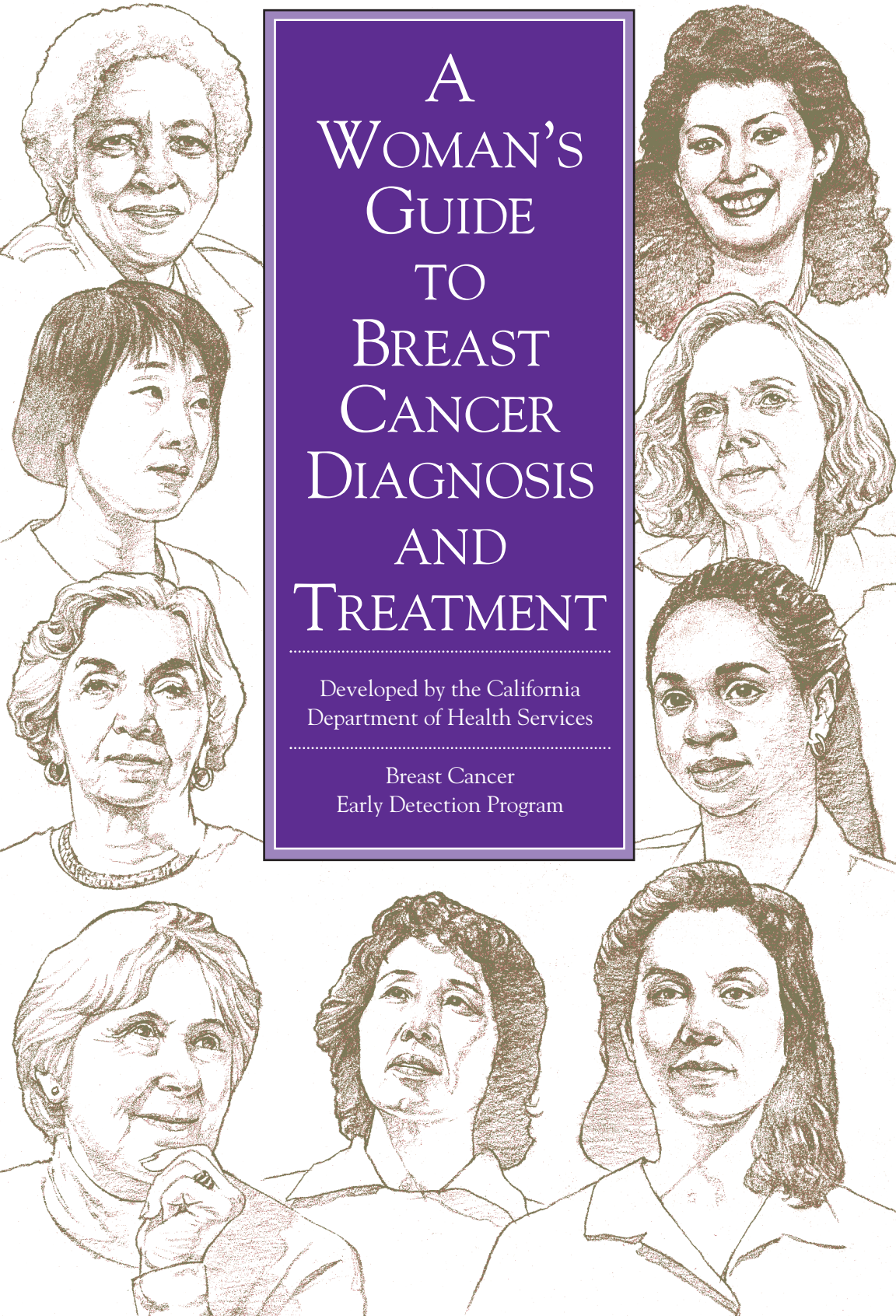
A Woman's Guide to Breast Cancer Diagnosis and Treatment

Developed by the California Department of Health Services

Breast Cancer Early Detection Program



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1 Introduction

The State of California requires that your doctor give you this brochure if you are about to have a breast biopsy or have been diagnosed with breast cancer.

You may be going through all kinds of feelings. You may be worried and anxious. You may be in shock or feel alone. It may be hard for you to concentrate. These reactions are normal.

The hope is that this booklet will prove to be a valuable guide. It is intended to help you become a partner in making choices with your health care team. These tips may make it easier for you to use this booklet:

- Read the material as you need it. If you are about to get a biopsy, only read the section on Breast Biopsy. You may feel better finding out that most breast lumps are not cancer.
- If you already have been diagnosed with cancer, have a friend or someone on your health care team read this booklet along with you. Or have them read it and discuss the material with them when you are ready.
- The medical words that you hear as you go through biopsy and treatment are used in this brochure. Knowing the meaning of the words that you are hearing can help you understand what is happening and make informed choices. Remember, there is no one "right" treatment for every woman. New options are available today that were not offered even a few years ago.
- As you go through the diagnosis and treatment processes, you may find it helpful to write out questions **before** you meet with your doctor. Some of the questions you may want to ask are in the side margins of this brochure. (You may also want to tape record information that is given to you. Consider asking a friend or family member to come with you during health care appointments.)
- Most important, never be afraid to have information repeated and to ask questions. There is no "dumb" question when you are faced with cancer.
- For more free information or to talk to someone (in English or Spanish), call the National Cancer Institute's hotline:

1-800-4-CANCER

2 Breast Biopsy

When you discover a lump or other change in your breast, it is important to find out what it is. It is normal to be alarmed. But you have reasons to be reassured:

- Most women, sometime in their lives, develop lumps in their breasts.
- Most lumps are NOT breast cancer. In fact, 8 of 10 lumps are harmless.
- To be sure that a lump or other change is not breast cancer, you need to have some or all of the lump removed (a **biopsy**). A diagnosis can then be made by a **pathologist,** a doctor who looks at the cells under a microscope to find out if the tissue is normal or cancerous.

When Your Lump Can Be Felt

If your lump can be felt, you will most likely have one of the following types of biopsies.

Fine Needle Aspiration (FNA)

A thin needle is placed into the lump. If fluid comes out, and the lump disappears, it means that the lump is a cyst and is usually not cancer.

- **Advantage:** You can avoid a scar and surgery. If cancer is found, you can start to plan your treatment.
- **Disadvantage:** If the needle removes only normal cells, and the lump does not go away, then you may need more tests to make sure that the lump is not cancer.

Core Biopsy

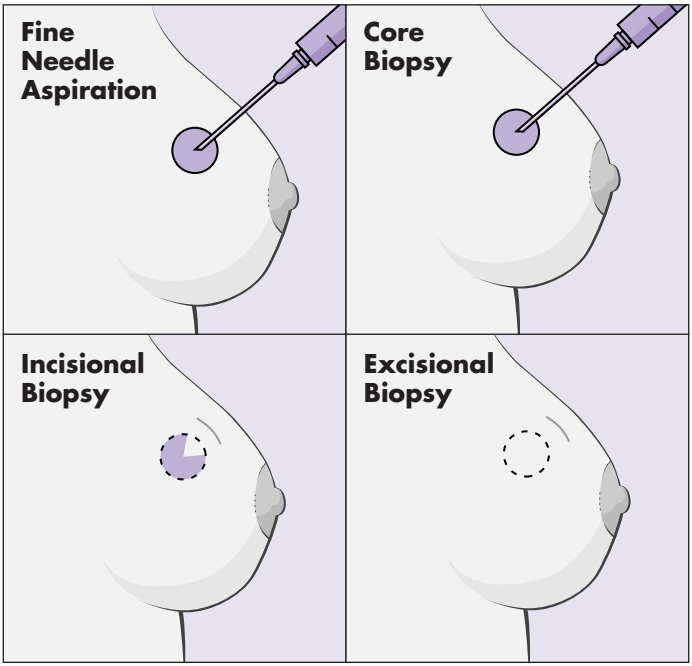
A larger needle is used to remove a small piece of tissue from the lump.

- **Advantage:** Your scar will barely be noticeable. Even if the lump is cancer, you will have avoided the stress of one surgery.
- **Disadvantage:** If this biopsy finds cancer, you will need more surgery to remove the part of the cancer that is still in your breast. If this biopsy does not find cancer, you may still need a surgical biopsy to make sure that the lump that is still in your breast does not contain any cancer cells.

Surgical Biopsies

An **incisional biopsy** removes only a portion of the lump. An **excisional biopsy** removes the entire lump.

You will have a scar on your breast, which will heal with time. There may be some change in the shape or size of your breast.



Anesthesia

- If the lump is small and near the skin's surface, you will likely be given **local anesthesia.** Medication is injected into the site. You will be awake, but you should not feel pain. Medication also may be injected into a vein in your arm as an extra way to reduce pain and help you relax.
- If you are given **general anesthesia,** you will be given medication that will place you in a deep sleep. You will not feel pain during surgery. These medications are most often inhaled as a gas. They may be used when the tumor is large, located deep in the breast, or when the woman does not want to be awake.

When Your "Lump" Can Be Seen But Not Felt

Sometimes you can have an area of concern that cannot be felt in the breast but shows up on pictures of the inside of the breast. These pictures are taken by either **mammography** (a type of x ray) or **ultrasound,** a process that shows harmless soundwaves as they travel through a breast. In these cases you may have:

Needle Localization Biopsy

Using a mammogram or an ultrasound as a guide, a doctor places a needle or fine wire into the suspicious area. The area is then removed with a surgical biopsy. A second picture of the biopsy area may be taken later to make sure that the area of concern was entirely removed.

Stereotactic Needle Biopsy

This fairly new procedure pinpoints the area of concern with a double-view mammogram. A computer plots the exact area and guides a fine needle or a large-core needle so that a doctor can remove a sample of tissue for the pathologist.

Questions to Ask Your Doctor

- Do you think I need to have a biopsy? If not, why?
- What type of biopsy do you recommend? Why?
- How soon will I know the results?
- What will the scar look like after the biopsy and after it heals?
- Do you suggest local or general anesthesia? What are the advantages of each?

If your biopsy result is **negative,** your treatment is over. It still will be important to have your breasts checked regularly for any future signs of change.

If the result is **positive,** the cells did contain cancer and you will need to make decisions about your treatment options. Information on the following pages can help you understand your options.

Remember, there are people who can help you through this process.

3 Making a Decision

Doctors used to believe that it was best to biopsy a woman's lump and remove her breast in the same operation if cancer was found. A woman went into surgery for a biopsy not knowing whether she would wake up with her breast. This rarely happens today.

Studies show that it is safe to start treatment within several weeks after your biopsy. This two-step procedure gives you time to:

- Read more and think through the information.
- Get a second opinion.
- Call **1-800-4-CANCER** or breast cancer organizations for information and support groups near you.
- Talk to other women who have had breast cancer.
- Have a complete study of your breast tissue, and, if needed, of other parts of your body.
- Prepare yourself and loved ones for your treatment.

4 About Breast Cancer

What Causes Breast Cancer?

Nobody knows for certain why some women develop breast cancer and others do not. What is known:

- You should not feel guilty. You have not done anything "wrong" in your life that caused breast cancer.
- You CANNOT "catch" breast cancer from other women who have the disease.
- Breast cancer is NOT caused by stress or by an injury to the breast.
- Most women who develop breast cancer DO NOT have any known risk factors or a history of the disease in their families.
- Getting older DOES increase your risk of getting breast cancer, starting at the age of 40 and continuing into your 80s.

Who Gets Breast Cancer?

Breast cancer is the most common cancer diagnosed in women today. It even occurs in a small number of men.

- In California alone, close to 20,000 women are diagnosed with breast cancer each year.
- In the United States, close to 200,000 women are diagnosed with breast cancer each year.
- All ages and races are affected: 1 in 9 white, 1 in 11 African-American, and 1 in 20 Hispanic and Asian women will develop breast cancer during their lifetimes.

You have more choices for treatment when breast cancer is found early. Also, treatments have changed. Today, many women who are diagnosed with breast cancer DO NOT have to lose a breast. Even when breast cancer is

not found early, you still have choices. Because there are new ways to treat breast cancer, it is more important than ever for you to learn all you can. Working with a team of specialists, you play a key role in choosing your treatment.

Staging of Breast Cancer

Breast cancer is a complex disease. There is no right treatment for all women. Your breast cancer will be placed into one of 5 stages. The chart on the next page explains each stage for you. How your cancer is staged and your treatment choices will depend on:

- How small or large your tumor is and where it is found in your breast.
- If cancer is found in the lymph nodes in your armpit.
- If cancer is found in other parts of your body.

The following words and information also can help you understand how your cancer is "staged."

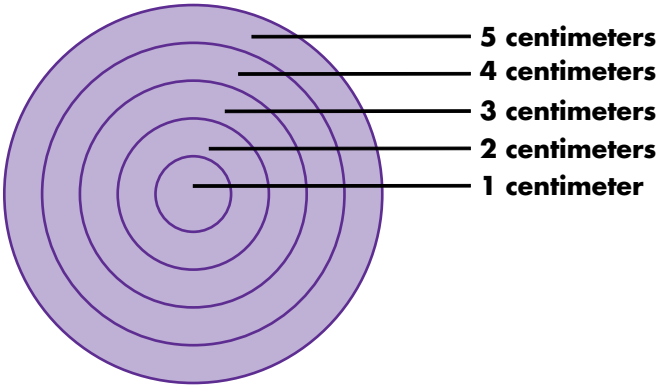
- **Benign** means that your lump or other problem was NOT cancer.
- **Malignant** means that your tissue DOES contain cancer cells.
- **In situ or noninvasive cancer** is a very early cancer or a precancer that has NOT SPREAD beyond the breast, to the lymph nodes in the armpit, or to other parts of the body. This type of cell is still totally contained in the milk ducts or lobules of the breast.
- **Invasive cancer** HAS SPREAD to surrounding tissue in the breast and MAY HAVE SPREAD to the lymph nodes in the armpit or to other parts of the body. All breast cancers, except in situ cancer, are invasive.
- **Metastasized cancer** HAS SPREAD to other parts of the body, such as the bones, lungs, liver, or brain.

Staging of Breast Cancer

Stage 0	■ Very early breast cancer or preinvasive cancer. This type of cancer has NOT spread within or outside of your breast (also called in situ or noninvasive cancer).
Stage I	■ Tumor smaller than 2 cm. (1 inch*). No cancer is found in lymph nodes in the armpit, or outside the breast.
Stage II	■ Tumor smaller than 2 cm. (1 inch). Cancer is found in the lymph nodes in the armpit, **OR** ■ Tumor between 2 and 5 cm. (1 and 2 inches). Cancer may or may not be found in the lymph nodes in the armpit, **OR** ■ Tumor larger than 5 cm. (2 inches). Cancer is not found in the lymph nodes in the armpit.
Stage III	■ Tumor smaller than 5 cm. (2 inches) with cancer also in the lymph nodes that are stuck together, **OR** ■ Tumor larger than 5 cm. (2 inches), **OR** cancer is attached to other parts of the breast area including the chest wall, ribs, and muscles, **OR** ■ Inflammatory breast cancer. In this rare type of cancer, the skin of the breast is red and swollen.
Stage IV	■ Tumor has spread to other parts of the body, such as the bones, lungs, liver, or brain.

* Cm. means centimeters. One inch equals 2.5 centimeters. Inches listed above are not exact measurements.

Tumor Sizes



One inch equals 2.5 centimeters.

Survival Rates

When cancer is detected early, five-year survival rates are very high. Almost all women with Stage 0 cancer will have a normal lifespan. Five-year survival rates are as high as 95% when the cancers in Stage 1 are smaller than one centimeter. Even when a cancer falls into a Stage II category, five-year survival rates are close to 70%.

Risk Factors for Recurrence

Some women are at higher risk for the spread and return of breast cancer. Remember, the risk factors for recurrence are complex. They ARE NOT absolute forecasts of what your future will be. The factors are:

- **Tumor size.** The larger your tumor, the higher your risk.
- **Lymph nodes.** The more lymph nodes in your armpit that have cancer, the higher your risk.
- **Cell studies.** New tests can measure the growth rate and aggressiveness of the tumor cells. The cancer cells that show the most rapid growth are linked to higher risk for the return of cancer.

Questions to Ask Your Doctor

- What stage of breast cancer do I have?
- Do I have a type of cancer that should be treated at a specialized center?
- Will a pathologist with experience in diagnosing in situ "cancer" read my slide? Does the doctor read a high volume of breast cancer slides?
- For in situ "cancer," do you think my biopsy slides should be reread? Why or why not?
- What are the chances that my cancer has spread beyond the breast?

In Situ "Cancers"

Because of the success of x-ray mammography, tiny growths are being discovered that raise concerns about a woman's risk of developing breast cancer. These growths are called carcinoma in situ or noninvasive cancer. Today 15% to 20% of breast "cancers" fall into this category. Two types exist:

- **Ductal carcinoma in situ** (DCIS) is noninvasive, which means it is limited to the milk ducts of the breast. It has NOT spread beyond the breast, to the lymph nodes in the armpit, or to other parts of the body. However, there are several types of DCIS. If it is not removed, some types may in time change and develop into an invasive cancer. Some may NEVER progress to an invasive cancer.
- **Lobular carcinoma in situ** (LCIS) is a noninvasive growth limited to the milk lobules of the breast. It is NOT cancer, only a warning sign of increased risk of developing cancer, according to the National Cancer Institute. Women with LCIS have about a 1% risk of developing invasive breast cancer equally in either breast per year. At 20 years, this risk is about 18%.

To be sure that you have the right diagnosis, have your slides read by an experienced pathologist. If you still have questions, the National Cancer Institute suggests that your biopsy slides be reread. You can have them reread at a university hospital, cancer center, a second opinion service, or at the Armed Forces Institute of Pathology in Washington, D.C. This step is important because of the difficulty today in making an accurate diagnosis. Treatment choices vary from close follow-up, to removing only the affected tissue, to removing both breasts.

For more information on in situ "cancers":

- Talk to your doctor.
- Call **1-800-4-CANCER** (the National Cancer Institute's hotline).

Your Treatment Team

If your lump does contain cancer cells, you will need a team of medical experts. No one doctor is able to provide all the services you may need. Here are some of the experts you may need.

- **Anesthesiologist:** a doctor who gives medications that keep you comfortable during surgery.
- **Clinical Nurse Specialist:** a nurse with special training who can help answer questions and provide information on resources and support services.
- **Oncologist:** a doctor who uses chemotherapy or hormone therapy to treat cancer.
- **Pathologist:** a doctor who examines tissue and cells under a microscope to decide if they are normal or cancer.
- **Physical Therapist:** a medical professional who teaches exercises that help restore arm and shoulder movements after surgery.
- **Plastic Surgeon:** a doctor who can rebuild **(reconstruct)** your "breast."
- **Radiation Oncologist:** a doctor who uses radiation therapy to treat cancer.
- **Radiologist:** a doctor who reads mammograms and performs other tests, such as x rays or ultrasound.
- **Social Worker:** a professional who can talk with you about your emotional or physical needs.
- **Surgeon:** a doctor who performs biopsies and other surgical procedures such as the removal of your lump **(lumpectomy)** or your breast **(mastectomy).**

Second Opinions

Second opinions are your right and are commonly asked for today. Get a second opinion if you:

- Want to confirm your diagnosis or treatment.
- Have concerns about your treatment plan.
- Feel uncomfortable with your doctor.

To get a second opinion:

- Ask your doctor to refer you to another breast cancer specialist who is outside his or her treatment team.
- Call the National Cancer Institute's hotline: **1-800-4-CANCER.**
- Call local or national medical associations.
- Talk to women in breast cancer organizations or to women who have been through the same experience.

5 Treatment Options

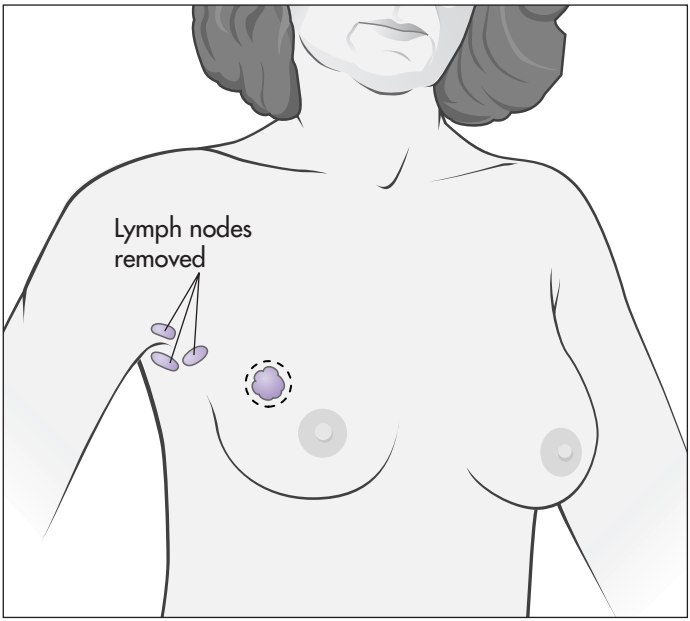
Surgery

Most women who have breast cancer today are diagnosed with Stage 0, I, or II breast cancer. Many of these women will live a long life. Most of these women can choose:

- Lumpectomy and radiation therapy, **OR**
- Mastectomy.

Studies show that both options provide the same long-term survival rates. However, neither option gives you a 100% guarantee that cancer will not return at the treated site. Whichever choice you make, you will still need medical follow-up and monthly breast self-exams for the rest of your life. Here is a closer look at today's most common breast surgeries:

Lumpectomy



With a lumpectomy, a surgeon removes the breast cancer, a little normal breast tissue around the lump, and some lymph nodes under the arm. This procedure tries to totally remove the cancer while leaving you with a breast that looks much the same as it did before your surgery. Women who choose a lumpectomy almost always have radiation therapy as well. Radiation decreases the risk of cancer coming back in the remaining breast tissue.

Possible problems: Infection, poor wound healing, bleeding, and a reaction to the drugs (anesthesia) used in surgery are the main risks of any kind of surgery, including lumpectomy. Women may have a change in the shape of the breast that was treated.

Questions to Ask Your Doctor

- How large will my scar be? Where will it be?
- How much breast tissue will be removed?
- Will I have local or general anesthesia?
- Will I need radiation or chemotherapy? Why? When should it start?

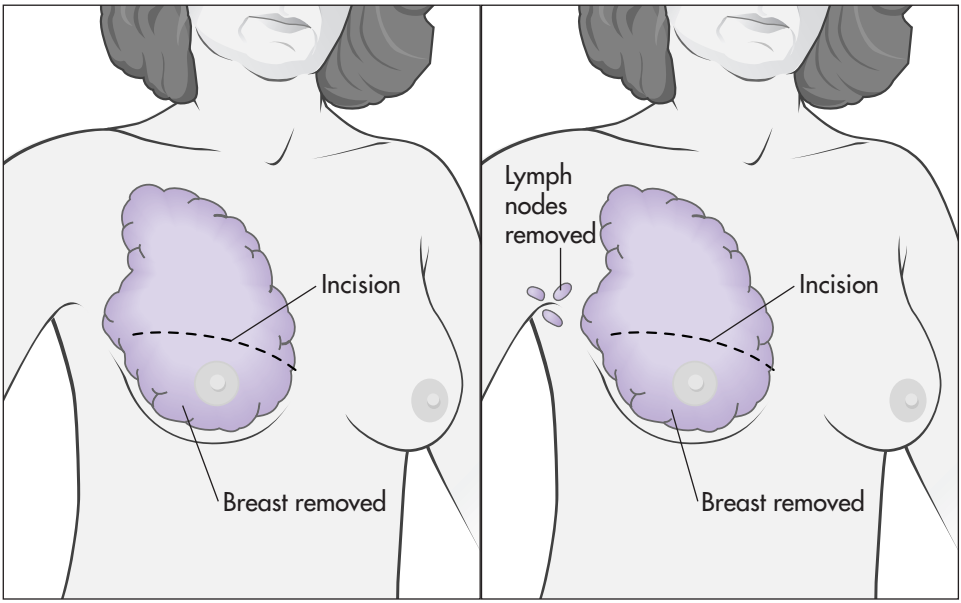
Mastectomy

A mastectomy—the surgical removal of the breast—used to be the only treatment for breast cancer. Today a woman who has a mastectomy is likely to have either:

- **Total Mastectomy.** This surgery removes as much breast tissue as possible, the nipple, and some of the overlying skin. The lymph nodes in the armpit are not removed.
- **Modified Radical Mastectomy.** This surgery removes as much breast tissue as possible, the nipple, some of the overlying skin, and some lymph nodes in the armpit.

A mastectomy is needed when:

- The cancer is found in numerous areas in the breast.
- The breast is small or shaped so that removal of the entire cancer will leave little breast tissue or a deformed breast.
- The woman does not want to have radiation therapy.



Total Mastectomy **Modified Radical Mastectomy**

Possible problems: Infection, poor wound healing, drug reactions, and a collection of fluid under the skin are possible complications.

After a mastectomy, a woman may choose to:

- Wear a breast form (a **prosthesis**) that fits in her bra. To get information on stores that have good fitters and breast forms, talk to your doctor, nurse, American Cancer Society volunteer, breast cancer organizations, and other women who have had breast cancer.
- Have her breast reconstructed by a plastic surgeon.
- Decide to do neither.

Group health insurance plans in California are required to pay for costs of a prosthesis or reconstruction. However, there may be restrictions as to where a woman can purchase the prosthesis or receive the breast reconstruction. For details of your plan, contact your insurance company.

Removal of Lymph Nodes

Whether you have a lumpectomy or mastectomy, your surgeon will usually remove some of the lymph nodes under your armpit. This procedure (an **axillary node dissection**) is most often done at the same time as the breast surgery. If cancer is found in the lymph nodes, your doctor will talk to you about additional treatments. These additional therapies are designed to control and kill cancer cells that could be in other parts of your body (see pages 16–19).

Advantage: Finding out the stage of your cancer.

Possible problems: Stiffness of the arm, numbness under your arm, and swelling of the arm. Physical therapy is often helpful to restore full motion of your arm.

Lymphedema. The lymph nodes in your armpit filter lymph fluid from the breast and your arm. Both radiation therapy and surgery can change the normal drainage pattern. This can result in a swelling of the arm called **lymphedema.** The problem can develop right after surgery or months to years later. About 5% to 20% of women develop this problem.

Treatment of lymphedema will depend on how serious the problem is. Options include an elastic sleeve, an arm pump, arm massage, and bandaging of the arm. Exercise and diet also are important. Should this problem develop, talk to your doctor and see a physical therapist as soon as possible. Many hospitals and breast clinics now offer help for this problem.

Protecting Your Arm

To avoid lymphedema or to protect your arm after treatment:

- Avoid sunburns and burns to the arm or hand.
- Have shots (including chemotherapy) and blood pressure tests done on the other arm.
- Use an electric razor for shaving underarms.
- Carry heavy packages or handbags on the other arm or shoulder.
- Wash cuts promptly, apply antibacterial medication, cover with a bandage, and call your doctor if you think you have an infection.
- Wear gloves to protect your hands when gardening and when using strong detergents.
- Avoid wearing tight jewelry on your affected arm or elastic cuffs on blouses and nightgowns.

Radiation Therapy

In most cases, a lumpectomy is followed by radiation therapy. High-energy radiation is used to kill cancer cells that might still be present in the breast tissue.

In standard therapy, a machine delivers radiation to the breast and in some cases to the lymph nodes in the armpit. The usual schedule for radiation therapy is 5 days a week for 5 to 6 weeks. Sometimes a "boost" or higher dose of radiation is given to the area where the cancer was found.

During treatment planning, your chest area will be marked with ink or with a few long-lasting tattoos. These marks need to stay on your skin during the entire treatment period. They mark where the radiation is aimed.

Possible problems: Side effects may include feeling more tired than usual and skin irritations, such as itchiness, redness, soreness, peeling, darkening, or shininess of the breast. Radiation to the breast DOES NOT cause hair loss, vomiting, or diarrhea. Long-term changes may include changes in the shape and color of the treated breast, spider veins, and heaviness of the breast.

Radiation after Mastectomy

There are times when radiation will be suggested after a mastectomy. It is suggested if:

- The tumor is larger than 5 cm. (2 inches).
- Cancer is in many lymph nodes in the armpit.
- The tumor is close to the rib cage or chest wall muscles.

Thoughts to Remember about Radiation Therapy

- You often will be alone in a room, but your radiation therapist can hear you and see you on a television screen.
- The treatment lasts a few minutes. You will not feel anything.
- The radiation is delivered to a small area—your treated breast.
- You are NOT radioactive during or after your therapy.
- You CAN hug, kiss, or make love as you did before your therapy.

Chemotherapy & Hormone Therapy

Research suggests that—even when your lump is small—cancer cells may have spread beyond your breast. Most of these cells are killed naturally by your body's immune system. When the growth of cancer cells is large enough to be detected, it means that your immune system is having difficulty fighting the cancer and needs additional help.

Help in killing cancer cells comes from two other forms of therapy—**chemotherapy** and **hormone therapy.** Now, more than ever before, these treatments are chosen for your individual case: your age, whether you are still having periods, and how willing and able you are to cope with the possible side effects. These therapies are used to:

- Prevent cancer from coming back in women who are newly diagnosed with breast cancer, especially if they are at high risk for spread of the disease to other organs of the body.
- Control the disease when cancer is found in the lungs, bones, liver, brain, or other sites.
- Control the disease in women whose cancers have come back one or more times.

Chemotherapy

Chemotherapy drugs are designed to travel throughout your body and slow the growth of cancer cells or kill them. Most often the drugs are injected into the bloodstream through an intravenous **(IV)** needle that is inserted into a vein. Some are given as pills. Treatments can be as short as 4 months or as long as 2 years. The drugs you take will depend on the stage of the cancer at the time you are diagnosed or if the cancer returns.

Questions to Ask Your Doctor

- Do I need chemotherapy? What drugs do you recommend?
- What are the benefits and risks of chemotherapy?
- How successful is this treatment for the type of cancer I have?
- How long will I need chemotherapy?
- Can I work while I'm having chemotherapy?
- How can I manage side effects like nausea?

Managing Nausea

Feeling nauseous, or as though you have to vomit, is a common side effect of chemotherapy. The following suggestions may help:

- Ask for new drugs that reduce nausea and vomiting.
- Eat small meals often; do not eat 3 to 4 hours before your treatment.
- Eat popsicles, gelatin desserts, cream of wheat, oatmeal, baked potatoes, and fruit juices mixed with water.
- Chew your food thoroughly and relax during meals.
- Learn stress reduction exercises.

Chemotherapy is usually given in cycles. You get one treatment and are given a few weeks to recover before your next treatment. The drugs most often are given in a doctor's office or in an outpatient department of a hospital or clinic.

Possible problems: The most common side effects are fatigue, nausea, vomiting, diarrhea, constipation, weight change, mouth ulcers, and throat soreness. Some drugs cause short-term hair loss. Hair WILL grow back after or sometimes during treatment.

Before you start your therapy, you may want to have your hair cut short, buy a wig, hat, or scarves that you can wear while you are going through treatment. Also, finish dental work before starting your therapy. You cannot have dental work during chemotherapy because you are more prone to infections.

Fighting Infections. Your body is less able to fight infections while you are on chemotherapy. The following steps can help you stay healthy:

- Stay away from large crowds and from people with colds, infections, and contagious diseases.
- Bathe daily, wash hands often, and follow good mouth care.
- Wear work gloves to protect hands against cuts and burns.
- If you cut yourself, keep the wound clean and covered.
- Eat a healthy diet and get plenty of rest.

Pregnancy and Early Menopause. During chemotherapy, you may stop having periods or enter into an early menopause. You can still get pregnant, however, so talk to your doctor about birth control. The effect of chemotherapy on an unborn baby is unknown. After your treatment has stopped, your ability to get pregnant will vary, depending on the drugs you received. If you plan to become pregnant after treatment, talk with your doctor **before** starting treatment.

Hormone Therapy

Tests are routinely done on breast cancer cells to decide if the cancer is "sensitive" to natural hormones (estrogen or progesterone) in the body. If the tests find that the cancer is "positive," it means that cancer cells may grow when these hormones are present in a tumor. You may be given a **hormone blocker** (a drug called tamoxifen) that will prevent your body's natural hormones from reaching the cancer. These drugs are taken daily in pill form.

Possible problems: Hot flashes, nausea, vaginal spotting. Less common side effects include depression, vaginal itching, bleeding or discharge, loss of appetite, headache, and weight gain. Studies show that there is a slight increased risk of uterine cancer and blood clots for women on this drug. You should have an annual pelvic exam and notify your doctor if you are taking tamoxifen.

Questions to Ask Your Doctor

- Am I at high risk for cancer to come back?
- Will hormone therapy help me?
- What are the side effects of hormone therapy?
- Is there anything that will help me deal with side effects?
- How long do I have to take hormone therapy?

What You Should Know

Discuss information on implants with:

- A plastic surgeon(s).
- The American Cancer Society, **1-800-ACS-2345.**
- The National Cancer Institute's hotline, **1-800-4-CANCER.**
- The Food and Drug Administration, **1-800-532-4400.**
- Breast implant groups and other women who have had reconstruction.

Breast Reconstruction

Breast reconstruction—surgery to "rebuild" a breast—is a routine option for any woman who has lost a breast because of cancer. California law requires that group health insurers pay for reconstruction and for surgery to the other breast to obtain a good match.

Reconstruction will not give you back your breast. The rebuilt breast will not have natural feelings. But the surgery can give you a result that looks like a breast.

If you are thinking about reconstruction, discuss this option with a plastic surgeon ***before*** your mastectomy. Ask your surgeon for a referral to an experienced plastic surgeon. Some women start reconstruction at the same time as their mastectomy; others wait several months or even years. Your body type, age, and cancer treatment will determine which reconstruction will give you the best result.

Reconstruction with Implants

Implants are plastic sacs filled with silicone (a type of liquid plastic) or saline (salt water). The sacs are placed under your skin behind your chest muscle.

There are concerns about silicone-filled implants.

- Manufacturers and recent studies report that the silicone-filled implants are safe. They say that the safety record of implants is based on 30 years of experience with more than one million women.
- However, lawsuits have been filed for women who claim that the implants caused them to develop immune system disorders (such as lupus, scleroderma, and rheumatoid arthritis) and other complications.

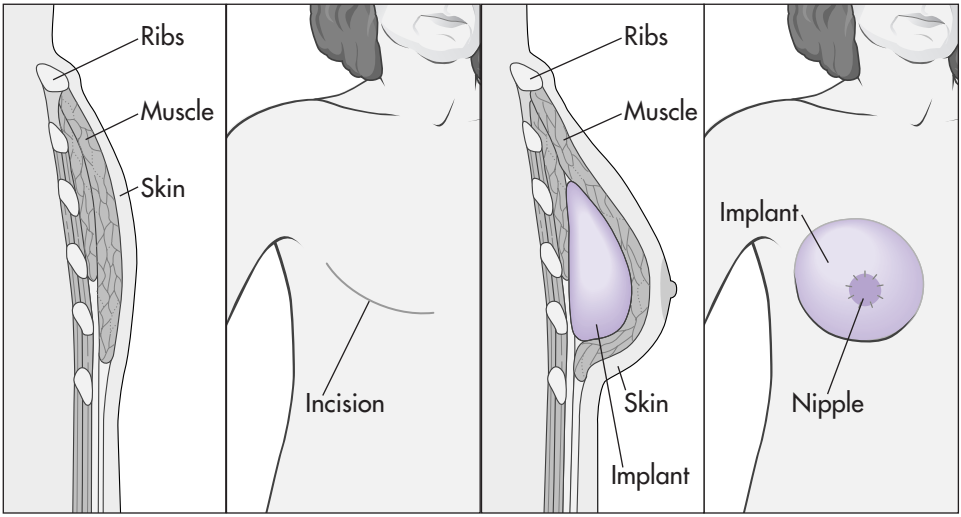
The Food and Drug Administration (FDA) reports that implants do not cause cancer. There also is no scientific evidence to link implants with immune system disorders. But the FDA states that more studies are needed before a final decision can be made. These studies are now under way.

Studies also are looking at saline-filled implants, but these implants cause less concern. If major problems do exist with either type of implant, they appear to affect a small number of women. For this reason, women who have a mastectomy can still choose to have their breast rebuilt with either a silicone or saline implant.

Possible problems: It is natural for scar tissue to form around an implant. Sometimes this scar may shrink, causing the implant to ball up and feel firm. This can cause pain or a deformed breast. This scar tissue may have to be treated with surgery. Breakage of the implant's cover is another possible problem.

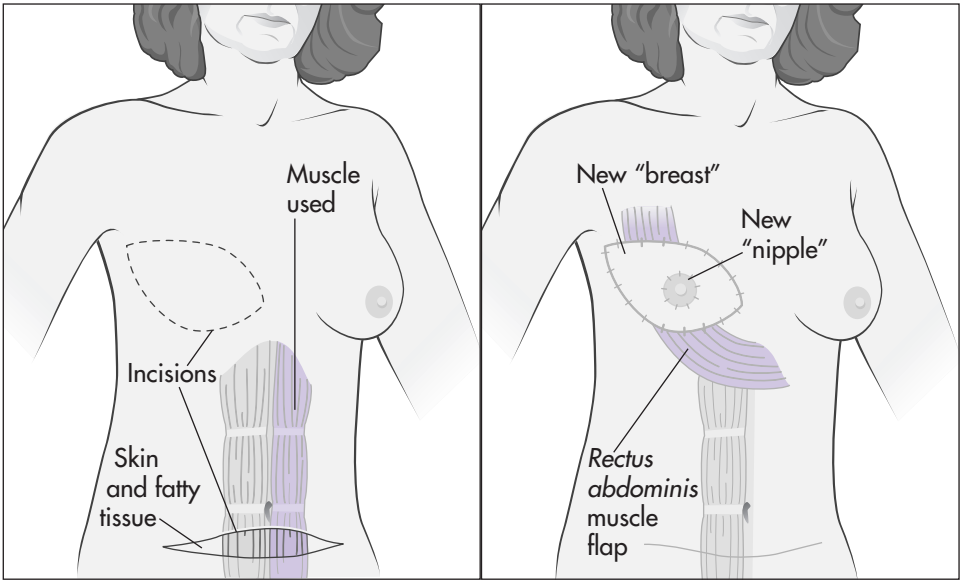
Questions to Ask Your Plastic Surgeon

- What is the latest information on the safety of implants?
- How many breast reconstructions have you done?
- How many surgeries will I need?
- Which type of surgery will give me the best result?
- Can I see pictures of women you have reconstructed? Could I contact someone?
- How long will my recovery take?



After Mastectomy **After Reconstruction with Implants**

Reconstruction with Tissue Flaps



This flap of muscle, skin, and fatty tissue is moved, still connected to its blood supply. It is shaped to form a new "breast."

What You Should Know

Most women who have breast reconstruction are happy with their decision. A woman starting this process, however, should know that it is seldom finished with one surgery. Extra steps may include:

- Adding a nipple.
- Surgery on the opposite breast to create a good match.
- Refinements in the shape of the rebuilt breast.

With most of these extra surgeries, you can go home the same day as the operation.

Muscle, fat, and skin from another part of the body can be moved to the chest area, where it is shaped into the form of a breast. This tissue can be taken from the:

- Lower stomach area (*rectus abdominis* muscle flap)
- Back (*latissimus dorsi* muscle flap)
- Buttocks (*gluteus* muscle flap).

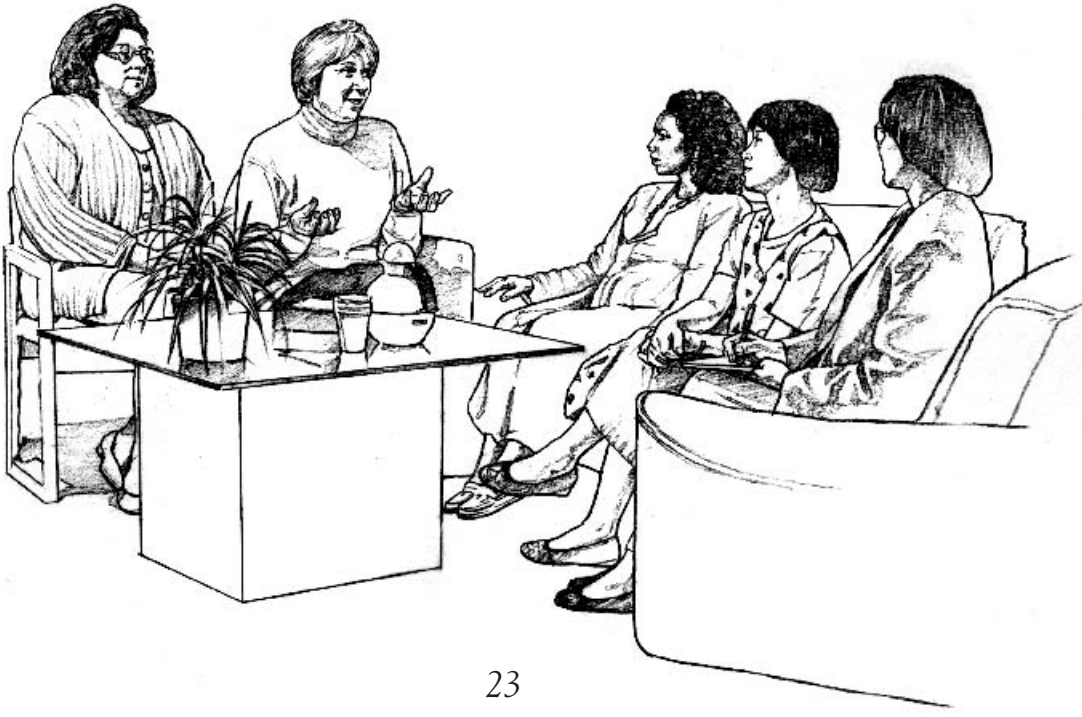
Possible problems: There are larger wounds. It takes longer to recover. If there is a poor blood supply to the flap tissue, part or all of the new breast can be lost. Infection and poor wound healing are possible problems. Choose a plastic surgeon who has been trained in this procedure and has performed it successfully on many other women.

6 Emotional Healing

It is normal to have trouble coping with a diagnosis of breast cancer. Some women feel fear, anger, denial, frustration, loss of control, confusion, and grief. Others feel lonely, isolated, and depressed. Women also have to deal with issues about their self-image, future priorities, sexuality, and possible death.

Each woman has to deal with these issues and her diagnosis of cancer in her own way and on her own time schedule. Many women find that it helps to talk about their feelings with their loved ones or close friends. When you reach out, you are giving loved ones and friends the chance to show their support during this difficult time.

As much as you feel comfortable, talk about your concerns with members of your health care team. Many women are helped by talking about their feelings with other women



"Cancer might rob you of the blissful belief that tomorrow stretches into forever. In exchange, you are granted the vision to see each day as precious, a gift to be used wisely and richly. No one can take that away."
National Cancer Institute

who have had breast cancer. You may want to talk to the friend or family member who can just listen and allow you to sort out your feelings without giving any advice.

Hospitals often offer a support group or meetings with counselors as part of standard treatment. Ask your doctor if your hospital has this service. You also may want to look into family or individual therapy. Growing numbers of therapists offer services to individuals, families, and friends affected by cancer.

Complementary Therapies

Persons living with cancer sometimes want to explore complementary therapies in addition to their medical treatment. These therapies are often not proven by scientific studies. Some women feel that they have benefited from some of these therapies.

Complementary therapies include acupuncture, herbs, biofeedback, visualization, meditation, yoga, nutritional supplements, and vitamins. If you decide to try these therapies, discuss the side effects and data on their value with your doctors. Also be aware that these therapies may be expensive and most are not paid for by health insurance.

Living with Cancer

Concerns and fears about breast cancer are likely to stay with you. A new ache or pain, a medical test, or the anniversary of your diagnosis may unexpectedly get you down or worried. These feelings are part of being a cancer survivor. But the emotions will be fewer and farther between as you return to your regular activities.

7 Helpful Information

This brochure is one starting point to help you understand your diagnosis and treatment options. To get up-to-the-minute information on the changes taking place in breast cancer treatment and research and for insights into treatments or studies that are now in progress, call the toll-free telephone number:

1-800-4-CANCER.

This number puts you in contact with the Cancer Information Service, operated by the National Cancer Institute. Trained cancer specialists, who speak English and Spanish, can:

- Mail you free literature on a range of topics including surgery, radiation therapy, chemotherapy, eating hints, and pain control.
- Provide names and addresses of doctors or cancer centers that provide second opinions .
- Provide fact sheets on current issues and controversies that show up in the daily news media.
- Give you access to Physician Data Query (PDQ), a computer information center that provides the most up-to-date information on treatments for most types of cancer.
- Give you information on **clinical trials.**

Clinical Trials

People who join clinical trials have a chance to benefit from new research and to make a contribution to medical science. Each study is designed to answer a scientific question on how to prevent, detect, or treat cancer. Studies place a portion of the patients in a "control group." These study participants receive the standard treatment so that their results can be compared with those of participants who receive the new treatment. During the trial, you may not know in which group you have been placed. Clinical trials take time. Until a trial is over, the true value of the new treatment will not be known. There may also be unknown side effects. If you are thinking about joining a clinical trial, you will receive written material that will help you decide whether to join. You can quit the trial at any time.

Words to Know

Anesthesia: drugs given before and during surgery so you won't feel the surgery. You may be awake or asleep.

Axillary node dissection: removal of some of the lymph nodes in the armpit.

Benign: a growth that is not cancer.

Biopsy: removal of a sample of tissue to see if cancer is present.

Chemotherapy: treatment with drugs to kill or slow the growth of cancer.

Clinical trial: controlled scientific studies set up to answer questions about how to prevent, detect, or treat cancer.

Core biopsy: a biopsy that uses a small cutting needle to remove a sample of tissue from a breast lump.

Estrogen or progesterone receptor test: laboratory tests done to determine if cancer is sensitive to estrogen and progesterone hormones in the body.

Excisional biopsy: surgical removal of the whole lump and some surrounding tissue.

Fine needle aspiration: a biopsy that uses a fine needle to remove fluid from a cyst or a cluster of cells from a solid lump.

Hormones: substances produced by various glands in the body that affect the function of body organs and tissues.

Implant: a silicone or saline-filled sac inserted under the chest muscle to restore breast shape.

Incisional biopsy: surgical removal of a portion of an abnormal area of tissue or lump.

Intravenous (IV): injection into the vein.

Invasive cancer: cancer that has spread to nearby tissue, lymph nodes in the armpit, or other parts of the body.

In situ "cancer": very early or noninvasive growths that are confined to the ducts or lobules in the breast.

Localization biopsy: using mammography or ultrasound to locate an area of concern that cannot be felt by hand.

Lumpectomy: surgical removal of breast cancer and a small amount of normal tissue surrounding the cancer.

Lymph nodes: part of the lymph system that removes wastes from body tissues and filters the fluids that help the body fight infection. Lymph nodes in the armpit are usually removed to determine the stage of breast cancer.

Lymphedema: swelling in the arm caused by fluid that can build up when the lymph nodes are removed during surgery or damaged by radiation.

Malignant: cancer.

Mammogram: an x ray of the breast.

Mastectomy: removing the breast by surgery.

Metastasis: spread of cancer from one part of the body to another.

Needle localization biopsy: use of mammography or ultrasound to guide a needle to a suspicious area that cannot be felt but shows up on a mammogram.

Prosthesis: an external breast form that may be worn in a bra after a mastectomy. Also, the technical name of a breast form that is placed under the skin in breast reconstruction.

Radiation: energy carried by waves or by streams of particles. Various forms of radiation can be used in low doses to diagnose cancer and in high doses to treat breast cancer.

Recurrence: reappearance of cancer at the same site (local recurrence), near the original site (regional recurrence), or in other areas of the body (distant recurrence).

Risk factors: conditions that increase a person's chance of getting cancer. Risk factors do not cause cancer; rather, they are indicators, linked with an increase in risk.

Silicone: a synthetic liquid gel that is used as an outer coating on implants and to make up the inside filling of some breast implants.

Staging: classifying breast cancer according to its size and spread.

Stereotactic needle biopsy: a technique that uses double-view mammography to pinpoint a specific target area; most often used with needle biopsy when a lump cannot be felt.

Tamoxifen: a hormone blocker used to treat breast cancer.

Tumor: an abnormal growth of tissue. Tumors may be either benign (not cancer) or malignant (cancer).

Two-step procedure: biopsy and treatment done in two stages, usually a week or more apart.

Ultrasound-guided biopsy: fine needle aspiration or core biopsy with guidance from ultrasound.

X rays: a high-energy form of radiation used for detecting or treating cancer.

Where to Get Help

Your local hospital, breast cancer organization, or cancer center will usually have **patient education materials** that they will send you if you call them for information.

Your doctor or the organizations listed below can help you get lists of local organizations or support groups. Also ask if your area has a local **resource guide** that lists providers, support groups, wig and prosthesis shops, etc.

Your local library or bookstore has numerous **books and publications** about breast cancer that have been written by women survivors and by medical professionals. **Breast cancer organizations** can also give you up-to-date lists of suggested books for further reading.

Breast Cancer Organizations and Services

These statewide or national organizations can provide you with information, materials, and services related to breast cancer. They also can refer you to breast cancer organizations and support groups in your area if available.

American Cancer Society, Information Line, **1-800-ACS-2345.** Local chapters are listed in the white pages of your telephone book. Provides free information and emotional support from trained volunteers anytime before, during, or after treatment. Programs include Reach to Recovery, Partners, Early Support, and Look Good Feel Better. Supplies free brochures on treatment, reconstruction, sexuality, what to do about job discrimination, and other topics.

Breast Cancer Consultation Service, 450 Stanyan St., San Francisco, CA 94117, **(415) 750-5848,** Fax (415) 750-8123. Self-referral service specializing in second opinions and diagnosis of **in situ "cancers."** Cost depends on extent of review. Fees may be covered by insurance. Sliding scale exists.

California Breast Cancer Organizations (CABCO), 555 W. Beech St. #452, San Diego, CA 92101, **(619) 239-9283.** A statewide coalition of breast cancer advocacy groups; members support legislation on breast cancer issues, increase awareness of breast cancer, and provide support and education. Contact group for local organizations.

Mary-Helen Mautner Project for Lesbians with Cancer, 1707 L St., NW, Ste. 1060, Washington, DC 20036, **(202) 332-5536,** Fax (202) 265-6854.

National Alliance of Breast Cancer Organizations (NABCO), 9 E. 37th St., 10th Floor, New York, NY 10016, **(212) 889-0606,** Fax (212) 689-1213. National coalition of breast cancer organizations; supplies fact sheets, articles, and a newsletter on topics of breast cancer.

National Breast Cancer Coalition, 1707 L Street NW, Suite 1060, Washington, DC 20036, **(202) 296-7477.** A national advocacy group that lobbies for increased research funding, access to medical services, and education.

National Cancer Institute's Cancer Information Hotline, 1-800-4-CANCER. Offers free state-of-the-art information in English or Spanish on treatment, clinical trials, eating hints, advanced cancer, and services in your area.

National Coalition for Cancer Survivorship, 1010 Wayne Avenue, 5th Floor, Silver Spring, MD 20910, **(301) 650-8868.** Promotes the awareness of cancer survivorship by peer support and information.

National Women's Health Network, 514 10th St. NW, Suite 400, Washington, DC 20005, **(202) 347-1140.** Provides newsletters and position papers on women's health topics.

Susan G. Komen Breast Cancer Foundation, Komen Help Line, 1-800-462-9273. Dedicated to advancing research, education, screening, and treatment of breast cancer.

Women's Information Network (WIN) Against Breast Cancer, 19325 E. Navilla Place, Covina, CA 91723-3244, **(626) 332-2255, Fax (626) 332-2585, email: winabc@flash.net.** Provides educational information on breast cancer treatment, support, and resources to physicians and survivors.

YWCA of the USA/Encore Plus, 624 9th Street NW, 3rd floor, Washington, D.C., 20001, **(202) 628-3636.** Contact the national headquarters for the location of a group near you. Provides support and rehabilitative exercises for women with breast cancer.

Y-ME National Breast Cancer Hotline, 1-800-221-2141. Cancer survivor volunteers share personal experiences on everything from treatment information to emotional recovery. Local branches also provide wig and prosthesis bank. Contact group for local chapters.

Complementary Treatment Information

National Cancer Institute's Office of Alternative Medicine, 6120 Executive Blvd., Suite 450, Bethesda, MD 20892, **(301) 402-2466.**

National Council Against Health Fraud, Consumer Health Information Research Institute, 3521 Broadway, Kansas City, MO 64111, **1-800-821-6671.**

Breast Reconstruction

Breast Implant Hotline of the Food and Drug Administration, **1-800-532-4400.**

American Society of Plastic and Reconstructive Surgeons, 444 E. Algonquin Rd., Arlington Heights, IL 60005, **1-800-635-0635.** A list of 5 certified plastic and reconstructive surgeons in your area will be mailed upon request.

California Society of Plastic and Reconstructive Surgeons: Maintains a consumer information and referral service at **1-800-722-2777.**

Lymphedema

National Lymphedema Network, 2211 Post St., Ste. 404, San Francisco, CA 94115, **1-800-541-3259.** Provides complete information on prevention and treatment of lymphedema.

Arnold Schwarzenegger
Governor of California

The California Department of Health Services would like to acknowledge the breast cancer advocates and medical experts whose hard work and commitment to empowering women to make informed decisions helped create this booklet.

January 1995

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