It's easy to get lost in the cancer world

Let NCCN Guidelines for Patients® be your guide

✓ Step-by-step guides to the cancer care options likely to have the best results
✓ Based on treatment guidelines used by health care providers worldwide
✓ Designed to help you discuss cancer treatment with your doctors
NCCN Guidelines for Patients® are developed by the National Comprehensive Cancer Network® (NCCN®)

NCCN®

- An alliance of leading cancer centers across the United States devoted to patient care, research, and education

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NCCN Clinical Practice Guidelines in Oncology (NCCN Guidelines®)

- Developed by doctors from NCCN cancer centers using the latest research and years of experience
- For providers of cancer care all over the world
- Expert recommendations for cancer screening, diagnosis, and treatment

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- Present information from the NCCN Guidelines in an easy-to-learn format
- For people with cancer and those who support them
- Explain the cancer care options likely to have the best results

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and supported by funding from NCCN Foundation®

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NCCN Foundation® seeks to support the millions of patients and their families affected by a cancer diagnosis by funding and distributing NCCN Guidelines for Patients®. NCCN Foundation is also committed to advancing cancer treatment by funding the nation’s promising doctors at the center of innovation in cancer research. For more details and the full library of patient and caregiver resources, visit NCCN.org/patients.

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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 Patients: Metastatic 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

Breastcancer.org
Breastcancer.org is a leading resource for people to make sense of the complex medical and personal information about breast health and breast cancer. Our mission is to engage, educate, and empower people with expert information and our dynamic peer support community to help everyone make the best decisions for their lives. breastcancer.org

DiepCFoundation
DiepCFoundation applauds the National Comprehensive Cancer Network (NCCN) for their ongoing work in the development of Patient Guidelines. We endorse the NCCN Guidelines for Patients: Metastatic Breast Cancer for patients seeking information about all options for breast reconstruction after cancer. The Principles of Breast Reconstruction Following Surgery in the NCCN Guidelines directly aligns with the mission of the Foundation to educate and empower more patients with the information needed to make an informed decision about breast reconstruction after surgical treatment for breast cancer. diepcfoundation.org

FORCE: Facing Our Risk of Cancer Empowered
As the nation’s leading organization serving the hereditary cancer community, FORCE is pleased to endorse the NCCN Guidelines for Patients: Metastatic 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

Sharsheret
Sharsheret is proud to endorse this important resource, the NCCN Guidelines for Patients: Metastatic 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

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• Benjamin Anderson, MD, in honor of Joan McClure
• Patricia Andrews
• Kristina Griffin
• Kate Townsend

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1 Breast cancer basics

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Ductal carcinoma in situ (DCIS) is a type of cancer of the cells that line the ducts. Ducts are thin tubes that carry milk in the breast. DCIS is stage 0 or noninvasive cancer. This means the cancerous cells are in place (in situ) and have not spread to other areas. DCIS is treated to prevent a more serious form of cancer.

The breast

The breast is an organ and a gland found on the chest. The breast is made of milk ducts, fat, nerves, lymph and blood vessels, ligaments, and other connective tissue. Behind the breast is the pectoral muscle and ribs. Muscle and ligaments help hold the breast in place.

Breast tissue contains glands that can make milk. These milk glands are called lobules. Lobules look like tiny clusters of grapes. Small tubes called ducts connect the lobules to the nipple.

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.

Lymph is a clear fluid that gives cells water and food. It also helps to fight germs. Lymph drains from breast tissue into lymph vessels and travels to lymph nodes near your armpit (axilla). Nodes near the armpit are called axillary lymph nodes (ALNs).
Ductal carcinoma in situ

Ductal carcinoma in situ (DCIS) is a type of cancer of the cells that line the ducts. Ducts are thin tubes that carry milk in the breast. DCIS is noninvasive. Noninvasive means the cancerous cells are in place (in situ) and have not spread. Anyone can have this kind of breast cancer, including men. Ductal carcinoma in situ is also called intra ductal carcinoma. You may hear that DCIS is preinvasive or pre-cancerous. DCIS is treated to prevent a more advanced form of cancer.

How breast cancer spreads

Cancer cells don’t behave like normal cells. Cancer cells differ from normal cells in the following ways.

- **Primary tumor**
  Over time, cancer cells form a mass called a primary tumor.

- **Invasive**
  Cancer cells can grow into surrounding tissues. Invasive breast cancer is breast cancer that has spread from the milk ducts or milk glands (lobules) into the breast tissue or nearby lymph nodes.

- **Metastasis**
  Unlike normal cells, cancer cells can spread and form tumors in other parts of the body. Cancer that has spread is called a metastasis. In this process, cancer cells break away from the first (primary) tumor and travel through blood or lymph vessels to distant sites. Once in other sites, cancer cells may form secondary tumors.

Axillary lymph nodes

Lymph is a clear fluid. It drains from breast tissue into lymph vessels where it travels to lymph nodes. Most of the breast lymph nodes are located near the armpit. These are called axillary lymph nodes.
Cancer stages

The American Joint Committee on Cancer (AJCC) created a way to determine how much cancer is in your body, where it is located, and what subtype of cancer you have. This is called staging. Based on testing, your cancer will be assigned a stage. Staging is needed to make treatment decisions.

Cancer staging is often done twice.

- **Clinical stage (c)** is the rating given before any treatment. It is based on a physical exam, biopsy, and imaging tests.
- **Pathologic stage (p)** or surgical stage is determined by examining tissue removed during an operation.

TNM scores

The tumor, node, metastasis (TNM) system is used to stage breast cancer. In this system, the letters T, N, and M describe different areas of cancer growth. Based on cancer test results, your doctor will assign a score or number to each letter. The higher the number, the larger the tumor or the more the cancer has spread. These scores will be combined to assign the cancer a stage. A TNM example might look like this: T2, N1, M1.

- **T (tumor)** - Size of the main (primary) tumor
- **N (node)** - If cancer has spread to nearby (regional) lymph nodes
- **M (metastasis)** - If cancer has spread to distant parts of the body or metastasized

Numbered stages

Number stages range from stage 1 to stage 4, with 4 being the most advanced. Doctors write these stages as stage I, stage II, stage III, and stage IV.

Stage 0 is noninvasive

Noninvasive breast cancer is rated stage 0. DCIS is found only in the ducts (Tis). It has not spread to the surrounding breast tissue, lymph nodes (N0) or distant sites (M0).

Stages 1, 2, and 3 are invasive

Invasive breast cancer is rated stage 1, 2, or 3. It has grown outside the ducts, lobules, or breast skin. Cancer might be in the axillary lymph nodes.

Stage 4 is metastatic

In stage 4 breast cancer, cancer has spread to distant sites. Your first diagnosis can be stage 4 metastatic breast cancer or it can develop from earlier stages.
Review

- Inside breasts are lobules, ducts, fat, blood and lymph vessels, ligaments, and connective tissue. Lobules are structures that make breast milk. Ducts carry breast milk from the lobules to the nipple.

- Breast cancer often starts in the ducts or lobules and then spreads into the surrounding tissue.

- Breast cancer that is found only in the ducts or lobules is called noninvasive. Ductal carcinoma in situ (DCIS) is found only in the ducts.

- Invasive breast cancer is cancer that has grown outside the ducts or lobules into surrounding tissue. Once outside the ducts or lobules, breast cancer can spread through lymph or blood to lymph nodes or other parts of the body.

- Metastatic breast cancer has spread to distant sites in the body.

- Anyone can have breast cancer, including men. Although there are some differences between men and women, treatment is very similar.
2 Testing for DCIS

12 General health tests
13 Fertility and birth control
14 Imaging tests
15 Tissue tests
16 Hormone receptor tests
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21 Review
Treatment planning starts with testing. This chapter presents an overview of the tests you might receive and what to expect.

General health tests

Medical history
A medical history is a record of all health issues and treatments you have had in your life. Be prepared to list any illness or injury and when it happened. Bring a list of old and new medicines and any over-the-counter medicines, herbs, or supplements you take. Tell your doctor about any symptoms you have. A medical history will help determine which treatment is best for you.

Family history
Some cancers and other diseases can run in families. Your doctor will ask about the health history of family members who are blood relatives. This information is called a family history. You can ask family members about their health issues like heart disease, cancer, and diabetes, and at what age they were diagnosed.

Physical exam
A physical exam is a study of your body. A doctor will check your body for signs of disease.

A health care provider may:

- Check your temperature, blood pressure, pulse, and breathing rate
- Weigh you
- Listen to your lungs and heart
- Look in your eyes, ears, nose, and throat
- Feel and apply pressure to parts of your body to see if organs are of normal size, are soft or hard, or cause pain when touched. Tell your doctor if you feel pain.
- Feel for enlarged lymph nodes in your neck and underarm. Tell the doctor if you have felt any lumps or have any pain.
- Complete a breast exam

Doctors should perform a thorough physical exam along with a complete health history. For recommended tests, see Guide 1.

Guide 1
Testing for DCIS

<table>
<thead>
<tr>
<th>Test</th>
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<td>Medical history and physical exam</td>
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<tr>
<td>Diagnostic mammogram</td>
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<td>Determine estrogen receptor (ER) status</td>
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<td>Genetic counseling if at risk for hereditary breast cancer</td>
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<tr>
<td>Breast MRI, as needed</td>
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</table>
Fertility and birth control

Treatment can affect your fertility or your ability to have children. If you think you want children in the future, ask your doctor how cancer and cancer treatment will change your fertility and sexual health.

In order to preserve your fertility, you may need to take action before starting cancer treatment. Those who want to have children in the future should be referred to a fertility specialist before starting treatment to discuss the options.

More information can be found in the NCCN Guidelines for Patients®: Adolescents and Young Adults with Cancer, available at NCCN.org/patientguidelines.

**Those with ovaries**
Those who can have children will have a pregnancy test before starting treatment. Cancer treatment can hurt the baby if you are or get pregnant during treatment. Therefore, birth control to prevent pregnancy during and after treatment is recommended. Hormonal birth control may not be recommended, so ask your doctor about options.

**Those with testicles**
Cancer and cancer treatment can damage sperm. Therefore, use contraception (birth control) to prevent pregnancy during and after cancer treatment. If you think you want children in the future, talk to your doctor now. Sperm banking is an option.

**Infertility**

Infertility is the complete loss of the ability to have children. The actual risk of infertility is related to your age at time of diagnosis, treatment type(s), treatment dose, and treatment length. Talk to your doctor about your concerns.
Imaging tests

Imaging tests take pictures of the inside of your body. These tests are used to find and treat DCIS. Imaging tests show the primary tumor, or where the cancer started, and look for cancer in other parts of the body.

A radiologist, an expert who looks at test images, will review test images and write a report. The radiologist will send this report to your doctor who will discuss the results with you. Feel free to ask as many questions as you like.

Diagnostic mammogram

A mammogram is a picture of the insides of your breast. The pictures are made using x-rays. A computer combines the x-rays to make detailed pictures.

Diagnostic mammograms look at specific areas of your breast which may not be clearly seen on screening mammograms. A bilateral mammogram includes pictures of both breasts. It is used to see if there is more than one tumor and the size of the tumor(s). Mammogram results are used to plan treatment. Other tests on your breast may be ultrasound or breast MRI.

Breast MRI

A magnetic resonance imaging (MRI) scan uses radio waves and powerful magnets to take pictures of the inside of the body. It does not use x-rays. If needed, an MRI would be used in addition to a mammogram.

In most cases, contrast material is used to improve the pictures of the inside of the body. Contrast materials are not dyes, but substances that help certain areas in the body stand out. Contrast is used to make the pictures clearer.

Tell your doctors if you have had bad reactions to contrast in the past. This is important. You might be given medicines, such as Benadryl® and prednisone, for an allergy to contrast. Contrast might not be used if you have a serious allergy or if your kidneys aren’t working well.

Breast MRI should be performed and interpreted by an expert breast imaging team working together with a multidisciplinary treatment team.

Ultrasound

An ultrasound uses high-energy sound waves to form pictures of the inside of the body. Ultrasound is good at showing small areas of cancer that are near the skin. Sometimes, an ultrasound or MRI is used to guide a biopsy.
Tissue 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 a sample of tissue or fluid. The sample is sent to a lab for testing. A pathologist will test the biopsy for cancer and write a report called a pathology report. Ask questions about your biopsy results and what it means for your treatment.

There are different types of biopsies. Some biopsies are guided using imaging, such as an ultrasound or MRI. The primary or main tumor is biopsied first. Other tumors or tumors in different areas may also be biopsied. You may have tissue removed from the breast, lymph nodes, or both.

Types of possible biopsies include:

- **Fine-needle aspiration (FNA)** uses a thin needle to remove a sample of tissue or fluid.
- **Core needle biopsy** removes tissue samples with a wide, hollow needle.
- **Incisional biopsy** removes a small amount of tissue through a cut in the skin or body.
**Sentinel lymph node biopsy**
A sentinel lymph node is the first lymph node that cancer cells are most likely to spread to from a primary tumor. Sometimes, there can be more than one sentinel lymph node. A sentinel lymph node biopsy (SLNB) is done during surgery such as a mastectomy (surgery to remove the breast) or or lumpectomy (surgery to remove the tumor) to determine if any cancer cells have traveled to the lymph nodes. The lymph nodes removed are called the sentinel nodes (SNB). They may or may not contain any cancer cells. It is also called a sentinel node biopsy (SNB).

To find the sentinel lymph nodes, a radioactive material and other dyes are injected into the body near the breast where they travel through the lymphatics in the breast to the lymph nodes. This helps the surgeon find the sentinel lymph nodes. Once the nodes are found, one is removed and tested by a pathologist. If cancer is found, more than one lymph node may be removed.

**Hormone receptor tests**
A hormone is a substance made by a gland in your body. Your blood carries hormones throughout your body. A receptor is a protein found inside or on the surface of a cell. Substances such as hormones attach (bind) to these receptors. This causes changes within the cell.

**Hormone receptors**
Hormones recognize and bind to specific hormone receptors.

There are 2 types of hormone receptors:

- **Estrogen** – plays a role in breast development
- **Progesterone** – plays a role in menstrual cycle and pregnancy

Once these hormones attach to receptors inside breast cancer cells, they can cause cancer to grow. If found, these receptors may be targeted for treatment using endocrine therapy.

**Immunohistochemistry**
Immunohistochemistry (said immunohistochemistry or IHC) is a special staining process that involves adding a chemical marker to cells. These cells are then studied using a microscope. IHC can find estrogen receptors in breast cancer cells. A pathologist will measure how many cells have estrogen receptors and the number of estrogen receptors inside each cell. Test results will either be estrogen receptor-positive (ER+) or estrogen receptor-negative (ER-).
**Testing for DCIS**

**Hormone receptor tests**

**Estrogen receptor-positive**
In estrogen receptor-positive (ER+) breast cancer, IHC finds estrogen hormone receptors in at least 1 out of every 100 cancer cells. ER+ cancer cells may need estrogen to grow. These cells may stop growing or die with treatment to block estrogen. Treatment to block estrogen is called endocrine therapy.

**Estrogen receptor-negative**
Estrogen receptor-negative (ER-) breast cancer cells do not have estrogen hormone receptors. These cancer cells do not need estrogen to grow and continue to grow despite treatment to block estrogen.

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**Pathology report**

All lab results are included in a pathology report. This report is sent to your doctor who will share the results with you. Ask for a copy of the report.

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**Hormone receptors**

Cells in the ovaries, testes, and adrenal glands secrete hormones. Hormones recognize and bind to specific hormone receptors.

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**Secreting cell**

**Target cell**

**Not a target cell** (no receptors)
Genetic tests

Anything that increases your chances of cancer is called a risk factor. Risk factors can be activities that people do, things you have contact with in the environment, or traits passed down from parents to children through genes (inherited or hereditary). Genes are coded instructions that tell your cells what to do and what to become. An abnormal change in these instructions—called a gene mutation—can cause cells to grow and divide out of control.

Genetics can increase the risk of breast cancer. Your disease or family history may suggest you have hereditary breast cancer. About 1 out of 10 breast cancers are hereditary.

Your health care provider might refer you for genetic testing to learn more about your risk of developing breast cancer and other cancers. A genetic counselor will speak to you about the results. A genetic counselor is an expert who has special training in genetic diseases and will explain your chances of having hereditary breast cancer.

Genetic counseling
Your genetic counselor or oncologist might recommend genetic testing. BRCA1 and BRCA2 gene mutations are related to breast cancer. Other genes may be tested as well. Tests results may be used to guide treatment planning.

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. BRCA1 and BRCA2 mutations put you at risk for more than one type of cancer. Mutations in BRCA1 or BRCA2 increase the risk of breast, ovarian, prostate, colorectal, and melanoma skin cancers. Mutated BRCA genes can also affect how well some treatments work. These tests do not need to be repeated if done before. They are done using blood or saliva (spitting into a cup).
Test results

Results from blood tests, imaging studies, and the biopsy will determine your treatment plan. It is important you understand what these tests mean. Ask questions and keep copies of your test results. Online patient portals are a great way to access your test results.

Whether you are going for a second opinion, test, or office visit, keep these things in mind:

- Bring someone with you to doctor visits. Encourage this person to ask questions and take notes. Perhaps, they can record the conversation with your doctor.
- Write down questions and take notes during appointments. Don’t be afraid to ask your care team questions. Get to know your care team and let them get to know you.
- Get copies of blood tests, imaging results, and reports about the specific type of cancer you have. It will be helpful when getting a second opinion.
- Organize your papers. Create files for insurance forms, medical records, and test results. You can do the same on your computer.
- Keep a list of contact information for everyone on your care team. Add it to your binder or notebook. Hang the list on your fridge or keep it by the phone.

Create a medical binder

A medical binder or notebook is a great way to organize all of your records in one place.

- Make copies of blood tests, imaging results, and reports about your specific type of cancer. It will be helpful when getting a second opinion.
- Choose a binder that meets your needs. Consider a zipper pocket to include a pen, small calendar, and insurance cards.
- Create folders for insurance forms, medical records, and tests results. You can do the same on your computer.
- Use online patient portals to view your test results and other records. Download or print the records to add to your binder.
- Organize your binder in a way that works for you. Add a section for questions and to take notes.
- Bring your medical binder to appointments. You never know when you might need it!
Treating breast cancer takes a team approach. Some members of your care team will be with you throughout cancer treatment, while others will only be there for parts of it. Get to know your care team and let them get to know you.

- **Your primary care doctor** handles medical care not related to your cancer. This person can help you express your feelings about treatments to your cancer care team.

- **A pathologist** reads tests and studies the cells, tissues, and organs removed during a biopsy or surgery.

- **A diagnostic radiologist** reads the results of x-rays and other imaging tests.

- **A surgical oncologist** or breast surgeon performs operations to remove cancer.

- **A medical oncologist** treats cancer in adults using systemic therapy. Often, this person will lead the overall treatment team and keep track of tests and exams done by other specialists.

- **Advanced practice providers** are an important part of any team. These are registered nurse practitioners and physician assistants who monitor your health and provide care.

- **Oncology nurses** provide your hands-on care, like giving systemic therapy, managing your care, answering questions, and helping you cope with side effects.

- **Nutritionists** can provide guidance on what foods or diet are most suitable for your particular condition.

- **Psychologists and psychiatrists** are mental health experts that can help manage issues such as depression, anxiety, or other mental health conditions that can affect how you feel.

Depending on your diagnosis, your team might include:

- **An anesthesiologist** who gives anesthesia, a medicine so you do not feel pain during surgery or procedures

- **An interventional radiologist** who performs needle biopsies of tumors

- **A radiation oncologist** who prescribes and plans radiation therapy to treat cancer

- **A plastic surgeon** who performs breast reconstruction for those undergoing mastectomy, if desired.

- **An occupational therapist** who helps people with the tasks of daily living

- **A physical therapist** who helps people move with greater comfort and ease

You know your body better than anyone. Help other team members understand:

- How you feel
- What you need
- What is working and what is not

Keep a list of names and contact information for each member of your team. This will make it easier for you and anyone involved in your care to know who to contact with questions or concerns.
Review

- Tests are used to find cancer, plan treatment, and check how well treatment is working.
- You will have a physical exam, including a breast exam, to see if anything feels or looks abnormal.
- Treatment can affect your fertility or your ability to have children.
- Imaging tests take pictures of the inside of your body.
- During a biopsy, tissue or fluid samples are removed for testing.
- Some breast cancers grow because of estrogen. If this is the case, you will probably take endocrine therapy to prevent the return of cancer.
- Genetic mutations can increase the risk of breast cancer. Your doctor might refer you for genetic testing or to speak with a genetic counselor.
- Treatment takes a team approach. Get to know your care team and let them get to know you.
3
Treating DCIS

23 Overview
23 Surgery
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27 Your treatment options
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DCIS is treated with surgery. It might be surgery to remove a lump (lumpectomy) or breast (mastectomy) with lymph node(s). Radiation therapy might follow. The goal of treatment is to prevent DCIS from progressing to invasive breast cancer. Together, you and your doctor will choose a treatment plan that is best for you.

Overview

Ductal carcinoma in situ (DCIS) is treatable. The goal of treatment is to prevent DCIS from progressing to breast cancer. Talk to your doctor about what to expect from treatment.

There are 2 types of treatment:

- **Local therapy** focuses on a certain area. It includes surgery and radiation therapy.
- **Systemic therapy** works throughout the body. It includes endocrine therapy.

**Birth control during treatment**

If you become pregnant during radiation therapy or endocrine therapy, it can cause serious birth defects. Use birth control without hormones. Condoms are an option. “The pill” is not. Speak to your doctor about preventing pregnancy while being treated for DCIS.

Those who want to have children in the future should be referred to a fertility specialist before starting endocrine therapy to discuss the options.

**Surgery**

Surgery is the main or primary treatment for DCIS. Surgery might be a lumpectomy or mastectomy. For a total mastectomy with reconstruction, surgery requires collaboration between a breast surgeon and the reconstructive (plastic) surgeon. Radiation therapy usually only follows after a lumpectomy. A lymph node biopsy is not done with a lumpectomy.

**Lumpectomy**

Lumpectomy is the removal of abnormal cells or tumor. It is also called breast-conserving therapy. In a lumpectomy, only the tumor area with a rim of normal tissue will be removed. The rest of your breast is left alone. Extra tissue is removed around the tumor to create a cancer-free area. This cancer-free area is called a surgical margin. Having a surgical margin will decrease the chance that cancer may return in that area of the breast. You may have more than one surgery to ensure all of the cancer was removed.

A lumpectomy is usually followed by radiation therapy to part of or the whole breast. A boost is extra radiation to the tumor area.

The breast might not look the same after a lumpectomy. Speak to your doctor about how a lumpectomy might affect the look and shape of your breast and what reconstruction options are available.
Mastectomy
A total mastectomy is a surgery that removes the whole breast. Chest muscle is not removed. This operation is also called a simple mastectomy. A skin-sparing mastectomy removes the breast but not all of the skin, in order to have reconstruction. Nipple-sparing mastectomy preserves the nipple areola complex as well. Not everyone is a candidate for nipple-sparing mastectomy.

Before removing the breast, the surgeon may do a sentinel lymph node biopsy (SLNB). Sentinel lymph nodes are the first place cancer cells are likely to have spread.

Breast reconstruction is an option after a mastectomy. It might be done at the same time as mastectomy (“immediate”) or at some time following the completion of cancer treatment (“delayed”). Breast reconstruction is often done in stages.

Radiation therapy
Radiation therapy (RT) uses high-energy radiation from x-rays, gamma rays, protons, and other sources to kill cancer cells and shrink tumors. It is given over a certain period of time. Radiation therapy is given to kill any remaining cancer cells. A boost is extra radiation to the tumor area.

Endocrine therapy
The endocrine system is made up of organs and tissues that produce hormones. Hormones are natural chemicals released into the bloodstream.

There are 4 hormones that might be targeted in endocrine therapy:

- Estrogen is made mainly by the ovaries
- Progesterone is made mainly by the ovaries
- Luteinizing hormone-releasing hormone (LHRH) is made by a part of the brain called the hypothalamus. It tells the ovaries to make estrogen and progesterone.
- Androgen is made by the adrenal glands, testicles, and ovaries.

Hormones can cause breast cancer to grow. Endocrine therapy will stop your body from making hormones or it will block what hormones do in the body. This can slow tumor growth or shrink the tumor for a period of time. In DCIS, endocrine therapy is used to prevent the return of cancer.

Endocrine therapy is sometimes called hormone therapy. It is not the same as hormone replacement therapy used for menopause.

The goal of endocrine therapy is to reduce the amount of estrogen or progesterone in your body.
There are 2 types of endocrine therapy that might be used for DCIS:

- **Aromatase inhibitors** stop a type of hormone called androgen from changing into estrogen by an enzyme called aromatase. 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.

- **Anti-estrogens** prevent hormones from binding to receptors. Selective estrogen receptor modulators (SERMs) block estrogen from attaching to hormone receptors. They include tamoxifen and toremifene (Fareston®). Selective estrogen receptor degraders (SERDs) block and destroy estrogen receptors. Fulvestrant (Faslodex®) is a SERD.

Those who want to have children in the future should be referred to a fertility specialist before starting endocrine therapy to discuss the options.

**Menopause**

Options for endocrine therapy are partly based on if you started or are in menopause. In menopause, the ovaries stop producing hormones and menstrual periods stop. After menopause, estrogen and progesterone levels continue to stay low.

When menstrual periods stop for 12 months or more, it is called postmenopause. If you don’t have periods, a test using a blood sample may be needed to confirm your status. If you have menstrual periods, you are in premenopause.

**Men with breast cancer**

1 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. The options are the same as for women in postmenopause. However, if men take aromatase inhibitors, they should also take a treatment to block testosterone. Aromatase inhibitors alone won’t stop hormone-related cancer growth in men.

**Premenopause**

In premenopause, your ovaries are the main source of estrogen and progesterone. Tamoxifen is the endocrine treatment for this group.

**Postmenopause**

In postmenopause, your adrenal glands, liver, and body fat make small amounts of estrogen. Tamoxifen or an aromatase inhibitor is the endocrine treatment for this group. Aromatase inhibitors include anastrozole, letrozole, and exemestane.
Clinical trials

Clinical trials study how safe and helpful tests and treatments are for people. Clinical trials find out how to prevent, diagnose, and treat a disease like cancer. Because of clinical trials, doctors find safe and helpful ways to improve your care and treatment of cancer.

Clinical trials have 4 phases.

- **Phase I trials** aim to find the safest and best dose of a new drug. Another aim is to find the best way to give the drug with the fewest side effects.
- **Phase II trials** assess if a drug works for a specific type of cancer.
- **Phase III trials** compare a new drug to a standard treatment.
- **Phase IV trials** evaluate a drug’s safety and treatment results after it has been approved.

To join a clinical trial, you must meet the conditions of the study. Patients in a clinical trial often are alike in terms of their cancer and general health. This helps to ensure that any change is from the treatment and not because of differences between patients.

If you decide to join a clinical trial, you will need to review and sign a paper called an informed consent form. This form describes the study in detail, including the risks and benefits. Even after you sign a consent form, you can stop taking part in a clinical trial at any time.

Ask your treatment team if there is an open clinical trial that you can join. There may be clinical trials where you’re getting treatment or at other treatment centers nearby. Discuss the risks and benefits of joining a clinical trial with your care team. Together, decide if a clinical trial is right for you.

NCCN experts encourage patients to join a clinical trial when it is the best option for the patient.

Finding a clinical trial

- Search the National Institutes of Health (NIH) database for clinical trials. It includes publicly and privately funded clinical trials, whom to contact, and how to enroll. Look for an open clinical trial for your specific type of cancer. Go to [ClinicalTrials.gov](https://clinicaltrials.gov).
- The National Cancer Institute’s Cancer Information Service (CIS) provides up-to-date information on clinical trials. You can call, e-mail, or chat live. Call 1.800.4.CANCER (800.422.6237) or go to [cancer.gov](https://www.cancer.gov).
Your treatment options

The goal of treatment is to prevent DCIS from growing outside the duct into surrounding tissue. When cancer spreads into the surrounding tissue, it is called invasive breast cancer. For more information on invasive breast cancer, read the NCCN Guidelines for Patients®: Breast Cancer – Invasive, available at nccn.org/patientguidelines.

Surgery is a central part of treatment for DCIS. Your wishes about treatment are important. Treatment options are found in Guide 2.

Guide 2
Treatment options: DCIS

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Option 1

**Lumpectomy with whole breast radiation therapy**

A lumpectomy is also called breast-conserving therapy.

A lumpectomy followed by radiation therapy is an option for many but not all with DCIS. This is not an option if you cannot get radiation because you are pregnant or have some health issues. The surgical margin must be cancer-free.

Most of your breast will be treated with radiation in whole breast radiation therapy (WBRT). Whole breast radiation will help to prevent the return of cancer. For every cancer that returns there is an equal chance of developing DCIS again or a more invasive type of cancer. Ask your doctor if your risk of the cancer coming back is low or high. If it’s high, you may receive extra radiation called a boost.

Option 2

**Total mastectomy with or without sentinel lymph node biopsy**

A total mastectomy is a surgery that removes the whole breast. Chest muscle is not removed. This operation is also called a simple mastectomy. A skin-sparing mastectomy removes the breast but not all the skin. Breast reconstruction is an option after a mastectomy.

Before removing the breast, the surgeon may do a sentinel lymph node biopsy (SLNB). Sentinel lymph nodes are the first place cancer cells are likely to have spread. An SLNB finds and removes a few of these nodes. The nodes are then tested for cancer. Once the breast is removed, an SLNB can’t be done. Instead, many lymph nodes would have to be removed to test for cancer. This is because a mastectomy permanently changes lymph flow and drainage. Therefore, if needed, an SLNB will be done at the time of a mastectomy, just in case there is a small area of invasive cancer in the breast.

There are many reasons why a total mastectomy might be the best choice.

- Cancer may be found at the surgical margin.
- The tumor might be large, too big, or widespread.
- You may be at risk for a second cancer.
- You might have a health issue.
- You may want a mastectomy.
- You may not be able to receive radiation to the breast area.

Option 3

**Lumpectomy with accelerated partial breast irradiation**

A lumpectomy is also called breast-conserving therapy. The tumor will be removed with negative surgical margins followed by radiation therapy (RT). When RT is given only to the lumpectomy site, it is called partial breast irradiation. Accelerated partial breast irradiation (APBI) therapy is a higher dose of radiation to a smaller area, given over a shorter period of time.
Option 4
Lumpectomy only

A lumpectomy is also called breast-conserving therapy.

Treatment with a lumpectomy only (no radiation) is an option for a small group of people. It is not done when there is cancer in the lymph nodes. Radiation therapy is not used either. You must have a very low risk of the cancer coming back. Surgical margins must be large and cancer-free. Ask your doctor if a lumpectomy without radiation is an option for you.

Radiation therapy

Radiation therapy uses high-energy radiation from x-rays, gamma rays, protons, and other sources to kill cancer cells and shrink tumors. It is also used to treat pain caused by cancers.
After-surgery treatment

After breast-conserving surgery
Breast-conserving surgery is a lumpectomy. It may or may not be followed by radiation therapy. For treatment after breast-conserving surgery, see Guide 3.

Endocrine therapy
Endocrine therapy includes treatments that stop cancer growth caused by hormones. It is sometimes called hormone therapy. It is not the same as hormone replacement therapy.

Your doctor will consider endocrine therapy. It may help prevent a second breast cancer in those who were treated with:

- Breast-conserving therapy (lumpectomy) with radiation therapy
- Lumpectomy alone

Endocrine therapy will be considered, especially if your cancer was estrogen receptor-positive (ER+). It is unknown how well endocrine therapy works if you had estrogen receptor-negative (ER-) cancer. Endocrine therapy has side effects.

There is more than one type of endocrine therapy. The type prescribed by doctors is partly based on if you have menstrual periods. If you still have menstrual periods, then you are considered to be in premenopause. If your menstrual periods have stopped for more than 12 months, they you are considered to be in postmenopause.

- For premenopause, tamoxifen is an option.
- For postmenopause, tamoxifen or an aromatase inhibitor is an option. An aromatase inhibitor might be preferred if you are less than 60 years of age or at risk for blood clots.

Guide 3
Treatment after breast-conserving surgery

Consider endocrine therapy for 5 years for:

- Those treated with breast-conserving therapy (lumpectomy) and radiation therapy, especially for those with ER+ (positive) DCIS.
- The benefit of endocrine therapy for ER- (negative) DCIS is uncertain
- Those treated with lumpectomy alone

Endocrine therapy:

- For pre-menopause, tamoxifen
- For post-menopause, tamoxifen or aromatase inhibitor
While taking endocrine therapy, you will have follow-up visits with your doctor. Tell your doctor about any new or worsening symptoms. There may be ways to get relief.

**Lowering your risk**
There are things you can do to lower your chance of breast cancer in the future. Changes in your lifestyle include eating a healthy diet, exercising, limiting alcohol, and quitting smoking. You will have counseling to learn how to lower your risk.

**Follow-up care**
Follow-up care is important for your long-term health. It is started after treatment ends. See Guide 4.

**Medical history and physical exam**
An update of your medical history and a physical exam are part of follow-up care. Both should be done every 6 to 12 months for 5 years. After 5 years of normal results, these tests should be done once a year.

---

**Guide 4**

**Follow-up care**

| Medical history and physical exam every 6 to 12 months for 5 years, then once a year |
| Mammogram every 12 months (If after breast-conserving treatment, then first mammogram will be in 6 to 12 months) |
Review

- Ductal carcinoma in situ (DCIS) is treatable. The goal of treatment is to prevent DCIS from progressing to invasive breast cancer. Invasive breast cancer is breast cancer that has spread from the milk ducts or milk glands (lobules) into the breast tissue or nearby lymph nodes. It is important to prevent invasive cancer, so there is no chance of breast cancer going to other parts of your body.

- Local therapy focuses on the breast and armpit (axilla) only. It includes surgery and radiation therapy.

- Systemic therapy works throughout the body. It includes endocrine therapy. Chemotherapy is not used to treat DCIS.

- Treatment for DCIS is usually a combination of surgery and radiation therapy followed by endocrine therapy.

- Lifestyle changes, endocrine therapy, and surgery help to prevent future breast cancer.

- Follow-up care includes medical history, physical exams, and mammograms.
4 Breast reconstruction

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- 35 Nipple replacement
- 36 Review
Breast reconstruction is surgery to rebuild the shape and look of the breast. In many cases, breast reconstruction involves a staged approach. It might require more than one procedure. This chapter offers more information on breast reconstruction.

Volume displacement

With a lumpectomy, most people have a scar with some volume loss, but are satisfied with the way their breast looks. However, if you need a large lumpectomy and your surgeon thinks your breast will look more abnormal afterwards, your breast can be re-shaped at the time of surgery. This procedure is called volume displacement. It is often done by the cancer surgeon right after the lumpectomy. The surgeon will shift the remaining breast tissue to fill the gap 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.

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 and flaps

Breasts can be 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. Reconstruction can also be done in a staged fashion, with part of the reconstruction done at the time of the original cancer surgery, and finished with another surgery at a later time. A plastic surgeon performs breast reconstruction.

Implants

Breast implants are small bags filled with salt water, silicone gel, or both. They are placed under the breast skin or muscle to look like a new breast. 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. When your skin is stretched to the proper size, you will have surgery to place the final implant.

Implants have a small risk of leaking or causing other issues. You may feel pain from the implant or expander. Scar tissue or tissue death can occur.
Breast reconstruction

Flaps
Breasts can be remade using tissue from your body, known as “flaps.” Flaps are taken from the belly area, butt, or from under the shoulder blade. Some flaps are completely removed and then sewn in place. Other flaps stay attached to your body but are slid over and sewn into place.

Flaps can cause problems. There may be tissue death which can cause lumps. A hernia may occur from muscle weakness. Problems are more likely to occur among those 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 remaining 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. It is important to note that while you can remake something to look like a nipple, it will not have the sensation of your real nipple.

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.
Review

- Breast reconstruction is surgery to rebuild the shape and look of the breast.
- Volume displacement is a shifting of the breast tissue to fill the gap left by a lumpectomy.
- Breasts that are fully removed can be remade with breast implants, flaps, or both.
- Removed nipples can be remade with body tissue.
5
Making treatment decisions

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It’s important to be comfortable with the cancer treatment you choose. This choice starts with having an open and honest conversation with your doctor.

It’s your choice

In shared decision-making, you and your doctors share information, discuss the options, and agree on a treatment plan. It starts with an open and honest conversation between you and your doctor.

Treatment decisions are very personal. What is important to you may not be important to someone else.

Some things that may play a role in your decisions:

- What you want and how that might differ from what others want
- Your religious and spiritual beliefs
- Your feelings about certain treatments like surgery or chemotherapy
- Your feelings about pain or side effects such as nausea and vomiting
- Cost of treatment, travel to treatment centers, and time away from work
- Quality of life and length of life
- How active you are and the activities that are important to you

Think about what you want from treatment. Discuss openly the risks and benefits of specific treatments and procedures. Weigh options and share concerns with your doctor. If you take the time to build a relationship with your doctor, it will help you feel supported when considering options and making treatment decisions.

Second opinion

It is normal to want to start treatment as soon as possible. While cancer can’t be ignored, there is time to have another doctor review your test results and suggest a treatment plan. This is called getting a second opinion, and it’s a normal part of cancer care. Even doctors get second opinions!

Things you can do to prepare:

- Check with your insurance company about its rules on second opinions. There may be out-of-pocket costs to see doctors who are not part of your insurance plan.
- Make plans to have copies of all your records sent to the doctor you will see for your second opinion.

Support groups

Many people diagnosed with cancer find support groups to be helpful. Support groups often include people at different stages of treatment. Some people may be newly diagnosed, while others may be finished with treatment. If your hospital or community doesn’t have support groups for people with cancer, check out the websites listed in this book.

Questions to ask your doctors

Possible questions to ask your doctors are listed on the following pages. Feel free to use these questions or come up with your own. Be clear about your goals for treatment and find out what to expect from treatment.
Questions to ask about diagnosis

1. Tell me more about this cancer. What should I think about now?

2. What tests do you recommend for me? Will I have any genetic tests?

3. What will you do to make me comfortable during testing?

4. What if I am pregnant or want to become pregnant?

5. How can I get a copy of the pathology report and other test results?

6. How soon will I know the results and who will explain them to me?

7. Who will talk with me about the next steps? When?

8. What can I do before my next appointment?
Questions to ask about options

1. What will happen if I do nothing?
2. How do my age, overall health, and other factors affect my options?
3. What if I am pregnant? What if I’m planning to get pregnant in the near future?
4. Which option is proven to work best?
5. Does any option offer a cure? What are the chances cancer will return with this treatment?
6. What are the possible complications and side effects?
7. Is surgery an option? Why or why not?
8. How do you know if treatment worked? How will I know?
9. What can be done to prevent or relieve the side effects of treatment?
10. Are there any life-threatening side effects of this treatment? How will I be monitored?
11. Can I stop treatment at any time? What will happen if I stop treatment?
12. Are there any clinical trials that I should consider?
Questions to ask about treatment

1. What are my treatment choices? What are the benefits and risks?

2. Which treatment do you recommend and why?

3. How long do I have to decide?

4. Will I have to go to the hospital or elsewhere for treatment? How often? How long is each visit? Will I have to stay overnight in the hospital or make travel plans?

5. Do I have a choice of when to begin treatment? Can I choose the days and times of treatment? Should I bring someone with me?

6. How much will the treatment hurt? What will you do to make me comfortable?

7. How much will this treatment cost me? What does my insurance cover? Are there any programs to help me pay for treatment?

8. Will I miss work or school? Will I be able to drive?

9. When will I be able to return to my normal activities?

10. What kind of treatment will I need to do at home?

11. I would like a second opinion. Is there someone you can recommend? Who can help me gather all of my records for a second opinion?
Questions to ask about clinical trials

1. What clinical trials are available for my type and stage of breast cancer?

2. What are the treatments used in the clinical trial?

3. What does the treatment do?

4. Has the treatment been used before? Has it been used for other types of cancer?

5. What are the risks and benefits of this treatment?

6. What side effects should I expect? How will the side effects be controlled?

7. How long will I be on the clinical trial?

8. Will I be able to get other treatment if this doesn’t work?

9. How will you know the treatment is working?

10. Will the clinical trial cost me anything? If so, how much?

11. How do I find out about clinical trials that I can participate in? Are there online sources that I can search?
Questions to ask about side effects

1. What are the side effects of treatment?
2. How long will these side effects last?
3. What side effects should I watch for?
4. When and who should I call about side effects? Can I text?
5. What medicines can I take to prevent or relieve side effects?
6. What can I do to help with pain and other side effects?
7. Will you stop treatment or change treatment if I have side effects?
8. What can I do to prevent side effects? What will you do?
Websites

American Cancer Society
cancer.org/cancer/breast-cancer.html

Breast Cancer Alliance
breastcanceralliance.org

Breastcancer.org
breastcancer.org

DiepCFoundation
diepcfoundation.org

FORCE: Facing Our Risk of Cancer Empowered
facingourrisk.org

Living Beyond Breast Cancer (LBBC)
lbcc.org

National Cancer Institute (NCI)
cancer.gov/types/breast

Sharsheret
sharsheret.org

Young Survival Coalition (YSC)
youngsurvival.org
Words to know

**accelerated partial breast irradiation (APBI)**
Treatment with radiation of part of the breast with cancer. A higher dose is given over a shorter period of time compared to whole breast radiation therapy.

**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.

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

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

**breast-conserving surgery**
A cancer treatment that includes removing a breast lump.

**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.

**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.

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

**clinical trial**
A type of research that assesses health tests or treatments.

**connective tissue**
Supporting and binding tissue that surrounds other tissues and organs.

**contrast**
A substance 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.

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

**ductal carcinoma in situ (DCIS)**
A breast cancer that has not grown outside the breast ducts.

**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.

**estrogen receptor**
A protein inside of cells that binds to estrogen.

**estrogen receptor-negative**
A type of breast cancer that doesn’t use estrogen to grow.

**estrogen receptor-positive**
A type of breast cancer that uses estrogen to grow.

**gene**
Coded instructions in cells for making new cells and controlling how cells behave.
Words to know

**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.

**immunohistochemistry (IHC)**
A lab test of cancer cells to find specific cell traits involved in abnormal cell growth.

**invasive breast cancer**
The growth of breast cancer into the breast’s supporting tissue (stroma).

**lobule**
A gland in the breast that makes breast milk.

**lumpectomy**
An operation that removes a small breast cancer tumor.

**lymph**
A clear fluid containing white blood cells.

**lymph node**
A small, bean-shaped disease-fighting structure.

**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.

**mutation**
An abnormal change.

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

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

**pathologist**
A doctor who’s an expert in testing cells and tissue to find disease.

**primary tumor**
The first mass of cancer cells.

**radiation therapy (RT)**
A treatment that uses high-energy rays.

**risk-reduction treatment**
Methods that aim to lessen the chance of getting a disease.

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

**sentinel lymph node biopsy (SLNB)**
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.

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

**total mastectomy**
An operation that removes the entire breast but no chest muscles. Also called simple mastectomy.
ultrasound
A test that uses sound waves to take pictures of the inside of the body.

vulva
The outer female organs that are between the legs.

whole breast radiation therapy (WBRT)
Treatment with radiation of the entire breast.
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This patient guide is based on the NCCN Clinical Practice Guidelines in Oncology (NCCN Guidelines®) for Breast Cancer. It was adapted, reviewed, and published with help from the following people:

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