

# Organizing Your Care

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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

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- 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!***