

Organizing Your Care



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

It is important to know that you are not alone. One out of eight women in America will develop breast cancer at some point during her lifetime. You may even know someone with breast cancer who has experienced what you are going through now. Many women go on to lead active, healthy lives.

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

The more you learn about breast cancer and the available treatment options, the better prepared you will be to handle the challenges ahead and to make informed decisions about what is right for you. We hope this notebook helps you during your personal journey.

Don't be afraid to reach out to others during this difficult time. Your family and friends, your doctors and 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.*

Notebook Tips



- Keep a list of all of your doctors and other health care providers with their business cards in the holder provided in this notebook.
- If available, take advantage of My Health Online, Sutter's electronic health record system where you can access your health records and email your doctors. To sign up, ask your doctor's office, or go to myhealthonline.sutterhealth.org/mho.
- Take this notebook to every doctor's appointment and test for your reference.
- Keep records 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
- Record the results of your tests and procedures.
- Make note of any imaging scans and reports you receive; they can be placed on disc for your convenience.
- You will be filling out many papers when you visit doctors and other health care providers. This section includes a blank medical history form and medications list you can complete and take with you to your visits. The forms are not meant to replace the papers you will be asked to fill out at your medical visits, but they will help you remember important information. Use the charts and forms included in this notebook to keep track of medical appointments and important information, such as your medical history and medications.
- Record any reactions you have to medications and treatments, as well as unusual symptoms and report them to your doctor.
- Update your medication list and provide a copy to your health care provider.
- In addition to this notebook, 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.
- **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. Handle this notebook as you would any confidential record. Do not leave your notebook and 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 a:

Primary Care Doctor

The doctor you see for regular medical care.

Gynecologist

The doctor who specializes in women's health issues over her lifetime.

Surgeon

A doctor who specializes in surgical procedures for cancer.

Pathologist

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

Medical Oncologist

A doctor who specializes in using medicine to treat cancer.

Radiation Oncologist

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

Breast Reconstructive Surgeon

A doctor, usually a plastic surgeon, who specializes in restoring the appearance of the breast.

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.

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.

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. It is important to keep notes during your visits and to compare the information you receive. If you have questions or receive conflicting information, share it with a trusted doctor who will be your main source of information. 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. If you have questions, don't be afraid to ask. Many women 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.

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. It is very important to keep track of your test results and the physicians and providers you visit.

The following tips will help reduce the stress of lost or delayed records and provide you with an ongoing record of your care.

- Ask every doctor who orders a test to write “cc to patient” so that you will be given a copy of the results as well as all the providers who care for you.
- File the reports in this notebook with the most recent report in front.



The types of reports you may receive include:

- ▶ Imaging reports (for example, Mammograms, Ultrasound, MRI, PET/CT reports, other scans).
- ▶ Pathology reports, often two or three different reports. (Refer to the “Understanding Your Diagnosis” section of this notebook.)
- ▶ Blood tests
- ▶ Cardiac studies (EKG, echocardiograms, MUGA scans)
- ▶ Surgical reports

My Family History

Relation/Name	Living?		Medical History <i>Please circle appropriate history</i> C (cancer), CV (heart problem), D (diabetes), S (stroke)	Age at Cancer Diagnosis	Cancer Genetic Testing
	Yes (age)	No			
Paternal grandfather			C Type: _____ CV D S Other: _____		Y / N Results _____
Paternal grandmother			C Type: _____ CV D S Other: _____		Y / N Results _____
Maternal grandfather			C Type: _____ CV D S Other: _____		Y / N Results _____
Maternal grandmother			C Type: _____ CV D S Other: _____		Y / N Results _____
Father			C Type: _____ CV D S Other: _____		Y / N Results _____
Mother			C Type: _____ CV D S Other: _____		Y / N Results _____
Maternal aunt			C Type: _____ CV D S Other: _____		Y / N Results _____
Maternal uncle			C Type: _____ CV D S Other: _____		Y / N Results _____
Paternal aunt			C Type: _____ CV D S Other: _____		Y / N Results _____
Paternal uncle			C Type: _____ CV D S Other: _____		Y / N Results _____
Brother			C Type: _____ CV D S Other: _____		Y / N Results _____
Brother			C Type: _____ CV D S Other: _____		Y / N Results _____
Sister			C Type: _____ CV D S Other: _____		Y / N Results _____
Sister			C Type: _____ CV D S Other: _____		Y / N Results _____
1st degree cousin			C Type: _____ CV D S Other: _____		Y / N Results _____
1st degree cousin			C Type: _____ CV D S Other: _____		Y / N Results _____
Children			C Type: _____ CV D S Other: _____		Y / N Results _____
Children			C Type: _____ CV D S Other: _____		Y / N Results _____

My Medication Record

Name _____

Allergies _____ No known drug allergies

Primary care doctor or practitioner _____ Tel: () _____

Pharmacy 1 _____ Tel: () _____

Pharmacy 2 _____ Tel: () _____

Medicine (include strength, dose and frequency)	Prescribed By	Purpose	Start Date	Times to Take			
				Morn	Noon	Eve	Bed

- Questions to ask your doctor/practitioner
- Why am I taking this medicine?
 - 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 you?
 - Could I save money by using a generic drug that would be equally effective?

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.

Read medication labels carefully. Record herbal and other supplements you are taking on the next page.

Maintain this medication record with your other important medical documents. Keep it updated and with you at all times.

