

Breast Cancer

Metastatic

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LEARNING that you have cancer can be overwhelming.

While many people know about breast cancer, most patient information focuses on early-stage breast cancer. The goal of this book is to help you get the best care for metastatic 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 27 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 metastatic breast cancer. Key points of the book are summarized in the related [NCCN Quick Guide™](#). NCCN also offers patient resources on early and locally advanced 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](https://www.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](https://www.nccnfoundation.org).

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Supporters

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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

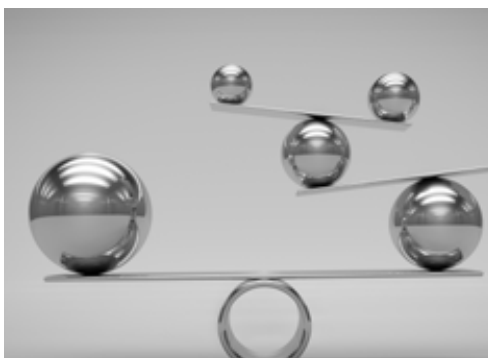
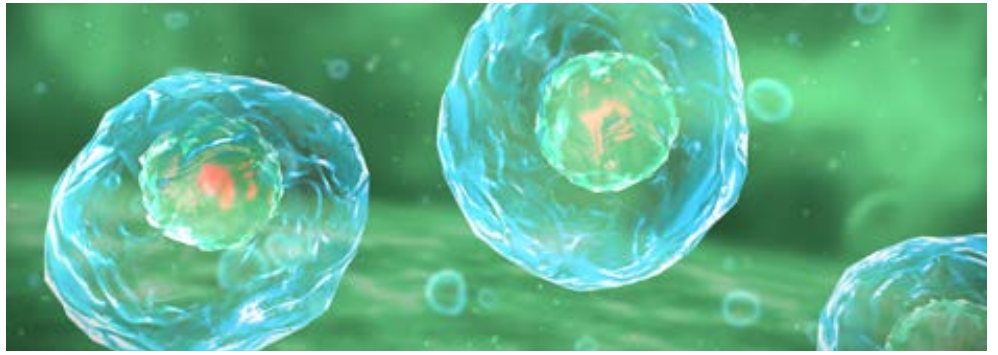
Sharsheret is proud to endorse this important resource, the NCCN Guidelines for Patients: Breast Cancer. With this critical tool in hand, women nationwide have the knowledge they need to partner with their healthcare team to navigate the often complicated world of breast cancer care and make informed 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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Orange Theory Fitness, Gwynedd, Pennsylvania
Warren & Linda Smedley In Honor of Janet M. Smedley



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Who should read this book?

Treatment for metastatic breast cancer is the focus of this book. This cancer has spread to distant sites beyond the breast. 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?

Starting with **Part 1** may be helpful. It explains what metastatic breast cancer is. Read **Part 2** to learn what health care is needed before treatment. Cancer tests are used to plan the best treatment for you.

Not all women get the same treatment. In **Part 3**, treatment options based on cancer features are listed. Tips for making treatment decisions are presented in **Part 4**.

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 the 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 **d**eoxyribo**n**ucleic **a**cid.

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Breast cancer basics

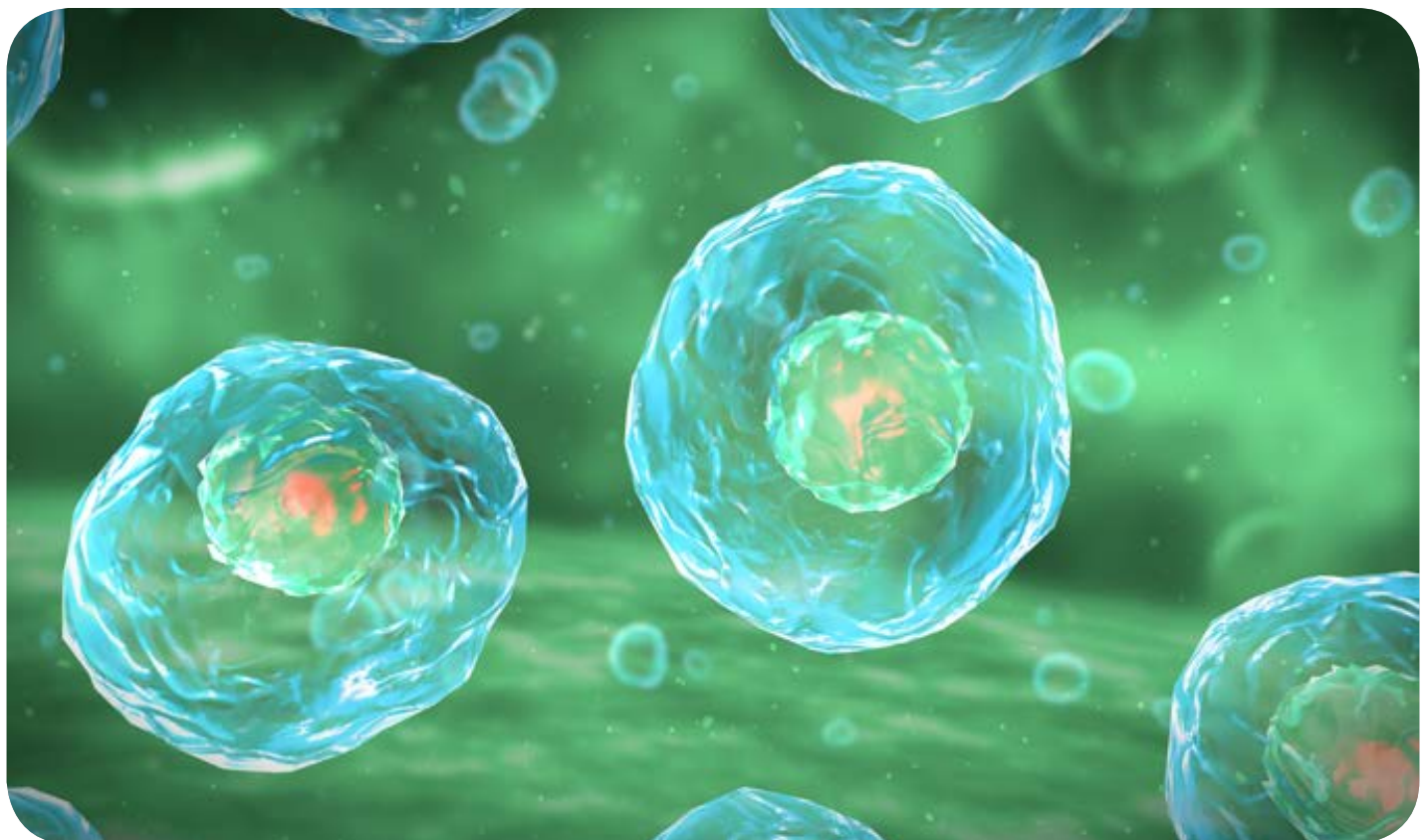
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You've learned that you have metastatic breast cancer. It's common to feel shocked and confused. This chapter reviews some basics that may help you learn about this cancer.

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.

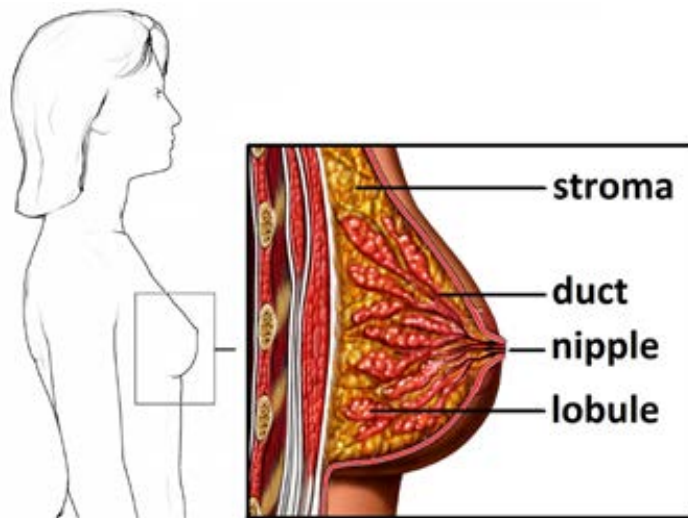


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Figure 2
Axillary lymph nodes

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 in 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. These cancers are 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.

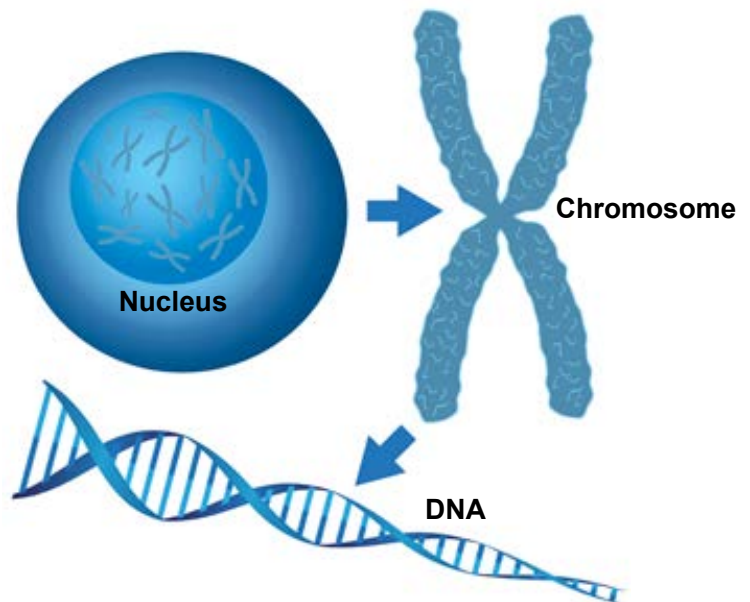


Figure 4
Normal cell growth vs. cancer cell growth

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.

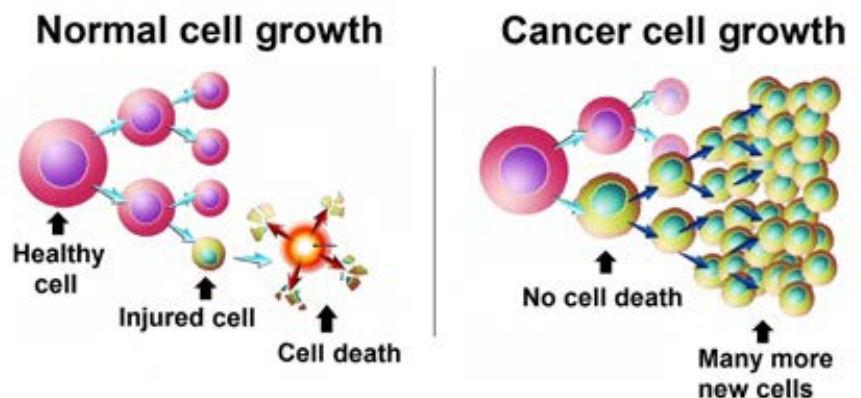


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Cancer stages

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 receiving only 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 numerals—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 sites. None have spread to distant parts of the body.

Stage IV

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

**SNAPSHOT****Metastatic
breast cancer**

- ✓ Has spread to body parts distant from the breast
- ✓ Often spreads to the bones, lungs, brain, and liver
- ✓ Is still breast cancer; it's not lung cancer, for example
- ✓ When present at diagnosis is rated stage IV
- ✓ Includes earlier stages of breast cancer that have spread far after diagnosis

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 not grown into the stroma is called noninvasive.
- Once in the stroma, breast cancer can spread through lymph or blood to other sites.
- Metastatic breast cancer has spread to body sites distant from the breast.

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Treatment planning

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Not all metastatic 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](#) and described in this chapter. Another source is you. Tell your doctor your concerns and goals for treatment. Together, you can share the decision-making process. Read Part 4 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

Tests and services	Who should get this care?
Medical history	Everyone
Physical exam	Everyone
CBC	Everyone
Comprehensive metabolic panel	Everyone
Chest diagnostic CT scan with contrast	Everyone
Abdomen ± pelvis diagnostic CT or MRI with contrast	Everyone
Spine MRI with contrast	Women with certain symptoms
Brain MRI with contrast	Women with certain symptoms
Bone scan or sodium fluoride PET/CT	Everyone
FDG PET/CT instead of other imaging	It's an option
X-rays of bones	Women with certain symptoms or signs
Biopsy	Everyone
Hormone receptor test	Everyone
HER2 test	Everyone
Genetic counseling	Women who may have hereditary breast cancer

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 about having your breasts touched. Keep in mind that this exam is quick and provides key information your doctor needs.

Blood tests

Doctors test blood 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.

Imaging

Imaging tests make pictures of the insides of your body. They can show which sites have cancer. Some imaging tests also reveal some features of a tumor and its cells. A radiologist is a doctor who is an expert in reading images. He or she will convey the test results to your doctor.

You may need to stop taking some medicines. You may need to stop eating and drinking for a few hours before the scan. Tell your doctor if you get nervous when in small spaces. You may be given a pill to help you relax.

Some imaging tests use contrast. It is a dye that makes the pictures clearer. Tell your doctor if you've had problems with contrast in the past.

Chest diagnostic CT

CT (computed tomography) is used to look for cancer in the chest. Contrast should be used. During the scan, you will lie face up on a table that moves through the machine. **See Figure 5.** Many pictures will be taken from different angles using x-rays. A computer combines the x-ray images to make a detailed picture.

Abdomen ± pelvis diagnostic CT or MRI

Your abdomen is the space below your chest and above your hipbones. It is often called the belly. Your pelvis is the space between your hipbones.

You will need to get a scan of your abdomen. Your doctor may also want a scan of your pelvis. Pictures of these sites can be obtained with either CT or MRI (magnetic resonance imaging). Contrast should be used.

MRI uses a magnetic field and radio waves to make pictures. You may be fitted with coil devices that emit radio waves. Straps may be used to help you stay in place. You will be inside the scanning machine

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.



unless you have access to an open scanner. You can wear earplugs to block noise.

Spine and brain MRI

Breast cancer can spread to your spine or brain. It spreads much less often to the brain than to the spine. Images of these sites will be needed if your symptoms suggest cancer is present. MRI with contrast should be used. For a brain MRI, a device will be placed around your head that sends and receives radio waves. For spinal MRI, no device is worn.

Bone scan

Breast cancer often spreads to bones. Cancer in the bones may be detected with a bone scan. Your entire skeleton will be checked.

A bone scan 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 taken. Areas of bone damage appear as dark spots in the pictures.

PET/CT

Sometimes CT is combined with PET (**positron emission tomography**). When used together, they are called a PET/CT scan. Some health centers have one machine that does both scans. At other centers, the scans are done with two machines.

PET requires injecting a radiotracer into your bloodstream. Cancer cells absorb more radiotracer than normal cells. They appear brighter in pictures. PET 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 FDG PET/CT. This scan is most helpful when other imaging is unclear. It may help find cancer in lymph nodes and distant sites. If it clearly shows cancer in the bone, a bone scan and sodium fluoride PET/CT may not be needed.

The radiotracer consists of FDG (**fluorodeoxyglucose**). It is made of fluoride and a simple form of sugar called glucose. You must fast for at least 4 hours before the scan. FDG PET/CT can be done at the same time as diagnostic CT.

Bone x-rays

X-rays are good at showing bone problems but don't show small amounts of cancer. Your doctor may order x-rays if your bones hurt. Long and weight-bearing bones that weren't normal on bone scan may be x-rayed, too.

Cancer cell tests

To confirm cancer is present, a tissue sample needs to be removed and tested. If cancer is confirmed, more lab tests will be done to learn about the cancer. Not all breast cancers are alike. Your doctor will use the lab results to decide which treatment options are right for you.

Biopsy

A biopsy is a procedure that removes tissue or fluid samples. The samples are sent to a lab for testing. A sample from a distant site is needed unless it would be unsafe to remove. The methods to remove the sample will depend on where the cancer has spread.

A biopsy is needed even if you were treated for earlier stages of breast cancer. The biology of the tumor changes in a few women. Such changes can greatly impact treatment options.

Cell receptors

A receptor is a protein found on the surface or inside of cells. Substances bind to the receptors and cause changes within the cell. The type of receptor in breast cancer cells differs between women.

Hormone receptors

Estrogen and progesterone are hormones. Among some women, these hormones attach to receptors inside breast cancer cells. **See Figure 6.** Once inside the nucleus, they help start cell growth.

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

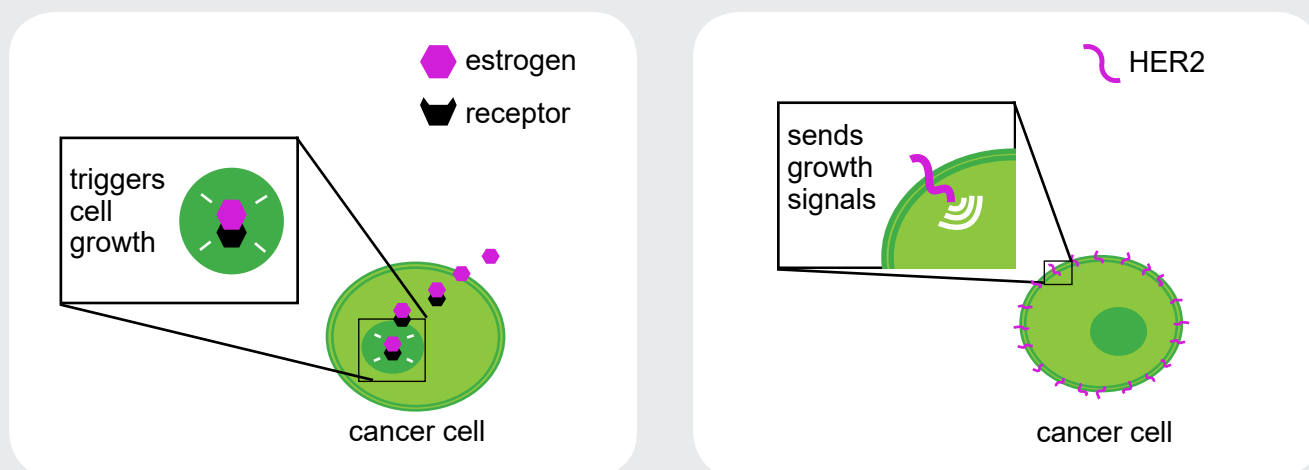
Hormone receptor–negative breast cancer consists of fewer cells with hormone receptors. These cancers are sometimes simply called hormone negative. Hormone-negative cancers often grow faster than hormone-positive cancers.

HER2

HER2 (human epidermal growth factor receptor 2) is on the surface of breast cells. When turned on, it causes cells to grow and divide. **See Figure 6.** Normal breast cells have two copies of the gene that makes HER2. They also have a normal number of HER2 on the cell surface.

Figure 6. Key receptors in breast cancer

Hormone and HER2 receptors help breast cancer 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 right cancer treatment is received.



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In contrast to normal cells, some breast cancers have cells with more than two *HER2* genes. Too many genes produce too many HER2. Other breast cancers have cells with two *HER2* genes but still too many 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 many HER2. ISH (in situ hybridization) counts the number of copies of the *HER2* gene.

BRCA tests

Everyone has genes called *BRCA1* and *BRCA2*. Normal *BRCA* genes help to prevent tumor growth. They help fix damaged cells and help cells grow normally. Mutations in these genes increase the risk of breast and some other cancers. Mutated *BRCA* genes can also affect how well some treatments work.

Your doctor may order a test of *BRCA1* and *BRCA2* if you have HER2-negative metastatic breast cancer. These tests do not need to be repeated if done before. They require a blood or saliva sample.

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 (variants of unknown significance), 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.

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.

Review

- A medical history is a report of your health problems and treatment during your lifetime. You will also be asked about health problems among your close blood relatives.
- Your doctor will assess your body for signs of disease. He or she will touch parts of your body, including your breasts, to see if anything feels abnormal.
- Blood tests may be done to look for signs of cancer outside of your breast.
- Imaging tests make pictures of the insides of your body. Your doctor will be able to see inside your body without cutting into it.
- During a biopsy, tissue or fluid samples are removed for testing. Samples are needed to confirm the presence of cancer and to perform cancer cell tests.
- Some breast cancers consist of cells with too many hormone receptors, HER2s, or both. These features are used to plan treatment.
- Genetic counseling may help you decide whether to be tested for hereditary breast cancer.



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

Treatment guide

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Based on the test results, your treatment can be tailored to you. This chapter presents treatment options based on features of the cancer. It also explains how results of treatment are assessed.

Overview

Treatment of metastatic breast cancer includes treatment of the cancer and support for you. Read this section to learn about treatment and supportive care.

Systemic vs. local therapy

Metastatic breast cancer is unlikely to be cured. Instead, long-term cancer control is often achieved with systemic therapy. Systemic therapy affects all cancer in the body. Medical oncologists are cancer doctors trained to use systemic therapy.

Surgery and radiation therapy are local treatments. They treat cancer in one spot. It is unknown if surgery helps to prolong life in people with metastatic breast cancer. There is ongoing research. The best time to have surgery is also being studied.

Clinical trials

One of your treatment options may be 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 can't usually be received. Ask your treatment team if there is an open clinical trial that you can join.



SNAPSHOT

Treatment

- ✓ Can often control metastatic breast cancer for long periods of time
- ✓ Consists of systemic therapy, which affects cancer throughout the body
- ✓ May be received within a clinical trial
- ✓ May involve a series of different types
- ✓ Can cause unwanted health issues that may be prevented or relieved by supportive care

Treatment approach

The treatment approach for metastatic cancer is to use one treatment after another. A treatment is used until it stops working or side effects get too bad. Then another treatment is started. This approach is followed until you want to stop or there are no options. This allows long-term cancer control for many women.

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.

Cancer complications

Metastatic breast cancer can cause a range of health problems. For example, it can stop organs from working as they should. When in the bone, it can cause fractures, pain, and high calcium levels.

Your doctor will tailor supportive care to your health issues. Some women receive surgery and radiation therapy to relieve cancer symptoms. If the cancer has spread to your bones, denosumab (Xgeva™), zoledronic acid (Zometa®), or pamidronate (Aredia®) may prevent bone problems. These drugs are often taken with calcium and vitamin D.

Treatment side effects

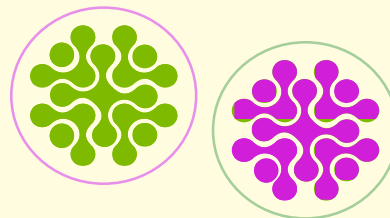
All cancer treatments can cause unwanted health issues. Such health issues are called side effects. Side effects depend on many factors. These factors include the drug type and dose, length of treatment, and the person. Some side effects may be harmful to your health. Others may just be unpleasant.

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.



I could focus on the lifetime of treatments or I could focus on my life in-between treatments. That's my struggle.

– Rosalie



Treatment options by cell receptor type

There are many treatments for metastatic breast cancer. Which ones are right for you are based on many factors. Two important factors are the hormone receptor and HER2 status.

- ✓ Endocrine therapy stops cancer growth caused by hormones. It is a standard treatment for hormone-positive cancers.
- ✓ CDK4/6 inhibitors and mTOR inhibitors are targeted therapies for hormone-positive, HER2-negative cancers.
- ✓ HER2-targeted therapy is a standard treatment for HER2-positive cancers.
- ✓ Chemotherapy includes drugs that disrupt the life cycle of cancer cells. It is often the first treatment for hormone-negative cancers and sometimes first used for hormone-positive cancers.
- ✓ PARP inhibitors may help *BRCA1/2*-positive, hormone- and HER2-negative (triple negative) cancer cells die.

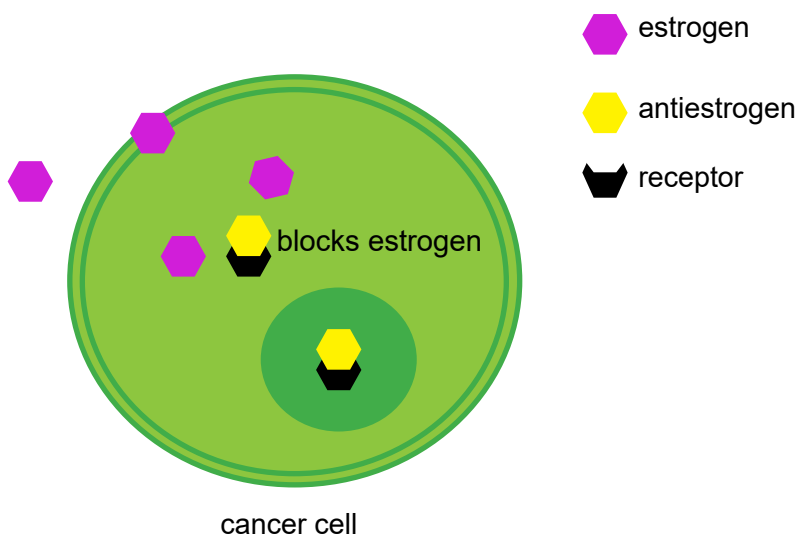
Endocrine therapy

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. There are five main types of endocrine therapy.

- **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.
- **Antiestrogens** stop hormone receptors. **See Figure 7.** SERMs (selective estrogen receptor modulators) block estrogen from attaching to hormone receptors. They include tamoxifen and toremifene (Fareston®). SERDs (selective estrogen receptor degraders) block and destroy estrogen receptors.
- **Hormones** may treat breast cancer when taken in high doses. It is not known how hormones stop breast cancer from growing. Hormones are not often used for treatment. They include ethinyl estradiol, fluoxymesterone, and megestrol acetate.

Figure 7
Antiestrogens

Antiestrogens are drugs that stop the effect of estrogen on cancer cell growth. There are two types—SERMs and SERDs. Both block estrogen from attaching to its receptor and starting cell growth. SERDs also help to destroy the receptor.



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Hormone-positive cancer

Your doctor may first prescribe chemotherapy if the cancer is spreading fast. It works faster than endocrine therapy. Next, you may receive endocrine therapy, which is often less toxic.

As shown in [Guides 2 and 3](#), 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 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.

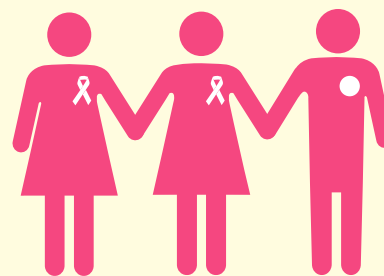
Premenopause

In premenopause, your ovaries are the main source of estrogen and progesterone. Ovarian ablation or suppression will greatly reduce these hormones to postmenopause levels. Adding treatment for postmenopause will stop estrogen that is made from other body parts. Instead of combined treatment, your first treatment may be a SERM.

Postmenopause

In postmenopause, your adrenal glands, liver, and body fat make small amounts of estrogen. An aromatase inhibitor is often the first treatment. Other options are antiestrogens and hormones.

If an endocrine therapy stops working, your doctor may prescribe another type. Chemotherapy may be another option. Chemotherapy may also be started when the cancer within internal organs causes symptoms.

**Men with breast cancer**

One out of every 100 breast cancers occurs in men. Men with breast cancer are treated much like women. One important difference is treatment with endocrine therapy. Your options are the same as for women in postmenopause. However, aromatase inhibitors should be taken with a treatment that stops the making of testosterone by your testes. Aromatase inhibitors alone won't stop hormone-related cancer growth.

Hormone-negative cancer

Endocrine therapy is very rarely used. It may be tried for breast cancer that has spread only to the bones or soft tissue only. Examples of soft tissue include muscle, fat, and lymph nodes.

Endocrine therapy may also be an option if the breast cancer is in the internal organs. But, the cancer must not be causing symptoms. Examples of internal organs are the liver, brain, and lungs.

Guide 2. Treatment for hormone-positive, HER2-negative cancer

No endocrine therapy in past year

Menopause status	What are the options?
Either	<ul style="list-style-type: none"> For fast-spreading cancers, maybe chemotherapy listed in Guide 5 first
Premenopause	<ul style="list-style-type: none"> Ovarian ablation or suppression + treatment for postmenopause SERM
Postmenopause	<ul style="list-style-type: none"> Aromatase inhibitor SERM or SERD CDK4/6 inhibitor + aromatase inhibitor

Took endocrine therapy in past year

Menopause status	What are the options?
Either	<ul style="list-style-type: none"> For fast-spreading cancers, maybe chemotherapy listed in Guide 5 first
Premenopause	<ul style="list-style-type: none"> Ovarian ablation or suppression + treatment for postmenopause
Postmenopause	<ul style="list-style-type: none"> For some women, a different endocrine therapy (± CDK4/6 or mTOR inhibitor)

CDK4/6 inhibitors

CDK (cyclin-dependent kinase) is a cell protein that helps cells grow and divide. For hormone-positive, HER2-negative cancer, taking a CDK4/6 inhibitor with endocrine therapy helps control the cancer longer. CDK4/6 inhibitors include palbociclib (Ibrance®), ribociclib (Kisqali®), and abemaciclib (Verzenio™).

For postmenopausal women on first-line endocrine therapy, a CDK4/6 inhibitor with an aromatase inhibitor is an option. [See Guide 2](#). For premenopausal women, ribociclib with tamoxifen and ovarian suppression may be an option, too. If the cancer worsens, there is no research to support staying on a CDK4/6 inhibitor for second-line treatment.

If not part of first-line treatment, a CDK4/6 inhibitor may be added to second-line fulvestrant. A second-

line aromatase inhibitor with a CDK4/6 inhibitor may also be an option. In some cases, abemaciclib alone may be received if the cancer worsens after endocrine therapy and chemotherapy.

mTOR inhibitors

mTOR is a cell protein that helps cells grow and divide. Endocrine therapy may stop working because mTOR becomes overactive. mTOR inhibitors may allow treatment to work again.

As listed in [Guide 2](#), an mTOR inhibitor may be taken with second- or later-line endocrine therapy. Everolimus (Afinitor®) is the only available drug of this type. Most often, it is taken with exemestane. For some women, it may be taken with fulvestrant or tamoxifen. If the cancer worsens, there is no research to support staying on everolimus.

Guide 3. Treatment for hormone-positive, HER2-positive cancer

No endocrine therapy in past year

Menopause status	What are the options?
Premenopause	• Ovarian ablation or suppression + treatment for postmenopause
	• SERM ± HER2-targeted therapy
	• HER2-targeted therapy ± chemotherapy as listed in Guide 4
Postmenopause	• Aromatase inhibitor ± HER2-targeted therapy
	• SERM ± HER2-targeted therapy or SERD ± HER2-targeted therapy
	• HER2-targeted therapy ± chemotherapy as listed in Guide 4

Took endocrine therapy in past year

Menopause status	What are the options?
Premenopause	• Ovarian ablation or suppression + treatment for postmenopause
	• HER2-targeted therapy ± chemotherapy listed in Guide 4
Postmenopause	• For some women, a different endocrine therapy (± HER2-targeted therapy with or without chemotherapy as listed in Guide 4)
	• HER2-targeted therapy ± chemotherapy as listed in Guide 4

HER2-targeted therapy

HER2-targeted therapy uses HER2s to treat HER2-positive cancer. Most often, this treatment is given with chemotherapy. But, it is also sometimes used alone or with endocrine therapy. HER2-targeted therapies include:

- **HER2 antibodies** prevent growth signals from HER2 from outside the cell. **See Figure 8.** They also increase the attack of immune cells on cancer cells. These drugs include trastuzumab (Herceptin®) and pertuzumab (Perjeta®).
- **HER2 inhibitors** stop growth signals from HER2 from within the cell. Lapatinib (Tykerb®) is the only approved drug of this type.

- **HER2 conjugates** deliver cell-specific chemotherapy. They attach to HER2s then enter the cell. Once inside, chemotherapy is released. Ado-trastuzumab emtansine (Kadcyla®) is the only approved drug of this type.

Hormone-positive, HER2-positive cancer

Adding HER2-targeted therapy to endocrine therapy may better control cancer growth. More research is needed. [See Guide 3.](#) An aromatase inhibitor with trastuzumab, lapatinib, or both is an option. Another option is trastuzumab with tamoxifen or fulvestrant.

Instead of endocrine therapy, HER2-targeted therapy with chemotherapy or alone is also an option. Combined treatment works well. It works faster than

endocrine therapy, but severe side effects are more likely.

Some women need to switch chemotherapies. Keep taking HER2-targeted therapy with the new chemotherapy. Research has shown HER2 therapy still helps.

Hormone-negative, HER2-positive cancer

As shown in [Guide 4](#), preferred regimens include both trastuzumab and pertuzumab with taxane chemotherapy. Other regimens include ado-trastuzumab emtansine, HER2-targeted therapy with other types of chemotherapies, and HER2-targeted therapy alone.

Some women need to switch chemotherapies. Keep taking HER2-targeted therapy with the new chemotherapy. Research has shown HER2 therapy still helps.

Guide 4. Treatment for hormone-negative, HER2-positive cancer

Preferred regimens

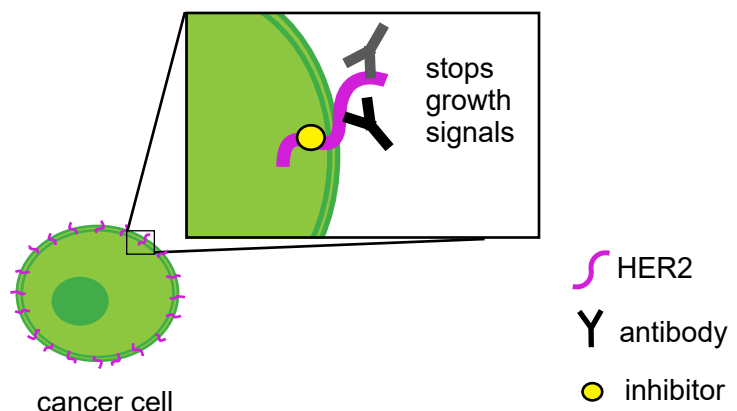
- Trastuzumab + pertuzumab + docetaxel
- Trastuzumab + pertuzumab + paclitaxel

Other regimens

- Ado-trastuzumab emtansine
- Trastuzumab + paclitaxel ± carboplatin
- Trastuzumab + docetaxel
- Trastuzumab + vinorelbine
- Trastuzumab + capecitabine
- Lapatinib + capecitabine
- Trastuzumab + lapatinib
- Trastuzumab + other types of chemotherapy

Figure 8 HER2 antibodies and inhibitors

Antibodies are Y-shaped proteins that are made by your body to help fight illness. HER2 antibodies are human-made antibodies. They attach to the HER2 on the outside of the cell, which prevents growth signals from starting. HER2 inhibitors attach to HER2 inside the cell and stop growth signals.



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Chemotherapy

Chemotherapy works by stopping the cell life cycle. A cell goes through many changes to divide into two cells. Science has grouped these changes into 7 main phases. There may be another phase of rest, too. Some chemotherapy drugs work in any phase. Other chemotherapy drugs work in one or two growth phases. The types of chemotherapy are grouped by the way they stop the cell life cycle.

- **Alkylating agents** damage DNA by adding a chemical to it. These drugs include carboplatin, cisplatin (Platinol®), and cyclophosphamide.
- **Anthracyclines** damage and disrupt the making of DNA. These drugs include doxorubicin, doxorubicin liposomal injection (Doxil®), and epirubicin (Ellence®).
- **Antimetabolites** prevent the “building blocks” of DNA from being used. These drugs include capecitabine (Xeloda®), fluorouracil, gemcitabine (Gemzar®), and methotrexate.
- **Microtubule inhibitors** stop a cell from dividing into two cells. These drugs include docetaxel (Taxotere®), eribulin (Halaven™), ixabepilone (Ixempra® Kit), paclitaxel (Taxol®, Abraxane®), and vinorelbine (Navelbine®). Docetaxel and paclitaxel are also called taxanes.

If you're still premenopausal, 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”).

Hormone-negative or -positive, HER2-positive cancer

As listed in [Guide 4](#), a taxane with both HER2 antibodies is the preferred treatment. This treatment extends life the most. If taxanes aren't an option, ado-trastuzumab emtansine or other options may be used instead. In general, HER2 inhibitors with anthracycline should be avoided. This treatment can harm your heart.

Some women need to change their treatment. A regimen may stop working or may cause severe side effects. Discuss your options with your doctor. Your options may include another regimen, a clinical trial, or supportive care.

Hormone-negative, HER2-negative cancer

This cancer is also called triple-negative breast cancer. In [Guide 5](#), single agents are grouped into preferred and other agents. These groups are based on how well the drug works, side effects, and treatment schedules.

Combination regimens are also listed. They do not usually work better than using single agents one after another. They also have worse side effects. But, they can work faster. Most combined regimens consist of only chemotherapy. Paclitaxel with bevacizumab—a targeted therapy—is also an option in certain cases.

Some women need to change their treatment. A regimen may stop working or may cause severe side effects. Discuss your options with your doctor. Your options may include another regimen, a clinical trial, or supportive care.

Guide 5. Treatment for hormone-negative, HER2-negative cancer (AKA triple-negative)

Preferred single agents

- Doxorubicin
- Paclitaxel
- Gemcitabine
- Eribulin
- Liposomal doxorubicin
- Capecitabine
- Vinorelbine
- Olaparib if *BRCA1/2* mutations

Other single agents

- Cyclophosphamide
- Docetaxel
- Cisplatin
- Ixabepilone
- Carboplatin
- Albumin-bound paclitaxel
- Epirubicin

Other combination regimens

- AC (doxorubicin + cyclophosphamide)
- EC (epirubicin + cyclophosphamide)
- CMF (cyclophosphamide + methotrexate + fluorouracil)
- Docetaxel + capecitabine
- GT (gemcitabine + paclitaxel)
- Gemcitabine + carboplatin
- Paclitaxel + bevacizumab

PARP inhibitors

Cancer cells often become damaged. PARP is a cell protein that repairs damaged cells and allows them to survive. Among people with inherited *BRCA1/2* mutations, damaged breast cancer cells are not good at repairing themselves. Blocking PARP in these cancer cells results in their death.

Olaparib (Lynparza®) is a PARP inhibitor. As listed in [Guide 5](#), it may be an option for some women. You must have an inherited *BRCA1/2* mutation. The breast cancer must be HER2 negative.

Checking treatment results

Your doctor will want to know how well treatment is working. The cancer might improve (response). It may stay the same (stable disease). It could also worsen (progression).

Cancer progression occurs because treatment doesn't work. Treatment may not work from the start. Other times, treatment works at first but then stops working. This is called drug resistance. Resistance to endocrine therapy occurs often.

Different types of tests are used to check treatment results. Some assess the status of cancer. Others assess for side effects of treatment.

Testing

Guide 6 lists the types and frequency of tests that are advised by NCCN experts. How often these tests are given may differ based on how well treatment is working.

Your doctor will ask you about any new or worse symptoms. He or she will also perform a physical exam and measure your body weight.

Your state of general health will be rated using a performance status scale. The two scales commonly used are the ECOG (**E**astern **C**ooperative **O**ncology **G**roup) Performance Scale and the KPS (**K**arnofsky **P**erformance **S**tatus). For either scale, your doctor will choose a score that best represents your health.

Blood samples will need to be drawn to perform three tests. CBC is used to assess the extent of cancer growth within bones. Liver function tests are used to assess the extent of cancer growth within the liver and other organs.

Your blood may also be tested for proteins that can indicate whether treatment is working. These proteins are called tumor markers. Examples of tumor markers include CEA (carcinoembryonic antigen),

Guide 6. Testing schedule

	Before new treatment	During endocrine therapy	During chemotherapy	Signs of cancer progression
Symptoms	Yes	Every 1–3 months	Before each cycle	Yes
Physical exam	Yes	Every 1–3 months	Before each cycle	Yes
Weight	Yes	Every 1–3 months	Before each cycle	Yes
Performance status	Yes	Every 1–3 months	Before each cycle	Yes
CBC	Yes	Every 1–3 months	Before each cycle	Yes
Liver function tests	Yes	Every 1–3 months	Before each cycle	Yes
CT scan	Yes	Every 2–6 months	Every 2–4 cycles	Yes
Bone scan	Yes	Every 4–6 months	Every 4 cycles	Yes
PET/CT scan	It's an option	It's an option	It's an option	It's an option
Tumor markers	It's an option	It's an option	It's an option	It's an option

CA 15-3 (cancer antigen 15-3), and CA 27.29 (cancer antigen 27.29).

An increase in tumor markers doesn't always mean that the cancer has progressed. Your doctor will look for rising levels across a series of tests. Tumor markers may be more helpful than imaging tests when metastases are mainly in bone.

Three imaging tests may be used to check treatment results. CT with contrast of your chest, abdomen, and pelvis and a bone scan are advised. PET/CT is an option. These scans can show larger or new areas of cancer.



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

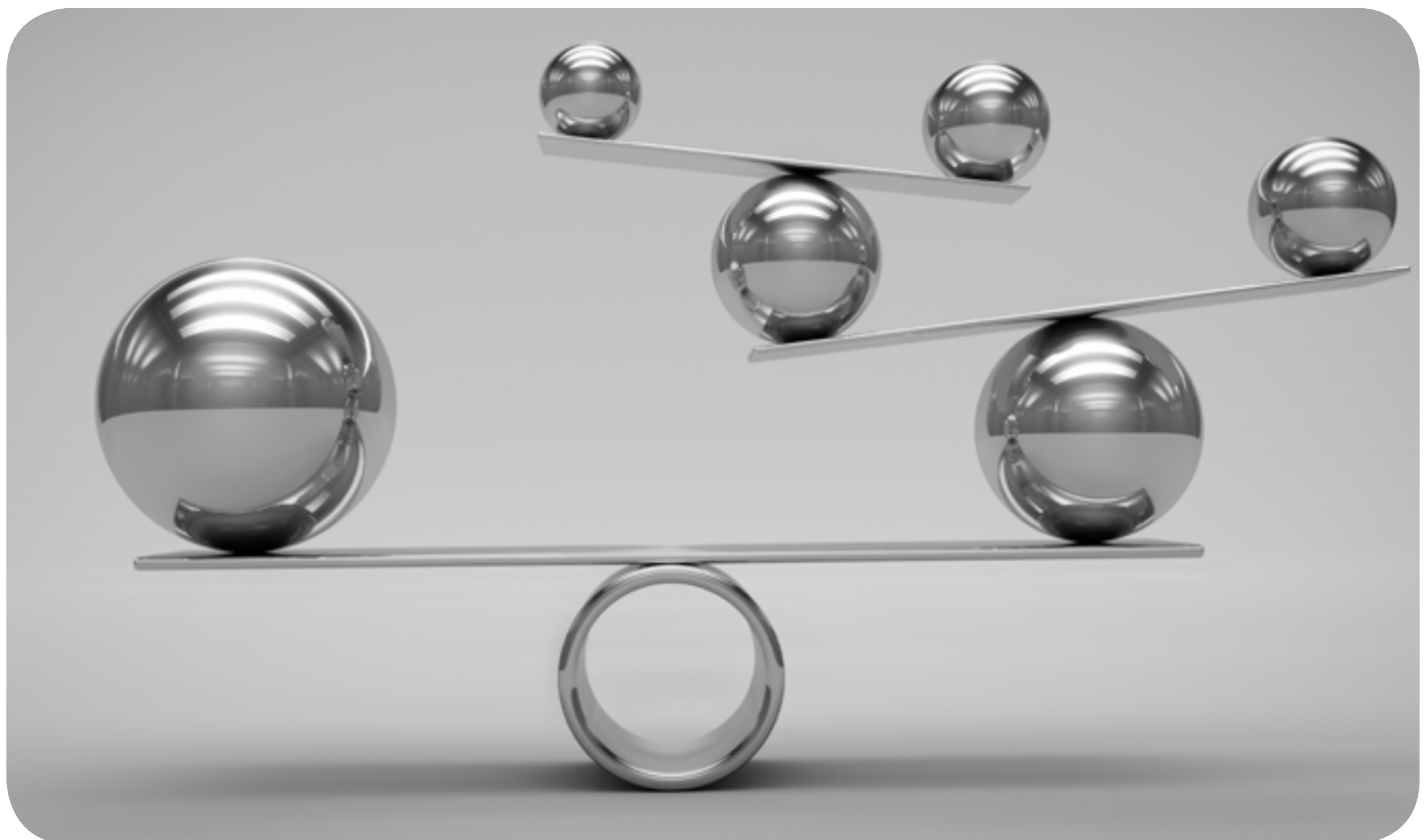
Review

- The treatment approach for metastatic breast cancer is to use a whole-body treatment until it doesn't work and then use another. This allows long-term cancer control for many women.
- Clinical trials give people access to new tests and treatments that they otherwise can't receive.
- Hormone-positive cancers are often well controlled with endocrine therapy. Targeted therapies (ie, CDK4/6, mTOR, HER2 inhibitors, HER2 antibodies) are often part of treatment. Instead of endocrine therapy, fast-growing cancers may be treated with chemotherapy.
- Hormone-negative cancers are usually treated with chemotherapy. For HER2-positive cancers, HER2-targeted therapy should also be part of treatment.
- Regular testing during treatment is needed to check treatment results.

4

Making treatment decisions

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- 35 Questions to ask
- 40 Deciding between options
- 41 Websites
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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 3 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. Prepare questions before your visit and ask questions if the person isn't clear. You can take notes 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 take notes. 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

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 my metastatic disease? 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 patients. 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 patients 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, a DVD of 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.

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, attending support groups, and comparing benefits and downsides may help you decide which treatment is best for you.

Glossary

43 Dictionary

45 Acronyms

Dictionary

areola

A darker, circular area of skin on the breast surrounding the nipple.

aromatase inhibitor

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

bilateral oophorectomy

A surgery that removes both ovaries.

biopsy

Removal of small amounts of tissue or fluid to be tested for disease.

cancer stage

Rating of the growth and spread of tumors.

carcinoma

Cancer that starts in cells that form the lining of organs and structures in the body.

clinical breast exam

A physical exam of the breasts by a health professional to feel for disease.

clinical trial

Research on a test or treatment to assess its safety or how well it works.

computed tomography (CT)

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

connective tissue

Supporting and binding tissue that surrounds other tissues and organs.

contrast

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

duct

A tube in the breast that drains breast milk.

endocrine therapy

Treatment that stops the making or action of hormones in the body. Also called hormone therapy.

estrogen

A hormone that develops female body traits.

estrogen receptor

A protein inside of cells that binds with estrogen.

gene

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

genetic counseling

Discussion with a health expert about the risk for a disease caused by changes in genes.

hereditary breast cancer

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

hormone

Chemical in the body that activates 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 send signals for the cell to grow.

immunohistochemistry (IHC)

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

invasive breast cancer

Cancer cells have grown into the supporting tissue of the breast.

kinase inhibitor

A cancer drug that blocks the transfer of phosphase.

liver function test

A test that measures chemicals made or processed by the liver.

lobule

A gland in the breast that makes breast milk.

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

Small groups of special disease-fighting cells located throughout the body.

magnetic resonance imaging (MRI)

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

medical history

All health events and medications taken to date.

medical oncologist

A doctor who's an expert in cancer drugs.

menopause

The point in time when menstrual periods end.

metastasis

The spread of cancer beyond the breast and nearby lymph nodes to distant sites like bone, lung, liver, or brain.

mutation

An abnormal change in the instructions in cells for making and controlling cells.

noninvasive breast cancer

Cancer cells have not grown into the supporting tissue of the breast.

ovarian ablation

Methods used to stop the ovaries from making hormones.

ovarian suppression

Methods used to lower the amount of hormones made by the ovaries.

pathologist

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

performance status

A rating of general health.

physical exam

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

positron emission tomography (PET)

Use of radioactive material to see the shape and function of body parts.

postmenopause

The state of the end of menstrual periods.

premenopause

The state of having regular menstrual periods.

primary tumor

The first mass of cancer cells in the body.

progesterone

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

prognosis

The expected pattern and outcome of a disease based on tests.

puberty

The time when teens sexually develop.

radiation therapy

The use of high-energy rays to destroy cancer cells.

selective estrogen receptor down-regulator (SERD)

Cancer drug that blocks the effect of estrogen.

selective estrogen receptor modulators (SERM)

Cancer drug that blocks the effect of estrogen.

side effect

An unhealthy physical or emotional response to treatment.

stroma

Fatty tissue of the breast.

supportive care

Treatment for the symptoms or health conditions caused by cancer or cancer treatment.

systemic therapy

Treatment of cancer throughout the body.

triple-negative breast cancer

Breast cancer that is not hormone-positive or HER2-positive.

Acronyms

AJCC

American Joint Committee on Cancer

CA

cancer antigen

CBC

complete blood count

CDK

cyclin-dependent kinase

CEA

carcinoembryonic antigen

CT

computed tomography

DNA

deoxyribonucleic acid

ECOG

Eastern Cooperative Oncology Group

FDG

fluorodeoxyglucose

HER2

human epidermal growth factor receptor 2

IHC

immunohistochemistry

ISH

in situ hybridization

LHRH

luteinizing hormone-releasing hormone

KPS

Karnofsky Performance Status

mTOR

mammalian target of rapamycin

NCCN®

National Comprehensive Cancer Network®

MRI

magnetic resonance imaging

PET

positron emission tomography

PET/CT

positron emission tomography/computed tomography

SERD

selective estrogen receptor degrader

SERM

selective estrogen receptor modulator

VUS

variants of unknown significance

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Massachusetts General Hospital
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877.332.4294
dfbwc.org
massgeneral.org/cancer

Duke Cancer Institute
Durham, North Carolina
888.275.3853
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Fox Chase Cancer Center
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foxchase.org

Huntsman Cancer Institute
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Salt Lake City, Utah
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Fred Hutchinson Cancer
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Mayo Clinic Cancer Center
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Rochester, Minnesota
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904.953.0853 • Florida
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www.mayoclinic.org/cancercenter

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New York, New York
800.525.2225
mskcc.org

Moffitt Cancer Center
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800.456.3434
moffitt.org

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

Roswell Park Comprehensive
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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
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877.668.7535
cancer.stanford.edu

University of Alabama at Birmingham
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UC San Diego Moores Cancer Center
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University of Colorado Cancer Center
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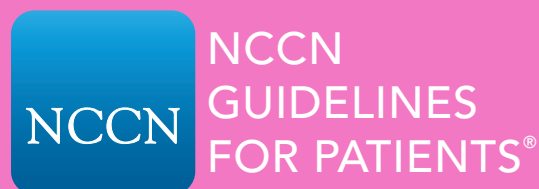
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