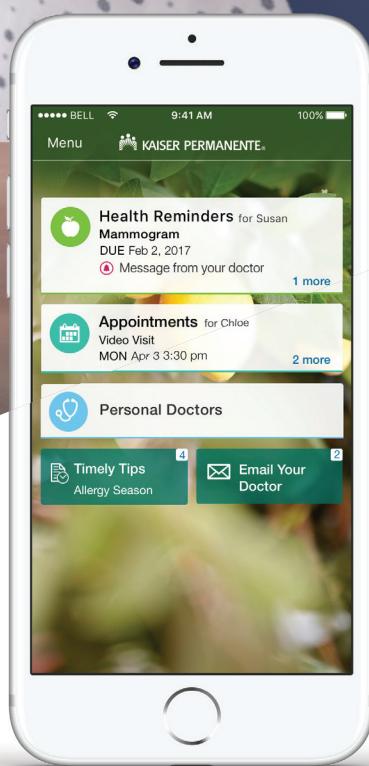




Breast Cancer Care Multi-disciplinary Clinic

Santa Clara Medical Center



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This booklet is provided to help explain breast cancer and its treatment. It is not intended to provide medical advice, and does not replace any information or advice provided by your doctors and medical staff. Any trade names listed are for easy identification only.

Produced by the Santa Clara Medical Center Cancer Care Committee, 2018.

Illustrations by Chris Topper; christopperart.com

Introduction

Kaiser Permanente's Comprehensive Cancer Care Program is dedicated to supporting you throughout your breast cancer treatment. Your primary doctor will continue to see you for your routine medical needs. In addition, you will have a cancer care team who are specialists in advanced cancer treatments, including a medical oncologist, a surgeon, and a radiation oncologist. The best outcomes occur when patients are fully involved in decision making throughout their treatment process. Everyone's cancer experience is unique and treatment decisions will be made to best fit your personal circumstances. Your care team is looking forward to

answering your questions, providing you with clear information, and helping you to remain positive throughout your treatment.

This booklet describes the range of breast cancer diagnoses and treatments. Not all of the topics here will apply to you. We hope it will help to guide you through your individual experience and our services. You may wish to bring this booklet with you to doctor appointments to keep your information handy and your notes in one place. Medical terms that are not defined in the text are listed in the glossary at the end of the booklet.

*Your Kaiser Permanente
Cancer Care Team*

Santa Clara Medical Center



Medical Office Building
710 Lawrence Expressway
Santa Clara, CA 95051

Cancer Treatment Center
3800 Homestead Road
Santa Clara, CA 95051

My Doctor Online



My Doctor Online (MDO) is Kaiser Permanente's website. MDO contains a broad range of information about breast cancer, cancer treatments and other health topics. Creating your own MDO account will give you an easy way to interact with your doctors and care team. If you are not already registered with MDO, please follow the simple steps shown below to set up your own confidential, secure account.

kp.org/mydoctor

My Doctor Online

To set up your own MDO account:

- Go online to **kp.org/mydoctor**
- Select the “**sign on**” option in the top selection bar.
- If you do not have a user name and password to sign on, select **Register here**.
- Select English or Spanish language
- And continue to the following page where you will choose, **“I have a Kaiser Permanente plan and want to use online services.”**
- The website will then guide you through the simple process of signing on to My Doctor Online.
- If you have any questions, please call Member Website Support at **1-800-556-7677**.

Only you can access communications with your doctor and your personal medical information using your secure MDO account.

Highlighted information boxes appear in this booklet to help you access related videos on the MDO website. You will see the term “Emmi” in many video titles. Emmi is a term that describes a type of computer program used to create the videos. The easiest way to access a video on the MDO website is to enter a search for the video title; for instance, “Understanding Breast Cancer Emmi” will take you to that online video.

Understanding Breast Cancer

online video

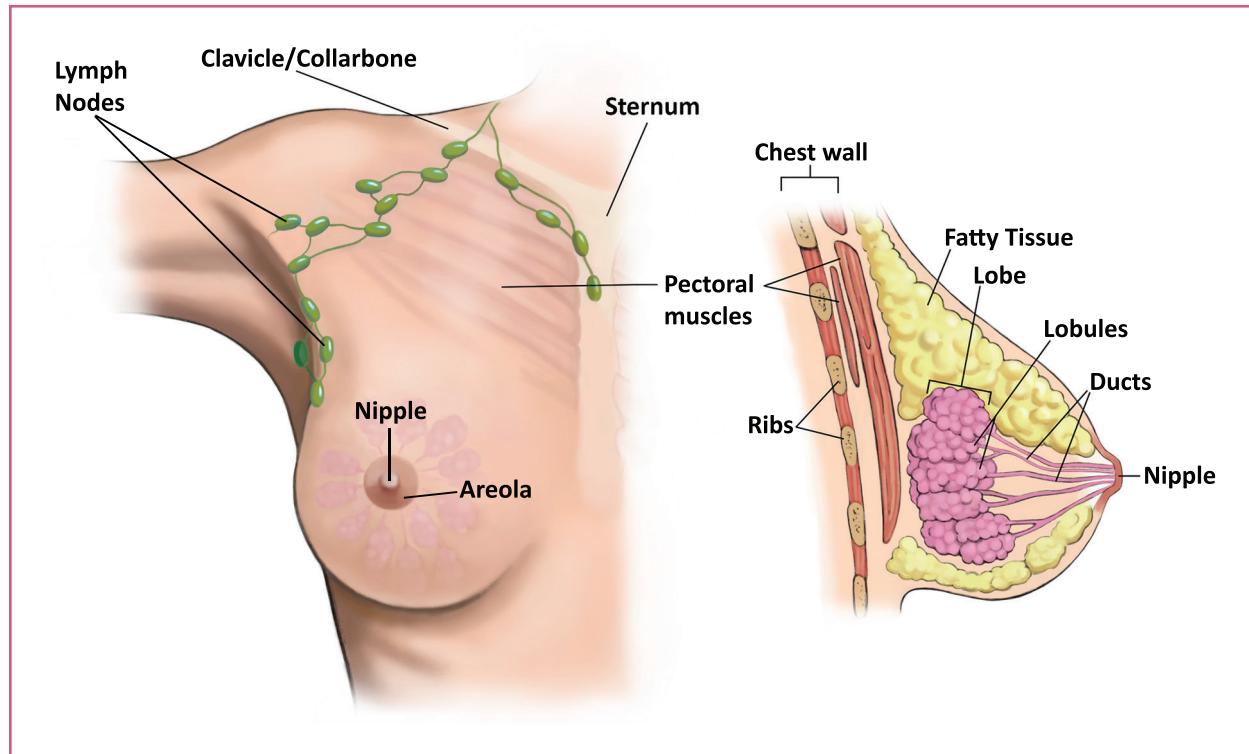
**kp.org/mydoctor, search for
“Understanding
Breast Cancer Emmi”
or go to
kpdoc.org/breastcancerprogram**

Anatomy of the Breast

The female breast is the mammary gland, which creates milk to feed infant children. The breast lies atop the woman's pectoral (chest) muscles over the upper rib cage and below the clavicle (collar bone). It is made up of milk-producing lobules that are clustered into lobes and ducts that carry the milk to the nipple. The dark circle of skin surrounding the nipple is called the areola.

Dense breast tissue can make cancer detection more difficult. Breast density is a term that describes how much of the breast is glandular and how much of it is fatty tissue. Breasts that are more dense, have an increased risk of developing cancer.

Anatomy of the breast

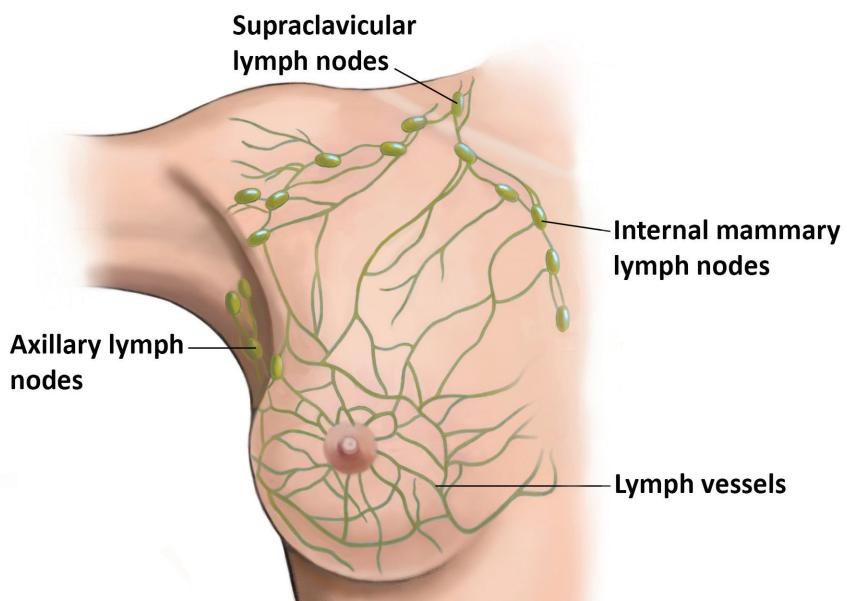


The Lymphatic System

The lymphatic system is a network of vessels and nodes that carry lymph fluid throughout the body as part of the body's immune system. Lymph nodes are bean sized structures clustered at various locations around the body that filter lymph fluid to remove toxins. Illness and disease often cause lymph nodes to enlarge, swell, or harden and sometimes can be felt under the skin. Some lymph vessels and nodes are contained in the

breast and are closely connected with lymph nodes located in the under arm (axilla) area. Lymph nodes in the axilla are called axillary lymph nodes. Lymph nodes just above the collar bone area are referred to as supraclavicular lymph nodes. Lymph nodes in the inner chest area are called internal mammary lymph nodes. Cancer can spread from the breast to these lymph nodes through the lymph system.

Lymphatic system of the breast



Breast Cancer

Approximately 1 in 8 U.S. women (about 12%) are estimated to develop breast cancer over the course of their lifetime. Eighty percent of women with breast cancer are more than 50 years of age. Ninety-nine percent of breast cancers occur in women and about 1% occur in men. The diagnosis and treatment choices for men and women are essentially the same.

Breast cancer is the most common form of cancer diagnosed among women. Almost all breast cancer types are called adenocarcinoma (cancers that originate in glandular tissue). Breast cancer most often develops in the walls of the ducts or in the milk-producing lobules.

Tumors occur for unknown reasons when cells multiply and gather to form an identifiable mass. Some types of tumors are benign or non-malignant, and are noncancerous. Others are malignant, or cancerous. Unlike benign tumors that don't invade surrounding tissues, cancerous tumors can invade nearby tissues and spread to other parts of the body. Cancer cells can spread through neighboring tissue, the lymph system, and the blood stream. When cancer has spread to other parts of the body, it is called metastatic cancer.

Breast Cancer Risk Factors

It is not clear what causes breast cancer. Most women who develop breast cancer have no known history of cancer and no significant risk factors for cancer. Breast cancers are likely caused by a combination of factors that may include family history (genetics), life style activities (e.g. smoking or drinking alcohol), and environmental factors such as exposure to certain chemicals or toxic materials. Women who have had breast cancer in one breast are at higher risk of developing another breast cancer, either in the same breast, or in the other breast.

Breast cancer in men

While breast cancer in men is rare, risk factors include:

- Age 60 and above
- Family history of breast cancer
- A rare genetic disorder (Klinefelter's syndrome) that causes overproduction of estrogen
- Radiation to the chest



Genetics and Gene Mutations

Some gene mutations inherited from family appear to increase the risk of breast cancer. DNA makes up the genes that control every cell's behavior. About 1 in 10 breast cancer cases show changes in genes from parents and family heritage. Your doctor will collect a medical history from you about your background and your knowledge of medical conditions of your ancestors. This helps determine whether your risk for hereditary breast cancer warrants genetic testing. Doctors may involve the expertise of genetic counselors. Advances in genetic research have enabled identification of some of these genes, like BRCA1 and BRCA2. Mutations of these and other genes have been found to increase the likelihood of developing breast cancer.

Types of Breast Cancer

When cancer tissue is examined under a microscope, the pathologist determines the kind of cancer cells and their characteristics. This tells us whether or not the cancer is invasive. Invasive cancers have the ability to grow beyond the original duct or lobule and can spread to other parts of the body. Most breast cancers are the invasive type, though most have not spread beyond the breast when the cancer is first discovered.

Non-invasive breast cancer is also called *in situ* cancer, which is limited to its original location (e.g. duct walls). These cancer cells do not spread to other places. They do not metastasize.

Less common breast cancers include: inflammatory breast cancer, invasive pleomorphic lobular carcinoma, medullary cancer, metaplastic carcinoma, mucinous carcinoma, and Paget's disease of the nipple.

Types of Breast Cancer

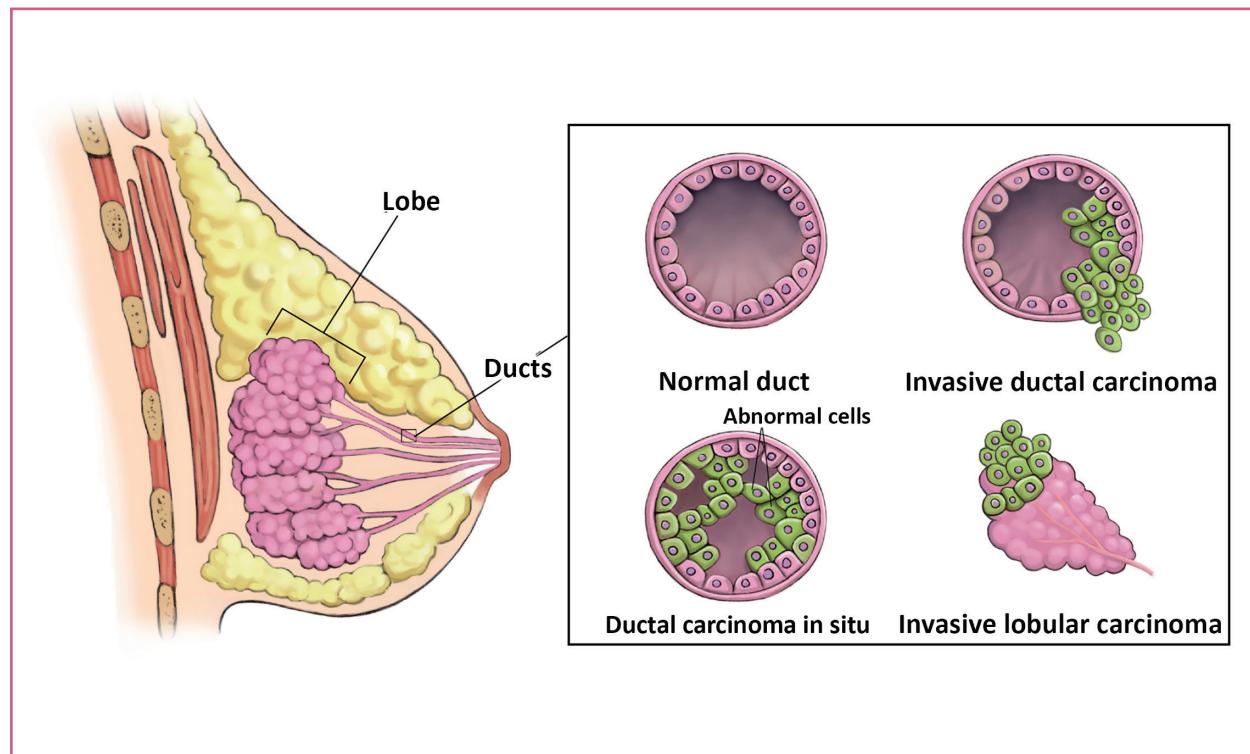
Invasive ductal carcinoma is cancer that originates in a breast duct, grows through the duct wall and can spread to other tissues. About 80% of all breast cancers are invasive ductal carcinomas.

Ductal carcinoma in situ is non-invasive cancer cell growth that is confined to the breast duct. While this is a non-invasive cancer, it is treated similarly to invasive cancer.

Invasive lobular carcinoma is cancer that originates from a breast lobule. Approximately 10% to 15% of breast cancers are of this type.

Lobular carcinoma in situ is non-invasive cancer cell growth that is confined to the breast lobules. LCIS is not considered a true cancer and is often called lobular neoplasia. It is, however, a marker for increased risk of developing breast cancer. Treatments include observation over time with regular screening and hormone therapy for risk reduction, or in rare cases, removal of both breasts as a precaution (bilateral prophylactic mastectomy).

Invasive and in situ carcinomas



Breast Imaging

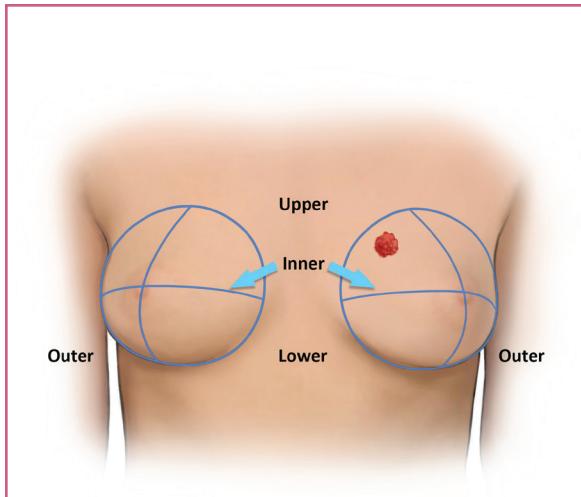
The Women's Imaging and Mammography Department plays a vital role in screening for, diagnosing, and treating breast cancer.

Mammograms

Mammograms are X-ray imaging of the breast and are the standard screening test to look for breast disease. It is often the first indicator of abnormal or cancerous tissue growth. Mammograms can often find abnormalities before they are felt. Women usually have mammograms every 2 years after age 40, or annually for women who are at higher risk of developing breast cancer.

Ultrasound

Ultrasound scans are used to produce images of the breast and nearby lymph nodes. The scanning equipment produces sound waves and their echoes are processed into images. Ultrasound scans are often used in combination with a mammogram to target specific areas of concern and to help determine whether a tissue is abnormal.



Identifying the location of the cancer tissue

The cancer tissue diagnosis identifies the tumor location. The description includes labeling the parts of the breast containing the tumor, such as the inner, outer, upper, and lower parts of the breast. Inner refers to the side of the breast closest to the center of the chest. Outer refers to the side of the breast closest to the arm. Upper and lower describe whether the tumor is located in the upper half of the breast or the lower half. The part of the breast containing the cancer tissue is labeled a quadrant. The spot above would be identified as being in the "upper, inner quadrant of the left breast."

Breast Imaging

Sometimes there is a need for additional imaging. The following techniques may or may not be used, depending on the particular circumstance of the patient.

Magnetic Resonance Imaging

MRI scans acquire detailed images that help to assess the size of a tumor and to identify other abnormalities in the breast. MRI scans use a combination of sound and magnets. The breast MRI involves lying face down on an exam platform that is moved into a large circular machine. A contrast dye is injected into a vein so that more detail can be seen in the images.

Computed Tomography

CT is often used to look for disease that has spread outside the breast. CT scanners use X-ray scans from different angles to create detailed images. A contrast dye may be used so that features can be seen more clearly.

Bone Scan

Bone scans seek to determine if cancer cells have travelled to the bones. Before the scan, a radioactive substance is injected into a vein. This substance collects in cells that are growing faster than normal. The bone scan will show spots where the substance has collected. These spots would be considered worrisome for possible metastatic cancer.

Positron Emission Tomography Scan

PET scans, similar to the bone scan, are used to look for metastatic cancer spread to other areas of the body. The procedure involves an injection of a radioactive substance into a vein so that images show where it collects in the body. It is often done together with a CT scan.

Diagnosing Breast Cancer

Physical exams of the breast and regular mammograms are the first and primary evaluations to detect possible breast cancer. A diagnosis of breast cancer can be made when a pathologist examines tumor tissue using a microscope. The process of taking the tissue sample from the breast is called a biopsy. The pathologist determines whether the cells appear normal, atypical, or cancerous. A diagnosis of cancer is made if there are cancer cells present in the biopsy sample. There are different methods used to acquire breast and lymph node tissue samples. They include fine needle aspiration, core needle biopsy, and surgical biopsy.

Needle Breast Biopsy

online video

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Diagnosis Emmi”

Diagnosing Breast Cancer

Fine Needle Aspiration Biopsy

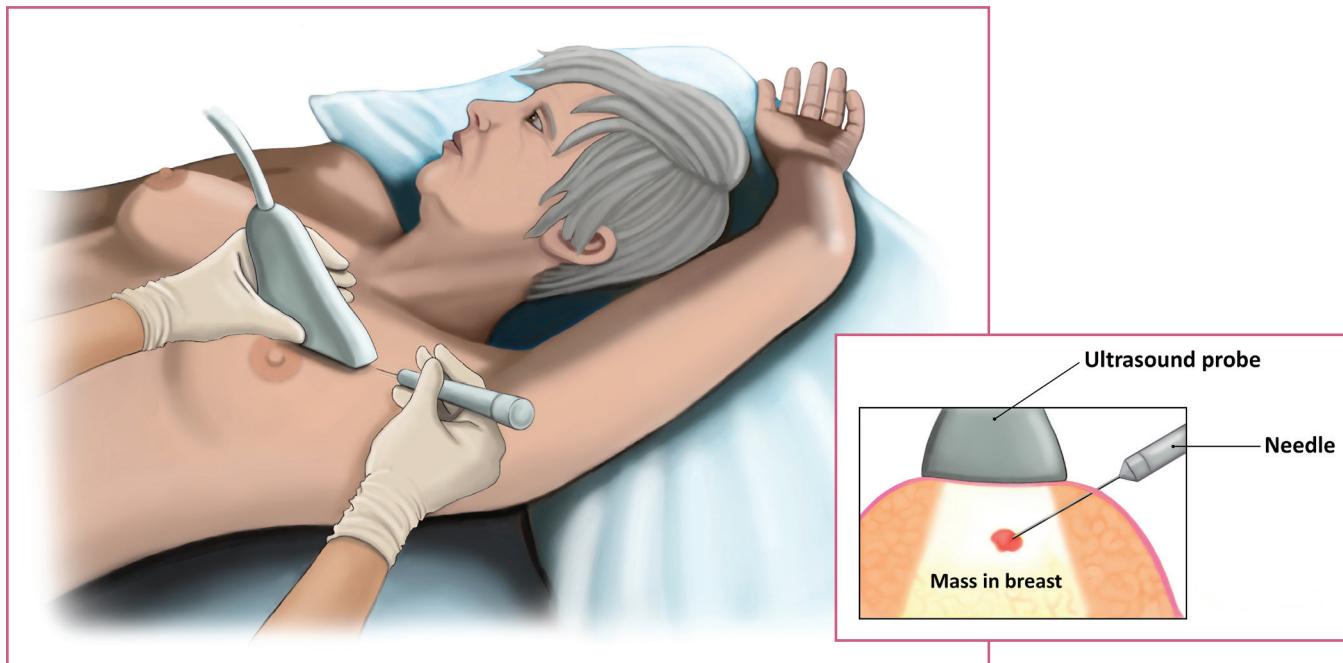
Fine needle aspiration (FNA) is sometimes used to examine suspect, or abnormal tissue, that is palpable (felt by touch) under the skin. A very fine needle is inserted into the breast to obtain a small sample of cells from the identified area. While FNA may show some abnormal cells, this method is unable to discern anything about the surrounding tissue structure. For this reason, it is not commonly used.

Core Needle Biopsy

A large hollow needle is commonly used to acquire tissue samples when an abnormality is found in the breast (either by imaging or by touch). This is a good way to get definitive results.

The core needle is inserted into the suspect tissue and a slight suction pulls tissue into the needle. The needle may be inserted numerous times to collect several samples. The exact location of the suspect tissue can be found using multiple mammogram exposures taken from two different angles. This is called stereotactic biopsy. Ultrasound-guided biopsies can also be performed where the radiologist uses ultrasound imaging to help locate the tissue to be sampled. Often, at the time of these image-guided core needle biopsies, a tiny metal clip is placed at the biopsy site to mark the site for future mammograms. The tiny clip is made of surgical-grade metal that you will not feel. The clip remains in place and should never cause any problems.

Ultrasound assisted biopsy



Diagnosing Breast Cancer

Surgical Biopsy

A surgical biopsy may be needed if FNA or core needle biopsy cannot be done, or if those samples are insufficient to make a diagnosis. When the lump can be identified by touch, the tissue can be removed using an open excisional biopsy. The surgeon makes an incision over the lump, just large enough to excise (remove) the tissue. When the surgeon is not able to easily feel the abnormality, imaging scans are used to locate the suspect tissue. Mammogram or ultrasound scans guide the radiologist as a needle is inserted to the site seen in the images. The needle leaves a wire attached to the tissue when the needle is withdrawn.

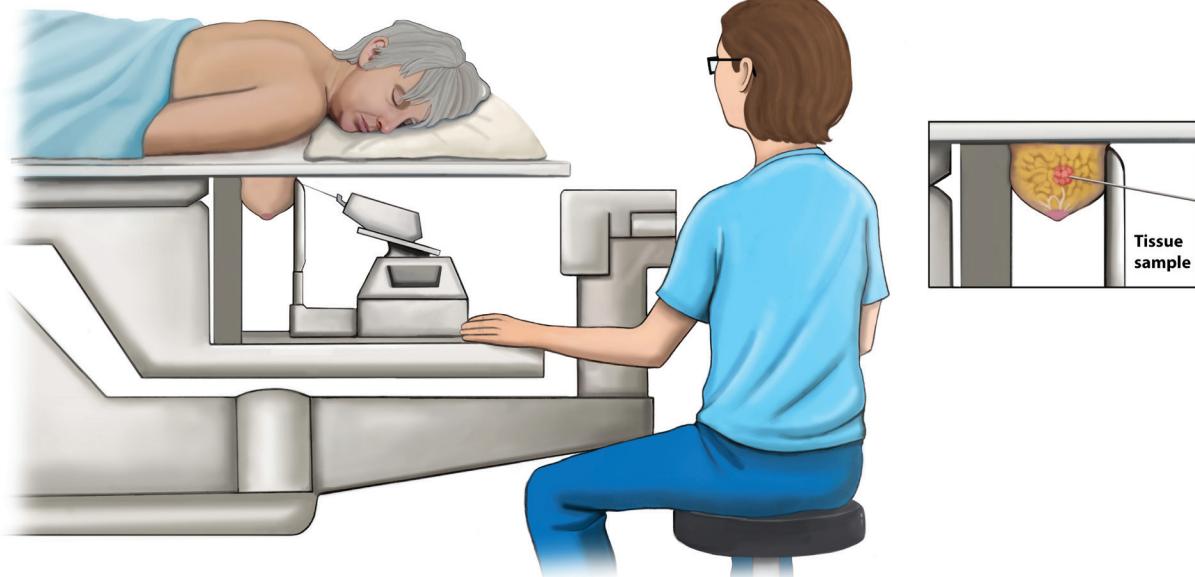
Alternatively, a specialized marker may have already been placed at the site of the tissue, removing the need to use a wire. The wire or marker then guides the surgeon to the tissue to be excised. This is called an excisional biopsy after a wire, or needle localization. The needle localization and wire insertion is done in the Women's Imaging and Mammography Department. The patient then goes to the operating room for surgery. The patient can return home the same day.

Surgical Breast Biopsy for Diagnosis

online video

kp.org/mydoctor, search for
“Surgical Breast Biopsy for
Diagnosis Emmi”

Stereotactic biopsy



Pathology

The pathologist examines all tissue removed from the breast and generates a report. The pathology report identifies the characteristics of the cancer cells, including the cancer cell grade and its hormone receptor status. We want to know how large the tumor is, how fast it may be growing, and whether cancer has spread to lymph nodes. This is vital information about the cancer that will guide treatment decisions.

Grade

The cancer cell grade is identified by comparing the appearance of the cancer cells to that of normal, healthy cells under the microscope. Normal cells have clearly defined internal structures and cell walls.

Cancer cells have deformed cell structures. A grade number indicates how different the cancer cells appear compared to normal cells. The higher the grade number, the more deformed are the cancer cells and the more aggressive the cancer is likely to be.

- **Grade 1** – Cancer cells appear similar to normal cells and are called well differentiated.
- **Grade 2** – Cancer cells have some cell structure change and are called moderately differentiated.
- **Grade 3** – Cancer cells are very deformed and are called poorly differentiated.



Pathology

Hormones and Hormone Receptors

Hormones are chemicals made by the body that stimulate or give instructions to cells in various organs. Estrogen hormone governs the development of female sex and reproductive organs. Progesterone hormone governs a woman's reproductive system including menstruation, pregnancy, and embryo development. The presence of these hormones often encourages the growth of breast cancer cells.

One feature breast cancers share is the presence or absence of hormone receptors on the cancer cells. Receptors are structures that allow hormones to

attach to the cancer cell. Some cancer cells may have receptors for only estrogen or only progesterone. Some may have receptors for both hormones. Some cancer cells do not have receptors for either of these two hormones. Cancer cells with receptors for estrogen are labeled as "ER +," or estrogen receptor positive, and cancer cells with receptors for progesterone are labeled "PR +," or progesterone receptor positive. Most breast cancers are hormone receptor positive. Cancer cells that do not have receptors for estrogen or progesterone are hormone receptor negative and therefore do not respond to hormone therapy as a treatment.





Human Epidermal Growth Factor Receptor Type 2 (Her2)

Her2 (also referred to as Her2/neu) is another receptor that is found in many cells in the body, including some breast cancer cells. Some breast cancer cells have a genetic alteration that causes them to make too many Her2 receptors. This is called over-expression of Her2 receptors and causes these cancer cells to grow and multiply. These cancer cells are more aggressive and are more likely to spread.

- **Her2 positive** – Cancer cells have over-expressed Her2 receptors. About 1 in 5 women with breast cancer are Her2 positive.
- **Her2 negative** – Cancer cells do not have too many Her2 receptors and therefore cannot be treated with drugs that target Her2 proteins.

Oncotype

Oncotype is a genetic test of the patient's breast cancer tissue that can help predict the risk of breast cancer recurrence. The test results will also help to decide if chemotherapy treatment should be used. The test might be performed if your breast cancer has been determined to be stage I or II and estrogen receptor positive (to be treated with hormone therapy), Her2 receptor negative, and lymph node negative.

The test result is a numerical score which is then categorized as low, medium, or high risk of recurrence after local treatment (surgery with or without radiation). This score will guide the recommendation on the benefit of chemotherapy. If this test is useful to your circumstance, it will be discussed with you by your oncologist.

Triple Positive and Triple Negative

Cancer cells that are ER+, PR+, and also Her2+, are called triple positive. These cancer cells can be treated with both hormone drugs and drugs targeting Her2. Cancers that have none of these receptors are called triple negative. These cancers do not respond to hormone treatments or targeted therapy for Her2.

Pathology Report

The following is a snapshot of your pathology report for you to fill in. This information may be collected over time and may be revised if more information is obtained. The first column is for details of your initial biopsy report. The second column reflects characteristics reported after your surgery.

My report says I have _____ type of cancer.

Initial Biopsy Report

(Core needle or excisional biopsy)

Date: _____

Cancer grade _____

Tumor size _____

Margins _____

Hormone receptors are:

ER (+ / -) _____

PR (+ / -) _____

Her2 status (+ / -) _____

Oncotype score _____

After Surgery Report

Date: _____

Cancer grade _____

Tumor size _____

Margins _____

Hormone receptors are:

ER (+ / -) _____

PR (+ / -) _____

Her2 status (+ / -) _____

Oncotype score _____

Lymph nodes contain cancer:

Yes _____ No _____

Staging



All cancers are characterized by categories called stages. Staging is important because it describes the extent of disease and because it is our best predictor of survival. The designation takes into account the size of the tumor (T), the extent of lymph node involvement (N), and whether the cancer has metastasized to distant parts of the body (M). The tumor size (T) is identified from 0 - 4 as tumor size increases. Lymph node involvement (N) is also expressed as 0 - 4 as more lymph nodes are affected by the cancer. Metastasis (M) is usually identified as no spread of cancer (M0), or cancer spread to other parts of the body (M1). Staging revisions can occur as more information is gathered.

Stage 0 Called carcinoma in situ. The cancer tissue is confined to the inside of a milk duct or lobule and has not spread from its original location.

Stage I The cancerous tumor has not spread beyond the breast to lymph nodes or other locations. The cancerous tumor is 2 centimeters (cm) or less in size. Two centimeters is about the same length as 3/4 of an inch.

Stage II The cancerous tumor is 2.1 cm to 5 cm in size (3/4 inch to 2 inches) or has spread to a nearby lymph node. Usually, only one of these conditions must be met for it to be classified as stage II disease.

Stage III This is also known as locally advanced cancer with the tumor being 5.1 cm (2 inches) or larger or it has spread to numerous neighboring lymph nodes or into the chest wall, muscles, or skin. Inflammatory breast cancer is also classified as Stage III cancer.

Stage IV The cancer has spread beyond the breast area and beyond nearby lymph nodes to distant organs, such as the lungs, liver, brain, or bones.

Treatment Options

Once breast cancer has been diagnosed and we understand the type of cancer, you will have decisions to make about how you want to proceed. The goal of treatment is to cure whenever possible, and if not possible, to ensure the longest and best quality of life. Most breast cancer patients will receive some kind of surgery. Many will receive some radiation therapy and some may receive systemic treatments, such as chemotherapy, hormone therapy, or targeted therapy. All treatment plans are prepared to fit your individual cancer, your medical needs, and your personal goals and circumstances.

"You are the main decision maker and the key person on your medical team. Stay involved. It's a sign of health."

You will meet members of your care team in the Breast Cancer Multi-disciplinary Clinic. Before your clinic meeting your test results and other diagnostic information will have been discussed by a team of providers including a surgeon, a medical oncologist, and a radiation oncologist. You and your doctors will discuss details of your breast cancer and their treatment recommendations. We encourage you to bring your primary support person to this meeting.

My Treatment Journey

Examples of Treatment Progression

1. Surgery first, then Chemotherapy, then Radiation, etc.



2. Chemotherapy first, then Surgery, then Radiation, etc.



Write in your own plan of treatment.



Surgery

Surgery is the primary local treatment used to physically remove cancer from the breast. The goal of surgery is local control of the cancer by removing all cancer cells to prevent return of cancer at that same location. The surgery may be a lumpectomy, where part of the breast is removed, or a mastectomy, where the entire breast is removed. The removed breast tissue is sent to pathology for examination and testing.

Your doctor or breast care coordinator will discuss your pathology report with you, as soon as it is available. The pathology report will provide more information about your cancer and will guide further treatment. It may take 1 - 2 weeks to get the results.

Treatment Information

online video

kp.org/mydoctor, search for
**"Treatment Options
for Early Stage,
Invasive Breast Cancer Emmi"**



Treatment Options

Lumpectomy

Lumpectomy is a surgical procedure to remove the cancer and some normal tissue surrounding the cancer, called the margin. It is also referred to as breast conservation surgery. Lumpectomy leaves the breast largely intact. On the day of surgery, if the cancer cannot be located by touch, the radiologist uses mammogram or ultrasound imaging and a needle to insert a wire into the breast at the site of the cancer. This is called wire or needle localization.

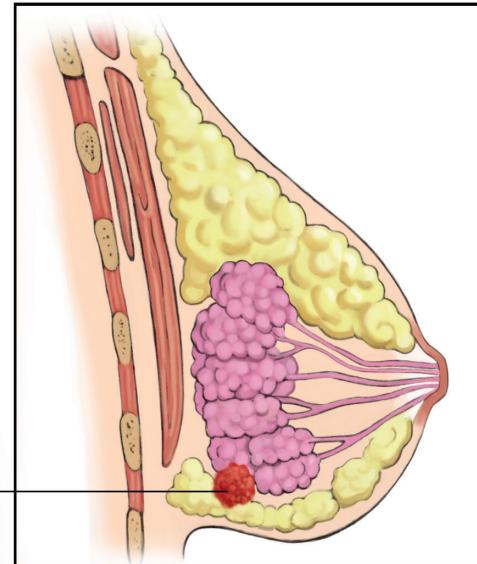
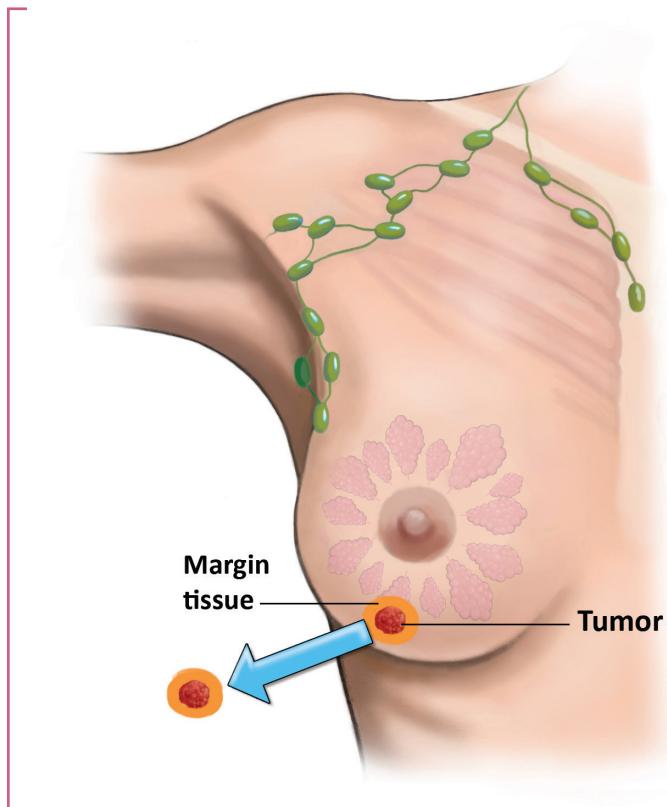
Alternatively, a specialized marker or clip may be placed at the site of the tissue, replacing the need for a wire. The wire or marker then guides the surgeon to the targeted tissue. At the time of surgery, the surgeon uses the wire or marker to locate the cancer tissue for lumpectomy. The patient is normally

Lumpectomy

online video

kp.org/mydoctor, search for
“Lumpectomy Emmi”

Lumpectomy





provided with sedation and local anesthesia or general anesthesia. Most patients go home the same day. Patients often receive radiation therapy after the incision from surgery has healed. The combination of lumpectomy and radiation therapy lowers the risk of local cancer recurrence.

Margins

Surgery removes (excises) the tumor and some normal tissue that surrounds the tumor. The normal tissue is called the margin. A pathologist examines the excised margin tissue to determine if cancer is present. Margins that show no cancer are called negative margins. Positive margins show cancer cells at the edge of the margin tissue. This suggests that there may still be cancer tissue in the breast. If this is the case, further surgery (called re-excision) may be needed to establish clear, or cancer-free margins.

Surgical and Healing Support Programs

Prepare for Surgery Video

kp.org/mydoctor, search for
“Anesthesia for an Adult Emmi”

Imagery for Surgery, Healing, and Other Meditation Audio Podcasts

kp.org/podcasts

“Prepare for Surgery – Heal Faster” Workshop

Phone: 408-851-2399



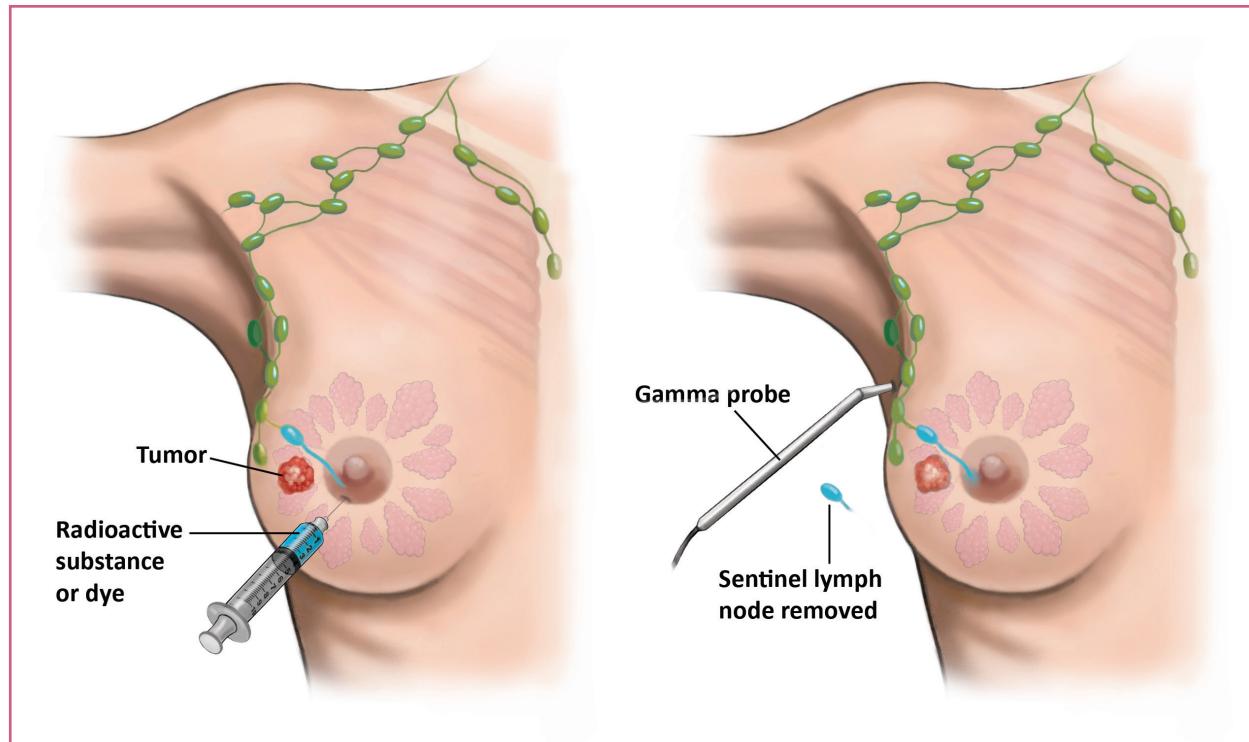
Treatment Options

Sentinel Lymph Node Biopsy

Almost every patient with invasive breast cancer will have a sentinel lymph node biopsy (SLNB). The SLNB is often done at the same time as a lumpectomy or a mastectomy. The biopsy is a way to see if cancer has spread from breast tissue to nearby lymph nodes. During this procedure a small amount of radioactive substance, or dye (often both) is injected into the breast close to the nipple. The radioactive substance and dye travel to and collect in the lymph nodes associated with the breast. These are called sentinel lymph nodes (SLNs). For some people there may be just one SLN, and for others there may

be several. A probe is used to sense the location of the radioactive substance under the skin. A small incision is made in the skin and the lymph nodes containing the radioactive substance are removed. The SLNs are examined by the pathologist. If cancer cells are found in the SLNs it means the cancer cells have spread outside of the breast, at least to the SLNs. This information is critical to determine further treatment plans.

Sentinel lymph node biopsy

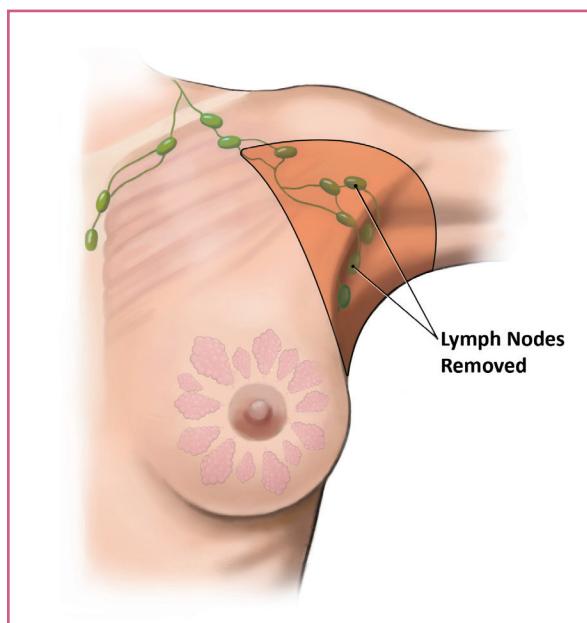




Axillary Lymph Node Dissection

If cancer cells are found in the sentinel lymph nodes, then cancer cells have traveled into the lymph system and possibly to other parts of the body. More lymph nodes may need to be removed to assess how many lymph nodes are involved. To do this, the surgeon may remove most of the lymph nodes in the axilla. This is called an axillary lymph node dissection (ALND). Not everyone with positive sentinel lymph nodes will need an ALND. This procedure is sometimes done in connection with a lumpectomy or mastectomy. The procedure is done under general anesthesia and most patients will leave the hospital the same day with a drain in place for removing fluid that gathers in the surgical wound following surgery.

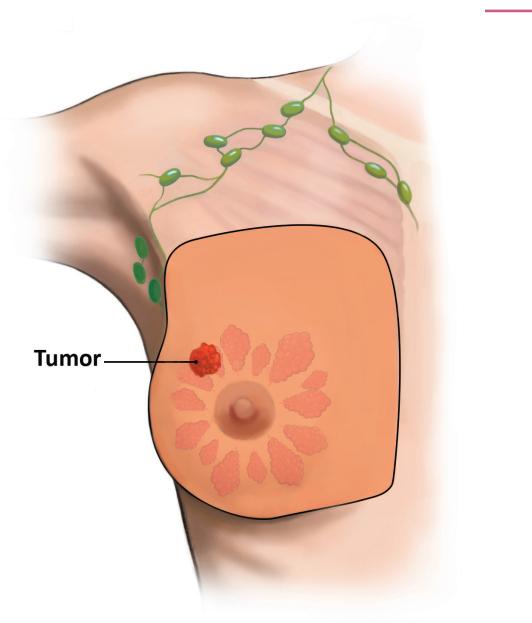
Axillary lymph node dissection



Mastectomy

Mastectomy, also referred to as total or simple mastectomy, is a surgical procedure that removes nearly all of the breast tissue. A mastectomy is the surgical alternative to a lumpectomy. Both are done to achieve local control of the cancer. Most of the skin is left in place but the nipple is often removed. Mastectomy may be recommended for the patient when a tumor is very large, or if there are multiple tumors in a breast, or if the cancer involves a large portion of the breast. Some patients may choose mastectomy after considering all of the treatment options. The mastectomy procedure requires general anesthesia. Many patients leave the hospital the following day with a drain in place to collect normal post-surgery fluid.

Total mastectomy

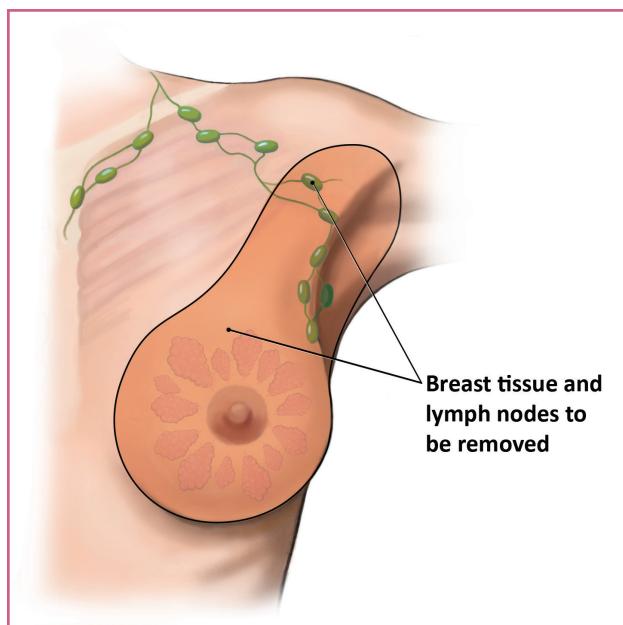


Treatment Options

Modified Radical Mastectomy

A modified radical mastectomy removes the entire breast and some amount of associated lymph nodes. The procedure consists of a simple mastectomy plus an axillary lymph node dissection. This is different from what used to be called a radical mastectomy, which included removing chest wall muscle. A radical mastectomy is now considered excessive and unnecessary surgery, and therefore is no longer done.

Modified radical mastectomy



Prophylactic Mastectomy

Prophylactic mastectomy is surgery to remove one or both breasts even if there is no information showing the presence of cancer. Removing tissue of one or both breasts reduces the chances of developing breast cancer in the future. It is not a guarantee that cancer will not occur. We encourage you to fully understand the potential benefits and consequences of this procedure.

Mastectomy

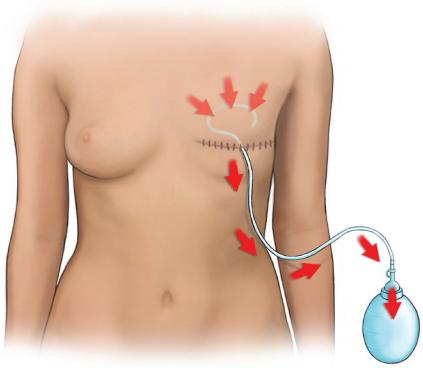
online video

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"Mastectomy Emmi"

Closed Bulb Care

online video

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"Closed Bulb Drains Emmi"



JP (Jackson Pratt) Drain Tube and Bulb Drain Care

Fluid normally collects after surgery where tissue has been removed. This is a normal part of recovery.

A drain tube is placed during surgery that will draw away the fluid as it accumulates. The tube will extend out from your chest area to a small collection bulb. Sometimes a person can have more than one drain.

When the bulb fills with fluid, you will empty the drain. Your care team will guide you on how to empty the drain. You might do this once or twice a day. The fluid may initially contain some blood and will gradually become clear to a more watery appearance.

The tube has a one-way valve, so fluid cannot back up into your surgery site. It should not be painful, but it will probably be somewhat uncomfortable.

Your doctor will remove the tube when the fluid buildup decreases. This is usually done in clinic several days or sometimes as much as several weeks after surgery.

After Surgery Instructions

- After a lumpectomy, wear a well-fitted and supportive bra for 1 week or longer, even during the night.
- After a mastectomy, wear a loose-fitting camisole.
- Rest quietly through the day following surgery. The next day be more active by walking and only very gentle stretching. Walk more each day.
- You may apply cold packs to the breast area to help minimize pain.
- If you have gauze bandaging you may remove the gauze after 2 days.
- You may shower 2 days after surgery or when your surgeon instructs you to do so. If you have a surgical drain, avoid getting the drain wet.
- If you have glue or steri-strips on your skin, allow them to fall off on their own in about 1 - 2 weeks.
- Many people are constipated after surgery. Get plenty of fluid and fiber.
- Do not drive if you are taking narcotic pain medication.

Treatment Options

Recovering from Surgery

With either a mastectomy or a lumpectomy you will be given detailed post-operative care instructions. You will have a post-operative appointment within 7 - 10 days after surgery with either your surgeon or breast care coordinator. She or he will check your wound healing, review your pathology report, and discuss next steps. It is the goal of your care team to make sure you heal as quickly and as painlessly as possible. Each person recovers at a different pace. You may be able to return to work in a few days or several weeks, depending on the kind of surgery performed, the work that you do, and your recovery.

Side Effects of Surgery

Side effects of surgery vary among patients and largely depend on the type of surgery performed. Most women will experience some pain following surgery and may need pain medication for several days. Some women experience pain or significant discomfort for a longer duration. It is normal for fluid to accumulate (seroma) where tissue has been removed. Your body will slowly absorb the fluid. Other typical experiences after surgery include feeling tired and fatigued. Skin covering the breast area may be discolored or gradually feel hard. The hard tissue may last for 3 - 6 months. This is the incision healing and the formation of scar tissue.

Some will have numbness in the breast, skin, axilla, and upper arm from the surgery which tends to improve over several weeks.

Many women may feel out of balance following a mastectomy, or even after a large lumpectomy. This can cause discomfort with muscles of the shoulder and neck. You may be uncomfortable, or even dislike the appearance of the breast area after surgery. Be sure to communicate your impressions and feelings to your care team.





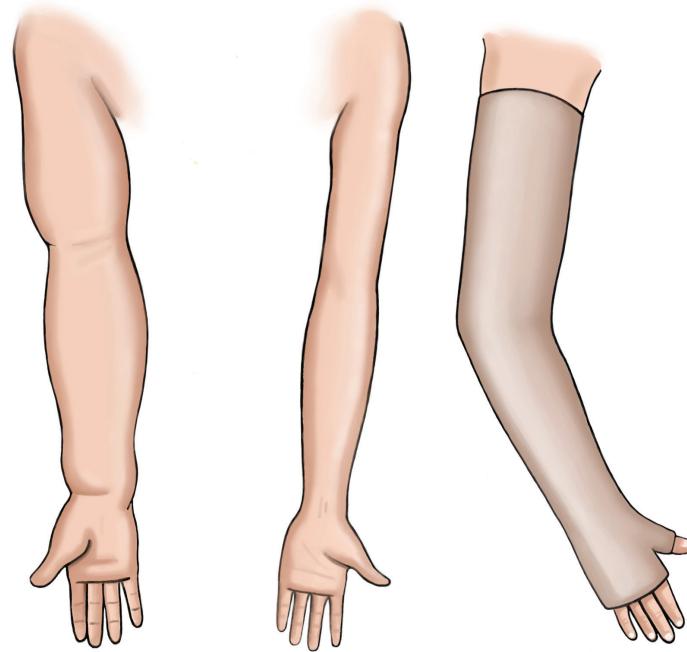
Lymphedema

Lymphedema is swelling in the arm or chest caused when the lymphatic system does not work properly. When lymph nodes are surgically removed or irradiated, it is more difficult for the lymphatic system to do its job. This makes lymphedema a potentially serious side effect of breast cancer treatment. Lymphedema can develop at any time, shortly after your cancer treatment or later. Some people will develop lymphedema and some will not. It is important to not use your arm too much or too soon after surgery, to

minimize the chances of developing lymphedema. (See the following Activity Guidelines regarding arm movement and lifting.) Watch for signs of lymphedema as you resume use of your arm, including arm swelling, heaviness, aching, fatigue, generalized numbness, and tingling. If you think you are developing signs of lymphedema, you should be referred to a lymphedema physical therapist to help manage the symptoms. Lymphedema is managed with the use of compression garments, manual lymphatic drainage, specific exercises, and care of the skin.

Lymphedema arm comparison:

Swollen arm at left, normal arm center, swollen arm with compression sleeve at right.



Treatment Options

Post-Surgery Garments

Women scheduled for mastectomy (and sometimes for lumpectomy) will receive two breast surgery camisoles, a breast prosthesis (artificial breast form) and three prosthetic bras that hold the breast forms in place. Camisoles are soft undershirts that can be worn immediately following surgery. They can be used to help with the adjustment period after surgery and before you are fitted for a breast prosthesis. They come with soft breast forms and pockets to hold the surgical drain.

If you choose not to have reconstruction surgery, you can use a breast prosthesis to create the appearance of a breast shape. They come in many sizes, shapes, and weights. They are made with silicone gel, foam, or fiberfill interior.

Your breast care coordinator will provide you with a prescription and a list of places where breast prostheses and prosthetic bras can be purchased. You may have a co-pay with some products. To learn what your plan coverage provides, you may drop-in to any Member Services office or call them at **800-464-4000**.



Breast Prosthesis

Kaiser Permanente will prescribe a breast prosthesis every two years, or when medically necessary. This may be due to significant weight change, or changes in breast size, shape, etc. Three prosthetic bras are provided every 12 months.

All replacements for covered products are ordered by calling Kaiser Permanente's Durable Medical Equipment (DME) Department directly. You can reach DME at **877-317-6231**.



Physical Therapy

Physical therapy services can be very helpful as you cautiously return to activity. After your surgery, talk with your doctor about a possible referral to the Physical Therapy Department for post-surgery rehabilitation. Surgery and radiation treatments for breast cancer often leave physical effects that will take time to heal and return to normal. You may experience decreased upper body strength, weakness in the arms and shoulders, impaired movement, and swelling in the arm and shoulder on the side of the body being treated. These conditions can limit your return to work and your routine activities. Physical therapy is often started after your surgical incisions have healed. The physical therapist will determine appropriate exercises to help alleviate these conditions. Seek advice about what exercises are safe before experimenting on your own.

Every patient's treatment course is different. We encourage you to begin moving very gently after surgery. Be aware of feeling your physical limits and do not strain yourself beyond simple movement. Your range of movement and strength will return over time. On the next page are some general guidelines for movement and physical activity.

Breast Cancer Rehabilitation Class

The Physical Therapy Department holds a single-session class to discuss the management of lymphedema. There is no copay or fee to attend. Led by a physical therapist, discussion includes education on the lymphatic system, guidelines for exercise while in cancer treatment, activity guidelines after breast surgery, and shoulder stretching to regain mobility. Many people find this class to be helpful when taken before surgery. For information call **408-851-1400**.



Treatment Options

Activity Guidelines after Mastectomy or Axillary Lymph Node Dissection

Exercises after breast cancer surgery:

- Discuss any exercise activity after surgery with your doctor or physical therapist.
- Begin very gently and move very slowly. You do not want to strain your tissues during the first month.
- Recognize when your body feels tired and take breaks as needed.
- Before drains are out, practice deep breathing and shoulder rolls.

First 10 - 14 days after surgery and until drains are removed:

- Don't reach the involved elbow/arm above your shoulder.
- Use your arms and hands for light activity within this limited range, e.g. dressing, bathing, and preparing simple meals.
- Change activity or rest the arm if it gets tired when you are using it.
- Start light aerobic exercise such as walking 20 minutes at a comfortable pace, 3 times a week.

After 10 - 14 days and once the drains are removed:

- Start gentle stretch exercises to regain your shoulder motion.
- Gradually resume your normal activities of light intensity, such as easy dusting or washing light-weight dishes for no more than 5 minutes.
- Try to walk for 30 minutes a day, 5 days a week.

6 - 8 weeks after surgery:

- Gradually begin to increase your activity level.
- Gradually increase shoulder stretches to reach your full range of motion.
- By 8 weeks you may be able to begin very light resistance/strengthening exercises.
- Continue to be active and exercise as a regular part of your day.



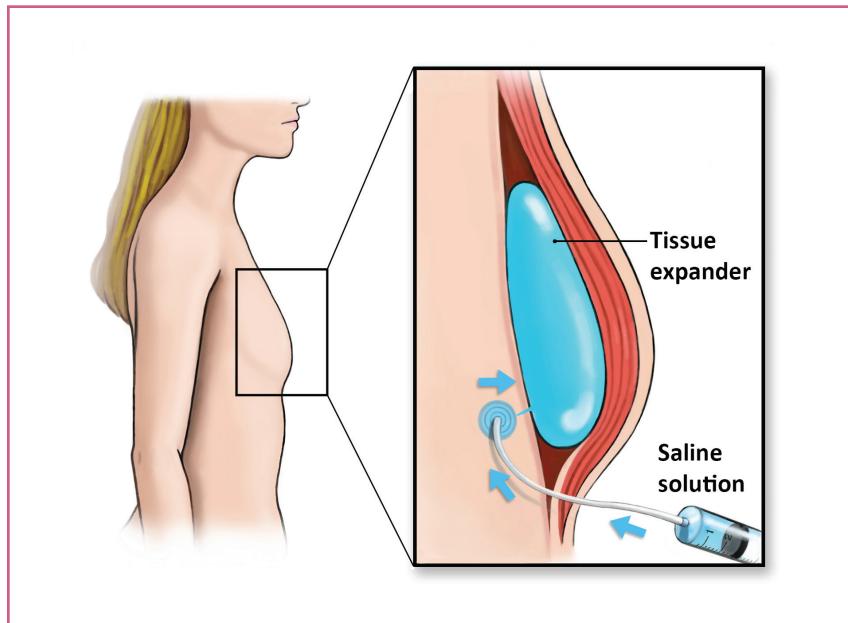
Breast Reconstruction

Breast reconstruction is an option for most women and consists of surgical procedures to rebuild the breast (or breasts) to near their normal shape. These procedures are done by a plastic surgeon.

For many women, having their breast (or breasts) reconstructed is a positive step forward in their treatment. Some feel that they've regained what they lost to cancer. The reconstructed breast will not have the exact same shape as the original breast; there will be some scarring resulting from the incisions. There will be very little, if any, feeling from the breast and it may not feel the same to you or to others when touched.

The choice for reconstruction should be considered carefully. We encourage you to discuss the options with your care team, your family, and friends. Body image, self-esteem, and sexuality may be important factors when choosing breast reconstruction surgery. If you are in an intimate physical relationship, sharing your feelings with your partner may provide a helpful perspective. Decisions regarding whether to have breast reconstruction do not need to be made before a mastectomy. Reconstruction surgery can be done at any time after mastectomy. Some partial reconstruction surgery can be done at the time of a mastectomy. Most likely, future surgeries will be needed to complete the breast reconstruction.

Breast reconstruction implant



Treatment Options

There are several types of breast reconstruction techniques. Breast implants use a tissue expander (balloon-like device) under the skin and muscle that is inflated over a period of time to stretch the skin. The expander is then replaced with a silicone-rubber implant that is filled with either saline (saltwater) or silicone gel. Implants are not expected to last more than 10 to 15 years. It is possible that some implants will leak and need to be removed or replaced. The body would absorb the saline solution, and the use of silicone gel is safe.

More complicated surgical procedures include moving connected tissue, called a rotational flap, from the abdomen or back, and placing it into position to form the breast. Another method is to surgically remove tissue from another place further away on the body (e.g. lower abdomen, inner thigh, buttocks) and transfer it to the location of the breast, called a free flap.

Nipple or areola reconstruction often uses tissue from flap skin to create the appearance of the nipple. Tissue created to look like a nipple will never function or feel like the original.

Breast reconstruction is usually not recommended before radiation therapy. If reconstruction surgery has placed transplanted or flap tissue, it could be harmed by radiation treatment. The same could be true of placing a permanent implant under breast tissue before radiation of the breast area.

Breast Reconstruction

online video

kp.org/mydoctor, search for
“Breast Reconstruction Emmi”

Radiation Therapy

Many women receive radiation treatment following breast surgery. Radiation therapy involves high energy X-rays directed at the area containing cancer cells. The cancer cells are either killed or damaged enough to prevent their continued growth. Most normal cells affected by the X-rays will heal. Almost all patients with a lumpectomy will receive radiation treatment after surgery. Radiation treatments cause little to no physical discomfort. Most

patients feel well and can continue their daily activities during treatment, including work. The radiation visits do not begin until surgical scars are healed, with no signs of infection. Radiation treatments include external beam radiation, brachytherapy, and intraoperative radiation therapy (IORT). A consultation visit is set up for you and your radiation oncologist to review the findings of your tests, imaging results, and your surgical pathology reports. You will discuss treatment choices as well as the benefits and risks of each type of treatment.



Treatment Options

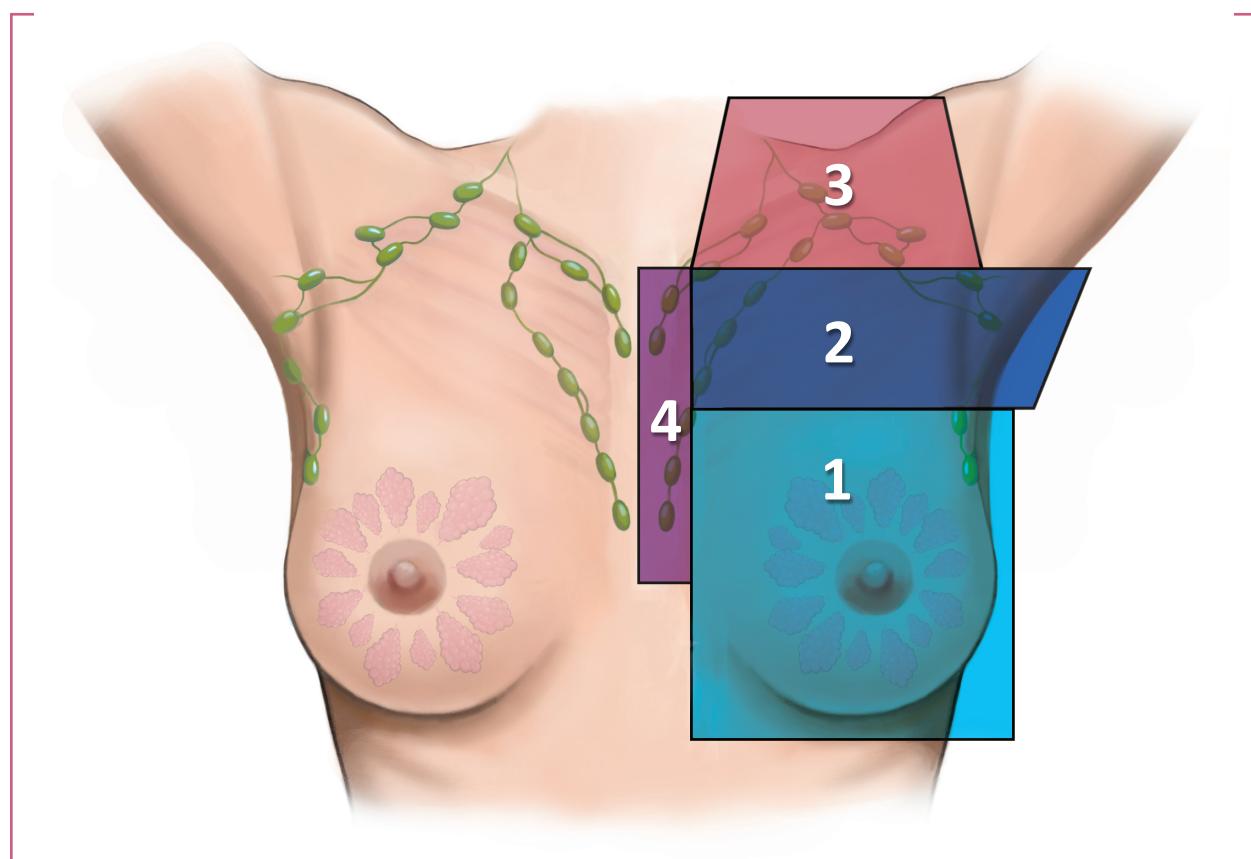
External Beam Radiation Therapy

External beam radiation therapy (EBRT) is directed to the entire breast area. Depending on the extent of your cancer, radiation may be directed to include the low axilla, high axilla, supraclavicular area, and internal mammary lymph area. See illustration below.

EBRT is delivered while you lie still on a treatment table. Equipment called a linear accelerator directs X-rays to the treatment area. The equipment stays about 1-3 feet away from you. Great care is used to minimize radiation exposure to nearby tissues and organs. Some nearby tissue cells will be damaged, though most healthy cells will heal.

Radiation treatment areas:

1. Breast and low axilla
2. High axilla
3. Supraclavicular area
4. Internal mammary area

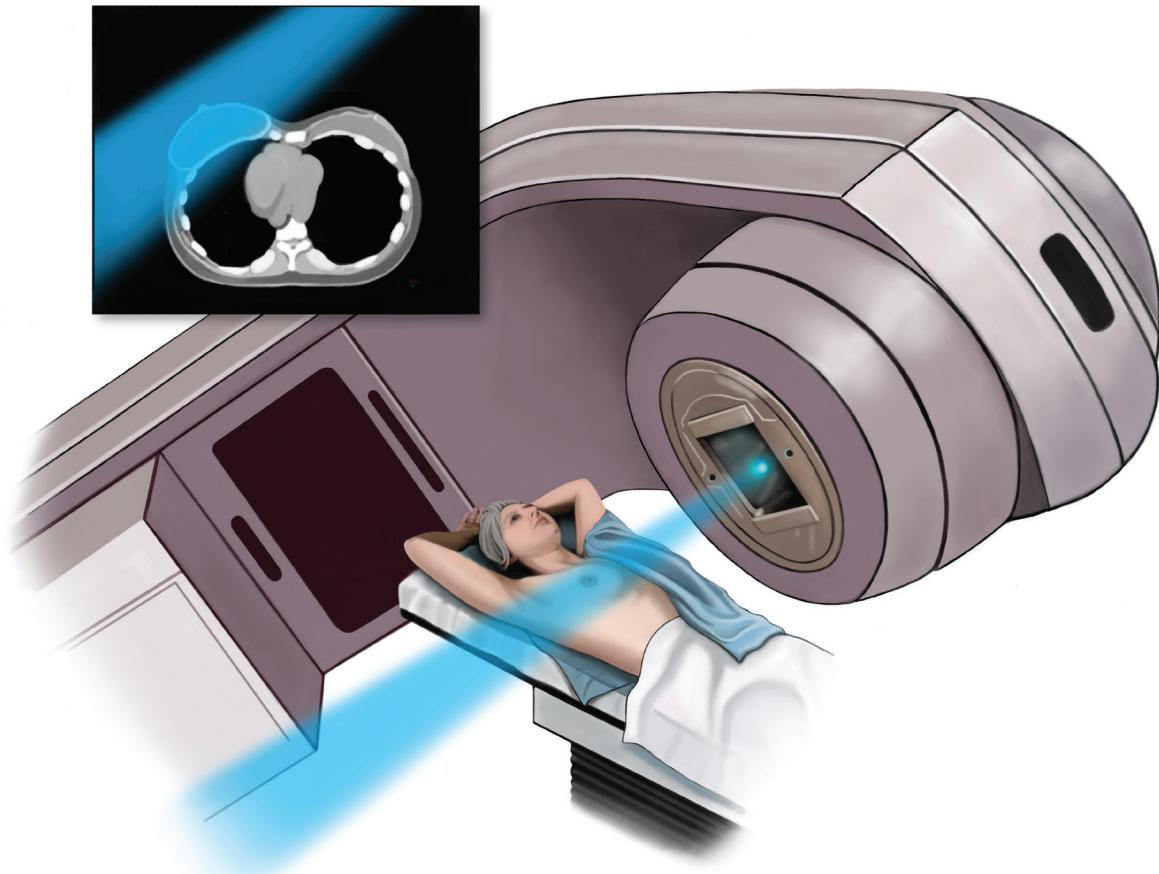


Radiation Therapy Schedule

Before your radiation treatment begins, you will visit the Cancer Treatment Center and meet a radiation oncology nurse. You will receive instructions on caring for yourself during and after treatments. Treatments are normally done daily, Monday through Friday, for a number of weeks. The time of day for your treatment is usually the same each

day. If you have scheduling concerns, please discuss them with your nurse. Your next visit will be a simulation of your typical radiation treatment. We will have you lie on the treatment table with your arms resting above your head. If you need pain medication to lie on a hard surface for up to 30 minutes, take it one hour before your appointment time. While you remain very still, a CT scan

External beam radiation



Treatment Options

is done to map your body's position on the table. Small permanent tattoo marks will be made on your skin for visual reference points to the treatment area. Following the simulation visit, your radiation oncologist usually needs several days to prepare your treatment plan and will meet with you each week during your active treatment period.

At your first treatment visit, you will change into an examination gown. The radiation therapists will position you on the table. They will then step out of the room and watch you through a window. You can speak with them through microphones in the room. If treatments are directed to your left side, the therapists may ask you to inhale and briefly hold your breath. This will help to minimize your heart's exposure to radiation. Your entire treatment visit lasts about 15 minutes. Once you are dressed, you may go about your normal day. You will not feel any physical changes and there is no risk of radioactive exposure to anyone else. Please allow 30 minutes for each appointment to undress and dress after the treatment.

Partial Breast Radiation

Partial breast radiation limits the treatment area, to limit radiation exposure to healthy tissue. The goal is to treat a portion of breast tissue that surrounds the site of a removed tumor. There are two types of partial breast radiation treatments. One is brachytherapy and the other is intra-operative radiation therapy (IORT). These therapies are not appropriate for all patients.

Brachytherapy can be used after a lumpectomy by temporarily placing a tiny radioactive seed into the breast tissue space left by removing the cancer. A catheter with a small balloon is placed into the empty space at the time of the lumpectomy. The balloon expands to fill the space. A tiny radioactive seed is inserted into the balloon for a few minutes and removed. This treats the margin tissue surrounding the site of the lumpectomy. After two treatments each day for five days, the catheter and balloon are removed from the breast.

IORT is a one-time focused X-ray treatment carried out during surgery for a lumpectomy. IORT is offered within the Kaiser Permanente Northern California service area, only at the Oakland Medical Center.



Side Effects of Radiation Treatment

The side effects of radiation therapy vary by person and by dose given. The most common are feeling tired and changes in the skin at the area being treated. Radiation therapy does not cause hair loss, vomiting, or diarrhea. Some patients have very few side effects, while others have more. Your radiation oncologist will work with you to help minimize and manage your symptoms. The effects tend to begin about 2 – 3 weeks after treatment has started, and may worsen during the course of treatment. Effects usually begin to lessen about 2 – 3 weeks after treatment ends, but could take months to years to completely resolve.

Some long-term effects can include changes to the size and shape of the breast, changes in skin color, and discomfort in the breast. More serious side effects are rare, but may include arm swelling and effects on the lungs, heart, and bones. Most patients find long-term side effects of radiation therapy to be mild and tolerable.

The key to dealing with side effects...

...is prevention. Be prepared to deal with them before they occur. Take advantage of the experience and knowledge of the clinic staff. Discuss side effects early in your treatment process. Usually, once the best method is found to control side effects, they do not become worse with future treatments, with the exception of fatigue.

Skin-Care Following Radiation Treatment

It is very important to take care of your skin in the treatment area. After treatment your skin will probably feel tender and dry, and appear pink, red, tan, or brown. Sometimes skin can blister or bleed. Specialized skin care products can help to moisturize your skin to keep it healthy. Your care team will recommend types and brands of skin care products. Apply them as instructed. Avoid sun exposure to treated areas by covering them with sun-protective clothing.

Treatment Options

Systemic and Medical Therapies

Systemic and medical therapies are drugs that work throughout the entire body, attacking cancer cells even if we don't see them or know where they are. This is different from local treatments like surgery and radiation that focus treatment on the specific area of the primary cancer. There are three main types of systemic therapy for breast cancer: chemotherapy, hormone therapy, and targeted Her2 therapy. In most cases, recommendations for systemic treatment are made after surgery, once detailed pathology results are available.

The Medical Oncology Department holds an informational meeting for patients and family before therapies begin. You will be given detailed information about your treatment process, minimizing potential side effects, and taking care of yourself during treatment.

Chemotherapy

online video

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"Chemotherapy Emmi"

Chemotherapy

Chemotherapy is most often given following surgery, when it is called an adjuvant therapy. In some cases, if a patient has extensive disease, chemotherapy may be used before surgery, when it is called neo-adjuvant therapy. The purpose of neo-adjuvant chemotherapy is to shrink the cancer before surgery. Regardless of the type of surgery performed (mastectomy or lumpectomy), chemotherapy may be recommended.

There are many different kinds of chemotherapies, and their use depends upon the type, the stage, the hormone status, and the Her2 status of the cancer. Usually, chemotherapies are medicines that are given intravenously (infused into a vein). The goal of this therapy is to treat cancer cells that may have spread beyond the breast.

Chemotherapy is often given in cycles, with an infusion given once every few weeks over a period of months. A peripherally inserted central venous catheter (PICC) or port may be placed to make it easier to receive each infusion. Chemotherapy is provided in the Outpatient Infusion Clinic and patients return home the same day.



Side Effects of Chemotherapy

Side effects of chemotherapy depend on the type of medications and the amounts used. Everyone reacts to chemotherapy differently. The most common side effects are fatigue, hair loss (partial or total), loss of appetite, nausea, mouth sores, low blood cell counts, easy bruising, and increased chance of infections. Ninety-nine percent of the time, people's hair will regrow after chemotherapy ends. Nausea is often well controlled with use of medications.

Hair Loss

Hair loss (or alopecia) may result from chemotherapy. You may feel uncomfortable with the change in your appearance. Many women buy scarves, hats, or wigs. These can be valuable for appearance sake. There are new and innovative ways to help minimize hair loss such as "scalp cooling." Your breast care coordinator can help you find resources for these vendors.



Treatment Options

Hormone Therapy

Hormone therapy is a systemic therapy that is most often given after completion of surgery, radiation treatment, and chemotherapy. Patients are eligible for this treatment if their breast cancer cells are estrogen receptor (ER) or progesterone receptor (PR) positive. When cancer cells are ER+ or PR+, hormones can stimulate the cancer to grow and spread. Hormone therapy medications are used to block the receptors that stimulate the cancer cells. If the cancer cells do not have these receptors, then hormone therapy will not be effective and would not be used.

There are several types of hormone therapy. A woman's menopausal status will determine which medication is given. For premenopausal women, estrogen is made primarily by the ovaries and some by the adrenal glands. A class of drugs known as selective estrogen receptor modulators (SERMs) are often used in this case. The most commonly used SERM is Tamoxifen.

Ovarian suppression may be recommended for premenopausal women to dramatically decrease the production of estrogen. This creates a sudden postmenopausal state. Women are considered postmenopausal when they have not had a period for over one year, or have had their ovaries medically suppressed or surgically removed (oophorectomy).

In the postmenopausal state, estrogen is no longer produced by the ovaries. Small amounts of estrogen may still be produced by the adrenal glands, using an enzyme called aromatase. Aromatase inhibitors (AI's) are treatments to prevent the aromatase enzyme from producing estrogen. Although a SERM can also be used, AI's are often recommended because they are more effective and possibly have less severe side effects. Anastrozole, Letrozole, and Exemestane are commonly used aromatase inhibitors.

Side Effects of Hormone Therapy

Side effects from hormone therapy are primarily due to the body sensing lower levels of estrogen. Common symptoms include hot flashes, sweating, vaginal dryness, mood swings, and joint stiffness. Medication dose levels can affect the severity of these symptoms. The symptoms are not permanent and tend to resolve once medication is stopped.

Use of Tamoxifen and other drugs can continue for years. Ongoing postmenopausal conditions and symptoms can be personally challenging. We encourage you to discuss your experiences with your care team.



Her2 Targeted Therapy

Her2 positive breast cancers are those breast cancers that express more Her2 than normal cells. These cancers tend to be more aggressive and often require chemotherapy combined with Her2 targeted therapy. About 25% of breast cancers are Her2 positive.

Medications that target Her2 positive breast cancers are used to block Her2 receptors and prevent cancer cell growth. The most common Her2 targeted drug is Trastuzumab (Herceptin). It is given intravenously. The drug is given for about 1 year, after surgery and chemotherapy treatments. Trastuzumab is usually infused once every few weeks.



Side Effects of Her2 Targeted Therapy

Trastuzumab is well tolerated by most patients. Approximately 15% of patients receiving Trastuzumab may experience temporary problems with heart function. If this occurs, the treatment is paused until the heart function returns to normal. Medication can then be safely resumed. Because of this potential side effect, all patients undergo echocardiograms to monitor their heart function while on Her2 targeted therapy.

Clinical Trials and Research Studies

Clinical trials are investigational research studies to test new and potentially more effective cancer treatments. Kaiser Permanente's Oncology Clinical Trials Program is recognized for state of the art cancer research and contributes to exciting advances in the field of cancer treatment and prevention. Your cancer care team will review your circumstance to determine if you might be eligible to participate in any of our clinical trial studies. Participation in a research trial is entirely voluntary. If this is an opportunity that you would like to know more about, be sure to ask your cancer care team members for more information.

Pregnancy and Breast Cancer

Though it is rare, some women develop breast cancer during pregnancy. This can raise concerns about risks for cancer progression and its effects on the fetus. If a woman is pregnant at the time of cancer diagnosis, decisions will need to be made about whether to wait or proceed with treatment, as well as whether to continue the pregnancy. Chemotherapy and hormone treatments can affect development of the fetus, especially during the early stages of pregnancy. Treatment delivered later in pregnancy is less likely to affect the fetus. Most surgical and radiation procedures are less likely to affect the fetus.

There is no evidence suggesting that pregnancy itself increases the likelihood

of cancer recurrence. However, delaying or stopping treatment may increase the risk of the cancer's spread or future recurrence.

Some cancer treatments can affect a woman's fertility and her ability to become pregnant. Some chemotherapy and hormone therapies intentionally prevent the ovaries from functioning normally. This treatment can sometimes damage the ovaries, reducing chances for becoming pregnant in the future. If you are not pregnant at the time of your diagnosis and hope to become pregnant in the future, discuss your plans and concerns with your gynecologist or obstetrician and your cancer team before treatment begins.



Disability and Supplemental Income

You may be eligible to receive State Disability Insurance (SDI) payments for work earnings lost due to your medical condition. If you are eligible for SDI and you have filed the necessary forms with the State Employment Development Department (EDD), you will begin to receive disability benefits beginning the first day of your surgery. Disability benefits include monetary payments to replace lost wages or salary, your right to take time from your employment while disabled, and protections that your job will be available to you when

your doctor authorizes your return to work. You must submit the claim yourself. See box for instructions. Your primary contact for this purpose will be the Release of Medical Information (ROMI) Department. Ask your doctor or surgeon to complete an electronic statement that verifies your work status, the beginning of your disability period, and the expected date that you might return to work. You will need this information to create your claim for state disability.

Applying for State Disability Insurance (SDI)

Your Verification of Work Status is a statement entered into your medical record by your doctor. The statement verifies your treatment and dates that you will not be available for work. Once this statement is available to the ROMI Department, the department staff will continue to provide status updates to the State Disability Office as needed.

You can submit your claim for disability to the State Employment Development Department on or after your first day of treatment. You cannot submit it before you receive treatment.

Your disability claim must be submitted online: www.edd.ca.gov/disability.

When you submit your claim, you will be given an Application Receipt Number. Give this number to the ROMI Dept. by using any of these methods:

Email: santa.clara.roi.dept@kp.org

Telephone: **408-851-1750**

Fax: **1-877-627-8407**

In person: ROMI Department, #160, Medical Office Building

Survivorship

Survivorship

For many people, cancer survivorship means having no signs of cancer after finishing treatment. Another common meaning of survivorship is living with, through, and beyond cancer. This means that cancer survivorship begins at diagnosis and continues through treatment and beyond.

It can be useful to think of survivorship in three phases. Survivorship that begins at diagnosis and ends with the completion of initial cancer treatment is referred to as acute survivorship. Extended survivorship follows initial cancer treatment and focuses on the effects of the cancer and treatment, including efforts to decrease the risk of recurrence. Finally, permanent survivorship is the period when years have passed since the initial cancer treatment and the risk of recurrence is much lower. The focus during this time is on long-term effects of cancer and treatment.

The number of breast cancer survivors has steadily increased over the last 45 years. Breast cancer survivors have created strong networks for mutual support. Local community programs and services provide places where people with breast cancer meet and find solutions. We encourage you to take advantage of these services. Your care team will help you to locate them.

After completing initial treatment, some patients feel a new-found freedom following weeks, or months, of appointments, tests, and treatments. Some people will continue with their lives much as they did before treatment, while others may have difficulty adjusting to treatment side effects that can continue for months or years. Concerns about breast cancer recurrence are very common, even when treatments have been successful.



Cancer CAREpoint provides personalized support services at no cost for anyone impacted by cancer in Silicon Valley:

- Individual & Family Counseling
- Nutrition, Yoga, and Exercise Classes
- Guided Imagery/Meditation
- Wig Bank
- Meditation & Therapeutic Massage
- Survivorship Programs

2505 Samaritan Dr., Suite 402
San Jose, CA 95124

Phone: **408-402-6611**

Website: **cancercarepoint.org**



You may have lost some upper body strength and it will take time to regain it. Changes in your physical appearance may feel uncomfortable. Clothes and breast forms can cover the areas affected by treatment and may help to increase your comfort and self-confidence.

If you had not previously received breast reconstruction surgery, you can still choose this procedure at any time.

"Embrace the support system being offered. Listen and learn from others who have been through the process."



BAY AREA
CANCER CONNECTIONS
Breast & Ovarian Cancer Information & Support

Personalized free services for patients and family members, including emotional support, information resources, wellness programs, and a boutique for wigs and breast prostheses.

2335 El Camino Real
Palo Alto, CA 94306
Phone: **650-326-6299**
Website: **bcconnections.org**

Seeds of Hope

Kaiser Permanente holds an annual day of celebration and education for hundreds of breast cancer patients and their families. The event is called Seeds of Hope. You and your family are invited to attend. Ask your care team for dates and details.

Family, Friends, and Emotional Support

It is normal to seek support from those closest to you. At times they may not notice if you are having side effects from treatment or if you need support. They may not understand your emotional and psychological experiences.

We encourage you to talk with your family and friends about your feelings and needs. This can help them to better understand your experience. You might find new friends by attending support groups with others who have breast cancer. Support groups are held at Kaiser Permanente and other organizations, including groups for young women and those with children.

Survivorship

Intimacy and Sexuality

Rarely are so many intimate aspects of a person's life affected by a single circumstance. At times you may feel frustration, anger, loneliness, or sadness. Remember your care team is here to support you.

Physical changes brought on by breast cancer and its treatment often cause symptoms of menopause. These can



BAYS

Bay Area Young Survivors

Non-profit community programs for those under age 45 with breast cancer:

- Support groups with child care
- Online peer support network
- Social and education events

P.O. Box 190056
San Francisco, CA 94119
Phone: **628-400-2297**
Email:
bayareayoungsurvivors@yahoo.com

include vaginal dryness, sensations of itching or burning, problems with urination and pain with sexual intercourse. These symptoms are referred to as genitourinary syndrome, or vaginal atrophy. There are treatment options, though not all of them are suitable for breast cancer patients.

In addition, your personal journey may change your understanding about your self-identity, your sexuality, and physical intimacy. An intimate partner may also have difficulty coping with physical and emotional changes. We are here to support them as well.

We encourage you to be patient with yourself. Express your feelings and be open to learning new things about yourself and others. These pages offer a few suggestions for meeting people who are in similar situations and may be experiencing the same things. You may find new friends. You may gain deeper relationships with existing friends. Your care team is always available to help you manage physical symptoms as well as locate emotional support.

Kaiser Permanente Breast Cancer Support Group

Meets at Santa Clara Medical Center
For more information call
408-851-3845

Nutrition



Our registered dieticians work with cancer patients to improve their nutrition.

The National Cancer Institute and cancer research studies have found the following nutrition recommendations may help to reduce the incidence of breast cancer and breast cancer recurrence:

- Achieve and maintain a healthy weight. Being overweight has a strong association with an increased risk for breast cancer.
- Follow a plant-based diet. Include a variety of colorful fruits and vegetables, whole grains, and plant-based proteins such as legumes (beans and lentils), nuts, and seeds in your diet.
- Limit fat intake to less than 30 percent of total calories per

day. Limit intake of animal fats (saturated fats), and hydrogenated or partially hydrogenated fats (trans fats). Include moderate amounts of healthy fats from extra virgin olive oil, avocados, nuts, seeds, and cold-water fish such as salmon, sardines, and tuna.

- Avoid red meat, processed or cured meats, and charred meats. Limit intake of grilled and smoked meats.
- Choose non-fat or low fat dairy products.
- Limit intake of processed foods that contain highly refined grains, added sugars, salt, and fat.
- Consume less than 3 alcoholic beverages per week. Many studies suggest that regular alcohol consumption may increase the risk for breast cancer.
- The relationship between soy foods and breast cancer is not certain. There are concerns that the phytoestrogen content of soy may increase the risk of breast cancer. Nonetheless, whole soy foods do contain healthy nutrients including calcium, fiber, and B vitamins. Moderate consumption of traditional soy foods (miso, tempeh, tofu, unsweetened soy milk and edamame) does not increase the risk of developing breast cancer.



Support Services

Release of Medical Information (ROMI) Department (Patient Records)

The ROMI Department releases patient medical information at the written request of the patient. The ROMI Department also assists with forms that require a doctor's signature. Medical information from outside health service providers is delivered to the Department to place into a patient's medical record.

ROMI Department staff will assist with applications to California State Disability Insurance (SDI), California Paid Family Leave Program, and Family Medical Leave (FMLA).

The ROMI Department #160 is located in the Santa Clara Medical Office Building.
For information call **408-851-1750**.

FAX: **877-627-8407**

Member Services Department (Patient Relations)

The Member Services Department helps to answer questions about Kaiser Permanente services and your Health Plan benefits. Member outreach specialists also assist with selecting or changing primary care doctors and creating your personal account with Kaiser Permanente's online website, at **kp.org**.

Member Services Department #162 is located in the Santa Clara Medical Office Building.

Member Services can assist with:

- Health Plan benefits
- Patient enrollment status
- Kaiser Permanente services
- Health Plan ID cards
- Patient complaints and grievances
- Travel out of area plan coverage
- Health Plan documents

Contact Member Services by calling:

800-464-4000 (English)

800-788-0616 (Spanish)

800-757-7585 (Chinese dialects)

711 (TTY)



Financial Services Department

The Financial Services Department helps patients with questions regarding their medical bills, payments to accounts, refunds, and insurance-related issues. The department bills non-Kaiser plans for patients including: Medicare, MediCal, third party liability (TPL), coordination of benefits (COB), Health Maintenance Organization (HMO), and secondary insurance companies. Financial advisors are available to answer questions regarding alternative payment needs and to help locate other resources. Financial Services Department #112 is located in the Santa Clara Hospital Building. For information call **408-851-5950**.

Health Education Department

The Health Education Department programs and services are provided through classes, individual consultations in person, telephone appointments, internet video connections, and Telephone Wellness Coaching. Health programs can also be found at Kaiser Permenente's website, "My Doctor Online," and accessed in Spanish at La Salud Permanente. Program areas include:

- Cancer programs for patients and families
- Nutrition education and weight management (English and Spanish)
- Diabetes management
- Fall prevention
- Insomnia
- Life Care Planning and Advance Health Care Directive
- Registered dietician
- Stress, anxiety and depression
- Tobacco cessation

The Health Education Department, #182 is located in the Santa Clara Medical Office Building. For information call **408-851-3800**.

Support Services

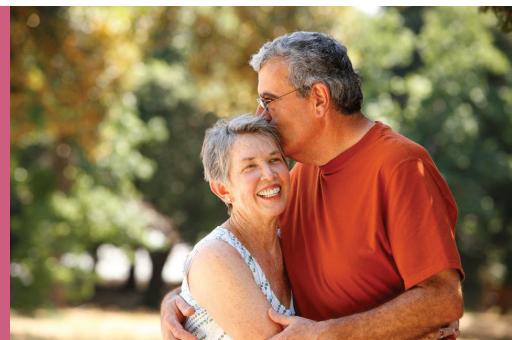
Life Care Planning

Effective life care planning is the best way to make sure your views are respected by loved ones and by health care providers. Life care planning is done at any age and is often very important for patients who have continuing critical illnesses or who may be experiencing end-of-life situations. The discussion can also give comfort to those who may need to make difficult, life-sustaining treatment decisions on your behalf. If your health changes over time, revisions to existing life care plans may be appropriate.

Advance Health Care Directive

An Advance Health Care Directive is a witnessed, legal document, naming a person you choose to be your healthcare agent. It authorizes that person to act on your behalf if you are not able to communicate your own medical decisions and health care wishes. A copy of your completed advance health care directive is submitted to the Health Education Department or Member Services Department and is placed in your medical record. Kaiser Permanente's life care planning consultants and classes are available to you, your family, and those you choose to act as your health care agent. Information can be found online at kp.org/lifecareplan. Register for an appointment or class by contacting the Health Education Department #182. For information call **408-851-3800**.





Oncology Supportive Care Clinic

The Oncology Supportive Care Clinic is a counseling service that focuses on the whole person: body, mind, and spirit. The clinic is designed to provide symptom and pain management with the goal of improving quality of life. You will meet with a team of health care professionals who will assist you with treatment choices, personal decisions, planning for future needs, and locating additional resources. The clinic also offers individual and family counseling. For information call **408-851-0537**.

Psychiatric Oncology

Psychiatric oncology is the practice of managing emotional and behavioral effects that cancer can have on mental and physical health. Psychiatric services, including counseling, are available through all stages of active treatment and follow-up care. Psychiatric medications may be an integral part of your care and treatment. We encourage you to be open to asking for help. Adult Psychiatry is located in the Tantau Building of the Santa Clara Medical Center. For information call **408-366-4400**.

Palliative Care

Palliative Care is specialized care for people with serious illness. This type of care is focused on providing relief from symptoms of pain and stress while facing a serious illness. The goal of palliative care is to assist with making choices to improve quality of life for both you and those around you while in treatment. It is appropriate at any age and at any stage in a serious illness. It can also be provided together with curative treatments. For information call **408-851-0537**.

Hospice Service

Hospice service provides support and care to patients who are approaching the end of life. Services are provided by doctors, nurses, social workers, home health aides, and volunteers. Hospice services are normally provided in the home or in a licensed care facility. Personal caregivers must be available around the clock. Visits by hospice staff occur once or more times per week, depending on need. Assistance can be provided for bathing, pain management, wound care, counseling, spiritual care, and social support. Kaiser Permanente Health Plan offers hospice services to patients of all ages. For information call **408-235-4100**.

Internet Resources

Kaiser Permanente My Doctor Online
kp.org/mydoctor

KaiserLa Salud Permanente (Spanish)
mydoctor.kaiserpermanente.org/ncal/lasalud/#

Kaiser Permanente Santa Clara Comprehensive Cancer Care
kp.org/santaclara/cancercare

Cancer Care Support Programs Calendar
kaisersantaclara.org/cal/cancer

American Cancer Society
cancer.org

Bay Area Cancer Connections
bcconnections.org

Breast Cancer Emergency Fund (bay area financial assistance)
bcef.org

Cancer CAREpoint
cancercarepoint.org

Male Breast Cancer Coalition
malebreastcancercoalition.org

National Cancer Institute
cancer.gov

National Comprehensive Cancer Network
nccn.org

Susan G. Komen Foundation
komen.org

Suggested Reading



After Breast Cancer: A Common Sense Guide to Life After Treatment.

By Hester Hill Schnipper and Lowell E. Schnipper, Sep 2006.

A Woman's Guide to Breast Cancer Treatment, California Department of Health Services. Obtain online, http://www.mbc.ca.gov/Publications/Brochures/Breast_Cancer.aspx

(English, Spanish, Arabic, Armenian, Cambodian, Chinese, Hindi, Hmong, Japanese, Korean, Punjabi, Russian, Tagalog, Thai, Vietnamese.)

Breast Cancer Husband: How to Help Your Wife (and Yourself) during Diagnosis, Treatment, and Beyond.

By Marc Silver, Sep 2004.

The Cancer-Fighting Kitchen, 2nd Edition.

By Rebecca Katz and Mat Edelson, Feb. 2017.

Dr. Susan Love's Breast Book, 6th Edition.

By Susan M. Love M.D., Sep 2015.

Johns Hopkins Patients' Guide to Breast Cancer.

By Lillie D. Shockney, September 2009

Let Me Get This Off My Chest: A Breast Cancer Survivor Over-Shares.

By Margaret Lesh, Jul 2013.

The Plant-Based Diet Booklet, Kaiser Permanente

<https://share.kaiserpermanente.org/wp-content/uploads/2015/10/The-Plant-Based-Diet-booklet.pdf>

NOTE: The booklet title in the url, "The-Plant-Based-Diet" requires the use of capital letters in the url.

Glossary

Acute - Symptoms or signs that begin and worsen quickly; not chronic.

Adenoid cystic (or adenocystic) carcinoma - Any cancer that begins in glandular tissues.

Adipose tissue - Female breast tissue composed mostly of fat cells.

Adjuvant treatment - Treatment given after the primary treatment is used to cure disease.

Adrenal gland - A small organ on top of each kidney that makes hormones including estrogen.

Anesthesiologist - A doctor who provides and monitors anesthesia and medications, before and during the time of surgery.

Antiestrogen - A drug that stops estrogen from attaching to cells

Asymptomatic - Having no signs or symptoms of disease.

Benign - Not cancerous. Benign tumors may grow larger but do not spread to other parts of the body. Also called nonmalignant.

Bilateral mastectomy - surgical removal of both breasts.

Bilateral oophorectomy - Surgical removal of both ovaries.

Breast Care Coordinator - A nurse or physician's assistant who supports, educates, and advocates for you, answers your questions, and helps you schedule your appointments.

Carcinoma - Cancer that starts in cells that form the lining of organs and structures in the body.

Catheter - A flexible tube inserted in the body to give treatment or drain fluid from the body.

Chronic - A disease or condition that persists for a long time, lasting 3 months or more.

Clavicle - or collarbone are 2 long bones that serve as struts between the shoulder blades and the sternum or breastbone.

Clinical breast exam (CBE) - A physical exam of the breasts by a health professional to feel for disease.

Compression garments - Tightly fitting pieces of clothing, such as socks, pantyhose, sleeves, etc., that provide support for poor circulation.

Contralateral - Relating to or denoting the side of the body opposite to that on which a particular structure or condition occurs.

Contrast - A dye put into the body to make clearer pictures during imaging tests.

Deoxyribonucleic acid (DNA) - A very thin and long molecule that contains genetic code.

Ductal lavage - A technique used to detect pre-cancerous and cancerous breast cell changes by applying suction to the nipple to bring out fluid from the milk ducts.

Emmi - a web-based program used to explain medical information in a way that is easy to understand.

Express - to manifest or produce (a character, or effect) by a genetic process.

Fibro adenoma - Benign tumors made up of both glandular breast tissue and stromal tissue.

Fibrosis - Development of excess fibrous connective tissue.

Follicle-stimulating hormone (FSH) - A hormone made by the ovaries.

Gene (Genetic) - Coded instructions in cells for making new cells and controlling how cells behave. A complete set of DNA in a single cell is called the genome.

Genetics Counselor - A health care professional who works with medical and familial implications of genetic involvements with disease.

General anesthesia - A controlled loss of wakefulness from drugs. **Gland** - An organ in the body that secretes particular chemical substances or discharge.

Genomic - A study of the structure, function, and evolution of genomes.

Immune system - a network of cells, tissues, and organs that work together to defend the body against attacks by "foreign" invaders, such as infection-causing microbes.

Glossary

Inflammation - A protective reaction to injury, disease, or irritation of tissues, usually associated with redness, swelling, pain, and/or a feeling of heat in an area of the body.

Inflammatory breast cancer (IBC) - An uncommon invasive type of breast cancer causing skin of the breast to feel warm, look red, and possibly become thick and pitted.

Infuse - To introduce (a solution) into the body through a vein.

Invasive pleomorphic lobular carcinoma (IPLC) - A rare variant of invasive lobular carcinoma.

Irradiate - To affect or treat by radiant energy.

Isoflavones - Naturally occurring estrogen-like compounds in mammals, produced by various legumes and beans.

Luteinizing hormone-releasing hormone (LHRH) - A hormone made in the brain that helps regulate estrogen production by the ovaries.

Marker - A diagnostic indication that disease may develop.

Medical Oncologist - A doctor specially trained in treatment of cancers with chemotherapy drugs and other medications.

Medullary cancer - A rare type of invasive ductal carcinoma.

Metaplastic carcinoma - A distinct identified malignancy characterized by the histologic presence of two or more cellular types.

Mixed carcinoma - Cancer that has more than one cell type.

Mucinous carcinoma - Cancer that has a lot of mucus around the cells. Also called colloid breast cancer.

Mutation - An abnormal change in the instructions in cells for making and controlling cells.

Neoadjuvant therapy - Treatment given before the primary treatment used to cure disease.

Oncologist - A medical doctor specializing in the field of cancer diagnosis and treatment.

Ovarian ablation - Methods used to stop the ovaries from making estrogen.

Paget's disease of the nipple - A rare type of cancer involving the skin of the nipple and usually the areola.

Pathologist - A doctor who examines body tissues, and interprets results to facilitate a diagnosis of disease.

Phyllodes tumor - A rare breast tumor that starts in the connective (stromal) tissue.

Physical Therapist - A licensed health care professional, specially trained to assist patients with restorative and therapeutic exercise and physical movement.

Phytoestrogen - Plant-derived compounds, in soy and other foods, that have not been determined to have either beneficial or detrimental effects to physical health.

Plastic Surgeon - A surgeon, specially trained in cosmetic and reconstructive surgery.

Proliferative lesion with atypia - Benign lesion of the breast that indicates an increased risk of breast cancer.

Radiation Oncologist - A medical doctor whose specialty is radiation treatment of cancers.

Radiation Therapist - A technician specially trained to deliver radiation treatments.

Radiologist - A doctor who specializes in interpreting images obtained by various techniques, such as X-ray, CT scan, and MRI.

Recurrence - Cancer that has returned, usually after a period of time during which the cancer could not be detected. The cancer may come back to the same place as the original (primary) tumor or to another place in the body.

Refractory - A cancer that does not respond to (or is resistant to) cancer treatment.

Registered Dietician - A clinical specialist who provides nutrition counseling to patients coping with medical conditions and treatment.

Sarcoma - A type of cancer that grows in connective tissue.

Social Worker - A licensed care provider supporting patients with counseling and resources.

Glossary

Stroma - fatty tissue and connective tissue surrounding the internal parts of the breast (ducts, lobes, blood vessels, etc.).

Supraclavicular lymph nodes - Lymph nodes found just above the clavicle or collarbone, toward the hollow of the neck.

Surgeon - A doctor specially trained to perform operations.

Systemic - affecting the whole body, or multiple related organ systems.
Contrast with local.

Tracer - A substance (such as a radioisotope) used intravenously in imaging procedures.

Important Telephone Numbers

Advice Nurse **866-454-8855 or 408-554-9800**

Breast Care Coordinator

Surgery Department

Surgeon MD

Medical Oncology Department

Medical Oncology RN

Medical Oncology Social Worker

Oncology Pharmacist

Women's Imaging & Mammography

Cancer Treatment Center

Radiation Oncology Nurse

Oncology Dietician

Oncology Social Worker

Hospital Admitting Department

Physical and Occupational Therapy

Cosmetic Services

Laboratory

Member Services

Release of Medical Information Dept.

Health Education Department

Kaiser Permanente

Santa Clara Medical Center

710 Lawrence Expressway

Santa Clara, CA 95051

866-454-8855 or 408-554-9800

408-851-2000

408-851-7750

408-851-5020

408-851-8000

408-851-5400

408-851-1400

408-851-8200

800-464-4000

408-851-1750

408-851-3800

Cancer Treatment Center

Santa Clara Medical Center

3800 Homestead Road

Santa Clara, CA 95051

Notes

Salud en español para usted y su familia



Envíe un mensaje de
texto con la palabra SALUD al 45356
o visite kp.org/mydoctor/español

