



# **a woman's guide to breast cancer treatment**

California Department of Health Care Services  
Cancer Detection and Treatment Branch

January 2016



# table of contents

Introduction .....	2
Getting a Second Opinion .....	3
For More Information .....	3
About Breast Cancer.....	5
What is Breast Cancer? .....	5
What Causes Breast Cancer?.....	5
How Common is Breast Cancer? .....	6
Types of Breast Cancer.....	7
Non-Invasive Breast Cancer .....	7
Invasive Breast Cancer .....	7
Less Common Types of Breast Cancer .....	8
Breast Cancer Staging .....	9
Additional Tests .....	10
Types of Treatment.....	14
Local and Systemic Therapy.....	14
Adjuvant and Neoadjuvant Therapy.....	14
Surgery.....	15
Breast-Conserving Surgery.....	15
Mastectomy.....	16
Lymph Node Removal .....	17

Radiation Therapy .....	18
External Beam Radiation.....	18
Internal Radiation Therapy .....	20
Chemotherapy .....	21
Hormone Therapy.....	22
Drugs That Block Hormones .....	22
Drugs That Lower Hormone Levels.....	23
Targeted Therapy .....	24
Clinical Trials .....	25
Complementary Therapy .....	27
Treatment by Stage .....	29
Recurrent Breast Cancer.....	31
Breast Reconstruction.....	32
Reconstruction with Implants .....	32
Reconstruction with Your Own Tissue.....	33
Nipple and Areola Reconstruction.....	34
Breast Prosthesis .....	35
Follow-Up Care.....	36
Words to Know .....	38

# introduction

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. Knowing your treatment options can help you take an active part in making decisions about your care.

As you read the booklet, keep in mind that it does not replace your doctor's advice but is another resource for learning about your choices. Your doctor and other members of your healthcare team will help with deciding the best treatment plan for you.

*Talk openly with your doctor and other members of your healthcare team about your medical needs and concerns. They are trained to help women with breast cancer.*

For some women, treatment should start right away, but for most newly diagnosed patients, it is safe to take a little time for thinking through all the options. Go through the information in this booklet at your own pace. Here are some suggestions that may help.

- Read sections of the booklet as you need them. You don't have to read it all at once.
- Ask a friend or family member to read the booklet with you. Your friends and family can be an important source of support.
- Look up words that are new to you in the *Words to Know* section in the back of the booklet. Keep a pen or pencil handy for making notes.
- Write down questions to ask your doctor before your medical appointments. This guide has some suggestions for what to ask.
- Bring a friend or family member with you when you see your doctor to help you remember what was said, to ask questions, or just to listen with you.
- If your doctor tells you something that isn't clear, ask that it be explained differently. Always ask that your doctor talk to

you in a way that you understand.

- Keep your notes and documents well organized. A binder with subject dividers can help keep important materials in order and easy to find when you need them.
- Carry a small notebook in your purse for jotting down questions and thoughts as you think of them.
- Think about how much information you want to have. Some women want to learn everything they can about breast cancer while others are more comfortable leaving the details to their doctors. Think about which approach is best for you.

### Getting a Second Opinion

Before starting treatment, you may want to get a second opinion. A second opinion is common practice for confirming a cancer diagnosis or treatment plan. It is also your right.

Most insurance companies will pay for a second opinion. However, before making an appointment with another doctor, check to make sure your insurance covers it. For coverage to apply, you may need to choose from a specific list of health providers or get a referral from your doctor. Doctors are used to having patients ask for second opinions and generally welcome the information that a second opinion can provide.

### For More Information

This booklet is a starting point for learning about your treatment options. It may not include all treatments or tell you all you need to know about side effects and possible problems. For more information, you can contact the American Cancer Society or the National Cancer Institute. Most materials and services are provided in English and Spanish. For other languages, the American Cancer Society can assist with finding the help you need.

*Before calling an organization, think about the questions you want to ask. Write down your questions before you call and be ready to take notes.*

### American Cancer Society (ACS)

Call 1 800-227-2345 or go online at [www.cancer.org](http://www.cancer.org). ACS provides information on all aspects of cancer through the toll-free

information line, website, 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.

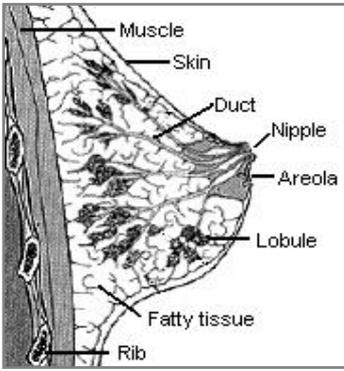
*Some women find it helpful to talk with other women who have been treated for breast cancer. The American Cancer Society and National Cancer Institute can connect you with an individual or support group in your area.*

### **National Cancer Institute (NCI)**

Call 1 800-422-6237 or go online at [www.cancer.gov](http://www.cancer.gov). NCI information specialists are available by phone or through *LiveHelp* on the NCI web site. (Please note that *LiveHelp* is available in English only.)

# about breast cancer

## What is Breast Cancer?



A woman's breast is made up of fatty tissue, lobules (milk-producing glands), and ducts (tubes that carry milk to the nipple). 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 other

parts of the body through the bloodstream or through the lymphatic system.

## What Causes Breast Cancer?

It is not yet known what causes breast cancer or why some women get it and others do not. These are topics of ongoing research. We do know that:

- More women than men get it. (*About 99% of all breast cancers occur in women.*)
- More older women than younger women get it. (*Nearly 80% of breast cancers occur in women older than 50.*)
- Most women who get breast cancer do not have a family member who has had it. (*Less than 15% of women with breast cancer have a family member with the disease.*)
- Most women who get breast cancer have no known risk factors other than being older and being a woman. (*A risk factor is anything that increases the chances of getting a disease.*)

We also know that breast cancer is NOT caused by caffeine, antiperspirants, underwire bras, abortions, hair dyes, injury to the breast, or by living near power lines. And, breast cancer is NOT contagious. You can't catch it from someone else.

## 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 at some point during her lifetime.
- In California, about 25,000 women are diagnosed with breast cancer each year.
- In the United States, about 230,000 women are diagnosed with breast cancer each year.
- Currently, there are about 2.8 million breast cancer survivors living in the United States.

# types of breast cancer

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 is called non-invasive or carcinoma in situ.

(Carcinoma is a form of cancer and “in situ” means “in place.”) You may hear about two types of carcinoma in situ.

One of them, however, is not a true cancer.

*Eighty-nine percent of women diagnosed with breast cancer can expect favorable outcomes, according to the American Cancer Society.*

**Lobular Carcinoma in Situ (LCIS)** 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 of increased risk for developing breast cancer. Treatment is not usually needed for LCIS; however, regular follow-up exams are very important for detecting any changes. Your doctor may also ask you to consider certain therapies to help reduce your risk.

**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 almost always recommended. About 20% of newly diagnosed breast cancers are DCIS.

## Invasive Breast Cancer

Invasive (or infiltrating) breast cancer is cancer that has spread from where it began in the breast into nearby tissue. About 75% to 80% of all breast cancers are invasive. There are several types.

**Invasive Ductal Carcinoma (IDC)** is the most common type of invasive breast cancer. It describes 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 nearby lymph nodes or other parts of the body. About 80% of invasive breast cancers are IDCs.

**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% of invasive breast cancers are of this type.

### Less Common Types of Breast Cancer

Other types of invasive breast cancer affect fewer women, such as inflammatory breast cancer, which accounts for only 1% to 3% of all newly diagnosed cases. Other uncommon types, sometimes called “special types,” include medullary carcinoma, tubular carcinoma, mucinous carcinoma, papillary carcinoma, cribriform carcinoma, metaplastic breast cancer, and adenoid cystic carcinoma, among others. A woman’s breast cancer may also be mixed, meaning that it has features of more than one type. In general, treatments for these special types of breast cancer are the same as for invasive ductal carcinoma - although some, such as inflammatory breast cancer, require more immediate and aggressive treatment.

#### **Inflammatory Breast Cancer**

Inflammatory Breast Cancer (IBC) is a rare and fast-growing type of invasive cancer that usually begins suddenly. Its main symptoms are swelling and redness of a large part of the breast (a third of the breast or more). The breast skin may also have a dimpled appearance, like the skin of an orange. Sometimes the breast may contain a lump that can be felt during a physical exam but more often, a lump cannot be felt. IBC has a higher chance of spreading to other parts of the body compared with other types of breast cancer. Because of this, it is usually treated more aggressively.

# breast cancer staging

Cancer staging is a rating system for describing the extent of cancer in the body. It is used for helping you and your doctor make decisions about your treatment (see *Treatment by Stage*, page 29).

Staging is also used for making predictions about how well your breast cancer is likely to respond to treatment.

*No matter what the type or stage of your breast cancer, there are treatments that can help.*

The stage of a breast cancer depends on:

- whether the cancer is invasive or non-invasive
- the size of the cancer
- whether the cancer is in the lymph nodes
- whether the cancer has spread to other parts of the body

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.

## FOR YOUR INFORMATION

The spread of breast 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 lymphatic system.

## Roman Numeral Staging

There are five main stages of breast cancer: Stages 0, I, II, III, and IV. (Stages I, II, and III are further divided into subcategories.) Stage 0 describes non-invasive breast cancer. Stages I through IV describe invasive breast cancer.

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

**T** describes the size of the **T**umor.

**N** describes whether regional lymph **N**odes are involved.

**M** describes **M**etastasis (the spread of cancer to distant parts of the body).

See *Breast Cancer Stages*, page 12, for more detailed information about breast cancer staging.

### Additional Tests

There are lab tests that give more information about your cancer. Along with staging, they help you and your doctor decide the best treatment plan for you.

**Hormone Receptor Test:** This test shows if there are estrogen and/or progesterone receptors in your cancer cells. Breast cancers with either or both of these receptors are called hormone receptor-positive. Hormone receptor-positive breast cancers rely on hormones (estrogen or progesterone) to grow. All breast cancers – both non-invasive and invasive - should be tested for hormone receptors. There are treatments to help stop hormones from causing cancer growth (see *Hormone Therapy*, page 22). About 2 out of 3 breast cancers are hormone receptor-positive.

#### Triple Negative Breast Cancer

Triple Negative Breast Cancer describes breast cancers that test negative for both types of hormone receptors (estrogen and progesterone) and for HER2. Because the cancer cells lack these three receptors, neither hormone therapy drugs, (such as tamoxifen or aromatase inhibitors), nor targeted therapy drugs, (such as trastuzumab), are helpful for stopping cancer growth. Instead, chemotherapy is almost always recommended for women whose cancer tests triple negative, even for those with early-stage disease. About 15% of breast cancers are triple negative.

**HER2 Receptor Test:** This test measures a substance called HER2 (also called HER2/neu) in invasive breast cancers. Breast cancer cells with extra HER2 protein on their surfaces are called HER2-positive. Like with hormone receptors, there are

treatments for helping to stop these cancer cells from growing and spreading to other parts of the body (see *Targeted Therapy*, page 24). About 1 out of 5 women with breast cancer have HER2-positive cancer.

**Gene Expression Profiling Test:**

This test looks at the patterns of different genes within the cancer cells. Many doctors use this test to help plan treatment and to assess the risk of cancer spreading or coming back, but it isn't needed in all cases. Ask your doctor if gene expression profiling would be helpful in your case.

**Genetic Testing:** Based on your medical and family history, your doctor may recommend genetic testing. Genetic testing examines your DNA to determine whether you have hereditary breast cancer (cancer that is passed down from a parent to a child). Test results may be used to guide treatment planning. Only about 5% to 10% of breast cancers are hereditary.

**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 breast cancer?
- \* Does my cancer have hormone receptors?
- \* Has my cancer been tested for HER2?
- \* Would genetic testing be helpful to me or my family?
- \* Do I need any other tests?
- \* What if I want a second opinion? How do I get one?
- \* What are my choices for treatment?
- \* What treatments do you recommend for me? Why?
- \* How soon do I need to begin treatment?
- \* How do you think my cancer will respond to treatment?
- \* What is the treatment likely to cost?
- \* Will my insurance cover it?
- \* Are there breast cancer survivors who have had these treatments that I can talk with?
- \* Who do I call if I have more questions?

## BREAST CANCER STAGES

### Stage 0

There is no evidence of cancer having spread from where it began in the breast. Stage 0 cancer has not invaded nearby tissue.

### Stage IA

The breast tumor is 2 cm or smaller **and** cancer is not found in the lymph nodes.

### Stage IB

The breast tumor is 2 cm or smaller (or no tumor has been found) **and** small groups of cancer cells (between 0.2 and 2.0 mm) are found in 1 to 3 underarm lymph nodes.

### Stage IIA

The breast tumor is 2 cm or smaller (or no tumor has been found) **and** cancer (larger than 2.0 mm) is found in 1 to 3 underarm lymph nodes or in the lymph nodes near the breastbone;

**OR**

the tumor is between 2 and 5 cm **and** cancer is not found in the lymph nodes.

### Stage IIB

The breast tumor is between 2 and 5 cm **and** small groups of cancer cells (between 0.2 and 2.0 mm) are found in the lymph nodes;

**OR**

the tumor is between 2 and 5 cm **and** cancer is found in 1 to 3 underarm lymph nodes or in the lymph nodes near the breastbone;

**OR**

the tumor is larger than 5 cm **and** cancer is not found in the lymph nodes.

### Stage IIIA

The breast tumor may be any size (or no tumor has been found) **and** cancer is found in 4 to 9 underarm lymph nodes or in the lymph nodes near the breastbone;

**OR**

the tumor is larger than 5 cm **and** small groups of cancer cells (between 0.2 and 2.0 mm) are found in the lymph nodes;

**OR**

the tumor is larger than 5 cm **and** cancer is found in 1 to 3 underarm lymph nodes or in the lymph nodes near the breastbone.

### Stage IIIB

The breast tumor may be any size **and** cancer has spread to the chest wall and/or to the skin of the breast and caused swelling or an ulcer.

Also, cancer may be found in up to 9 underarm lymph nodes or the lymph nodes near the breastbone.

(Inflammatory breast cancer is classified as at least stage IIIB. It may also be classified as stage IIIC or IV.)

### Stage IIIC

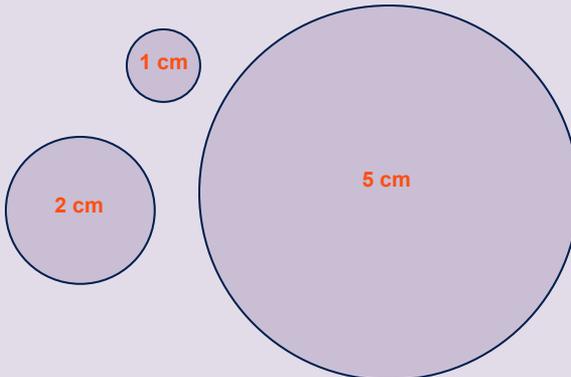
The breast tumor may be any size (or no tumor has been found) **and** cancer may have spread to the skin of the breast and caused swelling or an ulcer and/or has spread to the chest wall.

Also, cancer is found in 10 or more underarm lymph nodes, or lymph nodes above or below the collarbone, or in underarm lymph nodes and the lymph nodes near the breastbone.

### Stage IV

The breast tumor may be any size **and** cancer is found in other areas of the body, most often in the bone, lung, liver, or brain.

**Actual size in centimeters:**



# types of treatment

There are five main types of treatment for breast cancer. The use and order of these treatments will vary, based on a woman's unique situation.

- surgery
- radiation therapy
- chemotherapy
- hormone therapy
- targeted therapy

Several factors will affect your treatment plan, including the stage of your cancer, whether your cancer is hormone receptor-positive or HER2-positive, the results of gene expression profiling tests and/or tests to determine if your cancer is hereditary, your age and menopausal status, and your overall health. Lifestyle and personal preferences are also important factors when planning treatment.

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

## Local and Systemic Therapy

Treatments for cancer are grouped into either local or systemic types of therapy.

**Local therapy** is used to remove or destroy cancer directly where it is found. It involves the cancer and a small area around the tumor. Surgery and radiation therapy are examples of local therapy.

**Systemic therapy** includes treatments that are sent throughout the body to reach cancer cells anywhere they might be. Chemotherapy, hormone therapy, and targeted therapy are all examples of systemic therapy.

## Adjuvant and Neoadjuvant Therapy

Adjuvant and neoadjuvant therapy describe treatments that may be given before and/or after the main treatment (usually surgery).

**Neoadjuvant therapy** is used before surgery to shrink the

cancer. Shrinking the size of the cancer gives some women with larger cancers the option of choosing breast-conserving surgery over mastectomy. Neoadjuvant therapy 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.

**Adjuvant therapy** describes treatment 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 adjuvant therapy 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. Adjuvant therapy lowers this risk.

Both neoadjuvant and adjuvant therapy for breast cancer can include chemotherapy, hormone therapy, targeted therapy, and/or radiation therapy. Any of these therapies may also be used as the main treatment (instead of surgery) for women diagnosed with advanced breast cancer.

## **SURGERY**

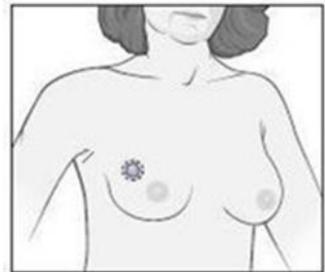
Surgery is the most common treatment for breast cancer. Surgery is also used for removing and sampling underarm lymph nodes (also called axillary lymph nodes). The purpose of lymph node removal is to see if the cancer has spread beyond the breast (see *Lymph Node Removal*, page 17).

There are two main types of surgery for removing the cancer:

- breast-conserving surgery
- mastectomy

### **Breast-Conserving Surgery**

Breast-conserving surgery (also called lumpectomy or partial mastectomy) removes the cancer along with a small rim of normal, healthy tissue (called a negative or clean margin). The goal of breast-conserving surgery is to save as much of the breast as possible while removing all of the cancer. During



**Breast-Conserving Surgery**

surgery for invasive cancer, one or more underarm lymph nodes may also be removed to see if the cancer has spread beyond the breast (see *Lymph Node Removal*, page 17). Breast-conserving surgery is almost always followed by radiation therapy to help destroy any remaining cancer cells.

Women with one small area of breast cancer who are able to have radiation therapy can usually choose breast-conserving surgery (instead of mastectomy). Studies have repeatedly shown that breast-conserving surgery followed by radiation therapy is just as effective as mastectomy with early-stage breast cancer.

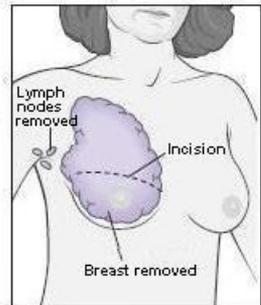
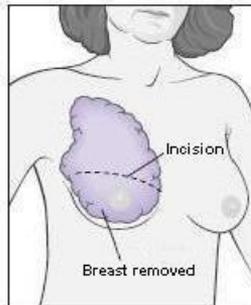
### **Possible Problems**

*Breast-conserving surgery may cause temporary swelling, pain, and tenderness. Hard scar tissue may form along the site of the incision. Wound infection, poor healing, a reaction to anesthesia, and excessive bleeding are possible with any type of surgery but rare. Sometimes, another surgery (called re-excision) is needed if the first surgery failed to remove all of the cancer. (This is called a positive margin.) Depending upon how much tissue is removed, breast-conserving surgery leaves a small scar and often an indentation (a dimple) in the breast. Reconstructive options are available for most women but are rarely needed with this type of surgery (see *Breast Reconstruction*, page 32). Breast-conserving surgery with lymph node removal can result in numbness in the upper arm and underarm areas, reduced arm or shoulder motion, and/or arm swelling (see *About Lymphedema*, page 19).*

### **Mastectomy**

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

**Total mastectomy** (also called simple mastectomy) removes the breast, including the nipple, but not the underarm lymph nodes. It is most often used for women with large or multiple areas of ductal



Total (or Simple) Mastectomy      Modified Radical Mastectomy

carcinoma in situ (DCIS). It is also used for greatly reducing risk in women whose chances for getting breast cancer are very high (called prophylactic mastectomy). Removing nearly all of the breast tissue leaves very few breast cells behind that could develop into cancer.

**Modified radical mastectomy** removes the breast, including the nipple, some of the underarm lymph nodes, and the lining over the chest muscles. Mastectomy is most often needed if cancer is found in more than one area of the breast, or if the cancer is very large in relation to the size of the breast. It is usually recommended for women who are not able to have, or do not want, radiation therapy after surgery. In addition, some women who are eligible for breast-conserving surgery may prefer mastectomy.

Most women who have a mastectomy can also have breast reconstruction surgery. Depending on the type of procedure, breast reconstruction may be done, or at least begun, at the same time as mastectomy (called immediate reconstruction) or at a later time (delayed reconstruction). For women planning immediate reconstruction, skin-sparing techniques can be considered with either total or modified radical mastectomy. Breast reconstruction is usually not needed for women who have had breast-conserving surgery.

### **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. As with breast-conserving surgery, mastectomy with lymph node removal can result in numbness in the upper arm and underarm areas, reduced arm or shoulder motion, or arm swelling (see About Lymphedema, page 19).*

### **Lymph Node Removal**

Lymph node removal may be done with either breast-conserving surgery or with mastectomy. There are two main methods.

**Axillary Lymph Node Dissection (ALND)** removes lymph nodes (usually 10 or more) from the underarm area. The lymph

nodes are then examined under a microscope for cancer cells. Finding cancer in any of these nodes means that cancer cells may 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. 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. SLNB may be used for some women whose tumors are 5 cm or less and who have lymph nodes that feel normal before surgery.

### **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. 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.*

## **RADIATION THERAPY**

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 more than 5 cm or cancer was found in the lymph nodes. Radiation therapy is also used to treat cancer that has spread to other areas of the body. Radiation is not used for women who are pregnant.

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

There are two main types of radiation therapy:

- external beam radiation
- internal radiation

### **External Beam Radiation**

External beam radiation sends a high-energy beam of radiation to the breast area and sometimes to the (cont. on page 20)

## 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 builds up in tissue and causes swelling. This swelling - which can occur in the hand, wrist, elbow, shoulder, or in the entire arm - is called lymphedema.

Lymphedema can start soon after treatment or many years later. The symptoms can range from mild to severe. Currently, there is no way to know who will develop lymphedema or when it will occur. However, there are things you can do to lower your risk:

- Protect yourself from falls and fractures. Take special care with the affected arm.
- Avoid extreme hot and cold temperatures, including heating pads and ice packs.
- Avoid burns, including sunburns.
- Avoid skin punctures to the affected arm, including injections, blood draws, acupuncture, animal bites, and scratches.
- Avoid constriction, including blood pressure cuffs, tight jewelry and clothing, thin bra or camisole straps, and wearing heavy bags over the affected shoulder.
- Avoid sprains and strains by rebuilding your strength through gentle progressive exercise.
- Ask your doctor if you should be fitted for a compression sleeve for use in certain situations, such as air travel.
- Practice good daily hygiene. Keep the affected arm both clean and dry.

**IMPORTANT!** Swelling or feelings of tightness or heaviness in the hand, wrist, elbow, shoulder, or in the entire arm, should be reported to your doctor right away. Lymphedema is easier to treat when it first starts.

To learn more about the prevention and treatment of lymphedema, talk to your doctor or a certified lymphoma therapist. You can also contact the National Lymphedema Network. Call 1 800-541-3259 or go online at [www.lymphnet.org](http://www.lymphnet.org)

underarm lymph nodes. The radiation is delivered from a machine outside the body, called a linear accelerator. The procedure is painless, much like getting an x-ray, and is provided in an outpatient setting. Treatment is given once a day, 5 days a week, for 5 to 7 weeks. This is the most common type of radiation therapy for women with breast cancer.

**Accelerated Partial Breast Irradiation (APBI)** is a newer approach that delivers larger daily doses of radiation to a smaller portion of the breast. APBI may be delivered by external beam radiation or more commonly, by methods that place radioactive material inside the body (called internal radiation). APBI delivered with either method is typically given twice a day, 5 days a week, and can usually be completed in 1 week. Women interested in learning more about APBI should talk with their doctors.

**Intraoperative Radiation Therapy (IORT)** is another type of external beam radiation that is given as a single dose during breast-conserving surgery, after the cancer has been removed. IORT is also a relatively new approach and is only available in some treatment centers. Currently, doctors disagree on whether IORT is as good a treatment choice as traditional external beam radiation for women undergoing lumpectomy. More research is being done.

### **Possible Problems**

*The most common side effect with external beam radiation therapy is fatigue (tiredness). Other side effects may 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. Increased or decreased sensitivity are also possible, especially in the area of the nipple. Radiation to the underarm lymph nodes can increase the chance of lymphedema (see About Lymphedema, page 19).*

### **Internal Radiation Therapy**

Internal radiation therapy (also called brachytherapy) is another way of delivering radiation. Radioactive material (contained within tiny tubes) is placed inside the body near the area where

the cancer was removed. It is often used along with external radiation as a way to add an extra boost of radiation to the tumor site. It may also be used alone. Your doctor will consider the size and location of your cancer to decide if internal radiation is an appropriate treatment option for you.

### **Possible Problems**

*Compared with traditional external beam radiation, side effects with internal radiation are generally fewer and milder due to a shorter course of treatment. Side effects may include redness, bruising, breast pain, and infection.*

## **CHEMOTHERAPY**

Chemotherapy is a type of systemic therapy. It uses drugs to destroy or slow the growth of cancer cells anywhere in the body. Chemotherapy may be given by mouth (as a pill) or by injection into a vein (IV). It is given at repeating intervals, such as once a week or once every two weeks, and usually lasts for several months.

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

Each woman's treatment schedule varies, depending upon the specific drug or drug combinations used.

Chemotherapy is used in several ways to treat breast cancer:

- before surgery, to shrink a large cancer
- after surgery, to lower the risk of cancer coming back
- either after or instead of surgery, to treat breast cancer that has spread

The most common chemotherapy drugs used for treating early breast cancer are anthracyclines (such as doxorubicin or epirubicin) and taxanes (such as paclitaxel or docetaxel). These may be used in combination with other drugs like fluorouracil, cyclophosphamide, or carboplatin. Advanced breast cancer is more often treated with a single chemotherapy drug although combinations may still be used.

### **Possible Problems**

*The side effects of chemotherapy vary based on the drugs used, the dosage, 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. Infections are more likely during treatment. 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. Doctors watch closely for these side effects. In younger women, chemotherapy can cause infertility or premature menopause. Premenopausal women should discuss both birth control and plans for future pregnancies with their doctor before starting treatment.

## HORMONE THERAPY

Hormone therapy is a type of systemic therapy that works by blocking or lowering the amount of hormones in the body. It is used only for women whose breast cancer relies on hormones to grow (called hormone receptor-positive breast cancer). Hormone therapy is most often used after surgery (adjuvant therapy) to help lower the risk of cancer coming back but it can be also used before surgery

(neoadjuvant therapy). It is also used to treat breast cancer that has come back after treatment or has spread.

There are different types of hormone

therapy. Some block hormone receptors in breast cancer cells while others lower the amount of hormones in the body. The most effective treatment may involve using more than one type of hormone therapy over the course of several years.

Common Hormone Therapy Drugs	
Generic Name	Brand Name
Tamoxifen	Nolvadex
Toremifene	Fareston
Fulvestrant	Faslodex
Anastrozole	Arimidex
Letrozole	Femara
Exemestane	Aromasin

### Drugs That Block Hormones

Tamoxifen (Nolvadex) is the most common hormone therapy for treating hormone receptor-positive breast cancer. It works to stop or slow cancer by blocking the effect of hormones on cancer cells. Taken after surgery, tamoxifen lowers the risk of cancer

coming back by about one half. It also helps women whose cancer has spread and women whose risk for developing breast cancer is higher than average. It is not usually recommended for women who have a mastectomy for hormone receptor-positive DCIS, since the risk of invasive cancer or recurrence of DCIS is very low. Tamoxifen is taken as a pill.

Tamoxifen can be used for women who are either premenopausal (still having menstrual periods) or postmenopausal (no longer having menstrual periods). Women who begin tamoxifen while premenopausal may be switched to an aromatase inhibitor once they reach menopause.

Toremifene (Fareston) is a newer hormone-blocking drug used for treating breast cancer that has spread. It is not likely to work if tamoxifen was used and stopped working. Fulvestrant (Faslodex) may be used for women whose cancer has stopped responding to tamoxifen or an aromatase inhibitor.

#### **FOR YOUR INFORMATION:**

Hormone 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.

### **Drugs That Lower Hormone Levels**

Aromatase inhibitors (AIs) are drugs that lower the amount of hormones in the body. Unlike tamoxifen, aromatase inhibitors can only be used for postmenopausal women. Three AIs are currently used for treating breast cancer: anastrozole (Arimidex), letrozole (Femara), and exemestane (Aromasin). Used either alone or after a course of tamoxifen, all of these drugs help to reduce the risk of cancer coming back. As with tamoxifen, AIs are taken daily as pills.

### ***Possible Problems***

*The side effects of hormone therapy depend upon the drug used.*

Generally, hormone 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 blood clots, stroke, liver toxicities, fertility issues, and vision problems, such as cataracts. Tamoxifen can also increase the risk of developing cancers of the uterus. Tamoxifen, toremifene, and fulvestrant are not used for women who are pregnant. Aromatase inhibitors typically have less serious side effects. Possible problems are stomach upset, an increase in cholesterol, joint stiffness or pain, and potential loss of bone strength. A rare but serious possible side effect with AIs is the development of heart problems. AIs do not increase risk for uterine cancers and very rarely cause blood clots.

**TARGETED THERAPY**

Targeted therapy is a newer systemic therapy option that works by blocking the action of specific substances contained in cells, such as HER2, that can cause cancer to grow and spread. Targeted therapy drugs, usually given by intravenous injection, often help women with breast cancers that contain too much HER2 (called HER2-positive breast cancer).

Used with chemotherapy, trastuzumab (Herceptin) lowers the risk of cancer coming back after surgery. It can also shrink or slow

<b>Common Targeted Therapy Drugs</b>	
<b>Generic Name</b>	<b>Brand Name</b>
Trastuzumab	Herceptin
Pertuzumab	Perjeta
Lapatinib	Tykerb
Ado-trastuzumab emtansine	Kadcyla

the growth of HER2-positive breast cancer that has spread. Pertuzumab (Perjeta), another targeted therapy drug, may be used along with trastuzumab and chemotherapy, either for early-stage cancer before surgery or for treating advanced breast cancer. Lapatinib (Tykerb) and ado-trastuzumab emtansine (Kadcyla) are two other drug options currently available for women with advanced HER2-positive breast cancer. Other targeted drugs are being studied in clinical trials (see *Clinical Trials*, page 25).

## Possible Problems

*The side effects of targeted therapy depend upon the drug used. Flu-like symptoms, such as fever, chills, and nausea are common with trastuzumab, especially with the first dose. More rarely, 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. Severe or life-threatening breathing problems and/or allergic reaction are possible, but rare. Common side effects of pertuzumab include diarrhea, hair loss, nausea, fatigue, rash, and low white blood cell counts when given with trastuzumab and chemotherapy. Similar side effects may occur with ado-trastuzumab emtansine. The most common side effects with lapatinib include diarrhea, nausea, vomiting, rash, and irritation of the palms of the hands and the soles of the feet. In rare cases, lapatinib may cause liver problems or a decrease in heart function. Targeted therapies should not be used during pregnancy.*

## CLINICAL TRIALS

Clinical trials are research studies that test new drugs and new medical devices. Their purpose is to find better and safer ways to prevent, detect, diagnose, and treat disease. Each treatment described in this booklet went through years (*cont. on page 27*)

## Questions to Ask Your Doctor...

- \* How many different types of treatment will I be getting?
- \* What are the benefits and risks of each treatment?
- \* What are the possible side effects?
- \* When are they likely to occur?
- \* Are there side effects that I should report right away?
- \* How do I manage side effects?
- \* How much experience do you have with these treatments?
- \* When will I get my first treatment?
- \* How long will each treatment last?
- \* How will we know if a treatment is working?
- \* Do I need to have someone stay with me after my treatments?
- \* How do I contact a health professional after hours?
- \* Are there any clinical trials that would be appropriate for me?
- \* What is treatment likely to cost? Will my insurance cover it?

## YOUR HEALTHCARE TEAM

No one healthcare professional is able to provide all of the types services 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
- Clinical Nurse Specialist
- Lymphedema Therapist
- Occupational Therapist
- Oncologist
- Oncology Nurse
- Pathologist
- Patient Advocate
- Patient Navigator
- Physical Therapist
- Plastic Surgeon
- Primary Care Provider
- Psychologist
- Radiation Oncologist
- Radiation Therapist
- Radiologist
- Radiology Technologist
- Registered Dietician
- Social Worker
- Surgeon

of careful testing in clinical trials before becoming standard treatment (also called 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 medical research. 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 rules for who may enroll, based on such factors as age, cancer stage and type, and prior treatments. Once enrolled, patients are monitored during and after treatment. They may leave a trial at any time and 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 pages 3 and 4).

## **COMPLEMENTARY THERAPY**

Complementary therapy includes a broad range of products and practices that are not currently considered part of standard medical care. Most have not been tested in clinical trials and have not been scientifically proven to be effective for treating cancer. However, certain complementary therapies may be used along with standard treatments to help manage symptoms and side effects. Acupuncture for pain, ginger for nausea, and yoga or meditation to reduce stress are a few examples.

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 integrative treatment, or integrated treatment programs). At the same time, some major insurance companies have started to cover a few of the more widely accepted methods. Still, most complementary therapies are not covered by insurance.

Women who are thinking about using any form of complementary therapy should talk with their doctors. Some products that may seem safe, such as herbs or dietary supplements, can get in the way of your cancer treatment. For instance, St. John's wort, an herb used for treating depression, may reduce the tumor-fighting ability of some chemotherapy drugs. Always tell your doctor about the product or practice you are considering and make sure to ask questions about safety, effectiveness, and any possible interactions with your current treatments and medications (prescription and nonprescription).

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 4).

#### 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. This section shows you the most typical treatment options for each stage. Your own treatment plan may be different. You and your doctor will determine the best plan for your specific situation.

## **STAGE 0 (DCIS)**

- breast-conserving surgery followed by radiation, OR
- total mastectomy, OR
- breast-conserving surgery without radiation (*for a limited subgroup of women*)

Systemic treatment after surgery may include the following:

- hormone therapy (*for women with hormone receptor-positive breast cancer*)

## **STAGES IA and IB**

- breast-conserving surgery followed by radiation, OR
- total mastectomy, OR
- breast-conserving surgery without radiation (*for a limited subgroup of women*)

AND

- sentinel lymph node biopsy (SLNB) OR axillary lymph node dissection (ALND)

Systemic treatment after surgery may include one or more of the following:

- chemotherapy
- hormone therapy (*for women with hormone receptor-positive breast cancer*)
- targeted therapy (*for women with HER2-positive breast cancer*)

## **STAGES IIA, IIB, IIIA, and Operable IIIC**

- breast-conserving surgery followed by radiation, with possible systemic therapy before surgery, OR
- total mastectomy, with possible systemic therapy before surgery, possibly followed by radiation

AND

- sentinel lymph node biopsy (SLNB) OR axillary lymph node dissection (ALND), possibly followed by radiation to lymph nodes near the breast and chest wall

Systemic treatment after surgery may include one or more of the following:

- chemotherapy
- hormone therapy (*for women with hormone receptor-positive breast cancer*)
- targeted therapy (*for women with HER2-positive breast cancer*)

## **STAGES IIIB and Inoperable IIIC**

- total mastectomy followed by radiation, with systemic therapy before surgery

AND

- axillary lymph node dissection (ALND), possibly followed by radiation to lymph nodes near the breast and chest wall

Systemic treatment after surgery may include one or more of the following:

- chemotherapy
- hormone therapy (*for women with hormone receptor-positive breast cancer*)
- targeted therapy (*for women with HER2-positive breast cancer*)

## 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:

- surgery
- lymph node removal
- radiation
- chemotherapy
- hormone therapy
- targeted therapy
- bisphosphonate drugs

No matter what the stage of your breast cancer, clinical trials testing new anticancer drugs, new drug combinations, and new ways of giving treatment may also be considered. Ask your doctor if a clinical trial might be right for you.

### 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.

With any breast cancer that has recurred or spread, the cancer cells should be retested for hormone receptor status and for HER2, as these can change from the original cancer. Cancer that is found in the opposite breast is not a recurrence. It is a new breast cancer that requires its own tests and treatment plan.

# breast reconstruction

Breast reconstruction is surgery to recreate the shape of a breast after mastectomy. It is usually not needed for women who have had breast-conserving surgery (lumpectomy).

*Breast reconstruction may help a woman feel better about her appearance after mastectomy.*

Breast reconstruction may be done at the same time as mastectomy (immediate reconstruction) or weeks to years later (delayed reconstruction). In either case, it is important to talk to your doctor about your options before your mastectomy. The choices you make may influence where incisions are made and how much skin is saved during surgery.

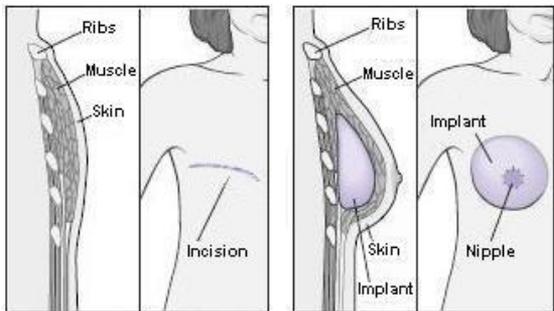
There are two main types of breast reconstruction:

- reconstruction with implants
- reconstruction with your own tissue (with or without implants)

Your plastic surgeon will explain which option is best for your age, overall health, body type, lifestyle, treatment history, and personal goals.

## Reconstruction with Implants

Reconstruction with implants is the simplest type of procedure and is often started at the time of mastectomy. For most women, it involves two steps.



After Mastectomy

After Implant Reconstruction

The first step places a temporary tissue expander under the skin and chest muscle. Over the next few weeks to months, the tissue expander is slowly filled with a saline (saltwater) solution through a tiny valve placed under the skin. Once the tissue has been stretched enough for an

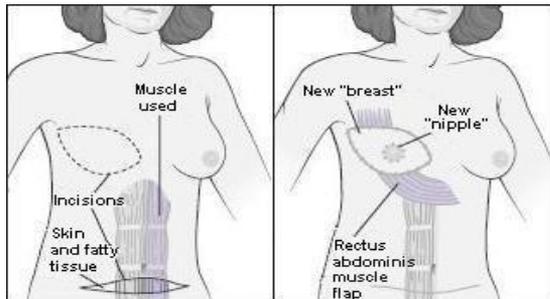
implant, the second step replaces the expander with a saline or silicone gel-filled implant.

### **Possible Problems**

*In addition to risks associated with all surgery, possible problems with implant reconstruction are rupture (breakage of the implant cover) and capsular contracture (scar tissue forming around the implant). While silicone implants are expected to last at least 10 years, one or more replacement surgeries may be needed over the course of a woman's lifetime. Imaging tests with MRI may be needed if implant rupture is suspected. Insurance may or may not cover the costs of these tests.*

### **Reconstruction with Your Own Tissue**

Tissue reconstruction uses a woman's own tissue to form the shape of a breast. The tissue, taken from the abdomen (tummy) or back, or more rarely, the buttocks or thigh, is moved to the chest where it is used to form the new breast shape. Tissue reconstruction procedures may sometimes include the use of an implant.



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.

The two most common methods are called the TRAM flap (transverse rectus abdominis flap) and the LAT flap (latissimus dorsi flap). The TRAM flap uses tissue from the lower abdomen; the LAT flap uses tissue from the upper back. Other reconstructive options using tissue from the buttocks or inner thigh may be used for some women (for example, women who are very slim). Tissue reconstruction is not usually recommended for women who smoke, have diabetes, or have vascular or connective tissue diseases.

### **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 where muscle 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 always a possibility with any breast reconstruction. The reconstructed breast will not look or feel exactly like the breast that was removed.*

### **Nipple and Areola Reconstruction**

Sometimes a woman's own nipple can be saved during mastectomy but most often, the nipple and areola (the small darkened area around the nipple) will be removed. Reconstruction of the nipple and areola is an option with either implant or tissue reconstruction for recreating a breast that looks as natural as possible.

Nipple reconstruction is usually done on an outpatient basis, under local anesthesia, after the reconstructed breast has had time to heal (about 2 to 4 months). A variety of techniques may be used to create the new nipple and areola. A method that is similar to tattooing is often used for matching the areola to a woman's natural color.

### **Questions to Ask Your Doctor...**

- \* What type of breast reconstruction do you recommend? Why?
- \* When do you recommend that I begin breast reconstruction?
- \* What results are realistic for me?
- \* Will there be scars? Where? How large?
- \* Will the reconstructed breast match my other breast?
- \* What kinds of changes to the breast can I expect over time?
- \* How many surgeries will I need?
- \* 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?

## 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 (1 800-514-5058).

## Breast Prosthesis

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

*Some women are comfortable with their body after mastectomy and do not want breast reconstruction or a breast prosthesis. Choosing reconstruction, prosthesis, or nothing is a personal decision.*

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. The American Cancer Society *Reach to Recovery* program provides information on types of prostheses as well as suppliers (for contact information, see page 3).

## Women's Health and Cancer Rights Act of 1998

Both Federal and California law contain important provisions for breast cancer patients who choose breast reconstruction. For most women whose health insurance covers mastectomy, breast reconstruction procedures, including matching procedures on the natural breast, are also covered. This provision extends to women who choose an external breast prosthesis. Women whose coverage is provided by a "church plan" or "governmental plan," should check with their plan administrator. Certain plans that are church plans or governmental plans may not be subject to the Women's Health and Cancer Rights Act.

For more information, call the U.S. Department of Labor (DOL) at 1 866-487-2365 or go online at [www.dol.gov/ebsa/publications/whcra.html](http://www.dol.gov/ebsa/publications/whcra.html) to view or print the DOL publication called *Your Rights After a Mastectomy*.

# follow-up care

Women who have finished breast cancer treatment will still see their doctor regularly. For the first three years after treatment, you will usually see your doctor every 3 to 6 months, then every 6 to 12 months for the next two years, then once a year.

During these visits you should get a thorough clinical breast exam that includes feeling the lymph nodes and looking for any visual changes. 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 treated with an aromatase inhibitor should have a bone density test before, during, and after treatment.

*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.*

Almost all women who have been treated for breast cancer will continue needing regular 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.

Immediately report any of the following, so your doctor can address possible problems:

- a new lump in the breast or on the chest wall
- 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
- spontaneous nipple discharge (liquid coming from the nipple without anything touching, stimulating, or irritating your breast)

Let your doctor know about any changes in general health as soon as you can. 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 pain, 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 soon as possible.

In addition to keeping your scheduled medical appointments and reporting any unusual symptoms, talk with your doctor about a plan to support your full recovery and future health. A proper diet and moderate exercise can help rebuild your strength and energy. A support group can provide emotional comfort and guidance.

### 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. The tummy.

**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, hormone therapy, and/or targeted therapy.

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

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

**aromatase inhibitor** A drug that lowers the amount of hormones in the body. A type of hormone therapy for postmenopausal women who have hormone receptor-positive breast cancer.

**axillary lymph node dissection (ALND)** Surgery to remove lymph nodes from the underarm region.

**axillary lymph nodes** Lymph nodes in the underarm region.

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

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

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

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

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

**cancer stage** A rating 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** Cancer that begins in the skin or in tissues that line or cover internal organs.

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

**case manager** A person who assists in the planning, coordination, monitoring, and evaluation of medical services for a patient.

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

**clean margin** A rim of normal, healthy tissue surrounding a cancer. Also called a negative or clear margin.

**clinical nurse specialist** A nurse who is trained and educated beyond the basic nursing education 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 extra HER2 protein on the surface of cells.

**hormone therapy** A type of treatment that blocks or lowers hormones in the body to slow or stop the growth of breast cancer. Also called hormonal therapy 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.

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

**local therapy** Treatment used to remove and destroy cancer where it is found. This includes the cancer and a small area around it. Surgery and radiation therapy are examples of local therapy.

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

**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** The lymphatic system filters waste and foreign material from fluid (called lymph) to help fight infection 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.

**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.

**mastectomy** Surgery to remove the breast. There are different types of mastectomy that differ in the amount of tissue and lymph nodes removed.

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

**modified radical mastectomy** Surgery that removes the breast, including the nipple, some of the underarm lymph nodes, and the lining over the chest muscles.

**negative margin** A rim of normal, healthy tissue surrounding a cancer. Also called a clean or clear margin.

**neoadjuvant therapy** Treatment given before the primary treatment (usually surgery) to shrink cancer. It may include chemotherapy, radiation therapy, hormone therapy, and/or targeted therapy.

**non-invasive breast cancer** Breast cancer that has not spread from where it began in the breast into nearby tissue.

**occupational therapist** A health professional who helps 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.

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

**patient advocate** A person who helps a patient work with others who have an effect on the patient's health, including doctors, insurance companies, employers, case managers, and lawyers.

**patient navigator** A person who provides support and guidance to patients with accessing medical services, helping to overcome any barriers to timely and quality care.

**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.

**positive margin** The rim of tissue surrounding a surgically removed tumor in which cancer cells are found.

**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.

**prophylactic mastectomy** Surgery to reduce the risk of developing breast cancer by removing one or both breasts before disease develops. Also called preventive mastectomy.

**psychologist** A professional who is educated and trained to provide mental healthcare.

**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** The use of high-energy radiation to destroy cancer cells and shrink tumors.

**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.

**re-excision** Surgically reopening the lumpectomy site to remove more tissue to insure a margin that is cancer-free (a clean margin).

**registered dietitian** A professional trained in nutrition and the management of diets to promote good health.

**risk factor** Anything that increases the chance of developing a disease, such as being female or aging, in the case with breast cancer.

**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.

**standard of care** Treatment that is accepted by medical experts as a proper treatment for a certain type of disease. Also called best practice, standard medical care, and standard therapy.

**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. Chemotherapy, hormone therapy, and targeted therapy are all examples of systemic therapy.

**tamoxifen (Nolvadex)** A drug used to treat breast cancer that is hormone receptor-positive and to prevent breast cancer in women who are at a high risk for developing the disease.

**targeted therapy** A type of treatment that uses drugs or other substances to identify and attack specific types of cancer cells with less harm to 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, including the nipple, but not the underarm lymph nodes. Also called simple mastectomy.

**trastuzumab (Herceptin)** A drug used to treat breast cancer that is HER2-positive.

**tumor** An abnormal mass of tissue. Tumors can be benign (not cancerous), or malignant (cancerous). Cancer is a particular type of tumor.

**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*

# A Woman's Guide to Breast Cancer Treatment

January 2016

*Copyright © 2016*

California Department of Health Care Services  
Cancer Detection and Treatment Branch

Published by the  
California Department of Health Care Services  
Cancer Detection and Treatment Branch  
PO Box 997417, MS 4600  
Sacramento, CA 95899-7471



Developed by the Institute for Public Health,  
Graduate School of Public Health, San Diego State University.

The California Department of Health Care Services would like to acknowledge the medical experts and breast cancer advocates who helped create this booklet.

*California physicians are required by law to give the booklet to patients upon diagnosis of breast cancer or, if the physician chooses, prior to a biopsy, and to note receipt of it in the patient's chart. This booklet provides information to patients on breast cancer treatment options (H&S §109275). There is no charge for this booklet. Requests can be faxed to (916) 263-2497 and copies are available in bundles of 25 up to a maximum of one case (250 copies per case).*