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GUIDELINES
FOR PATIENTS®

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Breast Cancer Invasive

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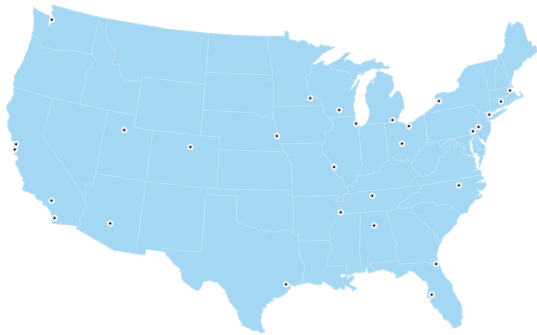
LEARNING that you have cancer can be overwhelming.

The goal of this book is to help you get the best care for breast cancer. It presents which tests and treatments are recommended by experts in breast cancer.

The National Comprehensive Cancer Network® (NCCN®) is a not-for-profit alliance of 28 of the world's leading cancer centers. Experts from NCCN have written treatment guidelines for doctors who treat breast cancer. These treatment guidelines suggest what the best practice is for cancer care. The information in this patient book is based on the guidelines written for doctors.

This book focuses on the treatment of invasive breast cancer. Key points of the book are summarized in the related [NCCN Quick Guide™](#). NCCN also offers resources on early and metastatic breast cancer, ovarian cancer, sarcoma, lymphomas, and other cancer types. Visit [NCCN.org/patients](https://www.nccn.org/patients) for the full library of patient books, summaries, and other resources.

About



These patient guidelines for cancer care are produced by the National Comprehensive Cancer Network® (NCCN®).

The mission of NCCN is to improve cancer care so people can live better lives. At the core of NCCN are the NCCN Clinical Practice Guidelines in Oncology (NCCN Guidelines®). NCCN Guidelines® contain information to help health care workers plan the best cancer care. They list options for cancer care that are most likely to have the best results. The NCCN Guidelines for Patients® present the information from the NCCN Guidelines in an easy-to-learn format.

Panels of experts create the NCCN Guidelines. Most of the experts are from NCCN Member Institutions. Their areas of expertise are diverse. Many panels also include a patient advocate. Recommendations in the NCCN Guidelines are based on clinical trials and the experience of the panelists. The NCCN Guidelines are updated at least once a year. When funded, the patient books are updated to reflect the most recent version of the NCCN Guidelines for doctors.

For more information about the NCCN Guidelines, visit NCCN.org/clinical.asp.

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NCCN Foundation was founded by NCCN to raise funds for patient education based on the NCCN Guidelines. NCCN Foundation offers guidance to people with cancer and their caregivers at every step of their cancer journey. This is done by sharing key information from leading cancer experts. This information can be found in a library of NCCN Guidelines for Patients® and other patient education resources. NCCN Foundation is also committed to advancing cancer treatment by funding the nation's promising doctors at the center of cancer research, education, and progress of cancer therapies.

For more information about NCCN Foundation, visit NCCNFoundation.org.

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Endorsed by

Breast Cancer Alliance

Receiving a cancer diagnosis can be overwhelming, both for the patient and their family. We support the NCCN Guidelines for Breast Cancer with the knowledge that these tools will help to equip patients with many of the educational resources, and answers to questions, they may seek. breastcanceralliance.org

FORCE: Facing Our Risk of Cancer Empowered

As the nation's leading organization serving the hereditary breast and ovarian cancer community, FORCE is pleased to endorse the NCCN Guidelines for Patients with breast cancer. This guide provides valuable, evidence-based, expert-reviewed information on the standard of care, empowering patients to make informed decisions about their treatment. facingourrisk.org

LIVING BEYOND BREAST CANCER

Receiving a diagnosis of breast cancer is overwhelming. Having trusted information is essential to help understand one's particular diagnosis and treatment options. The information found in the NCCN Guidelines for Patients: Breast Cancer is accessible, accurate, and will help every step of the way—from the moment of diagnosis through treatment. People can use the NCCN Guidelines for Patients: Breast Cancer to become an informed partner in their own care. lbbc.org

Sharsheret

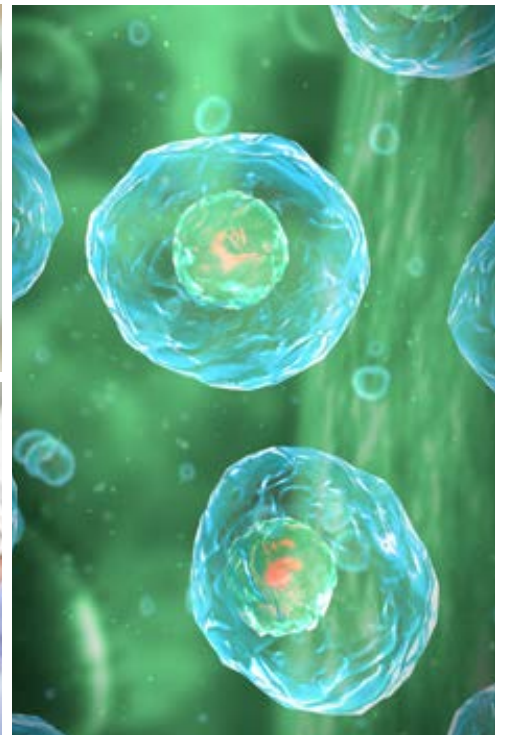
Sharsheret is proud to endorse this important resource, the NCCN Guidelines for Patients: Breast Cancer. With this critical tool in hand, women nationwide have the knowledge they need to partner with their healthcare team to navigate the often complicated world of breast cancer care and make informed treatment decisions. sharsheret.org

Young Survival Coalition (YSC)

Young Survival Coalition (YSC) is pleased to endorse the NCCN Guidelines for Patients: Breast Cancer as an invaluable resource for young women diagnosed with breast cancer and their co-survivors. This in-depth, illustrated series clearly explains what breast cancer is, how it is treated and what patients can expect on the journey ahead. youngsurvival.org

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NCCN Clinical Information Operations employees in honor of Joan McClure's retirement
Orangetheory Fitness, Gwynedd, Pennsylvania
Warren & Linda Smedley in honor of Janet M. Smedley (breast cancer survivor)



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Who should read this book?

Treatment for invasive breast cancer is the focus of this book. This cancer has grown into the breast's fatty tissue, skin, or both but has not spread to distant sites. Treatment of metastatic breast cancer is covered in the *NCCN Guidelines for Patients: Breast Cancer – Metastatic*.

Patients and those who support them—caregivers, family, and friends—may find this book helpful. It is a good starting point to learn what your options may be.

Almost all breast cancers occur in women. As such, this book is written with women in mind. However, men with breast cancer are treated like women, except where noted.

Are the book chapters in a certain order?

The book chapters follow a common treatment pathway. Starting with **Part 1** may be helpful. It explains what invasive breast cancer is.

Part 2 lists what health care is needed before treatment. Some types of health care help your doctors plan treatment. Other health care addresses issues besides cancer treatment.

Not all breast cancers are the same. In **Parts 3–5**, treatment options are listed based on features of the cancer. **Part 6** describes long-term health care that starts when there are no signs of cancer. Tips for making treatment decisions are presented in **Part 7**.

Does this book include all options?

This book includes treatment options for most people. Your treatment team can point out what applies to you. They can also give you more information. While reading, make a list of questions to ask your doctors.

The treatment options are based on science and the experience of NCCN experts. However, their recommendations may not be right for you. Your doctors may suggest other options based on your health and other factors. If other options are given, ask your treatment team questions.

Help! What do these words mean?

In this book, many medical words are included. These are words that your treatment team may say to you. Most of these words may be new to you. It may be a lot to learn.

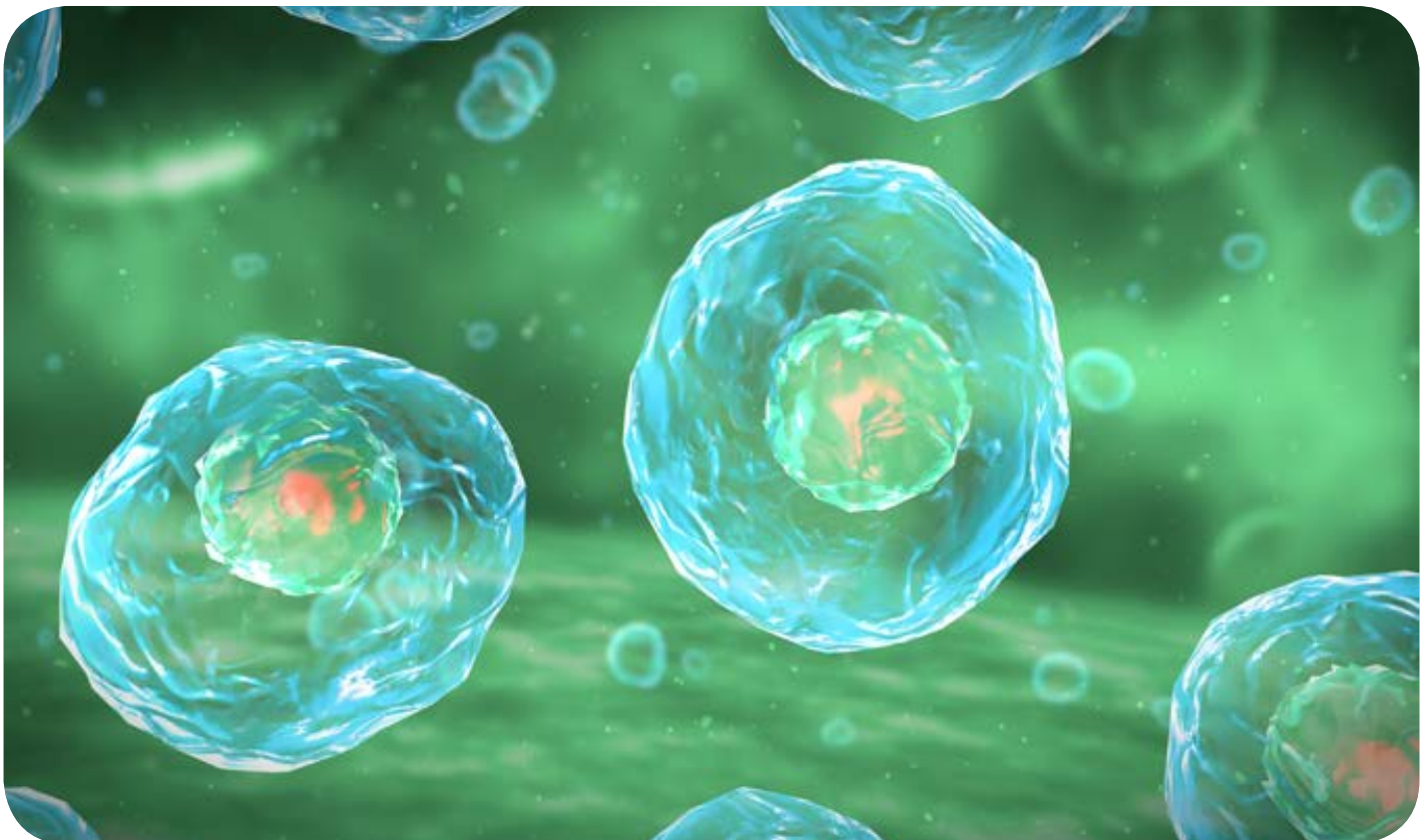
Don't be discouraged as you read. Keep reading and review the information. Ask your treatment team to explain a word or phrase that you do not understand.

Words that you may not know are defined in the text or in the *Dictionary*. *Acronyms* are also defined when first used and in the *Glossary*. Acronyms are short words formed from the first letters of several words. One example is **DNA** for **deoxyribonucleic acid**.

1

Breast cancer basics

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You've learned that you have breast cancer. It's common to feel shocked and confused. This chapter reviews some basics that may help you learn about breast cancer.

Women's breasts

Before learning about breast cancer, it is helpful to know about breasts. The ring of darker breast skin is called the areola. The raised tip within the areola is called the nipple. The nipple-areola complex is a term that refers to both parts.

Under the nipple are ducts within a fatty tissue called stroma. During puberty, the breasts of girls change a lot. The stroma increases. The ducts grow and branch out into the stroma. At the end of the ducts, millions of small sacs called lobules form. **See Figure 1** for a look inside women's breasts.

Lymph is a clear fluid that gives cells water and food. It also helps to fight germs. Lymph drains from breast tissue into vessels within the stroma. **See Figure 2.**

From the breast, lymph travels to the breast's lymph nodes. Lymph nodes are small structures that remove germs from lymph. Most of your breast's lymph nodes are in your armpit. Nodes near the armpit are called axillary lymph nodes.

Figure 1 Inside of breasts

Inside of women's breasts are millions of lobules. Lobules form breast milk after a baby is born. Breast milk drains from the lobules into ducts that carry the milk to the nipple. Around the lobules and ducts is soft tissue called stroma.

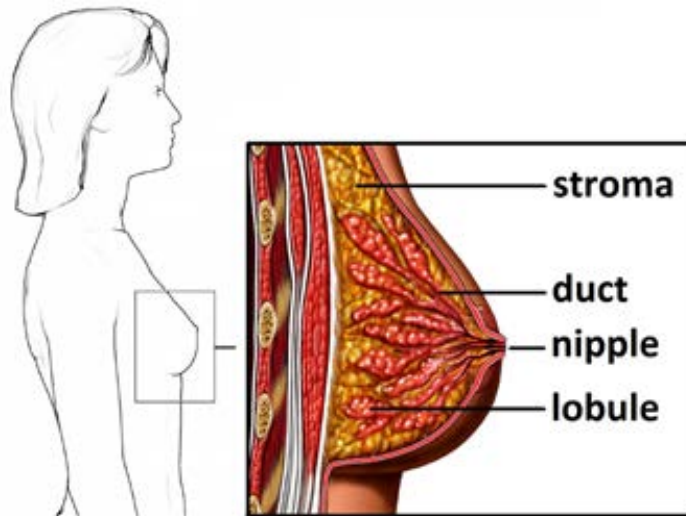


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Figure 2 Axillary lymph nodes

Lymph is a clear fluid that gives cells water and food. It drains from breast tissue into lymph vessels within the stroma. It then travels to the breast's lymph nodes. Most of the breast's lymph nodes are near the armpit. These nodes are called axillary lymph nodes.



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A disease of cells

Your body is made of trillions of cells. Cancer is a disease of cells. Each type of cancer is named after the cells from which it formed. Breast cancer is a cancer of breast cells.

Almost all breast cancers are carcinomas. Carcinomas are cancers of cells that line the inner or outer surfaces of the body. There is more than one type of breast carcinoma.

Ductal breast cancer is formed in ductal cells. It is the most common type of breast cancer. Among 100 women with breast cancer, about 85 to 90 have ductal breast cancer. Breast cancer can also start in the lobules. This type of cancer is called lobular breast cancer.

Mutations

Cells have a control center called the nucleus. Within the nucleus are chromosomes. Chromosomes are long strands of DNA (deoxyribonucleic acid) that are tightly wrapped around proteins. **See Figure 3.** Within DNA are coded instructions for building new cells and controlling how cells behave. These instructions are called genes.

There can be abnormal changes in genes called mutations. Some types of mutations that are linked to cancer are present in all cells. Other mutations are present only in cancer cells. Mutations cause cancer cells to not behave like normal cells. They sometimes cause cancer cells to look very different from normal cells.

Cancer's threat

When needed, normal cells grow and then divide to form new cells. When old or damaged, they die as shown in **Figure 4**. Normal cells also stay in place. Cancer cells don't behave like normal cells. Cancer cells differ from normal cells in three key ways.

Mass of cells

Cancer cells make new cells that aren't needed. They don't die quickly when old or damaged. Over time, cancer cells form a mass called the primary tumor.

Invasion

Cancer cells can grow into surrounding tissues. If not treated, the primary tumor can grow through a duct or lobule into the stroma. Breast cancers that haven't grown into the stroma are called "noninvasive." Breast cancers that have grown into the stroma are called "invasive."

Metastasis

Third, unlike normal cells, cancer cells can leave the breast. This process is called metastasis. In this process, cancer cells break away from the tumor and merge with blood or lymph. Then, the cancer cells travel through blood or lymph vessels to other sites. Once in other sites, cancer cells may form secondary tumors. Over time, major health problems can occur.

Figure 3 Genetic material in cells

Most human cells contain a plan called the “blueprint of life.” It is a plan for how our bodies are made and work. It is found inside of chromosomes. Chromosomes are long strands of DNA that are tightly wrapped around proteins. Genes are small pieces of DNA. Humans have about 20,000 to 25,000 genes.

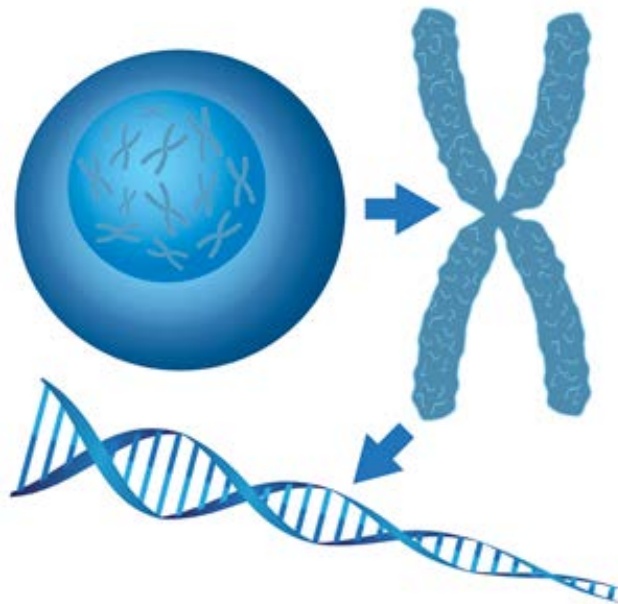


Figure 4 Normal cell growth vs. cancer cell growth

Normal cells increase in number when they are needed. They also die when old or damaged. In contrast, cancer cells quickly make new cells and live longer.

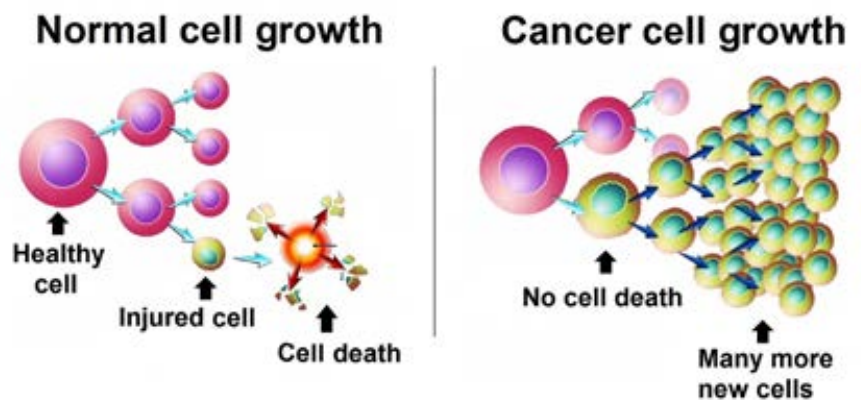


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Cancer stages

A cancer stage is a rating of the cancer based on test results. Your doctor uses it for many things. It is used to assess the outlook of the cancer (prognosis). It is used to plan treatment. It is also used for research.

Cancer staging is often done twice. The rating before any treatment is called the clinical stage. The rating after surgery is called the pathologic stage.

Staging system

The AJCC (**A**merican **J**oint **C**ommittee on **C**ancer) staging system is used to stage breast cancer. In the past, breast cancer was staged only based on its extent in the body. The current system has staging charts that are based on extent as well as other factors.

TNM scores

Three scores are used to describe the extent of the cancer. The T score describes the size of the primary tumor. The N score describes the cancer status of nearby lymph nodes. The M score tells if the cancer has spread to body sites distant from the breast.

Numbered stages

The TNM scores and other factors are used to stage cancer. The stages of breast cancer are labeled by numbers. They range from stage 0 to stage 4. Doctors write these stages in Roman numbers—stage 0, stage I, stage II, stage III, and stage IV.

Stage 0

Noninvasive breast cancers are rated stage 0. These cancers have not grown into the stroma. They have not spread to other tissues.

Stages I–III

Invasive breast cancers are rated stage I, II, or III. These cancers have grown into the stroma or breast skin. Some have spread to nearby tissue. None have spread to body parts distant from the breast.

Inflammatory breast cancer is a rare type of breast cancer. The cancer has blocked the lymph vessels within the skin of the breast. It is a stage III breast cancer unless it has metastasized.

Stage IV

Metastatic breast cancers have spread far from the breast. Stage IV is metastatic cancer that was present at diagnosis. Over time, other stages of breast cancer sometimes metastasize.

Treatment options

Treatment for invasive breast cancer often has many parts. More than one type of treatment is used. You will likely have surgery, radiation therapy, and, as for many women, endocrine therapy.

Despite common treatment types, treatment differs among women. For example, not everyone receives the same surgery. The order of some treatments may differ, too. You will be making many choices about your treatment.

Clinical trials

One treatment choice may be whether to join a clinical trial. Joining a clinical trial is strongly supported. NCCN believes that you will receive the best management in a clinical trial.

A clinical trial is a type of research that studies a test or treatment in people. It gives people access to health care that otherwise couldn't usually be received. Ask your treatment team if there is an open clinical trial that you can join.

**SNAPSHOT****Invasive
breast cancer**

- ✓ Often starts in ductal cells but can start in lobular cells
- ✓ Has grown into the breast's fatty tissue or skin
- ✓ May have spread outside the breast to nearby lymph nodes
- ✓ Has not spread to body parts distant from the breast like the lungs or bones
- ✓ Is rated stage I, II, or III

Review

- Inside of women's breasts are lobules, ducts, and stroma. Lobules are structures that make breast milk. Ducts carry breast milk from the lobules to the nipple. Stroma is a soft tissue that surrounds the lobules and ducts.
- Breast cancer often starts in the ducts and then spreads into the stroma.
- Breast cancer that has grown into the stroma is called invasive.
- Once in the stroma, breast cancer can spread through lymph or blood to other body parts.
- Metastatic breast cancer has spread to body parts distant from the breast.
- More than one type of treatment is used to treat breast cancer.
- Clinical trials give people access to new tests and treatments that they otherwise couldn't have received.

2

Treatment planning

15 Medical history

16 Physical exam

16 Imaging

19 Biopsy

20 Cancer cell tests

22 Blood tests

22 Genetic counseling

23 Fertility and pregnancy

23 Distress screening

24 Review



Not all breast cancers are the same. Your cancer doctor will want to learn all about the cancer you have. This chapter describes what health care you may receive before treatment.

Doctors plan treatment using many sources of information. These sources include the health care listed in [Guide 1](#). Another source is you. Tell your doctor your concerns and goals for treatment. Together, you can share in the decision-making process. Read **Part 7** to learn more about making treatment decisions.

Medical history

Your doctor will ask about any health problems and their treatment during your lifetime. Be prepared to tell what illnesses and injuries you have had. You will also be asked about health conditions and symptoms. It may help to bring a list of old and new medicines to your doctor's office.

Some cancers and other health problems can run in families. Thus, your doctor will ask about the medical history of your close blood relatives. Such family includes your siblings, parents, and grandparents. Be prepared to tell who has had what diseases and at what ages. Read *Genetic counseling* at the end of this chapter to learn about hereditary breast cancer.

Guide 1. Health care before cancer treatment

| Main tests and services | As-needed tests and services |
|---|---|
| Medical history | Ultrasound |
| Physical exam | Breast MRI |
| Diagnostic bilateral mammogram | Chest diagnostic CT scan |
| Biopsy | Abdomen ± pelvis diagnostic scans (CT or MRI) |
| Hormone receptor test | Bone scan or sodium fluoride PET/CT |
| HER2 test | FDG PET/CT instead of other imaging |
| Genetic counseling if guided by medical history | Complete blood count |
| Pregnancy test if you can have babies | Comprehensive metabolic panel |
| Fertility counseling if you can have babies | |
| Distress screening | |

Physical exam

A physical exam is a study of your body. It is done to look for signs of disease. It is also used to help assess what treatments may be options.

To start, your basic body functions will be measured. These functions include your temperature, blood pressure, and pulse and breathing rate. Your weight will also be checked.

Your doctor will listen to your lungs, heart, and gut. He or she will also assess your eyes, skin, nose, ears, and mouth. Parts of your body will be felt. Your doctor will note the size of organs and if they feel soft or hard. Tell your doctor if you feel pain when touched.

Clinical breast exam

Your doctor will look closely at and touch your bare breasts. The area around your breasts will also be viewed and touched. Your doctor may want you to sit, stand up, or lie down during the exam. You may feel nervous having your breasts touched. Keep in mind that this exam is quick and provides key information your doctor needs.

Imaging

Imaging tests make pictures of the insides of your body. They can show where cancer is in your body. Some imaging tests also reveal some features of a tumor and its cells.

Diagnostic bilateral mammogram

A mammogram is a picture of the insides of your breast. Diagnostic mammograms are made with more x-rays than screening mammograms. With more x-rays, tumors can be better seen. A recent diagnostic mammogram of both breasts will be needed to plan treatment.

Ultrasound

Ultrasound has more than one use for breast cancer. If needed, it helps doctors assess if a breast mass is cancer or a cyst. It may be used to look for cancer in lymph nodes. It is also sometimes used to remove tissue samples.

Ultrasound uses sound waves to make pictures. A probe will be held on your bare breast. It may also be placed below your armpit. The picture will be seen on a screen while the probe is in use.

MRI

MRI (**m**agnetic **r**esonance **i**maging) may help find cancer. For example, it may detect lobular breast cancer when a mammogram did not. MRI is also used to assess the extent of cancer in the breast or lymph nodes. It does produce false alarms. So, tissue samples should be removed and tested.

MRI uses strong magnetic fields and radio waves to make pictures. Contrast, a dye that makes images from scans clearer, should be used. You will lie face down on a table that has padded openings for your breasts. During the scan, the table will move slowly through a machine.

Chest diagnostic CT

Chest CT (**c**omputed **t**omography) is done for inflammatory and some other advanced breast cancers. It is used to look at your lungs. Diagnostic scans use more x-rays. Contrast should be used.

During the scan, you will lie face up on a table that moves through the machine. **See Figure 5.** A computer combines the x-ray images to make a detailed picture.

Abdomen ± pelvis diagnostic CT or MRI

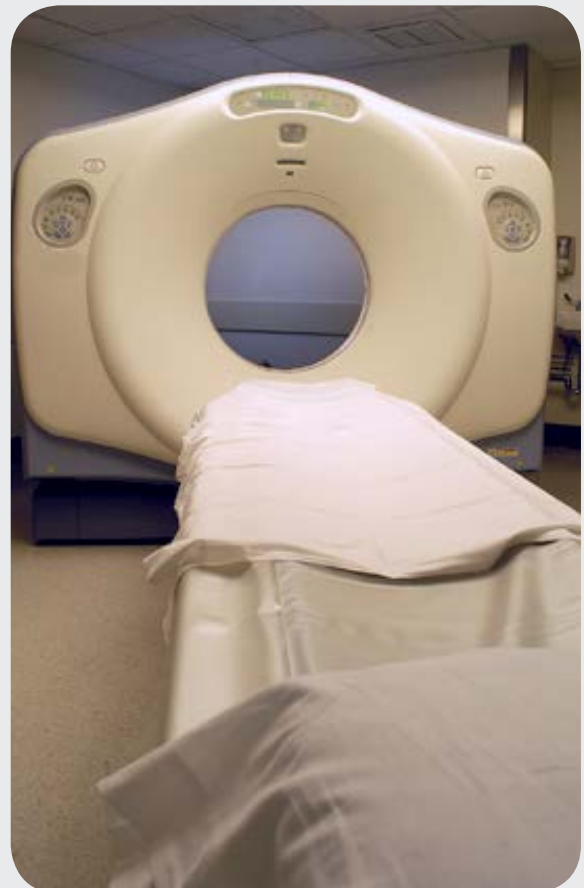
A scan of your belly (abdomen) will show your liver and other organs. A scan may be done based on your test results or symptoms. It is also used for inflammatory breast cancer. You may also get a scan of your pelvis. Contrast should be used with CT and MRI.

Bone scan

A bone scan is given for inflammatory and some other advanced breast cancers. It is used to look for cancer in your bones. It requires injecting a radiotracer into your bloodstream. It takes about 3 hours for the radiotracer to enter your bones. You may lie still on a table for up to an hour while pictures are being taken.

Figure 5
CT machine

Pictures of the insides of your body can be made with an imaging test. During the scan, you will lie on a table that will move into the tunnel of the imaging machine. The images will be viewed by a doctor who will look for signs of cancer.



PET/CT

Sometimes CT is combined with PET (positron emission tomography). When used together, they are called a PET/CT scan. PET requires injecting a radiotracer into your bloodstream. It can show even small amounts of cancer.

Sodium fluoride PET/CT

Instead of a bone scan, images of bones can be made with PET/CT. The radiotracer is made of sodium fluoride. This scan is costly but shows bone damage better than a bone scan. It also has a shorter waiting time and a shorter scanning time.

FDG PET/CT

Your doctor may order an PET/CT with a radiotracer called FDG (fluorodeoxyglucose). FDG is made of fluoride and a simple form of sugar called glucose. You must fast for at least 4 hours before the scan.

This scan is most helpful when other imaging is unclear. It may help find cancer in lymph nodes, organs, and bones. If it clearly shows cancer in the bone, a bone scan and sodium fluoride PET/CT may not be needed. FDG PET/CT can be done at the same time as diagnostic CT.



Snapshot: Imaging

- ✓ Recent diagnostic mammograms of both breasts are needed.
- ✓ Ultrasound or breast MRI can help assess cancer in the breast and nearby lymph nodes.
- ✓ Scans may be done to look for cancer in organs and bones.
- ✓ Your treatment team will tell you how to prepare for each test.
- ✓ Contrast is a dye that will make the images from scans clearer.
- ✓ A radiologist will review the images and send the results to your doctor.

Biopsy

A biopsy is a procedure that removes tissue or fluid samples for testing. The tissue may be tested to confirm diagnosis, staging, or cancer features. Numbing medicine may be injected into the site before the biopsy.

Breast biopsy

If not done before, a core needle biopsy of the breast tumor may be needed. It removes a slightly larger sample than other needle biopsies. A larger sample is better for certain tests. NCCN experts advise having a core needle biopsy before preoperative therapy. This treatment can cause the cancer to shrink a lot.

A core needle biopsy removes more than one tissue sample. The samples are small. A “vacuum” may be used to remove a larger sample. The needle is often guided into the tumor with imaging.

When mammography is used, it is called a stereotactic needle biopsy.

One or more clips will be placed near the breast tumor. The clips are small and made of metal. They will mark the site for future treatment and imaging.

Lymph node biopsy

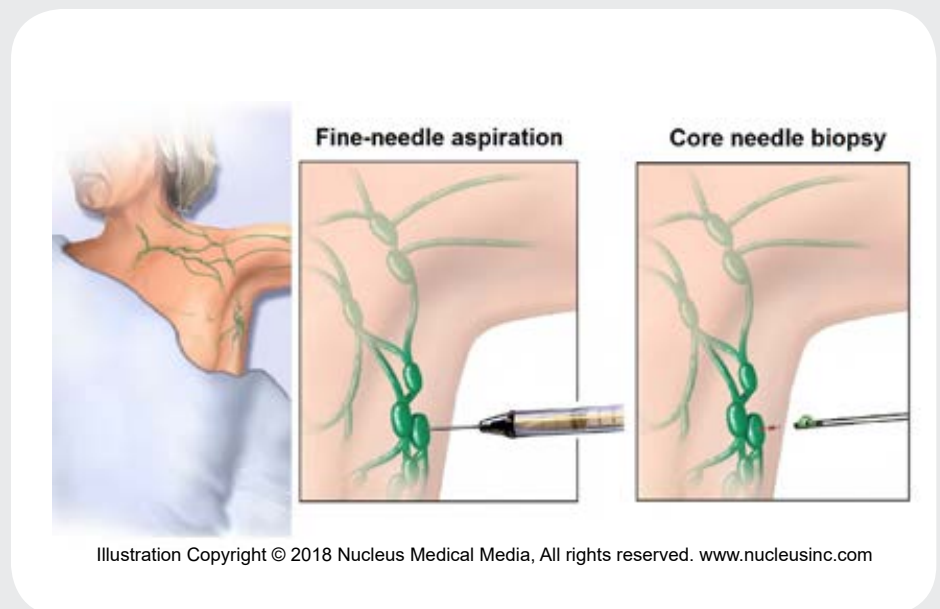
If not done before, a biopsy of your lymph nodes may be done. Your doctor may suspect cancer in nodes based on an exam or imaging. In these cases, NCCN experts advise getting a needle biopsy.

Either one of two methods may be used. An FNA (fine-needle aspiration) removes a small group of cells. **See Figure 6.** A core needle biopsy removes a solid tissue sample. These biopsies are often done with ultrasound.

Lymph nodes with possible cancer may be marked with a clip or tattoo. The markings will help doctors find these nodes after preoperative therapy.

Figure 6 Lymph node biopsies

Breast cancer can spread to the lymph nodes by your armpit. Signs of cancer in lymph nodes can be found with a physical exam or imaging test. If a test suggests there’s cancer, a biopsy is needed. An FNA removes a small group of cells and a core needle biopsy removes a solid tissue sample.



Cancer cell tests

There are many types of breast cancer. A pathologist is a doctor who's an expert in testing tissue and cells. He or she will pinpoint what type of breast cancer you have. Results are used to plan treatment.

Tissue types

The pathologist will study the tissue samples using a microscope. He or she will determine from which type of tissue the cancer formed. This is called histologic typing. The most common type is ductal carcinoma. Lobular carcinoma is the second most common type.

Receptor types

A receptor is a protein found on the surface or inside of cells. Substances bind to the receptors and cause changes within the cell. For breast cancer, there are two key receptors.

Hormone receptors

Estrogen and progesterone are hormones. Among some women, these hormones attach to receptors inside breast cancer cells. **See Figure 7.** Then, they enter the nucleus and start cell growth.

IHC (immunohistochemistry) is a lab test that detects hormone receptors. The pathologist will stain the cancer cells and then view them with a microscope.

Figure 7
Key receptors in breast cancer

Hormone and HER2 receptors help breast cancer to grow. Some women have a high amount of one or both types of receptors. It is important to test for these cell receptors so that the best cancer treatment can be received.

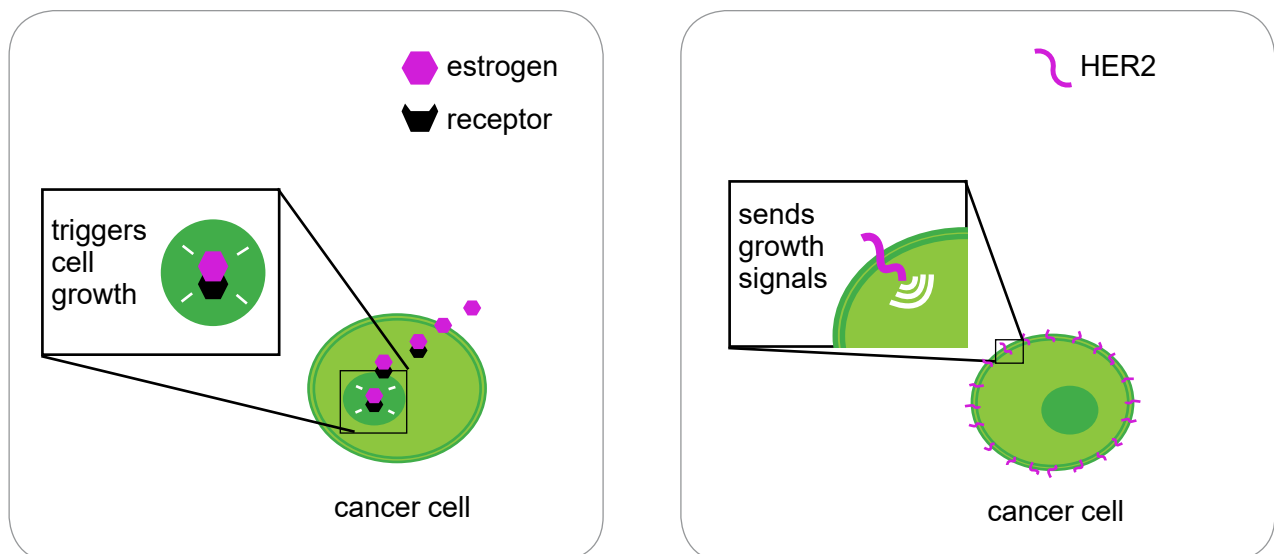


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He or she will assess how many cells have hormone receptors. Also, the amount of hormone receptors in the cells will be measured.

Hormone receptor–positive breast cancer is defined by hormone receptors in at least 1 out of 100 cancer cells. These cancers are sometimes simply called hormone positive. Most breast cancers are hormone positive.

Hormone receptor–negative breast cancer consists of fewer cells with hormone receptors. These cancers are sometimes simply called hormone negative. Hormone-negative cancers often grow faster than hormone-positive cancers.

HER2

HER2 (**h**uman **e**pidermal growth factor **r**eceptor **2**) is on the surface of breast cells. When turned on, it causes cells to grow and divide. **See Figure 7.** Normal breast cells have two copies of the gene that makes HER2. Normal cells also have a normal amount of HER2.

In contrast to normal cells, some breast cancers have cells with more than two *HER2* genes. Too many genes produce too much HER2. Other breast cancers have cells with two *HER2* genes but still too much HER2. HER2-positive breast cancer has too many *HER2* genes or receptors.

There are two tests for HER2. IHC measures receptors. An IHC score of 3+ means that the cancer cells have a high level of HER2. ISH (**i**n **s**itu **h**ybridization) counts the number of copies of the *HER2* gene.

Molecular types

Doctors sometimes use molecular typing to predict cancer outcomes. It is not required since there other tests that can be used. The 4 main molecular types of breast cancer are:

- ▶ **Luminal A** and **luminal B types** are estrogen receptor–positive. (Note: Not all estrogen receptor–positive cancers are luminal types.)
- ▶ The **HER2-enriched type** always has a high amount of HER2.
- ▶ The **basal type** lacks estrogen receptors and has low amounts of HER2.

Pathology report

All lab results are included in a pathology report. This report will be sent to your doctor. Ask him or her for a copy. Your doctor will review the results with you. Take notes and ask questions.

Blood tests

Blood tests are done for inflammatory and some other advanced breast cancers. These tests are used to look for signs of disease. Blood tests require a sample of your blood. Blood samples can be removed with a blood draw.

Blood draw

Some blood draws require no eating and drinking for hours. Your doctor will say if you can eat or drink. Blood samples will be removed with a needle placed into your vein.

The samples will be tested by a pathologist. A pathologist is a doctor who's an expert in testing cells to find disease. The lab results will be sent to your doctor.

Complete blood count

A CBC (**complete blood count**) measures parts of the blood. This lab test gives a picture of your overall health. Test results include counts of white blood cells, red blood cells, and platelets. Cancer and other health problems can cause low or high counts.

Comprehensive metabolic panel

Chemicals in your blood come from your liver, bone, and other organs. A comprehensive metabolic panel often includes tests for up to 14 chemicals. The tests show if the levels of chemicals are too low or high. Your doctor will use this test to check how well your organs are working before and during treatment.

Genetic counseling

Hereditary breast cancer is due to abnormal genes that were passed down from parent to child. It is not common. About 1 out of 10 breast cancers are hereditary.

Your disease or family history may suggest you have hereditary breast cancer. In this case, your doctor will refer you for genetic counseling. A genetic counselor is an expert in gene mutations that are related to disease. Your counselor can tell you more about your chances of having hereditary breast cancer.

Your counselor may suggest that you undergo genetic testing. *BRCA1* and *BRCA2* gene mutations are related to breast cancer. Other genes may be tested as well. Some genes may cause cancers other than just breast cancer. Your counselor will explain your test results and what to do next. Your test results may be used to guide treatment planning.

Some abnormal changes in genes, called VUS (**v**ariants of **u**nknown **s**ignificance), are not fully understood by doctors. Your doctors may know of research that aims to learn more. If interested, ask your doctors about taking part in such research.

Fertility and pregnancy

You may be of childbearing age. If so, talk to your doctor about fertility and pregnancy. He or she will have important information to share.

Fertility

Some cancer treatments can limit your ability to have a baby. If you want to have a baby after treatment or are unsure, talk to your doctor about fertility options. It may also help to talk with a fertility specialist. A fertility specialist is an expert in helping people have babies.

Pregnancy

Tell your treatment team if there is any chance you may be pregnant. Some cancer tests and treatments can harm an unborn baby. Your treatment team will give you a pregnancy test. Your treatment options will depend on the results. During treatment, take steps to avoid getting pregnant. Your doctor can tell you which birth control methods are best to use.

Distress screening

Distress is an unpleasant experience of a mental, physical, social, or spiritual nature. It can affect how you feel, think, and act. It can include feelings of sadness, fear, helplessness, worry, anger, guilt, and so forth. Everyone with cancer has some distress at some point in time. It is to be expected.



Feeling distressed may be a minor problem or it may be more serious. You may be so distressed that you can't do the things you used to do. Serious or not, it is important that your treatment team knows how you feel. They may ask you to complete a list of screening questions

to assess how distressed you are. Read the [NCCN Guidelines for Patients®: Distress](#) to learn more.

If needed, your treatment team can get you help. Help can include support groups, talk therapy, or medication. Some people also feel better by exercising, talking with loved ones, or relaxing. There may also be helpful community resources, such as support groups and wellness centers.

Review

- A medical history is a report of all health events in your lifetime. It will include questions about your family's health to help assess if you have hereditary breast cancer.
- Your doctor will examine your body for signs of disease. He or she will touch parts of your body, including your breasts, to see if anything feels abnormal.
- Imaging tests allow your doctor to see how far the cancer has spread without cutting into your body.
- Some breast cancers consist of cells with too many hormone receptors, too much HER2, or both. These features are used to plan treatment.
- Blood tests may be done to look for signs of cancer outside of your breast.
- Genetic counseling may help you decide whether to be tested for hereditary breast cancer.
- Fertility counseling may help with planning to have a baby after treatment.
- Get screened for distress so you can receive help if needed.



Waiting for results is often the hardest part of this journey. I am an overachiever when it comes to thinking about worse case scenarios when I don't have all the information.

– Deb

3

Preoperative therapy

- 26 Who gets it
- 28 Treatment types
- 29 Supportive care
- 29 Checking results
- 30 Review



Treatment before surgery is called **preoperative or neoadjuvant therapy**. The treatment goal is to shrink the cancer. This chapter explains who receives it and the treatments used.

Who gets it

Not all invasive breast cancers are treated with preoperative therapy. Read [Guide 2](#) to learn who may get it. Doctors take into account many factors, including TNM scores. Talk with your doctor to decide if preoperative therapy is right for you.

Early cancers: T0-T1, N1

Treatment for some small cancers will include both surgery and chemotherapy. Such cancers include HER2 positive and triple negative (ie, hormone and HER2 negative). Preoperative therapy can show early on how well chemotherapy is working. Your doctor will use the results to plan future treatment.

Another reason for preoperative therapy is to treat cancer in axillary nodes. It may downstage the cancer from N1 to N0. In this case, fewer nodes may be removed during surgery.

Large breast tumors: T2-T3, N0-N1

A breast tumor is large if it is bigger than 2 cm. When a tumor is large, the whole breast will likely be removed. Preoperative treatment may shrink the tumor enough so that breast tissue can be spared. Preoperative treatment may also treat cancer in lymph nodes. If it does, fewer nodes may be removed during surgery.

Advanced cancers: T4 or N2 or N3

Preoperative therapy is advised for inflammatory and other locally advanced cancers. Often, surgery can't be the first treatment. Preoperative therapy may shrink the cancer enough to allow for surgery. It may also reduce the chance of the cancer returning after treatment.

Guide 2. Preoperative therapy

| Clinical stage | Is preoperative therapy given? |
|--|--|
| T1, N0, M0 | <ul style="list-style-type: none"> No |
| T0, N1, M0 T1, N1, M0 | <ul style="list-style-type: none"> Sometimes if: <ul style="list-style-type: none"> HER2-positive breast cancer or Axillary lymph node dissection is not desired |
| T2, N0, M0 T2, N1, M0 T3, N0, M0 T3, N1, M0 | <ul style="list-style-type: none"> Often if: <ul style="list-style-type: none"> Breast-conserving therapy is the desired treatment or Axillary lymph node dissection is not desired |
| T4 tumors N2 disease N3 disease | <ul style="list-style-type: none"> Very often |

TNM scores for clinical stage

T Breast tumor

T0

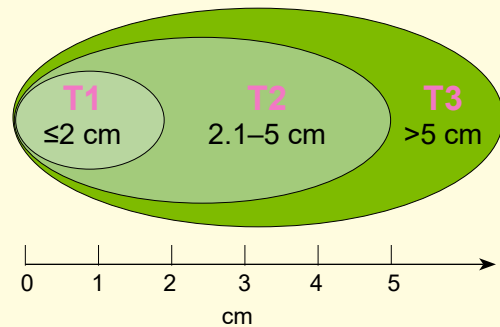
No sign of a breast tumor

T1–T3

The breast tumor has not grown into the breast skin or chest wall; the T scores are based on tumor size

T4

The breast tumor extends to the breast skin, chest wall, or both



N Regional lymph nodes

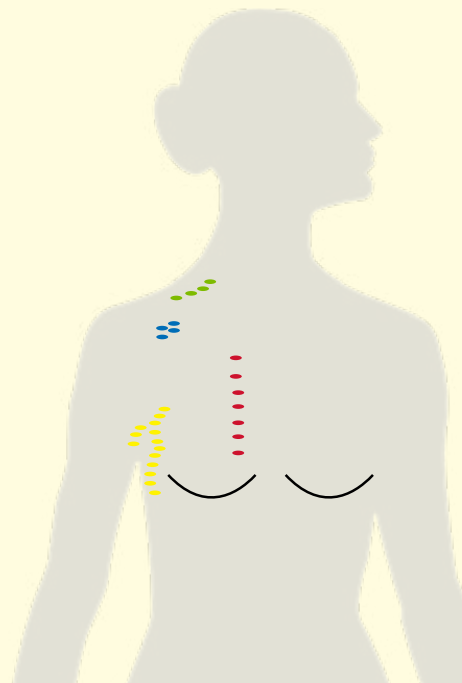
N0 No signs of cancer in regional nodes

N1 Cancer is in mobile axillary nodes (●)

N2 Cancer is in fixed axillary nodes (●) or internal mammary nodes (●)

N3 Cancer is in:

- Axillary nodes + internal mammary nodes (● + ●)
- Infraclavicular nodes (●) or
- Supraclavicular nodes (●)



M Distant metastasis

M0 No signs of breast cancer in body parts distant from the breast

M1 Signs of breast cancer in distant sites

Treatment types

Systemic therapy is used for preoperative therapy. It treats all cancer in the body, including in any part of the breast, in lymph nodes, or elsewhere. Medical oncologists are cancer doctors trained to use systemic therapy.

Chemotherapy

Chemotherapy is often used for preoperative therapy. It works by stopping the cell life cycle. As a result, cancer cells cannot make new cells. Chemotherapy can also cause cells to destroy themselves.

Guide 3 lists regimens that best treat invasive breast cancer. You should be treated for at least 9 weeks before surgery. However, it is ideal that you finish chemotherapy before surgery.

Guide 3. Chemotherapy regimens

| HER2-negative breast cancer | HER2-positive breast cancer |
|---|--|
| <p>Preferred</p> <ul style="list-style-type: none"> • Dose-dense AC then paclitaxel • TC | <p>Preferred</p> <ul style="list-style-type: none"> • AC then paclitaxel + trastuzumab • AC then paclitaxel + trastuzumab + pertuzumab • Paclitaxel + trastuzumab • THC • THC + pertuzumab |
| <p>Sometimes useful</p> <ul style="list-style-type: none"> • Dose-dense AC • AC • CMF • AC then paclitaxel | <p>Sometimes useful</p> <ul style="list-style-type: none"> • Docetaxel + cyclophosphamide + trastuzumab |
| <p>Other</p> <ul style="list-style-type: none"> • AC then docetaxel • EC • TAC | <p>Other</p> <ul style="list-style-type: none"> • AC then docetaxel + trastuzumab • AC then docetaxel + trastuzumab + pertuzumab |

Abbreviations:

AC = doxorubicin + cyclophosphamide

CMF = cyclophosphamide + methotrexate + fluorouracil

EC = epirubicin + cyclophosphamide

Do not start chemotherapy if you've been pregnant for fewer than 3 months. Chemotherapy may harm your baby. Some types of chemotherapy are safe in the second and third trimesters.

Chemotherapy may cause menopause. However, don't depend on chemotherapy for birth control. You can become pregnant while on chemotherapy, which can cause birth defects. If you had menstrual periods before chemotherapy, use birth control without hormones (eg, condoms and not "the pill").

HER2-targeted therapy

HER2-targeted therapy uses HERs to treat HER2-positive cancer. HER2 antibodies are used with chemotherapy for preoperative therapy. They stop signals from HER2 that tell the cell to grow and divide. They also increase the attack of immune

TAC = docetaxel + doxorubicin + cyclophosphamide

TC = docetaxel + cyclophosphamide

TCH = docetaxel + carboplatin + trastuzumab

cells on cancer cells. HER2 antibodies include trastuzumab (Herceptin®) and pertuzumab (Perjeta®).

HER2 antibodies are taken for up to one year. When finished, your doctor may advise taking neratinib (Nerlynx®). Neratinib is an oral HER2 inhibitor for hormone- and HER-positive cancers. This type of drug stops growth signals from HER2 from within the cell.

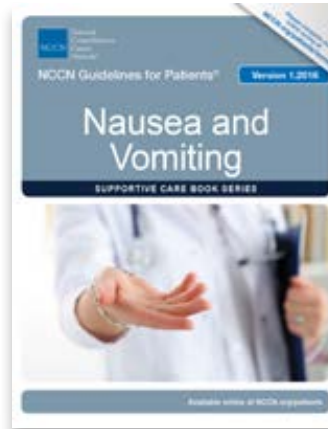
Endocrine therapy

Endocrine therapy is sometimes used instead of chemotherapy for hormone-positive cancers. It may be an option for slow-growing cancers. For example, it may be an option for luminal types. It may also be an option because of health issues. Read **Part 5** to learn more about endocrine therapy.

Supportive care

Supportive care aims to improve your quality of life. It includes care for health issues caused by cancer or cancer treatment. It is sometimes called palliative care. This book focuses on cancer treatment, but supportive care is important, too. Talk with your treatment team to plan the best supportive care for you.

All cancer treatments can cause unwanted health issues. Such health issues are called side effects. Side effects depend on many factors. These factors include the drug type and dose, length of treatment, and the person. Some side effects may be harmful to your health. Others may just be unpleasant.



During chemotherapy cycles, you may be given drugs to help you feel better. You may be given drugs to fight nausea and vomiting. To learn more, read the [NCCN Guidelines for Patients®: Nausea and Vomiting](#).

Ask your treatment team for a complete list of side effects of your treatments. Also, tell your treatment team about any new or worse symptoms you get. There may be ways to help you feel better. There are also ways to prevent some side effects.

Checking results

Your doctor will want to know how well treatment is working. The cancer might improve in part (partial response). It may improve so much that tests cannot detect it (complete response). It may stay the same (stable disease). It could also worsen (progression).

Treatment results should be assessed with a physical exam and imaging tests. Imaging tests that best showed the tumor when it was found should be received. Your doctors should meet to select which imaging tests would be best to use.

If the cancer doesn't respond to treatment, your treatment plan will change. You may receive different chemotherapy or radiation therapy. Radiation therapy is discussed in **Part 5**.

Review

- ▶ Preoperative therapy is used to shrink breast cancer. It may help plan future treatment for early, high-risk cancers. It may lessen the amount of tissue removed at surgery. It also may allow locally advanced cancers to be treated with surgery.
- ▶ Chemotherapy is often used for preoperative therapy.
- ▶ You should receive HER2 antibodies with chemotherapy if the cancer is HER2 positive.

4

Surgery

32 Breast surgery

34 Lymph node surgery

37 Breast reconstruction

38 Review



Surgery to remove the cancer is often a key part of treatment. This chapter explains which types of surgery may be options for you. It also provides some details on ways to rebuild breasts after cancer surgery.

Breast surgery

Lumpectomy and mastectomy are surgeries that remove cancer in the breast. Decades ago, mastectomy—loss of the whole breast—was the only option. Today, many women have a choice. [Guide 4](#) lists the deciding factors for each surgery. If you have a choice, a decision aid may help you think through the issues. Read [Part 7](#) for more information.

Lumpectomy

A lumpectomy removes the breast tumor(s) while sparing healthy tissue. **See Figure 8.** The tumor is removed along with normal-looking tissue around its edge. The normal-looking tissue is called a surgical margin.

Most often, a lumpectomy is followed by radiation therapy. This combined treatment is called breast-conserving therapy. One treatment goal is to extend life as much as a mastectomy would. The second goal is to reduce the chance of the cancer coming back. Also, enough tissue should be spared so that your breast will look as much the same after treatment. Read the last section, *Breast reconstruction*, to learn about re-shaping the breast during lumpectomy.

Who can have a lumpectomy?

A lumpectomy requires that only a small part of your breast will be removed. Removing a large part may make your breast look too disfigured. A lumpectomy may not be an option if the tumor is still large after

Guide 4. Breast cancer surgery

What are the options?

- **Lumpectomy** may be an option if you:
 - Don't need a large part of your breast removed,
 - Can have radiation therapy, and
 - Don't have an inherited risk for breast cancer
- **Mastectomy** may be an option if you:
 - Are not approved for a lumpectomy, or
 - Are approved for a lumpectomy but decline.

preoperative therapy. It is not advised when more than one cut is needed to remove all the cancer. It is not advised if worrisome spots throughout the breast should be removed with the cancer.

A lumpectomy should be followed by radiation therapy for most women. Do not get radiation therapy during pregnancy. Radiation may not be an option if you had it before. It depends on the treatment site and radiation dose and volume. With certain connective tissue diseases, radiation may cause severe health problems after treatment. Such diseases include scleroderma and lupus.

Certain abnormal genes passed down within families may exclude lumpectomy. Li-Fraumeni syndrome raises the risk for a second breast cancer. Also, health problems from radiation would be worse. *BRCA* mutations increase breast cancer risk but do not worsen radiation side effects.

Lumpectomy is not advised if both *ATM* genes are mutated. Risk for a second breast cancer is high. Radiation should be avoided.

Mastectomy

There is more than one type of mastectomy. For invasive breast cancer, a total mastectomy is advised. It is also called a simple mastectomy. The whole breast but no chest muscle is removed. Sometimes the breast skin can be spared. Read the last section, *Breast reconstruction*, for more information.

Who can have a mastectomy?

A mastectomy is an option for many women. It may be required for cancer control. It is used to treat inflammatory breast cancer if preoperative therapy worked. It is sometimes done after a lumpectomy that didn't remove all the cancer.

Mastectomy is also an option for women who decline a lumpectomy. Some women decline because of how they want their breast to look. Others decline because cancer can't return in a breast that's been removed. However, breast cancer may still occur elsewhere.

Figure 8 Breast surgery

There are two types of surgeries that remove cancer from the breast. The top picture shows details of a lumpectomy. A cut was made large enough to remove the tumor. The bottom picture shows a total mastectomy. An oval-shaped cut was made into the breast. Next, the breast was detached from the skin and muscle and removed.

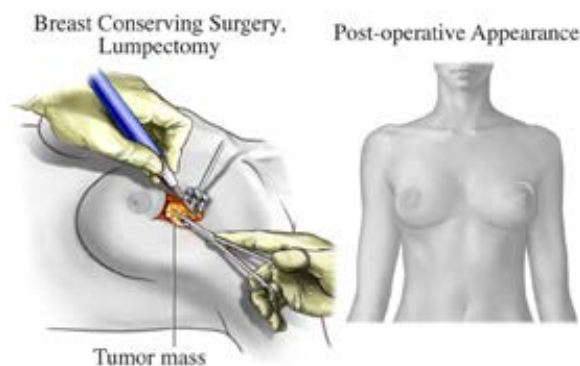


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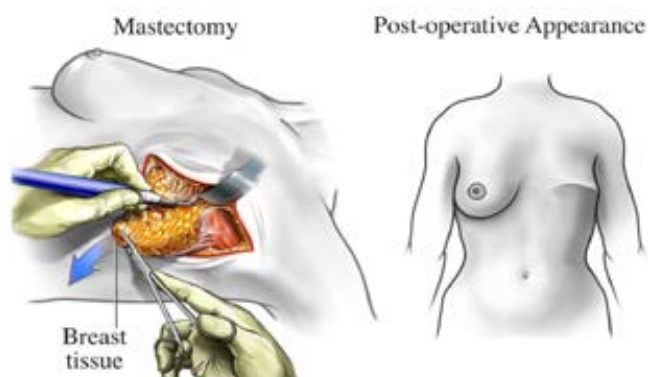


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Lymph node surgery

Invasive breast cancer can spread outside the breast through lymph. Most of the lymph in the breast drains to axillary lymph nodes. The other lymph drains to nodes near the breastbone or collarbone.

Removing axillary lymph nodes is helpful for two reasons. It will remove nodes with cancer, which can improve treatment outcomes. Also, it is needed for pathologic N staging. The N stage helps to predict the outlook of the cancer and plan for future treatment.

In some cases, lymph node surgery is not needed. [See Guide 5](#). Some women with low-risk breast cancer or other major health problems may go without axillary surgery.

Sentinel lymph node biopsy

A sentinel lymph node biopsy removes lymph nodes to which breast cancer first spreads. These nodes are called sentinel nodes. A radioactive tracer, blue dye, or both will be injected into your breast. **See Figure 9**. The tracer and dye will drain into lymph vessels within your breast. Then, they will travel to and mark the sentinel node(s). Often, 2 or 3 nodes are removed.

If you are pregnant, the blue dye should not be used. It may harm your baby. A radioactive tracer can be used instead.

Who can have a sentinel biopsy?

A sentinel lymph node biopsy may be an option if TNM scores are T0-T3, N0-N1, M0. N0 means there is no cancer in lymph nodes. N1 means there is cancer in axillary nodes but the nodes aren't stuck together.

Guide 5. Lymph node surgery

What are the options?

- **No lymph node surgery** may be an option if:
 - Cancer spread outside of the breast is unlikely,
 - Results of lymph node surgery would not impact future treatment,
 - You are of older age, or
 - You have major health problems besides breast cancer.

- **Sentinel lymph node biopsy** may be an option for T0-T3, N0-N1 if:
 - Cancer was not detected in nodes by physical exam and imaging before treatment,
 - Cancer was not found in nodes by needle biopsy before treatment, or
 - N stage is N0 after preoperative therapy.

- **Axillary lymph node dissection** is advised if:
 - Preoperative therapy was not given and...*
 - Cancer in nodes is confirmed by needle biopsy or sentinel biopsy,* or
 - Sentinel node was not found.

*Except if T stage is T1 or T2, cancer is in 1 or 2 sentinel nodes, and you will have lumpectomy with whole-breast radiation
 - Preoperative therapy was given and...*
 - T stage is T4 or N stage is N2-N3 before preoperative therapy, or
 - N stage is N1-N3 after preoperative therapy.

A sentinel biopsy can confirm a score of N0. Lymph nodes may be cancer-free if no cancer was detected by an exam and imaging. Lymph nodes may be cancer-free if no cancer was found by needle biopsy. If cancer is found in sentinel nodes, an axillary dissection is often needed.

After preoperative therapy, N1 nodes can be staged again. If re-staged to N0, some women may get a sentinel biopsy. To improve results, biopsied nodes should be marked. Blue dye and a tracer should be used. Your surgeon should remove 3 or more sentinel nodes.

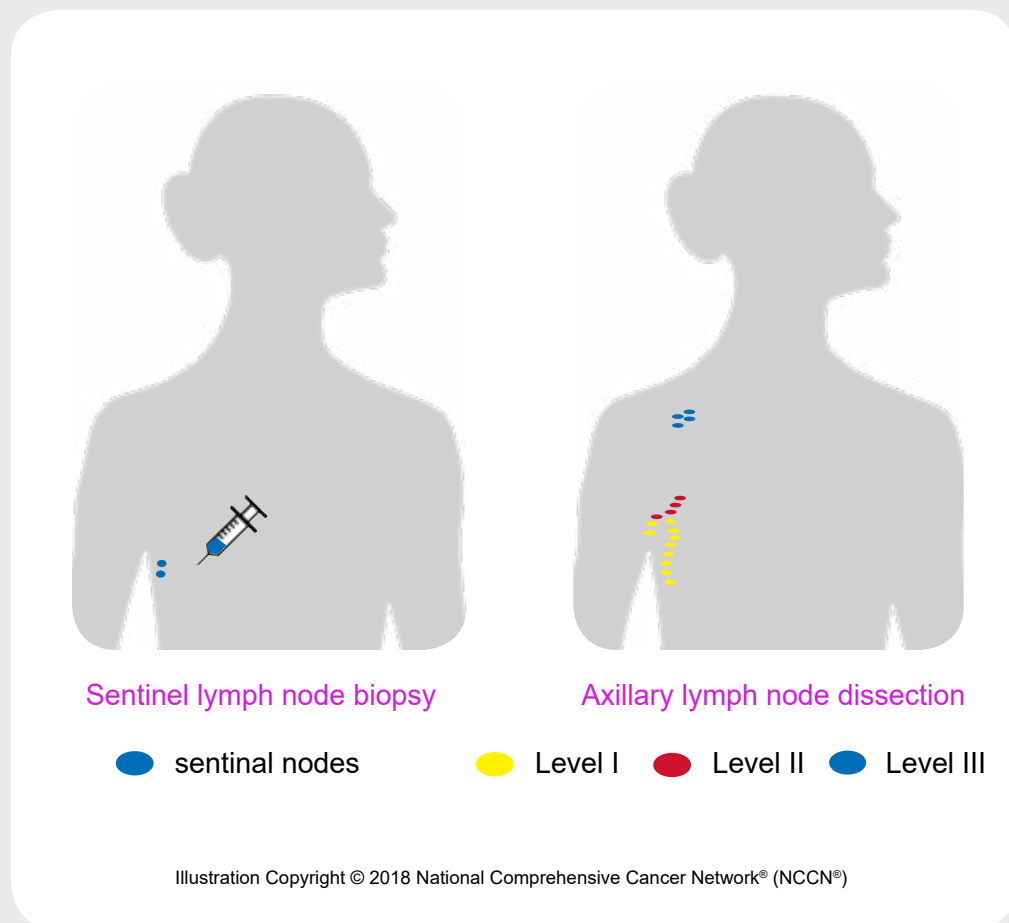
Axillary lymph node dissection

An axillary lymph node dissection removes more nodes than a sentinel biopsy. At least 10 lymph nodes will be removed from Levels I and II. Level I lymph nodes are in the armpit. Level II nodes are higher and deeper in the armpit.

If cancer is found in Level II nodes, nodes from Level III may be removed. Level III nodes are below the collarbone. They are also called infraclavicular lymph nodes.

Figure 9 Lymph node surgery

There are two types of surgeries to remove lymph nodes. A sentinel lymph node biopsy finds and removes the lymph nodes to which breast cancer first spreads. An axillary lymph node dissection removes at least 10 lymph nodes from Levels I and II.



Who can get an axillary dissection?

Without preoperative treatment, axillary dissection is often done when cancer is in lymph nodes. Cancer in nodes can be confirmed with a needle biopsy or sentinel lymph node biopsy. Axillary dissection may not be done for early breast cancer in only 1 or 2 sentinel nodes and treated with lumpectomy and whole-breast radiation.

Axillary dissection is often performed when the sentinel node is not found. For some women, radiation to the axillary nodes may be done instead. There must have been no signs of cancer in nodes at diagnosis. Treatment must consist of a mastectomy and radiation therapy.

Axillary dissection is standard of care for cancers rated T4, N2, or N3. It is also performed when cancer is found in nodes after preoperative therapy.



What to expect: Surgery

- ✓ To prepare, you may need to stop taking some medicines. If you smoke, quit to improve treatment results.
- ✓ Pain will be prevented with either local or general anesthesia.
- ✓ A plastic drain tube is often placed under the skin after mastectomy.
- ✓ You will have pain, swelling, and a scar afterward.
- ✓ Your arm may swell due to a buildup of lymph. This is called lymphedema. There is no way to know who will have it or when it will occur.
- ✓ Breast reconstruction can be done at the same time as the cancer surgery or later.

Breast reconstruction

After surgery, some women choose to have breast reconstruction. Other women use breast forms or do nothing. This section explains some details about breast reconstruction.

Volume displacement

If you will have a lumpectomy, your breast can be re-shaped. This procedure is called volume displacement. It is often done by the cancer surgeon right after the lumpectomy. He or she will shift the remaining breast tissue to fill the hole left by the removed tumor.

If volume displacement is planned, a larger piece of your breast will need to be removed. Despite a larger piece being removed, the natural look of your breast will be kept. Having a larger piece removed will likely reduce the chance of the cancer coming back.

You may not like the results of the volume displacement. In this case, breast revision surgery may help. This surgery is done by a plastic surgeon. A second volume displacement may be an option, too. A third option is to get breast implants or flaps, which are described next.

Implants & flaps

Breasts can be fully reconstructed with implants and flaps. All methods are generally safe, but as with any surgery, there are risks. Ask your treatment team for a complete list of side effects.

You may have a choice as to when breast reconstruction is done. Immediate reconstruction is finished within hours after removing the breast. Delayed reconstruction can occur months or years after the cancer surgery. A plastic surgeon performs breast reconstruction.

Implants

Breast implants are small bags filled with salt water, silicone gel, or both. See Figure 10. They are placed under the breast skin and muscle. A balloon-like device, called an expander, may be used first to stretch out tissue. It will be placed under your skin or muscle and enlarged every few weeks for two to three months.

Implants have a small risk of leaking. You may feel pain from the implant or expander. Scar tissue or tissue death occurs in some women.

Flaps

Breasts can be remade using tissue from your body, known as “flaps.” Flaps are taken from the belly area,

Figure 10 Breast implants

Breast implants are one method of reconstructing breasts. They are small bags filled with salt water, silicone gel, or both. They are placed under the breast skin and muscle. A balloon-like device, called an expander, may be used first to stretch out tissue.



butt, or from under the shoulder blade. Some flaps are completely removed and then sewn in place. Other flaps stay attached but are slid over and sewn into place.

Flaps can cause problems. There may be tissue death. Death of fat cells may cause lumps. A hernia may occur from muscle weakness. Problems are more likely to occur among women who have diabetes or smoke.

Implants and flaps

Some breasts are reconstructed with both implants and flaps. This method may give the reconstructed breast more volume to match the other breast. For any reconstruction, you may need surgery on your real breast to match the two breasts in size and shape.

Nipple replacement

Like your breast, you can have your nipple remade. To rebuild a nipple, a plastic surgeon can use surrounding tissues. Also, nipples can be remade with tissue from the thigh, other nipple, or the sex organs between your legs (vulva). Tissue can be darkened with a tattoo to look more like a nipple.

Review

- ▶ Surgery is a key part of treatment for invasive cancer.
- ▶ The breast tumor will be removed by one of two methods. A lumpectomy removes the tumor and a rim of healthy tissue around it. A total mastectomy removes the whole breast but no chest muscle.
- ▶ Lymph nodes will be removed to stage the cancer. Sentinel lymph node biopsy removes the lymph nodes to which breast cancer first spreads. Axillary lymph node dissection removes at least 10 lymph nodes near the armpit.
- ▶ Volume displacement is the shifting of breast tissue to fill the hole left by the lumpectomy.
- ▶ Breast reconstruction after mastectomy is done with breast implants, flaps, or both.

5

Adjuvant therapy

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- 44 Radiation therapy
- 48 Endocrine therapy
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Treatment that is given after surgery is called adjuvant therapy. The treatment goal is to stop the cancer from coming back. This chapter explains who receives which treatments.

Overview

Doctors call the return of cancer a recurrence. Treatments that help stop a recurrence are called adjuvant therapy. Adjuvant therapy treats tiny amounts of cancer left in your body after surgery.

Most women receive adjuvant therapy. And, many women receive more than one type. Types of adjuvant therapy include:

- Chemotherapy (or “chemo”),
- HER2 antibodies,
- Radiation therapy, and
- Endocrine therapy.

Radiation therapy is used to stop a recurrence in or near the breast. The other adjuvant therapies treat breast cancer in any part of the body. Treatment for the whole body is called systemic therapy.

If you'll get chemotherapy, it is often given before radiation therapy. Likewise, chemotherapy should be finished before starting endocrine therapy. It is safe to receive radiation, HER2 antibodies, and endocrine therapy at the same time.

Cancer stage

Doctors decide whether adjuvant therapy is needed based on many factors. A very important factor is the cancer stage. Breast cancer is often staged twice. The clinical stage is rated before surgery. The pathologic stage is rated after surgery. Both stages depend on TNM scores as described in **Part 1**.

The meaning of the T scores is the same for clinical and pathologic stages. For example, for both stages, T1 means the tumor is no larger than 2 cm.

For some women, Tis will be changed to T1mi after surgery. Tis means the cancer is only in the breast duct or nipple. With a microscope, your doctor may see that a little of the cancer has grown into the breast's fatty tissue. So, the pathologic T stage is T1mi.

The meaning of the N scores is not the same for clinical and pathologic stages. The pathologic stage is based on the test results of removed lymph nodes.

- **Node-negative** is a term that describes lymph nodes that are cancer-free (N0).
- **Node-positive** is a term that describes lymph nodes with cancer. It includes N1, N2, and N3.

Pregnancy

Treatments used for adjuvant therapy can cause birth defects. So, do not become pregnant. Use birth control without hormones (eg, condoms and not “the pill”).

If you are pregnant, timing of adjuvant therapy is important. Do not get chemotherapy in the first trimester. Some types of chemotherapy are safe in the second and third trimesters. Also, radiation therapy and endocrine therapy should be delayed until after your baby is born.

Do not breastfeed during adjuvant treatment. Chemotherapy and endocrine therapy may harm your baby. After radiation, you may not be able to breastfeed from the treated breast.

Supportive care

This book focuses on cancer treatment, but supportive care is also important. Supportive care aims to improve the quality of your life.

During adjuvant therapy, you may have side effects from treatment. Examples include nausea from chemotherapy and hot flashes from endocrine therapy. Tell your treatment team about any new or worse symptoms you get. There may be ways to help you feel better.

N stage

The N stage is the rating of the extent of cancer in regional lymph nodes. It is key to planning adjuvant therapy.

Clinical N stage

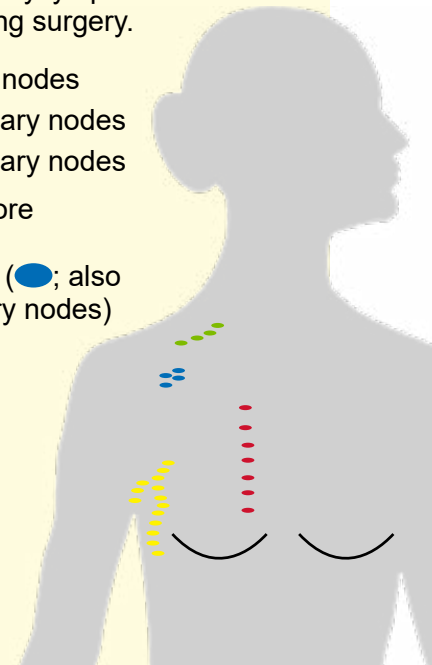
The cancer stage before surgery is called the clinical stage. It is based on an exam, imaging, or biopsy.

- N0** No signs of cancer in regional nodes
- N1** Cancer in mobile axillary nodes (●)
- N2** Cancer in fixed axillary nodes (●) or internal mammary nodes (●)
- N3** Cancer in:
 - Axillary nodes + internal mammary nodes (● + ●)
 - Infraclavicular nodes (●) or
 - Supraclavicular nodes (●)

Pathologic N stage

The cancer stage after surgery is called the pathologic stage. Most often, it is based on tests of the axillary lymph nodes (●) removed during surgery.

- N0** No cancer in axillary nodes
- N1** Cancer is in 1–3 axillary nodes
- N2** Cancer is in 4–9 axillary nodes
- N3** Cancer is in 10 or more axillary nodes or in infraclavicular nodes (●; also called Level III axillary nodes)



Chemotherapy

Women who did not have chemotherapy before surgery may get it afterward. It is given to stop a recurrence outside the breast. It works by stopping the cell life cycle. As a result, cancer cells cannot make new cells. Chemotherapy can also cause cells to destroy themselves.

Who gets it

Doctors decide to give chemotherapy based on many factors. First, you must be healthy enough. Otherwise, chemotherapy may be too harmful or not extend your life.

The chance (risk) of a recurrence is a key factor for chemotherapy decisions. A recurrence is more likely with younger age. Features of the cancer are also used to assess recurrence risk. Examples include higher cancer stages, cancer grade, cancer cell type, and receptor cell type. For hormone-positive, HER2-negative cancers, tests called multigene assays predict recurrence risk.

Another key factor is the likelihood of chemotherapy being helpful. Chemotherapy does not work well for all breast cancers. It also can cause harmful side effects. More research is needed to pinpoint whom chemotherapy helps. For example, it is unknown if chemotherapy helps women who are 70 years of age or older.

Guide 6 shows when chemotherapy is given for common cancer types. These types include ductal, lobular, metaplastic, and mixed breast cancer. Chemotherapy is not often used for rare breast cancers (eg, tubular, mucinous, papillary). These cancers don't often recur.

Hormone-positive, HER2-negative cancers

Endocrine therapy is a standard treatment for many hormone-positive breast cancers. It stops the

Guide 6. Adjuvant chemotherapy

Hormone-positive, HER2-negative

No cancer in lymph nodes (N0)

| T score | Oncotype Dx score | Is chemotherapy given? |
|------------------|-------------------|------------------------|
| T1mi, T1a | – | • Very rarely |
| T1b, T1c, T2, T3 | ≤25 | • Very rarely |
| | 26–30 | • Varies based on risk |
| | ≥31 | • Very often |
| | Not done | • Often if high risk |

Cancer in lymph nodes (N1–N3)

| N score | Oncotype Dx score | Is chemotherapy given? |
|---------|-------------------|------------------------|
| N1 | ≤17 | • Not often |
| | ≥18 | • Often if high risk |
| | Not done | • Often if high risk |
| N2, N3 | – | • Very often |

Any hormone status, HER2-positive

| T score | N score | Is chemotherapy with HER2 therapy given? |
|-------------|----------|--|
| T1mi, T1a | N0 | • Varies based on risk |
| | N1mi | • Varies based on risk |
| T1b | N0, N1mi | • Varies based on risk |
| T1c, T2, T3 | N0, N1mi | • Very often |
| T1–T3 | N1a–N3 | • Very often |

Hormone-negative, HER2-negative

| T score | N score | Is chemotherapy given? |
|-------------|----------|------------------------|
| T1mi, T1a | N0 | • Very rarely |
| | N1mi | • Often if high risk |
| T1b | N0, N1mi | • Often if high risk |
| T1c, T2, T3 | N0, N1mi | • Very often |
| T1–T3 | N1a–N3 | • Very often |

cancer from coming back in many women. For some women, adding chemotherapy improves results.

A recurrence is very uncommon for tiny, node-negative breast cancers. So, chemotherapy is very rarely used for these cancers. In contrast, cancer with an N2 or N3 stage often returns, so chemotherapy is often given.

For other breast cancers, multigene assays may be used for treatment decisions. Oncotype Dx assesses recurrence risk, and for node-negative cancers, predicts if chemotherapy will help. MammaPrint, Prosigna, EndoPredict, and the Breast Cancer Index assess recurrence risk.

Node-negative cancers with low Oncotype Dx scores are rarely treated with chemotherapy. Although, chemotherapy may be helpful for women ages 50 years and younger with scores between 16 and 25. Chemotherapy for node-negative cancers with midrange scores is based on a doctor's assessment of recurrence risk. Chemotherapy is very often given when Oncotype DX scores are high.

Multigene assays may be used for N1 disease. Chemotherapy is not often given if the Oncotype Dx score is 17 or less. For scores of 18 and higher, chemotherapy is based on a doctor's assessment of recurrence risk.

Any hormone status, HER2-positive cancers

Research is lacking to guide decisions on chemotherapy for small, N0 or N1mi, HER2-positive cancers. It is unclear if chemotherapy is helpful. Also, your risk for serious side effects, such as heart damage, may be too high. Your doctor may offer chemotherapy if a recurrence is likely.

Research on chemotherapy for large and node-positive cancers has been done. Chemotherapy has been shown to improve outcomes. Therefore, chemotherapy is very often used for these cancers.



You had preoperative therapy. Is adjuvant chemotherapy an option?

Chemotherapy is most often used for preoperative therapy. So, it is not often used for adjuvant therapy. You may be given adjuvant chemotherapy for these reasons:

- Preoperative chemotherapy was not completed.
- Endocrine therapy was used for preoperative therapy.
- Standard chemotherapy did not fully treat triple-negative tumors. In this case, capecitabine may be given for adjuvant therapy.

For HER2-positive cancers, chemotherapy is given with HER2 antibodies. HER2 antibodies stop growth signals and mark cancer cells for attack by your body. HER2 antibodies are taken for up to one year. When finished, your doctor may advise taking neratinib (Nerlynx®). Neratinib is a HER2 inhibitor for hormone- and HER-positive cancers. This type of drug stops growth signals from HER2 from within the cell.

Hormone-negative, HER2-negative cancers

For triple-negative cancers, chemotherapy is the only systemic therapy that can be used. It is of very little or no help for small, node-negative cancers. Other triple-negative cancers are more likely to recur, so chemotherapy may be given. Your doctor will plan treatment based on your risk for a recurrence. Chemotherapy is standard treatment when breast tumors are large or cancer is in lymph nodes.



Side effects from treatment can be difficult to manage. I sometimes wish that treatment wasn't such a bully... except when it comes to fighting the cancer.

– Lynn

Radiation therapy

Radiation therapy treats cancer that wasn't removed from the breast or nearby tissue. It uses high-energy x-rays to damage DNA in cancer cells. The cells either die or can't make new cells.

Who gets it

Despite surgery, cancer may remain in the treated area. There may be cancer cells within your breast or chest wall. Cancer may also be in nearby lymph nodes.

Many women with invasive breast cancer receive radiation therapy. But, it may not be given if a recurrence is not likely.

- Radiation after lumpectomy may be omitted if you: 1) are 70 years of age or older; 2) have a T1 tumor and N0 lymph nodes; and 3) will receive endocrine therapy.
- Radiation after mastectomy may be omitted if: 1) a T1 or T2 tumor was removed with large, cancer-free margins; and 2) the nodes are cancer-free.

Treatment options

A radiation oncologist will oversee your treatment. This doctor is an expert in treating cancer with radiation. He or she will tailor treatment to you.

After lumpectomy

Options for radiation after lumpectomy are listed in [Guide 7](#). For most women, the whole breast will receive radiation. The lumpectomy site may receive more radiation called a boost.

For some women, only the lumpectomy site will be treated. This method is called APBI (**a**ccelerated **p**artial **b**reast irradiation). More research is needed to know how well it works. Outside of a clinical trial, it is safest among older women (=50 years old) with

Guide 7. Radiation therapy after lumpectomy

Preoperative therapy not given

| T stage | N stage | Where is radiation needed? |
|----------|---|--|
| T1 | Clinical and pathologic N stages are N0 | <ul style="list-style-type: none"> No radiation for very-low-risk cancers |
| T1 | Clinical and pathologic N stages are N0 or Pathologic N stage is N0 | <ul style="list-style-type: none"> Part of the breast for certain low-risk cancers Whole breast ± boost Regional lymph nodes may be treated when cancer is high risk |
| T0 or T1 | Pathologic N stage is N1 | <ul style="list-style-type: none"> Whole breast ± boost Regional lymph nodes + at-risk axillary tissue may be treated |
| T0 or T1 | Pathologic N stage is N2 or N3 | <ul style="list-style-type: none"> Whole breast ± boost to surgery site Infraclavicular lymph nodes Supraclavicular lymph nodes Internal mammary lymph nodes Axillary tissue at risk for cancer |

Preoperative therapy was given

| T stage | N stage | Where is radiation needed? |
|----------|--|--|
| T2 or T3 | Clinical and pathologic N stages are N0 | <ul style="list-style-type: none"> Whole breast ± boost Regional lymph nodes may be treated when cancer is high risk |
| T0–T3 | Clinical N1 downstaged to pathologic N0 | <ul style="list-style-type: none"> Whole breast ± boost Regional lymph nodes + at-risk axillary tissue may be treated |
| T0–T3 | Clinical N stage is N2 or N3 or Pathologic N stage is N1–N3 | <ul style="list-style-type: none"> Whole breast ± boost Infraclavicular lymph nodes Supraclavicular lymph nodes Internal mammary lymph nodes |
| T4 | Any N stage | <ul style="list-style-type: none"> Axillary tissue at risk for cancer |

hormone-positive, T1N0 ductal carcinoma removed with large, cancer-free margins. *BRCA* genes should be normal.

Besides your breast, regional lymph nodes may be treated. These nodes are on the same side of your chest as the breast cancer. If axillary nodes were removed, other tissue in the area will be treated instead.

Radiation to nodes is often done when a recurrence is likely. The risk is higher for T4 tumors and N2 or N3 disease. Radiation is also advised when breast cancer remains after preoperative therapy. For other women, radiation is advised based on cancer stage and other factors.

After mastectomy

Options for radiation after mastectomy are listed in [Guide 8](#). When radiation is given, the chest wall and sometimes the drain sites will be treated. The mastectomy scar may get more radiation called a boost. Regional lymph nodes are often treated, too. If axillary nodes were removed, other tissue in the area will be treated instead.

Radiation is often done when a recurrence is likely. The risk is higher for T4 tumors and N2 or N3 disease. Radiation is also advised when breast cancer remains after preoperative therapy. For other women, radiation is advised based on cancer stage and other factors.

Guide 8. Radiation therapy after mastectomy

Preoperative therapy was not given

| T stage | N stage | Where is radiation needed? |
|---|--------------------------------|--|
| T1 or T2 tumor removed with large and cancer-free margins | Pathologic N stage is N0 | <ul style="list-style-type: none"> No radiation therapy |
| T1 or T2 tumor removed with small and cancer-free margins | Pathologic N stage is N0 | <ul style="list-style-type: none"> Chest wall may be treated Regional lymph nodes may be treated when cancer is high risk |
| T1 or T2 with cancer in margins | Pathologic N stage is N0 | <p>If a second surgery is not an option:</p> <ul style="list-style-type: none"> Chest wall + regional nodes + at-risk axillary tissue may be treated |
| T3 | Pathologic N stage is N0 | <ul style="list-style-type: none"> Chest wall + regional lymph nodes + at-risk axillary tissue may be treated |
| T0–T3 | Pathologic N stage is N1 | |
| T0–T3 | Pathologic N stage is N2 or N3 | <ul style="list-style-type: none"> Chest wall Infraclavicular lymph nodes Supraclavicular lymph nodes Internal mammary lymph nodes Axillary tissue at risk for cancer |

Preoperative therapy was given

| T stage | N Stage | Where is radiation needed? |
|---------|--|--|
| T0–T3 | Clinical N1 downstaged to N0 | <ul style="list-style-type: none"> Chest wall + regional lymph nodes + at-risk axillary tissue may be treated |
| T0–T3 | Clinical N stage is N2 or N3 or Pathologic N stage is N1–N3 | <ul style="list-style-type: none"> Chest wall Infraclavicular lymph nodes Supraclavicular lymph nodes Internal mammary lymph nodes Axillary tissue at risk for cancer |
| T4 | Any N stage | |

Endocrine therapy

Endocrine therapy stops cancer growth caused by hormones. It is sometimes called hormone therapy. It is not the same as hormone replacement therapy for menopausal symptoms.

Who gets it

Endocrine therapy is used for hormone receptor-positive breast cancers. The cancer cells have estrogen or progesterone receptors or both. Since these cancers are common, many women will get endocrine therapy.

Endocrine therapy may not be used for adjuvant therapy if a recurrence is unlikely. The risk is low if a breast tumor is 0.5 cm or smaller and lymph nodes are cancer-free. The breast tumor may be larger (>3 cm) if the type of cancer grows slowly. Endocrine therapy may be used instead to prevent a second breast cancer in the other breast.

Main types

There are four main types of endocrine therapy for invasive cancer. Each type stops hormone-related growth by a different method.

- Ovarian ablation permanently stops the ovaries from making hormones. Most often, both ovaries are removed from the body. This surgery is called a bilateral oophorectomy.
- Ovarian suppression temporarily stops the ovaries from making hormones. It is achieved with drugs called LHRH (luteinizing hormone-releasing hormone) agonists. These drugs stop LHRH from being made, which stops the ovaries from making hormones. LHRH agonists include goserelin (Zoladex®) and leuprolide (Lupron Depot®).
- Aromatase inhibitors stop a hormone called androgen from changing into estrogen.

They do not affect estrogen made by the ovaries. Non-steroidal aromatase inhibitors include anastrozole (Arimidex®) and letrozole (Femara®). Exemestane (Aromasin®) is a steroidal aromatase inhibitor. None of these drugs is preferred over another.

- Antiestrogens stop hormone receptors. Of the antiestrogens, tamoxifen is used for adjuvant therapy. It is a SERM (selective estrogen receptor modulator). These drugs block estrogen from attaching to hormone receptors.

Treatment options

As shown in [Guide 9](#), options for endocrine therapy are partly based on menopausal status. Menopause is the point in time when you won't have another menstrual period again. Estrogen and progesterone levels remain low after menopause starts.

When a woman hasn't had a period in one or more years, she's often considered to be in postmenopause. If you don't get periods, a test using a blood sample may be needed to confirm your status. If you get menstrual periods, you are in premenopause.

Treatment occurs for at least 5 years and often longer. The first regimen received is called the initial treatment. Sometimes a second medicine is taken within the 5-year period. This is called sequential treatment. Endocrine therapy taken beyond the 5-year period is called extended treatment.

Premenopause

Treatment options are often based on the chance of the cancer coming back. Breast cancer is more likely to recur in younger women. Cancer in lymph nodes and a high cancer grade also raises the risk.

If the risk is low, tamoxifen is given for 5 years. Another 5 years of treatment may extend good results. Your doctor may offer tamoxifen for 5 more

Guide 9. Endocrine therapy

Premenopause

What are the options?

- Tamoxifen for 5 years; ovarian suppression or ablation may be added
 - If postmenopausal after 5 years, an aromatase inhibitor for 5 more years or
 - For pre- or postmenopause, tamoxifen for 5 more years may extend good results
- Aromatase inhibitor for 5 years with ovarian suppression or ablation

Postmenopause

What are the options?

- Aromatase inhibitor for 5 years, then consider staying on it for another 5 years
- Aromatase inhibitor for 2–3 years and then tamoxifen to complete 5 years of treatment
- Tamoxifen for 2–3 years and then an aromatase inhibitor to complete 5 years of treatment
- Tamoxifen for 2–3 years, then an aromatase inhibitor for up to 5 years
- Tamoxifen for 4.5–6 years, then an aromatase inhibitor for 5 years
- Tamoxifen for 4.5–6 years, then consider staying on it to complete 10 years of treatment
- Tamoxifen for 5 years if aromatase inhibitors aren't an option
- Consider taking tamoxifen for up to 10 years if aromatase inhibitors aren't an option

years. Or, if you're now postmenopausal, a second option is an aromatase inhibitor for 5 more years.

If the risk is high, treatment may include ovarian suppression or ablation. Stopping ovarian function may improve results, but side effects may be worse. Side effects include bone loss and joint pain. Ovarian suppression or ablation with an aromatase inhibitor for 5 years is an option. A second option is to add either treatment to the use of tamoxifen.

Postmenopause

For postmenopause, treatment that contains an aromatase inhibitor is often used. More research is needed to learn if one regimen is better than another. The best length of treatment also needs to be studied.

Review

- Adjuvant therapy helps stop the breast cancer from coming back.
- The cancer stage and type are key to planning adjuvant treatment.
- Chemotherapy is advised when cancer is in lymph nodes. Chemotherapy may not be needed if the nodes are cancer-free.
- Radiation therapy is often given to the whole breast after lumpectomy. Lymph nodes are treated as well if the cancer is likely to return. After mastectomy, the chest wall and lymph nodes are treated when the cancer is likely to return.
- Endocrine therapy is used for most hormone receptor-positive breast cancers.

6

Follow-up and recurrence

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Follow-up care is important for your long-term health. It is started when there are no signs of cancer. This chapter lists key parts of follow-up care. It also lists treatment options if the cancer returns.

Health and wellness

Follow-up care includes help to achieve better overall health. Routine health care should be followed. A healthy lifestyle should be practiced. Your doctor can help you achieve your goals.

Follow-up care also includes care for health problems caused by cancer treatments. These health problems may first appear after treatment is done. So, tell your doctors about any new or worse symptoms. Your doctor may be able to help you feel better.

Healthy lifestyle

Be active and achieve a healthy weight. Both are linked to better treatment results. Doctors advise having a BMI (**body mass index**) of 20 to 25. BMI is a rough measure of body fat based on height and weight.

Healthy eating may also improve treatment results. Healthy eating includes: 1) a balanced diet; 2) eating the right amount of food; and 3) drinking enough fluids. Alcohol should be limited. A registered dietician—an expert in creating a healthy diet—can help.

Medicine check

If on endocrine therapy, don't stop taking your medicine. If you do, the cancer will be more likely to return. Tell your doctor about any side effects that make you think about quitting. There may be ways to get relief.

GYN exam

If on tamoxifen, you need a GYN (**gynecologic**) exam each year. This drug can increase your chance for cancer of the uterus. Tell your doctor if you've had any vaginal bleeding that isn't normal for you. If not on tamoxifen, continue your routine GYN care.

Bone mineral density

Regular testing of bone mineral density is needed in two cases. Get tested if on an aromatase inhibitor or if cancer treatments caused menopause. Aromatase inhibitors and starting menopause early can cause bone loss. Bone mineral density tests reveal how strong your bones are.

Lymphedema

Lymphedema is swelling due to buildup of lymph. It occurs in the arms after treatment of the lymph nodes. It may happen just after treatment or months to years later. Some women never get it. It's important to know about lymphedema so you can watch out for it.

If you have lymphedema, your doctor will check it. He or she will also refer you to an expert in lymphedema management. The swelling may be reduced by exercise, massage, compression sleeves, and other means.

Cancer surveillance

During follow-up care, your doctor will assess for breast cancer. Breast cancer may return after a cancer-free period. Finding cancer early may lead to better treatment results.

Medical history and physical exam

Your doctor will update your medical history and perform a physical exam at follow-up visits. These visits should occur between 1 to 4 times a year as needed for the first 5 years. If results are normal, you should then have these visits every year starting in the 6th year after cancer treatment.

Tell your treatment team about any new cancer in your family. Your doctor may refer you to a genetic counselor.

Mammograms

After breast-conserving therapy, mammograms are used to look for cancer in the treated breast. A mammogram every 12 months is advised. The first mammogram should occur at least 6 months after radiation ends. Mammograms are also used for cancer screening of a breast that hasn't had cancer.

Routine use of other breast imaging isn't advised. Mammograms aren't done after mastectomy since the breast has been removed. Imaging of reconstructed breasts on a regular basis isn't needed. Screening for metastases isn't needed unless cancer signs or symptoms appear.

Recurrence treatment

For some women, the cancer returns. This section reviews treatment for cancer that returns in a breast or nearby tissue. If distant organs have cancer, read the *NCCN Guidelines for Patients®: Breast Cancer – Metastatic*.

Treatment planning

Guide 10 lists the tests that are used to tailor your treatment to you. Many were described in **Part 2**. A biopsy is needed to confirm cancer. MRI of your

Guide 10. Treatment planning

Main tests and services

Medical history

Physical exam

CBC

Comprehensive metabolic panel

Chest diagnostic CT scan

Abdomen ± pelvis diagnostic scans (CT or MRI)

Spine MRI if certain symptoms present

Brain MRI if certain symptoms present

Bone scan or sodium fluoride PET/CT

FDG PET/CT instead of other imaging

X-rays of bones for certain symptoms or signs

Biopsy

Genetic counseling if guided by medical history

spine or brain may be done based on symptoms. Cancer spread to the brain is much less common than to the spine.

X-rays of bones that hurt are advised. Long and weight-bearing bones that aren't normal on bone scan or PET/CT and may fracture should also be x-rayed.

Treatment options

Options for recurrence are listed in [Guide 11](#). Surgery is advised if it can be done. Radiation may

follow surgery or be used alone for treatment. It depends on where you had radiation before and how much.

Systemic therapy may be an option. These treatments travel in the bloodstream to any place with cancer. They include chemotherapy, chemotherapy with HER2 antibodies, and endocrine therapy.

Guide 11. Recurrence treatment

Cancer in breast or chest wall only

| Your prior treatment included: | What treatment is needed? |
|--|---|
| Breast-conserving therapy | <ul style="list-style-type: none"> • Total mastectomy • Axillary lymph node dissection • Systemic therapy may be given |
| Total mastectomy only | <ul style="list-style-type: none"> • Surgery if possible • Radiation therapy • Systemic therapy may be given |
| Total mastectomy with axillary lymph node dissection and radiation therapy | <ul style="list-style-type: none"> • Surgery if possible • Systemic therapy may be given |

Cancer in lymph nodes

| The lymph nodes with cancer are: | What treatment is needed? |
|--|---|
| Near your armpit (axillary) | <ul style="list-style-type: none"> • Surgery if possible • Radiation therapy if possible • Systemic therapy may be given |
| Above the collarbone (supraclavicular) | <ul style="list-style-type: none"> • Radiation therapy if possible • Systemic therapy may be given |
| Just inside the ribs near the breast bone (internal mammary) | <ul style="list-style-type: none"> • Radiation therapy if possible • Systemic therapy may be given |

Review

- Be active, keep a healthy weight, and have a healthy diet.
- Don't stop taking endocrine therapy without your doctor's approval. Without treatment, the cancer will be more likely to return.
- Tell your doctor about any new or worse symptoms. Health problems from cancer treatments may start during follow-up.
- See your cancer doctor a few times a year. Get a mammogram once a year.
- Breast cancer may return after a cancer-free period. Tests of the cancer will be used to tailor treatment to you.
- For a recurrence in or near the breast, surgery is advised if it can be done. Radiation may follow or be the main treatment. Systemic therapy may be added.

7

Making treatment decisions

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Having cancer is very stressful. While absorbing the fact that you have cancer, you have to learn about tests and treatments. In addition, the time you have to accept a treatment plan feels short. Parts 1 through 6 described breast cancer and treatment options. This chapter aims to help you make decisions that are in line with your beliefs, wishes, and values.

It's your choice

The role patients want in choosing their treatment differs. You may feel uneasy about making treatment decisions. This may be due to a high level of stress. It may be hard to hear or know what others are saying. Stress, pain, and drugs can limit your ability to make good decisions. You may feel uneasy because you don't know much about cancer. You've never heard the words used to describe cancer, tests, or treatments. Likewise, you may think that your judgment isn't any better than your doctors'.

Letting others decide which option is best may make you feel more at ease. But, whom do you want to make the decisions? You may rely on your doctors alone to make the right decisions. However, your doctors may not tell you which to choose if you have multiple good options. You can also have loved ones help. They can gather information, speak on your behalf, and share in decision-making with your doctors. Even if others decide which treatment you will receive, you still have to agree by signing a consent form.

On the other hand, you may want to take the lead or share in decision-making. Most patients do. In shared decision-making, you and your doctors share information, weigh the options, and agree on a treatment plan. Your doctors know the science

behind your plan but you know your concerns and goals. By working together, you are likely to get a higher quality of care and be more satisfied. You'll likely get the treatment you want, at the place you want, and by the doctors you want.

Questions to ask

You may meet with experts from different fields of medicine. Strive to have helpful talks with each person. Prepare questions before your visit and ask questions if the person isn't clear. You can also record your talks and get copies of your medical records.

It may be helpful to have your spouse, partner, or a friend with you at these visits. A patient advocate or navigator might also be able to come. They can help to ask questions and remember what was said. Suggested questions to ask are listed on the following pages.



It's a fine line between advocating for myself with my treatment team and wanting to be viewed as a good patient.

— Eileen
Cancer Survivor

What's my diagnosis and prognosis?

It's important to know that there are different types of cancer. Cancer can greatly differ even when people have a tumor in the same organ. Based on your test results, your doctors can tell you which type of cancer you have. He or she can also give a prognosis. A prognosis is a prediction of the pattern and outcome of a disease. Knowing the prognosis may affect what you decide about treatment.

1. Where did the cancer start? In what type of cell? Is this cancer common?
2. Is this a fast- or slow-growing cancer?
3. What tests do you recommend for me?
4. My first breast cancer was years ago. Should I get a biopsy of a recurrence? If no, why not?
5. Where will the tests take place? How long will the tests take and will any test hurt?
6. What if I am pregnant or want to become pregnant?
7. How do I prepare for testing?
8. Should I bring a list of my medications?
9. Should I bring someone with me?
10. How often are these tests wrong?
11. How do I get a copy of the pathology report and other test results?
12. Who will talk with me about the next steps? When?

What are my options?

There is no single treatment practice that is best for all women. There is often more than one treatment option along with clinical trial options. Your doctor will review your test results and recommend treatment options.

1. What will happen if I do nothing?
2. Can I just carefully monitor the cancer?
3. Do you consult NCCN recommendations when considering options?
4. Are you suggesting options other than what NCCN recommends? If yes, why?
5. Do your suggested options include clinical trials? Please explain why.
6. How do my age, health, and other factors affect my options? What if I am pregnant or want to get pregnant?
7. Which option is proven to work best? How good is the research? Which options lack scientific proof?
8. What are the benefits of each option? Does any option offer a cure or long-term cancer control? Are my chances any better for one option than another? Less time-consuming? Less expensive?
9. What are the risks of each option? What are possible complications? What are the rare and common side effects? Short-lived and long-lasting side effects? Serious or mild side effects? Other risks?
10. How do you know if treatment is working?
11. What are my options if my treatment stops working?
12. What can be done to prevent or relieve the side effects of treatment?

What does each option require of me?

Many women consider how each option will practically affect their lives. This information may be important because you have family, jobs, and other duties to take care of. You also may be concerned about getting the help you need. If you have more than one option, choosing the option that is the least taxing may be important to you.

1. Will I have to go to the hospital or elsewhere? How often? How long is each visit?
2. What will I need to do if I will travel for treatment?
3. Do I have a choice of when to begin treatment? Can I choose the days and times of treatment?
4. How do I prepare for treatment? Do I have to stop taking any of my medicines? Are there foods I will have to avoid?
5. Should I bring someone with me when I get treated?
6. Will the treatment hurt?
7. How much will the treatment cost me? What does my insurance cover?
8. Will I miss work or school? Will I be able to drive?
9. Is home care after treatment needed? If yes, what type? How soon will I be able to manage my own health?
10. When will I be able to return to my normal activities?

What is your experience?

More and more research is finding that patients treated by more experienced doctors have better results. It is important to learn if a doctor is an expert in the cancer treatment he or she is offering.

1. Are you board certified? If yes, in what area?
2. How many patients like me have you treated?
3. How many procedures like the one you're suggesting have you done?
4. Is this treatment a major part of your practice?
5. How many of your patients have had complications?

Deciding between options

Deciding which option is best can be hard. Doctors from different fields of medicine may have different opinions on which option is best for you. This can be very confusing. Your spouse or partner may disagree with which option you want. This can be stressful. In some cases, one option hasn't been shown to work better than another. Some ways to decide on treatment are discussed next.

2nd opinion

The time around a cancer diagnosis is very stressful. People with cancer often want to get treated as soon as possible. They want to make their cancer go away before it spreads farther. While cancer can't be ignored, there is time to think about and choose which option is best for you.

You may wish to have another doctor review your test results and suggest a treatment plan. This is called getting a 2nd opinion. You may completely trust your doctor, but a 2nd opinion on which option is best can help.

Copies of the pathology report, the imaging tests, and other test results need to be sent to the doctor giving the 2nd opinion. Some people feel uneasy asking for copies from their doctors. However, a 2nd opinion is a normal part of cancer care.

When doctors have cancer, most will talk with more than one doctor before choosing their treatment. What's more, some health plans require a 2nd opinion. If your health plan doesn't cover the cost of a 2nd opinion, you have the choice of paying for it yourself.

If the two opinions are the same, you may feel more at peace about the treatment you accept to have. If the two opinions differ, think about getting a 3rd opinion. A 3rd opinion may help you decide between your options. Choosing your cancer treatment is a

very important decision. It can affect your length and quality of life.

Decision aids

Decision aids are tools that help people make complex choices. For example, you may have to choose between two options that work equally as well. Sometimes making a decision is hard because there is a lack of science supporting a treatment.

Decision aids often focus on one decision point. In contrast, this book presents tests and treatment options at each point of care for women in general. Well-designed decision aids include information that research has identified as what people need. They also aim to help you think about what's important based on your values and preferences.

A list of decision aids can be found at decisionaid.ohri.ca/AZlist.html. Decision aids for breast cancer include:

Genetic testing

uofmhealth.org/health-library/zx3000

Breast-conserving therapy vs. mastectomy

uofmhealth.org/health-library/tv6530#zx3718

Breast reconstruction after mastectomy

uofmhealth.org/health-library/tb1934#zx3672

Support groups

Besides talking to health experts, it may help to talk to patients who have walked in your shoes. Support groups often consist of people at different stages of treatment. Some may be in the process of deciding while others may be finished with treatment. At support groups, you can ask questions and hear about the experiences of other people with breast cancer.

Compare benefits and downsides

Every option has benefits and downsides. Consider these when deciding which option is best for you. Talking to others can help identify benefits and downsides you haven't thought of. Scoring each factor from 0 to 10 can also help since some factors may be more important to you than others.

Websites

American Cancer Society

cancer.org/cancer/breast-cancer.html

Breast Cancer Alliance

breastcanceralliance.org

Breastcancer.org

breastcancer.org

FORCE: Facing Our Risk of Cancer Empowered

facingourrisk.org

Living Beyond Breast Cancer (LBBC)

lbbc.org

National Cancer Institute (NCI)

cancer.gov/types/breast

NCCN for Patients®

nccn.org/patients

Sharsheret

sharsheret.org

Young Survival Coalition (YSC)

youngsurvival.org

Review

- ▶ Shared decision-making is a process in which you and your doctors plan treatment together.
- ▶ Asking your doctors questions is vital to getting the information you need to make informed decisions.
- ▶ Getting a 2nd opinion, using decision aids, attending support groups, and comparing benefits and downsides may help you decide which treatment is best for you.

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Dictionary

abdomen

The belly area between the chest and pelvis.

adjuvant therapy

Treatment that is given to lower the chances of the cancer returning.

antiestrogen

A cancer drug that stops estrogen from attaching to cells.

areola

A darker, round area of skin on the breast around the nipple.

aromatase inhibitor

A drug that lowers the level of estrogen in the body.

axillary lymph node

A small disease-fighting structure that is near the armpit.

axillary lymph node dissection

An operation that removes the disease-fighting structures (lymph nodes) near the armpit.

bilateral diagnostic mammogram

Pictures of the insides of both breasts that are made from a set of x-rays.

bilateral oophorectomy

An operation that removes both ovaries.

biopsy

A procedure that removes fluid or tissue samples to be tested for a disease.

bone mineral density

A test that measures the strength of bones.

bone scan

A test that makes pictures of bones to assess for health problems.

boost

An extra dose of radiation to a specific area of the body.

breast implant

A small bag filled with salt water, gel, or both that is used to remake breasts.

breast reconstruction

An operation that creates new breasts.

breast-conserving therapy

A cancer treatment that includes removing a breast lump and radiation therapy.

cancer stage

A rating of the outlook of a cancer based on its growth and spread.

carcinoma

A cancer of cells that line the inner or outer surfaces of the body.

chemotherapy

Cancer drugs that stop the cell life cycle so cells don't increase in number.

chest wall

The layer of muscle, bone, and fat that protects the vital organs.

clinical breast exam

Touching of a breast by a health expert to feel for diseases.

clinical stage

The rating of the extent of cancer before treatment is started.

clinical trial

A type of research that assesses health tests or treatments.

complete blood count (CBC)

A lab test that includes the number of blood cells.

computed tomography (CT)

A test that uses x-rays from many angles to make a picture of the insides of the body.

contrast

A dye put into your body to make clearer pictures during imaging tests.

core needle biopsy

A procedure that removes tissue samples with a hollow needle. Also called core biopsy.

deoxyribonucleic acid (DNA)

A chain of chemicals in cells that contains coded instructions for making and controlling cells. Also called the "blueprint of life."

diagnostic bilateral mammogram

Pictures of the insides of both breasts that are made from a set of x-rays.

duct

A tube-shaped structure through which milk travels to the nipple.

ductal carcinoma

A cancer derived from cells that line small tube-shaped vessels.

endocrine therapy

A cancer treatment that stops the making or action of estrogen. Also called hormone therapy.

estrogen

A hormone that causes female body traits.

fertility specialist

An expert who helps people to have babies.

fine-needle aspiration (FNA)

A procedure that removes tissue samples with a very thin needle.

flap

Body tissue that is taken from one site and used in another site.

gene

Coded instructions in cells for making new cells and controlling how cells behave.

genetic counseling

Expert guidance on the chance for a disease that is passed down in families.

hereditary breast cancer

Breast cancer that was likely caused by abnormal genes passed down from parent to child.

hormone

A chemical in the body that triggers a response from cells or organs.

hormone receptor–negative cancer

Cancer cells that don't use hormones to grow.

hormone receptor–positive cancer

Cancer cells that use hormones to grow.

human epidermal growth factor receptor 2 (HER2)

A protein on the edge of a cell that sends signals for the cell to grow.

(HER2)-negative cancer

A cancer of cells with normal numbers of a protein called HER2.

(HER2)-positive cancer

A cancer of cells with a high number of HER2 receptors.

imaging test

A test that makes pictures (images) of the insides of the body.

immune system

The body's natural defense against infection and disease.

immunohistochemistry (IHC)

A lab test of cancer cells to find specific cell traits involved in abnormal cell growth.

in situ hybridization (ISH)

A lab test of the number of a gene.

infraclavicular

The area right below the collarbone.

internal mammary

The area along the breastbone.

invasive breast cancer

The growth of breast cancer into the breast's supporting tissue (stroma).

lobular carcinoma

A breast cancer that started in cells that line the breast glands (lobules).

lobule

A gland in the breast that makes breast milk.

lumpectomy

An operation that removes a small breast cancer tumor.

luteinizing hormone-releasing hormone (LHRH)

A hormone in the brain that helps control the making of estrogen by the ovaries.

lymph

A clear fluid containing white blood cells.

lymph node

A small, bean-shaped, disease-fighting structure.

lymphedema

Swelling in the body due to a buildup of fluid called lymph.

magnetic resonance imaging (MRI)

A test that uses radio waves and powerful magnets to make pictures of the insides of the body.

mammogram

A picture of the insides of the breast that is made by an x-ray test.

mastectomy

An operation that removes the whole breast.

medical history

A report of all your health events and medications.

medical oncologist

A doctor who's an expert in cancer drugs.

menopause

The point in time when menstrual periods end.

mutation

An abnormal change.

neoadjuvant treatment

A treatment that is given before the main treatment to reduce the cancer. Also called preoperative treatment if given before an operation.

nipple replacement

The rebuilding of a breast nipple.

noninvasive breast cancer

Breast cancer that has not grown into tissue from which it can spread.

ovarian ablation

Methods used to stop the ovaries from making hormones.

ovarian suppression

A drug treatment that lowers the amount of hormones made by the ovaries.

partial breast irradiation

Treatment with radiation that is received at the site of the removed breast tumor.

pathologic stage

A rating of the extent of cancer based on tests given after treatment.

pathologist

A doctor who's an expert in testing cells and tissue to find disease.

pelvis

The body area between the hipbones.

physical exam

A study of the body by a health expert for signs of disease.

positron emission tomography (PET)

A test that uses radioactive material to see the shape and function of body parts.

postmenopause

The state of having no more menstrual periods.

premenopause

The state of having regular menstrual periods.

primary tumor

The first mass of cancer cells.

progesterone

A hormone in women that is involved in sexual development, periods, and pregnancy.

prognosis

The likely course and outcome of a disease based on tests.

radiation therapy

A treatment that uses high-energy rays.

recurrence

The return of cancer after a cancer-free period.

selective estrogen receptor modulators (SERM)

A drug that blocks the effect of estrogen inside of cells.

sentinel lymph node

The first lymph node to which cancer cells spread after leaving a tumor.

sentinel lymph node biopsy

An operation to remove the disease-fighting structures (lymph nodes) to which cancer first spreads. Also called sentinel lymph node dissection.

side effect

An unhealthy or unpleasant physical or emotional response to treatment.

skin-sparing mastectomy

An operation that removes all breast tissue but saves as much breast skin as possible.

stroma

A type of body tissue that supports and connects other tissue.

supportive care

Health care that includes symptom relief but not cancer treatment. Also called palliative care.

supraclavicular

The area right above the collarbone.

surgical margin

The normal-looking tissue around a tumor that was removed during an operation.

systemic therapy

A type of treatment that works throughout the body.

total mastectomy

An operation that removes the entire breast but no chest muscles. Also called simple mastectomy.

triple-negative breast cancer

A breast cancer that does not use hormones or the HER2 protein to grow.

ultrasound

A test that uses sound waves to take pictures of the inside of the body.

volume displacement

A method to shift breast tissue during an operation to fill a gap.

whole breast radiation

Treatment with radiation of the entire breast.

Acronyms

AJCC

American Joint Committee on Cancer

BMI

body mass index

CBC

complete blood count

cm

centimeters

CT

computed tomography

DNA

deoxyribonucleic acid

FDG

fluorodeoxyglucose

FNA

fine-needle aspiration

GYN

gynecologic

HER2

human epidermal growth factor receptor 2

IHC

immunohistochemistry

ISH

in situ hybridization

LHRH

luteinizing hormone-releasing hormone

NCCN®

National Comprehensive Cancer Network®

MRI

magnetic resonance imaging

PET

positron emission tomography

PET/CT

positron emission tomography/computed tomography

SERM

selective estrogen receptor modulator

VUS

variants of unknown significance

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pennmedicine.org/cancer

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nebraskamed.com/cancer

Case Comprehensive Cancer Center/
University Hospitals Seidman Cancer
Center and Cleveland Clinic Taussig
Cancer Institute
Cleveland, Ohio
800.641.2422 • UH Seidman Cancer Center
uhhospitals.org/seidman
866.223.8100 • CC Taussig Cancer Institute
my.clevelandclinic.org/services/cancer
216.844.8797 • Case CCC
case.edu/cancer

City of Hope National Medical Center
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800.826.4673
cityofhope.org

Dana-Farber/Brigham and
Women's Cancer Center
Massachusetts General Hospital
Cancer Center
Boston, Massachusetts
877.332.4294
dfbwcc.org
massgeneral.org/cancer

Duke Cancer Institute
Durham, North Carolina
888.275.3853
dukecancerinstitute.org

Fox Chase Cancer Center
Philadelphia, Pennsylvania
888.369.2427
foxchase.org

Huntsman Cancer Institute
at the University of Utah
Salt Lake City, Utah
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huntsmanccancer.org

Fred Hutchinson Cancer
Research Center/Seattle
Cancer Care Alliance
Seattle, Washington
206.288.7222 • seattlecca.org
206.667.5000 • fredhutch.org

The Sidney Kimmel Comprehensive
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Baltimore, Maryland
410.955.8964
hopkinskimmelfcancercenter.org

Robert H. Lurie Comprehensive Cancer
Center of Northwestern University
Chicago, Illinois
866.587.4322
cancer.northwestern.edu

Mayo Clinic Cancer Center
Phoenix/Scottsdale, Arizona
Jacksonville, Florida
Rochester, Minnesota
800.446.2279 • Arizona
904.953.0853 • Florida
507.538.3270 • Minnesota
www.mayoclinic.org/cancercenter

Memorial Sloan Kettering
Cancer Center
New York, New York
800.525.2225
mskcc.org

Moffitt Cancer Center
Tampa, Florida
800.456.3434
moffitt.org

The Ohio State University
Comprehensive Cancer Center -
James Cancer Hospital and
Solove Research Institute
Columbus, Ohio
800.293.5066
cancer.osu.edu

Roswell Park Comprehensive
Cancer Center
Buffalo, New York
877.275.7724
roswellpark.org

Siteman Cancer Center at Barnes-
Jewish Hospital and Washington
University School of Medicine
St. Louis, Missouri
800.600.3606
siteman.wustl.edu

St. Jude Children's Research Hospital
The University of Tennessee
Health Science Center
Memphis, Tennessee
888.226.4343 • stjude.org
901.683.0055 • westclinic.com

Stanford Cancer Institute
Stanford, California
877.668.7535
cancer.stanford.edu

University of Alabama at Birmingham
Comprehensive Cancer Center
Birmingham, Alabama
800.822.0933
www3.ccc.uab.edu

UC San Diego Moores Cancer Center
La Jolla, California
858.657.7000
cancer.ucsd.edu

UCSF Helen Diller Family
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San Francisco, California
800.689.8273
cancer.ucsf.edu

University of Colorado Cancer Center
Aurora, Colorado
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University of Michigan
Rogel Cancer Center
Ann Arbor, Michigan
800.865.1125
mcancer.org

The University of Texas
MD Anderson Cancer Center
Houston, Texas
800.392.1611
mdanderson.org

University of Wisconsin
Carbone Cancer Center
Madison, Wisconsin
608.265.1700
uwhealth.org/cancer

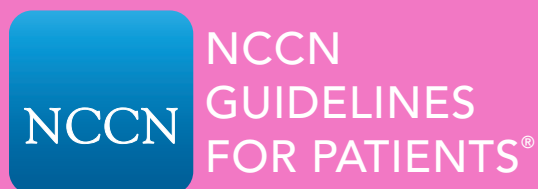
Vanderbilt-Ingram Cancer Center
Nashville, Tennessee
800.811.8480
vicc.org

Yale Cancer Center/
Smilow Cancer Hospital
New Haven, Connecticut
855.4.SMILOW
yalecancercenter.org

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