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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 Medical History

Name _____ Date of birth _____

Recent cancer diagnosis _____ Date of diagnosis _____

Allergies/reaction _____

Emergency contact _____ Tel: () _____

Surgeon _____ Tel: () _____ Fax: () _____

Primary doctor _____ Tel: () _____ Fax: () _____

Medical oncologist _____ Tel: () _____ Fax: () _____

Radiation oncologist _____ Tel: () _____ Fax: () _____

Other doctor _____ Tel: () _____ Fax: () _____

Pharmacy _____ Tel: () _____ Fax: () _____

Do you have Advance Directives: No Yes kept in (location) _____

My designated agent's name and telephone number _____ Tel: () _____

Date of immunizations: Tetanus _____ TB skin test _____ Flu shot _____

Pneumonia vac _____ Hepatitis _____ Others _____

Date of tests: Mammogram _____ Bone density _____ Pelvic exam _____

Pap smear _____

Medical Problem(s) *Encircle the problem for yes answer*

Other cancer/date

Lung

Asthma/bronchitis

Chronic cough

Emphysema pneumonia

Tuberculosis

Did you or do you smoke

No

Yes pack/yr _____

Musculoskeletal

Arthritis

Bone/joint pain

Osteoporosis

Abdomen

Abdominal swelling

Blood in the stool

Constipation/diarrhea

Gall Bladder

Heart burn/ulcer

Hepatitis

Nausea/vomiting

Ulcer

Bladder

Low back pain

Bladder infection

Blood in the urine

Frequent urination

Kidney infection

Others

Convulsion/seizure

Diabetes

Hypothyroidism

Hyperthyroidism

Leg pain/leg swelling

Anxiety/depression

Weight loss _____ lbs

Over what time period:

Current symptoms

bothering you

Gynecology History

Age at first menstrual period _____ Age at menopause _____ Age at first live birth _____

Number of pregnancies _____ Number of live births _____ Total months of breast feeding _____

Hysterectomy No Yes , age _____ Were ovaries removed too? No Yes

Hormone therapy: a. Birth control pills No Yes Total months/years _____

b. Estrogen No Yes Total months/years _____ c. Progesterone No Yes Total months/years _____

Past Surgeries or Invasive Procedures/Date

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.

Breast Cancer Resources

Additional Information Sources

The following pages include a list of websites and other resources that can help you in your search for information. *The information provided by these sources is not meant to replace the expertise and clinical judgment of your doctors or health care team.* Please be sure to discuss the information you find with your doctors and health care team.



The listings are grouped into six categories:

- Breast Cancer Specific Information
- General Cancer and Medical Information
- Complementary Treatment Information
- Research Information
- Recommended Reading

There is additional information about breast cancer and our programs at www.sutterhealth.org.

Learning About Breast Cancer

When you are diagnosed with breast cancer, there can be many new words and terms to learn. A comprehensive **glossary** can be found by visiting <https://ww5.komen.org/BreastCancer/Glossary.html>.

Breast Cancer Specific Information

	Notes
<p>The Advocacy Connector A list of not-for profit, mostly non-governmental resources. www.advocacyconnector.com</p>	
<p>American Cancer Society Breast cancer information covering all types of issues (risk through treatment and survivorship). Information is also available in 14 other languages. www.cancer.org • 1-800-ACS-2345</p>	
<p>American Society of Clinical Oncologists (ASCO) Patient Education Site Timely, comprehensive, oncologist-approved information. www.cancer.net</p>	
<p>American Society of Plastic Surgeons Descriptions and images of various reconstruction options. www.plasticsurgery.org/reconstructive-procedures</p>	
<p>BreastCancer.org Medical information about diagnosis through treatment and survivorship. www.breastcancer.org</p>	
<p>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. www.csn.cancer.org</p>	
<p>FORCE Information about hereditary breast or ovarian cancer. www.facingourrisk.org</p>	
<p>John Nick Foundation Information on male breast cancer. www.malebreastcancer.org</p>	
<p>Living Beyond Breast Cancer Provides programs and services to help people whose lives have been impacted by breast cancer. www.lbbc.org</p>	
<p>Male Breast Cancer Coalition Provides information and resources about male breast cancer. www.malebreastcancercoalition.org</p>	
<p>MD Anderson Cancer Center Breast cancer information. www.mdanderson.org</p>	

Breast Cancer Specific Information continued

Medline Plus	Notes
<p>Health information from the Library of Medicine and National Institute of Health Information on drug supplements. www.medlineplus.gov</p>	
<p>METavivor Provides support for patients with metastatic breast cancer, advocates for greater awareness and funds research into metastatic breast cancer. http://www.metavivor.org/</p>	
<p>National Breast Cancer Foundation, Inc. Provide help and inspire hope to those affected by breast cancer. http://www.nationalbreastcancer.org/about-breast-cancer</p>	
<p>National Cancer Institute Comprehensive information on cancer prevention and screening, diagnosis and treatment, research across the cancer spectrum, and clinical trials. www.cancer.gov</p>	
<p>National Comprehensive Cancer Network Information on treatment guidelines and information on supportive care. www.nccn.org/patients/</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. www.patientadvocate.org</p>	
<p>Patient Education Center Information provided by Harvard Medical School. http://www.patienteducationcenter.org/articles/breast-cancer/</p>	
<p>Susan G Komen for the Cure Comprehensive information on breast cancer and treatment. www.komen.org</p>	
<p>Triple Negative Breast Cancer Foundation Information and support for patients with triple negative breast cancer. www.tnbcfoundation.org</p>	
<p>Young Survivor Coalition Supports and educates younger women about breast cancer. www.youngsurvival.org</p>	
<p>Zero Breast Cancer Dedicated to finding the causes of breast cancer through community participation in research and identifying environmental factors. www.zerobreastcancer.org • 415-507-1949</p>	

General Cancer and Medical Information

	Notes
<p>American Institute of Cancer Research Research findings on diet and cancer. www.aicr.org/</p>	
<p>Cancer and Careers Empowers and educates people with cancer to thrive in their workplace. http://www.cancerandcareers.org/en</p>	
<p>Cancercare Counseling, education, financial assistance and practical help are provided by trained oncology social workers. www.cancercare.org</p>	
<p>Cancer Hope Network Matching patients and/or family members with trained volunteers throughout the US who have recovered from similar cancer experiences. www.cancerhopenetwork.org</p>	
<p>Cancer Support Community Provides free professional programs of emotional support, education and hope. www.cancersupportcommunity.org</p>	
<p>Consumer Lab Independent testing of non-prescription supplements. www.consumerlab.com</p>	
<p>LIVESTRONG (Fertility) Provides information on fertility risks and options and fertility preservation discounts. https://www.livestrong.org/we-can-help/livestrong-fertility</p>	
<p>LIVESTRONG (General) Tools and information regarding all cancers, current research and fertility. livestrong.org</p>	
<p>Mayo Clinic Information on cancer and treatments. www.mayoclinic.org</p>	
<p>National Coalition for Cancer Survivorship Advocacy organization for quality cancer care. www.canceradvocacy.org</p>	
<p>National Lymphedema Network Information on lymphedema prevention and treatment. www.lymphnet.org • 800-541-3259</p>	
<p>Oncolink University of Pennsylvania site's cancer education website. www.oncolink.org</p>	

	Notes
<p>Prevent Cancer Foundation Research and education directed towards preventing cancer. www.preventcancer.org</p>	
<p>PubMed National Library of Medicine search engine for literature. www.ncbi.nlm.nih.gov/pubmed</p>	
<p>Springboard Beyond Cancer Gives you information and resources to help you cope and be in control. https://www.smokefree.gov/springboard</p>	
<p>Stupid Cancer Addresses young adult cancer. http://stupidcancer.org/</p>	

Complementary and Alternative Information

<p>American Cancer Society Complementary and alternative medicine guide. www.acs.org</p>	
<p>American Institute of Cancer Research Research findings on diet and cancer. www.aicr.org</p>	
<p>Forks Over Knives Changing the way the world understands nutrition. https://www.forksoverknives.com/</p>	
<p>Consumer Lab Independent testing of non-prescription supplements. www.consumerlab.com</p>	
<p>Memorial Sloan Kettering Medical Center Guide to herbal medicines. https://www.mskcc.org/cancer-care/treatments/symptom-management/integrative-medicine</p>	
<p>National Center for Complementary & Alternative Medicine Describes treatments and methods of evaluation for complementary and alternative modalities. www.nccam.nih.gov</p>	
<p>Natural Medicines Objective product information, on dietary supplements, natural medicines, and complementary alternative and integrative therapies. https://naturalmedicines.therapeuticresearch.com/</p>	

Research Information

American Institute of Cancer Research

Research findings on diet and cancer.

www.aicr.org

Notes

BreastCancerTrials.org

Web-based service to match breast cancer patients with clinical trials, sponsored by the National Cancer Institute and UCSF.

www.breastcancertrials.org

Clinical Trials.Gov

A database of publicly and privately supported clinical studies.

www.clinicaltrials.gov



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.

Recommended Reading

Anticancer: A New Way of Life

David Servan-Schreiber
SURVIVORSHIP

Be a Survivor-Your Guide to Breast Cancer Treatment

Vladimir Lang, MD, Lange Publications
TREATMENT

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

(A Johns Hopkins Press Health Book)
Julie K. Silver
TREATMENT

And in Health: A Guide for Couples Facing Cancer Together

Dan Shapiro (Trumpeter Books)
EMOTIONAL SUPPORT

Breast Cancer Recurrence and Advanced Disease

Barbara Gordon (Duke University Press)
TREATMENT

Breast Cancer Survivor Manual

John Link, MD (Owl Books)
TREATMENT

Crazy Sexy Cancer

Kris Carr
EMOTIONAL SUPPORT

Dr. Susan Love's Breast Book

Susan M. Love, MD and Karen Lindsey
GENERAL

The Cancer Fighting Kitchen (2nd edition)

Rebecca Katz
Ten Speed Press
COOKBOOKS, NUTRITION

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

Intimacy After Breast Cancer

Gina Maisano
Square One Publishers
INTIMACY, EMOTIONAL SUPPORT

Just Get Me Through This: The Practical Guide to Breast Cancer

Deborah A. Cohen Kensington Publishing Corp.
EMOTIONAL SUPPORT

Living Well With Lymphedema

Ann B. Ehrlich
Lymphnotes
LYMPHEDEMA

Lymphedema: Understanding and Managing Lymphedema After Cancer Treatment

American Cancer Society
LYMPHEDEMA

Now What? A Patient's Guide to Recovery After Mastectomy

Amy Curran Baker Demos Health
TREATMENT

Nourishing Connections

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

Overcoming the Emotional Challenges of Lymphedema (1st edition)

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

Radical Remission: Surviving Cancer Against All Odds

Kelly A. Turner, PhD
SURVIVORSHIP

The Healing Consciousness: A Doctor's Journey to Healing

Beth Baughman DuPree
EMOTIONAL SUPPORT, SURVIVORSHIP

The Breast Reconstruction Guidebook

Kathy Steligo
(John Hopkins University Press)
TREATMENT

The Breast Cancer Survivor's Fitness Plan

Carolyn Kaelin
(McGraw-Hill Publishers)
SURVIVORSHIP, FITNESS

The Longevity Kitchen

Rebecca Katz and Mat Edelson
COOKBOOKS, NUTRITION

Recommended Reading continued

The Silver Lining: A Supportive and Insightful Guide to Breast Cancer

Hollye Jacobs RN MS MSW and Elizabeth Messina
EMOTIONAL SUPPORT

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

Carolyn S. Kortge
SURVIVORSHIP, FITNESS

Thriving After Breast Cancer: Essential Healing Exercises for Body & Soul

Sheryl Lebed Davis
SURVIVORSHIP, FITNESS

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

Elise Babcock Bantam Books
EMOTIONAL SUPPORT

Women Cancer Sex

Anne Katz
INTIMACY, EMOTIONAL SUPPORT

100 Questions and Answers about Breast Cancer

Zora K. Brown & Karl K. Boatman Jones and Bartlett Publishers, LLC Karen
GENERAL

100 Questions and Answers about Advanced and Metastatic Breast Cancer

Lilly Shockney
Jones and Bartlett Publishers, LLC
TREATMENT

100 Questions and Answers about Life after Breast Cancer: Sensuality, Sexuality, Intimacy

Michael Krychman, Susan Kellog & Sandra Finestone
Jones and Bartlett Publishers, LLC
INTIMACY

100 Questions & Answers about Lymphedema

Nicole L. Stout, MPT, Paula J Stewart, and Saskia R.J
Jones and Bartlett Publishers, LLC (2009)
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 Schessel-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

Barklay and Even Explaining Cancer to Children

Karen Carney

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

The Hope Tree: Kids Talk About Breast Cancer

Laura Numeroff, Wendy S. Harpham, M.D.

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

Understanding Your Diagnosis

Not all breast cancers are the same.

There are different types of breast cancer, 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 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.**

What is a Cell? How Does a Cell Become a Cancer?

Cells are the building blocks of all tissue and organs in the human body. Each cell contains genetic material (DNA) and other elements. DNA controls the growth rate of cells.

Normal cells grow and multiply at a specific rate. Cells that grow and multiply without stopping are called cancerous or malignant. Cancerous cells are not detectable when they first start growing. At a certain point, the cancerous cells continue to multiply and form a mass which can be detected. Abnormal cell growth could go on for years before it is large enough to be detected.



Breast anatomy

There are two separate ideas used when describing cancer: grade and stage. A cancer's grade, along with stage, are important in determining your recommended treatment. Grade refers to how much your cells look like normal tissue. Stage for invasive cancer is determined by how big the tumor is and if it has spread beyond the breast to the lymph nodes and other areas of the body. Ductal Carcinoma In Situ (DCIS) is not invasive, so it is always stage 0 regardless of size. More information about staging will be discussed later in this chapter.

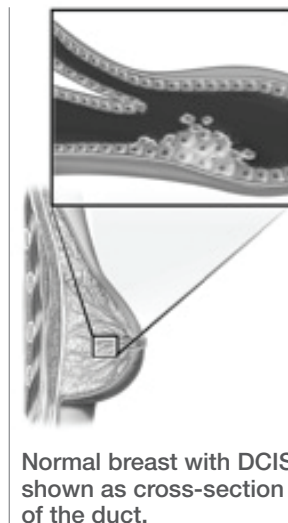
Ductal Carcinoma In Situ (DCIS)

Ductal Carcinoma In Situ (DCIS) is a change in the cells that line the milk ducts, which are the “tubes” that bring milk from the milk lobules to the nipple.

Normally, a thin layer of breast epithelial cells lines the inside of the milk duct. DCIS happens when the cells of this thin layer grow and multiply without stopping and have abnormal features that can be detected only under the microscope.

In DCIS, the abnormal breast cells are confined to the milk duct. They do not spread outside the milk duct into the surrounding breast tissue, lymph nodes or other parts of the body. We call this a non-invasive type of cancer because it has not invaded other tissue. DCIS is “Stage 0” breast cancer. That means it has been detected at the earliest stage possible.

If left untreated, sometimes DCIS will spread outside the milk duct and turn into an invasive or infiltrating cancer. At this point in time, we cannot predict which patients with DCIS will develop invasive or infiltrating cancers. Therefore, it is recommended that DCIS be surgically removed before it can become an invasive cancer. Radiation treatment of the breast is often recommended following removal of the affected tissue. Radiation is not recommended following a mastectomy (removal of the entire breast) to treat DCIS. In addition, a medication such as Tamoxifen may be recommended to reduce the risk of breast cancer in the future.

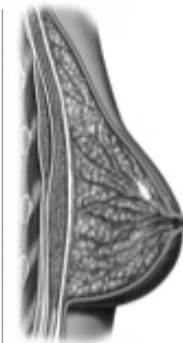


Normal breast with DCIS shown as cross-section of the duct.

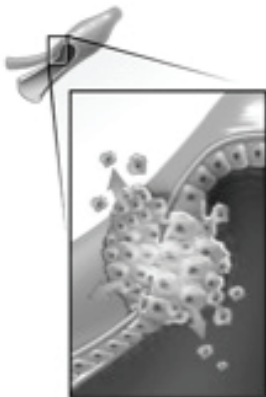
DCIS is often found on a mammogram. The mammogram may show microcalcifications that are worrisome. These are small calcium deposits that form within or near the DCIS. Not all microcalcifications seen on a mammogram indicate DCIS. Those that form a line, are new or have increased in number may be suspicious. Less commonly, DCIS may show up as a nodule or thickening of tissue on a mammogram. In rare cases, DCIS may be felt as a thickening or nodule in the breast on self-exam or during a physical exam by a health care provider.

Invasive or Infiltrating Ductal Carcinoma (IDC)

Invasive or infiltrating ductal carcinoma (IDC) is the most common type of breast cancer. This may also be diagnosed as “invasive mammary carcinoma of no special type (ductal, not otherwise specified)” in your report. IDC occurs when the cells that line the milk duct become abnormal. The ductal cancer cells look different from normal milk duct cells, and the



Infiltrating ductal carcinoma



IDC shown on a cross section of duct.

body produces too many of them. They spread outside the milk duct into the surrounding breast tissue. IDC does not mean that the cancer has traveled to other parts of the body beyond the breast, but it has the ability to do so. It is not uncommon to have DCIS along with IDC.

When the pathologist examines the cells under the microscope, a grade is assigned. The cancer

will be graded from 1 to 3. Grade 1 means that the cancer cells are very similar to the normal cells. Grade 3 indicates that the cancer cells are very different from the normal cells in breast tissue. Higher grade tumors are generally more aggressive than lower-grade tumors.

Surgery, radiation, hormonal therapy and chemotherapy can all be used to treat IDC. Most women will receive a combination of treatments, although not necessarily all four types of treatment. The types of treatment recommended will depend upon the size of the cancer, whether the cancer is in the lymph nodes, features of the cancer cells themselves and your general health.

Inflammatory Breast Cancer

Inflammatory breast cancer is a type of invasive ductal breast cancer.

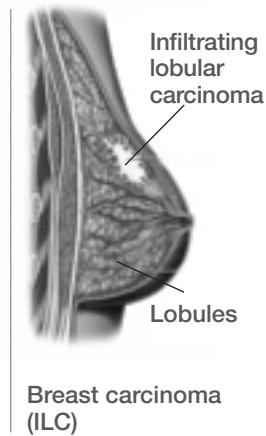
The cancer cells spread outside the milk duct into the surrounding breast tissue and into the small lymphatic vessels in the breast, particularly those in the skin of the breast. The invasion of the cancer cells into the lymphatic vessels of the breast skin causes the breast to look inflamed, i.e., red, warm and even swollen. It often looks like there is an infection in the breast. A biopsy of the breast and the skin is necessary to diagnose inflammatory breast cancer.

Inflammatory breast cancer behaves differently than other invasive ductal breast cancers and must be treated differently. It is important to control the growth of the inflammatory breast cancer cells, and chemotherapy is often recommended first. Once chemotherapy is completed, the need for surgery and radiation will be determined.

Invasive or Infiltrating Lobular Carcinoma (ILC)

Invasive or infiltrating lobular breast cancer (ILC) occurs when the cells in the milk lobule become abnormal. The lobular cancer cells look different from normal lobular cells and multiply without stopping. They spread outside the lobule into the surrounding breast tissue. ILC does not mean that the cancer has traveled to other parts of the body beyond the breast, but it has the ability to do so.

When the pathologist examines the cells under the microscope, a grade is assigned. The cancer will be graded from 1 to 3. Grade 1 means that the cancer cells are very similar to the normal cells (classic). Grade 3 indicates that the cancer cells are very different from the normal cells in breast tissue (pleomorphic). Higher grade tumors are generally more aggressive than lowergrade tumors.



Surgery, radiation, hormonal therapy and chemotherapy can all be used to treat ILC. Most women will receive a combination of treatments, although not necessarily all four types of treatments. The types of treatment recommended will depend upon the size of the cancer, whether the cancer is in the lymph nodes, features of the cancer cells themselves and your general health.

Interpreting Your Pathology Report

Tissue removed from the breast, lymph nodes or other parts of the body are sent to a laboratory to be viewed by a pathologist, (a doctor who identifies diseases by studying cells and tissues under a microscope). The pathologist's written report of his or her findings is called a pathology report, which usually includes:

- A detailed record of the specimens received and examined
- A complete description of the appearance of the tissue cells, such as size, grade, color and the presence of any visible abnormality
- A report of all of the diagnostic findings after microscopic examination
- A complete documentation of all of the studies performed on the tissue

A copy of the pathology report is sent to your doctor and becomes part of your medical record.

The next two pages describe some common terms routinely used in breast cancer pathology reports.

Final microscopic diagnosis

This section summarizes the pathologist's findings.

Infiltrating/invasive ductal breast carcinoma (IDC): cancer that started in the milk duct of the breast and has spread into surrounding breast tissue. In the final pathology report, the diagnosis may be more specific.

Infiltrating/invasive lobular breast carcinoma (ILC): cancer that started in the milk lobule of the breast and has spread into surrounding breast tissue

Ductal carcinoma in situ (DCIS): early cancer cells growing in the lining of the milk duct in the breast.

Grade: describes how much the cancer cells look like their normal cell counterparts. The Scarff-Bloom-Richardson (SBR) scale is one method used to determine the grade.

- Well-differentiated (grade 1) SBR (3, 4, 5) – the cells still have many of the features of normal cells.
- Moderately differentiated (grade 2) SBR (6, 7) – the cells have some of the features of normal cells.
- Poorly differentiated (grade 3) SBR (8, 9) – the cells have few of the features of normal cells.

Tumor size: size of the tumor, measured as a whole and under the microscope.

In situ component: If invasive cancer was found, there may be surrounding DCIS as well (see definition above), which will be noted in this section. If an extensive intraductal component (EIC) is noted, it means that the area of invasive cancer contains at least 25% DCIS.

Necrosis: cells that have died. Necrosis is usually associated with a more aggressive DCIS.

Architectural pattern: the pattern of growth of the DCIS cells. Descriptions used include cribriform, comedo, solid, micropapillary and papillary.

Angiolymphatic invasion: cancer cells have entered the small blood vessels or lymphatic vessels in the breast.

Margins: the area of normal tissue around the tumor that is removed during surgery. Ideally there are no cancer cells at the margin (clear or negative margin), only a rim of normal tissue. The pathologist will measure the distance between the cancer and the edge of normal tissue. If cancer cells are detected at the edge of the tissue removed, it is called a positive margin, and more surgery may be required.



Negative and positive margins are the distance between the tumor and the edge of the tissue. The bottom example shows where there is still some tumor at the margins.

Calcification: notes whether calcium deposits were found in the tumor.

Biopsy site: if a prior needle biopsy has been done, it will be noted whether the biopsy site is seen in the sample.

Nipple: if the nipple was removed, it will be noted if cancer is present in the nipple.

Sentinel node biopsy: if a sentinel lymph node biopsy was done, the report will note the number of lymph nodes containing cancer cells (positive lymph nodes), the size of the lymph nodes, and the total number of lymph nodes removed with the sentinel lymph node biopsy.

Axillary lymph node dissection: the report will note the total number of lymph nodes removed, the number that had cancer and the size of the lymph nodes. If a sentinel lymph node biopsy was done before, the report will note the number of additional lymph nodes removed, the number containing cancer cells (positive lymph nodes), and the size of the lymph nodes.

Extracapsular extension: means the cancer cells have spread outside the wall of the lymph node. Your report will state if it is present.

Pathologic tumor stage (AJCC): a scale used by pathologists to summarize features of the tumor (T), number of lymph nodes with cancer (N), and metastatic sites (M).

Comments: includes specific pathologic findings and clarifications of what was seen in the pathologic specimen.

Clinical History

This section contains information on why surgery is needed.

Gross description

This section gives specific details on what was given to the pathologist at the surgery and what it looks like without a microscope.

Tumor characteristics and other tests

Other reports will be made for your breast cancer. These reports will contain the following information:

Estrogen and progesterone receptors: The tissue will be tested in a laboratory for estrogen and progesterone hormone receptors in the cancer cells. These receptors are found on the surface of the cancer cell. The receptors bind the specific hormones (like a key in a lock) and this binding activates the cell internal processes resulting in the cell growth. Both hormones stimulate the growth of normal breast cells (as they contain these receptors) and some breast cancer cells (those that are hormone receptor positive). If hormone receptors are present (ER+, PR+) then these hormones circulating in the body may affect the cancer's growth. The report will list how strongly the cancer cells pick up a special stain for hormone receptors. Any staining is considered hormone receptor positive.

HER2 Assessment: The tissue will be tested to see if the cancer cells contain an increased amount of a protein on the surface of the cells called HER2. Some cells have too many copies of the HER2 gene and they make too much HER2 protein. If a person has HER2 positive breast cancer, that means that the HER2 protein sends messages to the inside of the cancer cells causing them to grow and divide.

About 20% of women with breast cancer have HER2 positive tumors. Tumors that are HER2 positive can grow very fast, and this type of tumor is considered to be aggressive. The presence of too much HER2 in the breast cancer specimen identifies people who

might benefit from treatments directed against the HER2 protein. If you are HER2 positive, there are newer drugs called biologic agents that may be prescribed by your medical oncologist to treat HER2 positive breast cancer.

There are several methods for testing HER2 status: Some HER2 tests (IHC) look for the HER2 protein on the surface of the cancer cells, and other tests look for the amount of HER2 inside the cancer cells. An inconclusive IHC result should be followed by additional testing.

Here are the different methods of testing:

IHC = Immunohistochemistry

CISH = Chromogenic in situ hybridization

FISH = Fluorescence in situ hybridization

SISH = Silver enhanced in situ hybridization

DISH = Dual in-situ hybridization

Tumor Profiling

For some patients who have ER+ breast cancer, your physician may send a piece of the tumor to an outside lab company to look at the genetic profile of the tumor. The results of this test can help your medical oncologist determine whether chemotherapy would be of benefit for you. Another possible use for this kind of testing, is to determine whether radiation would be beneficial for DCIS after lumpectomy.

Other kinds of genetic tumor profiling tests may be ordered by your physician to help guide your treatment and tell your physician if targeted therapy may be beneficial. This type of genetic tumor profiling is not a standard test.

Discuss with your medical oncologist if you have questions about any genetic tumor profile tests and whether they would be beneficial in your situation.

Staging in Breast Cancer

Once your cancer is diagnosed, your doctors will want to know exactly how big the cancer is, whether it has spread to the lymph nodes or other parts of your body, as well as some specific features of the cancer. This is called staging a cancer.

Knowing the stage of your cancer will help your doctors develop the best treatment plan for you.

Breast cancer used to be staged looking only at the tumor size, lymph node involvement and if the cancer spread beyond the original tumor site. Due to advances in cancer research, breast cancer staging now includes estrogen and progesterone receptor status, HER2 status, and in some cases, cancer genomics (the DNA of the cancer cells).

Staging may be done before and/or after surgery. If you are getting neoadjuvant treatment (treatment before surgery), your cancer can be clinically staged based on your biopsy, other test results and physical exam. When you have surgery, your cancer will be pathologically staged after the cancer cells are examined under the microscope. Your doctor may order specific tests to help determine the stage of your cancer.

Sometimes during the course of your treatment and follow-up your cancer may be re-staged. This allows your doctor to get an updated estimate of the size and location of your cancer. It will allow your doctor to adjust your treatment plan.

Stage 1 through 4 breast cancers are all referred to as invasive or infiltrating cancers. This means that the cancer cells have spread, invaded or infiltrated into the tissue surrounding the milk duct or lobule in the breast.

Five Stages of Breast Cancer

Stage 0

The lining of the milk duct contains abnormal cells, but the cells have not spread to the surrounding breast tissue or to the lymph nodes. This stage is also called noninvasive carcinoma, ductal carcinoma in situ (DCIS), or intraductal carcinoma.

Stages 1-3

As mentioned above, there are many variables that are considered when staging breast cancer. Prognostic factors (characteristics that help determine the aggressiveness of the cancer) play a large role in staging. Prognostic factors include anatomic factors (tumor, node, metastasis), biologic factors (ER, PR, HER2, grade), and genomic factors (the DNA of the cancer cell). Prior to 2018, the size of the tumor and number of lymph nodes determined the stage. As of 2018, that is no longer the case. It is possible to have a larger tumor with favorable biologic and genomic factors and have early stage breast cancer. Conversely, it is possible to have a smaller tumor with less favorable biologic and genomic factors and have a later stage cancer. Your physician will discuss staging in detail with you.

Stage 4

Tumor is any size and has spread beyond the breast and lymph nodes to other parts of the body (usually bone, liver, lung or brain). This is often called metastatic cancer.

Hereditary Breast Cancer and Genetic Testing

Family history can play a role in the development of breast cancer. Approximately 20-30% of women who develop breast cancer report a family history of breast cancer. A genetic predisposition, where there is a strong family history of breast cancer is responsible for 5-10% of all breast cancer.

A number of genes associated with a high risk of breast cancer have been identified, including BRCA1 and BRCA2. Women who harbor a BRCA1 or BRCA2 gene mutation have an elevated lifetime risk of developing both breast and ovarian cancer. There are other genes that may also increase the risk of breast and other cancers. If you carry a harmful mutation, there may be additional recommendations for your treatment and follow-up care. There also may be important implications for family members.



Genetic testing may help you learn if you are at increased risk for another cancer or a second breast cancer. Having the gene for a specific cancer does not mean that you will develop that cancer. It only means that you may have a tendency toward developing the cancer and that the gene may be passed down to your children.

DISCRIMINATION

Federal legislation went into effect in 2008, entitled the Genetic Information Nondiscrimination Act or GINA, to prevent discrimination in health coverage and employment based on genetic information.

Women should ask their doctor whether genetic counseling and testing may be helpful if:

- They were 45 or younger when they developed breast cancer
- They have a close relative who developed breast cancer at a young age (50 years old or younger)
- They have a close relative with ovarian cancer
- They have a male relative with breast cancer
- They are of Ashkenazi Jewish descent
- They have “triple negative” breast cancer (estrogen and progesterone receptor negative and HER2 negative) and are 60 years old or younger
- They have multiple close family members on the same side of the family with breast, ovarian, prostate or pancreatic cancer.
- They were 50 years old or younger with one close blood relative with breast cancer, aggressive prostate cancer, or pancreatic cancer or went on to develop a second breast cancer.

It is important to discuss genetic testing and its possible implications with your doctor and a genetic counselor. If you decide to get testing, a small sample of your blood or a saliva sample will be sent to a genetic laboratory. Your DNA will be studied to detect mutations or changes in the genes. A report of the findings will be sent to the genetic counselor and doctor that ordered the test, and they will share the results with you.

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

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Depending on the type and extent of your breast cancer, you will very likely need surgery. The following information covers different surgical options your doctors and 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. Neoadjuvant chemotherapy or targeted therapy is given before surgery to shrink, weaken or destroy the cancer. This may allow you to have a lumpectomy rather than a mastectomy.

Prior to any surgery, you may be asked to see your primary care physician for a general physical exam. If you have special medical concerns, such as heart or breathing problems, you may be asked to see a doctor who is a specialist in those areas. You may also need to have blood work, x-rays or heart tests before surgery.

Preparing Yourself for Surgery

➔ Several weeks before surgery:

- Complete the testing your doctor requests before surgery: usually lab work, additional imaging, a chest x-ray and in some cases, an EKG.
- Recovery after breast surgery often includes restrictions on lifting, pushing and pulling. Now is a good time to make arrangements for the care of your children, other family members who need your help, and the care of your pets. If you feel the need to clean your house try to do it during this time.
- Consider preparing larger portions when you cook and freezing the extra food for meals after surgery. *Ask for help!*
- If you are having a mastectomy, you might like to move items from higher shelves so that you can reach things easier in the first days after surgery. Gather some extra pillows for your bed.
- Consider getting a hand-held shower to make it easier to care for yourself after surgery.
- Driving may be restricted for some time after surgery. Discuss this with your surgeon. This is another chance for you to ask for help from other people.
- Consider what clothes you will wear to the hospital. Usually the clothes you wear to the hospital will be the clothes you wear home. Clothes that button or zip are easier to slip your arms into rather than clothes you pull over your head. If you are having a lumpectomy some surgeons will suggest you wear good supportive bras as you are recovering.

➔ The day before surgery

- Try to eat well, sleep, go on a walk and do diversional activities. Please drink plenty of fluids the day before surgery.
- If possible, remove your jewelry, especially rings, the day before surgery.
- If you are staying overnight in the hospital, gather the items you will need to bring for your surgery stay. Pack lightly, as there are usually only a few items you will need. Bring your photo ID and your insurance card. If you are spending the night at the hospital pack a toothbrush, toothpaste or items needed to care for your dentures. Most women like to bring their own brush or comb. If you wear glasses pack your glasses case.
- Take a shower the night before surgery and apply the surgical wipes or soap as instructed. These are used to reduce the chance of getting an infection from surgery. You will repeat the process in the morning, before surgery. Do not take a shower or bath in between applications.
- It is a good idea to wash your hair the night before surgery, *before the surgical wipe or wash*.
- You may be given further instructions from your health care team.
- Typically, the night before surgery you will be asked not to eat anything after midnight. If you take regular medication for high blood pressure, diabetes or another condition, ask your doctor whether you should take the medicine the morning of surgery. If you do need to take your regular medicine, it should be with a small sip of water.



Remember, 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 surgeon and medical team.

Lumpectomy

During a lumpectomy (partial mastectomy), a surgeon will remove the cancer (or lump) and a small amount of normal breast tissue surrounding it in order to obtain clear margins or edges. The amount of tissue removed depends upon the size of the cancer. The surgery is usually done on an outpatient basis.

If your surgeon cannot feel the cancer, he or she will need some help locating this area of tissue. Because of this, a procedure called a dye or wire localization may be performed just prior to your surgery. This procedure will be completed in the radiology department. Using mammography or ultrasound, the radiologist will place a small needle in the breast where the cancer is located. Once the needle is in place, the radiologist places a fine wire and/or blue dye through the needle and then removes the needle. You will be awake for this procedure. Local anesthetic is often given prior to the needle being inserted. This procedure usually takes 30 to 60 minutes. Alternatively, in some cases, a small marker may be placed in the breast at the cancer by the breast radiologist several days before surgery, similar to a marker placed during a biopsy. During your surgery your surgeon will make an incision guided by the dye, wire, or marker to the area where the cancer is to be removed. The wire or marker and the tissue are removed at the same time.

The pathologist will make a detailed description of what the cancerous cells look like and perform tests on these cells. The pathologist will also determine if there are cancer cells at or very near the edge (margin) of the tissue removed. If cancer cells are found at or near the edge, the surgeon may recommend a second, larger lumpectomy or a mastectomy if that is the best option.

If no cancer cells are found at or near the edge (“clear margins”), you will start your next course of treatment, which could be chemotherapy or radiation.

Your doctor may recommend a **lumpectomy** if you:



- Have a small cancer compared to the size of your breast,
- Have cancer in only one area of your breast,
- Are comfortable having radiation therapy after the lumpectomy and,
- Wish to preserve your breast.

If chemotherapy is recommended after your surgery, it is administered prior to whole breast radiation. In this case, radiation is started after completion of chemotherapy/immunotherapy (See the Medical Oncology chapter for more information).

There are several different ways to administer radiation therapy after lumpectomy. Talk to your surgeon and radiation oncologist to determine what will be the best option for you. (see the Radiation Oncology section for more information). External beam radiation therapy begins after you have healed from the lumpectomy. If brachytherapy radiation is recommended, it is administered soon after surgery. Radiation therapy is recommended following a lumpectomy to reduce the chance that the cancer will return in the breast. It also offers a small survival advantage for women with invasive cancer.

After a lumpectomy, your breast may look a little smaller or have less fullness than your other breast. If a large amount of tissue is removed, you may wish to wear a partial breast prosthesis (an artificial breast form) in your bra to fill in the area and balance your breasts. Certified prosthesis fitters are available to assist you if you choose to wear a prosthesis. You may also want to have a consultation with a reconstructive (plastic) surgeon to determine if there are any surgical procedures that can help restore your breast to a more natural appearance.

Mastectomy Without Reconstruction

During a mastectomy, a surgeon removes all or almost all of the tissue of the breast and may include the nipple. The muscle behind the breast tissue is not removed.

Your doctor may recommend a **mastectomy** if:

- The cancer is large,
- There is cancer in multiple areas of the breast,
- You cannot or do not wish to have radiation therapy after a lumpectomy, or
- You feel that a mastectomy is the best option for you.

Your surgeon will try to minimize scarring as much as possible during surgery. However, once you heal from the mastectomy, you will be left with a scar across your chest and the area will be relatively flat. If possible, your surgeon may leave some extra skin if you are planning to have reconstruction at a later time. In rare cases, your ribs may look like small bumps underneath your skin. Occasionally, radiation therapy may be recommended after a mastectomy when certain features are found on the pathology report.

Following a mastectomy, you may wish to wear an artificial breast form (prosthesis) in a bra or attached to your skin.

Another option is to have the breast reconstructed or rebuilt, using artificial breast implants or your own body tissue such as skin and fat from the lower abdomen. Reconstructive surgery can be done at the time of the mastectomy or you can wait and have it done at a later time. Reconstructive surgery is discussed in more detail later in this chapter.

Prophylactic Mastectomy

A prophylactic (or preventive) mastectomy is removal of a breast even though no cancer has been found in that breast. Prophylactic mastectomies are most commonly done for women who are at very high risk for developing breast cancer and want to reduce that risk, such as women with hereditary cancer syndromes (i.e., BRCA 1 and 2). Although a prophylactic mastectomy removes all or almost all of the breast tissue, there is still a small chance that breast cancer may develop in the remaining breast tissue. During a prophylactic mastectomy, a surgeon removes almost all of the breast tissue, and may include the nipple. The muscle behind the breast tissue is not removed.

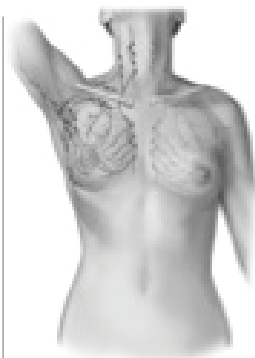
You may want to consider a **prophylactic mastectomy** if you:

- Have breast cancer in one breast and a high risk of developing breast cancer in the unaffected breast over the course of your lifetime,
- Have breast cancer in one breast and a great deal of anxiety about developing breast cancer in your unaffected breast,
- Carry a BRCA 1 or BRCA 2 genetic mutation, regardless of whether you have had breast cancer,
- Have radiation therapy after a lumpectomy,
- Have a substantial family history of breast cancer occurring at an early age.

Lymph Nodes

Lymph nodes are small bean-shaped structures that run close to your vascular system (arteries and veins) and are part of the lymphatic system running throughout your body. This elaborate network of vessels and nodes helps fight infection and clean up waste products made by the body. However, if cancer cells enter these lymph nodes, they can spread to other parts of the body.

The lymph vessels in the breast drain into the lymph nodes under the arm (the axilla). If cancer cells are found in these lymph nodes during a node biopsy, additional treatments may be recommended.



Chest and arm lymph node area

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.

Sentinel Lymph Node Biopsy

If you have an invasive ductal or lobular cancer (refer to the “Understanding Your Diagnosis” section of this notebook) or a large amount of ductal carcinoma in situ (DCIS) that requires a mastectomy, your surgeon will need to remove a few of the lymph nodes under your arm to see if the cancer has spread from the breast to the nearby lymph nodes in the axillary (armpit) region.

Since a surgeon cannot see normal lymph nodes, there are two methods that can be used to help the surgeon locate the lymph nodes during surgery. A radioactive tracer can be injected into the breast before surgery and/or a blue dye can be injected at the time of surgery. The surgeon will make a small cut (incision) in your armpit and find and remove the first lymph nodes into which the breast tissue drains. These are called the sentinel lymph nodes.

Usually between one and four lymph nodes are removed during surgery. A pathologist will examine the lymph nodes, in some cases during the lumpectomy. If cancer cells are found in a sentinel lymph node, more lymph nodes may need to be removed depending upon the type of surgery you had and additional treatments that are planned (see next section).

Axillary Lymph Node Dissection

If you have an invasive breast cancer, and it has spread to the sentinel lymph nodes (refer to the “Understanding Your Diagnosis” section of this notebook), your surgeon may need to remove more lymph nodes under your arm to see if the cancer has spread from the breast to the nearby lymph nodes. This is called an axillary lymph node dissection.

An axillary lymph node dissection is recommended, if the surgeon’s exam or a preoperative lymph node biopsy shows a suspicious or a cancerous lymph node in the axilla (armpit). An axillary lymph node dissection is usually done at the same time as the breast surgery. In some cases, if a sentinel lymph node contains cancer, an axillary lymph node dissection may be recommended. Sometimes this can be done at the same time as your breast surgery.

Your surgeon will make a cut (incision) under your arm on the side the cancer was found. He or she will remove fatty tissue called the axillary fat pad, which contains lymph nodes. The number of lymph nodes found in the fat pad varies from person to person. After your surgery, a pathologist will remove the lymph nodes from the fat pad and examine them under a microscope to see if they contain cancer cells.

You may notice numbness or tingling in the area under and at the back of your upper arm following an axillary lymph node dissection. In addition, scarring in the armpit may cause a feeling of tightness and limit range of motion immediately after surgery. This should get better over time. There are specific exercises (included later in this section) to help with this stiffness.

Throughout your lifetime, you will be at greater risk of developing a condition called lymphedema (refer to the lymphedema section later in this chapter) on the side where the lymph nodes were removed. Lymphedema is a chronic swelling of the hand and/or arm. It can affect as many as 15-20% of women who undergo axillary lymph node dissections. The chance of developing lymphedema increases with additional treatment like radiation therapy (see “Radiation Therapy” section). It is not life threatening, but it can limit movement, increase the chance of infection and change your body’s appearance. Treatment to minimize and/or manage lymphedema is available. Ask your medical team about resources available in your community to reduce your risk of developing lymphedema.



Breast Reconstruction

Following a mastectomy, your chest wall will be relatively flat where the breast was removed. The shape of the breast can be restored through reconstructive surgery. A breast reconstructive plastic surgeon can reconstruct the breast using your own tissue or a breast implant.

Yes or no?

- The decision to have reconstructive surgery is a personal decision influenced by many factors. Be sure to utilize your health care team for information and support.

What to Consider

- How comfortable will I be with my body if I do not have a breast?
- What activities do I participate in and how will I manage with a prosthesis or reconstruction?
- How do I feel about additional surgery?
- How comfortable am I with my prosthesis (if you already wear one)?
- Am I ready to make a decision about reconstruction now?

- Breast cancer reconstruction surgery is not the same as breast enhancement surgery. The goal is to get the best cosmetic effect, but your breasts may look different than imagined.
- You may not have sensation in your reconstructed breasts and/or nipples.

When?

- Reconstructive surgery can be done at the time of the mastectomy or delayed until months or years after the mastectomy. Your doctor may recommend delaying reconstruction if you will need further treatments, such as radiation or chemotherapy, or if you have health or other problems.

What to consider about the timing of reconstruction

- How comfortable will I be with my body if I do not have immediate reconstruction?
- Am I ready to make a decision about reconstruction now? Do I need more time to think about it?
- Will immediate reconstruction have any negative impact on future treatments I need for the breast cancer, such as radiation or chemotherapy?
- If I have immediate reconstruction, how will other treatments, such as radiation or chemotherapy, affect the reconstructed breast?
- Will I have the same options for reconstruction if I do it immediately or delay it?
- Will the reconstructed breast have a different appearance if I have the surgery immediately versus delaying it?

How?

The breast shape can be surgically recreated in one of two ways:

- ➔ **Using an artificial implant:** The implant, much like those used in breast enlargement operations, can be placed behind or above the pectoralis muscle of the chest. Talk to your breast reconstructive (plastic) surgeon to see what option is best for you.
- ➔ **Using your own tissue:** A tissue flap, often taken from the lower abdomen or back, is moved to the chest to create the breast shape.

Each method varies in the amount of surgical and recovery time required, number of surgeries, short and long term complications, and the final appearance of the breast. Almost all reconstructive procedures require more than one operation to complete.

What to consider about type of reconstruction

- How is my general health?
- How will my smoking affect my healing?
- What type of anesthesia is used?
- How long does the surgery take?
- What is the size of my other breast, and what size do I want my reconstructed breast?
- How well will the reconstructed breast match my remaining breast?
- Do I have enough tissue available from my abdomen or back for a tissue flap reconstruction?
- Do I want to change the size of the remaining breast to attain symmetry or make it larger or smaller?
- What is the expected recovery time?
- How many follow-up procedures and how much time is required to complete all of the reconstruction procedures?
- How will the reconstructive process fit into my overall treatment plan for breast cancer?
- What are the benefits and risks of the recommended procedure?
- How many times has the surgeon done this particular procedure?
- Does the surgeon have photographs of women as they go through various stages of the procedure? Does the surgeon have pictures of women when their reconstruction is completed who he/she has done this procedure on?
- What is the cost? How much will my insurance cover?

Specific information on a particular type of reconstructive surgery can be found on the following pages.

➔ Reconstruction with Breast Implants

Breast implants are made of an outer shell of silicone-based plastic. Permanent implants are filled with saline (sterile water similar to our own body fluids) or with silicone gel. The saline filled implants feel firmer, while silicone feels more like natural breast tissue. Implants come in two basic shapes, round or teardrop. The size of the implant depends upon the amount of saline or silicone in the implant and is typically described by bra cup size.

Overview

Artificial breast implants are placed underneath or on top of the pectoralis muscle in the chest.

Number of operations needed

Usually two to three operations are needed for reconstruction. Implants may need to be replaced over time.

Surgery description

- If the implant will be placed underneath the muscle, a temporary tissue expander is placed at the time of the mastectomy or any time afterwards. The tissue expander is a collapsed implant that can be filled with fluid (saline) over time through a “port” under the skin. Its purpose is to slowly stretch the muscle and skin to hold the permanent implant. Fluid is added to the expander every one to two weeks until the desired size is achieved. Once the chest wall is stretched sufficiently, a second operation is performed.
- During the second operation, the expander is removed and the permanent implant is inserted. The nipple and areola can be added through further outpatient procedures, if desired. Both the initial operation to place the expander and the operation to replace the expander with the permanent implant take about one to two hours.
- For implants that are placed over the pectoralis muscle, only one operation is needed. The implant will be placed immediately after your breast surgeon completes the mastectomy. The nipple and areola can be added through further outpatient procedures, if desired.

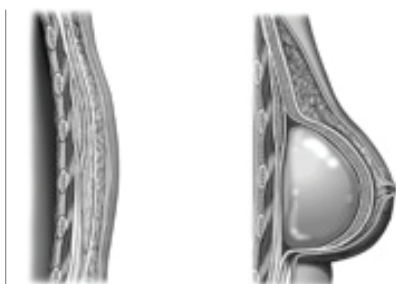
Possible complications

- *Infection or fluid collection:* as with any invasive surgery or procedure, you can develop an infection or collection of fluid (clear fluid or blood) around the implant shortly after surgery. These complications may require treatment with antibiotics or removal of the fluid, but occasionally require the implant to be removed (if removed, the implant can usually be replaced at a later time).
- *Necrosis:* death of the tissue around the implant usually due to poor blood flow to the tissue after the operation. It rarely happens with breast implants and usually does not harm the woman. However, it may leave the breast feeling hard and may distort the look of the breast.
- *Capsular contracture:* the development of scar tissue around the implant that distorts or changes the shape of the breast. If severe, capsular contracture may be uncomfortable or painful. Capsular contractures can be corrected surgically by removing the scar tissue and replacing the implant, but it may reoccur.
- *Ruptures or leaks:* although it doesn't happen often, breast implants may leak or rupture, spilling the saline or silicone into the surrounding tissues. Leaking usually occurs due to injury, age of the implant or for unknown reasons. The implant must be replaced if leaking occurs. Breast implants will need to be replaced over time to prevent leakage.
- *Pain:* any of the above situations can cause pain. Occasionally, women develop chronic pain following reconstruction that cannot be explained, but it can be treated. Discuss issues of pain with your physician.

Advantages vs. disadvantages of **breast implants**:

Advantages

- Surgery time with implants is much shorter than reconstruction surgery using tissue flaps. (See next section on tissue flaps.)
- Breast implants only require incisions in the chest and not other parts of the body required during tissue flap reconstruction.
- Muscle and fat tissue are not moved from another area of your body as they are during tissue flap reconstruction.
- The shorter surgery time and less extensive initial surgery can make recovery easier with breast implants than with tissue flap reconstruction.



Breast implant

Disadvantages

- Some women find that implants do not feel like normal breast tissue.
- The reconstructed breast may feel firmer and less resilient than the natural breast tissue.
- The reconstructed breast will not droop like your natural breast.
- The breast implant will not change size with weight fluctuations like your natural breast.
- If you have one breast reconstructed, you may need additional surgery to your natural breast so that it looks more like the reconstructed breast.
- The total amount of time required and number of surgeries needed to complete the reconstructive process may be longer with breast implants than with tissue flap reconstruction.
- With either type of surgery, the sensation or feeling in the nipple, if preserved, will be lost. Although it may look like a breast, the feeling in the breast will not be the same as the natural breast.

➤ Autologous Reconstruction with Tissue Flaps

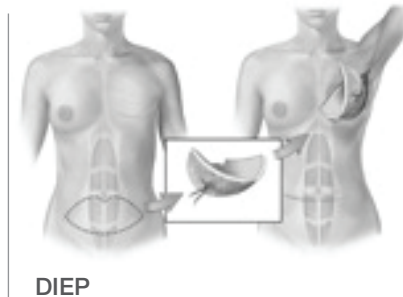
Autologous reconstruction uses your own body tissue to rebuild the breast. Flaps of tissue can be taken from various sites in the body (such as the abdomen, back or buttocks) to create the breast. There are three ways tissue flaps can be created: attached flaps, free flaps and perforator flaps.

Perforator or DIEP Flap

In DIEP (Deep Inferior Epigastric Perforator) flap reconstruction, no muscle is removed. Instead, the plastic surgeon locates the blood vessels in the abdomen that supply blood to the fat and skin of the lower abdomen.

Only these blood vessels, and the skin and fat these blood vessels feed, are removed and moved to the chest to form the new breast.

The abdominal muscles are left in place. The blood supply must be carefully reconnected to blood vessels in the armpit and/or along the breastbone to keep the fat and skin of the new breast healthy.



Surgery with **tissue flaps** compared with surgery with implant:

Advantages

- Creates a very natural appearing breast.
- The reconstructed breast will change size as you gain and lose weight.
- Maintains more sensation in the reconstructed breast than reconstruction with implants.
- Total time required to complete the reconstruction includes one surgery to create the nipple, if you desire. You may need additional surgery to make your breast sizes and shapes match.
- If abdominal tissue is used to create the breast, you may have a flatter stomach (“tummy tuck”).
- Does not require replacement, as implants do, over time.

Disadvantages

- The initial surgery is more complicated than surgery with implants and takes more time, usually six to eight hours.
- Requires incisions in the chest and the area where the tissue flap is taken – i.e., the abdomen, back or buttock – resulting in more scars than surgery with implants.
- Recovery time is longer than surgery with implants and requires a longer hospital stay.
- The TRAM and latissimus dorsi flap surgeries requires transferring all or part of a muscle. In such cases, you may not have the same strength in your abdomen, back or shoulder following surgery.
- Not all surgeons are skilled in performing all of these procedures. You may need to consult with several surgeons, which may result in additional costs.

Attached (Pedicled) TRAM Flap

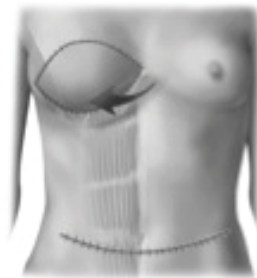
The attached abdominal tissue flap is also known as the TRAM (Transverse Rectus Abdominis Myocutaneous) flap. TRAM flap surgery can be done to recreate one or both breasts.

Overview

Tissue and muscle taken from the abdomen are used to recreate the breast.

Surgery description

During the initial surgery, an incision is made from hip to hip at the bikini line, right above the pubic area. The surgeon then cuts the lower end of the rectus abdominis muscle on the side opposite the new breast. The surgeon rotates the muscle and tunnels it up under the skin to the chest area to create the new breast. The upper part of the muscle remains attached in its original position to provide blood to the tissue flap. Skin and fat are also transferred from the abdomen to the new breast to provide fullness and skin coverage. If both breasts are to be reconstructed, both rectus abdominis muscles are used, along with additional fat and skin from the abdomen.



Abdominal muscle flap graft:
breast reconstruction

Recovery

Recovery from TRAM flap surgery takes time. Your activities will be limited to allow the abdominal incision time to heal. You will also have several drains inserted in the reconstructed breast and under the abdomen skin to remove fluid that accumulates.

You will be given medication to help manage any pain or discomfort. You can slowly return to normal activities and should be back to most of your regular activities after about two months.

Possible complications

Although uncommon, several complications can occur following TRAM flap reconstruction.

- If the blood supply to the new breast becomes restricted, the tissue can become hard or thickened. This is called fat necrosis and will not harm you.
- Fluid can collect in the new breast or abdominal wall forming a seroma (clear fluid) or a hematoma (bloody fluid). The body may reabsorb the fluid on its own, or it may need to be drained with a needle.
- Infections in the breast or abdominal incision can occur. They can be treated with antibiotics.
- As you heal and return to normal activities, you may find that some of your activities are limited due to weakened abdominal muscles. Most women do not have difficulty adjusting.
- Occasionally the loss of abdominal muscles will result in a hernia. Hernias occur when intestines slip through muscles and create a bulge, which is sometimes uncomfortable. A hernia may need to be surgically corrected.
- Occasionally other lumps will form in the abdominal wall or the new breast due to the trauma of the abdominal tunneling. Such lumps may soften with time.

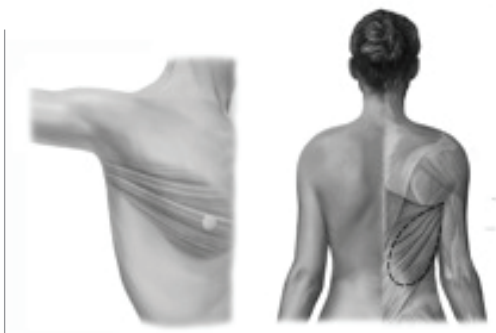
Other Tissue Flaps

Other areas of the body can also be used for autologous tissue reconstruction. These alternate flaps may be used in women who:

- Do not have enough abdominal tissue for reconstruction,
- Have back injuries and need to keep their abdominal muscles,
- Had prior abdominal surgery, or
- Wish to maintain their abdominal strength for a variety of reasons.

Latissimus Dorsi Flap

The latissimus dorsi is the muscle that runs below the shoulder in the back. Similar to TRAM flap surgery, the latissimus dorsi muscle is cut and tunneled under the skin to the chest, along with skin and fat from the back. The skin and tissue of the back are not quite the same as the breast, so the reconstructed breast may look and feel a little different. A breast implant is often necessary to create a fuller breast. Muscle strength in the shoulder and back may be weakened, but most women adjust without much difficulty. Recovery from the surgery may be easier than when an abdominal flap is used.



Latissimus dorsi muscle flap

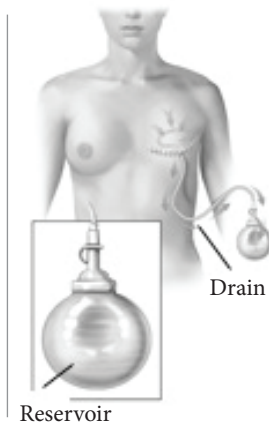
Gluteal Flaps

Gluteal flaps come from the buttock and are done as free flaps similar to the free TRAM flap. They can also be done without muscle, similar to the DIEP flap, in which case it is called an S-GAP flap, (Superior Gluteal Artery Perforator) flap. Gluteal flaps produce very realistic reconstructed breasts. Minimal muscle is used so strength is not impaired. Due to their complexity, however, a gluteal flap usually cannot be done at the time of the mastectomy. Two procedures are necessary to reconstruct both breasts. The gluteal or sciatic nerves that supply sensation to the buttock or thigh can also be temporarily or permanently damaged during the reconstruction.

Wound Dressing and Drain Care After Your Surgery

When you go home, you will have a dressing over your incision or wound where the surgery was done. If you had a mastectomy, axillary lymph node dissection, or reconstructive surgery, you may also have suction drains for a few days or several weeks after your surgery. Below are some general care guidelines. Your surgeon will give you more specific instructions on how to care for your dressing and drains. *(If these instructions differ from what your individual surgeon recommends, follow the directions from your surgeon's office.)*

- Make sure that the dressing stays clean and dry. The dressing should not become saturated with blood or clear fluid. If it does, apply an extra dressing and contact your surgeon.
- Your surgeon will let you know when you can take a shower.
- Your surgeon will tell you when to remove or change the dressing. When you remove the dressing you will see what method your surgeon has used to hold the edges of the wound together. After a lumpectomy many surgeons use either steri-strips or DermaBond. Steri-strips are small strips of special tape. They usually remain in place 1-2 weeks. Do not remove them but allow them to gradually fall off on their own. After a shower the steri-strip may look loose. Just pat the strips dry and they will continue to adhere to your skin.



- Your surgeon may use Dermabond, a sterile, liquid skin adhesive or glue that is used to hold your wound edges together. Dermabond is transparent, so you won't see any strips of tape or sutures. This film usually remains in place for 7-10 days, and then will naturally fall off your skin. It is safe to shower, just gently wash over the incision area and gently towel dry.
- Check the incision or wound to make sure it is healing well. The wound should be dry without a lot of redness or pink surrounding it. It is normal to have some swelling, tenderness and numbness in the area.

Symptoms to watch for include:

- Redness around the wound
- Leakage of clear, bloody or white fluid
- Large amount of swelling
- Excessive warmth around the wound
- Fever or chills

If any of these symptoms develop, contact your surgeon. You may have an infection at the wound that requires treatment.

- The suction drain(s) need to be emptied regularly. Your nurse will show you how to empty them before you leave the hospital. It may be easier to have someone help you empty the drains. To empty the reservoir, pull the stopper out of the top of the drain and pour the liquid into the container your nurse sent home with you. After the drain is empty, squeeze the reservoir flat with one hand and push the stopper back into the top of the drain. The collapsed drain will create suction and help pull the excess fluid out of the wound. Record the date, time and amount of fluid collected for each drain. The amount of fluid coming out of each drain will decrease over time. The fluid may be thin or watery and range in color from light red to pinkish clear. You may also see small pieces of tissue or clotted blood in the drain.

- An infection can develop around a drain, so it is important to watch the area around the tube for redness, warmth, drainage (clear, bloody or white) and fever or chills. Call your surgeon if you have any of these symptoms. Sometimes fluid may drain around the tube instead of into the drain, this may be due to a blockage in the tubing or bulb on the drain. If this occurs, you can apply a small dressing around the tube. Change it frequently if it becomes wet. Call your surgeon for an appointment if there is a lot of drainage around the tube.
- Occasionally, the drain may come partially out or fall out on its own. If this happens, do not try to push the drain back in. Call your surgeon and do not panic. Let your surgeon know how much you drained in the 24 hours before the drain came out.

Seroma

Sometimes after surgery fluid may collect at the surgery site under the skin and/or in the tissues under your arm. This may feel like a fluid filled ball and look visibly swollen. This collection of fluid is called a seroma. Seromas can develop after a lumpectomy, mastectomy and/or lymph node removal. Seromas can develop about 7 to 10 days after surgery, or after the drainage tubes have been removed.

In most cases the seroma fluid is reabsorbed back into your body in about a month, though it can take longer. If it is uncomfortable, you can contact your surgeon, and the fluid can easily be drained. If a seroma does develop, watch for signs of infection, such as redness, warmth, increasing tenderness or a fever. Report any signs of infection to your surgeon.

Activities after Surgery

The time it takes to return to normal activities after surgery depends on the type of surgery performed. In general, lumpectomies require the least amount of recovery time, while a mastectomy with a tissue flap reconstruction takes the longest. Always check with your breast and reconstructive surgeons to determine when it is safe for you to resume specific activities.

General guidelines

- When you first return home, you will be able to do much of your own personal care, such as bathing, dressing, preparing simple foods, etc.
- You may find that you need to take rest breaks between activities, but you should not stay in bed for prolonged periods during the day. It is important to get up and move frequently to help your recovery.
- A short walk each day will help your recovery.



- You can resume light household and work activities such as simple meal preparation, folding laundry, using your computer and completing paperwork as you feel ready.
- Avoid activities that require moderate to heavy lifting (grocery shopping, carrying a load of laundry) or pushing/pulling (vacuuming) and repetitive motions (such as washing windows or long hours at the computer).
- A good rule during this time is to listen to your body, do what is comfortable, and stop and rest when you feel tired.

Driving

If you had a lumpectomy or a simple mastectomy without lymph nodes removed, you may be able to resume driving within a few days. If you had lymph nodes removed and/or reconstructive surgery, you may need to wait several days or weeks before you feel comfortable driving. You should not be driving as long as you are on pain medications. A pillow or seat belt positioning device may help cushion or adjust the seat belt to a more comfortable position when you drive.

Returning to work

Most women are ready to return to work within several days to weeks after their surgery. Again, this time frame depends upon the extent of the surgery and the type of work a woman does. Some women may choose not to return to work while they undergo adjuvant (additional) treatments, such as radiation therapy and chemotherapy. Another option may be to return to work part-time, gradually adding additional hours as you feel ready. Your doctor will help you determine what is best for you.

Exercising

You will gradually be able to resume all of your pre-surgery activities over the course of the first several weeks and months after your surgery. Again, the best rule is to listen to your body, do what is comfortable, and stop and rest when you feel tired or sore. If you participated in vigorous sports before your surgery, check with your doctor to determine when it is safe to return to these activities.

When trying the exercises included in this chapter, be sure to check with your surgeon before you begin. You can do these exercises once or twice a day. Start with 1 to 5 repetitions of each exercise and gradually increase the number as you feel able.

Stretches

During your early recovery period, you need to maintain the range of motion in your arm and shoulder. At your first post-operative check-up, ask your surgeon if you can start some of these simple stretches and exercises. Try to hold the stretch for 15 seconds and do not bounce.

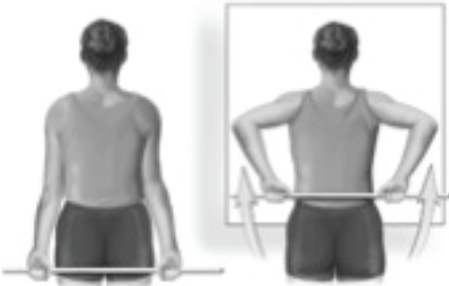
- Shoulder shrugs: with your arms at your sides, pull your shoulders up towards your ears and hold for a few seconds. Repeat several times.
- Raise your arms in front and to the side
- Wall walks
- Broomstick/yardstick behind the back or climbing
- Hands behind head stretch
- Arm away from body stretch (broomstick/yardstick to the side)
- Overhead stretch



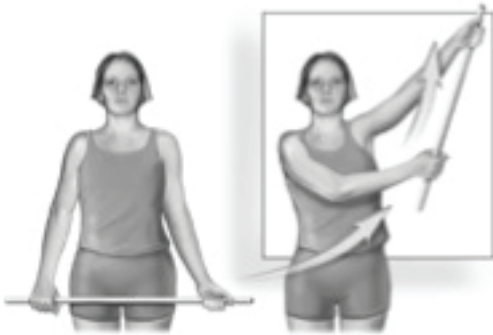
Post Surgery Stretches



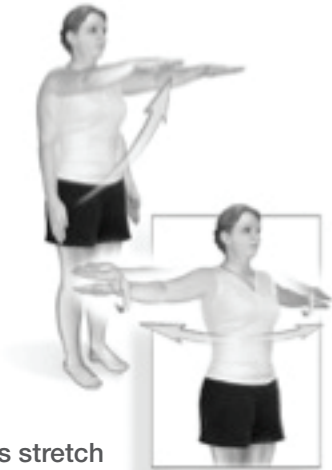
Hands head stretch



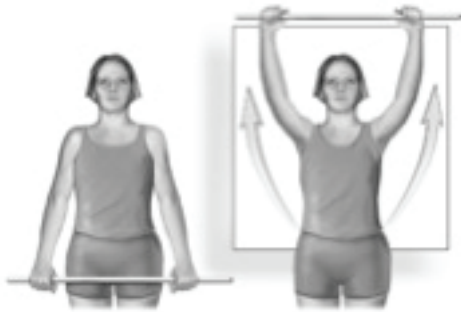
Behind back stretch



Arm body stretch



Arms stretch



Overhead stretch



Climbing

Post Surgery Stretches



Clasp lift stretch



Biceps curl



Arm stretch



Arm extension



Upper torso stretch

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First Aid for Your Arm Following Surgery

Despite all the planning and care you take with your arm following surgery, sometimes you may find yourself with an injury that requires treatment. Be prepared to handle any of these minor emergencies by keeping the following supplies on hand: bandages, antibiotic ointment, antihistamine cream and lotion without dyes or fragrance.

Cut or scratch to the hand or arm

- 1 Apply pressure gently to stop any bleeding.
- 2 Wash the cut with tepid water and soap.
- 3 Dry the area.
- 4 Apply antibiotic ointment to cut.
- 5 Cover with a bandage.
- 6 Clean, reapply ointment and bandage once a day or more often if wet or soiled. Do not leave a wet bandage on a cut or scratch.
- 7 Watch for signs of infection at the site and arm: redness, warmth, drainage, fever or chills. Contact your doctor if you experience any of these symptoms.

Small burn to the hand or arm

- 1 Rinse area with tepid water and pat dry.
- 2 If burned skin is open, contact your doctor. Otherwise follow the steps below.
- 3 Apply an antibiotic ointment to burn.
- 4 Apply a non-adherent bandage.
- 5 Watch for signs of infection at the burned area and arm: redness, warmth, drainage, fever or chills. Contact your doctor if you experience any of these symptoms.

For large burns, consult your doctor or go to an emergency room.

Insect bite to the hand or arm

- 1 Wash area and dry.
- 2 Do not scratch site. Apply an antihistamine cream, such as Benadryl, to site to decrease itching. A cool compress may also help decrease itching.
- 3 Watch for signs of infection at the site and arm: redness, warmth, drainage, fever or chills. Contact your doctor if you experience any of these symptoms or if you experience swelling that does not improve in 48 to 72 hours.

Sunburn to the hand or arm

- 1 Bathe in tepid water.
- 2 Liberally apply lotion containing aloe vera, without fragrance or dyes, to arm at least four times a day.
- 3 Expect some swelling in the arm, but the swelling should begin to decrease after 48 to 72 hours. When sitting or lying down, try to keep your arm elevated. If it is still swollen as the sunburn improves, contact your doctor.
- 4 Wear loose fitting clothing.
- 5 Watch for signs of infection: redness, warmth, drainage, fever or chills. Contact your doctor if you experience any of these symptoms.

Overuse of the arm

- 1 It is okay to use the arm for everyday tasks, but try not to do any heavy lifting or repetitive motions with the arm without your doctor's approval.
- 2 Rest the arm if it is sore or tired.
- 3 Try to keep the arm elevated when sitting or lying down.
- 4 Contact your doctor if swelling does not improve within 48 hours.

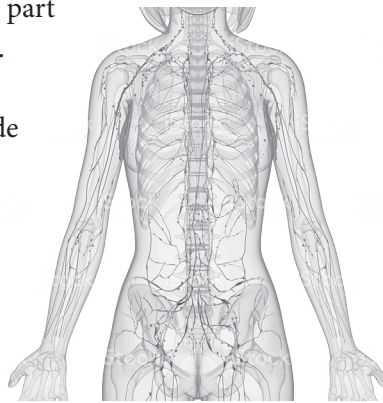
Lymphedema

Lymphedema can occur for various reasons. For breast surgery, it is the collection of protein-rich lymph fluid in the tissues of the hand, arm and/or chest wall on the side of the breast surgery, which causes swelling. Swelling can cause feelings of heaviness, tightness and some discomfort. The condition occurs when the normal lymphatic drainage in the chest and arm are injured during surgery and/or radiation therapy.

Lymphatic system

The lymphatic system is part of your immune system.

It consists of a series of vessels that run alongside your circulatory system (veins) and lymph nodes that are located around major organs and in certain tissue (under your arm for instance). The lymph system helps to filter out dead cells, protein and waste products in your veins. It also plays a role in mobilizing your immune system to fight off an infection.



During your breast surgery, if you have a sentinel node biopsy or axillary node dissection, some lymph nodes are removed and the lymph vessels are cut.

This damages and disrupts the flow of lymphatic fluid in that region. Radiation therapy may cause further scarring. Most of the time, your body can adapt to these changes without excess fluid accumulating in the arm on the side of the breast surgery. However, lymphedema can occur from overusing that arm, or from an infection, bug bite, cut or some other type of injury. Exercising the arm is beneficial, however, it is important to slowly return to exercise after any breaks, such as after surgery.

Development and risk reduction

Most women who undergo breast cancer and lymph node surgery and radiation therapy do not develop lymphedema. However, it is important to learn and follow a few strategies to reduce your risk of developing lymphedema.

Risk factors and occurrence

- Women who have had breast cancer surgery (either mastectomy or lumpectomy) with a lymph node dissection have the highest risk of developing lymphedema over their lifetimes.
- Women who have only a sentinel lymph node procedure have a small risk of developing lymphedema.
- Women who have not had lymph nodes removed very rarely develop lymphedema.
- Lymphedema may not occur at all.

Some women will have very mild lymphedema that may fluctuate over time. However, most women with lymphedema will have chronic, constant swelling that requires regular management to prevent further problems. Physical therapists specially trained in lymphedema management techniques can help.

They will teach you how to reduce swelling using a special type of self-massage, how to apply compression bandages, and how to wear a compression sleeve to maintain the arm's size. Treatment to manage lymphedema is also available in some locations through a lymphedema clinic.

Risk Reduction

You can also take precautions to reduce the chance of developing lymphedema following breast surgery that includes a sentinel lymph node biopsy or an axillary lymph node dissection (with or without radiation therapy). The following are some suggestions to minimize your risk:

- Do not carry heavy objects with your affected arm, including heavy handbags.
- Avoid vigorous, repetitive motions with your affected arm that you are not used to doing. For example, clean only one or two windows at a time instead of all the windows in your house at the same time.
- If possible, avoid needle sticks of any type in the affected arm.
- If possible, avoid blood pressure readings, blood draws, regular injections and intravenous injections in your affected arm to reduce the chance of trauma.
- Maintain a healthy weight. Being overweight or obese can increase your chance of developing lymphedema.
- Gradually build up exercise according to your surgeon or physical therapists' recommendations. Research has shown proper aerobic and strength training exercise can reduce your risk of developing lymphedema. Take frequent rests to allow for limb recovery.
- Monitor your arm for change in size, shape, tissue, texture, soreness, heaviness and firmness.
- When taking a long plane flight (greater than two to three hours), you may choose to wear a compression sleeve on your affected arm. You may also want to wear a sleeve when at high altitudes (greater than 5,000 feet) or while exercising.
- Keep the skin on the affected arm and chest clean and well moisturized. Healthy intact skin is the best defense against infection. Use sunscreen with an SPF 30 or higher when outside.
- Avoid tight clothing or jewelry on the affected arm. Make sure bra straps fit comfortably. If you choose to wear a breast prosthesis, make sure it is a lightweight one.
- Avoid dramatic changes in temperature, such as long soaks in a hot tub or using a sauna. Avoid prolonged exposure to heat (anything more than 15 minutes).
- Wear gloves when doing housework or gardening to protect your hands and forearms.
- Avoid cutting cuticles on the hand of the affected arm. Push cuticles back gently instead.
- If you must shave, use an electric razor.
- Use thimbles when sewing.
- Treat cuts, burns and insect bites promptly. Be alert for signs of infection: redness (including a red streak up the arm), swelling, drainage, warmth and fever or chills. For more information, see the "Surgery Options and Post Operative Care" in this notebook.
- Seek treatment immediately if an infection occurs. Alert your physician if swelling persists for longer than four days.
- Use insect repellent



Treatment

Lymphedema is usually treated by physical methods and complications from lymphedema are treated with medication.

- **Physical methods**
 - Support the arm in a raised position.
 - Undergo manual lymphatic drainage (a specialized form of very light massage that helps to move fluid from the end of the arm toward the trunk of the body).
 - Wear a custom-fitted compression sleeve that applies controlled pressure around the arm. (see next section)
 - Clean the skin carefully to prevent infection.
 - Surgery, in some cases.
- **Compression garments**
 - These should cover the entire area of swelling.
 - Compression pumps may be used with garments, but only under the supervision of a trained health care professional.
- **Medication**
 - Antibiotics may be used to treat and prevent infections.
- **Pain Management**
 - Pain is caused by the swelling and pressure on nerves, loss of muscle tissue and function, or scar tissue causing shortening of muscles and less movement in joints.
 - Pain may be treated with medications, and relaxation techniques; however, the most successful treatment is to decrease the lymphedema.
- **Weight Management**
 - Weight should be monitored regularly, and you are encouraged to eat a healthy diet.

Support

Coping with lymphedema after breast cancer can be a challenge. Group and individual counseling can help by providing emotional support and information about ways to minimize lymphedema. Additional information and resources can be found in the “Breast Cancer Resources” section of this notebook.

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

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.

Chemotherapy and Immunotherapy

Medicines to treat cancer may also be also known as:

- Chemotherapy (or “chemo”)
- Immunotherapy, also sometimes called “biotherapy”
- Anti-cancer drugs
- Anti-neoplastic agents

Many different drugs are used to treat breast cancer. The most common (in alphabetical order) are listed below. Please note that with clinical research there are continual additions to this list.

- Capecitabine (Xeloda)
- Carboplatin
- Cyclophosphamide (Cytosan)
- Docetaxel (Taxotere)
- Doxorubicin (Adriamycin)
- Epirubicin (Ellence)
- Everolimus (Afinitor)
- Gemcitabine (Gemzar)
- Lapatinib (Tykerb)
- Paclitaxel (Taxol)
- Pertuzumab (Perjeta)
- T-DM1 (ado-trastuzumab, Kadcyła)
- Trastuzumab (Herceptin)

Usually given in combination, these drugs target cancer cells that are growing or dividing.

How they work

Chemotherapy

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.

Immunotherapy

Immunotherapy is a type of cancer treatment that boosts the body’s natural defenses to fight cancer. Other types of biotherapy may target a specific trait of the cancer, such as a gene, to selectively kill cancer cells. These medicines may work in several ways:

- Stopping or slowing the growth of cancer cells.
- Stopping cancer from spreading to other parts of the body.
- Helping the immune system work better at destroying cancer cells.

One of the immunotherapies that your doctor may discuss with you is called monoclonal antibodies or a “targeted therapy”.

One example of this is trastuzumab (Herceptin) used to treat HER2 (or HER2/neu) positive breast cancers. HER2 positive means that there are either too many HER2 genes, higher levels of HER2 protein, or both. Approximately 25% of breast cancers are HER2 positive. Herceptin is considered a targeted therapy because it binds to HER2 receptors

and blocks the signals that normally tell the cells to grow. Because the signal is blocked, cancer cells either slow down or stop growing. Herceptin is commonly prescribed with chemotherapy for HER2 positive breast cancer. The outcome for women with this subtype of breast cancer has been improved by the addition of this targeted therapy.

Another agent that targets the HER2 receptor is pertuzumab (Perjeta). Like Herceptin, it binds to the HER2 receptor but in a different location of the receptor. Perjeta is given in combination with Herceptin and chemotherapy for a select group of patients with HER2 positive breast cancer both before surgery and for people with metastatic disease. For women with metastatic breast cancer that overproduces HER2 protein, they may also benefit from an oral targeted monoclonal antibody called lapatinib (Tykerb). Additional therapies that target specific cell features are currently under development.

Your medical oncologist will work with you to discuss the most appropriate medication for you.



How and when they 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 (neoadjuvant therapy) or after surgery (adjuvant therapy) to treat your cancer.

- Neoadjuvant therapy: given prior to surgery to shrink large breast tumors and make surgery easier. This may allow a woman to have a lumpectomy instead of a mastectomy. Neoadjuvant chemotherapy may also be used for women who have HER2 positive tumors.
- 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 axillary lymph nodes.
- Ongoing therapy: If a patient has 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.

Side effects of Chemotherapy and Immunotherapies

Different people 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 systemic therapy session. 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.

Chemotherapy side effects can range from minor to life-threatening conditions depending on the chemotherapy drug used, the dosage and a person's overall health. Medical professionals must tell you about all 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.

Suppressed bone marrow, or low blood counts, result in low production of white blood cells, platelets and red blood cells.

- White blood cells are the “soldiers” of the body. When there are too few white blood cells (neutropenia), your immune system may not be able to fight infection as well as it does normally.
- Red blood cells deliver oxygen to the body and carry away carbon dioxide from the tissues. A low red blood cell count (anemia) may make you feel weak and tired.
- Platelets help blood to clot when you get a cut or there is a leak in a blood vessel. If your platelet count is low (thrombocytopenia), you may be at risk for bleeding or bruising.

Other common chemotherapy side effects include fatigue, nausea and vomiting, diarrhea and mucositis (sore mouth and throat). These side effects are discussed in detail later in this section.

Common immunotherapy side effects include fever, chills, body aches, nausea/vomiting, loss of appetite and fatigue.

Vascular Access Devices

(Includes Ports and PICC lines)

Most systemic breast cancer drugs and blood product transfusions are given intravenously every few weeks. Frequent blood tests are needed before, during, and after chemotherapy and immunotherapy. Because of the frequent use of the veins for testing and treatment, patients may benefit from placement of an IV access device (VAD) to facilitate blood draws and intravenous infusions.

VAD devices are small, flexible tubes or 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”. They can remain in place for weeks, months or even years. Depending on the type of VADs they may be inserted by a doctor or by trained nurses in a special procedure room, operating room, or at the bedside.

There are several types of VADs, but the two VADs that are commonly used for breast cancer treatments are:

- Implantable port (usually called a “port”)
- Peripherally inserted central catheters (PICCs).

Your doctor will recommend a specific type for you based on your preference, how long and how often you need it, and how much care you will be able to give it.



Ports

Implantable ports consist 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. 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 chemo/immunotherapy. Ports need flushing before and after use and monthly when not in use. Ports are designed to stay in for longer periods of time.

PICC Lines

PICC lines are usually inserted by a trained registered nurse in a special procedure room or at the bedside using ultrasound. PICC catheters are long, very thin, soft, and flexible. Using local anesthesia, PICCs are inserted into a large vein of the arm through a needle and then advanced or "threaded" through the vein to the SVC.

Once in position, the needle is removed, leaving just a small section of the catheter exposed on the arm and taped in place. PICCs can last for months with proper care.

Safety and Maintenance of Your VAD

To keep VADs functioning well, they need flushing, cleaning and, for PICC lines, dressing changes. 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, and 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
- Inability to flush or draw blood from the VAD

Hormone or Endocrine Therapy

Medical oncologists prescribe hormone or endocrine therapy for people with estrogen positive and/or progesterone positive breast cancer.

Estrogen is primarily produced in the ovaries of premenopausal women. In post-menopausal women, the ovaries stop making estrogen but small glands above the kidneys, called adrenal glands, produce hormones (androgens) that are converted to estrogen by an enzyme (aromatase) found in muscle and fat cells.

In premenopausal women, hormone therapy blocks the estrogen signals in the cancer cell and stops cell growth. Sometimes a hormone therapy is used to stop the ovaries from producing estrogen, putting a woman in a medicine-induced menopause.

In post-menopausal women, hormone therapy prevents the hormone made by the adrenal gland from being turned into estrogen.

Endocrine therapies commonly used to treat hormone receptor-positive breast cancer include:

- Selective Estrogen Receptor Modulators (SERM's) and Estrogen Receptor Downregulators (ERD's) attach to or occupy the estrogen receptors in the cancer cell, blocking estrogen's ability to stimulate cell growth. SERM's/ERD's are commonly used to treat premenopausal women, women with DCIS and women at high risk of developing breast cancer. Common drugs in this category are:
 - Tamoxifen (Nolvadex)
 - Fulvestrant (Faslodex)
- Aromatase Inhibitors (AI's) prevent the conversion of the hormones produced by the adrenal glands in post-menopausal women to active estrogen, thereby reducing the estrogen available to the cancer cells. AI's are commonly used to treat postmenopausal women. Common drugs in this category are:
 - Anastrozole (Arimidex)
 - Letrozole (Femara)
 - Exemestane (Aromasin)
- Luteinizing Hormone-Releasing Hormones (LHRH's) are medications that shut down the ovaries, stopping them from producing estrogen, so there is less estrogen to encourage the cancer cells to grow. LHRH's are given to premenopausal women and create a medicine-induced menopause. They may be combined with tamoxifen or an AI to further reduce the amount of estrogen available to the cancer. Common drugs in this category are:
 - Leuprolide (Lupron)
 - Goserelin (Zoladex)
 - Triptorelin (Trelstar)

Side Effects of Hormone or Endocrine Therapy

The side effects you may experience depend upon the type of hormone or endocrine therapy you are receiving. Some of the more common side effects of each class of hormone or endocrine therapy are:

SERM's (tamoxifen, fulvestrant) most common side effects include hot flashes, night sweats, vaginal discharge, mood changes, edema or swelling and menstrual irregularity. Although infrequent, SERM's can cause clots to form in the veins in your legs or other areas of your body and can rarely cause endometrial cancer (a cancer of the lining of the uterus). If you develop swelling or pain in your leg, shortness of breath, chest pain, numbness or tingling or abnormal vaginal bleeding you should contact your doctor immediately.

AI's (anastrozole, letrozole and exemestane) most common side effects include hot flushes, joint pain, mood changes, and edema or swelling. AI's can also cause osteoporosis, so your doctor may order a bone density test to monitor your bone strength.

LHRH's (leuprolide, goserelin, triptorelin) most common side effects include hot flashes, mood swings, loss of libido (sex drive) and osteoporosis. Goserelin may also cause vaginal dryness, breast swelling/tenderness, weight gain, headaches and bone pain.

Other Treatments

Biphosphonates

Biphosphonates are a class of drugs that are prescribed to reduce bone loss. They can be used to treat bone loss in postmenopausal women on hormone blockers. They are also used intravenously to treat women whose breast cancer has spread to bone to reduce the risk of fracture and to reduce pain.

Systemic Therapy Side Effects and Self-Care Tips

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

The following information could help prevent or lessen any side effects you may experience. You may need to experiment to see which ones work best for you, or you might find something else that can help you deal with the side effects.

Self-care Tips

Unless your doctor tells you differently, it is important to drink extra fluids while you are undergoing systemic therapy. Try to empty your bladder often.

- While you are undergoing treatment and after you stop treatment, do not have any immunizations or vaccinations without your doctor's approval. The annual flu vaccine is usually recommended.
- Regular doctor visits are very important. Your doctor needs to check your progress to make sure that the systemic therapy is working properly and to check for unwanted side effects. Your doctor will recommend a follow up visit schedule for you.



Blood Cell Counts

Chemotherapy often affects one's blood cell counts. Your doctor's office will give you routine progress reports on your blood cell counts. You can also get this information on My Health Online.

White Blood Cells

White blood cells (WBC) are cells that defend the body against infection. If your WBC count is low (a condition known as neutropenia) due to chemotherapy, your risk of developing an infection may increase. An infection can occur anywhere in your body or be caused by organisms normally found in your body or the environment. Your doctor may delay your treatment or decrease the dose of your chemo drugs if your white blood cell count is low.

Report to your doctor immediately if you have:

- **Fever of 100.5 or greater, unless their office instructs you differently**
- **Chills with or without fever**
- **Sweating, especially at night**
- **Earaches**
- **A severe cough or sore throat**
- **Mouth sores or ulcers, cold sores or fever blisters**
- **Infected hangnail or skin around toenails, including any redness, tenderness and /or swelling**
- **Rashes or redness, swelling or sores on the skin**

To prevent infection:

- Check your oral temperature whenever you feel you have a fever or have shaking chills
- Wash your hands throughout the day, especially before eating, and after using the bathroom
- Avoid people who have contagious illnesses, such as chicken pox or flu
- Do not tear or cut your nail cuticles. Use cuticle cream and push them back
- If you do cut or scratch your skin, clean the area at once with water and soap and call your doctor if you show any sign of infection, such as swelling, redness, tenderness and/or fever
- Brush your teeth with a soft toothbrush after meals or rinse your mouth after you eat
- Lubricate your lips frequently and use lotions/creams on your skin to prevent dryness
- Wash and cook all foods well
- Avoid handling fresh or dried flowers
- Avoid constipation. Ask your doctor for advice about stool softeners and/or laxatives if you experience problems. Avoid using enemas or suppositories unless instructed by your doctor
- After each bowel movement or urination, wipe yourself from front to back. If there is irritation, or if hemorrhoids are a problem, ask your doctor for advice
- Check with your doctor first before having elective dental work or surgery
- Avoid cleaning pet litter boxes
- Avoid diaper changes of children who have had recent immunizations
- Use gloves while gardening or washing dishes

Platelets

Platelets are blood cells that help in clotting to prevent bleeding. If your platelet count is very low, you may bleed or bruise more easily than usual.

To prevent bleeding

- Do not give yourself an enema. Ask your doctor for a stool softener and/or laxative if you are constipated
- Do not take any medication, not even aspirin or aspirin-free pain relievers, without first checking with your doctor or nurse
- Discuss alcoholic drinks with your doctor
- Continue good oral hygiene, use a soft bristled toothbrush to clean your mouth, and floss gently
- Clean your nose by blowing gently
- Be extra careful when using knives or other sharp objects
- Use an electric razor when shaving
- Be very careful not to burn yourself, especially when ironing or cooking. Use a padded glove when you reach into the oven
- Avoid contact sports and other activities that might result in injury
- Wear heavy gloves for digging in the garden or working near plants with thorns
- Do not have any elective dental work or surgeries without checking with your doctor first
- Discuss sexual intercourse with your doctor

Red Blood Cells

Red blood cells (RBC) carry oxygen to the tissues in your body. When the red blood cell count is low (a condition known as anemia), your body tissues may be low in oxygen as well. Over time, you may become very tired physically and mentally.

To help anemia

- Get plenty of rest; conserve your energy
- Try sleeping more at night and taking a short nap during the day
- Limit and prioritize your daily activities. Accept offers or ask family and friends to help you do your shopping, cooking or housework
- Try to eat a balanced diet, even when you are tired
- If you don't have help cooking your meals, use ready to eat foods. Double your recipes on days that you have energy to cook; place them in small containers and freeze them. You may want to contact "Meals on Wheels" about delivering food to you.

Report to your doctor immediately if you:

- Get dizzy or light-headed often
- Have headache or are unable to concentrate
- Tire easily
- Are getting weaker and unable to do everyday activities
- Have shortness of breath
- Have a pounding heart

- Drink plenty of fluids
- Continue to do things you enjoy. Walk if able, at your own pace, for at least 30 minutes each day.
- Move slowly to avoid getting dizzy. For example, when you wake up, instead of getting out of bed quickly, sit on the side of the bed for a while before standing. If you still feel dizzy, talk to your physician or nurse about what you should do.
- If you experience shortness of breath, breathe through your nose and exhale slowly with your lips pursed.

Fatigue

Fatigue is loss of energy that persists despite adequate rest and sleep. The feeling is disproportionate to or unrelated to activity. It can be mild, moderate or severe. Many things can cause fatigue, including:

- Anemia
- Cancer treatment
- Coexisting medical conditions, such as high blood pressure (hypertension), diabetes or thyroid disorders
- Depression
- Electrolyte imbalance/dehydration
- Immobility or lack of exercise
- Infection/fever
- Insomnia or not sleeping well at night
- Menopause
- Pain
- Poor nutrition
- Stress
- Surgery

Protective and Preventive Measures

- Be reassured that fatigue related to your cancer treatments is common
- Simplify your work or activities by breaking them down into smaller steps
- Plan your activities for times when you have energy. Pace your activities and include rest breaks in your plan
- Always check first with your doctor about exercise. If it is okay with your doctor, exercise for several short periods, rather than one long period. The duration of exercise is based on your normal level of activity. Walking at least half an hour a day is generally recommended, unless your doctor says otherwise.
- Practice energy conservation by alternating activities with short, frequent rests
- Relaxation, meditation, biofeedback and massage therapy may help
- Prioritize your activities by doing the things that are important or essential and decrease or eliminate activities that are not essential
- Limit alcohol and caffeine intake
- Eat a high protein, high calorie diet and maintain good hydration by drinking plenty of fluids
- If you do not have help cooking your meals, use ready to eat foods. Double your recipes on days that you have energy to cook. Place them in small containers and freeze them. You may want to contact “Meals on Wheels” about delivering food to you.
- Try to establish good sleeping habits at night and only take short naps during the day.
- Keep room temperatures moderate, not too hot or cold.
- Tell your doctor if your energy level is preventing you from completing your activities of daily living (ADL) or activities that you normally enjoy.



Nausea and Vomiting

Many of the systemic drugs used for breast cancer may cause nausea and vomiting (N&V) due to the effect of chemotherapy and immunotherapy on the stomach. The severity of this side effect depends on the type and dose of drugs used. If the drugs prescribed are known to cause moderate to severe N&V, your doctor may order anti-nausea (or “antiemetic”) drugs before you start taking them. You may also receive a prescription for anti-nausea medication to take for a few days following treatment whether or not you feel nauseous.

Sometimes women experience nausea even before receiving chemotherapy or immunotherapy. This type of nausea is called “anticipatory nausea,” which is usually associated with anxiety.

Protective and preventive measures

- Use anti-nausea medication prior to chemo and continue through the entire anticipated duration of N&V. There are many anti-nausea medications available. Ask your doctor which ones would be good for you. Let your doctor know if the medications do not work for you.
- Rinse your mouth often to reduce the metallic taste you may experience.
- Take anti-nausea medicine before meals.
- Helpful therapies might include counseling and relaxation techniques. Breathe deeply and slowly if you start to feel nauseous.
- Environmental changes.
- Choose a calm and comfortable area to rest, especially after meals. Avoid lying flat for at least one hour after a meal.
- Minimize distinctive odors, including perfumes, room deodorizers and disinfectants (strong smells can trigger nausea).
- “Aromatherapy” can be helpful for some people (see Integrative Therapy chapter).

Dietary Interventions

- Eat small frequent meals. Eat light meals before chemo/immuno therapy. Eat before you get hungry. An empty stomach will make N&V worse.
- Suck on mints or hard candy during chemotherapy.
- Try using ginger either as a tea (fresh or candied) or in broth
- Avoid concentrated sweets (cakes, cookies), fried, fatty, spicy and highly salty foods.
- Eat rice, bread, potatoes, hot cereals, puddings and other carbohydrate foods as they are more easily digested.
- Get adequate fluid intake to prevent dehydration: clear liquids or broth, unsweetened fruit juices, or light-colored sodas that have lost their fizz, such as ginger ale.



- Sip beverages slowly between meals to avoid bloating.
- If N&V occur in the morning, eat dry foods like toast, crackers or pretzels before getting out of bed.
- If you experience taste changes and N&V avoid your favorite foods. It may make it so you won't want to eat them in the future.
- Avoid food with strong smells.
- Dieting during cancer treatment is not recommended.

See the Wellness and Integrative Therapies sections of this binder for more information about diet and nutrition.

Mouth Sores (Mucositis)

Mucositis (mouth sores, also known as stomatitis) refers to inflammation and sores of the mucosa (lining) of the mouth. They are caused by the effects of chemo drugs (especially methotrexate, doxorubicin and fluorouracil) on rapidly dividing mucosa cells found from the mouth to the anus (gastrointestinal tract) and by suppression of the bone marrow (myelosuppression), which decreases blood cell production. Oral mucositis occurs within two to five days after chemo and can last up to two weeks or longer. You may not be able to prevent mucositis, but you can help lessen the symptoms and prevent secondary infection in your mouth by using good oral hygiene and frequent baking soda or salt mouth rinses. Talk to your doctor about your mucositis. Your doctor may order prescription mouth rinses if necessary.

Signs and symptoms of oral mucositis

- Burning sensation
- Sensitivity to hot and cold foods
- Sensitivity to salty and spicy foods
- Intolerance of citrus fruits
- Mild redness (erythema) or swelling (edema)
- Sensation of dryness

Mucositis can cause pain, difficulty eating and swallowing, and increased risk of infection because of open sores in the mucosa. Let your doctor or nurse know if you have any of the following:

- Red, shiny or swollen mouth and/or gums
- Blood in your mouth
- Sores, white patches or pus in your mouth (including gums and tongue)
- Soreness or pain in your mouth or throat
- Burning, pain or a feeling of dryness while eating
- Your saliva is thicker or you have mucus

Protective and preventive measures

- Treat dental problems before starting chemo.
- If you wear dentures, use them only when eating.
- Stop smoking. Smoke will make your mouth drier and more irritated.
- Check your mouth daily and tell your doctor if you have any of the signs and symptoms of significant oral mucositis. Make sure to look under dentures.
- Keep your lips moist with lip balm or other moisturizers to prevent dryness and cracking.
- Keep your mouth clean and moist to prevent secondary infections. Use a soft toothbrush and rinse your mouth frequently with one teaspoon of salt and/or baking soda in a glass of water. You may use a sponge swab if there is too much pain or bleeding. Avoid commercial mouthwashes since their alcohol content can be irritating and drying.
- Over the counter products like Biotene® may help with dry mouth.
- Avoid using lemon glycerine swabs to clean mouth because of their drying effect.
- Your doctor may prescribe some medications called “magic mouthwashes” that temporarily relieve mouth pain. He or she may also recommend topical medicine or pain relievers that you apply directly to mouth sores.

Nutritional support for mucositis

- You may need to change your diet if the mucositis is severe.
- Take small bites and chew slowly.
- Eat foods that require a minimum of chewing (i.e., food chopped or cut into small pieces, blended or pureed foods, casseroles and soups) and are easy to swallow, such as bananas, applesauce, mashed potatoes, custards, scrambled eggs, etc.
- Avoid eating citrus fruits, tomato products, spicy or salty foods, and dry and hard foods, especially those with rough surfaces.
- Add sauce or gravy, or dip foods in beverages to make food softer and easier to swallow.
- Cold foods may be more soothing. Try ice cream, popsicles, jello, cottage cheese, yogurt, pudding, etc.
- If you cannot eat solid foods because of severe mucositis, use nutritional supplements (such as canned liquid supplements or milkshakes).
- Drink plenty of fluids to keep your mouth moist. Avoid caffeinated coffee, tea and alcohol.



Diarrhea

Diarrhea is frequent bowel movements of soft, mushy or watery stools. It can be caused by the effects of chemo/immuno therapy on the lining of the bowel. It can also be caused by medications, certain foods, or possibly an infection.

Protective and preventive measures

- Tell your doctor or nurse if you have fever, excessive thirst, dizziness, palpitations, rectal spasms, abdominal cramps, watery stool, bloody stool, or diarrhea that will not go away despite treatment.
- Eat foods that are lactose-free (lactose is the simple sugar found in milk and milk products), low-fat, and low-residue (foods that do not contain high fiber or roughage).
- Your physician may recommend a change in the medications you take.
- If your diarrhea is bad, do not eat or drink for a few hours to allow the gut to rest. When you feel better, try drinking clear liquids, such as clear broth and beverages, then go to a bland diet such as the BRAT diet mentioned next.

Foods to eat

- BRAT diet (Bananas, rice, apple sauce or peeled apples, and toast without butter)
- Foods containing pectin (bananas, avocados, asparagus tips, beets)
- Foods rich in sodium and potassium (minerals lost due to diarrhea), such as peeled apricots; bananas; peach and apricot nectar; broccoli; skinless baked, boiled or mashed potatoes; meat; mushrooms; cottage cheese (lactose-free variety)
- Liquids: drink at least 1/2 oz per pound of your body weight (generally 1.5 to 3 quarts/liters) a day. Try peach nectar, bouillon and sports drinks, cranberry juice, grape juice, ginger tea, gelatin, non-carbonated or lightly carbonated drinks
- Try adding nutmeg to foods to reduce over-activity of the gut or small bowel



Foods to avoid

- Gluten (a wheat protein)
- Milk and milk products, except for:
 - Buttermilk and yogurt may be tolerable because the lactobacillus in buttermilk and yogurt alters the lactose.
 - Processed cheese may be tolerable because the lactose is removed when the whey is separated from the cheese curd.
 - Canned supplements, such as Ensure, are lactose free and may be used.
- Stimulating or irritating foods (spicy foods, coffee, tea, chocolate, alcohol)
- High fiber foods because of gas formation (prune and orange juice, nuts, whole grain, beans, popcorn, pickles, relishes, peas, cauliflower, broccoli, and cabbage)
- Raw vegetables and the skins, seeds and stringy fibers of vegetables and unpeeled fruits
- High fat foods

Antidiarrheals

There are many anti-diarrhea medications that can be bought over the counter or with a doctor's prescription. If one medication does not work for you, let your doctor know.

Drugs to avoid

- Bulk laxatives (such as Metamucil) may enhance gastrointestinal activity and contribute to more severe diarrhea. However, sometimes doctors may recommend a little bit of Metamucil to help form stools
- Stool softeners or laxatives
- Herbs

Skin Care

- Prevent skin irritation or breakdown on your rectal area by applying A&D ointment, Aquaphor, or other products on your clean skin to prevent the stool from sticking.
- Proctitis is an inflammation of the rectum/anus. Symptoms include mucousy rectal discharge, rectal pain and rectal bleeding. If you develop proctitis, your doctor may order rectal cream, hemorrhoidal preparations with hydrocortisone, or the use of sitz baths.
- Keep your perineal area (area between your rectum and vagina) clean and dry.

Heartburn

Heartburn is the burning or pressure sensation along the esophagus, a part of the body where food passes from the mouth to the stomach, and in the upper part of the stomach. It is usually caused by the reflux of stomach acid into the esophagus. This can also result in irritation of the esophagus. At times, this can feel like nausea.

Protective and preventive measures

- Eat small, frequent meals
- Avoid lying down but do walk around after eating. Wait for at least 2-3 hours before lying down
- Reduce your intake of tea, coffee, chocolate, sodas and alcohol
- Avoid spicy, acidic, fried and fatty foods
- Stop smoking
- Avoid exercising immediately after eating
- Use at least 2 pillows to elevate your head when lying down
- Take antacid as directed on the bottle or by your doctor to relieve heartburn.

Medications

If your symptoms are not getting better, or it is a recurring problem, your doctor may prescribe another medication to help.

Constipation

Constipation means not moving your bowels as often as you normally do, being unable to move your bowels, or needing to push harder to move your bowels.

Constipation may be caused by some chemo/ immunotherapy drugs, pain medications, anti-nausea medications, calcium and calcium containing medications, some antidepressants, and antispasmodic or medicine for stopping abdominal cramps. Other causes are from not drinking enough fluid, not eating enough foods containing fiber or being inactive.

Protective and preventive measures

- Drink plenty of liquids such as water, prune juice, warm juices, hot water with lemon juice and decaffeinated teas. Drink at least 1/2 oz per pound of your body weight. For example, if your weight is 140 lbs, drink about 70 oz of liquids.
- Try to move your bowel regularly at the same time each day to develop a regular bowel habit
- Over the counter Senokot or senna taken as directed maybe helpful
- If eating high fiber diet is not contraindicated, eat wheat bran, wheat germ, whole-grain bread and cereals, fruits (with skin on, fresh or dried) and vegetables, popcorn and dried beans and peas such as lentils, split peas, and kidney, garbanzo and lima beans. Make sure you are also drinking plenty of fluids with the fiber.
- Try to participate in regular, daily exercise. Check with your doctor if you have a limit as to what kind of exercises you should not be doing.
- If you are taking medications that can cause constipation, consider taking a stool softener.

Medications

If your constipation does not improve, your doctor may recommend a stool softener and a laxative regimen. There are many types of medications for constipation but your doctor will help you find the best option for you.

Hair Loss (Alopecia)

Hair loss is temporary. It usually starts between ten days to a few weeks after chemotherapy and will start to re-grow in about six to eight weeks after chemotherapy is completed. The degree of hair loss can be minimal, moderate or severe. It depends on the type of chemo drug used and the dose and duration of the therapy. Hair loss may not be limited to the scalp. It can affect the eyebrows, eyelashes and other body hair. Your hair may come back a different color and texture.



Helpful hints to cope before, during and after hair loss

- Remember that your hair will grow back.
- Be gentle with your hair. Use mild shampoo and a soft hairbrush.
- Avoid using electric curlers, curling irons or hair dryers.
- Avoid dyeing your hair or getting a “perm” as these may hasten hair loss and irritate the scalp.
- Before you start losing your hair, consider having it cut short. This will help you get used to the new look and can make hair loss less emotionally difficult.
- Start wearing a turban, especially at night, a week after starting chemo to catch falling hair. This will help prevent the sight of hair on your pillow, blankets or pajamas.
- Hair may fall out in clumps and can leave “patches” on your head. Some women choose to clip their hair short with hair clippers to avoid the patchy look.

Wigs and Head Coverings

- Before starting, or immediately after the first dose of chemo, consider buying and wearing a wig so that you, your family and friends can get used to your new look. Purchasing a wig prior to hair loss will also make it easier to match your own hair color and style. Wigs can be made of human hair or synthetic materials. Human hair wigs are expensive. Synthetic wigs are less expensive and easy to care for.
- Free wigs may be available through the American Cancer Society, local organizations or hospitals.
- Some women may not tolerate wigs because they find them uncomfortable or “just not their style.” Other head coverings are available, such as turbans, hats, scarves or hairpieces. You can use hair accessories to make your hat or turban more stylish or attractive.
- The American Cancer Society offers a free program, “Look Good...Feel Better,” for patients who are currently, or will be, receiving active cancer treatment that may cause changes to their skin or hair. Certified cosmetologists teach the program. They show women how to take care of their skin, how to apply makeup, and how to choose and fit wigs, turbans and hats. The

American Cancer Society can be reached at 1-800-ACS-2345.

- Keep your scalp covered and use sunscreen to prevent sunburn. Use mild shampoo to clean the scalp and apply soothing emollients or lotions to prevent itchiness and dryness.
- When hair starts to return, it may have a different color or texture compared to your “old” hair. The new hair may be curly.

Cold Caps

At the time of this binder creation, there is some disagreement about the use and effectiveness of cold caps. Some insurances do not cover them. You will need to talk with your medical team about using them.

Cold caps and scalp cooling systems work by narrowing the blood vessels beneath the skin of the scalp, reducing the amount of chemotherapy medicine that reaches the hair follicles. With less chemotherapy medicine in the follicles, the hair may be less likely to fall out. The cold also decreases the activity of the hair follicles, which slows down cell division and makes the follicles less affected by the chemotherapy medicine.

The most common side effects include headaches, neck and shoulder discomfort, chills and scalp pain.

Early Menopause and Fertility

Chemotherapy may induce early menopause, either temporarily or permanently, depending on your age and the type of treatments given. If you wish to consider having children following your treatment ask your medical oncologist about a referral to a fertility specialist that has expertise in treating women undergoing cancer treatments before starting treatments.

Menopausal symptoms may include hot flashes, vaginal dryness or 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. These symptoms are discussed in greater detail in the “Healthy Living” section of this notebook.

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.

Radiation Therapy

Radiation therapy is one of a number of treatments for breast cancer. It may be used in addition to surgery, chemotherapy or hormone therapy.

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 breast also 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.



How Radiation Affects Cancer Cells

Cancer cells grow and divide at a faster rate than healthy tissue. During radiation treatment, the breast is targeted with high energy beams. Radiation is very effective at stopping cancer cells from dividing and growing.

Radiation therapy is used to treat all stages and sizes of many types of cancers. It can be a treatment option for women with:

- Ductal carcinoma in situ (DCIS or stage 0)
- Early stage invasive breast cancer (stages 1 and 2)
- Advanced disease (stages 3 and 4)

Radiation therapy works best when the cancerous lump or area has been removed. It is commonly recommended following breast conservation surgery (also called a lumpectomy, wide excision or partial mastectomy). After this type of surgery, the remaining breast tissue may contain undetectable cancer cells. Because these cells are too small to see even on a mammogram, your surgeon cannot detect and remove them. Radiation treatments are given to eliminate any cancer cells that may be in the remaining breast and surrounding tissue. The radiation treatment is confined to the breast region and does not spread to other parts of your body.

Radiation therapy is sometimes given after mastectomy. If you are considering a mastectomy, talk with your surgeon about the possibility of needing radiation therapy after surgery. If you have further questions about this, ask to speak with a radiation oncologist.

Medical Conditions Requiring Special Consideration

Women with certain medical conditions may not be good candidates for radiation therapy. Let your doctor know if you have any of the following conditions: scleroderma, systemic lupus, prior radiation therapy to the breast or chest or if you are or may be pregnant. Your doctor will need this information to determine the best treatment plan for you.

The Radiation Therapy Process

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, mammogram, other 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 chance to share your concerns and fears and ask your doctor and radiation oncology staff questions. It is a good idea to bring another person to this appointment since you will receive a lot of information about your treatment plan.

The treatment planning or simulation appointment

If you and your doctor decide breast radiation therapy is best for you, you will have a treatment planning or “simulation” appointment. During treatment planning, the exact area or treatment field will be identified. Your radiation oncologist will use CT images to identify structures in your chest, such as your heart and lungs. After analyzing the images, your radiation oncologist will determine the best way to treat your breast tissue while reducing exposure to the normal tissue nearby.

If you are having whole breast radiation, your skin will be marked to make sure that the radiation therapy is administered exactly as planned. Most treatment centers use a combination of tiny tattoos (about the size of a period at the end of a sentence) and skin marks with semi-permanent ink to mark the treatment field. Do not wash these marks off when you bathe until your radiation oncologist or therapist says that you can. Your doctor will also determine how to position you during your treatment, including your arm position. A special brace or Styrofoam mold may be made to cradle your arm or back in a special position that will hold you securely during each radiation treatment session.

Your simulation visit typically lasts approximately one hour, and you will be lying on a firm surface most of the time. A bolster is often placed under your knees, but the table is very firm under the upper back. This can be uncomfortable. If you have difficulty lying on your back for this period of time, you may want to take some mild pain medication before your visit. Let your doctor know if you have difficulty raising your arm over your head. Stretching to increase the flexibility of your arm before the planning session can help with this. Ask the treatment staff for suggestions if arm mobility is an issue for you. Sometimes a brief course of physical therapy may be needed.

Some women find the process of being analyzed and measured impersonal and feel as if they are being worked on rather than worked with. Treatment planning is a very precise and technical process. Your doctor and the radiation center staff have not lost sight of you, but are concentrating on providing you with the safest and most effective treatment possible.

Whole breast radiation treatments

After you have adequately recovered from prior surgery or chemotherapy, generally about one month, you will begin your actual radiation treatments. If you are receiving whole breast irradiation (WBI), your treatment sessions will occur once a day, Monday through Friday, for three to seven weeks. Your treatment does not need to begin on a Monday, but could start any day of the week. 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 will normally be asked to change into a hospital gown from the waist up. It is best to remove necklaces or other jewelry in the neck and chest area during the radiation treatment (earrings do not need to be removed if they are close to the earlobe). You may then have to wait a bit before being called to the treatment area.

Special technologists trained in the delivery of radiation therapy will position you exactly as planned during your simulation appointment. Your unique radiation therapy treatment plan prescribed by your doctor is followed to deliver the



proper dose of radiation therapy for you each day. A high-energy machine called a linear accelerator will deliver the radiation to your breast, a process called external beam radiation therapy (EBRT). EBRT can be done using several techniques: 3D conformal radiation, or Intensity Modulated Radiotherapy (IMRT) or respiratory gated radiotherapy. The appropriate technique is selected for your treatment by your physician to maximize the safety and effectiveness of the treatment. Factors such as breast size, tumor size and location, chest wall shape, and the closeness of the heart to the treatment area help determine the optimal technique of radiation therapy.

No one can be in the treatment room with you during the actual treatment, but the technologist can hear you through a microphone and see you via television cameras during your treatment. If at any time during your treatment you needed assistance, the therapists can aid or reposition you. The treatment can then be safely restarted right where it left off. You need to remain very still during your treatment, but you do not need to hold your breath unless you are asked to do so as part of your treatment plan. Just breathe normally. You will receive radiation treatment from two or

more different angles so do not be surprised if the treatment machine changes position or stops and restarts during the course of your treatment. The linear accelerator makes a buzzing noise during treatment, and occasionally patients may taste or smell a metallic sensation during radiation treatment even when there is no radiation directed at the head or neck area.

Most of the time in the treatment room is taken up in positioning you for precise treatment using lasers to align you on your tattoo marks. The actual radiation treatment delivery usually takes only 3-5 minutes. Your total time in the treatment room will typically be 10-20 minutes. Approximately once a week during the treatment, x-ray pictures will be taken of the treatment position and checked by your doctor. These pictures verify the accuracy of the treatment, and are not like a mammogram to look for breast cancer. Although it takes just a few minutes to do the EBRT, you should plan to spend about 30 to 45 minutes at the treatment center each day to allow time to change clothes and consult with the doctor or nurse if needed. Most centers will schedule your visits for the same time each day.

After completing several weeks of radiation to the whole breast, you may receive additional EBRT targeting just the area where the tumor was removed. This is called boost radiation. The technologist will adjust the equipment so that the radiation field is much smaller and centered on that part of your breast. Boost radiation may use the same machine as EBRT, so you may not notice this change in your treatment. Boost radiation is administered daily at your usual treatment time, Monday through Friday, for one to two weeks.

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, social workers and dieticians available to help.

Radiation Side Effects

While each woman is unique and will respond differently to breast radiation treatments, there are a number of common side effects that many women experience. The most common short-term side effects are generalized fatigue, breast tenderness and skin changes of the treated breast.

Fatigue

It's hard to appreciate how radiation affects your body. Some women do not report any fatigue during breast radiotherapy, although it is common to have fatigue some of the time during treatment. Every day, the radiation works on both healthy and cancerous cells in your breast, and your body is expending energy as it heals. The effect of this work isn't noticeable at first. Around the third week of treatment, you may notice that you become more tired by the end of the day. Since the healing process continues after you finish your treatments, the fatigue may also continue for several weeks after completing radiation therapy.

Ways to improve your energy level

- Drink plenty of fluids and eat a healthy diet.
- Take a nap in the afternoon.
- Keep physically active even though you have less energy. Try small amounts of exercise. Some physical activity, such as walking, can energize you and help you feel better.
- Find a balance between activity and rest. You will feel most tired during the last few weeks of your treatment, so plan on taking extra time to rest during this time.
- Consider cutting back on extra activities and commitments during these few weeks. Most women continue to work outside the home while undergoing radiation therapy. If you become tired consider adjusting home and work commitments.

- Women receiving chemotherapy before their radiation treatments will feel more fatigued than those receiving only radiation therapy. Make sure to get enough rest so you don't become exhausted. Accept offers of help, such as cooking meals or cleaning your house. Think of what others can do for you, and don't be afraid to ask for help.



Temporary skin changes

At first you may not notice any skin changes. The skin changes of radiotherapy are gradual. Many women notice a tan that can progress over the weeks of radiotherapy to a light pink color similar to sunburn. There can be skin irritation or itching, and topical creams can help soothe the skin. The nurse and physician can help advise you on the best skin products for your particular situation. Don't use any product on your skin during radiotherapy without checking with your care team first. The skin irritation can continue for several weeks following treatment, but gradually improves after you complete treatment. Your breast skin may also become dry or sensitive. You need to be very gentle with the skin in the treatment area during radiation therapy. Your care team will advise you about skin care during the first week of treatment to help with any symptoms you may experience.

Skin care tips

- Take extra good care and avoid irritating the treated skin. Be gentle when you bathe or shower. Do not scrub, scratch or rub the treated area. Use only warm water and a mild soap, such as Dove or pure glycerin, when you wash. Patting the area dry is better than rubbing the area dry.
- Talk with your medical team about how to care for red, dry skin.
- If the area itches, apply a cool compress or one of the gels your medical team recommends.
- If uncomfortable, avoid constricting clothing, including bras. Instead wear something soft and loose, such as a cotton camisole with a “shelf” bra. If you feel you need a bra for support, ask the radiation oncology center nursing staff about what option is best for you.
- Heat and cold can be damaging to the skin. Avoid applying hot items to the area, such as hot packs that can be heated in the microwave.
- Avoid soaking in a hot tub or using a sauna during your treatment.
- Avoid applying ice or very cold items to the treatment area.
- Avoid shaving under your arm on the side of your treatment. If you must shave, use an electric razor.
- Some products such as deodorants, powders, creams, perfumes, body oils, ointments, lotions or home remedies can be irritating to your skin in the treatment area. Avoid such products while you’re being treated and for several weeks afterward. If you have any questions regarding skin care products talk with your doctor or nurse.
- Protect your treated skin from the harmful effect of the sun by wearing comfortable clothing over the treatment area when outdoors. Talk to your medical team about applying sunscreen. Do not use tanning beds as they expose you to the same harmful effects as the sun.

You can also develop another type of skin reaction called a moist reaction. This is caused by friction and irritation where two surfaces rub together. The most common sites are under the breast and the underarm area. When a moist reaction develops, the skin breaks down and becomes sore. If you notice any skin breakdown, talk with your doctor or nurse. They will tell you how to care for this type of skin condition.

Other short term side effects

After surgery or radiation therapy, the breast may be tender, especially when you have a mammogram or when your breast is examined. You may also experience a sharp stabbing or burning sensation occasionally. Muscles in your chest wall under the treated breast may feel tight or sore. These sensations are most common during the first months after surgery or radiation therapy. Such sensations will lessen in intensity and frequency over time.

Radiation therapy usually does not significantly affect your blood count. If you have chemotherapy prior to radiation therapy, your blood count may be monitored.

Lung tissue can rarely become inflamed after radiation treatment to the breast. This condition (called radiation pneumonitis) is not common but can occur within the first few months of treatment. If this happens, you may develop a dry cough, harder time breathing during activity, and possibly a low-grade fever. Radiation pneumonitis will usually go away without treatment. If it persists, your radiation oncologist may prescribe anti-inflammatory drugs to reduce the severity of the symptoms.

Long term side effects

Radiation therapy can cause a change in the feel, look or size of your breast. Breast swelling during treatment is common for the first one to four months. In some cases, your breast may become smaller over time. The shape and size of your breast is mostly determined by the amount and location of tissue removed during surgery. Most breasts are firmer and appear more uplifted after the radiation treatment. You may experience tanning of the breast that can last for months and may be permanent in some cases.

Many women worry that radiation therapy will harm their heart and lungs. With modern radiation therapy techniques specifically designed to minimize or eliminate radiation exposure to the heart, these risks are very small. If you are concerned about this, or have a history of heart disease, discuss your concerns with your radiation oncologist.

You are at greater risk of developing lymphedema (swelling of the hand or arm) if you have a lymph node dissection in the underarm area and then have radiation therapy to the underarm area where lymph nodes are located. This is caused by fluid that can build up when lymphatic channels under the arm are blocked by scarring caused by breast cancer surgery or radiation. For additional information about lymphedema prevention and treatment, refer to the “Surgery Options and Postoperative Care” section of this notebook.

Fortunately, serious side effects of radiation therapy for breast cancer are very uncommon. On rare occasions, radiation treatment to the breast can cause a second cancer to develop in the treated area later in life. It is important to realize that this risk is extremely small and for most patients is far outweighed by the benefits of treating your breast cancer.

Accelerated Partial Breast Irradiation

Accelerated partial breast irradiation (APBI) is an alternative to standard whole breast irradiation. Not all women are suitable candidates for this. One of the benefits of APBI is that APBI reduces the treatment area from the whole breast to the tissue surrounding the lumpectomy site, the area the cancer is most likely to reoccur. In addition, APBI requires fewer treatment sessions compared to WBI reducing the time and travel burdens of radiation treatments. With APBI, the radiation dose is concentrated to the tissue surrounding the lumpectomy cavity, sparing much of the breast tissue and critical organs such as the heart and lung from radiation. The best way to determine if APBI is a good choice for you is to discuss this with your surgeon and radiation oncologist. There are a number of ways of administering APBI.

APBI can be delivered using external beam radiotherapy. Treatments are delivered using the linear accelerator, two times a day for five days.

The more common forms of APBI use a technique called “brachytherapy,” in which a catheter is inserted into the breast with the tip in the space where the tumor was removed. The radiation only travels a very limited distance. Several of the most common types are listed below.

Strut Assisted Volume Implant (e.g. SAVI brachytherapy consists of a device that is made up of a bundle (7-11) of soft, tiny plastic catheters (struts) that can be adjusted to conform to your lumpectomy cavity. The radiation dose is adjusted for each individual’s needs by varying the placement of the radiation source in each of the catheters.

Balloon Devices are forms of brachytherapy that use a catheter (tube) that has a balloon on the end. The balloon end of the catheter is placed in the breast where the tumor was removed. The balloon is filled with sterile water to hold it in place. Balloon devices can contain a single catheter, or several catheters in which the radiation source can be placed.

The treatment administration is similar for both these types of APBI. After your lumpectomy, your surgeon and radiation oncologist will review your pathology report, and if appropriate, the option of APBI will be discussed with you. If you agree to this treatment, your surgeon will insert the device in the lumpectomy cavity. This procedure usually occurs about one to three weeks after your lumpectomy. Commonly the device will be inserted in your surgeon's office. You will be awake and able to talk during the insertion procedure. After injecting a local anesthetic, your surgeon will insert the device. The tip of the device that will contain the radiation source will be positioned in the space where the tumor was removed; the end of the catheter extends outside the breast. A CT scan will be performed to determine the position of the catheter and to help with treatment planning. The radiation therapy treatment will take place in the radiation oncology center. The radiation oncologist will determine the appropriate dose for you. The radiation dose is administered by attaching the end of the catheter that is outside your breast to a machine. The machine places the radiation pellets inside the catheter. The treatments take 10 to 20 minutes. When the treatment is completed the machine removes the radiation pellets. Treatments take place twice a day, at least six hours apart, for five days.

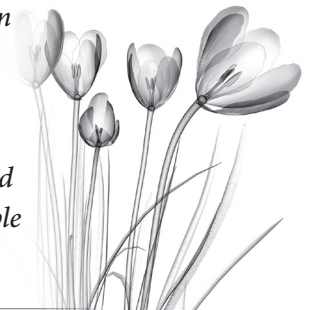
Intraoperative Radiotherapy (IORT) is a newer technique that delivers a single radiation treatment in the operating room during your breast surgery. While a woman is still under anesthesia, a special applicator is placed into the area of the breast where the tumor has just been removed. The radiation treatment is given through the applicator within the breast. The whole treatment lasts about 30 minutes. The goal of this therapy is that no additional radiation treatments will be needed. However in some cases external beam irradiation may still be needed. This will depend on your pathology results. Since this treatment occurs at the same time as your lumpectomy, you will meet with your radiation oncologist prior to surgery.

With all types of APBI there is less exposure of healthy breast tissue to radiation, so you will typically experience less fatigue, less redness of the skin, less burning of the skin and less skin discoloration. Side effects associated with APBI include increased wound infections, increased seroma formation (swelling of the breast) and a risk of developing fibrosis of the breast.

APBI is a quicker way to give radiation treatments; however, not all patients are suitable for APBI and not all centers provide all types of APBI. The best way to determine if APBI is the best treatment for you is to discuss it with your surgeon and radiation oncologist. If your physician refers you for brachytherapy, you will be provided with additional information at that time.

What happens when radiation treatments are over?
Once you have finished radiation therapy you will have follow-up care for a number of years. This will consist of check-ups with your radiation oncologist and your other physicians. During your check-up appointments, your radiation oncologist will talk to you about how you are feeling, examine the treated area, answer any questions and respond to your concerns.

You have gone through a great deal being diagnosed with breast cancer and going through your treatments. Give yourself some time to heal physically and emotionally. Often, as treatment is ending you have time to participate in support programs offered at your cancer center or in the community. This notebook has suggestions and you can ask your nurse about programs and resources that are available to assist in your recovery.



Clinical Trials

Because of research, we have better and more effective breast 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 women with breast 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 women feel that participating in a clinical trial gives them an opportunity to help other women with breast 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 breast cancer. Clinical trials are available for prevention, treatment and symptom management of breast cancer.

Breast cancer clinical trials can be sponsored by the National Cancer Institute, cancer cooperative groups, nonprofit organizations, pharmaceutical companies and device companies. Most breast 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).



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 this document 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.

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 form. You can change your mind about participating in the clinical trial at any time after signing the informed consent form. To stop your participation in a study, talk to your research team.

More Information on Clinical Trials

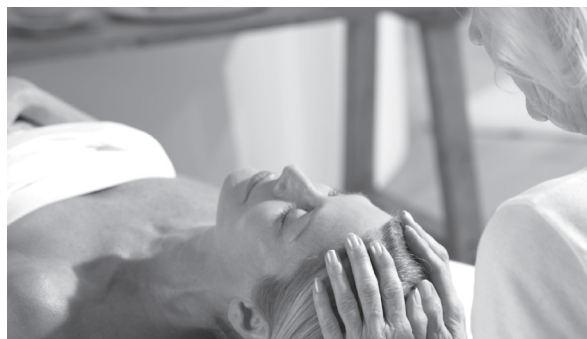
For more information on government-sponsored National Cancer Institute (NCI) trials, you can contact the NCI at 1-800-4-CANCER or you can find a comprehensive list of NCI-sponsored studies at <https://clinicaltrials.gov>. You can search for clinical trials available within the Sutter Health network at <https://www.sutterhealth.org> (look for the Research section). You can also ask your doctor or health care team for specific information regarding clinical trials available in your area.

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 out integrative therapy practitioners who have specialized training in cancer care and who have experience in working with people who have been diagnosed with cancer and who 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. Please discuss with your massage therapist how much pressure is appropriate. Lighter pressure is usually better to start with. It is important to note that while massage can be extremely therapeutic, if done incorrectly or by an inexperienced practitioner, it can cause harm.

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 Anti-Oxidants

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 “Breast Cancer 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 and with 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, and 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 cognitively 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 and 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.
- Always do a skin test with new oils. When using an oil for the first time, it's important to do a skin test on a small area of skin.
 - Spread a little bit on 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 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

For women who are usually the predominant caregivers, 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 breast 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 physician’s 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. Let this person know that the greatest gift they can give you is to 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
 - Baby-sitting children, taking them to and from school and evening activities
 - Offering to arrange play-dates 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 or books on tape/audio recording.
 - *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.
- **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.
- **I Can Cope:** is available at the American Cancer Society website *Cancer.org*, I Can Cope is a free educational program made up of self-paced classes on general support and treatment topics that can be taken online, any time, day or night.

There are a number of online social support resources that can help you organize your personal support team. These resources make it easier for you to decide what you want to share with family and friends. Please don't forget to check the “Resources” section of this binder for additional help.

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, not knowing what to say, and they may remain silent or stop telephoning you. It's a good idea to reach out to your friends to open 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 feel and 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. We do not want them to worry or be afraid. It may be difficult to decide when and how much to share with your children.

Consider your child's age and maturity, and what you believe your child can handle as you communicate with them.

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 more help 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 “Wellness” chapter of this binder 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 women with breast cancer may experience prolonged anxiety and depression. This is not unusual. The fear of cancer reoccurring is also a natural and very powerful response. After a cancer experience, your sense of self may be altered. You may feel fearful, anxious or uneasy. Know that over time you will regain a sense of well-being. It is important to open to 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 breast cancer patients to experience grief and sadness during their diagnosis and treatment. 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, tell your doctor, nurse navigator or social worker. 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 hot flashes 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 CD or recording, relaxing music, or to 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. Some things you may want to discuss while you are still feeling well include:

- *Advance Directive* is a legal document that contains written instructions specifying the type of future medical treatment to be used in the event you become unable to speak for yourself. Examples of advance directives include a Living Will and A Durable Power of Attorney for Health Care. Both of these documents let you decide ahead of time how you want to be treated.
- *Durable Power of Attorney for Healthcare* 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 the things that you would choose if you were making these decisions 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.



Wellness Throughout Your Journey

Your body will undergo many changes and stresses during your treatment and recovery period. Leading a healthy lifestyle before, during and after cancer treatment, and knowing what to expect, will help make your journey easier.

Nutrition

Good nutrition is a vital part of cancer treatment and survivorship. Healthy eating can improve your strength and energy levels, increase tolerance of side effects, help to maintain a healthy weight, decrease risk of infection, promote healing and lower breast cancer risk. Eating the right foods before, during and after treatment is important for recovery. Be aware that your treatment plan may affect your appetite.

Basic Dietary Guidelines

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

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

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



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

- **Eat fiber rich foods:** Fiber is the part of food that cannot be digested and is found in fruits, vegetables, whole grains and legumes. Start with Vegetables first. You should aim to eat 30 to 35 grams of fiber per day. Increase your fiber intake slowly and make sure to increase your fluid intake too.
- **Avoid processed foods and those high in sugar:** Eat whole foods that are minimally processed when possible 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.
- **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. Women who maintain a healthy weight after treatment are less likely to have their cancers reoccur and less likely to develop new breast cancers. If you are underweight, you may want to increase your portions of healthy foods to gain weight gradually.
- **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 <https://www.nongmoproject.org/>.
- **Soy:** Soy is an excellent source of plant based protein and contains healthful nutrients such as B-vitamins, iron, calcium and isoflavones. However concern has been raised that soy acts as a plant based estrogen and the effect on women who have breast cancer has been unclear. 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, but including 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.

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. 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 (<http://www.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.

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 (which are detailed elsewhere in this binder). 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. Discuss with your physician 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, as well as 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
 - Difficulties that may be experienced caused by the cancer or treatments.
 - 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 breath exercises, guided imagery or meditation to reduce any stress you may have.
- Prioritize your tasks, scheduling important things early in the day. Set alarms, keep lists, 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; you may get good support. 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 July 2017):

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

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- 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

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- 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

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- 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

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- 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/>)

See the “Resource” section. 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.”

Menopause

- For patients who have received chemotherapy, most women who are 40 years or older will stop their menstrual periods and only five to 25 percent will resume regular menstrual periods. Approximately 40 percent of women younger than 40 will stop their menstrual periods while on chemotherapy, 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.
- Menopause symptoms are commonly experienced by women receiving treatment with Tamoxifen or aromatase inhibitors regardless of age or menopausal status.
- *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, chamomile tea or teas that contain valerian 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. 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.

Osteoporosis

Osteoporosis is a condition common among postmenopausal women and is characterized by a decrease in bone mass and density. This causes the bones to become more fragile and increases the risk of hip and other fractures. Estrogen has a protective effect on bone; however, women produce less estrogen after menopause, which can lead to bone loss.

Women who have been treated for breast cancer may also be at increased risk for osteoporosis for several reasons:

- Loss of ovarian function due to surgery or chemotherapy will cause estrogen levels to drop.
- Chemotherapy may cause bone loss.
- Breast cancer itself may actually stimulate the production of osteoclasts, (cells in the body that break down bone).
- Side effects from some hormonal therapies, such as aromatase inhibitors, can cause bone loss.

Osteoporosis Risk Factors

- Gender
- Age
- Body size
- Ethnicity
- Family history of the disease.
- Being postmenopausal or having had early menopause
- Prolonged use of certain medications, such as steroids
- Low calcium intake
- Lack of physical activity
- Smoking
- Excessive alcohol intake

Management Strategies

- **Nutrition:** a well-balanced diet rich in calcium and vitamin D is important. Talk to your doctor about calcium supplements and whether you need them to meet your daily calcium requirement.
- **Exercise:** the best exercises for your bones are weight-bearing exercises that force you to work against gravity, such as walking, stair-climbing and dancing.
- **Smoking and alcohol:** smoking is bad for bones, as well as the heart and lungs. Smokers may actually absorb less calcium from their diets. Alcohol can also negatively affect bone health. People who drink heavily are more prone to bone loss and fracture.

Bone density testing: Bone mineral density testing should not be confused with nuclear bone scans. They are two very different types of imaging. Bone mineral density (BMD) tests measure bone density in various sites of the body. These tests can detect osteoporosis before a fracture occurs. They can also predict your chance of having a fracture in the future. Discuss with your doctor whether you need this testing.

- **Medication:** there is no cure for osteoporosis. However, medications are available for the prevention and treatment of the disease.

For more information, contact the National Institutes of Health, Osteoporosis and Related Bone Diseases National Resource Center at 1-800-624-BONE or OsteoInfo@oste.org, or the National Cancer Institute (NCI).

Survivorship Care Plan

One resource that may help you is a Survivorship Care Plan or Treatment Plan. This document will 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 doctor only once a year.
- You will need yearly mammograms on the non-cancerous breast and the cancerous breast if it was treated by lumpectomy.
- You should have yearly pelvic examinations if you are taking Tamoxifen due to the increased risk of uterine cancer.
- You should consider regularly testing your bone density if you are taking an aromatase inhibitor, since it blocks estrogen in the bones.
- 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 will need to have your heart function monitored if you are on Herceptin. Your oncologist will let you know how often testing needs to be done.

Long Term Side Effects and Fear of Cancer Coming Back

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. Some long-term side effects from surgery, chemotherapy, hormonal therapy and/or radiation therapy include:

- Lymphedema (swelling in the limbs)
- Headaches
- Skin changes
- Fatigue
- Pain in armpit or chest
- Heart problems
- Lung problems
- Menopausal symptoms including hot flashes, vaginal discharge or dryness, sleep problems, weight gain, hair thinning, mood changes and/or fatigue
- Bone loss
- Pain and numbness (peripheral neuropathy)
- Early menopause for pre-menopausal women
- Musculoskeletal symptoms affecting the joints, bones, muscles, ligaments, tendons or nerves
- Osteoporosis (weakening of the bones)
- New cancers
- Cataracts
- Blood clots
- Dental issues
- Sexual difficulties
- Infertility
- Concerns about memory loss and cognitive function (“chemo brain”)

These and 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 breast cancer recurrence:

- Changes to the skin of your breast
- Skin inflammation or area of redness, pain, heat, and swelling
- Nipple discharge
- A new area of thickening along or near the mastectomy scar
- A new lump or irregular area of firmness
- Lump or swelling on or under the skin of your chest wall
- Lump or swelling in the lymph nodes located under your arm, near your collarbone, in the groove above your collarbone or in your neck
- Persistent and worsening pain, such as chest or bone pain
- Persistent cough
- Difficulty breathing
- Loss of appetite
- Weight loss
- Severe headaches
- Seizures
- Or any other new, unusual and/or persistent symptoms

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

Intimacy & Sexuality

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 changes in the breasts.

Surgery, medication, and radiation therapy can cause problems for sexuality and intimacy. The most common sexual problems faced by women treated for breast cancer are vaginal dryness and thinning of the vaginal tissues leading to pain during penetration, decreased desire for sex, and reduced ability to orgasm. Medication side effects like nausea, vomiting, fatigue, urinary tract and vaginal infections can also cause a lack of energy and decreased sense of wellness. Some women may experience menopausal symptoms like hot flashes, sleep disturbances, and irritability from changes in hormone levels when undergoing systemic therapy or taking hormonal therapy. Surgery can result in pain and altered body image. Radiation therapy can result in skin changes and sensitivity to touch in the radiated area. 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 breast 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(s) 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. An easy way to maintain closeness is to have your partner help you with simple arm exercises after your breast surgery. You will be instructed to do light stretching exercises to maintain your range of motion (refer to the Surgery and Postoperative Care section of this book). Doing your 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. 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. For women with 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.
- 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 menopausal treatment.

The booklet, *Sexuality for the Woman with Cancer* 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, www.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.

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 every-day 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 will 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	
General Information	
Patient Name:	
Patient ID:	
Phone:	
Date of Birth:	
Health Care Providers	
Medical Oncologist:	
Surgeon:	
Radiation Oncologist:	
Primary Care Physician:	
Gynecologist:	
Cancer Diagnosis Information	
Tumor Type/Histology/Grade:	
Diagnosis Date:	
Staging Information:	
Cancer-Related History:	
Genetic Information:	
Recurrent Site:	
Toxicity/Usual:	
Alcohol/Drug Use:	
Treatment Summary	
Surgery:	
Chemotherapy:	
Endocrine Therapy:	
Radiation Therapy:	
Persistent symptoms or side effects at completion of treatment:	

SAMPLE

Treatment Summary and Survivorship Care Plan for Breast Cancer

General Information	
Patient Name:	
Patient ID:	
Phone:	
Date of Birth:	
Health Care Providers	
Medical Oncologist:	
Surgeon:	
Radiation Oncologist:	
Primary Care Physician:	
Gynecologist:	
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:	
Endocrine Therapy:	
Radiation Therapy:	
Persistent symptoms or side effects at completion of treatment:	

Follow-up Care Plan

Your follow-up care plan is design to inform you and primary care providers regarding the recommended and required follow-up, cancer screening and routine health maintenance that is needed to maintain optimal health.

Possible late- and long-term effects that someone with this type of cancer and treatment may experience:

Weakening of the heart presenting as shortness of breath and swelling of legs (rare < 5%); and bones become weak and at risk for fracture (osteoporosis). It is important to remember that these symptoms can be due to other causes like diabetes or with normal aging. If these or any other new symptoms occur bring these to attention of your health care provider.

These symptoms should be brought to the attention of your provider:

1. Anything that represents a brand new symptom;
2. Anything that represents a persistent symptom;
3. Anything you are worried about that might be related to the cancer coming back.

Please continue to see your primary care provider for all general health care recommended for a woman your age such as routine immunizations, and routine non-breast cancer screening like colonoscopy or bone density exams. Consult with your health care provider about prevention and screening for bone loss using bone density tests.

Schedule for Clinical Visits

Coordinating Provider	When/How Often

Cancer Surveillance Or Other Recommended Tests

TEST	How Often
Mammogram	
MRI Breast	
Pap/Pelvic Exam	
Colonoscopy	
Bone Density	

Breast cancer survivors may experience issues with the areas listed below. If you have any concerns in these or other areas, please speak with your doctors or nurses to find out how you can get help with them.

- | | | |
|---|---|---|
| <input type="checkbox"/> Anxiety or depression | <input type="checkbox"/> Insurance | <input type="checkbox"/> Sexual functioning |
| <input type="checkbox"/> Emotional and mental health | <input type="checkbox"/> Memory or concentration loss | <input type="checkbox"/> Smoking cessation |
| <input type="checkbox"/> Fatigue | <input type="checkbox"/> Parenting | <input type="checkbox"/> Weight changes |
| <input type="checkbox"/> Fertility | <input type="checkbox"/> Physical functioning | <input type="checkbox"/> Other |
| <input type="checkbox"/> Financial advice or assistance | <input type="checkbox"/> School/work | |

A number of lifestyle/behaviors can affect your ongoing health, including the risk for the cancer coming back or developing another cancer. Discuss these recommendations with your doctor or nurse:

- | | | |
|---|---|--|
| <input type="checkbox"/> Alcohol use | <input type="checkbox"/> Management of my other illnesses | <input type="checkbox"/> Tobacco use/cessation |
| <input type="checkbox"/> Diet | <input type="checkbox"/> Physical activity | <input type="checkbox"/> Weight management (loss/gain) |
| <input type="checkbox"/> Management of my medications | <input type="checkbox"/> Sunscreen use | <input type="checkbox"/> Other |

Resources you may be interested in: www.cancer.net

Prepared by _____ Provided by _____ On _____

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 in 2018, the information contained in this Healthcare Finances section is current. However, healthcare financing is in an uncertain state, and this information may not remain current.

Once diagnosed with breast 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.

Nurse navigators, social workers, and financial counselors are available to you at Sutter Health to assist you in finding the financial support you need.

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 <http://cancerlegalresources.org/publications-webinars/financial-publications/> and then clicking on that specific document .



Covered California

Covered California (www.CoveredCa.com) is the marketplace established for legal residents of California to purchase medical insurance as mandated through the Affordable Care Act. Many Californians will not need this website as they have obtained their medical insurance through their workplace, or have Medicare, or 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 (www.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.

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 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 www.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 their actual checklist at www.cancerinsurancechecklist.org/site/wp-content/uploads/2015/10/cancer_coverage_checklist_tabloid_dk-changes-03.pdf.



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 house or car insurance in that different policies cover different types of benefits. It is important to fully understand what your policy covers.
- 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,” not a brief overview or informational brochure. This document may have a number of 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.
- 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.* They include 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 if you find it useful.
- 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 coordination and answers to 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 an Insurance Claim is Denied

If you have health insurance and a particular claim is denied, you can take the following steps to resolve the problem:

- In all interactions with the insurance company about a claim, keep copies of all correspondence and note the claim number and policy or procedure code on all correspondence. Also note the name of any customer service or claims representative spoken with on the telephone.
- Call the insurance company to find out why the claim was denied. If it is still unclear, study the explanation of benefits form. In some cases, the denial may be the result of a claim being improperly documented, such as a particular service being inadvertently omitted.
- Check the facts. Review the policy to make sure that pre-certification, authorization and other procedures required by the insurer were followed. For example, claims for prosthetic bras, implants and wigs require a copy of both the prescription and the bill.
- Enlist a doctor’s help if fees, charges or procedures are questioned. Most physicians and their staff are experienced in working with insurance companies and can help answer questions. Ask the physician to write a letter to the insurance company documenting and/or justifying the charges, and be sure to keep a copy.
- If the claim is denied because the insurance company states that a particular treatment is experimental or under investigation, enlist a physician to provide assistance. If he/she can give the insurance company evidence that the scientific literature supports the use of a particular therapy for a particular patient, then the procedure cannot technically be labeled as experimental.

To accomplish this, ask the doctor to help obtain peer review study reports and support letters from other oncologists performing the same procedure. National patient support organizations can also help.

- Ask for a formal review of the denied claim. Often, claims that were denied initially are paid in subsequent reviews. If this fails, ask for an appeal of the review using outside oncology experts to review the medical records and claim.
- If these steps fail to yield reimbursement for a claim that a patient and her physicians believe is justified, a final recourse would be to contact a lawyer. National patient support organizations can help identify lawyers in each state who specialize in cancer-related insurance issues.

Information courtesy of the Susan G. Komen Breast Cancer Foundation, www.komen.org or 1-800- I'M AWARE® (1-877-465-6636)



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.
- 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 www.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 www.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.
- For further information contact your employer or call SDI directly at 1-800-480-3287 or visit www.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, 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 www.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. See the end of this section for resources.

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 www.cancercare.org.

Financial Assistance for Breast and Cervical Cancer Screening and Diagnostic Services

As of 11/1/17 women less than 40 with symptoms are eligible so eliminate.

CDP: Detection Programs: Every Woman Counts 1-800-511-2300. This program from the California Department of Health Services offers free breast and cervical cancer screening exams and necessary diagnostic procedures to women who qualify by age and income. California residents may enroll in the program through numerous clinics and some doctor’s offices statewide. Information about the program and referral to local health care providers may be obtained by calling the 800 number listed above. Assistance is available in six languages – English, Spanish, Mandarin, Cantonese, Korean and Vietnamese.

Women who live in one of 16 Northern California counties (Butte, Colusa, Del Norte, Glenn, Humboldt, Lake, Lassen, Mendocino, Modoc, Napa, Plumas, Shasta, Siskiyou, Sonoma, Tehama and Trinity) may also call the Northern California Breast and Cervical Cancer Partnership for assistance at 1-800-682-2282. Partnership staff provide helpful, client focused assistance with aspects of breast and cervical cancer screening, diagnosis and treatment.

To qualify for Cancer Detection Programs: Every Woman Counts, women must be:

- A California resident
- 40 years or older for breast screening and diagnostic services or under 40 years if symptomatic
- Un-insured or under-insured

Please be sure to call 1-800-511-2300 for updated guidelines.

Income Criteria for California’s Cancer Detection Programs: Every Woman Counts

All patients must have a household income at or below 200 percent of the poverty guideline. “Household income” includes the income of family members (spouse, children, parents, brothers and sisters) living together. Poverty guideline level incomes are adjusted on an annual basis. “Gross income” means before taxes and other deductions. More information can be found at <http://www.dhcs.ca.gov/>.

The following are guidelines from April 1, 2017 - March 31, 2018.

Family Members Living in Household	Monthly Gross Household Income	Annual Gross Household Income
1	\$2010	\$24,120
2	\$2707	\$32,480
3	\$3403	\$40,840
4	\$4100	\$49,200
5	\$4797	\$57,560
6	\$5493	\$65,920
7	\$6190	\$74,280
8	\$6887	\$82,640
For each additional member add:	\$697	\$8,360

The Breast Cancer Patient Navigation and Support Project (1-888-921-7465)

The Patient Navigation and Support Project is operated through the California Health Collaborative. The Project provides practical support and financial assistance to ensure early detection of breast cancer, access to care and treatment compliance. Participation in the project is available to uninsured, low-income patients who are diagnosed with breast cancer or those with breast

symptoms not eligible for the CDP: Every Woman Counts or other government programs. An English-Spanish bilingual Care Coordinator provides Project participants with emotional support, linkages to and coordination with a variety of financial and supportive services, guidance in securing coverage for treatment, and educational materials.

Financial Assistance for Breast and Cervical Cancer Treatment

California Department of Health Services, Breast and Cervical Cancer Treatment Program (BCCTP)

The federal Breast and Cervical Cancer Treatment Act was signed into law in 2000 as a result of grassroots efforts among cancer survivors and their families. California’s BCCTP is funded by state and federal matching funds to pay for breast cancer treatment for women or men and cervical cancer treatment for women who qualify by income. You may get more information by calling the Northern California Breast-Cervical Cancer Partnership at 1-800-682-2282.

You must enroll in BCCTP through the same providers who administer the Cancer Detection Programs: Every Woman Counts program and Family Pact Program (FPACT). This program offers Medi-Cal coverage during cancer treatment for those eligible. Applicants who do not meet federal requirements may still qualify for State-only BCCTP. Assistance may be available for those individuals who qualify financially and who have a high share of cost. Call 1-800-824-0088 for clarification regarding BCCTP benefits.

Once enrolled, participants may receive a letter informing them they must enroll in a Medi-Cal Managed Care plan. Talk with your doctor’s office staff if you receive such a letter about what options are best for you.

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: www.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: www.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: <http://www.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: www.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: www.pparx.org. Helps locate assistance programs from pharmaceutical companies.

Co-Pay Relief Program

Call 1-866-512-3861 or email *visit* www.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: www.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, check the white pages of your local telephone book.

Veteran's Administration

Call 1-877-222-8387. Web site: www.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.

Insurance Advocacy

California Department of Insurance Consumer Hotline 1-800-927-4357. Web site: www.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: www.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: www.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 www.cancerlegalresources.org E-mail: CLRC@dlrcenter.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.

Patient Advocate Foundation

See entry listed above in “Insurance Advocacy” section.

Utility Bills

Low Income Energy Assistance Program (LIHEAP)
Call 1-866-674-6327 or visit www.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

Call 1-800-743-5000. Offers utility discounts based on medical needs. Also, CARE at 1-866-743-2273. Monthly discounts for income-eligible customers.

REACH (Relief for Energy Assistance through Community Help)

Call 1-800-933-9677. 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

Most telephone phone companies have reduced rates based on low income or medical necessity. Call your phone company 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.

