

a
Woman's Guide
to
Breast Cancer
Treatment

Developed by the
Cancer Detection Section
California Department of Public Health
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*Cancer Detection Programs:
Every Woman Counts*

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introduction

Talk openly with your doctor and other members of your healthcare team. It is important to ask questions and share information.

The State of California requires that your doctor give you this booklet if you have been diagnosed with breast cancer. It was written to tell you about the many types of treatment available.

As you read the booklet, keep in mind that it is not a replacement for your doctor's advice but an additional resource for learning about your choices. Your doctor and other members of your healthcare team are available to help with deciding the most appropriate treatment plan for you.

For most women, a diagnosis of breast cancer comes as a shock. You may find it hard to focus on all the new information all at once.

Tips to Manage Information Overload

- Begin reading when you feel ready.
- Ask a friend or family member to read this booklet along with you.
- Read sections of the booklet as you need them.
- Keep a pen or pencil handy for making notes.
- Look up words that are new to you in the Words to Know section in the back of the booklet.
- Write down questions to ask your doctor before your medical appointments. This guide has some suggestions for what to ask.
- Tape record your doctor visits or take notes to help you remember what was said.
- Ask that information be explained to you in a way that you understand.
- Have a friend or family member go with you when you visit your doctor.
- Talk with other women who have been treated for breast cancer. The American Cancer Society and National Cancer Institute can link you to an individual or support group.

Asking for a Second Opinion

Second opinions are your right and are common for confirming a diagnosis or treatment plan. The American Cancer Society can help by referring you to organizations that provide lists of nearby doctors who specialize in breast cancer.

For More Information

This booklet is a starting point for learning about your treatment options. It may not include all possible treatments or tell you all you need to know about side effects and possible problems. For more information, you may want to contact the American Cancer Society or the National Cancer Institute. Most services are offered in English and Spanish. There are also several good comprehensive books on the subject.

American Cancer Society (ACS)

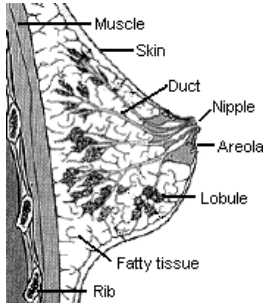
Call **1 800-227-2345** or go online at www.cancer.org. ACS provides information on all aspects of cancer through the toll-free information line, web site, and published materials. You can also find out about activities, news, and special programs, such as *Reach to Recovery and Look Good...Feel Better*. These programs have trained volunteers who offer support and comfort to women with breast cancer before, during and after treatment.

National Cancer Institute (NCI)

Call **1 800-422-6237** or go online at www.cancer.gov. NCI information specialists are available by phone or through LiveHelp on the NCI web site (click on LiveHelp online chat).

about breast cancer

WHAT IS BREAST CANCER?



A woman's breast is made up of fatty tissue, ducts, and lobules that produce milk (milk glands). Breast cancer develops when cells in a part of the breast become abnormal and begin to grow and divide out of control. If left untreated, these abnormal cells can invade and damage nearby tissue. They can also spread to more distant parts of the body through the bloodstream or through the lymphatic system.

WHAT CAUSES BREAST CANCER?

No one knows for sure what causes breast cancer or why some women get it and others do not. There is ongoing research in this area. What is known is that:

- More women than men get it. (About 99% of breast cancers occur in women.)
- More older than younger women get it. (Nearly 80% of breast cancers occur in women older than 50.)
- Most women do not have a family member who has had it. (Only 20% to 30% of women with breast cancer have a family member with the disease.)
- Breast cancer is not contagious. (It cannot be caught from someone else.)
- Breast cancer is not caused by stress or injury to the breast.
- Breast cancer is not caused by antiperspirants, underwire bras, or caffeine.

HOW COMMON IS BREAST CANCER?

Breast cancer is the second most common cancer diagnosed in women. Only skin cancer is more common.

- A woman who lives to be 80 years old will have a 1 in 8 chance of getting breast cancer. A woman in her thirties has a 1 in 233 chance.
- In California, about 25,000 women are diagnosed with breast cancer each year.
- In the United States, about 250,000 women are diagnosed with breast cancer each year.
- Currently, there are about 2.5 million breast cancer survivors living in the United States.

TYPES OF BREAST CANCER

Eighty-nine percent of women diagnosed today can expect favorable outcomes, according to the American Cancer Society.

Knowing the types of breast cancer is important for understanding your treatment options. There are two main types:

- non-invasive
- invasive

Non-Invasive Breast Cancer

Breast cancer that has not spread from where it began in the breast (usually the milk duct) is called non-invasive. It is also called carcinoma in situ. You may hear about two types of carcinoma in situ. One of them, however, is not a true cancer.

Lobular Carcinoma in Situ (LCIS) (also called lobular neoplasia) is a condition in which abnormal cells are found within the breast lobule. Despite its name, LCIS is not considered a true cancer. Instead, it is a warning sign that a woman's risk for developing breast cancer (in either breast) is increased.

Ductal Carcinoma in Situ (DCIS) is a non-invasive cancer that is found in the milk duct of the breast and has not spread outside the duct. However, some cases of DCIS will eventually change into invasive breast cancers if left untreated. Since it is not known which ones will change, surgical removal of the cancer followed by radiation therapy is usually recommended.

Invasive Breast Cancer

Cancer that has spread from where it began in the breast into nearby tissue is called invasive (or infiltrating) breast cancer. About 70% to 75% of all breast cancers are invasive.

Invasive Ductal Carcinoma (IDC) is the most common type of breast cancer. It is cancer that started in a milk duct, has broken through the wall of the duct, and has invaded nearby tissue. It may or may not have spread to lymph nodes or to more distant parts of the body. Most invasive breast cancers (about 80%) are of this type.

Invasive Lobular Carcinoma (ILC) is cancer that started and has spread from a breast lobule to nearby tissue. Like IDC, it may or may not have spread to lymph nodes or to other parts of the body. About 10% to 15% of invasive breast cancers are ILCs.

In addition to Invasive Ductal Carcinoma and Invasive Lobular Carcinoma, there are several less common types of invasive breast cancers, such as Inflammatory Breast

Cancer (IBC), Medullary Cancer, Metaplastic Carcinoma, Mucinous Carcinoma, Paget's Disease of the Nipple, and others. Women interested in learning more about these less common types of breast cancer can contact the **American Cancer Society** or the **National Cancer Institute** for information.

FOR YOUR INFORMATION:

- The spread of cancer is sometimes described as LOCAL, REGIONAL, or DISTANT.
- LOCAL cancer has not spread beyond the breast.
- REGIONAL cancer has spread to the lymph nodes, usually to those in the underarm area.
- DISTANT cancer has spread to other parts of the body through the bloodstream or lymph system. This is also called metastatic breast cancer.

BREAST CANCER STAGING

Cancer staging is used for helping you and your doctor make decisions about your treatment. Staging is also used for making predictions about how well your breast cancer is likely to respond to treatment.

The stage of a breast cancer depends on:

- how much cancer is present (tumor size)
- whether the cancer has spread
- where else in the body cancer is found

Information for staging is gathered from the results of your physical exam, biopsy, and imaging tests (called clinical staging), and from the results of surgery for removing the cancer (called pathologic staging). Blood tests may also be done.

Staging (Roman Numeral)

There are five main stages of breast cancer: Stage 0 through Stage IV (with Stages II and III further divided into subcategories). Stages 0 through IIIA are generally thought of as “early” forms of breast cancer. Stages IIIB and IIIC may be called “late” stage. Stage IV is “advanced.” (See Breast Cancer Stages, page 8, for more detailed information about breast cancer staging.)

FOR YOUR INFORMATION:

In addition to Roman Numeral Staging your doctor may use TNM Staging to describe your cancer:

- T describes the size of the Tumor and whether it has invaded nearby tissue.
- N describes whether regional lymph Nodes are involved.
- M describes Metastasis (the spread of cancer to distant parts of the body).

BREAST CANCER STAGES

Stage 0 This is Ductal Carcinoma in Situ (DCIS). The cancer has not spread beyond the breast duct.

Stage I The cancer is 2 cm or less across and is not found in the lymph nodes.

Stage IIA The cancer is 2 cm or less across and is found in 1 to 3 underarm lymph nodes and/or in the internal mammary lymph nodes, OR the tumor is between 2 and 5 cm across and is not found in the lymph nodes.

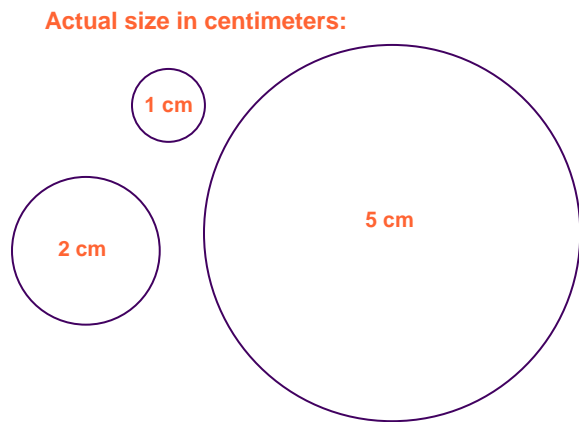
Stage IIB The cancer is between 2 and 5 cm across and is found in 1 to 3 underarm lymph nodes and/or in the internal mammary lymph nodes, OR the cancer is 5 cm or larger across and is not found in the lymph nodes.

Stage IIIA The cancer is 5 cm or less across and is found in 4 to 9 underarm lymph nodes or in the internal mammary lymph nodes, OR the cancer is 5 cm or larger across and is found in 1 to 9 underarm lymph nodes or in the internal mammary lymph nodes.

Stage IIIB The cancer has grown into the chest wall or skin. It may or may not be found in the underarm or internal mammary lymph nodes.

Stage IIIC The cancer can be any size and is found in 10 or more underarm lymph nodes, OR involves both underarm and internal mammary lymph nodes, OR the cancer involves lymph nodes under or above the collar bone.

Stage IV The cancer can be any size and is found beyond the breast area in more distant parts of the body, such as the bone, lung, or brain.



ADDITIONAL TESTS

There are additional tests that give more information about your cancer. They are used for helping you and your doctor determine the best treatment plan for you.

Hormone Receptor Test: This test shows whether your cancer cells have estrogen or progesterone receptors. Breast cancers with either or both of these receptors are called hormone receptor-positive. Hormone receptor-positive breast cancers rely upon hormones in order to grow. About 2 out of 3 breast cancers are hormone receptor-positive.

HER2 Test: This test is used for invasive breast cancers to measure a substance called HER2 (also called HER2/neu). Breast cancers with too much HER2 protein, or with too many copies of the HER2 gene, are called HER2-positive. HER2-positive breast cancers tend to grow and spread more rapidly than other breast cancers. About 1 out of 5 women with breast cancer have HER2-positive cancer.

Gene Expression Profiling Test: This test looks at the gene characteristics of cancer cells to help plan treatment and to assess the risk of cancer coming back. This test is newer and not yet offered on a regular basis. Ask your doctor if gene expression profiling would be helpful in your case.

Questions to Ask Your Doctor...

- What type of breast cancer do I have?
- What is the stage of my breast cancer?
- What is the grade of my cancer?
- Does my cancer have hormone receptors?
- Has my cancer been tested for HER2?
- Do I need any other tests?
- Can you explain my pathology report to me?
- What treatments do you recommend for me?
- Are there breast cancer survivors who have had these treatments that I can talk with?
- How soon do I need to begin treatment?
- How do you think my cancer will respond to treatment?
- What if I want a second opinion... How do I get one?
- Who will be on my treatment team?
- Who do I call if I have more questions?

YOUR TREATMENT TEAM

No one doctor is able to provide all of the types of treatment you may need. Here are some of the experts who could become part of your healthcare team. You will find their descriptions in the *Words to Know* section in the back of this booklet.

- Anesthesiologist
- Case Manager / Patient Navigator
- Clinical Nurse Specialist
- Lymphedema Therapist
- Occupational Therapist
- Oncologist
- Oncology Nurse
- Pathologist
- Physical Therapist
- Plastic Surgeon
- Primary Care Provider
- Psychologist
- Radiation Oncologist
- Radiation Therapist
- Radiologist
- Radiology Technologist
- Social Worker
- Surgeon

types of treatment

With breast cancer, it is important to realize that there is no one “right” treatment for every woman. The “right” treatment for you will take into account your individual case and your own personal preferences.

There are five main types of treatment for breast cancer: surgery, radiation therapy, chemotherapy, hormonal therapy, and targeted therapy.

Your treatment plan will be based on many factors, including the type and stage of your cancer, whether your cancer is HER2-positive or hormone receptor-positive, your medical history, and your overall health. Remember that no matter what the type and stage of your breast cancer, there are treatments that can help.

Local and Systemic Therapy

Treatments for cancer are grouped into one of two categories, called either local or systemic therapy.

Local therapy is used to remove and destroy cancer where it is found. This includes the cancer and a small area around it. Examples of local therapy are surgery and radiation therapy.

Systemic therapy includes treatments that are sent throughout the body to reach cancer cells anywhere they might be. Drugs may be given by mouth or directly into the bloodstream. Chemotherapy, hormonal therapy and targeted therapy are all examples of systemic therapy.

SURGERY

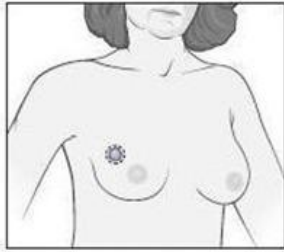
Most women will have surgery plus one or more additional types of treatment.

Surgery is a local therapy that removes the cancer. There are two main types for breast cancer:

- breast-conserving surgery (also called lumpectomy or partial mastectomy)
- mastectomy

Breast-Conserving Surgery

Breast-conserving surgery is an operation that removes the cancer along with a small surrounding rim of normal tissue. (If no cancer is found in the normal tissue, it is called a clean margin.) The goal is to save as much of the breast as possible while removing



Breast-Conserving Surgery

all of the cancer. Often, underarm lymph nodes are also removed (see Lymph Node Removal, page 13). Breast-conserving surgery is almost always followed by radiation therapy to help destroy any remaining cancer cells. This lowers the risk of cancer coming back.

Usually, women with one small area of breast cancer who are able to have radiation therapy can choose breast-conserving surgery. Studies have shown that breast-conserving surgery followed by radiation therapy is just as effective as mastectomy for most women with Stage I or II breast cancer.

Possible Problems

Side effects may include temporary swelling, pain and tenderness. Wound infection, poor healing, a reaction to anesthesia, and excessive bleeding are possible but rare. Sometimes, a second surgery is needed if the first surgery failed to remove all of the cancer.

Mastectomy

Mastectomy is surgery that removes the whole breast in order to treat the breast cancer. There are two main types:

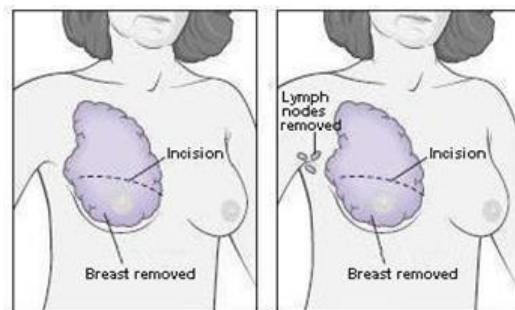
Total mastectomy (also called simple mastectomy) removes the breast, some of the breast skin and the nipple, but not the underarm lymph nodes.

Modified radical mastectomy removes the breast, some of the breast skin, the nipple, and most of the underarm lymph nodes.

Your doctor may recommend mastectomy if cancer is found in more than one area of your breast, or if you are not able to have (or not wanting) radiation therapy after surgery.

Breast size is also a factor. Breast-

conserving surgery is usually not possible if the cancer is large in relation to the size of the breast. In addition to these considerations, a woman may choose mastectomy over breast-conserving surgery for personal reasons.



Total (or Simple) Mastectomy Modified Radical Mastectomy

Most women who have a mastectomy can also choose to have breast reconstruction surgery (see Breast Reconstruction, page 23). Breast reconstruction may be done at the same time as the mastectomy or at any time later. Women planning to have their breast reconstructed should ask their doctors about skin-sparing mastectomy. Skin-

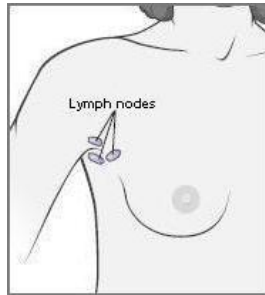
sparing mastectomy saves most of the breast skin (not including the nipple and areola) for improved cosmetic results.

Possible Problems

Risks with mastectomy are the same as with any major operation, including infection, problems with wound healing, unusual bleeding, and risk of blood clots. Risks with general anesthesia are higher than with local anesthesia but they are still very low. Mastectomy with lymph node removal can result in numbness in the upper arm and underarm areas, reduced arm or shoulder motion, or arm swelling (called lymphedema).

Lymph Node Removal

In addition to surgery for removing the cancer, surgery is used for removing and sampling underarm lymph nodes (also called axillary lymph nodes).



Lymph node removal may be done with either breast-conserving surgery or with mastectomy. Its purpose is to determine whether the cancer has spread beyond the breast. There are two main methods: axillary lymph node dissection (ALND) and sentinel lymph node biopsy (SLNB).

Axillary Lymph Node Dissection (ALND) is a long-standing method for removing lymph nodes. With ALND, lymph nodes (usually, 10 or more) are removed from the underarm area and examined under a microscope. Finding cancer in any of these nodes means that there is a greater risk that cancer cells have spread to other parts of the body.

Sentinel Lymph Node Biopsy (SLNB) is a newer and less invasive way to find out whether cancer has spread. SLNB removes just the first 1 to 3 nodes (called sentinel nodes) that are most likely to contain cancer cells (as determined by the injection of a special dye and/or weak radioactive substance). If cancer cells are not found in the sentinel nodes, most experts believe that the risk of cancer having spread to other parts of the body is very low.

Possible Problems

In addition to the usual risks of surgery (infection, problems with wound healing, problems with anesthesia, etc.), the main concern with ALND is lymphedema (see About Lymphedema, page 14). Other possible side effects are numbness in the upper arm (this can be temporary or permanent) and reduced movement in the arm and/or shoulder. Because SLNB removes fewer lymph nodes than ALND, the risk of possible problems, including lymphedema, is much lower.

ABOUT LYMPHEDEMA

Lymph nodes are found throughout the body, including the neck, chest, abdomen, groin and underarms. As part of the lymphatic system, lymph nodes filter waste and foreign material from fluid (called lymph) to help fight infection and disease.

Removal of underarm lymph nodes or radiation to the underarm can sometimes block the normal flow of lymph. When lymph is blocked, it collects in tissue and causes swelling. This swelling is called lymphedema.

About 5% to 20% of women who have an axillary lymph node dissection experience lymphedema of the arm. When surgery is combined with radiation therapy, the risk is even higher.

Swelling or feelings of tightness in the arm should be reported to your doctor right away. Lymphedema is easier to treat when it first starts.

Lymphedema can happen soon after treatment or many years later. To protect your arm, you should use the following precautions:

- Avoid temperature extremes, both hot and cold.
- Avoid injections, acupuncture, and blood pressure measurement with the affected arm.
- Avoid carrying heavy bags over the affected shoulder.
- Practice good hygiene. Keep the affected arm both clean and dry.

You can learn more about the prevention and treatment of lymphedema by contacting the **National Lymphedema Network**. Call **1 800-541-3259** or go online at www.lymphnet.org.

RADIATION THERAPY

The goal of radiation therapy is to destroy cancer cells with as little harm to healthy tissue as possible.

Radiation therapy is a local therapy used to destroy cancer cells that may have been left behind after surgery. It is almost always used after breast-conserving surgery to lower the risk of cancer coming back. It may also be used after mastectomy if the tumor was large or cancer was found in several lymph nodes. Radiation therapy is not used for women who are pregnant. There are two main types:

- external beam radiation
- internal radiation

External Beam Radiation Therapy

External beam radiation therapy sends a high-energy beam of radiation to the breast and sometimes to the underarm lymph nodes. The radiation is sent from a large machine outside the body. Treatment is given once a day, 5 days a week, for 5 to 7 weeks. This is the most common method of delivering radiation therapy to women with breast cancer.

A newer method, called accelerated partial breast irradiation (APBI), delivers radiation to a smaller part of the breast and involves just 5 to 7 days of treatment. APBI may be administered by external beam or by methods that place radioactive material inside the body (see Internal Radiation Therapy, page 15). Women interested in learning more about APBI should talk with their doctors.

Possible Problems

The most common side effect with radiation therapy is fatigue (tiredness). Other possible side effects include skin changes, such as swelling, redness, itchiness, or dryness in the treated area. Near the end of treatment, the skin may feel sore or moist. For some women, the treated breast may become firmer or smaller than before treatment. Increased sensitivity is also possible. Radiation to the underarm lymph nodes can cause lymphedema (see About Lymphedema, page 14).

Internal Radiation Therapy

Internal radiation therapy (also called brachytherapy) is another way of delivering radiation therapy. With this method, radioactive material (contained within tiny needles, wires, pellets, or a balloon) is placed inside the body at or near the area where the cancer was removed. Your doctor will consider the size and location of your cancer,

along with other factors, to determine whether internal radiation is an appropriate treatment option in your case.

Possible Problems

Side effects of internal radiation are generally fewer and milder due to a shorter course of treatment. Ask your doctor what side effects you might expect.

CHEMOTHERAPY

Each woman's course of chemotherapy is individually tailored. Many different drugs and drug combinations are possible.

Chemotherapy is a systemic therapy that uses drugs to reach and destroy cancer cells anywhere in the body. It is used in several ways to treat breast cancer:

- to lower the risk of cancer coming back
- to shrink a large cancer
- to treat breast cancer that has spread

Adjuvant and Neoadjuvant Therapy

Depending on how it is used, your doctor may refer to chemotherapy as either adjuvant or neoadjuvant therapy.

Adjuvant Therapy describes chemotherapy that is used after surgery to lower the risk of breast cancer coming back. Even when all of the cancer appears to be gone, doctors will sometimes recommend chemotherapy as an added measure of safety in case some cancer cells have escaped into the bloodstream. Over time, these cells could spread cancer to other places in the body. Chemotherapy helps to lower this risk.

Neoadjuvant Therapy is used before surgery to shrink cancer. Shrinking the size of a cancer gives some women with larger cancers the option of choosing breast-conserving surgery over mastectomy. Using chemotherapy before surgery also gives doctors a chance to see how well a certain drug or combination of drugs is going to work in a woman's individual case.

In some instances, chemotherapy may be the main treatment (instead of surgery) for women diagnosed with advanced breast cancer.

Possible Problems

The side effects of chemotherapy vary depending on the drugs used, the dosages, the overall length of treatment, and the individual woman. The most common side effects are weakness and fatigue, nausea and vomiting, loss of appetite, weight changes, nail changes, and hair loss. (The hair usually grows back after treatment.) Mouth sores,

diarrhea or constipation are less common. Ask your doctor about medicines and methods that can be used for managing these and other possible side effects. Infections are more likely during treatment so patients should take special care to avoid situations that increase this risk. Short or longer-term changes in thinking and memory are also possible. Certain chemotherapy drugs can cause lasting damage to the heart, lungs, liver and kidneys. In younger women, chemotherapy can cause infertility or premature menopause. Women planning to become pregnant (or able to become pregnant but not taking birth control) should talk with their doctors before starting treatment.

HORMONAL THERAPY

Hormonal therapy is another form of systemic therapy. It works against breast cancer by blocking or lowering the amount of hormones in the body. It is used for women whose breast cancer relies on hormones in order to grow (called hormone receptor-positive breast cancer). A hormone receptor test will tell you and your doctor if your breast cancer is hormone receptor-positive (see Additional Tests, page 9). About 2 out of 3 breast cancers are hormone receptor-positive.

Types of Hormonal Therapy

There are different types of hormonal therapy. Some block the effect of hormones while others lower the amount of hormones in the body. The most effective treatment may involve using more than one type over the course of several years. Your doctor will decide the most appropriate plan for you.

Tamoxifen works to stop or slow cancer by blocking the effect of hormones on cancer cells. It has been the standard drug for treating women with hormone receptor-positive breast cancer for many years. Taken after surgery, tamoxifen lowers the risk of cancer coming back by about half.

Tamoxifen also helps women whose cancer has spread and women whose risk for developing breast cancer is higher than average. **Raloxifene** is a newer drug that works similar to tamoxifen but with fewer serious side effects. However, it is not used to treat breast cancer, only to prevent breast cancer in some women with higher than average risk. Neither tamoxifen nor raloxifene are used for women who are pregnant.

Aromatase inhibitors are newer drugs that work by lowering the amount of hormones in the body. Examples are anastrozole, letrozole, and exemestane. Used either alone or after a course of tamoxifen, these drugs have been found to work as well or better than tamoxifen alone for reducing the risk of cancer coming back.

Unlike tamoxifen, which can be used for women who are either premenopausal (still having menstrual periods) or postmenopausal (no longer having menstrual periods),

aromatase inhibitors can only be used for postmenopausal women. In cases where treatment with tamoxifen or aromatase inhibitors stops working, there are other hormonal treatments that may still help.

Possible Problems

Hormonal therapy can cause similar side effects to those of menopause (hot flashes, weight gain, vaginal dryness, headaches, mood swings, hair-thinning, etc.). Rare but serious side effects of tamoxifen include increased risk for cancers of the uterus, blood clots, stroke, vision problems, such as cataracts, liver toxicities, and fertility issues. Aromatase inhibitors have less serious side effects than tamoxifen. Possible problems are stomach upset, an increase in cholesterol, joint stiffness or pain, and potential loss of bone strength. Aromatase inhibitors do not increase risk for uterine cancers and very rarely cause blood clots.

FOR YOUR INFORMATION:

- Hormonal therapy is NOT the same as hormone replacement therapy (HRT).
- HRT is used by some women to help with hot flashes and other symptoms of menopause.
- HRT is NOT recommended for women with breast cancer.

TARGETED THERAPY

Targeted therapy is a newer systemic therapy option. Women with breast cancers that contain too much of a substance called HER2 (called HER2-positive breast cancer) are often helped by a drug called trastuzumab (more commonly known as Herceptin). About 1 out of 5 women with breast cancer have HER2-positive cancer.

Used with chemotherapy, trastuzumab can lower the risk of cancer coming back after surgery. It can also shrink or slow the growth of HER2-positive breast cancer that has spread. Lapatinib, another targeted therapy drug, is used for treating HER2-positive breast cancer in women with metastatic disease who no longer respond to trastuzumab. Other targeted drugs are being studied in clinical trials (see Clinical Trials, page 19).

Possible Problems

Flu-like symptoms, such as fever, chills, and nausea, are common with trastuzumab, especially with the first dose. Less common, it can cause mild to severe heart damage. In combination with chemotherapy, trastuzumab may increase risk for other side effects as well, such as anemia and/or infection. Rarely, it can cause severe or life-threatening breathing problems and/or allergic reactions.

Questions to Ask Your Doctor...

- How many different types of treatment will I be getting?
- When will I get my first treatment?
- How long will each treatment last?
- Where will I go to get my treatments?
- What drugs will I be taking?
- What are the possible side effects? When are they likely to occur?
- Can I stay alone after my treatments or do I need to have someone stay with me?
- Are there side effects that I should report right away?
- What can be done to manage side effects?
- What are the risks with each treatment?
- How will we know if a treatment is working?
- Are there any other possible treatments for my type and stage of cancer?
- Are there any clinical trials that would be appropriate for me?
- How do I contact a health professional after hours and when should I call?

CLINICAL TRIALS

Clinical trials are research studies that test new medicines and new medical devices and approaches. Their purpose is to find better and safer ways to prevent, detect, diagnose and treat disease. Each treatment described in this booklet went through many years of careful testing in clinical trials before becoming standard of care.

People who join clinical trials have a chance to benefit from new treatments before they are widely available. They are also helping others by participating in valuable medical research conducted by leading physicians in the field of breast cancer. Nevertheless, there are some risks involved with any treatments that are still being tested.

Choosing to receive treatment through a clinical trial is an option for some women with breast cancer. Each study has specific rules for who may participate based upon such factors as age, cancer stage, prior treatments, and other considerations. Once enrolled, patients are carefully monitored during and after treatment. They may also leave a trial at any time, for any reason.

If you are interested in learning about clinical trials for women with breast cancer, the **National Institutes of Health** offers a searchable database at <http://ClinicalTrials.gov>. The **American Cancer Society** and the **National Cancer Institute** can also answer your general questions about clinical trials (for contact information, see page 3).

COMPLEMENTARY THERAPIES

Complementary therapies include a broad range of products and practices that are not currently considered part of standard medicine. Acupuncture, herbs, biofeedback, dietary supplements, meditation, hypnosis and yoga are just a few examples.

For women with breast cancer, some complementary therapies may be used along with standard treatments to help manage symptoms and side effects. Examples include ginger for nausea, acupuncture or massage therapy for pain, and meditation to reduce stress.

Because some complementary therapies have proved useful to cancer patients, several leading medical centers have begun programs that combine standard treatments with certain complementary therapies (called integrated treatment programs). At the same time, some major insurance companies have started to cover some of the more widely accepted methods. Still, most complementary therapies remain an uncovered expense.

Women who are thinking about using complementary therapies are urged to talk with their doctors. Unlike standard treatments, most complementary therapies have not been tested in clinical trials and none have been scientifically proven to be effective for treating cancer. For more information, the National Cancer Institute offers a free booklet called *“Thinking About Complementary and Alternative Medicine: A Guide for People with Cancer”* (for contact information, see page 3).

FOR YOUR INFORMATION:

It is important to know the difference between complementary therapy and alternative therapy.

- Complementary therapy is used **ALONG WITH** standard treatments. Alternative therapy is used **IN PLACE** of standard treatments. Alternative therapy is unsafe for people with cancer.
- Some complementary therapies can also cause harm, but if chosen and used under the guidance of your medical doctor, certain therapies may improve your quality of life.

treatment by stage

The stage of a woman's breast cancer is used for guiding decisions about treatment (see Breast Cancer Staging, page 7). This section shows you the most typical treatment options for each stage.

STAGE 0

Stage 0 breast cancer is ductal carcinoma in situ (DCIS). The standard treatment options for DCIS are:

- breast-conserving surgery and radiation therapy, with or without hormonal therapy, OR
- total mastectomy, with or without hormonal therapy, OR
- breast-conserving surgery without radiation therapy, OR
- clinical trials testing breast-conserving surgery and hormonal therapy, with or without radiation therapy

STAGES I, II, III

Surgery options for Stage I, II, and operable Stage III breast cancers are:

- breast-conserving surgery, lymph node removal, and radiation therapy, OR
- modified radical mastectomy, with or without radiation therapy

In addition to surgery, your doctor may recommend one or more systemic therapies. More aggressive treatment is usually recommended for Stage III than for Stage II; Stage II is typically treated more aggressively than Stage I. Any of the following may be used before surgery (neoadjuvant therapy) as well as after surgery (adjuvant therapy):

- chemotherapy
- hormonal therapy
- targeted therapy
- clinical trials testing new treatments

STAGE IV

Stage IV is metastatic breast cancer. There are treatments that can slow its growth and relieve symptoms. One or more of the following may be used:

- chemotherapy
- hormonal therapy
- targeted therapy

- surgery and/or radiation
- clinical trials testing new treatments
- bisphosphonate drugs (to reduce bone disease and pain)

RECURRENT BREAST CANCER

Breast cancer that comes back after initial treatment is called recurrent breast cancer. Although this can happen at any time, most recurrences happen within 3 to 5 years. Breast cancer may recur locally, regionally, or, it may recur in a more distant part of the body. Treatment for recurrent breast cancer depends on the place of recurrence and the initial treatment. Local recurrence is often treated with surgery, followed by radiation therapy, and/or one or more systemic therapies. Distant recurrence is metastatic breast cancer. The treatment is the same as with Stage IV.

breast reconstruction

The goal of breast reconstruction is to restore the look and feel of balance to a woman's body.

Breast reconstruction is surgery to recreate the shape of a breast after mastectomy. It is an option for most women who have had their breast removed because of cancer. Breast reconstruction may help a woman feel better about her appearance. However, it is important to note that the reconstructed breast will look and feel somewhat different than a natural breast.

Immediate and Delayed Reconstruction

Breast reconstruction may be done at the same time as mastectomy (called immediate reconstruction) or weeks to years later (delayed reconstruction). In either case, it is important to discuss options with your general surgeon early on, before your mastectomy. The choices you make may influence where incisions are made and how much skin is saved.

FOR YOUR INFORMATION:

Both Federal and California law contain important provisions for breast cancer patients who choose breast reconstruction.

For women whose health insurance covers mastectomy, certain breast reconstruction procedures are also covered, including matching procedures on the natural breast. This provision extends to women who choose an external breast prosthesis.

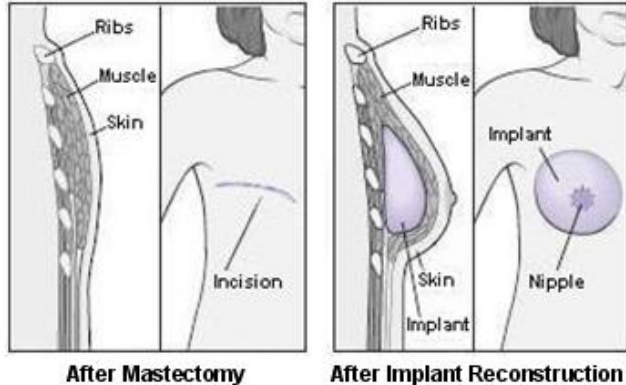
For more information, please call the **U.S. Department of Labor (DOL)** at **1 866-487-2365** or go online at www.dol.gov/ebsa/publications/whcra.html to view or print the DOL publication called "*Your Rights After A Mastectomy... Women's Health & Cancer Rights Act of 1998.*"

TYPES OF BREAST RECONSTRUCTION

There are two basic types of breast reconstruction. Your plastic surgeon will explain which options are best for your age, overall health, body type, lifestyle, treatment history and personal goals.

- reconstruction with implants
- reconstruction with your own tissue

Reconstruction with Implants



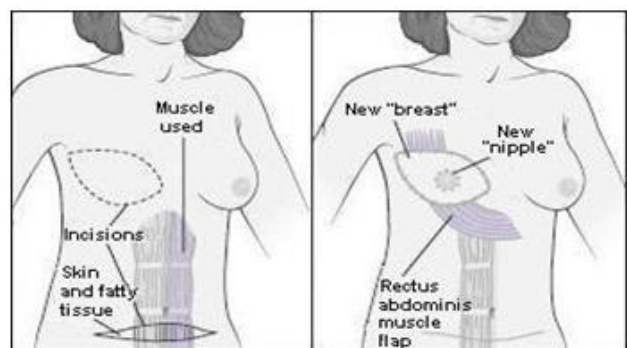
With implant reconstruction, a two-step procedure is usually needed for stretching the breast skin and chest muscle. The first step involves placing a temporary tissue expander under the chest muscle. Over the next few weeks to months, the tissue expander is gradually filled with a saline (saltwater) solution until the tissue has been stretched enough. Next, the expander is replaced by an implant (saline or silicone gel). If desired, nipple and areola reconstruction requires additional procedures (see Nipple and Areola Reconstruction, page 25).

Possible Problems

In addition to risks associated with all surgery, the most common long-term problems with implant reconstruction are rupture (breakage of the implant cover) and capsular contracture (scar tissue forming around the implant). It should also be noted that breast implants do not last forever. One or more replacement surgeries may be needed.

Reconstruction with Your Own Tissue

Tissue reconstruction uses a woman's own tissue to rebuild the shape of a breast. The tissue may be taken from the back, abdomen, buttocks, or more rarely, the thighs. With tissue reconstruction, a flap of skin, fat, and muscle is moved to the chest where it is formed into the shape of a breast. The most common two methods are called TRAM flap (transverse rectus abdominis flap) and LAT flap (latissimus dorsi flap). The TRAM flap uses tissue from the lower abdomen; the LAT flap uses tissue from the upper back. Some situations may also require the use of an implant. Tissue reconstruction is not usually recommended for women who smoke or have diabetes, vascular, or connective tissue diseases.



In this TRAM flap procedure, a flap of skin, fat, and muscle is moved to the chest area where it is formed into the shape of a breast. A nipple and areola are reconstructed after the new breast has had time to heal.

Possible Problems

Tissue reconstruction is a major operation. Large surgical wounds, considerable discomfort, swelling and bruising after surgery are common. Decreased strength in the area of the body from which the tissue was taken is also common. Complications such as excessive bleeding, excessive scar tissue, fluid collection, and problems with healing, including flap failure, are not typical but are possible. The chance that the cosmetic result will not be as pleasing as expected is a possible problem with any breast reconstruction.

Nipple and Areola Reconstruction

Reconstruction of the nipple and areola (the small darkened area around the nipple) is an option with either implant or tissue reconstruction. It is usually done on an outpatient basis, under local anesthesia, after the reconstructed breast has had time to heal (about 2-4 months). A variety of techniques may be used to create the new nipple and areola. Tattooing is often used for matching the areola to a woman's natural color.

Finding a Plastic Surgeon

Ask your doctor for a referral to a plastic surgeon who has been trained in the specific procedures that you are considering. Make sure that the surgeon has performed them successfully on many women. The **American Society of Plastic Surgeons (ASPS)** can provide referrals to board certified plastic surgeons in your area (**1 888-475-2784**).

BREAST PROSTHESES

A breast prosthesis is a form that is worn under clothing to match the shape of the breast. It may be used for women who delay breast reconstruction or decide not to have additional surgery. Custom-made forms can feel very much like breast tissue and are weighted to match a woman's natural breast. Some prostheses attach directly to the skin and others fit into pockets of a special bra. There are also partial prostheses for women who have had part of their breasts removed.

Most insurance companies are required to cover the cost of breast prostheses and post-mastectomy bras if they have been prescribed by a doctor. The American Cancer Society Reach to Recovery program provides information on types of prostheses as well as suppliers (for contact information, see page 3).

Some women are comfortable with their body image after mastectomy and prefer neither breast reconstruction nor a breast prosthesis. No one option is right for everyone. Choosing reconstruction, prosthesis or nothing is a personal decision.

Questions to Ask Your Doctor...

- What are my breast reconstruction options?
- What type of reconstruction do you recommend? Why?
- What results are realistic for me?
- What is the latest information about the safety of implants?
- When do you recommend that I begin breast reconstruction?
- How many surgeries will I need?
- Will there be scars? Where? How large?
- What are the risks at the time of surgery? Later?
- How long will I be in the hospital? Will I need help when I return home?
- How long will my recovery take?
- Will reconstruction interfere with any of my other treatments?
- How many reconstructions have you done?
- Can you show me photos of women who have had breast reconstruction?
- Can I talk with other women who have had the same surgery?

follow-up care

Generally, women are seen every 3 to 6 months for the first 3 to 5 years after treatment, then once a year.

Women who have completed treatment for breast cancer will continue to see a primary care provider on a regular basis. The purpose of follow-up care is to monitor and manage any long-term or late effects of treatment and to check for any signs that the cancer may have returned.

During these visits you should get a comprehensive clinical breast exam that includes feeling the lymph nodes and looking for any visual changes. (For more information, the **Cancer Detection Section, California Department of Public Health** offers an online pamphlet called “*What to Expect During a Clinical Breast Exam*” at www.cdph.ca.gov/programs/cancerdetection)

Your doctor will also ask about any symptoms you might be having. Lab and imaging tests may be ordered. Women taking tamoxifen should have yearly pelvic exams. Patients being treated with an aromatase inhibitor should have a bone density test before, during and after treatment, as recommended by their doctors. With few exceptions, all women who have been treated for breast cancer will continue needing annual mammograms. In some cases, Magnetic Resonance Imaging (MRI) may also be recommended.

You may also choose to do monthly breast self-examination. Your primary care provider can show you the proper method of checking for breast changes. The goal is to immediately report any of the following, so that possible problems can be diagnosed and treated as soon as possible:

- a new lump in the breast or chest area
- a new lump in the armpit or in the neck.
- a change in the shape of the breast
- a skin rash, swelling, or change in the color of the skin over the breast or chest

Any changes in general health should also be brought to the early attention of your primary care provider. Do not wait for a scheduled follow-up visit to report a sudden loss of appetite or weight, unusual vaginal bleeding, or extreme changes in energy level. Problems such as blurred vision, a new and persistent headache, chest pains, shortness of breath, a cough that won't go away, ongoing digestive problems, backaches, or any other persistent and unexplained pain should also be reported.

While these symptoms may occur for many reasons other than cancer, you should still be checked by your healthcare provider as early as possible.

In addition to keeping your scheduled medical appointments and reporting any unusual symptoms, you are encouraged to follow established guidelines for good physical and emotional health. A proper diet and moderate exercise can help rebuild your strength and energy. A support group can provide emotional comfort and guidance. Talk with your doctor about a plan to support your full recovery and future health.

Questions to Ask Your Doctor...

- How often should I see a doctor for follow-up care?
- Who will I see for my follow-up visits?
- What will happen during my follow-up visits?
- What follow-up tests should I have, if any?
- How often will I need these tests?
- What are the chances that my breast cancer will come back or that I will get another type of cancer?
- What symptoms should I watch for?
- If I develop any of these symptoms, who should I call?
- What are the most common long-term and late effects with the treatment I received?
- How do I get a copy of my medical records?
- What can I do to help maintain my health?
- How can I find a support group?

words to know

abdomen The area of the body between the chest and the hips.

adjuvant therapy Treatment given after the primary treatment (usually surgery) to lower the risk of breast cancer coming back. It may include chemotherapy, radiation therapy, hormonal therapy, and/or targeted therapy.

anesthesia Drugs used to keep patients from feeling pain or discomfort during surgery.

anesthesiologist A medical doctor who specializes in giving drugs to keep patients from feeling pain during surgery.

axillary lymph node dissection Surgery to remove lymph nodes from the underarm area.

axillary lymph nodes Lymph nodes in the underarm area.

brachytherapy Radiation therapy that places radioactive material directly into or near the cancer. Also called internal radiation.

breast-conserving surgery Surgery that removes the cancer along with a small amount of normal tissue around it. Also called partial mastectomy or lumpectomy.

breast implant A silicone- or saline-filled sac that is surgically placed beneath the skin and chest muscle to recreate the shape of the breast after mastectomy.

breast prosthesis An external form that is worn under clothing to match the shape of a breast.

breast reconstruction Surgery to recreate the shape of the breast after a mastectomy.

cancer A term for diseases in which abnormal cells grow and divide out of control.

cancer grade A system for describing how abnormal cancer cells look under a microscope. Grading provides information about how fast the cancer is likely to grow and spread.

cancer stage A system for describing the extent of a cancer, especially whether the disease has spread from the place where it began to other parts of the body.

carcinoma in situ Cancer that remains where it began. It has not spread into nearby tissue.

case manager A person trained to help patients access the healthcare services they need. Also called patient navigator.

chemotherapy Treatment with drugs that destroy or slow the growth of cancer cells.

clean margin A rim of normal, healthy tissue surrounding a cancer. The goal of surgery is to obtain a clean margin in order to confirm that the whole cancer was removed. Also called clear margin.

clinical nurse specialist A nurse who is educated and trained to work with a particular patient population, such as women with breast cancer.

diagnosis The identification of a disease, such as breast cancer.

duct A small tube that carries body fluid, such as tears. Breast ducts carry milk from the breast lobules to the nipple.

ductal carcinoma in situ (DCIS) Cancer that is found in the milk duct of the breast and has not spread outside the duct.

fatigue A feeling of tiredness. This may be caused by some cancer treatments.

gene The basic unit of a cell that passes on traits from parents to children.

gene expression profiling A test that looks at the gene characteristics of cancer cells to help plan treatment and to assess the risk of cancer coming back.

HER2 A protein involved in the growth of some cancer cells. Also called HER2/neu.

HER2-positive Breast cancers with too much HER2 protein, or with too many copies of the HER2 gene.

hormonal therapy Treatment that blocks or lowers the amount of hormones in the body. Also called hormone therapy, hormone treatment or endocrine therapy.

hormone receptor-positive Breast cancer that relies upon the female hormones, estrogen and/or progesterone, in order to grow. Also called hormone-positive.

hormones Chemicals made by various glands in the body that control the actions of certain cells or organs.

invasive breast cancer Cancer that has spread from where it began in the breast into nearby tissue. Also called infiltrating breast cancer.

invasive ductal carcinoma Cancer that started in a milk duct and has broken through the wall of the duct. Also called infiltrating ductal carcinoma.

invasive lobular carcinoma Cancer that started in a breast lobule and has spread to nearby tissue. Also called infiltrating lobular carcinoma.

lobular carcinoma in situ (LCIS) A condition in which abnormal cells are found within the breast lobule. This is not considered a true cancer. Also called lobular neoplasia.

lobular neoplasia A condition in which abnormal cells are found within the breast lobule. This is not cancer. Also called lobular carcinoma in situ.

lobule A small sac-like gland within the breast that makes milk. Also called milk gland.

local therapy Treatment used to remove and destroy cancer where it is found. This includes the cancer and a small area around it.

lumpectomy Surgery to remove the cancer and a small amount of normal tissue around it. Also called breast-conserving surgery or partial mastectomy.

lymph A fluid that travels through the lymphatic system. It carries cells that help fight infection and disease. Also called lymph fluid.

lymph nodes Small bean-shaped masses of tissue that filter lymph fluid. Also called lymph glands.

lymphatic system A filtering system for the blood that helps fight infections and disease. The lymphatic system includes lymph nodes, lymph fluid and lymph vessels.

lymphedema A condition in which excess fluid collects in tissue and causes swelling in the affected area. For breast cancer patients, this occurs in the arm on the same side of the surgery and/or radiation.

lymphedema therapist A health professional who has received education and training in the care and management of lymphedema.

magnetic resonance imaging (MRI) A procedure that uses a powerful magnet to create detailed pictures of areas inside the body. These pictures can show the difference between normal and diseased tissue.

mastectomy Surgery to remove the breast (or as much of the breast tissue as possible).

metastasis The spread of cancer from where it began to more distant parts of the body.

modified radical mastectomy Surgery that removes the breast, some of the breast skin, the nipple, and most of the underarm lymph nodes.

neoadjuvant therapy Treatment given before the primary treatment to shrink a cancer. Examples include chemotherapy, hormonal therapy and targeted therapy.

non-invasive breast cancer Breast cancer that has not spread from where it began in the breast (usually the milk ducts) into nearby tissue.

occupational therapist A health professional whose goal is to help patients regain independence with activities of daily living through movement, exercise, massage and other methods.

oncologist A medical doctor who specializes in the study and treatment of cancer.

oncology A branch of medicine that deals with the study and treatment of cancer.

oncology nurse A nurse who specializes in caring for people with cancer.

oncology social worker A professional who specializes in helping patients with cancer and their families deal with emotional and practical problems.

partial mastectomy Surgery that removes the cancer along with a small amount of normal tissue around it. Also called breast-conserving surgery or lumpectomy.

pathologist A medical doctor who identifies diseases by looking at cells and tissue samples under a microscope.

pathology report A report of the nature and extent of a disease. Used to guide treatment.

patient navigator A person trained to help patients access the healthcare services they need. Also called case manager.

physical therapist A health professional who helps patients regain strength and movement after surgery by using exercise, massage, and other methods.

plastic surgeon A medical doctor who does surgery to replace or improve the look of the breast after treatment for cancer.

primary care provider (PCP) A medical doctor that oversees general patient care and refers and coordinates with specialists. A PCP can also be a physician assistant (PA), nurse practitioner (NP), or certified nurse midwife (CNMW).

prognosis A medical term for describing the expected course of a disease or the expected response of a disease to treatment.

psychologist A professional who is educated and trained to provide mental health care.

radiation oncologist A medical doctor who specializes in using radiation (high-energy x-rays) for treating cancer.

radiation therapist A medical technician who works with the radiation oncologist and is trained in giving radiation therapy.

radiation therapy Treatment with a certain type of energy (ionizing radiation) to destroy or shrink cancer.

radiologist A medical doctor who specializes in creating and interpreting pictures of the body produced with x-rays, sound waves, or other types of energy.

radiology technologist A medical technician trained to position patients for x-rays, to develop the images, and check the images for quality.

recurrence Cancer that has come back after initial treatment.

sentinel node The first lymph node to which cancer is likely to spread.

side effects Unwanted things that happen from cancer treatment, such as nausea and fatigue.

social worker A professional who specializes in helping patients and their families deal with emotional and practical problems.

surgeon A medical doctor who performs operations, such as a lumpectomy or mastectomy.

systemic therapy Treatment sent throughout the body to reach cancer cells anywhere they might be. Drugs may be given by mouth or directly into the bloodstream.

tamoxifen A drug used to treat hormone receptor-positive breast cancer and to prevent breast cancer in women who are at a high risk for developing breast cancer. Also called tamoxifen citrate or Nolvadex (brand name).

targeted therapy A type of treatment that uses drugs or other substances to find and destroy cancer cells without harming normal cells.

tissue reconstruction A type of breast reconstruction in which tissue is moved from another area of the body to the chest where it is formed into the shape of a breast.

TNM staging A cancer staging system that uses the letters T, N, and M to stand for tumor, nodes, and metastases. Each of these is followed by a number to describe the total cancer stage.

total mastectomy Surgery that removes the breast, some of the breast skin and the nipple, but not the underarm lymph nodes. Also called simple mastectomy.

tumor An abnormal mass of tissue. Tumors can be benign (not cancerous), or malignant (cancerous).

x-ray A high-energy form of radiation used for detecting or treating cancer.

***“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

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