Keep your medication list and provide any changes to your health care provider.
- In addition to writing things down, you may find it helpful to record your medical visits and/or bring someone with you who can help you remember what was discussed during your visit. Should you choose to record your visit, please let your healthcare provider know.
- **Protect your personal health information (PHI)!** Many test reports and records contain personal information including your birthdate, address and medical information. Protecting your privacy is very important. Do not leave your records unattended and use care to prevent losing your information.

Your Health Care Team

You will have different types of doctors, nurses and other health care providers taking care of you throughout your course of treatment and afterwards. Your health care team may include the following:

Gastroenterologist

A doctor who specializes in the management of the gastrointestinal (GI) tract (aka digestive system), which includes the esophagus, stomach, small intestines, colon, rectum, pancreas, gallbladder, bile ducts and liver.

Medical Oncologist

A doctor who specializes in using medicine to treat cancer.

Nurse Navigator

A nurse who guides patients through the healthcare system to help them to overcome barriers to optimal care.

Nutritionist or Registered Dietitian

A health care professional who can recommend diet changes to help you get the proper nutrition before, during and after your treatment.

Ostomy Nurse

A nurse specially prepared and educated to care for patients with ostomies.

Oncology Nurse

A nurse specially prepared and educated to care for cancer patients.

Oncology Social Worker

A social worker who specializes in providing counseling and other mental health services for cancer patients. They also refer patients to other support services and can provide information about helpful community resources.

Pathologist

A doctor who examines tissue samples under a microscope to see if they contain cancer or abnormal cells.

Primary Care Doctor

The doctor you see for regular medical care.

Radiation Oncologist

A doctor who specializes in the use of radiation to treat cancer.

Surgeon

A doctor who specializes in surgical procedures.

Your Right to Know

You have the right to know – in a language you understand – as much as you want about your medical condition. However, you need to let your health care team know how much information you really want and when you are ready for the information. It can be a lot to take in at once.

You will receive information from many different people and sources. If you receive conflicting information, be sure to ask questions. Developing a good relationship with your doctor is an important part of your care. Your doctor should make you feel at ease when sharing information, asking questions or expressing your concerns.

You will feel more confident and secure in the choices you make if you understand the recommendations and explanations given to you by your doctor and other health care professionals. Many people seek a second opinion before deciding what to do about their course of treatment. Most insurance companies cover second opinions, but check with yours to be sure.

If you choose to use the Internet to get more information about your cancer, we recommend using the websites listed in the Resource section of this binder or websites recommended to you by your health care team. Remember, the Internet is filled with correct and incorrect information and is not personalized to your specific case.

Lab and Test Results

You will undergo a number of tests and studies throughout the diagnostic and treatment process. You will also consult with several physicians.

- Use “My Health Online” for access to your test results.
- You will need to ask your doctor for a copy of your pathology report since legally, pathology reports cannot be posted on “My Health Online”.
- You will get a printed *After Visit Summary (AVS)* at every appointment. It is important to read each one and follow any instructions given. If desired, you can keep your most recent summary until your next appointment.

Medications

You will most likely be receiving many different kinds of medications throughout your cancer treatment. Here are some questions you should ask your doctor:

- Why am I taking this medication?
- How long am I going to take it?
- Should I take it on an empty stomach or with food?
- What should I do if I forget to take it?
- What side effects should I look for?
- Is it safe to drink alcohol with it?
- Under what circumstances should I call my doctor?
- Could I save money by using a generic drug that would be equally effective?

Here are some helpful definitions:

Generic medicine: A drug that has the same medicine as the brand name drug. This will work the same way as the brand name drug but often costs less.

Prescription medicine: A drug that can only be bought with permission from the doctor.

Start date: The date that you first started taking this medication.



Medication Safety

It is very important that your doctors and nurses know everything you are taking. Your pharmacist will use the information you provide to ensure that there will be no interactions between what you already are taking and your cancer medications. The medication list you provide should include any prescribed medicines, as well as over the counter medications (such as Tylenol, Advil, allergy medicines, etc.) and vitamins, supplements or herbal treatments.

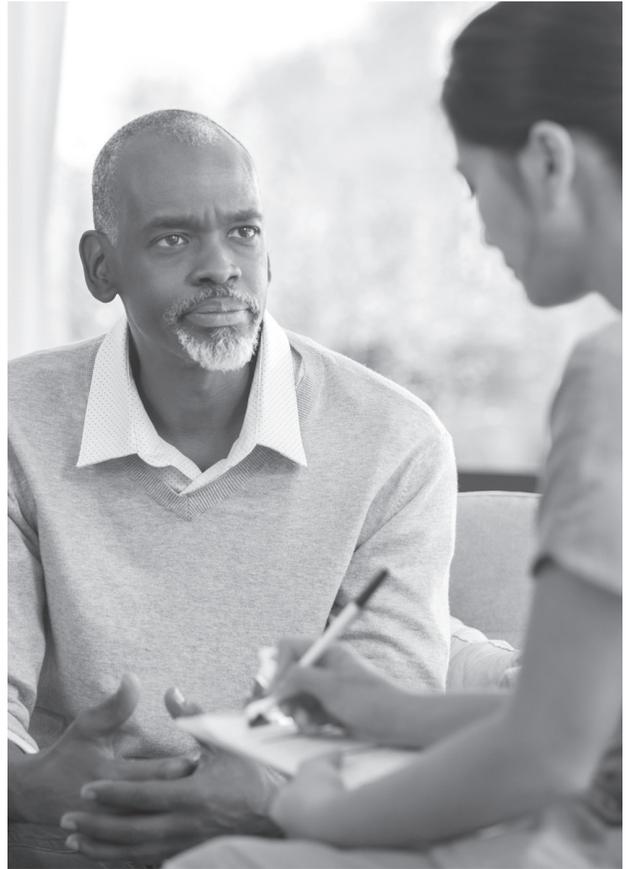
It is also very important to take all of your medications as prescribed. If you can't for any reason, let us know so we can help you. Some medications can be very expensive. There are programs that may be available help if you need it.

Read medication labels carefully!

Understanding Your Diagnosis

Not all colon and rectal cancers are the same.

There are different types of colon and rectal cancers, as well as different stages. Understanding how cancer works and how your particular cancer affects your body will help you make decisions about your care and what is best for you. The information in this section is from the National Comprehensive Cancer Network (NCCN) and will help you plan and prepare for your treatment. ***However, it is not meant to replace the individual attention, advice, and treatment plan of your oncologist and medical team.***



Resources

You may be overwhelmed with the information that exists on the Internet. The resources listed in this chapter are believed to be trusted. However, the information provided is not meant to replace the expertise and clinical judgment of your medical team. Please be sure to discuss the information you find with your doctors and health care team.



These resources are grouped into the following categories:

- Colon and Rectal Cancer Specific Information
- General Cancer and Medical Information
- Financial and Career Information
- Diet and Nutrition
- Getting Support
- Young Adults With Cancer
- Complementary and Alternative Information
- Research and Clinical Trial Information
- Recommended Reading

There is additional information about cancer and our programs at [sutterhealth.org](https://www.sutterhealth.org).

Learning About Colon or Rectal Cancer

When you are diagnosed with cancer, there can be many words and terms to learn. A comprehensive glossary can be found at <https://www.ccalliance.org/colorectal-cancer-information/glossary-of-terms>.

Colon and Rectal Cancer Specific Information

American Cancer Society

Cancer information covering all types of issues (risk through treatment and survivorship). Information is also available in 14 other languages.
cancer.org • 1-800-ACS-2345

Notes

American Society of Clinical Oncologists (ASCO) Patient Education Site

Timely, comprehensive, oncologist-approved information.
cancer.net

Colorectal Cancer Alliance

Colon and rectal cancer information and support.
ccalliance.org/colorectal-cancer-information/resources-for-patients

Fight Colorectal Cancer

Colon and rectal cancer information, support and advocacy.
fightcolorectalcancer.org
 Free downloadable guide:
fightcolorectalcancer.org/fight/library/your-guide-in-the-fight/

Inspire (Ostomy Support)

Leading social network for health that connects patients and caregivers in a safe permission-based manner.
inspire.com/groups/ostomy

National Cancer Institute

Comprehensive information on cancer prevention, screening, diagnosis treatment, research and clinical trials.
cancer.gov

National Comprehensive Cancer Network

Information on treatment guidelines and supportive care.
nccn.org/patients

United Ostomy Associations of America

Support, education, resources and advocacy for those living with an ostomy.
ostomy.org

Your Local Community Resources

Most communities have helpful resources for those who have been diagnosed with and are going through treatment for cancer. Please ask your health care team for a list of local recommendations.

General Cancer and Medical Information

	Notes
LIVESTRONG Tools and information regarding all cancers. <i>livestrong.org</i>	
Mayo Clinic Information on cancer and treatments. <i>mayoclinic.org</i>	
Medline Plus Notes Information from the National Institute of Health regarding, drugs, supplements and general health. <i>medlineplus.gov</i>	
National Coalition for Cancer Survivorship Advocacy organization for quality cancer care. <i>canceradvocacy.org</i>	
National Lymphedema Network Information on lymphedema prevention and treatment. <i>lymphnet.org</i> • 800-541-3259	
Oncolink University of Pennsylvania cancer education website. <i>oncolink.org</i>	
Prevent Cancer Foundation Research and education directed towards preventing cancer. <i>preventcancer.org</i>	
PubMed National Library of Medicine search engine for literature. <i>ncbi.nlm.nih.gov/pubmed</i>	
Springboard Beyond Cancer Information and resources to help you cope and be in control. <i>survivorship.cancer.gov</i>	
The Advocacy Connector A list of not-for profit, mostly non-governmental resources. <i>advocacyconnector.com</i>	

Financial and Career Information

	Notes
<p>Cancer and Careers Empowers and educates people with cancer to thrive in their workplace. <i>cancerandcareers.org/en</i></p>	
<p>Cancercare Counseling, education, financial assistance and practical help provided by trained oncology social workers. <i>cancercare.org</i></p>	
<p>Cancer Financial Assistance Coalition Provides financial help to patients with cancer using a searchable database. <i>cancerfac.org</i></p>	
<p>Good Days Provides assistance to underinsured patients who are diagnosed with chronic or life-altering diseases (including cancer) so that they get access to the medications they need. <i>mygooddays.org</i> • 877-968-7233</p>	
<p>Healthwell Foundation Provides financial assistance to eligible individuals to cover coinsurance, copayments, insurance premiums, deductibles, and out-of-pocket expenses for certain medications and therapies. <i>healthwellfoundation.org</i> • 800-675-8416</p>	
<p>National Cancer Institute: Organizations That Offer Support Services A database of government agencies and national organizations that provide financial and other assistance to patients with cancer and their families; provides information about patient assistance programs. <i>supportorgs.cancer.gov/home.aspx</i> • 800-422-6237 (1-800-4-Cancer)</p>	
<p>Patient Advocate Foundation Provides mediation and arbitration services to patients, providers, family members and caregivers of those dealing with significant medical issues. Programs include case management, grants, co-pay relief and outreach for eligible patients. <i>patientadvocate.org</i></p>	
<p>Patient Advocate Foundation: Co-Pay Relief Program Direct financial support to financially and medically eligible patients, including Medicare Part D beneficiaries. <i>copays.org</i> • 866-512-3861 • 757-952-0118</p>	
<p>The Assistance Fund (Look for Colorectal Cancer Copay Assistance Program) Helps patients and families facing high medical out-of-pocket costs by providing financial assistance for their copayments, coinsurance, deductibles, and other health-related expenses. <i>tafcares.org/</i>; Colorectal Cancer Copay Assistance Program - <i>tafcares.org/patients/apply/</i> • 855-845-3663</p>	
<p>Triage Cancer National, nonprofit organization that provides educational and practical and legal support for cancer survivors and their caregivers. <i>triagecancer.org</i> • 424-258-4628</p>	

Diet and Nutrition

American Institute of Cancer Research

Research findings on diet and cancer.

aicr.org

Notes

Forks Over Knives

Changing the way the world understands nutrition.

forksoverknives.com

Getting Support

Cancer Hope Network

Matching patients and/or family members with trained volunteers throughout the US who have recovered from similar cancer experiences.

cancerhopenetwork.org

Notes

Cancer Support Community

Provides free professional programs of emotional support, education and hope.

cancersupportcommunity.org

Cancer Survivor Network

Offshoot of the American Cancer Society. The purpose of the CSN is peer support and all content is contributed by its members.

csn.cancer.org

GiveInKind.com

Meal and help scheduling, wish list and financial donations.

giveinkind.com

MealTrain.com

Organize meals for a friend after surgery or illness.

mealtrain.com

TakeThemAMeal.com

Simplifying meal coordination so friends can show they care.

takethemameal.com

Young Adults With Cancer

LIVESTRONG (Fertility)

Provides information on fertility risks and options and fertility preservation discounts.

livestrong.org/we-can-help/livestrong-fertility

Notes

Stupid Cancer

Addresses young adult cancer.

stupidcancer.org

Complementary and Alternative Information

American Cancer Society

Complementary and alternative medicine guide.
cancer.org/treatment/treatments-and-side-effects/complementary-and-alternative-medicine.html

Notes

Consumer Lab

Independent testing of non-prescription supplements.
consumerlab.com

Memorial Sloan Kettering Medical Center

Guide to herbal medicines.
mskcc.org/cancer-care/treatments/symptom-management/integrative-medicine

National Center for Complementary & Alternative Medicine

Describes treatments and methods of evaluation for complementary and alternative modalities.
nccih.nih.gov

Natural Medicines

Objective product information, on dietary supplements, natural medicines, and complementary alternative and integrative therapies.
naturalmedicines.therapeuticresearch.com

Research and Clinical Trials Information

Clinical Trials.Gov

A database of publicly and privately supported clinical studies.
clinicaltrials.gov

Notes

Sutter Health - Research and Clinical Trials

Sutter's world-class research institutes are home to hundreds of clinical trials to investigate underlying causes of diseases and discover effective new ways to predict, prevent and treat them.
sutterhealth.org/research

Recommended Reading

And in Health: A Guide for Couples Facing Cancer Together

Dan Shapiro
EMOTIONAL SUPPORT

Anticancer: A New Way of Life

David Servan-Schreiber
SURVIVORSHIP

Before and After Cancer Treatment: Heal Faster, Better, Stronger

Julie K. Silver
TREATMENT

Crazy Sexy Cancer

Kris Carr
EMOTIONAL SUPPORT

Couples Confronting Cancer Keeping Your Relationship Strong

Joy Fincannon, & Katherine Bruss
Published by the American Cancer Society, found at acs.bookstore.ipgbook.com/
INTIMACY, EMOTIONAL SUPPORT

Eating Well Through Cancer

Holly Clegg
Favorite Recipes Press
COOKBOOKS, NUTRITION

Happiness in a Storm: Facing Illness and Embracing Life as a Healthy Survivor

Wendy Schlessel Harpham
EMOTIONAL SUPPORT

Living Well With Lymphedema

Ann B. Ehrlich
LYMPHEDEMA

Lymphedema: Understanding and Managing Lymphedema After Cancer Treatment

American Cancer Society
LYMPHEDEMA

Men Cancer Sex

Anne Katz
INTIMACY, EMOTIONAL SUPPORT

Nourishing Connections

C. Couch, J. DeNicola, etc. published by The Ceres Community Project
COOKBOOKS, NUTRITION

Overcoming the Emotional Challenges of Lymphedema

by Elizabeth McMahon, PhD
Published by Lymph Notes
LYMPHEDEMA, EMOTIONAL SUPPORT

Radical Remission: Surviving Cancer Against All Odds

Kelly A. Turner, PhD
SURVIVORSHIP

The Cancer Fighting Kitchen

Rebecca Katz
COOKBOOKS, NUTRITION

The Healing Consciousness: A Doctor's Journey to Healing

Beth Baughman DuPree
EMOTIONAL SUPPORT, SURVIVORSHIP

The Longevity Kitchen

Rebecca Katz and Mat Edelson
COOKBOOKS, NUTRITION

The Spirited Walker: Fitness Walking For Clarity, Balance, and Spiritual Connection

Carolyn S. Kortge
SURVIVORSHIP, FITNESS

When Life Becomes Precious: The Essential Guide for Patients, Loved Ones and Friends of Those Facing Serious Illness

Elise Babcock
EMOTIONAL SUPPORT

Women Cancer Sex

Anne Katz
INTIMACY, EMOTIONAL SUPPORT

100 Questions & Answers about Lymphedema

Saskia R.J. Thiadens, Paula J Stewart & Nicole L. Stout
LYMPHEDEMA

Recommended Reading for Helping Children When a Loved One Has Cancer

(We recommend reviewing any book you choose before reading it to a child.)

When a Parent Has Cancer, Wendy Schlessel-Harpham

How to Help Children Through a Parent's Serious Illness, Kathleen McCue

Just You and Me, Judy Richmond

Preparing the Children, Kathy Nussbaum

Can I Still Kiss You, Neil Russell

Helping Children Understand,
The American Cancer Society

Our Family Has Cancer, Too!, Christine Clifford

A Mom of Many Hats, Debbie Fink, Lisa Perea Hane
and Caroline Smith Heming

What About Me?, Allan Peterkin

When Mommy is Sick, Ferne Sherken-Langer

Someone Special is Very Sick, Jim and Joan Boulden

Little Tre, Joyce Mills

Zink, Cherie Bennett

Sort of Forever, Sally Warner

Sammy's Mommy Has Cancer, Sherry Kohlenberg

Gentle Willow, Joyce Mills

Promises, Elizabeth Winthrop

Gran-Gran's Best Trick, L. Dwight Holden, M.D.

The Paper Chain, Clair Blake, Eliza Blanchard,
Kathy Parkinson

It Helps to Have Friends, American Cancer Society

Henry and the White Wolf, Tim Karu & Tyler Karu

When Your Parent Has Cancer, A Guide for Teens,
National Cancer Institute, U.S. Department of Health &
Human Services

Surgery and Post Surgery

Depending on the type and extent of your colon or rectal cancer, surgery may be an option to treat it. The following information covers different surgical procedures your health care team may discuss with you. It also includes tips on how to care for yourself after surgery.

If the information included here differs from what your individual surgeon recommends, follow your surgeon's directions. If you have questions, we encourage you to ask your doctor or health care team regarding all your options.

In certain instances, your doctor may recommend that you have neoadjuvant chemotherapy, radiation or both. Neoadjuvant therapy is given before surgery to shrink, weaken or destroy the cancer. The goal of neoadjuvant therapy, specifically for rectal cancer, is to preserve the sphincter (anal muscle).

Surgery for colon cancer removes the section of the colon that contains the tumor and surrounding tissue with its blood vessels and lymph nodes. If the surgical pathology report finds that cancer has spread outside the colon to the wall of the abdomen, or to the blood vessels or lymph system, further treatment may be required.

Words to Know

See the next section for more information about each of these words.

Colectomy: Removes the cancerous part of the colon and nearby lymph nodes.

Colostomy: Colostomy refers to the creation of a stoma (artificial opening) creating a pathway for stool to exit the body that bypasses the rectum.

Ileostomy: An ostomy that is created high in the bowel in the small intestine (before the colon).

Ostomy of the bowel: A surgical procedure that diverts part of the colon to the abdominal wall through which waste material passes out of the body from the bowel.

Reanastomosis: Reconnection of the bowel.

Stoma: The opening on the abdomen that allows bodily waste to come out when part of the intestines are removed or not able to work properly.

Types of Surgery for Colon and Rectal Cancer

Surgery includes a colectomy (removal of all or part of the colon) with reanastomosis (reconnection of the bowel) or colectomy with the creation of an ostomy (an artificial opening), either temporary or permanent.

Colectomy:

A colectomy removes the cancerous part of the colon and nearby lymph nodes. This surgery can be done through a large incision in your abdomen or with laparoscopic (minimally invasive) surgery. Laparoscopic surgery is done through small incisions that allow a scope to be inserted and tunneled into the abdomen allowing the surgeon to visualize the abdominal cavity without cutting through the abdominal muscles. During the surgery, your surgeon will examine the abdominal cavity. To do a thorough exam, pieces of your intestine will be mobilized (cut free) so the curves of the intestine and the underlying abdominal wall are visible. After the cancerous part of the colon is removed, or “resected”, the surgeon will reconnect your digestive system so your body can get rid of waste by either rejoining the intestines or attaching your intestine to an opening on your abdomen (see next section).

Colostomy:

In some cases, your body may not be able to get rid of waste. In this case, a hole (stoma) is created in your abdomen. This procedure is called a colostomy. An ostomy pouch is placed over the stoma to collect waste. Seeing an ostomy therapy nurse prior to surgery is helpful to ensure the stoma is placed in the correct place on the abdominal wall. Ostomies can be temporary or permanent. When healing is complete (after a few months or years) a reverse colostomy surgery may be an option. This procedure is also called a “takedown”, as in taking the healed colon down off the abdomen and connecting it to the remaining colon or rectum using sutures that will dissolve. Reversal surgeries require several weeks (6-8 at a minimum) of recovery. Learning to care for your own ostomy (whether temporary or permanent) without help is essential for your wellbeing after colostomy surgery. People with ostomies can live active lives. Look for solutions that support you in your favorite activities. Waterproof pouch systems exist to allow you to swim and participate in water sports.

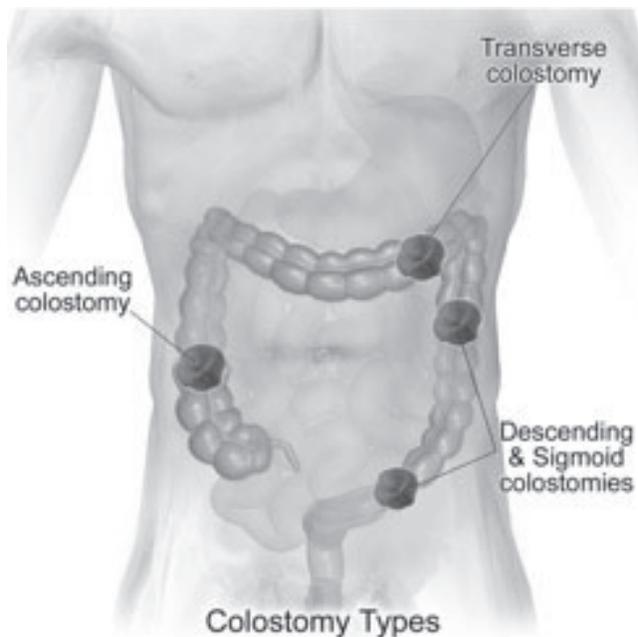


Image taken with permission from https://commons.wikimedia.org/wiki/File:Blausen_0247_Colostomy.png

Ileostomy:

An ostomy that is created high in the small intestine, before the colon, is called an ileostomy. It will have more output than a colostomy because it bypasses the colon and one function of our colon is reabsorption of water. Therefore, people with ileostomies are at a higher risk of dehydration and are often readmitted to the hospital because they are in need of fluids.

Keep a log of how much fluid you are drinking and how much is coming out of your ileostomy. Be proactive about communicating to your health care team as you may be able to avoid hospitalization by getting IV fluids in your doctor's office or avoid needing IV fluids altogether.

People with ostomies can live active lives. Look for solutions that support you in your favorite activities. For help, visit ostomy.org.



Image taken with permission from https://commons.wikimedia.org/wiki/File:Blausen_0247_Colostomy.png

Tips for taking care of yourself with an ostomy:

Be patient. It takes time to get used to caring for your ostomy and to find the pouch system that works best for you.

- If possible, practice beforehand! Many surgeons have ostomy models in the office for you to look at and practice with prior to surgery.
- Before your surgery, ask if your doctor can show you examples of the supplies you will need to care for your ostomy.
- After surgery, nurses and ostomy specialists can demonstrate how you can care for your ostomy independently.
- Watch carefully when the nurses care for your ostomy for the first time. Ask for a mirror to visualize if you are not able to see all of the care. Have your spouse or caregiver watch as well.

Things you will need to learn:

- How to empty and replace the pouch.
- How to care for and clean the skin around your stoma.
- Supplies to use when skin is irritated or needs extra care, such as skin protectant.
- How to manage your diet and activities.
- How to tell when you are getting dehydrated. A headache is often times the first sign of dehydration.
- Many times after surgery, multiple bowel movements are common. Recognizing how many is too many is important as it may indicate infection or surgical complication (see the stoplight tool in this binder).

- Once you have seen the care being done, do the care next time and allow the nurse to “coach you”. Doing it yourself will give you practice and help build your confidence when you go home.
- Ostomy specialists and case managers in the hospital will help you arrange for home care that can help support you as you learn to care for the ostomy. Your home care agency will deliver ostomy supplies to your home. ***Make sure you have the contact information for your home care company and reach out to them once you are discharged from hospital.***
- Ask your nurse or ostomy specialist to provide a few extra supplies to get you through until supplies are delivered to your home.
- Have a supply of gloves, towels and wipes available when you are changing your ostomy bag and when you are away from your home.
- Ask about alternative pouching systems if yours is uncomfortable.
- Be patient. It takes time to get used to caring for your ostomy and to find the pouch system that works best for you.
- Contact a local ostomy organization for support through the United Ostomy Association of America (ostomy.org).

Attend an ostomy support group if this is offered by your hospital or health care system. Support groups are also offered online at inspire.com/groups/ostomy.

Tips for taking care of yourself with an ileostomy:

- Review the signs and symptoms of dehydration with your health care team. These can include:
 - Headache and irritability.
 - Dark urine or no urine in cases of extreme dehydration.
 - Tenting of your skin. Lightly pinch the back of your hand. If you are properly hydrated the skin will spring back rather than staying gathered.
 - Use a scale at home to monitor for sudden weight loss. A loss of more than 2 pounds in a few days is concerning for dehydration.
- Drink enough fluids to replace your output from your ileostomy. Measure and keep a log of what you are taking in and what is coming out. Keep a log on your smartphone or keep a notebook in the bathroom for this purpose. You may see nurses in the hospital measure with a graduated container and you will need to do this for a while until you are able to estimate.
- When you call or visit your doctor for follow up, tell them how much your ileostomy puts out, how many times a day you empty it and how full it was each time when you did so. Use a measuring container provided or recommended by your team.
- Tell your doctor if your output is interrupting your sleep and not allowing you to get good rest.



Surgery for Rectal Cancer

For rectal cancer, or cancer that is 5 cm or less from the anus, you may be treated with radiation and chemotherapy before surgery. Neoadjuvant chemotherapy and radiation are used to shrink the tumor prior to surgery. The goal is to avoid loss of the anal sphincter (muscle) and the need for an ostomy. An endorectal ultrasound (EUS) or pelvic magnetic resonance imaging (MRI) is required to fully evaluate the layers of the rectal wall and see the depth of the cancer's invasion. The type of surgery done for rectal cancer depends on how deep the cancer has invaded into the muscle of the anus and the appearance of the cancer.



An example of a magnetic resonance imaging (MRI), which some patients may receive before surgery.

There are two surgeries done for rectal cancer: Low Anterior Resection (LAR) and Abdominoperineal Resection (APR).

Lower Anterior Resection (LAR) involves removing the descending colon, sigmoid and upper rectum. Next, the colon is attached to the remaining part of the rectum so that after the surgery your stool can exit through the anus like it did before surgery.

Abdominoperineal resection (APR) is used for large tumors that have invaded into the muscle as well as for tumors that are close to the anus and those where there are lymph nodes affected by cancer. An incision is made in the abdomen. A second incision is made in the perineal area between the legs to remove the anus and the muscle tissues surrounding it. After an APR you need a permanent colostomy because there is no muscle or supporting structure to attach to the bowel.

How to Prepare For Surgery

- Stop smoking. Talk to your doctor if you need help quitting. Those that get help are more likely to remain tobacco free after surgery. You will heal better and decrease your chances of the cancer coming back if you stop smoking.
- Pick up any pre-surgery medications or prescriptions you need. Follow your doctor's instructions exactly with regard to bowel prep and diet prior to surgery.
- While recovering from colon or rectal surgery you will be instructed not to lift, push or pull objects more than 15-20 pounds for approximately 4-6 weeks. Make arrangements for the care of your children, other family members or animals you may care for. You will need to focus on your own recovery for a time in order to prevent complications.
- Try to straighten and clean your home prior to surgery. You will want to remove tripping hazards and make things easy to reach.
- Consider preparing some food ahead and freezing portions so you will not have to cook. Alternatively, ask for help with meal preparation. See the resource section for a list of companies that can help organize meal delivery. These websites also have some good recipe ideas for comfort foods. Set up your site and email your friends and family before you start your treatment so they can help. Your diet after colectomy surgery may have to be adjusted until you heal (*see* Nutrition section).
- Consider getting a hand-held shower and a bar and/or a shower chair to make it easier to care for yourself after surgery. If you have an ostomy, empty the bag before you get in the shower. You may need to change your pouch system after the shower.
- Do not drive while you are on narcotic pain medications. This is another chance for you to ask for help from other people.
- Consider the clothes you will be wearing home from the hospital. Usually elastic waist loose fitting, non-binding waistbands are best.
- Remove jewelry, especially rings, the day before surgery.
- People usually stay 3-5 days in the hospital following colon surgery. Gather the items you will need to bring for your surgery stay. Pack lightly, as there are usually only a few items you need.
- Bring your photo ID and your insurance card and leave your valuables at home.
- Pack your toothbrush, toothpaste or items needed to care for your dentures. Most people like to bring their own brush or comb. If you wear glasses, pack your glasses case.
- Bring two packs of your favorite gum (unless you have dentures). This will be for the evening after your surgery to help your bowels start again.



Tips for managing symptoms after bowel surgery:

All bowel surgeries have the risk of causing a temporary paralysis of the bowel called an ileus. This is where the intestine is no longer moving as it should. Inflammation or swelling is the first step in the healing process. An ileus is only a problem if it does not resolve and the bowel does not drain.

Normally inflamed bowels starts to function in just a few days. An ileus can be accompanied by painful cramping and bloating. Move through the pain. The single best thing to do to prevent this complication is to move early and often. Get up and move!

Ask for help in getting up and learn how to roll to your side and use your arm muscles to help you push up out of bed. Use an upright walker to help support your weight if needed. Hospital physical therapists can be very helpful in coaching you on how to get up after abdominal surgery and teaching you to protect your injured belly muscles while they heal. Some people find it helpful to hug a pillow against the abdomen for support and comfort when rolling and rising. Gather several extra pillows by your bed at home to help support you when you go home.

The single best thing to do to prevent this complication is to move early and often.
Get up and move!

Managing Your Pain

You will likely need narcotics immediately after and for the first couple of days after surgery. You will also be given anti-inflammatory medication or IV Tylenol to help manage the pain and decrease the risk of ileus. You may not be able to completely eliminate pain and there will be some normal discomfort while healing.

An ileus that does not resolve can prolong your stay in hospital. Many people only need to use opioids or narcotics for a couple of days. Consider using pain medications like Tylenol without the narcotics. As soon as you are able to, take your pain medicine by mouth rather than IV.

It is very important that your pain is under control. Your health care team will help you do this before you leave the hospital.

Once you go home from hospital, take frequent walks during the day. During the day, try not to be at rest for more than 45 minutes at a time.

Side Effects

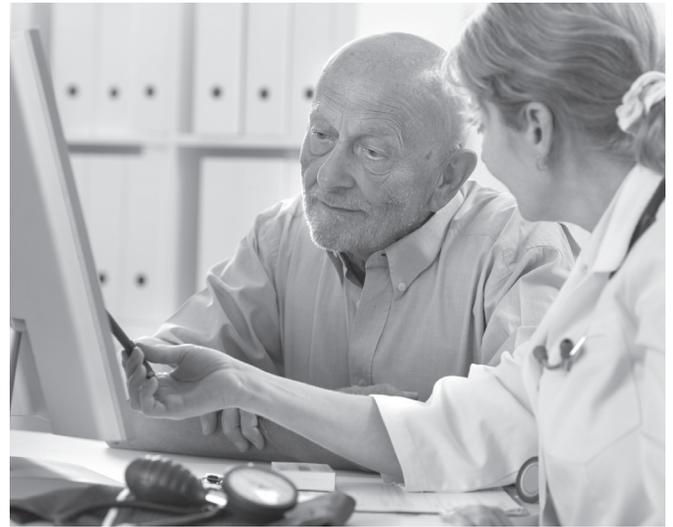
The most common side effects from surgery for the colon or rectum are nausea, constipation and diarrhea, but there are also others. Be sure to let your medical team know about what you are experiencing.

Your Pathology Report

Your pathology report (results of your surgery) can take up to 7–14 days.

The amount of tissue that is removed and additional specialized testing accounts for this length of time. All of our colon and rectal surgeons prefer to have the pathologists skilled in examining GI cancers look at the tissue and document their finding in full before they discuss them openly with you and your doctor. In some cases, they have to send tissues out to specialized labs. Doctors do not give preliminary results.

Expect your surgeon to share the findings at your first post-operative office visit.



Sex, Intimacy & Fertility

Sex & Intimacy Concerns

Cancer treatment can affect sexual function for both women and men and sexual concerns may occur while you are receiving treatment. Some concerns and changes may be physical, while others may be emotional. Your desire for sex may decrease, it may be painful to have intercourse, it may be difficult to reach a climax, surgery may have changed your physical appearance or you may be scared to resume any intimacy with your partner. Please do not be afraid to discuss any concerns with your team. Your nurse or doctor can provide you with information on sexual activity during treatment and recovery.

One of the best resources is found on the American Cancer Society's website. Go to [cancer.org/treatment/treatments-and-side-effects/physical-side-effects/fertility-and-sexual-side-effects.html](https://www.cancer.org/treatment/treatments-and-side-effects/physical-side-effects/fertility-and-sexual-side-effects.html)

From there, you can find information specific to men and women regarding sexual side effects of treatment.



Safe Sex During Chemotherapy

- While on chemotherapy, condom or dental dam use is recommended as a precaution to protect your partner from body fluids that may contain chemotherapy.
- Do not become pregnant or father a child while undergoing chemo or immunotherapy. It can damage a fetus.
- If you are a premenopausal woman and you stop your period during treatment, you can still get pregnant. Be sure to discuss this with your doctor. There is also additional information about this topic later in the chapter.

Intimacy

Continuing to share physical and emotional intimacy with our loved ones is important before, during and after cancer treatment. However, the physical and emotional changes that commonly occur as a result of cancer treatment and recovery may affect your responses to intimacy. Most people do experience some level of change in this area.

Many people feel a sense of vulnerability and uncertainty once they are diagnosed, throughout treatment and beyond. For those people who are sexually active and have a partner, the “cancer experience” sometimes allows couples to grow closer and become more intimate. Others may distance themselves because of physical limitations related to treatment, lack of desire, fear of rejection or fear of expressing one’s true thoughts and feelings. Some people experience changes in body image as a result of hair loss, weight changes and other body changes.

Surgery, medication and radiation therapy can cause problems with sexuality and intimacy. Common sexuality problems are a decreased interest or energy for sexual activity, pain with sex, changes in body image, incontinence, fertility problems, changes in your self esteem, changes in how you feel about your partner and relationship, changes in the ability to provide and receive pleasure, depression and anxiety. Some men may have problems with erections or ejaculation. Some women may have vaginal dryness, thinning of vaginal tissue, loss of sensation, trouble having an orgasm or experience menopausal symptoms.

Surgery can result in pain and altered body image. Couples can have difficulty being intimate after surgery because of the creation of an ostomy. Whether the ostomy is temporary or permanent, people with ostomies can still live fully. Ostomy nurses can help with necessary supplies and guidance.

Radiation therapy can result in skin changes and sensitivity to touch in the radiated area. It can also cause scarring of vaginal tissues exposed to radiation if the colon cancer is low in the sigmoid colon. Erectile dysfunction is very rare, but can occur due to any damage to the prostate.

Fatigue can be associated with most cancer treatments. If you have had surgery, ask your doctor about when you can resume sexual intimacy. This may vary depending on the type of surgery you have undergone.

As complex and individual as cancer treatments are, there are three concepts that can be quite powerful in helping you.

Adapt to Your New Body

- Explore your new body/sensations so that you can get comfortable with it and eventually share this information with your partner.
- The brain is the biggest sex organ in the body, use your mind to imagine what a fulfilling post-cancer sex life would be like.
- Consider fluctuations in your energy level so you can plan sex when you are feeling your best.
- Consider emotional changes that you have experienced and how they affect your desire for sex.
- Acknowledge relationship changes that may have happened during treatment.

If You Are Sexually Active, Communicate With Your Partner

- Unfortunately, many people are uncomfortable talking about sex. When cancer is involved, you and your partner may also feel worried, stressed or depressed.
- Instead of diving right into your own sexual concerns, try talking about sex in general. By working sex into your daily conversation you will build a vocabulary and comfort level that makes negotiating your own sex life feel more comfortable.
- When you're ready to talk, find a time when there are no distractions, when your energy level is good and you and your partner can talk freely.
- Your partner may be at a loss for words or may be hesitant to touch you, for fear of hurting you. If you and your partner are being intimate less often, try other activities that make you feel close to one another. Hugging, holding and sensual expression are important at this time.
- Your partner is not a mind-reader. Do not assume that your partner knows what to do or what not to do. Let your partner know what you want. Express yourself through your words and actions. Doing a light exercise routine with your partner, using soft music can be a way to ease back into physical intimacy. If you and your partner have always enjoyed dancing, that may be a familiar way to maintain physical closeness.
- A good rule of thumb regarding intimacy of any kind is to keep the channels of communication open and know that there is no "normal" time frame you must follow. Be sure to express your feelings, concerns and needs with your partner and allow your partner to do the same.



Communicate With Your Doctors And Nurses

Recognize and report to your doctors and nurses any symptoms you are experiencing.

For women:

Signs of bladder or vaginal infection include itching, pain or burning, frequent small amounts of urine, cloudy urine with abnormal odor and/or vaginal discharge, fever and/or abdominal pain. These are easily treated when caught early.

If you are experiencing menopausal side effects, some practical ways to relieve vaginal dryness include: the use of water or silicone-based lubricants (not oil-based) as well as some medicated creams that can be prescribed.

For men:

You may reach climax quickly or have problems staying erect. Sometimes practice in slowing down excitement will help. There may be creams or pills your doctor may prescribe to help.

Both men and women may experience pain during sex or when having an orgasm. If you are experiencing pain or discomfort with sexual intercourse that persists or does not improve after attempts at problem-solving, contact your doctor to discuss possible next steps. If you speak with a healthcare provider who is not comfortable or knowledgeable about sexual health, don't give up! You may have to ask for a referral to a specialist who is knowledgeable and experienced in post-cancer sexual and reproductive issues.



The booklet, *How Cancer Affects Sexuality* by the American Cancer Society, is an excellent guide that can help you and your partner begin to have open, honest talks about your sexual relationship with practical problem-solving techniques. You can find it on the ACS website, cancer.org or by calling 1-800-227-2345. You may also consider joining a support group to talk about your experience. Chances are, you will not be the only one in the room who is facing these issues.

Again, remember that sexual and intimacy issues are likely to improve over time.

Fertility

For women:

- If you wish to consider having children following your treatment, ask your oncology team about a referral to a fertility specialist that has expertise in treating women undergoing cancer treatments. **This should be done before starting treatment.**
- Your period could stop as a side effect of your treatment. It is important to talk with your doctor if this happens. Please remember that even if you are not having a period, you can still become pregnant.
- It is important that you not become pregnant while on chemotherapy and/or immunotherapy and for at least 6 months after your last dose, as it can affect a fetus. Talk to your doctor about birth control methods and how long to use them.

For men:

- *If you wish to consider having children following your treatment ask your oncology team about your options before starting treatment.*
- Chemotherapy can affect a man's hormone production, ability to make healthy sperm and sperm ejaculation. Chemotherapy works to kill rapidly dividing cells, like cancer. Sperm cells also rapidly divide, so they are often injured by chemotherapy. Sometimes the treatment can cause permanent infertility, but there is no way to know ahead of time. Chemotherapy can cause infertility in men older than 40.
- Radiation to the pelvis can also increase the risk of permanent infertility. Surgery for colon or rectal cancer may affect a man's ability to ejaculate. Sometimes nerves are damaged when removing lymph nodes to check for cancer (which is standard of care for these surgeries) and make it so the semen can't move out of the body.
- It is important that you not father a child while on chemotherapy and/or immunotherapy and for at least 6 months after your last dose as it can affect a fetus. Talk to your doctor about birth control and how long to use them.

More information about this can be found at [cancer.org/treatment/treatments-and-side-effects/physical-side-effects/fertility-and-sexual-side-effects.html](https://www.cancer.org/treatment/treatments-and-side-effects/physical-side-effects/fertility-and-sexual-side-effects.html)

Early Menopause

Chemotherapy may induce early menopause, either temporarily or permanently, depending on your age and the type of treatments given. Menopausal symptoms may include hot flashes, vaginal dryness, thinning of the vaginal wall, painful intercourse, decreased libido (sex drive), mood changes and sleep problems. Menopausal women are also at risk for developing osteoporosis or bone loss.

Radiation to the pelvis can be absorbed by the ovaries and could also cause early menopause. If you are going to have pelvic radiation, your surgeon may be able to move your ovaries outside of the target area before radiation begins.

Not enough is known about the effects of immunotherapy on pregnancy. It is important that you talk to your healthcare team about egg harvesting and birth control methods before you start treatment.

For women who have received chemotherapy, most women 40 years or older will stop their menstrual periods and only 5 to 25 percent will resume regular menstrual periods. Approximately 40 percent of women younger than 40 will stop their menstrual periods and about half will resume their regular cycles after finishing treatment.

The symptoms of treatment-induced or medical menopause are the same as natural menopause. However, they may be more severe since treatment-induced menopause comes on very quickly. This is particularly true for younger women.

Cancer treatments can cause early menopause, but menopause also happens naturally as a part of aging. If you experience changes to your period or any other side effect, it is important to speak with your oncology team. Together, you can determine whether it is occurring because of treatment or as a natural part of your aging process.

Common menopause symptoms include:

- Hot flashes, a sign that the ovaries are no longer producing enough estrogen.
- Problems with your vagina or bladder as tissues in these areas become thinner and drier.
- Lack of interest in sex, pain upon vaginal penetration and difficulty experiencing orgasm.
- Fatigue and sleep problems.
- Memory issues and other problems, such as depression, mood swings and irritability.
- Weight gain.

There are a variety of non-hormonal approaches available to treat menopause symptoms, including:

- For relief of hot flashes, avoid alcohol, caffeine, spicy foods and sugar. Wear layered cotton clothing. Try splashing cool water on your wrists.
- Try drinking warm milk or chamomile tea at bedtime to help you sleep better.
- Eat a well-balanced diet low in fat and high in fiber. Adding flaxseed, tofu and miso may provide additional relief, as they are dietary sources of estrogen. These are called phytoestrogens and their safety should be discussed with your physician.
- Try different relaxation techniques –such as visualization, deep breathing, massage or acupuncture – to help deal with irritability, stress or anxiety.
- Water soluble lubricants can help relieve vaginal dryness during penetration. You can also use Vitamin E capsules, inserted into the vagina at bedtime to provide relief from dryness. You can also try Replens, a long lasting vaginal moisturizer. If these methods do not help, ask your oncologist if using low dose vaginal estrogens, such as the Estring or Vagifem tablets, are safe for you.
- Drink lots of water, wear cotton underwear and urinate frequently to prevent bladder infections. Kegel exercises will also improve your bladder control.

Consult your health care provider before taking any additional medications or supplements and to discuss appropriate treatments for you.

Medical Oncology

Medical Oncology involves using medications to cure or control cancer. Since medications travel throughout the body, they are called “systemic treatments” as they treat the whole body (or whole body system). They can attack a cancer cell no matter where it is in the body. A medical oncologist prescribes and manages these medicines. Oftentimes, they also help coordinate care throughout a patient’s treatment course.

Types of Systemic Therapy for Colon and Rectal Cancer

Your medical oncologist may use several types of medications to treat your cancer. Each type differs by how they affect the cancer cells’ ability to grow and divide. Since your doctor will prescribe the best treatment for you, and since they come in different forms, you may be given these medications orally (by mouth) or intravenously (by vein/IV). Not every systemic therapy is recommended for all patients. Some treatments may work better if your cancer has specific mutations while others will not work if that mutation is present. Your medical oncologist will discuss your treatment options with you.

The following describes three common types of systemic therapy. Your oncology team will inform you what type of therapy you are receiving.

Three common types of systemic therapy are described on the next pages. They are:

- Chemotherapy
- Targeted therapy (biotherapy)
- Immunotherapy



How and when treatments are given

Systemic therapy (or medicine that treats the whole body system) is usually given intravenously (through a vein) or orally (by mouth) and travels throughout the body. It may be given before surgery or after surgery to treat your cancer.

- Neoadjuvant therapy: given prior to surgery to shrink large tumors and make surgery easier.
- Adjuvant therapy: given after surgery to decrease the likelihood of relapse or recurrence. It is typically given if the cancer is large or if it appears aggressive or involves lymph nodes.
- Ongoing therapy: given for metastatic disease. Systemic therapy may be used as a type of ongoing treatment.

Systemic therapy is given in cycles which include alternating treatment periods and rest periods. This gives normal cells a chance to recover but does not give cancer cells enough time to multiply. Each treatment may take a few hours, depending on the type of drugs used and the length of time it takes to administer each drug. Treatments may be repeated every one to three weeks, and may last four to six months or longer, depending on your treatment plan. For rectal cancer, systemic therapy is given at the same time as radiation.



Chemotherapy

Chemotherapy (or “chemo”), is also called “Anti-cancer drugs” or “Anti-neoplastic agents”.

Chemotherapy drugs work best on rapidly dividing cells. Since cancer cells divide rapidly, they are particularly vulnerable.

Some normal cells also divide rapidly, including:

- Bone marrow, which produces red and white blood cells and platelets
- Hair follicles
- The lining of the mouth, throat, stomach, intestines and rectum

Fortunately normal cells have the ability to recover, while cancer cells do not. While the normal cells are recovering, you may experience some side effects. Most of these side effects can be prevented or lessened with drugs and other supportive measures.

Chemotherapy side effects can range from minor to life-threatening conditions depending on the chemotherapy drug used, the dosage and the person’s overall health. Medical professionals must tell you about the potential side effects of any treatment they prescribe before you give your consent.

Most side effects involve suppression of the bone marrow, hair loss and temporary inflammation of the lining of the mouth, throat, stomach, intestines and rectum. Other common chemotherapy side effects include fatigue, nausea and vomiting, diarrhea, mucositis (sore mouth and throat) and neuropathy (numbness and tingling in hands and feet).

Targeted Therapy

Targeted Therapy is also called “biotherapy”. The goal of targeted therapy is to more precisely identify and attack cancer cells. Targeted therapy research has helped identify specific differences between normal cells and cancer cells. Thus the therapy can directly “target” the cancer cell’s inner workings and not affect normal healthy cells. There are many different targets on cancer cells and many drugs that have been developed to attack them.

Targeted drugs can work to:

- Block or turn off chemical signals that tell the cancer cell to grow and divide
- Change proteins within the cancer cells so the cells die
- Stop making new blood vessels to feed the cancer cells
- Trigger your immune system to kill the cancer cells
- Carry toxins to the cancer cells to kill them, but not normal cells

(Source: American Cancer Society website)

Targeted therapy is sometimes used alone, but most often other cancer treatments are used with targeted therapy.

Targeted therapy side effects can range from minor to life-threatening conditions depending on the drug used, the dosage and the person’s overall health. Medical professionals must tell you about the potential side effects of any treatment they prescribe before you give your consent.

Common side effects of targeted cancer therapies are diarrhea, liver problems, skin problems and problems with bleeding or wound healing, immune reactions and swelling.

Immunotherapy

Immunotherapy is a type of cancer treatment that boosts the body’s natural defenses (your immune system) to fight cancer. One way this can be achieved is to stimulate your own immune system to work harder or smarter to attack cancer cells. Another way is to give your immune system components, such as man-made immune system proteins.

The main types of immunotherapy now being used to treat cancer include:

Monoclonal antibodies: These are man-made versions of immune system proteins. Antibodies can be very useful in treating cancer because they can be designed to attack a very specific part of a cancer cell.

Immune checkpoint inhibitors: These drugs basically take the ‘brakes’ off the immune system, which helps it recognize and attack cancer cells.

Cancer vaccines: Vaccines are substances put into the body to start an immune response against certain diseases. We usually think of them as being given to healthy people to help prevent infections. But some vaccines can help prevent or treat cancer.

Other, non-specific immunotherapies: These treatments boost the immune system in a general way, but this can still help the immune system attack cancer cells.

(Source: American Cancer Society website)

Immunotherapy side effects may affect your lungs, intestines, thyroid or skin. It is extremely important to tell your team right away if you experience new onset of any symptoms, even if they seem minor. Common side effects with immunotherapy are fatigue and inflammation (which can be throughout the body including skin, lungs and colon). Immunotherapy side effects can range from minor to life-threatening conditions depending on the drug used, the dosage and the person’s overall health. Medical professionals must tell you about the potential side effects of any treatment they prescribe before you give your consent.

Side Effects

There are common side effects that most people experience when they are receiving medication for cancer. Please talk to your medical team about any side effects you experience.

Most of the time, chemotherapy drugs cause immediate side effects whereas immunotherapy drugs have delayed side effects (sometimes up to 4-6 weeks). Immunotherapy side effects may affect your lungs, intestines, thyroid or skin. It is extremely important to tell your team right away if you experience new onset of any symptoms, even if they seem minor.

Oral Anti-Cancer Treatments ("Oral Oncolytics")

IV medicines and oral medicines are equally important in the treatment of your cancer; your doctor will prescribe the treatment plan that will be most effective for your specific cancer.

When you are getting IV medications, your medical team is observing you and can ask you questions. Also, they assure that you have taken all of the medicine.

When you are taking oral medications for your cancer at home, your medical team can't observe you and ensure that you taking all of your medicine. Your ability to take your medication at home, in the amount prescribed, can greatly impact how well the treatment works against your cancer.

It is very important that you communicate with your medical team about any problems you have, even if it is before your next visit.

Some common problems you should report are:

- If you are not able to swallow your oral medicine
- If you have any side effects, even if they seem minor
- If you are not able to eat, drink or nourish yourself
- If you are having trouble paying for the medication
- If you have not received your refill on time

Vascular Access Devices

Most systemic cancer drugs and blood product transfusions are given intravenously every few weeks. Minimally, you will need blood tests before starting a cycle.

Because of the frequent use of the veins for testing and treatment, patients may benefit from placement of an IV vascular access device (VAD) to facilitate blood draws and intravenous infusions. VAD devices are small, flexible tubes (also known as catheters) that are inserted into a vein or blood vessel with the tip of the catheter in the large vein above the heart, called the superior vena cava (SVC). This is why VADs are sometimes referred to as “central venous access devices” or “central lines”.

Ports

The most common is an implantable port (usually called a “port”) which consists of a catheter attached to a small reservoir. Port placement is done under local anesthesia by surgeons in an operating room or special procedure room. With a small incision on the skin of the upper chest, the port is placed completely under the skin with the catheter tip ending into the SVC (the large vein above the heart). There is no segment of catheter showing outside the skin; just a slight raised area of the skin due to the raised center of the port’s reservoir which is called the “septum”. The septum is made of a self-sealing rubber material where a special needle is inserted to deliver the medication into the blood stream. Initially, ports will need to be bandaged until the incision is completely healed. After that, a dressing is used when you are receiving any type of infusion. Ports need flushing before and after use and monthly when not in use. Ports are designed to stay in for longer periods of time.

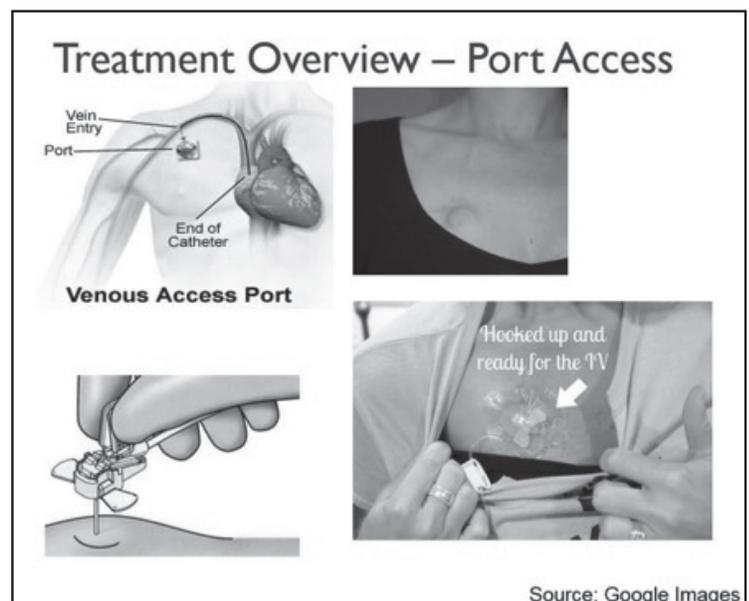
If you need another kind of central line, your doctor will talk with you about it.

Safety and Maintenance of Your VAD

If you have a VAD that is external (i.e. PICC or central line), wash your hands before and after you touch it. Make sure you follow directions on clamping the catheter when it is not being used. All external VADs require special bandages or dressings to reduce the chance of infection. Your healthcare team will provide specific instructions on how to care for your catheter. Flushing or irrigation is necessary to keep the catheter free from blood clots. All types of VADs need flushing before and after each use and regularly when not in use.

To help prevent or treat complications that can arise from having a VAD, it is important that you report the following symptoms or any unusual sensation that you are feeling immediately to your health care provider:

- Shortness of breath, light headedness, fainting, or discomfort on your chest within hours after the catheter has been inserted.
- Swelling, redness, heat, pain or tenderness along the vein in the upper arm and around the VAD
- Swelling of the hand, arm or neck on the side of the catheter insertion
- Leaking of fluid or pain around the VAD with injection or infusion
- Fever, chills, back pain, general malaise



Systemic Therapy Side Effects

People may have different reactions to the same systemic therapy treatments. If you undergo systemic therapy, you usually will not know how you will react or what side effects you will experience until a few days after your first infusion or starting oral medication. Listen to your body, pay attention to what you are feeling and always report these symptoms to your doctor or nurse. Your initial experience will help you prepare for and cope better with future treatments.

Before undergoing systemic therapy (i.e. chemotherapy, targeted therapy or immunotherapy), your medical oncologist will explain what to expect from your treatment, including possible side effects of the drugs.

If the systemic therapy you receive is known to cause certain side effects, your medical oncologist will prescribe medications to help prevent or lessen these symptoms. These medications are given/taken prophylactically - meaning they are given before you have any symptoms. Make sure you take these medications as directed.

Your medical oncologist may also order additional medications to take as needed, when you are having symptoms. It may take some experimenting to see what works best for you. It is important you communicate with your doctor and nurse if your side effects are not manageable.

One of the Best Things You Can Do For Yourself During Cancer Treatment No Matter What Your Age.... ***“Get Up, Get Moving!”***

Please watch a four minute Oncology Nursing Society video at ons.org/make-a-difference/quality-improvement/get-up-get-moving about their campaign, “Get Up, Get Moving”.

One of the best things you can do for yourself to feel better before, during and after cancer treatment, is to move and be as active as possible. Moving can be anything from short, light walks to more intense exercise, depending on your level of ability and doctor’s recommendation.

Radiation Therapy

Radiation therapy uses intense energy to kill cancer cells and shrink tumors by damaging the cells' DNA so they cannot repair themselves or divide. It can take days or weeks of treatment before the cancer cells start to die, but they also keep dying weeks to months after radiation therapy ends. Radiation therapy for colon and rectal cancer might be given before or after surgery, depending on the location and size of your cancer. The amount and location of radiation you are exposed to is carefully planned and monitored.

There is a whole team of specialists who create your treatment plan and administer your treatment; your radiation oncologist reviews and approves your plan and treatment at specific points along the way.

Unlike chemotherapy which provides treatment to the cells in your whole body (systemically), radiation therapy is directed to just the tumor cells and surrounding tissues (locally). Think of radiation as a large, powerful flashlight shining on your tumor. Surrounding healthy tissue can be affected. Since normal cells are often better able to heal from radiation injury than are cancer cells, most side effects from radiation will improve over time. Side effects from radiation vary depending on which area(s) of your body are treated.

Like many aspects of cancer treatment, radiation therapy techniques continue to improve over time. More accurate planning techniques and modern technology have improved the precision and safety of radiation treatment. Therefore, some of what you may have heard about radiation therapy in the past may no longer be true. The side effects of radiation therapy to the colon, rectum and anus differ from the side effects of radiation therapy to other parts of the body.

The information in this section will help you plan and prepare for your radiation therapy treatment. However, it is not meant to replace the individualized attention, advice and treatment planning of your radiation oncologist and medical team.

What is Radiation Therapy Used For?

- For **colon cancer**, depending on the location and stage of your cancer, radiation therapy can lower the chance of recurrence.
- For some **rectal cancers**, radiation therapy is given before surgery, with or without chemotherapy, to make the tumor smaller so it can be removed more easily. In some cases, radiation and chemotherapy are given after surgery instead of before surgery.
- **Anal cancer** can often be treated with radiation therapy and chemotherapy, as an “organ-preserving” approach that avoids the need for surgery.
- For **anal or rectal cancer**, frequently, the goal of treatment is “organ-preservation”. With organ preservation, the anus (the part of your body that controls your bowel movements), is not removed. Radiation therapy is often used in organ-preserving approaches, with the goal that you will continue to be able to have bowel movements through your anus. If the anus needs to be removed, you would have surgery to divert your colon and wear an ostomy bag on the outside of your abdomen to collect waste from your bowels.

The Radiation Therapy Process

What to Expect Before Treatment

Your initial visit

Before beginning radiation therapy, you will consult with a radiation oncologist (a doctor trained to use radiation to treat cancer). During your first visit, the radiation oncologist will review your medical history, imaging studies and pathology report. He or she will also perform a physical exam and discuss the risks and benefits of radiation therapy with you. This is your initial chance to share your concerns and fears and ask questions of your doctor and radiation oncology staff. It is a good idea to bring another person to this appointment since you will receive a lot of information about your treatment plan.

Simulation

Radiation therapy must be aimed precisely at the treatment target each and every time treatment is given. Simulation is the process of measuring your body and tumor to help your team direct the beams of radiation safely and accurately to their intended locations.

During simulation, your radiation oncologist and radiation therapist will place you on the simulation machine in the exact position you will maintain during the actual treatment. Devices such as molds, casts and headrests (also called immobilization devices) are customized to help you remain in the same position during the entire treatment. The radiation therapist marks the area to be treated on the immobilization devices and/or your skin with either a bright temporary paint or a set of small permanent tattoos about this size of a freckle or small mole. Do not wash these marks off when you bathe until your radiation oncologist or therapist says you can. Often, a special treatment planning CT scan is done to help with the treatment planning. This CT scan is only used to help with radiation treatment planning; it is not used to monitor your cancer.

Your simulation visit typically lasts approximately one hour and you will be lying on a firm surface most of the time. This can be uncomfortable. You

may want to take some mild pain medication before your visit if you have difficulty lying in one position for an extended time.

Treatment simulation/planning is a very precise and technical process. After it is completed, the radiation oncologist then reviews and approves your simulation. It will take a little time before you start your actual treatment. Your doctor and radiation center staff have not lost sight of you, but are concentrating on providing the safest and most effective treatment possible.

Treatment Planning

Once you have finished simulation, your radiation oncologist and other members of the treatment team review information obtained during simulation along with your previous medical tests to develop a treatment plan. The goal of radiation therapy is to develop a plan that maximizes the dose to the cancer and minimizes the dose to normal tissues. Radiation treatment technique, radiation dose, as well as beam angles and shapes will be selected during the planning process. A team of experts including your radiation oncologist, medical physicist and dosimetrist will work together to develop the radiation treatment plan. A sophisticated treatment-planning computer and associated software is used to help design the best possible treatment plan. After reviewing all of this information, your radiation oncologist will write a prescription that outlines exactly how much radiation you will receive and to what parts of your body.

Quality Assurance Before Treatment

Once your radiation oncologist approves the radiation therapy plan developed in treatment planning, members of the radiation treatment team work together to ensure that your specific treatment plan works correctly on the linear accelerator (the machine that delivers the radiation) before treatment begins. A 'dry run' is often completed for more complex treatments by a medical physicist to ensure that the radiation treatment designed for you is as accurate and as safe as possible.

What to Expect During Treatment

Most radiation therapy for colon and rectal cancers is non-invasive, meaning nothing is inserted inside of your body. There is a target dose of radiation that has been shown to be effective but it is too big to give at one time. The dose is divided up into small amounts (fractions) to reduce the side effects to your body.

External Beam Radiation Therapy Treatments

Generally, radiation therapy treatments are given daily, Monday through Friday, allowing your body to recover over the weekends. It is important not to interrupt your treatment schedule or to skip appointments. If you know that you will not be available during part of the time you are scheduled to receive your treatments, let your radiation oncologist know before you start your treatments. Some adjustments to the start time may be acceptable. It may be better for you to start your treatments a little later rather than interrupt your schedule.

After checking in at each visit, you may be asked to change into a hospital gown. You may then have to wait a bit before being called to the treatment area.

When you undergo external beam radiation therapy treatment, each session is painless, just like getting an X-ray. The radiation is directed at your tumor from a machine called a linear accelerator that will rotate around your body.

The radiation therapist will deliver your external beam treatment following your radiation oncologist's instructions. If an immobilization device was made during simulation, it will be used during every treatment to make sure that you are in the exact same position every day. The radiation therapist may move the treatment machine and treatment table to target the radiation beam to the exact area of the tumor.

Once you are positioned correctly, the therapist will leave the treatment room and enter the control room next door to begin your treatment. During your treatment, your therapist will closely monitor you on a screen. There is a microphone in the treatment room so you can always speak with the therapist if you have any concerns. The machine can be stopped at any time if you are feeling sick or uncomfortable. The radiation therapist is in complete control of the machine at all times. The machine makes clicking, knocking or whirring sounds; this is normal.

Total time in the treatment room will vary depending on the type of radiation, but treatments are typically between 10 - 20 minutes. Most of the time is spent positioning you for precise treatment using lasers to align you on your paint marks or tattoos. The actual radiation delivery usually takes only three to five minutes. Radiation has a cumulative effect and its best if you keep the schedule you have worked out with your physicians. It is best to arrive on time and show up to all of your appointments. Sometimes a course of treatment may need to be interrupted for a day or more. This may happen if you develop side effects that require a break in treatment. Unscheduled machine maintenance may also cause a missed treatment. These missed treatments may be made up by adding treatments at the end. However, it is best to arrive on time and not miss any of your appointments.

In some cases, you may receive chemo/immuno/targeted therapy and radiation therapy at the same time. Your treatment team will help coordinate these therapies and care for potential side effects. The chemotherapy may make the cancer cells more sensitive to radiation, thus making the radiation work better. Therefore, it is very important to let your radiation therapy team know if you miss a chemotherapy dose.

Weekly Checkups

You will meet with your radiation oncologist once a week during your treatment period. Each week you will have another opportunity to ask questions, discuss side effects and their management and share your concerns. You can also meet with other members of the radiation oncology team. Many centers have nurses, nurse navigators, social workers and dietitians available to help. If you have any concerns between weekly visits with your radiation oncologist, let your radiation therapist know.

Quality Assurance During Treatment

During your course of treatment, the positions of the treatment beams will be regularly verified to ensure accuracy. Images (e.g. CT scans) are obtained and represent an important quality assurance check, but do not evaluate the tumor itself. The type of images used may vary depending upon what kind of treatment you receive and what your doctor thinks will work best.

Side Effects

You may experience side effects from radiation therapy. When it is delivered to the abdomen and pelvis, it may cause more frequent bowel movements (occasionally with diarrhea) abdominal cramping and/or rectal discomfort and pain. It may also cause more frequent urination, sometimes with a burning feeling. Treatment may also cause a small amount of blood to appear in the urine or stool. These should gradually go away several weeks after treatment ends. Some patients may also feel tired or lose their appetite. This is temporary as well.

Every day your radiation therapist will be checking your side effects. It is important to let them know if they are worsening.

Talk with your doctor and treatment team (including the nurse and radiation therapist operating the radiation machine) about any new symptoms you experience during treatment.

Caring for your bottom

- During the last 3 weeks of radiation, many patients have found comfort from using perianal wipes or incontinence wipes with skin protectant. These medicated wipes can be more comforting than baby wipes.
- Look for a gentle product that has dimethicone 3% or higher. Dimethicone is a skin protectant helping to preserve fragile skin.
- Look for a product that is thick, soft and hypoallergenic. Products should also be alcohol free and fragrance free so that it doesn't dry or irritate skin.
- Use these wipes to clean and then apply cream given to you by radiation nurses. These can be expensive but you can cut them in half to help decrease cost.
- Do not flush these wipes, but dispose of them in the trash. These wipes are not kind to plumbing.

Here are examples of some brands:

- Sage Shield Barrier Cream Cloths
- Medline AloeTouch PROTECT skin protectant cleansing cloth wipes
- Medline Remedy Phytoplex
- Sensi-Care Skin Protectant Incontinence wipes

Clinical Trials

Because of research, we have better and more effective cancer drugs and therapies than ever before. As a result of these newer treatments, survival rates have increased, quality of life has improved, and treatment side effects are fewer for thousands of people with cancer. Many of these drugs and therapies would not be available today if it were not for cancer research programs and cancer patients willing to participate in clinical trials. Some people feel that participating in a clinical trial gives them an opportunity to help others with cancer through the knowledge gained from the study.

What is a Clinical Trial?

A clinical trial is a research study designed to answer one or more questions about how a certain drug, treatment or medical device affects a disease such as cancer. Clinical trials are available for prevention, treatment and symptom management of cancer.

Cancer clinical trials can be sponsored by the National Cancer Institute, cancer cooperative groups, nonprofit organizations, pharmaceutical companies and device companies. Most cancer clinical trials offered through Sutter Health are sponsored by the National Cancer Institute or a pharmaceutical company.

In cancer care, treatment clinical trials examine the current standard of care and what researchers are hoping will be more effective. Placebos are never used unless the standard of care is observation, meaning that no other treatments are recommended (just follow-up with your doctor).

Voluntary Participation

Participation in clinical trials is always voluntary. You will not be enrolled in a clinical trial without your permission. You give permission to participate in a clinical trial by signing the informed consent. You can change your mind about participating in the clinical trial at any time after signing the informed form. To stop your participation in a study, talk to your research team.



Is Participating in a Clinical Trial Right for Me?

The treatment you receive during a clinical trial may benefit you. Newer therapies may lead to better results. On the other hand, they may not be any better, or even as good as, standard therapies already available.

Participating in a clinical trial will require some extra time on your part. The research team will want to monitor you closely during the trial and collect follow-up information. This care is in addition to the care you will continue to receive from your oncologist and medical team.

Am I Eligible for a Clinical Trial?

Not everyone is eligible to participate in every clinical trial. Each clinical trial has criteria about who can participate. Criteria includes factors such as the stage of your cancer, previous treatment history and other medical conditions. These factors are called eligibility requirements. They are used to ensure that researchers will be able to answer the questions they plan to study. Your doctor and/or clinical research team will determine if you are eligible for a clinical trial after a physical examination and a review of your health history and medical records.

Considering a Clinical Trial

If you are eligible for a clinical trial, members of your research team will meet with you to discuss the details of the study. They will review a document called an informed consent.

The consent form will answer a number of questions, including:

- What is the purpose of the clinical trial?
- How long will the trial last?
- What is required of you to participate in this study?
- What treatments or drugs will you receive during the trial?
- What treatments, tests and/or procedures will be required during the study? How many and how often?
- Which treatments, tests, medications and/or procedures will be paid for?
- What are the risks and benefits of participating in this research study?
- What are all the treatment options, if you do not participate in a trial?



You will be given time to read the consent form and talk it over with your doctor, family or friends before deciding if you want to participate. The informed consent process continues as long as you are involved in the study. You will be notified of any modification, new information or changes that may affect your participation.

More Information on Clinical Trials

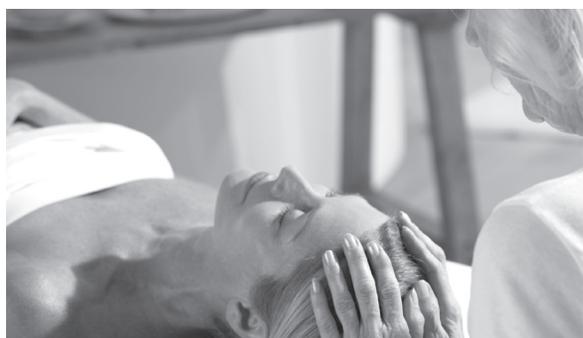
For more information on government-sponsored National Cancer Institute (NCI) trials, you can contact the NCI at 1-800-4-CANCER or you can find a comprehensive list of NCI-sponsored studies at <https://clinicaltrials.gov>. Contact your oncologist for information on cancer clinical trials offered within the Sutter Health network.

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

Integrative Medicine

Integrative Medicine

Integrative therapies engage the mind, body and spirit in the healing process. They help with your treatment program and can improve your quality of life. They are meant to complement, rather than replace the medical care you receive from your doctors and other health care providers. Talk to your doctor, nurse or social worker about the integrative therapies available at Sutter Health or in your community. We encourage you to seek integrative therapy practitioners who have specialized training in cancer care and who have experience working with people who have been diagnosed with cancer and are undergoing cancer treatment.



Guided Imagery

This gentle technique uses the power of mental imagery to assist in your healing. In mentally visualizing healing places, activities, sensations and experiences your sense of well-being can be enhanced and healing processes may be activated.

Guided imagery is a safe, easy and powerful tool to relieve tension, lower stress, improve sleep, and cope with anxiety and other emotions. By becoming attuned to your body and your breathing rhythm, you can send warm energy to parts of your body that may be tense, breathe out the tension and breathe in peace and healing.

You can listen to guided imagery recordings, or make an appointment with someone trained in guided imagery.

Massage

Massage should be performed by a certified massage therapist who is specially trained to work with cancer patients. Massage is a powerful therapeutic tool to help relieve muscle pain and tension. It also provides healing touch and comfort, enhances well-being and fosters nurturing.

There are many types of massage therapies. Craniosacral massage, for example, uses a light touch as the therapist monitors the rhythm of the craniosacral (brain and spinal) system to detect restrictions and imbalances. Delicate manipulations are used to improve the central nervous system and foster a deep sense of calm and well-being.

Massage therapists can use different degrees of pressure depending on your condition and preference. Make sure to discuss this with your massage therapist. Lighter pressure is usually better to start with. It is important to note that while massage can be extremely therapeutic, it can cause harm if done incorrectly or by an inexperienced practitioner.

Acupuncture

Acupuncture is an ancient Chinese technique based on the understanding that our life force or “chi” flows through channels in the body known as meridians or pathways. Needles as thin as a human hair are inserted at specific points along these meridians to stimulate, disperse and regulate the flow of chi. Acupuncture can be used before, during and after your treatment. The goal is to restore a healthful energetic balance, alleviate discomfort and treatment side effects, and support the immune system. Please let your doctor or nurse know if you choose to explore acupuncture.

Energy Therapies

The purpose of these therapies can be broadly defined as the healing of mental and physical illness by rebalancing the energy fields in the body. A gentle, non-invasive form of energy work is used to manage the side effects of treatment. Some of these include therapeutic touch, meditation, Qi-gong and Reiki therapy.

Yoga and Other Movement Therapies

Movement therapies are forms of exercise that integrate the mind, body and spirit. They use stretching, movement, breathing techniques and meditation to create a state of peacefulness, as well as physical and mental well-being. They may enhance your quality of life by reducing stress and increasing feelings of relaxation. Be sure to check with your doctor about what kind of movement would be helpful for you.



Expressive Art Therapy

Expressive art therapists work with your imagination and intuition to help you create healing images. Drawing a picture, creating a collage, writing a poem, listening to music or making a scrapbook may provide healing on many levels. They can improve your quality of life and help you understand or cope better with sadness, anxiety and other emotions. Expressive art therapists listen to your unique story and show you how to express your feelings in the most comfortable and appropriate way for you.

Herbal and Nutritional Supplements, Vitamins and Antioxidants

It is very important that you discuss herbs, supplements, vitamins and antioxidants with your oncology team. Some supplements may interfere with your cancer treatments. For more detailed information, please refer to the *Resources* section of this binder in the Complementary and Alternative Information section.

Nutrition and Integrative Nutrition

Your oncology team may refer you to a registered dietician to help you manage specific aspects of your health and cancer treatment. Your dietician will evaluate your nutritional status and help you develop a personalized nutritional plan that may include lifestyle changes, specific nutrition goals, supplements and healthy enjoyable ways of eating.

Optimal nutrition before, during and after cancer treatment can support your immune system as well as your level of strength, weight management and muscle mass. It can also reduce inflammation and decrease the stress on your digestive tract.

Some communities may also have access to certified and experienced integrative nutritionists or functional medicine nutritionists. Integrative nutrition examines both your diet and the root causes of chronic disease and symptoms. These professionals can offer detailed lab tests that will provide additional information and advice about your dietary needs and how you can use nutrition to support healing.

Ask your oncology team for a referral to a registered dietician who has experience working with people who have cancer. You may also ask your oncology team if they know of an experienced integrative nutritionist or certified functional medicine nutritionist in your area.

Counseling, Therapy and Integrative Psychotherapy

Counseling, (also known as “psychotherapy” or “therapy”) can be very helpful in lowering your stress and learning to cope with the feelings that may occur when going through cancer diagnosis and treatment. When choosing a counselor or therapist, it is recommended that you work with someone who is licensed and who has experience working with people diagnosed with cancer. Ask your oncology team for referrals to experienced professionals in your community.

Some therapy professionals practice “integrative psychotherapy”. Mind, body and spirit are not separate; and integrative psychotherapy attends to all the dimensions of human. It works with the body, feelings, beliefs, thoughts and one’s spiritual orientation.

Integrative psychotherapy uses practices that develop wisdom and compassion, heal the heart, balance the mind, receive the body’s wisdom and meet life’s challenges with responsiveness.

This focus supports you in deepening your connection with your whole self, cultivating self-compassion, wholeness and well-being.

You might choose to work with an integrative psychotherapist if you want to listen deeply to the wisdom of your body, heart and mind. You may wish to use mindfulness, art therapy and other healing methods to improve your mental health and well-being.



Some of the other forms of therapy which are also effective include:

- *Client Centered (or Supportive or Expressive) Therapy* provides a supportive environment where you can express your thoughts and feelings.
- *Cognitive Behavioral Therapy* focuses on developing coping strategies and changing unhelpful patterns in thoughts, beliefs and attitudes.
- *Dialectical Behavioral Therapy* helps you regulate emotionally and mentally by learning about what triggers cause you to react and helps you build coping skills for these situations.
- *Psychodynamic Therapy* is a form of depth psychology that invites the unconscious to be revealed in order to create greater wholeness, freedom and integration.

Many therapists are trained in one or more of these methods.

Aromatherapy

Aromatherapy is a practice in which scented oils are inhaled through the nose. Some people apply it to their skin, however, many oncologists believe this is harmful during cancer treatment. Even though these are natural, they can cause allergic or sensitivity reactions. Be sure to talk with your oncologist before using aromatherapy during your cancer treatment.

Aromatherapy is not used to treat cancer but rather to help manage symptoms and side effects. Research in cancer patients has shown that aromatherapy may help relieve anxiety, depression, lack of energy and nausea among other problems.

The oils used in aromatherapy, called "essential oils," are the highly concentrated extracts of flowers, leaves, stems, roots, seeds, bark, resin or fruit rinds. Essential oils can be purchased in most health food stores. Because of their high concentration level, essential oils must be diluted before they are applied to the skin. Oils are usually diluted with a "base" or "carrier" oil, which is a vegetable oil that helps spread the essential oil over a larger area and protects the skin from a reaction.

An aromatherapist can help to select an oil or combination of oils to fit each person's specific needs. Commonly used essential oils include: peppermint and ginger for nausea; lavender, bergamot, sage and chamomile for relaxation or sleep; peppermint for headache; lemon, orange, cedarwood, cinnamon for energy.

Other ways to use aromatherapy:

- Place a few drops of essential oil in a diffuser to allow a soothing fragrance to fill the room.
- Sprinkle 2-4 drops of oil on a tissue or a handkerchief, and hold it up to your nose. Keeping your eyes closed to avoid irritation, take 2-3 deep breaths through the nose.
- Place 10-15 drops of oil in a 4-ounce spray-bottle of water. Shake the bottle and then spray fragrance around a room.



Important things to consider before trying aromatherapy:

- Make sure you're using essential oil. The label should say "pure essential oil," not "blend" or "massage" oil. If the label isn't clear, don't purchase the oil.
- Some essential oils are poisonous. You should NEVER TASTE OR SWALLOW any essential oil.
- Pregnant women and children should not inhale essential oils or rub them on their skin.
- If your oncologist agrees with using essential oils directly on your skin, always do a skin test first.
 - Spread a little bit on a small area of your arm and put a bandage over it.
 - Wait 24 hours to make sure there is no skin reaction before trying it on a larger area.
 - If the area becomes red, swollen, or sore, do NOT use the oil again.
 - It's important to use "organic" oils that have been produced without chemicals. Oils made with chemicals can irritate the skin.
- If you find that you are sensitive to different aromas, you may need to avoid those essential oils.

Important: As with other integrative therapies, check with your oncologist before using essential oils or aromatherapy.

Mindfulness Meditation

Please see the *Survivorship and Wellness* chapter for more information about mindfulness meditation.

Coping and Living with Cancer

Overall quality of life depends on our physical, emotional, mental, social and spiritual well-being. All of these areas play an important role in our personal journey with cancer.

Support can come from many sources: family members, friends, coworkers, neighbors and also our spiritual practice or faith.

The following section is a resource for living life more fully after being diagnosed with cancer. Please also see the *Resources* section of this binder for a list of practical resources.



Helpful Suggestions

It is often difficult to accept help from others. Try to focus on yourself, making YOU the most important focus while you get through the initial phases of diagnosis and treatment. When facing a cancer diagnosis, accept support from family and friends.

Gather Your Team

One of the most helpful first steps is to establish a network of support. Many different people can make up your care team. Your physicians' primary role is to treat your cancer. Other supportive resources might include friends, neighbors, family members and people in your community.

- Learn to accept offers of help. Prepare a phone list of “helpers” and keep it handy.
- Try to find someone you can reach out and open up to. It should be someone with whom you feel safe sharing your thoughts, emotions and hopes. It is okay to let people know you would like them to just listen without giving advice.

Taking Control: How Can They Help Me?

- Remember that you are not alone. It's important to ask for help. Give yourself permission to delegate those things you want help with.
- Many people want to help, but will need your direction to guide them. Sometimes you have to reach out to them.
- Remember that when you allow others to help you, they also are benefitted.
- Assign specific tasks to each family member. Keep a list of tasks handy so that you can give a quick answer when someone says “let me know what I can do to help.” Keep track on your list of who is doing what. You might ask several people to each provide different kinds of support – depending on their strengths and availability.

- Some examples of practical tasks that can be delegated include:
 - Shopping for groceries and picking up prescriptions
 - Helping with chores around the house such as getting the mail, taking care of pets, doing laundry, taking care of plants and flowers, yard work, taking out the garbage
 - Cooking dinner and dropping it off (with or without “visiting time”)
 - Preparing lunch for a caregiver
 - Babysitting children, taking them to and from school and evening activities
 - Offering to arrange playdates for young children
 - Organizing a telephone chain or support team to check in and complete tasks on a regular weekly basis
 - Driving you to an appointment or support group meeting, taking notes during an important appointment
 - Keeping you company
 - Delivering newspapers to the door
 - Going to the post office
 - Driving family and friends to and from the airport or hotel
 - Returning or picking up library books
 - *Many other things can be added to this list!*
- **CancerCare:** *CancerCare.org* provides online counseling, education and financial assistance provided by trained oncology social workers.
- **Cancer Hope Network:** *Cancerhopenetwork.org* matches patient and/or family members to trained volunteers throughout the US who have recovered from similar cancer experiences
- **Cancer Support Community:** *cancersupportcommunity.org* is a nationwide nonprofit group with local chapters and support groups dedicated to supporting people and their loved ones who are living with cancer.
- **Communication websites:** *CaringBridge.org*, *MyLifeLine.org* and *PostHope.org* are all excellent services that allow you to create your own free, secure webpage where you or a family member can update and organize your friends and family around your healing. It is often a relief to patients and close family members to give an update only once; they only have to spend the energy explaining things once, and everyone who wants to be updated can be. Even though these websites are very helpful, please take precautions to protect your personal information and safety by not posting your address, insurance information, detailed medical information, times when you will be away from home for any length of time and anything else others should not have access to.
- **Food Tidings:** *FoodTidings.com* is a web-based tool that can be used to create and organize meal support schedules. You can invite friends and family as you wish to have them participate. An easy way to ask for practical help.

There are a number of online social support resources that can help you organize your personal support team (see “Communication websites” in the next column). These resources make it easier for you to decide what you want to share with family and friends. You can also find additional information in the *Resources* section of this binder. *Note: Be sure to protect yourself and avoid posting too much personal information (i.e. your address, insurance information, detailed medical information) on public social media sites like Facebook and Instagram.*

You can maintain a sense of control by continuing to do the things that make you happy and bring you inspiration and well-being. For instance, reading, music, art, being outdoors, family time and peaceful meditation can all help you maintain a sense of normalcy.

Communication and Relationships

People with cancer who have strong emotional support tend to have a more positive outlook in the long run.

Friendships and Cancer

We need support from our friends. Often, friends mean well and truly want to help, but may not know what to do. Some people feel awkward, and may not know what to say. They may remain silent or stop telephoning you. It's a good idea to reach out to your friends to open the line of communication and to reconnect with them. You might say, *"I'm not sure if you have heard, but I have been diagnosed with cancer. I am making a list of things that I think might be helpful to me. May I put your name on my list of helpers?"* Give them some choices of specific things they can do to help you. Your reaching out may be a great relief for those who might have been uncomfortable approaching you.

Family

A cancer diagnosis affects every member of the family and support system. Normal roles and routines may be suddenly changed or disrupted. It is normal for family members to respond to stress in different ways. Every member of the family may have a different way of coping with the stress of illness.

A general rule that has helped many people is to acknowledge how you are feeling and to openly share with one another. This is one of the best ways for family members to deal with their feelings. You can, of course, decide how much, with whom, and when to share your personal feelings about your cancer. Talk with your nurse navigator or social worker about resources available to help you and your family manage your emotional responses.



Children

Sometimes, parents don't want to burden children with information about their illness because they do not want their children to worry or be afraid. You may find yourself struggling with that decision. It may be difficult to decide when and how much to share. Consider your child's age, maturity and what you believe your child can handle as you communicate with them.

Even without any information from you, children sense that something has changed and may fear the unknown. With small children, it is important to maintain their routines as much as possible and let them know in advance when there will be changes. Invite them to draw special pictures for you to help you feel better.

For older children, let them know the household schedule may change. Inform them that this may include needing more help from them with household chores. If possible, involve them in decisions about any changes. Spend time with them and listen to their thoughts and feelings.

Change creates stress, no matter what the age. Adult children, adolescents, school-age and preschool-age children all have different needs and communication styles. There are resources available to help parents and children of all ages to communicate well. For example, teachers, school psychologists, counselors, pediatricians, church members and community groups are available. Ask your doctor, social worker or nurse navigator about resources near you that can help you and your children talk about your cancer. While this may be challenging, you are not alone.

Partner/Spouse

Spouses and partners often become the primary caregivers and advocates for their loved one with cancer. Being in the caregiver role can be tiring, demanding and sometimes overwhelming. At the same time, providing such service for a loved one with cancer can strengthen a relationship, inviting a deeper, closer bond between you and your loved one. It is common for spouses and partners to need emotional support as well as practical help during the time of your illness. There are resources available to help support spousal caregivers. Your healthcare team is available to help you find resources for you and your loved ones.

Intimacy & Sexuality

Please see the *Survivorship and Wellness* chapter in this binder about intimacy and sexuality for a full section on this topic.



Managing Emotions

Be gentle with yourself. Keep in mind there is no right way to feel. All feelings are welcome, even when unpleasant. Many people react with shock, denial, sadness, frustration, grief, confusion, anger and anxiety. Fear of the unknown, and changes in roles, routines and employment can add to feelings of loss of control. You may want to be strong for others, and at the same time, irritability and mood swings may happen for you more frequently than ever before. Feelings often come in waves and may change from day to day. This is quite normal when coping with cancer. Tell your healthcare team about your feelings and particularly mention if these emotions interfere with your daily life, activities, and quality of life.

Fear and Anxiety

Many people with cancer may experience prolonged anxiety and depression. This is not unusual. The fear of cancer recurring is also a natural and very powerful response. Your sense of self may be altered after a cancer experience. You may feel fearful, anxious or uneasy. It is important to acknowledge and express your feelings so that you can live your life to the fullest. Here are a few helpful tips:

- Talk about your fears and other feelings with someone you trust.
- Be proactive in your life – take charge, anticipate problems and act on your decisions.
- It is okay to say “no” as your priorities may shift.
- Knowledge is power. Ask your nurse navigator or social worker to help you find the information you need.
- Understand that there will be ups and downs: days that feel good and days that are more difficult.
- Exercise can help reduce anxiety and improve your mood.

Depression

It is common for all cancer patients to experience grief and sadness during their diagnosis and treatment. Tell your doctor, nurse navigator, social worker or other health care provider if you feel you are becoming depressed, if your feelings of sadness last more than two weeks or you have a past history of depression. They are there to help you and can offer support to help you through this difficult period.

Should I Join a Support Group?

You may feel overwhelmed, afraid and alone. It can be challenging to deal with these strong emotions, or to talk to even the most supportive family members and friends. If this is the case, a support group offers a safe place for you to share your thoughts and emotions with others who understand.

Cancer support groups can help you and your loved ones:

- Meet other people living with cancer who are experiencing the same problems and emotions
- Find a confidential atmosphere where you can discuss the challenges of your illness without feeling judged
- Improve your ability to regain control when dealing with the uncertainties and challenges that cancer brings
- Hear practical tips about what has worked for others who are living with cancer
- Join with others to share experiences and express a wide range of emotions
- Experience support and less aloneness
- Be a source of support and strength to others

Sometimes, others who have been through similar experiences can explain things differently than your health care providers. Be aware, however, that others may share information or experiences that do not apply to you. Never replace your healthcare team's advice with that given by another patient. If confused, always talk to your doctor.

There are many different ways of participating in support groups. You may want to try a few different approaches before finding the one that works for you. This may include: online groups, professionally led groups, lay survivor groups and other community groups. Talk with your nurse navigator or social worker about what groups and/or resources are available in your area.



Getting a Good Night's Sleep

The natural aging process, coupled with the side effects of treatment, may make getting a good night's sleep challenging.

It may be helpful to keep a record of your sleeping patterns for two weeks and share this record with your doctor.

Include such things as:

- When do you go to bed?
- Do you fall asleep immediately?
- When do you wake up?
- Are there symptoms waking you up at night?
- Is pain interfering with your ability to sleep?

You and your doctor can come up with a “sleep plan.” This may include medication and lifestyle changes.

The National Cancer Institute recommends the following to help promote rest and treat sleep disorders:

- Create an environment that decreases sleep interruptions by:
 - Lowering noise
 - Dimming or turning off lights
 - Adjusting room temperature
 - Placing pillows in a supportive position
 - Wearing loose, soft clothing to bed

- Eat a high protein snack two hours before bedtime
- If you can't fall asleep or stay asleep, leave your bedroom and engage in a quiet activity in another room: return to bed when you are sleepy
- Maintain a regular wake-up time
- Avoid using devices with electronic screens (computers, tablets, TVs, e-readers and smart phones). Research has shown that these devices stimulate areas of the brain that lead to wakefulness
- Soothe your mind. Try reading, listening to a relaxation recording or app, relaxing music or an audio book
- Avoid caffeine within four to six hours of bedtime
- Avoid the use of nicotine
- Be aware that alcoholic beverages may interfere with sleep
- Strenuous exercise close to bedtime may interfere with sleep



What Legal Issues Do I Need to Discuss with My Family?

When you've been diagnosed with cancer, concentrate on getting better and coping with your treatment. A cancer diagnosis may motivate you to make some important decisions with your family and doctor. Something you may want to discuss are advance directives. Advance directives include:

- *A Living Will*, which is a legal document that contains written instructions specifying your wishes concerning medical treatments at the end of your life.
- *Durable Power of Attorney for Healthcare*, which is a legal document that names a person of your choice to make personal medical decisions for you when you cannot make them yourself. This person is called your health care agent.

You can designate anyone you wish to be your decision-maker: your spouse, child or friend. It is best to have a conversation with this person about your wishes regarding your care and choices you would make for yourself.

Deciding to set up an advance directive does not mean you are giving up on life. Making decisions in advance helps you control your choices. Clarifying your wishes so others can follow them, can lower your anxiety about the future.



- **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.

Healthcare Finances

Dealing with money matters on top of treatment can be stressful. However, taking care of your finances is another way of taking care of yourself.

At the time of this printing, the information contained in this section is current. However, healthcare financing is in an uncertain state and this information may not remain so.

Once diagnosed with cancer, you should check with your insurance provider and your healthcare team for the most up-to-date information as it pertains to your situation. You can also check with local, state and federally funded programs to determine their availability to consumers. Please understand no insurance plan will pay 100% of your medical expenses.

Nurse navigators, social workers and financial counselors may be able to connect you with financial support resources. Ask your doctor if his or her office can refer you to one of these people.

The Cancer Legal Resource Center produces an excellent publication titled *Managing the Cost of Care/Consumer Rights*. It gives an excellent list of ways to manage the financial aspects of care. It can be found by going to cancerlegalresources.org/publications-webinars/financial-publications/ and then clicking on that specific document.

Covered California

Covered California (*CoveredCa.com*) is the marketplace established for legal residents of California to purchase medical insurance as mandated through the Patient Protection and Affordable Care Act. You may qualify for certain private insurance plans or California's Medi-Cal program.

Many Californians will not need this website as they have obtained their medical insurance through their workplace, have Medicare, receive their health insurance through other programs such as

the Veterans Administration or purchased their insurance through other means. The primary goal of Covered California is to increase the number of Californians with health insurance.

To learn how you might benefit from obtaining health insurance through this marketplace, log on to Covered California (*CoveredCa.com*). As part of the application process you will be asked several questions: the number of people in your household, combined annual income of all the members of your household, the ages of the members of your household and the county in California where you live. The site will quickly notify you if any members of your household could qualify for free coverage through Medi-Cal and direct you to the site where you can apply for Medi-Cal.

If you do not qualify for Medi-Cal the site will direct you to the marketplace. In the marketplace, there will be different health insurance companies offering different payment options for health care. All healthcare plans in the marketplace must meet certain requirements for care such as; hospital stays, prescriptions, doctors visits and emergency care. The plans do vary based on cost. The site will allow you to compare the cost of things like premiums (what you pay each month to purchase your health insurance), co-pays (the amount you must pay for things like lab tests, x-rays, or doctors' visits) and annual deductibles. You should check and see if your physician is participating in the plan you are interested in.

The marketplace will give you some guidance in deciding what plan makes financial sense for you. You cannot be denied coverage because you have a pre-existing condition.

It is critical that you look at the total out of pocket costs and not just monthly premiums. Often times, a plan seems more affordable because the monthly premium is low, but your total out of pocket cost

could be much higher than a plan with a slightly higher monthly premium. For example, let us say Plan A has a monthly premium of \$100 and requires you to pay 20% of your medical expenses until you reach a maximum out of pocket maximum of \$7500 a person whereas Plan B has a monthly premium of \$45 and states you are responsible for 20% of all incurred costs with no maximum. Unfortunately, health care is expensive. In this example, let us pretend a patient accrued \$200,000 in medical bills in one year. With Plan A the patient's responsibility would be \$8700 (\$1200 in premiums and \$7500 maximum out of pocket). With Plan B, the patient's responsibility would be \$40,540 (20% of \$200,000 is \$40,000 plus \$540 in premiums). While this example may seem extreme, these are the things you need to look for when picking a plan.

Covered California plans have an open enrollment period, (the time period during which you can sign up for insurance). If you do not sign up during the current open enrollment period you must wait until the next open enrollment period. There are financial penalties for those individuals who do not have health insurance.

There are various ways to enroll; online, through a paper process or over the phone. The Covered California site will explain each of these processes and how to complete the application with each of these methods.

Working Within the Health Insurance Marketplace

One very valuable resource for getting help working within the marketplace can be found at *CancerInsuranceChecklist.org*, a website, which is "designed to help you when shopping for insurance on your state's Health Insurance Marketplace if you have cancer, a history of cancer, or are at risk for cancer." You can download the checklist at <https://cancerinsurancechecklist.org/>

Using Health Insurance

- Always bring your health insurance card and photo ID (i.e. driver's license) to every doctor or medical visit.
- Notify your insurance company according to their guidelines. For most policies, you must call to pre-certify any inpatient hospital admission. Some require an authorization for any service costing over a set amount. Knowing your policy's guidelines and making that phone call will save you money and hassle. Sometimes your physician's staff will obtain authorization from your insurance company for certain procedures. Confirm with the staff if authorization has been obtained.
- Health insurance is like homeowners or car insurance in that different policies cover different types of benefits. It is important to fully understand what your policy covers. Your plan may exclude or have a separate out-of-pocket maximum for prescription drugs.
- Be aware that some health plans may not pay for some special medical consultations. Other plans may pay for them, but you may have a higher co-pay than for a regular visit. If you have any questions, call your insurance company. Try to talk with the same person each time you call if possible.
- Do not let your health insurance policy expire. New insurance may be difficult to obtain while you are in treatment. Pay premiums in full and mail them in plenty of time to arrive and be processed before the due date. Some policies have a grace period for late payments; however, if you require care during the grace period, any late payments may complicate authorizations.

Getting Organized

- Call your employee benefits administrator to request a copy of your complete insurance policy. Ask for the entire detailed benefit description, usually called a “Summary Plan Description.” This is different from a brief overview or informational brochure. This document may have many pages and your employer will give you a copy upon request.
- Put aside some time to review your health policy line by line, and highlight relevant sections. Closely read any sections on exclusions and exceptions. Understand the dollar amount of your policy’s “out-of-pocket maximum.” If you have questions, ask your employee benefits administrator for clarification.
- Find out how to call a “claims assistant” at your insurance company. These people can help you with accurate information if you have questions about coverage or a specific claim.
- You will receive lot of mail related to your medical expenses. An Explanation of Benefits (EOB), is a statement of charges created by your insurance company. It will detail the services you received, the providers’ charges and how the charges are processed by the insurance company. A medical bill is a statement created by your healthcare provider and/or the facility where you received services.
- It can take a few weeks to months before your insurance company receives all the information related to your cancer treatment charges and payments. For example, you may receive a bill from the hospital for surgery, but there may be separate bills from the surgeon and anesthesiologist. Sometimes the doctor and hospital bills do not reflect the insurance payment when they are initially sent out.
- While it can be confusing, it is important keep track of what you are billed, how much insurance is covering and the amount you are responsible for.
- It may be helpful to keep a spreadsheet or some kind of tally to see how much you pay out-of-pocket. Since bills can come from various places, your doctors’ offices or the hospital may not know you have reached your maximum out of pocket limit (if your insurance plan has one). Once you reach your limit, you can inform the offices/facilities that you have met your maximum so you should not have to pay any more out-of-pocket expenses for the year.
- Your insurance plan may treat prescription drugs differently than other medical expenses. Make sure you check your Summary Plan Description to find out how your insurance plan covers prescription drugs.
- If you have a hard time sorting out what has been paid and what has been applied to your deductible, call your insurance company’s claims assistant and ask that a “Claims Summary” be mailed to you. This should list dates of service, billed amounts, how much was applied to your deductible and how much your insurance company paid.
 - “Explanation of Benefits” (EOB) letters need special attention. Never throw them away. An EOB is not a bill, but it includes important information. An EOB may indicate a payment, a partial payment or a claim denial.
 - When you receive an “Explanation of Benefits” (EOB), carefully read every line including all footnotes. Also, read any printing on the back of the EOB. Watch for language such as, “Please contact your provider to resubmit the claim with a valid diagnostic code. If this information is not received within 90 days of your receipt of this request, please consider this claim denied.” Be sure to meet these stated guidelines on time.
 - “Pre-authorization” letters also need special attention. Watch for language such as, “This authorization does not guarantee payment.” Call your insurance company if you have any questions.
 - Dealing with insurance matters can be frustrating. Take things one step at a time. Take a break. Ask for help if you need it.

Phone Help

- If you phone your insurance company for any reason, enter each telephone call into the “Insurance Tracking” form at the end of this section or any other log you are using.
- Write down the name, title and phone number of anyone you speak with. Note what was discussed, mailed or promised. This will help you remember the details of each call.
- Ask your insurance company to connect you with a case manager if possible. This person, sometimes a nurse, may be able to help with care coordination and helping with insurance problems or answering insurance related questions. If you have Medi-Cal, ask to speak with your eligibility worker when you have questions.
- Try to establish a warm human connection when you call to talk with a claims assistant. “Thanks so much for your help,” will get you further than “I’m so frustrated with this whole thing I could scream.”
- After any phone call, take careful notes of the things you have to do. Make a list of things you need to do to help remind you of your responsibilities. To avoid missing deadlines, include a “do by” column. Mail important documents several days ahead.



Setting Up a System to Manage Paperwork

- Identify a small work area and stock it with a stapler, yellow highlighter, pens, stamps, blank insurance claim forms and file folders. Setting up this space can be a good job for a friend who wants to help.
- Remember to document, document, document. Create a “paper trail” to keep a record of telephone and mail contacts. The tracking forms at the end of this section will help.
- Be aware that you will receive a variety of mail such as insurance pre-authorization notifications, authorizations and bills from various sources.
- A strategy some people find useful is to put a basket by the front door for all treatment-related envelopes. Then schedule an hour or so once a week to sit down and open each envelope. Read the material line-by-line and use your highlighter to note important information. This may be a task you can turn over to a family member or good friend.
- As insurance “Explanation of Benefits” (EOB) forms arrive, attach the EOB to its related claim form, the original bill and any record of your own payments.
- Write the claim number and policy number on every document. Include the procedure code if one is given.
- If you are required to fill out a form and return it, always make a copy for your file.
- If the document is especially important and has a deadline, hand-carry it to the post office and pay for delivery tracking, such as certified mail with the green “return receipt requested” postcard or a computer-based “Delivery Confirmation” with a tracking number.
- Submit claims for all medical expenses even if you are not sure if a particular expense is covered.

What to do if Your Insurance Claim is Denied

Although the Susan G Komen organization is focused only on breast cancer, the area of their website about health care and insurance is very useful and applies to most types of cancer.

Taken directly from www5.komen.org/Health-Insurance these steps may help resolve the problem if a health insurance claim is denied:

- Keep copies of all correspondence (such as letters and e-mails) with the insurance company about the claim. Note the claim number and policy or procedure code on all correspondence. Also, note the name of any customer service or claims representative you speak with on the phone.
- Call the insurance company to find out why the claim was denied. If it's still unclear, study the explanation of benefits (EOB) form. In some cases, the denial may be the result of a claim being improperly recorded (such as a service being omitted by mistake).
- Check the facts. Review your policy to make sure pre-certification, authorization and other procedures required by the insurer were followed. For example, claims for wigs and colostomy supplies may need a copy of the prescription and the bill.
- Ask your health care provider for help if fees, charges or procedures are questioned. Most providers and their staff are used to working with insurance companies and can help answer questions. Ask your provider to write a letter to the insurance company recording and justifying the charges or procedures. Be sure to keep a copy of this letter.
- If the claim is denied because the insurance company says a treatment is experimental or under study, ask your provider to help. If your provider can give the insurance company proof the scientific literature supports the use of a certain treatment, then it cannot be called experimental. Your provider can get published studies as well as support letters from other oncologists using the same procedure. National organizations, such as the Patient Advocate Foundation, can also help.
- Ask for a formal review of the denied claim. Often, claims that first were denied are paid in later reviews. If this fails, ask for an appeal of the review using outside cancer experts to review the medical records and claim.

If these steps fail to get payment for a claim you and your providers believe is justified, a final option is to contact a lawyer.

Taxes

- Medical costs that are not covered by insurance policies can sometimes be deductible. Tax-deductible expenses might include mileage for trips to and from medical appointments; out-of-pocket costs for treatment, prescription drugs or equipment; and the cost of meals during lengthy medical visits away from home.
- Obtain publications related to medical deductions from the Internal Revenue Service and from the state where you file your taxes. Find out if there are special rules for people who are self-employed, have a business or domestic partner or other special situations.
- Internal Revenue Service and state publications are mailed free upon request and usually arrive within two or three weeks. You can also view them online and print them.
- Internal Revenue Service publications are available by phone at 1-800-829-1040 or online at irs.gov.
- If you file taxes in California, the California State Franchise Tax Board publications are available by phone at 1-800-338-0505 or online at ftb.ca.gov.
- If you use a tax advisor or financial planner, consult with that person after your diagnosis.
- The “Expense Tracking” form at the end of this section can be used to help document out-of-pocket expenses as you go.

COBRA (Consolidated Omnibus Budget Reconciliation Act)

- If you have a group health insurance plan through an employer with 20 or more employees, this federal legislation may enable you to keep your group coverage plan in the event of job loss, reduction in work hours, transition between jobs and certain other cases. Coverage may be available for 18 months. In California, you may be able to extend this time.
- Qualified individuals are required to pay the entire premium cost that the employer has been paying, plus a few percent. This may be quite expensive, yet it may be less costly than obtaining individual insurance outside of a group plan.
- Rules for COBRA are complex. Ask your employer for written information. You can obtain further information and a fact sheet from the U.S. Department of Labor Employee Benefits Security Administration. Visit www.dol.gov and enter Consolidated Omnibus Budget Reconciliation Act, or COBRA in the “search” line.

California State Disability Insurance (SDI)

- If you are out of work due to a non-work related surgery or illness, you may be eligible for disability benefits. These benefits are short-term, partial compensation for wages lost while you are unable to work. They are funded through your employee payroll deductions.
- If at all possible, plan ahead of time to use your disability benefits. This will help make things go more smoothly.
- Discuss the length of your disability with your physicians prior to completing your disability form if possible. Consider all the factors. Think about your job responsibilities and your financial situation. Be aware that the income you receive from State Disability Insurance is less than what you receive from your job wages.
- It may be possible to have partial SDI if you go back to work at reduced hours during treatment.
- Be aware that some doctor's offices require seven to 10 working days to complete the physician's portion of your application. It may also take four to six weeks from the time the state disability office receives your claim before the first check is issued.
- When you apply for SDI it is best to register online then call the physician's office with the receipt number so they can complete the physician's section. Or you can fill out a paper version. Fill out your section of the paperwork and hand carry the packet to your doctor's office. You can ask your doctor's office to mail in the signed application. Your physician's office may charge a nominal fee for filling out forms.
- For further information contact your employer or call SDI directly at 1-800-480-3287 or visit edd.ca.gov and follow the links for Disability Insurance. Disability forms can be filed online 24 hours a day, 7 days a week.
- The "State Disability Tracking" form at the end of this section can be used to document telephone calls regarding your claim.

- Under the Paid Family Leave Act (FMLA), disability compensation may be extended to cover individuals who take time off of work to care for a seriously ill spouse, parent, domestic partner or other reasons. The Paid Family Leave insurance program, also known as the Family Temporary Disability Insurance program, is administered by the State Disability Insurance (SDI) program. An estimated 13 million California workers covered by the SDI program are also covered for Paid Family Leave insurance benefits. The rules are complex, so check into whether you have job protection or return rights, whether benefits are taxable, and other issues. For general program and claim information, visit edd.ca.gov and follow the links to the Paid Family Leave Act or call 877-238-4373.

If You Begin to Feel Overwhelmed About Finances

- Even when we are in the best of health, money is a difficult area for many of us. In our culture, personal money issues are not usually discussed openly with friends or family. We may feel that we are supposed to "make it" on our own and never ask for help.
- To need help is simply part of being human. Break the silence. Ask for assistance. Take action in small but steady steps.
- Seek assistance before a crisis develops.
- Hospitals and physician offices usually have employees who specialize in insurance claims, reimbursement and public benefits. They may be called financial counselors, case managers or financial assistance planners. Hospital social workers may be able to suggest financial options and can offer emotional support as well.
- Talk about your situation with an advocacy organization, a family member or friend.

Getting the Most from a Service: What to Ask

No matter what type of help you are looking for, the only way to find resources to fit your needs is to ask the right questions.

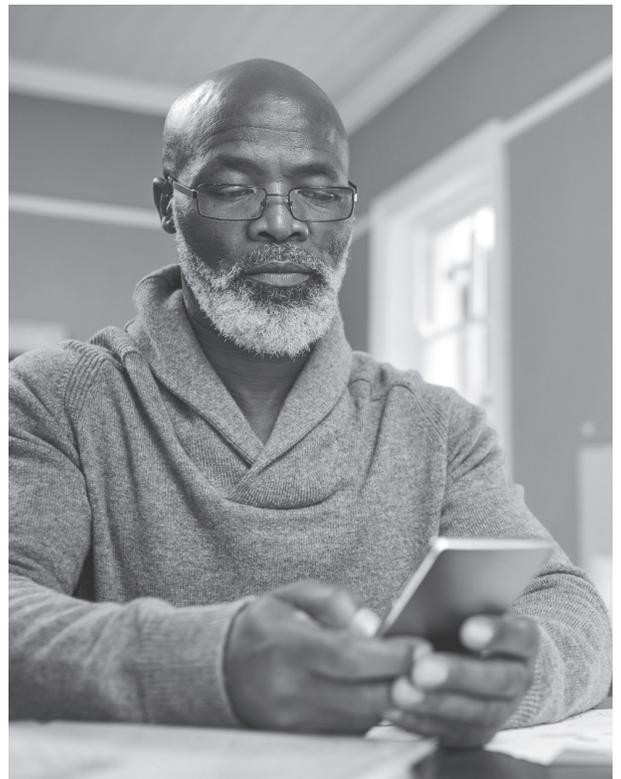
When you are calling an organization for information, it is important to think about what questions you are going to ask before you call. Many people find it helpful to write out their questions in advance and take notes during the call. Another good tip is to ask the name of the person with whom you are speaking in case you have follow-up questions.

Below are some questions you may want to consider when calling or visiting a new agency to learn how they can help you:

- How do I apply for your services?
- Are there eligibility requirements? What are they?
- Is there an application process? How long will it take? What information will I need to complete the application process? Will I need anything else to get the service?
- Do you have any other suggestions or ideas about where I can find help?

The most important thing to remember is that you need to be willing to ask for help to receive it. Asking can be the hardest part of getting help. Cancer is a very difficult diagnosis and disease, but there are people and services that can ease your burdens and help you focus on your treatment and recovery.

The information on “Getting the Most from a Service” was adapted with permission from CancerCare, a national nonprofit organization that provides free professional support services for people with cancer and their families. Find out more about CancerCare by calling 1-800-813- HOPE (4673) or visiting cancercares.org.



Additional Resources

American Cancer Society

Call 1-800-227-2345, 24 hours, seven days a week for cancer information, support and community resources. Web site: *cancer.org*. This respected organization offers a range of information, resources and publications. Local units provide practical and emotional services for cancer patients, including transportation to and from medical appointments, support services, and wigs and head coverings for women in treatment. Staff can accept calls in Spanish and distribute most publications in Spanish.

CancerCare

Web site: *cancercare.org*. CancerCare is a national nonprofit organization whose mission is to provide free, professional support services to anyone affected by cancer: people with cancer, caregivers, children, loved ones, and the bereaved. CancerCare programs – including professional counseling, education, financial assistance and practical help – are provided by trained oncology social workers and are completely free of charge.

Department of Social Service

This agency of your local county sometimes has emergency funds for rent, food, utilities, prescription drugs and medical expenses for those who are not eligible for other programs. Transportation services may be offered or mileage reimbursed. Funds are often limited. Information can be obtained by contacting your state or local Department of Social Services. Check with your cancer center social worker for contact information.

Fundraising

Some patients find that friends, family and community members are willing to contribute financially if they are aware of a difficult situation.

Medi-Cal

This program may provide medical coverage for people with low income, those with no/or limited medical insurance and people with disabilities. If you do not qualify for Medi-Cal, you may still qualify for a related program in your county that requires you to pay a monthly “share of costs.” Your doctor’s office or hospital can give you the best local telephone number to call. You can also call 1-800-541-5555 and listen carefully to the phone options. Unfortunately, many people with Medi-Cal have experienced delays because the pre-authorization process moves slowly. Use this time to learn about other options that may be available to you as you wait for Medi-Cal authorization.

Medicare

Call 1-800-633-4227. Web site: *medicare.gov*. Medicare is a federally-funded health insurance program that covers most Americans over age 65 and some people with disabilities. It provides for basic health coverage although not for all medical expenses. Co-payments and deductibles may be required. Basic benefits are determined by Congress and are the same across the country. Private supplemental insurance “Medigap” policies increase the range of coverage. Contact Medicare for information on eligibility, explanations of coverage and related publications. Some publications are available in Spanish and Spanish-speaking staff is available.

NeedyMeds

Web site: *needymeds.com*. Provides information about patient assistance programs funded by pharmaceutical companies with programs to assist people who cannot afford to buy the drugs they need. Your doctor’s office can supply you with direct lines to the Patient Assistance Programs of certain companies.

Partnership for Prescription Assistance (PPA)

Call 1-888-477-2669. Web site: pparx.org. Helps locate assistance programs from pharmaceutical companies.

Co-Pay Relief Program

Call 1-866-512-3861 or email visit copays.org. A subsidiary of the Patient Advocate Foundation (see entry below under “Insurance Advocacy”) that provides financial assistance to financially and medically qualified patients, including those insured through federally administered health plans such as Medicare, for co-payments, co-insurance and deductibles required by a patient’s insurer for pharmaceutical treatments and/or prescription medications prescribed to treat and/or manage his/her disease.

Programs of Assistance at Hospitals

Some hospitals have programs through which uninsured and low-income patients may qualify for assistance with their hospital expenses. Ask to speak with a hospital financial counselor or social worker about application procedures.

Social Security Administration

Call 1-800-772-1213. Web site: ssa.gov. Takes applications for Medicare, Social Security Insurance (SSI) and Social Security Disability Insurance (SSDI). Apply with Social Security if your doctor feels that your disability will last one year or more. Applications can take three to four months for processing.

United Way

This national organization’s information service can refer you to an agency that may provide financial help for rent, food and other basic necessities. To find the United Way serving your community, go to unitedway.org. You can enter your zip code or city information to find the United Way office nearest you.

Veteran’s Administration

Call 1-877-222-8387. Web site: [va.gov/ Health_Benefits](http://va.gov/Health_Benefits). Eligible veterans and their families may receive cancer treatment at a Veteran’s Administration Medical Center. Some publications are available in Spanish, and Spanish-speaking staff is available in some offices.

Pharmaceutical Patient Assistance Programs

Many pharmaceutical companies have financial assistance programs that may be able to help you manage payments for their medications. You can call the pharmaceutical company or go onto their website to find out more about their programs and how to apply for them.

Colorectal Cancer Alliance

Blue Hope Financial Assistance program provides a one-time stipend for screening or treatment for qualifying families. Visit ccalliance.org/patientfamily-support/financial-assistance-programs.

Life Insurance

You may be able to borrow money against your life insurance policy. Call your insurance agent to find out your options.

Insurance Advocacy

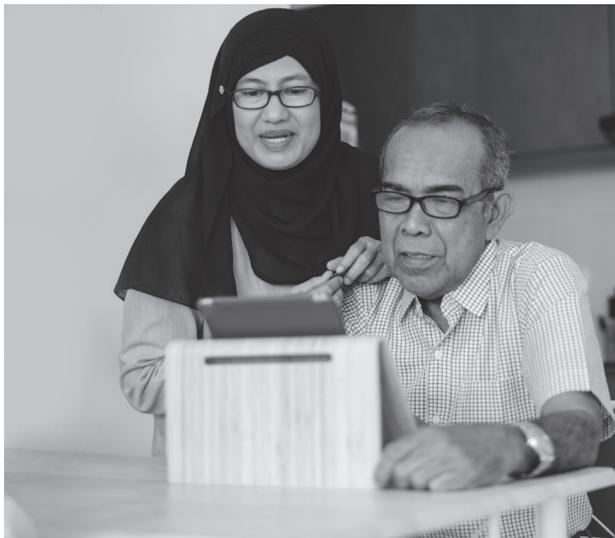
California Department of Insurance Consumer Hotline 1-800-927-4357. Web site: *insurance.ca.gov*. (Click on “Consumers”). This web site offers instructions and a form to request mediation of an insurance claim or coverage problem. Staff will review your complaint if you believe you have received improper denial or underpayment of a claim, delay in settlement of a claim, alleged illegal cancellation or termination of an insurance policy.

California Department of Managed Care HMO Help Center

Call 1-888-HMO-2219. Web site: *hmohelp.ca.gov*. Can help you resolve problems with your health plan, including issues about medical care, prescriptions, preventive testing and mental health services and the Affordable Care Act.

Patient Advocate Foundation

Call 1-800-532-5274. Web site: *patientadvocate.org* and follow the link to “Get Help.” Provides education, legal counseling and referrals for cancer patients and survivors concerning, insurance, financial issues, job discrimination and debt crisis matters. Professional case managers and attorneys specialized in mediation, negotiation and education will advocate on behalf of patients.



Legal Services

Cancer Legal Resource Center

Call 866-843-2572. The Cancer Legal Resource Center provides free and confidential information and resources on cancer-related legal issues to people with cancer, their families, friends, employers, health care professionals and others coping with cancer.

The Center, a joint program of Loyola Law School and the Disability Rights Legal Center (formerly Western Law Center for Disability Rights), has a national toll free Telephone Assistance Line (866-843-2572) where callers can receive information about relevant laws and resources for their particular situation. On the web at *cancerlegalresources.org*
E-mail: CLRC@drlcenter.org

Legal Services of Northern California

Provides legal services to low income and speciality populations including health care service access, senior healthcare insurance counseling (HICAP), senior legal hotline (800-222-1753), pension assistance and county specific speciality programs.

Utility Bills

Low Income Energy Assistance Program (LIHEAP)
Call 1-866-674-6327 or visit acf.hhs.gov/programs/liheap for this National Energy Assistance Referral program. May have assistance for bill payments and energy-related home repairs.

Pacific Gas and Electric Smarter Energy Line

Some medical conditions qualify for PG&E's Medical Baseline Program. Visit https://www.pge.com/en_US/residential/save-energy-money/help-paying-your-bill/longer-term-assistance/medical-condition-related/medical-baseline-allowance/medical-baseline-allowance.page or call 1-800-743-5000. Offers utility discounts based on medical needs. Also, CARE at 1-866-743-2273, or visit pge.com/care. Monthly discounts for income-eligible customers.

REACH (Relief for Energy Assistance through Community Help)

Call 1-800-933-9677 or visit pge.com/reach.

A one-time energy-assistance program sponsored by Pacific Gas and Electric Company and administered through the Salvation Army. REACH helps low-income customers who experience unplanned hardships and are unable to pay for their energy needs. Generally, recipients can receive REACH assistance only once within a 18-month period.

Telephone Assistance Programs

Many telephone and cell phone companies have reduced rates based on low income or medical necessity. Call yours for details.

Helpful Forms

You will find two copies of the forms listed below in the following section:

- Insurance Contact Tracking
- Expense Tracking
- State Disability Insurance Contact Tracking

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

