# ASCO<sup>answers</sup> Breast Cancer



Trusted Information to Help Manage Your Care from the American Society of Clinical Oncology





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# Introduction

It is one of many people's biggest fears—sitting in the doctor's office and hearing the word "cancer." People diagnosed with breast cancer often say they were stunned by their diagnosis and couldn't hear, much less remember, what was said afterward. However, absorbing the news of a cancer diagnosis is a key part of the coping process.

In the weeks to come, you may find it helpful to have family members or friends come to your appointments with you. They will not only give you some much-needed support, but they can also help listen to and remember the information given



by your health care team. Using this *ASCO Answers* guide may also be helpful. This booklet was designed to explain some of the medical terms doctors may use when talking about your cancer and help you keep track of the specifics of your breast cancer diagnosis and treatment plan. Throughout this guide, you will find questions to ask your doctor, nurse, or other members of your health care team, as well as plenty of space to write down their answers or other important information. There are also check boxes you can use to identify the tests, procedures, and treatments that will make up your cancer care plan.

However you choose to keep track of this information, it is important to do so. Getting the facts about your diagnosis will help you make the best decisions based on your situation in the coming days. Additionally, being an informed, involved patient and voicing your questions and concerns will help you and your health care team form a partnership in your care. Tell your doctor and nurse how you prefer to receive information and how much you want to know about your diagnosis, treatment, and prognosis, which is the chance of recovery. Don't be afraid to ask questions or to let your health care team know you don't know what questions to ask.

This guide does not contain information about inflammatory breast cancer or breast cancer in men. For information about those diagnoses, visit www.cancer.net/types.

# **Breast Cancer Basics**

The breast is mostly made up of different types of tissue, ranging from very fatty tissue to very dense tissue. Within this tissue is a network of lobes, which are made up of small, tube-like structures called lobules that contain milk glands. Tiny ducts connect the glands, lobules, and lobes, carrying the milk from the lobes to the nipple. The nipple is located in the middle of the areola, which is the darker area that surrounds the nipple. Blood and lymph vessels also run throughout the breast. Blood nourishes the cells, and the lymphatic system drains bodily waste products. The lymph vessels connect to lymph nodes, which are small, bean-shaped organs that help fight infection.

Breast cancer development

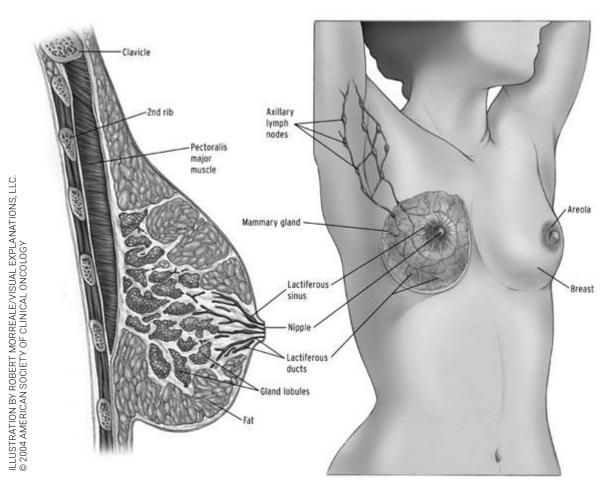
Breast cancer begins when healthy cells in the breast change and grow out of control, forming a mass called a tumor. A tumor can be cancerous or benign. A cancerous tumor is malignant, meaning it can spread to other parts of the body. A benign tumor can grow but does not spread to other parts of the body, and it is rarely life-threatening.

Breast cancer is the most common cancer in women (excluding skin cancer), but men can also be diagnosed.

## Types of breast cancer

Breast cancer can be invasive or noninvasive. Invasive breast cancer is cancer that spreads into surrounding tissues. Noninvasive breast cancer does not go beyond the milk ducts or lobules in the breast. Most breast cancers start in the ducts, called ductal carcinoma, or in the lobules, called lobular carcinoma. A pathologist determines whether a tumor removed during a biopsy is ductal or lobular cancer. A pathologist is a doctor who specializes in interpreting laboratory tests and evaluating cells, tissues, and organs to diagnose disease.

If the disease has spread outside the duct or lobule and into the surrounding tissue, it is called invasive or infiltrating ductal or lobular carcinoma. Cancer that is located only in the duct or lobule is called in situ, meaning "in place," and is noninvasive. Most in situ breast cancers are ductal carcinoma in situ (DCIS). DCIS is often treated with surgery, radiation **Breast Cancer Basics** 



MEDICAL ILLUSTRATIONS FOR MANY TYPES OF CANCER ARE AVAILABLE AT WWW.CANCER.NET.

therapy, and hormonal therapy (see "Breast Cancer Treatment," p. 14). Lobular carcinoma in situ (LCIS) is not considered cancer and is usually monitored by a doctor with regularly scheduled examinations and imaging tests. LCIS in 1 breast is a risk factor for developing invasive breast cancer in both breasts. To reduce this risk, LCIS is sometimes treated with hormonal therapy.

Other less common types of breast cancer include medullary, mucinous, tubular, metaplastic, and papillary breast cancer, as well as other even rarer types. Inflammatory breast cancer is a faster growing type of cancer that accounts for about 1% to 5% of all breast cancers. At first, it may be misdiagnosed as a breast infection because there is often swelling of the breast and redness of the breast skin that starts suddenly, and there may be no breast mass or lump. Paget's disease is a type of cancer that begins in the ducts of the nipple. The skin often appears scaly and may be itchy. Although it is usually in situ, it can also be an invasive cancer.



## Breast cancer spread

As a cancerous breast tumor grows, cancer cells may break away and be carried to other parts of the body through the bloodstream or lymphatic system. During this process, known as metastasis, the cancer cells can grow and develop in new locations in the body. One of the first places breast cancer usually spreads to is the regional lymph nodes located under the arm, in the neck, under the chest bone, or just above the collarbone.

Breast cancer can also spread farther away from the breast to other parts of the body, such as the bones, lungs, and liver. Less often, breast cancer may spread to the brain. Breast cancer that has spread to a distant location in the body is referred to as stage IV or metastatic breast cancer. However, even if the cancer has spread, it is still named for the area where it began. For example, if breast cancer spreads to the lungs, it is called metastatic breast cancer, not lung cancer. No matter whether the cancer has spread or how far it has spread, breast cancer can be treated and/or managed.

## Breast cancer genetics

Although most women who develop breast cancer have no known risk factors and no family history of breast cancer, about 5% to 10% of breast cancers occur when gene changes, called mutations, are passed down in a family from 1 generation to the next. Breast cancer may run in a family if other close relatives have been diagnosed with breast, ovarian, or other cancers, especially before age 50. If 2 first-degree relatives developed breast cancer, a person's risk is 5 times the average risk.

There are several genes linked to an increased risk of breast cancer, but 2 of the most common are *breast cancer genes 1* and 2. These are commonly shortened to *BRCA1* and *BRCA2*. A mutation in either of these genes gives a person an increased risk of developing breast and/or ovarian cancer, as well as other types of cancer. Men who inherit these gene mutations also have an increased risk of developing breast cancer, as well as prostate cancer.



Other gene mutations or hereditary conditions can increase a person's risk of breast cancer. They are far less common than *BRCA1* or *BRCA2*, and they do not increase the risk of breast cancer as much:

- ► Lynch syndrome, associated with the PMS2, MLH1, and MSH2 genes
- ► Cowden syndrome (CS), associated with the PTEN gene
- ► Li-Fraumeni syndrome (LFS), associated with the TP53 gene
- ▶ Peutz-Jeghers syndrome (PJS), associated with the STK11 gene
- ► Ataxia telangiectasia (A-T), associated with the ATM gene
- ► Hereditary diffuse gastric cancer (HDGC), associated with the CDH1 gene
- ► PALB2 gene
- ► CHEK2 gene

Genetic testing is available to check for known mutations in these genes. Your doctor may recommend a test called a panel test, which looks for mutations in several different genes at the same time. But this testing is not recommended for everyone. It is only recommended after a person has received appropriate genetic counseling.

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#### QUESTIONS TO ASK THE HEALTH CARE TEAM

- ► Who will be part of my health care team, and what will each member do?
- If I have a family history of breast cancer, what is the chance my cancer is hereditary (genetic)?
- Should I see a genetic counselor? Should my family members?
- Where can I find more information about breast cancer?
- Does this hospital or cancer center have a learning resource center? If so, where is it located?

# **Understanding Your Diagnosis**

The process of diagnosing breast cancer usually begins when a person or their doctor discovers an abnormality in the breast during a clinical or self-examination or when a mass or tiny spots of calcium appear on a screening mammogram. After this, the doctor will use a number of tests and procedures to determine whether the mass is cancerous and, if it is, to figure out if the cancer has spread.

Not every test is right for every person. Your doctor may consider factors such as your age, medical condition, signs and symptoms, and previous test results when deciding whether a specific diagnostic test is right for you.

## Imaging tests

#### Diagnostic mammography

Mammography is a type of x-ray designed to view the breast. The x-ray films produced by mammography, called mammograms, help doctors find small tumors or irregularities in the breast. Diagnostic mammography is similar to screening mammography except that more pictures are taken, and it is often used when a person is experiencing signs, such as nipple discharge or a new lump. Diagnostic mammography may also be used if something suspicious is found on a screening mammogram. A 3-dimensional version of mammography called digital breast tomosynthesis may also be used for breast cancer screening, especially for people who have dense breasts. However, it is not always covered by medical insurance, so talk with your provider about whether it may be covered for you.

#### Ultrasound

An ultrasound uses high-frequency sound waves to create an image of the breast tissue. An ultrasound can distinguish between a solid mass, which may be cancer, and a fluid-filled cyst, which is usually not cancer.

#### □ Magnetic resonance imaging (MRI)

An MRI uses magnetic fields, not x-rays, to produce detailed images of the body. An MRI can also be used to measure a tumor's size. A special dye called a contrast medium is injected into a patient's vein before the scan to help create a clearer picture of the possible cancer. A breast MRI may be used after a woman has been diagnosed with cancer to check the other breast for cancer or to find out how much the disease has grown throughout the breast. It may also be used before surgery to find out if chemotherapy is working to shrink the tumor.

## Biopsy

A biopsy is the removal of a small amount of tissue for examination under a microscope. Other tests can suggest that cancer is present, but only a biopsy can make a definite diagnosis. There are different types of biopsies, classified by the technique and/or size of the needle used to collect the tissue sample.



#### □ Fine needle aspiration biopsy

This type of biopsy uses a thin needle to remove a small sample of cells from a suspicious lump.

#### □ Core needle biopsy

This procedure uses a thicker needle to remove a larger sample of tissue. It is usually the preferred biopsy technique to find out whether an abnormality discovered during a physical examination or on an imaging test is cancer. A vacuum-assisted biopsy removes several large cores of tissue. Medication to block the awareness of pain, called local anesthesia, is used to reduce a person's discomfort during the procedure.

#### Image-guided biopsy

This test is done when a distinct lump can't be felt, but an abnormality is seen with an imaging test, such as on a mammogram. An image-guided biopsy can be done using a fine needle, core needle, or vacuum-assisted needle, depending on the amount of tissue that needs to be removed. During the procedure, the needle is guided to the best location with the help of an imaging technique, such as mammography, ultrasound, or MRI. A stereotactic biopsy is done using mammography to help guide the needle. A small metal clip may be put into the breast to mark where the biopsy sample was taken in case the tissue is cancerous and more surgery is needed. This clip is usually titanium so it will not cause problems with future imaging tests, but check with your doctor before you have any additional tests or scans.

#### □ Surgical biopsy

This type of biopsy removes the largest amount of tissue. A surgical biopsy is either "incisional" if it removes part of the lump or "excisional" if it removes the entire lump. Because surgery is best done after a cancer diagnosis has been made, a surgical biopsy is usually not the recommended procedure for diagnosing breast cancer. Most often, non-surgical core biopsies are recommended to diagnose breast cancer. This means that only 1 surgical procedure is needed to remove the tumor and to take samples of the lymph nodes.



## Examining the tissue

After a biopsy, a pathologist will look very closely at the tissue that was removed using a microscope. Based on this examination, the pathologist can tell which area of the breast the cancer started in (ductal or lobular), whether the tumor has spread outside this area (invasive or in situ), and how different the cancer cells look from healthy breast cells (the grade). If the tumor was removed, the healthy tissue around the edges of the tumor, called the margins, will also be examined to see if cancer cells are present and to measure their distance from the tumor, which is referred to as the margin width.

## Diagnostic testing

Additional laboratory testing will be performed on the tumor sample removed during a biopsy. This is done to identify specific genes, proteins, and other factors unique to your tumor. The standard tests used to further evaluate invasive breast cancer include estrogen receptor (ER), progesterone receptor (PR), and HER2 tests. ER status is often determined for DCIS as well.

#### ER and PR status

About 60% to 75% of breast cancers have estrogen and/or progesterone receptors. Breast cancer cells with these receptors depend on the hormones estrogen and/or progesterone to grow. The presence of these receptors helps determine the risk of the cancer coming

back after treatment and the type of treatment most likely to lower this risk. Generally, hormonal therapy works well for ER-positive and/or PR-positive cancers, also called hormone receptor-positive cancers. Two commonly used types of hormonal therapy are tamoxifen (Nolvadex, Soltamox) and aromatase inhibitors (see "Hormonal therapy," p. 21).

#### □ HER2 status

About 20% to 25% of breast cancers have more copies than usual of a gene called the *human epidermal growth factor receptor 2 (HER2)*. Because this gene makes a protein that fuels tumor cell growth, HER2-positive cancers may grow more quickly. The tumor's HER2 status also helps determine whether drugs that target HER2 might help treat the cancer. These drugs include trastuzumab (Herceptin), pertuzumab (Perjeta), ado-trastuzumab emtansine (Kadcyla), lapatinib (Tykerb), and neratinib (Nerlynx). About 50% of HER2-positive tumors also have hormone receptors, so people with breast cancer can benefit from both types of treatment.

#### □ Triple-negative

If a tumor does not express ER, PR, or HER2, the tumor is called "triple-negative." Triplenegative breast cancer makes up about 15% of invasive breast cancers. Triple-negative breast cancer may be more common among younger patients, particularly younger Black women. Triple-negative cancer is also more common in people with a mutation in the *BRCA1* gene. Experts recommend that all people under age 60 with triple-negative breast cancer be tested for *BRCA* gene mutations.



## Genomic testing of the tumor

Tests that look at the biology of a tumor are sometimes used to understand more about breast cancer, especially if the cancer has not spread to other parts of the body. These tests can help choose the most effective type of treatment, predict the risk of recurrence, and avoid possible side effects of a treatment that is not likely to work well.

Two commonly used genomic tests in the United States are Oncotype DX and Mammaprint. These tests are typically used to estimate the risk of the cancer coming back in a place other than the breast and nearby lymph nodes within 5 to 10 years



after diagnosis. These tests are usually used for people with stage I or stage II ER-positive breast cancer. The results help doctors decide whether chemotherapy should be added to treatment with hormonal therapy. Other types of genomic tests include PAM50 (Prosigna), EndoPredict, Breast Cancer Index, and uPA/PAI.

Other genomic tests may also be performed to examine changes in the tumor that may help doctors better understand what makes an individual cancer grow. These types of tests are typically used for metastatic cancer and not for early-stage cancer.

## Grades

Doctors may use the term "grade" when talking about breast cancer. The grade describes how much cancer cells look like healthy cells when viewed under a microscope. Knowing the grade of the cancer may help your doctor predict how quickly the cancer will spread. If the cancer looks similar to healthy tissue and contains different cell groupings, it is called differentiated or a low-grade tumor. If the cancerous tissues look very different from healthy tissue, it is called poorly differentiated or a high-grade tumor. In general, the lower the tumor's grade, the better the prognosis.

- GX-Cannot be evaluated; undetermined
- □ G1-Similar to healthy breast tissue, well differentiated, low grade
- □ G2—Still has some features of healthy breast tissue, moderately differentiated, intermediate grade
- □ G3-Very different from healthy breast tissue, poorly differentiated, high grade

## **Stages**

People with breast cancer are usually given a stage along with their diagnosis. The stage is a way of describing where the cancer is located, if or where it has spread, and whether it is affecting other parts of the body. Doctors use diagnostic tests to find out a cancer's stage, so information about staging may not be available until all the tests are finished. Knowing the stage will help your doctor decide which treatment plan will be most effective and help predict your prognosis.



Doctors assign the stage of breast cancer using a number zero (0) through 4 (Roman numerals I through IV). Doctors may refer to stage I and stage IIA cancer as "early stage" and to stage IIB and stage III as "locally advanced." Stage IV is called "metastatic breast cancer." This description is based on the pathologic or anatomic stage. There is also a prognostic stage that takes into account ER and PR status, HER2 status, grade, and Oncotype results, which better reflects the chances of the cancer coming back after recommended treatment.

**Stage 0.** The disease is only in the ducts of the breast and has not spread to the surrounding breast tissue. It is also called in situ or noninvasive cancer.

Stage IA. The tumor is small and invasive, but it has not spread to the lymph nodes.

**Stage IB.** A small number of cancer cells have spread to the axillary lymph nodes under the arm and formed tiny clusters larger than 0.2 millimeters (mm) but smaller than 2 mm in size. There is either no evidence of a tumor in the breast, or the tumor in the breast is 20 mm or smaller.

Stage IIA. The cancer has any of the following characteristics:

- There is no evidence of a tumor in the breast, but there is cancer in 1 to 3 axillary lymph nodes.
- ▶ The tumor is 20 mm or smaller and has spread to 1 to 3 axillary lymph nodes.
- ► The tumor is between 20 mm and 50 mm and has not spread to the axillary lymph nodes.

Stage IIB. The cancer has either of the following characteristics:

- ▶ The tumor is between 20 mm and 50 mm and has spread to 1 to 3 axillary lymph nodes.
- The tumor is larger than 50 mm but has not spread to the axillary lymph nodes.

**Stage IIIA.** The tumor may be any size, but it has spread to 4 to 9 axillary lymph nodes or to internal mammary lymph nodes. It has not spread to other parts of the body based on imaging tests. Stage IIIA may also describe a tumor larger than 50 mm that has spread to 1 to 3 lymph nodes.

**Stage IIIB.** The tumor has spread to the chest wall, caused swelling or ulceration of the breast, or is diagnosed as inflammatory breast cancer. It may or may not have spread to the axillary or internal mammary lymph nodes under the arm. It has not spread to other parts of the body based on imaging tests.

**Stage IIIC.** The tumor can be any size, but it has spread to 10 or more axillary lymph nodes, the internal mammary lymph nodes, and/or other lymph nodes under the collarbone. The cancer has not spread to other parts of the body based on imaging tests.

**Stage IV.** The tumor can be any size, but the distinguishing characteristic is that it has spread to other, distant sites in the body.

Recurrent. The breast cancer has come back after treatment.

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#### QUESTIONS TO ASK THE HEALTH CARE TEAM ABOUT YOUR DIAGNOSIS

- ► What type and stage of breast cancer do I have? What does this mean?
- ► Is there enough information to recommend a treatment plan for me? If not, which tests or procedures will be needed?
- ► How can I prepare myself for each test or procedure?
- ▶ Where do I need to go to have these tests?
- ► When will I get the results? How will I get the results (over the phone, at my next appointment, etc.)?
- ▶ Who will explain these results to me?
- ► Should I get a second opinion? Can you give me names of doctors I could see?
- ▶ If I get a second opinion, will I have to repeat any tests or procedures?
- ► What is my prognosis?
- ▶ If I am worried about the cost of treatment, who can help me with this concern?

# **Breast Cancer Treatment**

In cancer care, doctors with different specialties often work together to create an overall treatment plan that combines different types of treatments. This is called multidisciplinary care. The treatment options and recommendations your doctor gives you will depend on several factors, including the stage and subtype of the tumor, whether the cancer has spread, whether you have gone through menopause, your gender, your age and overall health, whether you have other medical issues, the tumor's hormone receptor (ER, PR) and HER2 status, and the presence of known mutations in inherited breast cancer genes (such as BRCA1 or BRCA2), as well as genomic markers. Your care plan should also include treatment for symptoms and side effects.



When making treatment decisions, you are also encouraged to consider participating in a clinical trial. A clinical trial is a research study that tests whether a new approach to treatment is safe, effective, and possibly better than the standard treatment.

Before treatment begins, it is important to discuss the goals and possible side effects of treatment with your doctor, including the likelihood that the treatment will work and its potential effect on your quality of life. To start a conversation with your doctor, you may want to ask:

- ▶ What are my treatment options?
- ▶ Will I need more than 1 type of treatment?
- ▶ What treatment plan do you recommend for me? Why?
- What is the goal of the treatment(s) you are recommending? Is it to eliminate the cancer? To relieve my symptoms? Or both?
- What is the expected timeline for my treatment plan?
- ▶ When do I need to make a decision about starting treatment?

## Surgery

Surgery to remove the tumor from the breast and/or evaluate the lymph nodes for cancer is often one of the first treatments for someone diagnosed with breast cancer that has not spread in the body. Sometimes, treatment with medication is given first and surgery is performed afterward. A surgeon or surgical oncologist, a doctor who specializes in treating cancer using surgery, performs this procedure.



The goal of breast cancer surgery is to remove the tumor along with a margin of healthy tissue around it. Your surgical oncologist will guide you in the decision of what kind of surgery to consider and which choices are preferred depending on you and your breast cancer diagnosis. Generally, the smaller the tumor, the more surgical options a person has. These options include:

#### Lumpectomy

This surgery removes the tumor as well as a small, cancer-free margin around it. Most of the breast remains. For both invasive and noninvasive cancer, radiation therapy to the remaining breast tissue is generally recommended after surgery. For DCIS, radiation therapy after surgery may be an option depending on the patient and the tumor. A lumpectomy may also be called breast-conserving surgery, a partial mastectomy, quadrantectomy, or a segmental mastectomy.

#### □ Mastectomy

This surgery removes the entire breast and may or may not be combined with reconstructive surgery. There are several types of mastectomies, and some can preserve the skin (called a skin-sparing mastectomy) and the nipple (called a total skin-sparing mastectomy).

Surgery is also used to evaluate nearby lymph nodes for cancer cells. This helps the doctor decide the most appropriate treatment. Lymph nodes serve as collecting stations for lymph, a clear fluid that flows throughout the body. As lymph drains out of the breast and into nearby lymph nodes, it can transport cancer cells that may have detached from the original tumor before it was removed. If there is cancer in the lymph nodes, the cancer is called lymph node.

The type of procedure you have will depend on a variety of factors, including the type of breast cancer and whether there is obvious evidence of cancer in the lymph nodes before surgery. The options are:

#### □ Sentinel lymph node biopsy

During a sentinel lymph node biopsy, the surgeon finds and removes about 1 to 3 sentinel lymph nodes from under the arm that receives lymph drainage from the breast. Sentinel lymph nodes are the first lymph nodes that are likely to collect cancer cells that have broken away from a tumor. The pathologist then examines these lymph nodes for cancer cells. To find the sentinel lymph nodes, the surgeon injects a dye and/or a radioactive tracer into the area of the cancer and/or around the nipple. The dye or tracer travels to the lymph nodes, arriving at the sentinel nodes first. The surgeon can find these nodes when they change color (if the dye is used) or gives off radiation (if the tracer is used).

If the sentinel lymph nodes are cancer-free, research has shown that there is a good possibility that the remaining lymph nodes will also be free of cancer and no further surgery will be needed. If the sentinel lymph nodes show evidence of cancer, usually no further surgery is needed. However, the surgeon may consider a dissection of the axillary lymph nodes, located under the arms, to look for additional cancer cells, depending on the type of breast surgery planned, the stage of the cancer, and the number of cancer cells found in the sentinel lymph nodes.

#### □ Axillary lymph node dissection

During an axillary lymph node dissection, the surgeon removes many lymph nodes from under the arm, which are then examined by a pathologist for cancer cells. Researchers have found that an axillary lymph node dissection may not be needed for all people with earlystage breast cancer who have small amounts of cancer in the sentinel lymph nodes. Those having a lumpectomy and radiation therapy who have a smaller tumor and no more than 2 sentinel lymph nodes with cancer may avoid a full axillary lymph node dissection, which helps reduce the risk of side effects and does not decrease survival rates.

#### Side effects of surgery

After a mastectomy or lumpectomy, the breast may be scarred and may have a different shape or size than before surgery. The area around the surgical site may also become harder. If any lymph nodes were removed as part of the surgery or were affected during treatment, lymphedema may occur. Lymphedema is swelling of the hand and/or arm, and it is a life-long risk.

Lymphedema develops when a blockage in the lymphatic system makes fluid build up in the arm. Lymphedema may develop immediately after surgery, or it may occur months or even years after cancer treatment has ended. Talk with your health care team about ways to reduce your risk of lymphedema, any lymphedema symptoms you may experience, and ways to manage this condition so it does not get worse.

#### QUESTIONS TO ASK THE HEALTH CARE TEAM ABOUT SURGERY

- ► Am I a candidate for a lumpectomy? Why or why not?
- If I have a lumpectomy, will my breast differ in size and shape compared to my other breast?
- Do I need to have a mastectomy? If so, would you recommend immediate breast reconstruction (plastic surgery)? What are the advantages and disadvantages of this?
- Do the lymph nodes under my arm need to be removed? Do you recommend a sentinel lymph node biopsy? If not, do you recommend an axillary lymph node dissection instead?
- Will I need to be admitted to a hospital for this operation? If so, how long will I need to stay in the hospital?
- Will my tumor be saved? Where will it be stored? For how long? How can it be accessed in the future?
- ▶ Am I at risk for developing lymphedema? If so, how can we reduce this risk?
- ▶ Where will the scar be, and what will it look like?
- What kind of pain should I expect to feel after surgery? What can be done to manage this pain?
- Will my arm be affected by surgery? If so, for how long? Will I need physical therapy?

#### Breast reconstruction and external breast prosthesis

Many people who have a mastectomy consider breast reconstruction surgery to rebuild and restore the appearance of a natural breast. Breast reconstruction can help a person regain their sense of identity and sexuality, which may have been lost after a mastectomy, and reduce feelings of self-consciousness.

Reconstruction may be done using tissue taken from another part of the body or either silicone or saline synthetic implants. Depending on your preference and treatment options, breast reconstruction may be done either at the same time as the mastectomy or months or years later. In general, the reconstruction results are better when done during a mastectomy because the skin and other soft tissues surrounding the area haven't tightened and scarred. However, your doctor may recommend delaying this reconstructive surgery if radiation therapy is part of your treatment plan following surgery.

If you choose not to have reconstructive surgery or need to delay surgery, you may want to consider an external breast prosthesis or artificial breast form. Breast prostheses are custom-designed for most people and help balance the body, keep your bra on the side of the mastectomy from riding up, and allow you to look the same in clothing as you did before the surgery.

# QUESTIONS TO ASK THE HEALTH CARE TEAM ABOUT BREAST RECONSTRUCTION/PROSTHESIS

- What types of breast reconstruction options do I have? What are the advantages and disadvantages of each type?
- ► If I have radiation therapy, does that change my options for reconstruction?
- ▶ When can I have my reconstruction?
- ▶ What results can I expect?
- ► Do you have photographs of reconstructed breasts I can see?
- How will my reconstructed breast feel? Will it match my other breast in size and shape?
- ► What type of sensation (feeling) will the reconstructed breast have?
- ► Will I be able to breastfeed in the future?
- ▶ Is a prosthesis a better option for me?
- ► How can I get fitted for a breast prosthesis?
- Will my insurance cover this?

## Radiation therapy

Radiation therapy uses high-energy x-rays or other particles to destroy cancer cells. A doctor who specializes in giving radiation therapy to treat cancer is called a radiation oncologist.

The most common type of radiation therapy used to treat breast cancer is external-beam radiation therapy. It delivers radiation from a machine located outside the body. Other types of radiation therapy, such as intra-operative radiation therapy and brachytherapy, are used less often to treat breast cancer.

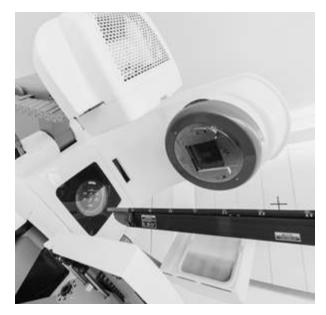
#### **Radiation therapy after lumpectomy**

Radiation therapy is most often given after a lumpectomy to help lower the risk of recurrence in the breast.

Standard radiation therapy after a lumpectomy is external-beam radiation therapy given Monday through Friday for 3 to 6 weeks. This often includes radiation therapy to the whole breast for the first few weeks, followed by a more focused treatment, called a boost, to the area in the breast where the tumor was located for the remaining treatments. For women with a low risk of recurrence, the boost may be optional. Some centers are studying and using a 5-day schedule of accelerated partial breast irradiation (PBI), a technique in which radiation is given only to the tumor area and not the entire breast. Other shorter treatment schedules are also being tested. It is important to discuss these treatment approaches with your doctor.

#### **Radiation therapy after mastectomy**

Radiation therapy may also be recommended for some people after a mastectomy, depending on their age; the size of the tumor; the number of lymph nodes under the arm that contain cancer; the width of healthy tissue around the tumor removed by the surgeon; the ER, PR, and HER2 status of the tumor; and other factors. This treatment is given to the chest wall, Monday through Friday, for 3 to 6 weeks. Rarely, radiation therapy may be given before surgery to shrink a large tumor, making it easier to remove.



#### **Radiation therapy side effects**

Radiation therapy causes side effects, including fatigue, swelling of the breast, redness and/or skin discoloration, and pain and/or burning in the skin where the radiation was directed, sometimes with blistering or peeling. Very rarely, a small amount of the lung can be affected by the radiation, causing pneumonitis, which is radiation-related inflammation of the lung tissue. Some people experience breathlessness, a dry cough, and/or chest pain 2 to 3 months after finishing radiation therapy because the treatment can cause swelling and a hardening or thickening of the lungs called fibrosis. These side effects are usually temporary.

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# QUESTIONS TO ASK THE HEALTH CARE TEAM ABOUT RADIATION THERAPY

- ► Which type of radiation therapy do you recommend? Why?
- ► How often will I receive radiation therapy?
- Will each treatment be the same? Or will the radiation dose or area treated change throughout the treatment period?
- Are there alternatives to the recommended treatment?
- ► How much time will each treatment take?
- What will I experience when I receive radiation therapy? Will it hurt or cause me discomfort?
- What can I do to get ready for this treatment? Are there recommendations on what clothes to wear?
- ► If I decide to have reconstructive surgery, how would it affect my treatment plan?
- What are the possible short- and long-term side effects of this treatment? How can these side effects be prevented and/or managed?

## Chemotherapy

Chemotherapy is the use of drugs to destroy cancer cells, usually by keeping the cancer cells from growing, dividing, and making more cells. It may be given before surgery to shrink the tumor or after surgery as an adjuvant treatment. It is also used to treat metastatic breast cancer and cancer that returns after treatment, called recurrent cancer. A medical oncologist, a doctor who specializes in treating cancer with medication, prescribes chemotherapy.

Systemic chemotherapy is delivered through the bloodstream to reach cancer cells throughout the body. Chemotherapy for breast cancer may be given through an intravenous (IV) tube placed into a vein or as a pill or capsule that is swallowed (orally). Patients may have treatment once a week, once every 2 weeks (also called dose-dense chemotherapy), once every 3 weeks, or even once every 4 weeks.

Common drugs for breast cancer include:

- □ Capecitabine (Xeloda)
- Carboplatin (Paraplatin)
- Cisplatin (Platinol)
- Cyclophosphamide (Neosar)
- Docetaxel (Docefrez, Taxotere)
- Doxorubicin (Adriamycin)
- Epirubicin (Ellence)
- □ Eribulin (Halaven)
- D Fluorouracil (5-FU, Adrucil)
- Gemcitabine (Gemzar)
- □ Ixabepilone (Ixempra)
- □ Methotrexate (multiple brand names)
- Paclitaxel (Taxol)
- Degylated liposomal doxorubicin (Doxil)
- Protein-bound paclitaxel (Abraxane)
- □ Vinorelbine (Navelbine)



A patient may receive 1 drug at a time or a combination of different drugs given at the same time. The type of chemotherapy a person receives and how often it is given will depend on what worked best in clinical trials for that type and stage of cancer.

Depending on the type of chemotherapy and the treatment schedule, your doctor may recommend that you have minor surgery before starting treatment to insert an implantable port. A port is a round metal or plastic disk that is used as the entry site for IV medications, eliminating the need to find a vein at each treatment session.

The side effects of chemotherapy depend on the individual, the drug(s), the schedule, and the dose used. In general, side effects include fatigue, risk of serious infection, nausea and vomiting, hair loss, loss of appetite, constipation, skin and nail changes, weight gain, temporary or permanent menopause, and diarrhea. These side effects can often be prevented or managed during treatment, and they usually go away once treatment has finished. Rarely, long-term side effects may occur, such as heart damage or secondary cancers. Permanent numbness and tingling of the hands and feet can occur with some chemotherapy drugs.

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#### QUESTIONS TO ASK THE HEALTH CARE TEAM ABOUT CHEMOTHERAPY

- ▶ Which type of chemotherapy do you recommend? Why?
- ► How long will I need to have chemotherapy?
- ► How will the treatment be given? Do I need a port?
- ► How will we know if the treatment is working?
- ▶ Will I receive this treatment at a hospital or clinic? Or will I take it at home?
- ► How will chemotherapy affect my daily life? Will I be able to work, exercise, and perform my usual activities?
- What are the potential short- and long-term side effects of each medication? Will I lose my hair?
- ► Where can I get more information about the medication(s) I will be taking?

## Hormonal therapy

For people with ER- or PR-positive breast cancer, hormonal therapy, also called endocrine therapy, is typically recommended. Because these types of tumors use hormones to fuel their growth, blocking the hormones can help prevent recurrence and death, either by itself or following adjuvant or neoadjuvant chemotherapy. Hormonal therapy is also effective as a treatment for metastatic breast cancer, shrinking the cancer and improving cancer-related symptoms.

#### □ Tamoxifen (Nolvadex, Soltamox)

Tamoxifen blocks estrogen from attaching to breast cancer cells. It is effective at reducing the risk of recurrence in the breast that had cancer, the risk of developing cancer in the other breast, and the risk of distant recurrence. It is also approved to reduce the risk of breast cancer in people at high risk for developing the disease and for reducing local recurrence for people with DCIS who had a lumpectomy.

The side effects of tamoxifen include hot flashes and vaginal dryness, discharge, or bleeding. Very rare risks include a cancer of the lining of the uterus, cataracts, and blood clots. However, tamoxifen improves bone health and cholesterol levels and can be effective for both premenopausal and postmenopausal women.

#### □ Aromatase inhibitors (Als)

Drugs such as anastrozole (Arimidex), exemestane (Aromasin), and letrozole (Femara) decrease the amount of estrogen made in tissues other than the ovaries in postmenopausal women. Research shows that all 3 Al drugs work equally well and have similar side effects, which may include muscle and joint stiffness and pain, hot flashes, vaginal dryness, an increased risk of osteoporosis and broken bones, and higher cholesterol levels. However, these medicines also reduce the risk of local and distant recurrence.



Women who have not yet gone through menopause should not take AIs by themselves because they do not block the effects of estrogen made by the ovaries. Often, doctors will monitor blood estrogen levels in women whose periods have recently stopped, or whose periods stop with chemotherapy, to make sure the ovaries are no longer producing this hormone. Premenopausal women can take AI medications if they also receive ovarian suppression, described below.

#### Ovarian suppression

Stopping the ovaries from making estrogen is 1 of the oldest hormonal treatments for hormone receptor-positive breast cancer and for premenopausal women with metastatic breast cancer. Medications called gonadotropin or luteinizing releasing hormone (GnRH or LHRH) analogues stop the ovaries from making estrogen, causing temporary menopause. Goserelin (Zoladex) and leuprolide (Lupron) are drugs given by injection under the skin that stop the ovaries from making estrogen for 1 to 3 months. Most commonly, these drugs are given with tamoxifen or AIs as part of adjuvant therapy for breast cancer in premenopausal women. Less commonly, they are given alone. Surgical removal of the ovaries, called an oophorectomy, may also be considered for some patients; however, the hormonal effects of this surgery are permanent.

#### □ Fulvestrant (Faslodex)

Fulvestrant is a selective estrogen receptor downregulator (SERD) that blocks the ability of estrogen to attach to estrogen receptors. Unlike other oral hormonal therapies, fulvestrant is given monthly by an injection into a muscle. Most commonly, 2 injections are given every 2 weeks for the first 3 doses and then continued monthly. Fulvestrant is only for women who have been through menopause, although it can also be used to treat men.

# QUESTIONS TO ASK THE HEALTH CARE TEAM ABOUT HORMONAL THERAPY

- ► Which type of hormonal therapy do you recommend? Why?
- ► How long will I need to continue this treatment?
- ► Are there any reasons why I might not benefit from hormonal therapy?
- What is my current menopausal status? How does this affect my options for hormonal therapy?
- ► Could this treatment affect my sex life? If so, how and for how long?
- Could this treatment affect my ability to become pregnant in the future? If so, should I talk with a fertility specialist before treatment begins?
- ► How do the side effects of Als compare with tamoxifen?

## Targeted therapy

Targeted therapy is a type of drug treatment that targets the cancer's specific genes, proteins, or the tissue environment that contributes to cancer growth and survival. This type of treatment blocks the growth and spread of cancer cells and limits damage to healthy cells.

Research studies show that not all breast tumors have the same targets. To find the most effective



treatment, your doctor may run specialized tests to identify genes, proteins, and other factors specific to your tumor.

The first targeted therapies used to treat breast cancer were hormonal therapies. Then HER2 targeted therapies were approved to treat HER2-positive breast cancer.

Talk with your doctor about possible side effects for a specific medication and how they can be managed.

#### **HER2-targeted therapy**

If your cancer is HER2 positive, your doctor may recommend medications that only affect HER2-positive cancer cells. These anti-HER2 treatments block HER2 to stop the growth of cancer cells.

#### □ Trastuzumab (Herceptin)

Trastuzumab is approved for the treatment of HER2-positive breast cancer. Currently, patients with stage I to stage III breast cancer typically receive a trastuzumab-based regimen, often including a combination of trastuzumab with chemotherapy, followed by completion of 1 year of adjuvant trastuzumab. Patients receiving trastuzumab have a small (2% to 5%) risk of heart problems, and this risk is increased if a patient has other risk factors for heart disease. These heart problems may go away when the medicine is stopped and can be treatable with medication. Trastuzumab is also an important part of treatment for metastatic HER2-positive breast cancer.

#### Pertuzumab (Perjeta)

Pertuzumab is approved as part of treatment for breast cancer in combination with trastuzumab and chemotherapy. It is also used in combination with trastuzumab and chemotherapy for metastatic HER2-positive breast cancer.

#### □ Pertuzumab, trastuzumab, and hyaluronidase-zzxf (Phesgo)

This combination drug, which contains pertuzumab, trastuzumab, and hyaluronidase-zzxf in a single dose, is approved for people with early-stage HER2-positive breast cancer. It may be given in combination with chemotherapy. It is given by injection under the skin and can be administered either at a treatment center or at home by a health care professional.

#### □ Ado-trastuzumab emtansine or T-DM1 (Kadcyla)

T-DM1 is a combination of trastuzumab linked to a type of chemotherapy. This allows the drug to deliver chemotherapy into the cancer cell while reducing the chemotherapy received by healthy cells. T-DM1 is approved to treat patients who receive trastuzumab plus chemotherapy followed by surgery and who are found to still have cancer cells present in the breast at the time of surgery.

#### Trastuzumab deruxtecan (Enhertu)

Trastuzumab deruxtecan is approved for treatment of patients with metastatic HER2positive breast cancer who have already received 2 or more HER2-targeted therapies. This HER2-targeted treatment is a combination of a drug that is similar to trastuzumab, called a biosimilar, linked to a small amount of a strong chemotherapy. The trastuzumab biosimilar carries the chemotherapy to the HER2-positive cancer cells, so it can destroy the cancer cells and limit damage to healthy cells. It is given by vein every 3 weeks.

#### Tucatinib (Tukysa)

Tucatinib, when added to capecitabine chemotherapy and trastuzumab, is approved for the treatment of advanced unresectable or metastatic HER2-positive breast cancer, including cancer that has spread to the brain, in those who have already received 1 or more HER2-targeted therapy. Unresectable means surgery is not an option. Tucatinib is a tyrosine kinase inhibitor designed to turn off HER2. It is an oral medication that is given twice daily.

#### □ Lapatinib (Tykerb)

Lapatinib is approved for the treatment of metastatic HER2-positive breast cancer. It may be given in combination with capecitabine or letrozole.

#### Neratinib (Nerlynx)

This oral drug is approved as a treatment for higher-risk HER2-positive, early-stage breast cancer. It is also approved for metastatic disease. It is taken for a year, starting after patients have finished 1 year of trastuzumab.

#### **Bone-modifying drugs**

Bone-modifying drugs block bone destruction and help strengthen bone. They may be used to prevent cancer from recurring in the bone or to treat cancer that has spread to the bone. Certain types are also used in low doses to prevent and treat osteoporosis, which is the thinning of the bones.

There are 2 types of drugs that block bone destruction. Bisphosphonates, such as zoledronic acid (Zometa), block osteoclasts, which are cells that destroy



bone. Denosumab (Xgeva) is an osteoclast-targeted therapy called a RANK ligand inhibitor. Both drugs are used to treat patients with metastatic disease that has spread to the bone.

For people with breast cancer that has not spread, receiving bisphosphonates after breast cancer treatment may help to prevent a recurrence. ASCO recommends zoledronic acid or clodronate (multiple brand names) as options to help prevent a bone recurrence for women who have been through menopause. Clodronate is only available outside of the United States.

#### Other types of targeted therapy Alpelisib (Piqray)

Alpelisib is an option along with the hormonal therapy fulvestrant for people with hormone receptor-positive, HER2-negative metastatic breast cancer that has a *PIK3CA* gene mutation and has worsened during or after hormonal therapy.

#### □ Everolimus (Afinitor, Zortress)

Everolimus is used with the AI exemestane for ER-positive, HER2-negative metastatic breast cancer that has grown despite treatment with another AI.

#### □ Drugs that target the CDK4/6 protein

The CDK4/6 protein may stimulate cancer cell growth. These drugs include abemaciclib (Verzenio), palbociclib (Ibrance), and ribociclib (Kisqali). They are approved for people with ER-positive, HER2-negative advanced or metastatic breast cancer and may be combined with some types of hormonal therapy. They may also be used in conjunction with fulvestrant in endocrine-resistant second-line disease.

#### □ Sacituzumab govitecan-hziy (Trodelvy)

This drug is approved for the treatment of people with metastatic triple-negative breast cancer who have already received at least 2 treatments. Sacituzumab govitecan-hziy is an antibody-drug conjugate, which means the antibody attaches to a cancer cell and then delivers the anticancer drug it carries to start destroying the cancer cell. Sacituzumab govitecan-hziy is given by vein on days 1 and 8 of every 21-day cycle.

#### □ Entrectinib (Rozyltrek) and larotrectinib (Vitrakvi)

These may be used for treatment of breast cancer with an *NTRK* fusion that is metastatic or cannot be removed with surgery and has worsened with other treatments.

#### 🗆 Olaparib (Lynparza)

This oral drug may be used for people with metastatic HER2-negative breast cancer and a *BRCA1* or *BRCA2* gene mutation who have previously received chemotherapy. It is a type of drug called a PARP inhibitor, which destroys cancer cells by preventing them from fixing damage to the cells. In patients who do not have metastatic breast cancer, ASCO does not recommend the use of PARP inhibitors to treat patients with either a *BRCA* mutation or a moderate-risk mutation.

#### Talazoparib (Talzenna)

This may be an option for people with locally advanced or metastatic HER2-negative breast cancer and a *BRCA1* or *BRCA2* gene mutation. It is a PARP inhibitor.

# QUESTIONS TO ASK THE HEALTH CARE TEAM ABOUT TARGETED THERAPY

- ▶ Based on my test results, will I benefit from targeted therapy? Why or why not?
- ► How long will I need to have this treatment?
- ► How will the treatment be given?
- ▶ Will I receive the treatment at a hospital or clinic, or will I take it at home?
- What are the possible side effects of this treatment? How will these side effects be managed?
- ► How will my treatment be monitored?
- If I am worried about managing the cost of treatment, who can help me with this concern?

## Immunotherapy

Immunotherapy, also called biologic therapy, is designed to boost the body's natural defenses to fight the cancer. It uses materials made either by the body or in a laboratory to improve, target, or restore immune system function. The following drugs are used for advanced or metastatic breast cancer.

#### □ Atezolizumab (Tecentriq)

The U.S. Food and Drug Administration (FDA) approved a combination of atezolizumab plus protein-bound paclitaxel, a chemotherapy, for treatment of locally advanced triple-negative breast cancer that cannot be removed with surgery and metastatic triple-negative breast cancer. In addition, it is only approved for breast cancers that test positive for PD-L1.



#### Pembrolizumab (Keytruda)

This is a type of immunotherapy that is approved to treat metastatic cancer or cancer that cannot be treated with surgery. These tumors must also have a molecular alteration called microsatellite instability-high (MSI-H) or DNA mismatch repair deficiency (dMMR). In addition, it is approved in combination with a few different chemotherapy drugs to treat metastatic or locally recurrent triple-negative breast cancer that cannot be treated with surgery and that tests positive for PD-L1.

Different types of immunotherapy can cause different side effects. Common side effects include skin rashes, flu-like symptoms, diarrhea, and weight changes. Other severe but less common side effects can also occur. Talk with your doctor about possible side effects of the immunotherapy recommended for you.

## Clinical trials

Doctors and scientists are always looking for better ways to treat people with breast cancer. To make scientific advances, doctors conduct research studies involving volunteers, called clinical trials.

Many clinical trials focus on new treatments. Researchers want to learn if a new treatment is safe, effective, and possibly better than the existing treatments. These studies evaluate new drugs, different combinations of existing treatments, new approaches to radiation therapy or surgery, and new methods of



treatment, including reducing the amount of treatment given. There are also clinical trials that study new ways to ease symptoms and side effects during treatment and ways to manage late effects that may occur after treatment. Clinical trials are often designed to be an option at any point in a patient's care, starting from the time of diagnosis.

Patients who participate in clinical trials can be some of the first to get a treatment before it is available to the public. However, there are some risks with a clinical trial, including possible side effects and that the new treatment may not work. People are encouraged to talk with their health care team about the pros and cons of joining a specific study.

People decide to participate in clinical trials for many reasons. For some people with breast cancer, a clinical trial is the best treatment option available. Because standard treatments are not perfect, people are often willing to face the added uncertainty of a clinical trial in the hope of a better result. Other people volunteer for clinical trials because they know these studies are a way to contribute to the progress in treating breast cancer. Even if they do not benefit directly from the clinical trial, their participation may help other people with breast cancer in the future.

Insurance coverage and the costs of clinical trials differ by location and by study. In some programs, some of the patient's expenses from participating in the clinical trial are reimbursed. In others, they are not. It is important to talk with the research team and your insurance company first to learn if and how your treatment in a clinical trial will be covered.

Some people worry if they participate in a clinical trial they may receive no treatment by being given a placebo or a "sugar pill." Breast cancer trials never use a placebo instead of standard treatment. Most often in a breast cancer treatment clinical trial, you will receive either the new treatment or the standard treatment. So even if you do not get the new

drug or other new therapy, your breast cancer will be treated the same as if you were not in the trial. Sometimes, you may get the standard treatment plus a placebo rather than the standard treatment plus the new treatment being studied. Study participants will always be told when a placebo is used in a study. In randomized clinical trials, participants and doctors do not get to choose which treatment the participant will receive.

To join a clinical trial, patients must participate in a process known as informed consent. During informed consent, the research team should:

- Describe all of the patient's options, so that the person understands the standard treatment and how the new treatment differs from the standard treatment.
- List all of the risks of the new treatment, which may or may not be different from the risks of standard treatment.
- Explain what will be required of each patient to participate in the clinical trial, including the number of doctor visits, tests, and the schedule of treatment.

Clinical trials also have certain rules called "eligibility criteria" that help structure the research and keep patients safe. You and the research team will carefully review these criteria together.

Patients who participate in a clinical trial may stop participating at any time for any personal or medical reason, including if the new treatment is not working or if there are serious side effects. Clinical trials are also closely monitored by experts who watch for any problems with each study. It is important that patients participating in a clinical trial talk with their doctor and researchers about who will be providing their treatment and care during the clinical trial, after the clinical trial ends, and/or if the patient chooses to leave the clinical trial before it ends.

#### To learn more about clinical trials, visit www.cancer.net/clinicaltrials.

#### QUESTIONS TO ASK THE HEALTH CARE TEAM ABOUT CLINICAL TRIALS

- ► How do clinical trials help people with breast cancer?
- ► What clinical trials are available for me?
- ▶ What happens during a clinical trial?
- How do the costs of participating in this clinical trial compare with the costs of standard treatment?
- ▶ Where can I learn more about clinical trials?

## Managing symptoms and side effects

In addition to treatment to slow, stop, or eliminate breast cancer, an important part of cancer care is relieving a person's symptoms and side effects. This approach is called palliative care.

Palliative care is any treatment that focuses on reducing a person's symptoms, improving quality of life, and supporting patients and their families. Any person, regardless of age or type and stage of cancer, may receive palliative care. Ideally palliative care should start as early as needed in the cancer treatment process and continue throughout all stages of the disease. It can be given at the same time as disease-directed treatment or on its own.

Palliative treatments vary widely and often include medication, nutritional changes, relaxation techniques, emotional support, and other therapies. You may also receive palliative treatments similar to those meant to eliminate the cancer, such as surgery, radiation therapy, or chemotherapy, so it is important to understand the goals of each treatment in your treatment plan. For people with breast cancer, palliative care may include:

#### □ Radiation therapy

Radiation therapy is often used to treat painful bone metastases.

#### Pain medications

Non-opioid medications, including acetaminophen (such as Tylenol) and ibuprofen (such as Advil and Motrin), are used to treat mild or moderate pain. They also are sometimes used along with other prescription pain medicines, called opioids, to treat more severe pain. Many hospitals and cancer centers have pain control specialists who provide pain relief, even for severe cancer pain.

#### Cancer rehabilitation

Cancer rehabilitation may be recommended, and this could mean any of a wide range of services, such as physical therapy, career counseling, pain management, nutritional planning, and/or emotional counseling. The goal of rehabilitation is to help people regain control over many aspects of their lives and remain as independent as possible.

#### Practical, emotional, and spiritual support

Your health care team can also give you advice and resources for addressing financial and legal concerns, transportation issues, employment concerns, depression, anxiety, and family and other relationship issues. If needed, they can also connect you with a chaplain or other spiritual or religious resources in your community.

For more information about palliative care, visit www.cancer.net/palliativecare.

#### QUESTIONS TO ASK THE HEALTH CARE TEAM ABOUT PALLIATIVE CARE

- ▶ What can be done to manage any symptoms and side effects I may experience?
- Can you recommend someone who specializes in palliative care?
- ► Where can I receive palliative care services?
- What support services are available to me? To my family?

### Developing a treatment plan

Although you and your doctor will create a treatment plan that is best for you and your situation, there are common approaches to treating certain types and stages of breast cancer.

#### DCIS and early-stage invasive breast cancer

For both DCIS and early-stage invasive breast cancer, doctors generally recommend surgery to remove the tumor. To make sure the entire tumor is removed, the surgeon will also remove a small area of healthy tissue around the tumor. Although the goal of surgery is to remove all of the visible cancer, microscopic cells may be left behind, either in the breast or elsewhere. In some situations, this means another surgery could be needed to remove any remaining cancer cells.



For larger invasive cancers, or those that are growing more quickly, or for those that are triple-negative or HER2-positive, doctors may recommend neoadjuvant treatment with chemotherapy before surgery. Neoadjuvant hormonal therapy may also be recommended in specific situations. Giving drug treatment before surgery can be used to shrink the tumor to make the surgery easier to perform. It can also yield important information about how well the tumor responded to therapy, which can help when decisions are being made about additional drug treatments.

After surgery, the next step in managing early-stage invasive breast cancer is to reduce the risk of recurrence by getting rid of any remaining cancer cells using adjuvant therapies like radiation therapy, chemotherapy, targeted therapy, and/or hormonal therapy. Whether adjuvant therapy is needed depends on the likelihood that any cancer cells remain in the breast or the body and the chance that a specific treatment will work to treat the cancer. Although adjuvant therapy lowers the risk of recurrence, it does not completely get rid of this risk.

#### **Recurrent breast cancer**

If breast cancer returns after treatment for early-stage disease, it is called recurrent cancer. Cancer recurs because tiny areas of cancer cells are difficult to find and sometimes remain in the body after treatment. Over time, these cells may multiply and grow large enough to be found and diagnosed.



Breast cancer may come back in the same breast (called a local recurrence), in the chest wall or lymph nodes under the arm (regional recurrence), or in another part of the body, such as the bones, lungs, liver, and brain (distant recurrence).

If a recurrence occurs, the cycle of testing will begin again to learn as much as possible about the recurrence and to learn about where the cancer is. A biopsy of the site is recommended to confirm the diagnosis and to check for ER, PR, and HER2 status, as this may have changed since the cancer was first diagnosed.

The treatment of recurrent breast cancer depends on the previous treatment(s), the time since the original diagnosis, the location of the recurrence, the other health conditions the person may have, and the characteristics of the tumor, such as ER, PR, and HER2 status.

#### Local or regional recurrence

For women who develop a local recurrence within the breast after having a lumpectomy followed by radiation therapy, the recommended treatment is generally a mastectomy. Usually the cancer can be completely removed during this surgery.

For women who develop a local or regional recurrence in the chest wall after having a mastectomy, surgical removal of the recurrent cancer followed by radiation therapy to the chest wall and lymph nodes is the recommended treatment, unless radiation therapy has already been given. Radiation therapy cannot usually be given at full dose to the same area more than once. Therapies using medication may either be given before radiation therapy to make it easier to remove the tumor with surgery, or after radiation therapy to decrease the chance of the cancer returning.

#### **Distant recurrence**

Treatments used to reduce the chance of experiencing a distant recurrence in the future include radiation therapy, chemotherapy, hormonal therapy, and targeted therapy. However, even when patients have received recommended treatment for the original cancer, it is still possible to have a distant recurrence.

A distant recurrence is generally considered incurable but treatable. Some patients live for years after a distant recurrence of breast cancer.

People with recurrent breast cancer often experience emotions such as disbelief or fear. Patients are encouraged to talk with their health care team about these feelings and ask about support services to help them cope.

#### Metastatic breast cancer

If breast cancer has spread to another location in the body, or if it comes back in another location, it is called metastatic cancer. People with this diagnosis are encouraged to talk with doctors who are experienced in treating this stage of cancer because there can be different opinions about the best treatment plan. You may want to seek a second opinion before starting treatment so you are comfortable with your treatment plan.

The primary goals of treatment for metastatic breast cancer are to extend or prolong life and to relieve the symptoms caused by the cancer. Your health care team may recommend a treatment plan that combines chemotherapy, targeted therapy, radiation therapy, and/ or hormonal therapy to shrink the cancer. Because it is not unusual for metastatic breast cancer to stop responding to various drug combinations, you may need to change therapies fairly often. Palliative care will also be important to help relieve symptoms and side effects.

For most patients, a diagnosis of metastatic cancer is very stressful and difficult. Patients and their families and caregivers are encouraged to talk about the way they are feeling with doctors, nurses, social workers, or other members of the health care team. It may also be helpful to talk with other patients, potentially through a support group.

Visit Cancer.Net to learn more about breast cancer (www.cancer.net/breast) and metastatic breast cancer (www.cancer.net/metastaticbreast).

## QUESTIONS TO ASK THE HEALTH CARE TEAM ABOUT YOUR TREATMENT PLAN

- ▶ Who will be coordinating my overall treatment and follow-up care?
- ► What is the goal of my treatment plan?
- ► How will each treatment option benefit me? What are the risks?
- What is the expected timeline for each treatment option?
- What clinical trials are open to me? Where are they located, and how do I find out more about them?
- ► What is my prognosis?

# **Coping With Side Effects**

Fearing the side effects of breast cancer treatment is common, but it may help to know that preventing and controlling side effects is a major focus of your health care team. Before starting treatment, talk with your doctor or nurse about which side effects are most likely to happen (and which are not). Then, once treatment begins, let your health care team know what side effects you are experiencing so they can help manage them.

Everyone's experience with breast cancer treatment is different. The specific side effects that may occur during and after treatment depend on a number of factors, including the cancer's location, your individual treatment plan, and your overall health. However, some of the potential physical, emotional, and social effects experienced by people receiving treatment for breast cancer are described in this section.

Preventing and controlling side effects is a major focus of your health care team.

## Physical effects

**Fatigue.** Cancer and its treatment often cause a persistent feeling of physical, emotional, or mental tiredness or exhaustion. Most people receiving cancer treatment experience some type of fatigue, which can make even a small effort, such as walking across a room, seem like too much. Fatigue can seriously affect all aspects of a person's life, from relationships with friends and family to the ability to perform at work. It is important to tell your doctor if you are experiencing fatigue because there are things your health care team can do to help.

**Pain.** Pain can be caused by the tumor, be a side effect of cancer treatment, or result from causes not related to the cancer. Untreated pain can make other aspects of cancer seem worse, such as fatigue, weakness, nausea, constipation, sleep disturbances, depression, anxiety, and mental confusion. However, it is important to know that up to 95% of cancer pain can be treated successfully using medication or other strategies. Your doctor or a pain specialist can help you find an effective pain-relief strategy.

**Lymphedema.** Lymphedema is the abnormal buildup of fluid in soft tissue, typically in an arm, a breast, or the chest wall, caused by a blockage in the lymphatic system. It can happen immediately after surgery or radiation therapy, or months or years after cancer treatment has ended. In some cases, the swelling goes away on its own as the body heals and normal lymph fluid flow resumes. However, lymphedema may become chronic when the lymphatic system changes and can no longer meet the body's demands for fluid drainage. There is no cure for chronic lymphedema; however, there are ways to keep it from getting worse. Talk with a member of your health care team about the best way to prevent and manage lymphedema.

**Infertility.** Some treatments for breast cancer may cause temporary or permanent infertility, which is the inability to become pregnant or have children. If this is a concern for you, talk with your doctor before treatment begins about the possible fertility-related side effects of your treatment plan and the options for preserving your fertility.

**Nausea and vomiting.** Nausea and vomiting are common side effects of many cancer treatments. Nausea is feeling the urge to vomit or throw up. Vomiting may happen before treatment as a result of anxiety, within 24 hours after treatment, or 2 or more days after treatment. Mild nausea and vomiting can be uncomfortable, but they usually do not cause serious problems. Severe vomiting, on the other hand, can cause dehydration, electrolyte imbalances (loss of minerals from the body, such as potassium and sodium), weight loss, and depression. In addition to medications that help prevent nausea and vomiting, many people find that behavioral treatments help control these side effects. Talk with your health care team about ways to change the expectation and fear of nausea and vomiting.

Hair loss. Many chemotherapy drugs can cause partial or complete hair loss. Hair may fall out entirely, gradually, or in sections. In some cases, hair may simply become thin, duller, or dryer. Hair loss is most noticeable on the scalp, but it may affect other parts of the body, such as the face (eyebrows and eyelashes), arms, legs, underarms, and pubic area. Hair loss is usually temporary, and in most cases, hair will grow back after treatment has finished.



**Chemobrain.** Cancer survivors commonly use the term "chemobrain" to describe difficulties thinking clearly after cancer treatment. This also can occur in patients who did not receive chemotherapy as part of breast cancer treatment. Cognitive side effects vary and sometimes make it hard to complete daily activities. People who experience severe problems concentrating, multitasking, or understanding or remembering things should talk with their doctor or another member of the health care team to learn about medication, cognitive rehabilitation and training, and other ways to manage these challenges.

**Peripheral neuropathy.** When the nerves that send information between your brain and body, called your peripheral nervous system, get damaged, doctors call damage to these nerves "peripheral neuropathy." It can cause problems related to sensing, feeling, and moving. Cancer or its treatment can cause peripheral neuropathy. Peripheral neuropathy might cause changes in feeling, or sensation, including numbness, tingling, or pain, especially in the hands and feet.

For more information about managing side effects, visit www.cancer.net/sideeffects.

### Emotional and social effects

For many people, the diagnosis and treatment of breast cancer is stressful and can trigger difficult emotions. Physical changes that occur during treatment, such as having a breast removed, hair loss, weight gain or weight loss, or scars from surgery, may make you feel uncomfortable and self-conscious. You may also feel differently about yourself and your body because of changes that aren't visible to others, such as infertility or early menopause.

Research has shown that sharing fears and anxieties with family or friends, counselors, clergy, or support groups helps strengthen patients emotionally, and perhaps even physically. If you don't find it easy to open up to others, you may want to express your feelings in other ways, such as:

- Writing in a journal or starting a blog
- Artistic projects, such as painting
- Praying or meditating
- ► Reading
- Slowing down and reflecting



However, even with outlets to express their feelings, patients and those closest to them may continue to experience emotional and social challenges. If you are feeling anxious, depressed, or stressed about your diagnosis and treatment, talk with a member of your health care team, such as an oncology nurse. Oncology nurses not only have a wealth of experience and knowledge about cancer, cancer treatment, and side effects, but they can also provide you with emotional and social support, as well as help you develop effective coping strategies.

Another good resource is an oncology social worker. An oncology social worker can help you navigate the health care system; find support to manage the day-to-day challenges of living with cancer; and provide counseling, education, information services, discharge and home care planning services, and referrals to community resources for you and your family and friends. Oncology social workers practice in many settings, including cancer centers, hospitals, doctors' offices, cancer-related agencies, hospices, and private practices. If there is not an oncology social worker at the place where you receive treatment, call the nearest cancer center or university/teaching hospital to ask if there is 1 on staff.

Learn more about coping with the physical and emotional effects of breast cancer at www.cancer.net/coping. For a list of support organizations and other resources, visit www.cancer.net/support.

#### QUESTIONS TO ASK THE HEALTH CARE TEAM ABOUT SIDE EFFECTS

- What are the potential short- and long-term side effects of each treatment in my treatment plan?
- Are there ways to help me prepare for treatment and decrease the chance of experiencing certain side effects?
- ► What can be done to manage any side effects I may experience?
- Could any of the recommended treatments affect my ability to have children? Should I talk with a fertility specialist before treatment begins? Are there other treatments available that do not pose as high of a risk to my fertility but are equally effective?
- ► If I develop a new side effect or an existing one gets worse, what should I do?
- Could my sexual health be affected by my cancer treatment? If so, how and for how long? How can this be prevented or treated?
- ► How can I keep myself as healthy as possible during treatment?
- What lifestyle changes should I consider making during my treatment? Do you recommend any nutritional supplements or changes to my diet?
- ▶ What support services are available to me? To my family?

## **Follow-Up Care**

After completing initial treatment for stage I to stage III breast cancer, talk with your doctor about developing a follow-up care plan. This plan may include regular physical examinations and medical tests, like mammography, to monitor your recovery for the coming months and years. It will also involve managing any ongoing or late effects of treatment. In general, blood tests will not be required.

Additionally, people taking tamoxifen should have yearly pelvic exams because this drug can slightly increase the risk of uterine cancer. Tell your doctor or nurse if you notice any abnormal vaginal bleeding or other new symptoms. People who are taking an AI should have a bone density test periodically because these drugs may cause some bone weakness or bone loss.

People recovering from breast cancer may also experience other side effects that continue after treatment has finished. However, these can usually be managed with the help of your health care team. For example, there are a number of ways to help manage peripheral neuropathy, menopausal symptoms, and joint pain. Treatment for vaginal dryness and lowered sex drive, which are also common during and after treatment, is individualized for each patient and may be best managed by a gynecologist working with your oncologist. Some patients may be able to visit a survivorship clinic, which specializes in the post-treatment needs of people diagnosed with breast cancer.

Breast cancer care does not end when active treatment has finished. It is also important for you to watch for signs that the cancer may have come back—even if this thought is scary. The symptoms of a breast cancer recurrence include:

- A new lump in the breast, under the arm, or along the chest wall
- Pain that is long lasting and not relieved by over-the-counter medication
- Bone pain or fractures
- ► Headaches or seizures
- ► Chronic coughing or trouble breathing
- Abdominal pain
- ► Jaundice (yellow skin or eyes)
- ► Extreme fatigue
- ► Feeling ill or generally unwell

Talk with your doctor if you have any of these or other symptoms.



People recovering from breast cancer are also encouraged to follow established guidelines for good health, such as maintaining a healthy weight, not smoking, minimizing alcohol intake, eating a balanced diet, and having recommended cancer screening tests. Talk with your doctor or nurse to develop a plan that is best for your needs. Moderate physical activity can help rebuild your strength and energy level and may lower the risk of cancer recurrence. Your health care team can help you create a safe exercise plan based on your needs, physical abilities, and fitness level.

For cancer treatment summary forms and survivorship care plans, visit www.cancer.net/survivorship.

#### QUESTIONS TO ASK THE HEALTH CARE TEAM ABOUT FOLLOW-UP CARE

- ► After treatment has ended, what follow-up care should I receive?
- ▶ Which follow-up tests will I need, and how often will those tests be needed?
- ▶ How often will I need to see a doctor?
- ▶ What is the chance that the cancer will return?
- ► Is there anything I can do to reduce the risk of recurrence?
- Which symptoms should I tell you about right away?

# **Breast Cancer Dictionary**

Adjuvant therapy: Treatment given after the main treatment to reduce the chance of cancer coming back by eliminating any remaining cancer cells. It usually refers to chemotherapy, radiation therapy, hormonal therapy, and/or targeted therapy given after surgery.

Aromatase inhibitor (AI): A type of hormonal therapy drug that decreases the amount of estrogen in the body by blocking the activity of the aromatase enzyme, which is needed to make estrogen.

**Benign:** A tumor that is not cancerous. The tumor does not usually invade nearby tissue or spread to other parts of the body.

**Biopsy:** The removal of a small amount of tissue for examination under a microscope. Other tests can suggest breast cancer is present, but only a biopsy can make a definite diagnosis.

**Bone-modifying drugs:** Medications, such as bisphosphonates and denosumab, used to help strengthen bones and reduce pain and bone breaks caused by bone metastases. They may also be used to prevent cancer from recurring in the bone or to treat cancer that has spread to the bone.

**Brachytherapy:** Radiation treatment given using a probe in the operating room or by placing small radioactive "seeds" or pellets inside the body near the tumor. Also called internal radiation therapy. **BRCA1 / BRCA2:** Breast cancer genes that can increase a person's risk of developing breast cancer and other cancers if they contain genetic changes (mutations).

**Carcinoma:** Cancer that starts in skin or tissues that line the inside or cover the outside of internal organs.

**Cells:** The basic units that make up the human body.

**Chemotherapy:** The use of drugs to destroy cancer cells.

**Clinical trial:** A research study that involves volunteers. Many clinical trials test new treatments and/or prevention methods to find out whether they are safe, effective, and possibly better than the current standard of care (the best known treatment).

**Cure:** To fully restore health. This term is sometimes used when a person's cancer has not returned for at least 5 years after treatment. However, the concept of "cure" is difficult to apply to breast cancer because undetected cancer cells can sometimes remain in the body after treatment, causing the cancer to return later. Recurrence after 5 years is still possible.

**Duct:** Tube-like structures in the breast that connect the glands, lobules, and lobes and carry milk from the lobe to the nipple.

**Early-stage breast cancer:** Breast cancer that is determined to be stage I to stage IIA.

**External-beam radiation therapy:** Radiation therapy given from a machine located outside the body.

**External breast prosthesis:** An artificial breast form made out of silicone gel, foam, fiberfill, or another material that has a similar weight and feel to natural breast tissue and can be worn after a mastectomy to re-create a natural appearance without surgery.

**Fibrosis:** Hardening or thickening of soft tissue. Fibrosis can occur in the lungs as a side effect of radiation therapy for breast cancer.

**Grade:** A way of describing how much a tumor looks like healthy breast tissue when viewed under a microscope.

**HER2:** A protein that normally helps control how breast cells grow, divide, and repair themselves, but it can lead to tumor development if too much is present.

**Hormonal therapy:** Treatment that removes or blocks hormones to destroy or slow the growth of cancer cells. Also called hormone therapy or endocrine therapy.

**Hormone receptors:** Proteins usually found inside a cell that a specific hormone attaches to. When a hormone binds to its receptor, it can trigger a number of different reactions and processes to take place inside the cell, including cell growth and division.

#### Hypofractionated radiation therapy:

Radiation therapy given in a shorter schedule than normal, possibly even as short as 3 weeks.

**Imaging test:** A procedure that creates pictures of internal body parts, tissues, or organs to make a diagnosis, plan treatment, check whether treatment is working, or observe a disease over time.

**Immunotherapy:** A type of cancer treatment that boosts the body's natural defenses to fight cancer. It uses substances made by the body or in a laboratory to improve how your immune system works to find and destroy cancer cells.

**In situ:** Means "in place." Refers to cancer that has not spread to nearby tissue. Also called localized or noninvasive cancer.

#### Intensity-modulated radiation therapy:

A technique in which the intensity of the radiation is varied and spread more evenly.

**Invasive breast cancer:** Cancer that has spread outside the layer of tissue in which it started and has the potential to grow into other tissues or parts of the body. Also called infiltrating cancer.

**Laboratory test:** A procedure that evaluates a sample of blood, urine, or another substance from the body to make a diagnosis, plan treatment, check whether treatment is working, or monitor a disease over time.

**Late effects:** Side effects of cancer treatment that occur months or years after treatment has finished.

**Learning resource center:** A location in a hospital or cancer center where patients and families can get information about healthrelated topics and learn about support resources. Also called a health or hospital library. **Lobe:** A structure in the breast that is made up of smaller parts called lobules.

**Lobules:** The glands that produce breast milk.

**Locally advanced breast cancer:** Breast cancer that is determined to be stage IIB to stage III.

**Lumpectomy:** Surgery that only removes the cancer and other abnormal tissue, leaving the rest of the breast intact. Also called breast-conserving surgery, a partial mastectomy, quadrantectomy, or a segmental mastectomy.

Lymph nodes: Small, bean-shaped organs that help fight infection. Lymph nodes are identified based on their location. Internal mammary lymph nodes are located in the breast; axillary lymph nodes are located under the arms; cervical lymph nodes are located in the neck; and supraclavicular lymph nodes are located just above the collarbone. Sentinel lymph nodes are the first lymph nodes that are likely to collect cancer cells that have broken away from a tumor.

**Lymphatic system:** A network of small vessels, ducts, and organs that carry fluid to and from the bloodstream and body tissues. Cancer can spread to other parts of the body through the lymphatic system.

**Lymphedema:** An abnormal buildup of fluid (lymph) that causes swelling, usually in an arm or leg.

**Malignant:** Refers to a tumor that is cancerous. It may invade nearby healthy tissue or spread to other parts of the body.

**Mammography:** A type of x-ray specifically designed to view the breast. The x-ray films produced by mammography, called mammograms, help doctors find small tumors or irregularities in the breast.

**Margin:** A small area of healthy tissue around the tumor that is removed during surgery. The goal of breast cancer surgery is to have no cancer cells in the surgical margins.

Mass: A lump in the body.

**Mastectomy:** Surgical removal of the breast to treat breast cancer. There are several types of mastectomies. A skin-sparing mastectomy preserves the skin of the breast, while a total skin-sparing mastectomy preserves both the skin and the nipple.

**Metastasis:** The spread of cancer from the place where it began to another part of the body. This occurs when cancer cells break away from the primary tumor and travel through the blood or the lymphatic system to the lymph nodes, brain, lungs, bones, liver, or other organs.

**Neoadjuvant therapy:** Treatment given before the main treatment, which is usually a lumpectomy or mastectomy. It may include chemotherapy, radiation therapy, or hormonal therapy given before surgery to shrink a tumor so it is easier to remove.

**Noninvasive breast cancer:** Breast cancer that does not go beyond the milk ducts or lobules in the breast.

**Oncologist:** A doctor who specializes in treating people with cancer. The main types are medical, surgical, radiation, gynecologic, and pediatric oncologists.

**Osteonecrosis:** An uncommon but serious side effect of treatment with bisphosphonates and denosumab. The symptoms of osteonecrosis of the jaw include pain, swelling, and infection of the jaw; loose teeth; and exposed bone.

**Ovarian suppression:** A type of hormonal therapy given after other treatments, such as surgery, chemotherapy, and/or radiation therapy, for early-stage breast cancer. Ovarian suppression using medication temporarily stops the ovaries from producing hormones and may be appropriate for women with hormone receptor-positive breast cancer who have not been through menopause. The surgical removal of the ovaries, called an oophorectomy, permanently stops the ovaries from producing hormones.

**Palliative care:** Any form of treatment that concentrates on reducing a patient's symptoms or treatment-related side effects, improving their quality of life, and supporting patients and their families. Also called supportive care.

**Panel test:** A test that looks for mutations in several different genes at the same time.

**Partial breast irradiation:** A technique in which radiation therapy is given only to the tumor area and not the entire breast.

**Pathologist:** A doctor who specializes in interpreting laboratory tests and evaluating cells, tissues, and organs to diagnose disease.

**Pneumonitis:** Radiation-related inflammation of lung tissue.

**Primary site:** The area in the body where a cancer started.

**Prognosis:** Chance of recovery; a prediction of the outcome of a disease.

**Psychosocial effects:** Emotional and social concerns related to cancer and cancer treatment that can greatly affect patients' well-being. These may include lack of information and support; emotional difficulties, including depression and anxiety; lack of transportation; disruptions to work, school, and family life; and difficulty with the cost of cancer care.

**Quality of life:** An overall sense of well-being and satisfaction with life.

**Radiation therapy:** The use of high-energy x-rays or other particles to destroy cancer cells. Also called radiotherapy.

**Reconstruction:** Plastic surgery that rebuilds and restores the appearance of a natural breast. This surgery can be done at the same time as a mastectomy or months or years later.

**Recurrence:** Cancer that has returned after a period during which the cancer could not be detected. Local recurrence means that the cancer has come back in the same general area where the original cancer was located. Regional recurrence refers to cancer that has come back in the lymph nodes or other tissues near the original cancer site, usually by direct spread. Distant recurrence refers to cancer that has come back and has spread to other parts of the body, usually by traveling through the lymphatic system or bloodstream.

**Regimen:** A treatment plan that includes which treatments and procedures will be done, medications and their doses, the schedule of treatments, and how long the treatment will last. **Response:** How the cancer reacts to the treatment; how effective the treatment is.

Risk: The likelihood of an event.

**Screening:** The process of checking whether a person has a disease or has an increased chance of developing a disease when the person has no symptoms.

**Secondary cancer:** Describes either a new primary cancer (a different type of cancer) that develops after treatment for the first type of cancer or cancer that has spread to other parts of the body from the place where it started (see "Metastasis").

**Side effect:** An undesirable result of treatment, such as fatigue, nausea, vomiting, pain, anxiety, infertility, sexual problems, or hair loss.

**Stage:** A way of describing where the cancer is located, if or where it has spread, and whether it is affecting other parts of the body.

**Standard of care:** Care that experts agree or research shows is the most appropriate and/or effective for a specific disease.

**Surgery:** The removal of cancerous tissue from the body during an operation.

**Survivorship:** This term means different things to different people. Two common definitions include having no disease after the completion of treatment and the process of living with, through, and beyond cancer.

**Survivorship care plan:** A personalized schedule of follow-up examinations and tests that the doctor recommends after a patient's active treatment period. This may include regular physical examinations and/ or medical tests to monitor the patient's recovery for the coming months and years. It is often used together with a treatment summary. Also called a follow-up care plan.

**Targeted therapy:** Treatment that targets specific genes, proteins, or other molecules that contribute to cancer growth and survival.

**Treatment summary:** A written summary of the different therapies that the patient had during the active treatment period. This is often used in conjunction with a survivorship care plan to help monitor a survivor's longterm health.

**Tumor:** A mass formed when healthy cells change and grow out of control. A tumor can be cancerous or benign. A cancerous tumor is malignant, meaning it can spread to other parts of the body. A benign tumor means the tumor can grow but will not spread.

For more definitions of common terms you may hear before, during, and after treatment, visit www.cancer.net/cancerterms.

# **My Health Care Team**

Medical Oncologist: Contact Information:	
Radiation Oncologist: Contact Information:	
Surgeon/Surgical Oncologist: Contact Information:	5
Plastic/Reconstructive Surgeon:  Contact Information:	
Primary Care Doctor: Contact Information:	Name: Contact Information:
Oncology Nurse: Contact Information:	
Oncology Social Worker: Contact Information:	

## **My Follow-Up Care Plan**

Use this page to help discuss your follow-up care with your doctor and keep track of their recommendations. Talk with a member of your health care team if you have any questions.

Need for ongoing (adjuvant) treatment for cancer: 
Yes No

Additional treatment name	Purpose	For how long

#### SCHEDULE OF FOLLOW-UP VISITS

#### CANCER SURVEILLANCE/OTHER RECOMMENDED TESTS

Doctor's name	When/How often

Test/Procedure	When/How often

It is important to continue to see your primary care doctor for all general health care recommended for a person of your age, including screening tests for other cancers, when appropriate. You should also tell your doctor about:

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

Signs or symptoms to tell the doctor about right away:

Possible late and long-term effects: \_\_\_\_\_

What concerns do you have as you transition into survivorship?

- Emotional and mental health
- □ Fatique
- □ Fertility
- Financial advice or assistance
- □ Insurance
- Memory or concentration
  Stopping smoking loss
- Parenting
- Physical functioning
- □ School/Work

- Sexual health
- U Weight changes
- Other:

# **Diagnosis Summary**

#### **BREAST CANCER TYPE:**

- Ductal carcinoma—Cancer that begins in the ducts
- □ Inflammatory breast cancer—A rare condition in which cancer cells block lymph vessels in the skin of the breast
- □ Lobular carcinoma—Cancer that begins in the lobules
- □ Rare subtype—Including: □ medullary carcinoma
  - metaplastic carcinoma
     papilla
  - mucinous carcinoma
- Paget's disease of the breast
- papillary carcinoma
   tubular carcinoma

Other:

#### SPREAD:

- □ In situ—The tumor has not spread outside the area where it began; "in situ" means "in place"
- □ Invasive/Infiltrating—The tumor has spread outside the area of origin, "invading" surrounding tissue

### DIAGNOSTIC TESTING RESULTS

#### Estrogen receptor (ER) status:

- Positive (ER+)—Tumor depends on estrogen for growth; generally responds to hormonal therapy
- Negative (ER-)—Tumor does not depend on estrogen for growth; generally does not respond to hormonal therapy

#### Progesterone receptor (PR) status:

- Positive (PR+)—Tumor depends on progesterone for growth; generally responds to hormonal therapy
- Negative (PR-)—Tumor does not depend on progesterone for growth; generally does not respond to hormonal therapy

#### HER2 status:

- □ Clearly Positive (HER2+)−Too much of the HER2 protein is present, or there is an increased number of gene copies
- Clearly Negative (HER2-)—Normal numbers of the HER2 protein or gene copies are present
- Equivocal—Results were unclear; retesting needed.

#### **OTHER TEST RESULTS:**

NOTE: If you checked all 3 negative boxes, your cancer may be referred to as "triple-negative."

#### STAGE AND GRADE:

- □ Stage 0 □ Stage IIB
- □ Stage IA □ Stage IIIA
- □ Stage IB □ Stage IIIB
- □ Stage IIA □ Stage IIIC

### □ Stage IV (metastatic)

Recurrent

#### **MY TREATMENT PLAN**

- Surgery
- □ Radiation therapy
- □ Chemotherapy
- □ Hormonal therapy
- □ Targeted therapy
- □ Immunotherapy
- Clinical trial
- Palliative care

#### **TREATMENT GOALS**

- □ Eliminate the cancer
- □ Slow cancer growth/spread
- □ Shrink the tumor
- Relieve symptoms
- Manage side effects
- Other:

#### SURGICAL SUMMARY MARGINS:

- □ Clear/Negative/Clean—No cancer cells found at the edge of the tissue removed during surgery
- Desitive/Involved—Cancer cells are right at the edge of the removed tissue
- □ Close-Cancer cells come close to the edge of the removed tissue

#### LYMPH NODE INVOLVEMENT:

- □ Node-positive-Lymph nodes show evidence of cancer
- □ Node-negative-Lymph nodes show no evidence of cancer



### **Looking for More Patient Information Resources?**

Visit www.cancer.net/ascoanswers to see all of the available titles in the ASCO Answers series.

**ASCO Answers Guides** are comprehensive booklets, covering specific cancer types, survivorship, and caregiving. Worksheets and checklists for managing care are included.

**ASCO Answers Fact Sheets** are brief introductions to different cancer types and topics in diagnosis, treatment, and side effects. More than 70 fact sheets are available, including translations in Spanish and more.

**ASCO Answers Booklets** are in-depth guides to specific topics in cancer care, including advanced cancer care planning, pain, cost of care, managing weight, palliative care, and stopping tobacco use.

**Patients and Caregivers:** For more educational materials, visit www.cancer.net/ascoanswers to find and download all of our available materials.

**Oncology Professionals:** Bulk quantities of high-quality print materials can be purchased at www.cancer.net/estore or by calling 1-888-273-3508. For free promotional materials for your practice, email contactus@cancer.net.





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For more information about ASCO's patient information resources, call toll-free 888-651-3038 or e-mail contactus@cancer.net. To order more copies of this booklet, call 888-273-3508 or visit www.cancer.net/estore.

#### WE WANT TO HEAR FROM YOU

If you found this material helpful or if you have comments or suggestions about how it could be better, please let us know at contactus@cancer.net.

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