



# Guide *for the* newly diagnosed



LIVING BEYOND  
BREAST CANCER®

# Tell us what you think of the *Guide for the newly diagnosed*

[surveymonkey.com/r/LBBCprogrameval](https://surveymonkey.com/r/LBBCprogrameval)



## Everyone's journey is different

If you have been diagnosed with **metastatic** breast cancer, or cancer that has traveled beyond the breast to other parts of the body, visit [lbbc.org](https://lbbc.org) to find resources created just for you, including our *Metastatic guide for the newly diagnosed*.

## Dear Friend,

You may have recently heard words you never wanted to hear:  
You have breast cancer.

A breast cancer diagnosis comes with a range of emotions, including fear, stress, anger, or numbness. It's normal to feel overwhelmed by medical terms, or to worry about your family's well-being, the costs of care, or the possibility of hair loss or other side effects of treatment. You may be asking: How will I get through this? Will I live?

Living Beyond Breast Cancer's *Guide for the newly diagnosed* is designed to help you cope with the next few days, weeks, and months of your life. Working closely with healthcare providers and people who have had breast cancer, LBBC developed this guide to help you understand your diagnosis, the possible treatment options, and the support that's available to you.

Everyone deals with breast cancer in their own way. Many people want to talk with someone who has been through it. We encourage you to contact our **Breast Cancer Helpline** at [lbbc.org](https://lbbc.org) or toll-free at **(888) 753-5222** for emotional support, guidance, and hope. At [lbbc.org](https://lbbc.org), you'll find a range of resource and support options, including links to LBBC's online groups to get peer support.

We hope you will keep this booklet nearby to serve as your guide. At LBBC, we're here to help you make it through.

Warmly,



Jean A. Sachs, MSS, MLSP  
Chief Executive Officer



A photograph of a woman with a shaved head, smiling warmly. She is wearing a light blue button-down shirt and is in a kitchen setting, with a black pot on the stove behind her. A man in a plaid shirt is partially visible in the foreground, slightly out of focus.

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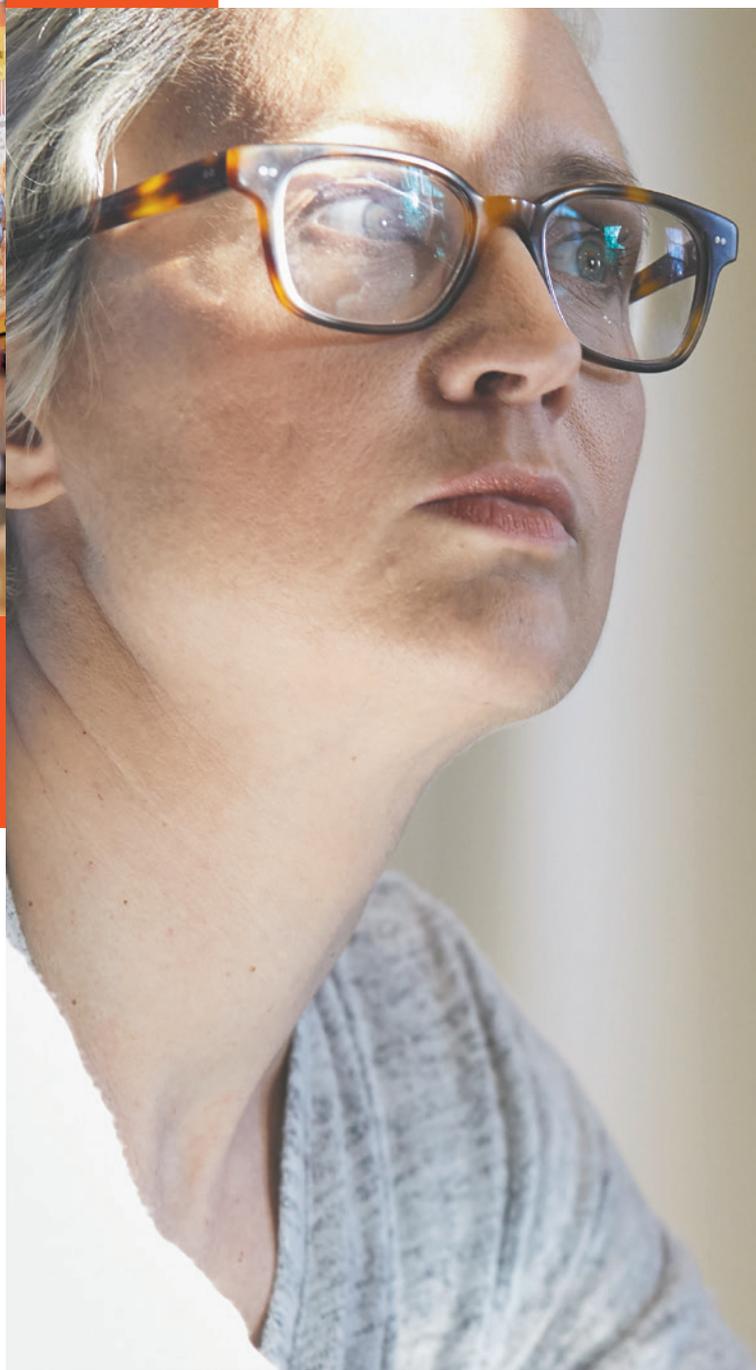
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# Facing your diagnosis



“Cancer has different meanings to different people, and the way you respond to your diagnosis will be *as unique as you are.*”

## Dealing with this moment

Each year, millions of Americans learn they have cancer. Yet hearing the words “You have cancer” never loses its power.

Cancer has different meanings to different people, and the way you respond to your diagnosis will be as unique as you are. It will reflect your personality, your past experiences with and memories about cancer or other health issues, the way you manage

stressful situations, and other things happening in your life. Your response may be very different than the response of someone else who has had breast cancer.

During the first few weeks after a diagnosis, it’s normal to have many different feelings, including anger, fear, anxiety, or sadness. Your feelings may change from day to day, or even hour to hour, as you start to process the news. It may be helpful to concentrate just on getting through the next day, or even the next hour. Try not to judge yourself. Almost everyone finds the

first few weeks after diagnosis to be extremely difficult emotionally. Allow yourself to experience your feelings. Things will improve over time as you learn more about your diagnosis and your treatment plan.

## Telling family and friends

Sharing news of a breast cancer diagnosis is never easy. But the people who know you and love you will want to be there for you. By telling them about your diagnosis, you are allowing them to help you and give you support.

It is your decision to share the news with others, and you can share it when and how you choose. You do not have to share the news immediately or with

everyone you know. When you begin to tell others, they may ask more questions than you want to answer. Remember, you are in control of how much information you share. Do what makes the most sense for you.

Just as you have your unique way of dealing with the news, so will your family and friends. Sometimes people do not respond the way you expect. Sometimes they just don’t know what to say. These responses have to do with their own fears and worries and not with how they feel about you.



During this time, it is very important for you to focus on your own needs. If you feel that those closest to you cannot help at this time, connect with your healthcare team about resources or call on other family members or friends. You can also join our Living Beyond Breast Cancer community, where you will meet others who have been where you are right now.

## Telling young people and children

If you have a young person close to you, we strongly encourage you to share the news.

Children sometimes feel anxious when they sense adults are hiding something. They may have questions if they notice changes in the way you look or behave. Talk with children in a way that makes sense for their age and emotional development. Be clear and reassuring.

With small children, you do not need to be specific. You can say, “I am sick, but I am taking medicine to make me better. The medicine may make me tired or make me lose my hair, but I am still the same person.” Using real words such as “cancer” and “chemotherapy” helps children understand that they won’t lose their hair or have other side effects the next time they get sick.

Visit [lbbc.org](https://www.lbbc.org) for more resources, including free books to help children in different age groups who have a parent or other loved one who has been diagnosed with breast cancer.

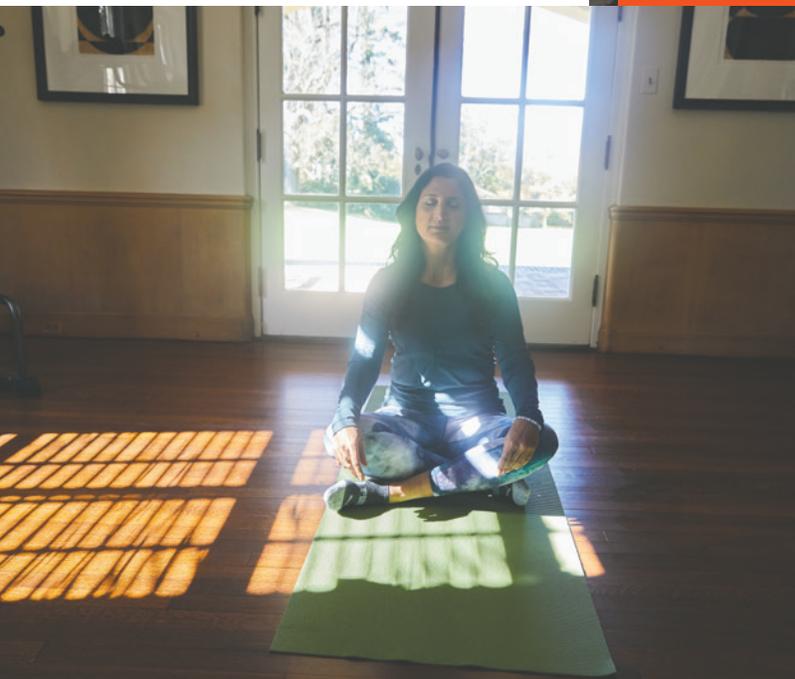


## 10 COMMON FEELINGS AND FEARS AT DIAGNOSIS

1. Why me? What did I do to get breast cancer?
2. Could I have prevented it?
3. Am I going to die?
4. Will I lose my breast?
5. Will I lose my hair?
6. Are my children at risk of getting cancer?
7. Will I feel pain?
8. How will I tell my family, friends, boss?
9. Who will take care of my family if I'm sick?
10. Will I still be able to work?

# What you need to know **today**

“There is no single cause of breast cancer, and there is nothing that you did or didn’t do that caused the breast cancer.”



Most of us learn about breast cancer from events and from studies in the news about research for a cure. But in reality, researchers are looking for many cures, because breast cancer is not a single disease. Breast cancer is a group of diseases that are related because they involve the tissues of the breast.

## What is breast cancer?

Breast cancer occurs when normal breast cells grow and reproduce out of control, turning into **malignant** (cancerous) cells. These abnormal cells grow so much that they fill the **ducts** (ductal cancer) or the **lobules** (lobular cancer) of the breast. The lobules are glands that make breast milk, and the ducts are the passageways that carry the milk from the lobules to the nipple. **Ductal cancers** tend to grow together in a mass, making them somewhat easier to find. **Lobular cancers** tend to grow in more than one area of the breast in a pattern like a sheet, making them more difficult to find.

When cancer cells stay inside the ducts, it is called **in situ** breast cancer or **ductal carcinoma in situ** (DCIS). If the cells grow through the walls of the ducts and lobules, invading nearby tissues, it is called **invasive** or **infiltrating cancer**. Invasive cancers can enter the bloodstream or blood **vessels** and possibly travel to the **lymph nodes** under the arm, or even to organs beyond the breasts.

When you first receive your diagnosis, you will have a small amount of information about the cancer and its behavior. Over the next few weeks, your doctors will do tests to learn more about the features and the extent of the cancer. Once you know more, you and your doctors can determine together the most appropriate treatment plan for you.

## Who gets breast cancer... or “Why me?”

Anyone with breast tissue can get breast cancer—even men. Women of all ages, including very young women in their 20s or 30s, can develop breast cancer. Your risk increases with age, so the older you are, the more likely you are to develop breast cancer.

People of all races and ethnicities get breast cancer. People with different lifestyle habits and from different walks of life develop breast cancer. People with breast cancer can be fit or overweight, vegans or meat-eaters, regular exercisers or people who are inactive most of the time. What all people with breast cancer have in common are abnormal changes, or **mutations**, in the **DNA** of their breast cells. DNA makes up the genes of a cell. It carries a set of directions that tells cells when to grow and how to stop growing.

Some people are more likely to develop a **mutation** because cancers run in the family. Others have been exposed to certain things during their lives that make them more likely to get a mutation. We are still learning about the causes of these mutations and why people get them.

Some breast cancer risk factors are things we can control, such as getting regular exercise, moderating alcohol intake, and maintaining a healthy weight. Having children before age 30 and breastfeeding can offer some protection, but these aren't always choices we can control. And there are risk factors that we simply can't control, such as being a woman, having a family history of breast cancer, starting menstrual periods at an early age, starting menopause at a later age, having dense breasts, and getting older. For all the risks we can control, the risk is never fully eliminated.

If you're asking yourself, “Why me? What did I do to bring on this breast cancer?” you are not alone. This is a completely normal response to the shock of diagnosis. There is no single cause of breast cancer, and there is nothing that you did or didn't do that caused the breast cancer.

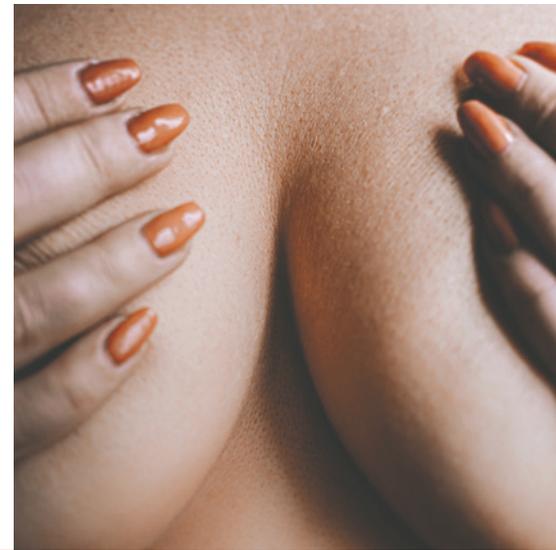
# How you will learn more about the type of breast cancer you have

Before you and your doctor agree on your treatment plan, your doctor must gather more information. By now, you may know whether the cancer is **noninvasive** (DCIS) or invasive. Next, you'll learn the extent of the cancer—

the size of the cancer, whether there is more than one area of cancer, and if there is cancer that has traveled outside the breast.

To find out, your doctor will order additional tests. These may include blood tests, a **chest x-ray, CAT/CT scan, PET scan, MRI, or bone scan**. Your doctor will also review tests you already had, including the **mammogram, ultrasound, or biopsy**. Other tests may be done on pieces of tissue taken from your breast during the biopsy. The combined test results will help you and your treatment team decide on next steps.

If others in your family have had breast cancer, your doctor might talk with you about genetic testing to see if a breast cancer gene mutation runs in your family. **Genetic testing for an inherited mutation** may also be recommended for other reasons, such as being very young at diagnosis. Genetic test results can help you and your doctor make treatment decisions.



## A note on waiting, and patience

One of the most difficult things about a new diagnosis of breast cancer is waiting: waiting for tests, for results, for explanations. Waiting may make you feel anxious, helpless, or frustrated. It can feel like a loss of control. Remember that you have time to gather information and make decisions with your healthcare team. Together, you can create the treatment plan that's best for you.

This time between gathering information, making decisions, and starting treatment requires patience with yourself and others. The next few weeks will be filled with doctors' appointments and tests. Plan calming activities for times when you may feel anxious. Talk with your doctors about when you can expect test results. If you feel you have waited long enough, call and ask for information.

Be kind to yourself. You are learning new medical information and making important decisions about your health and future. No one expects you to understand everything right away. If you have questions but you are not sure how or what to ask, there are

many resources available to you. Your doctors, nurses, or nurse or patient navigator may be able to connect you with others who've been treated for breast cancer who may be available to talk with you. You also can talk with a licensed mental health professional. Many social workers, psychologists, and psychiatrists have special experience working with people newly diagnosed with cancer. Ask your doctor to refer you.

LBBC is here for you, too. We invite you to join one of our online communities at [lbbc.org/community](https://lbbc.org/community), and to connect with a **Breast Cancer Helpline** volunteer at **(888) 753-5222**.



One of the most difficult things about a new diagnosis of breast cancer is waiting: waiting for tests, for results, for explanations.



## **10 THINGS TO DO RIGHT AWAY**

- 1.** Make a list of your providers and their contact information.
- 2.** Decide whether you want a second opinion about your diagnosis or treatment options.
- 3.** Find out whether you can take time off from work if you want to do so.
- 4.** Talk with your family and friends about your fears and concerns.
- 5.** Think about what you need most right now.
- 6.** Take good care of yourself.
- 7.** Seek information from trusted sources.
- 8.** Make necessary doctors' appointments.
- 9.** Keep track of your medical records.  
Make copies of everything you receive.
- 10.** Get a notebook or journal to write down questions or other information.



# Your medical team

Your healthcare providers are a key part of your support team. Many hospitals take a team-based approach to care, meaning your doctors work together to follow your situation and meet regularly to discuss your treatment.

When meeting with each healthcare professional, ask yourself whether you trust and feel confident about the person. Do we communicate well? Does the provider listen to my questions and concerns?

## These people may play a role in your care:

A **radiologist** reads pictures of organs and tissues and looks for disease. This work includes reviewing images from mammograms, ultrasounds, MRIs, CAT scans, bone scans, and PET scans. Some radiologists specialize in breast imaging, while others are general radiologists.

A **pathologist** makes a diagnosis by looking at tissues under a microscope and figuring out the specific type of breast cancer.

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A **surgical oncologist** performs surgery to remove cancer. Surgical oncologists are general surgeons who receive special training in the diagnosis and surgical treatment of cancer. In some cases, the surgical oncologist serves as the main doctor in charge of your treatment.

A **medical oncologist** diagnoses and treats cancer with medicines such as chemotherapy, targeted therapy, hormonal therapy, and immunotherapy. In some cases, your medical oncologist serves as the main doctor in charge of your case.

A **nurse navigator** is a nurse who guides you and your caregivers through the healthcare system so you can get the care you need to make informed decisions about treatment.

A **radiation oncologist** treats cancer with radiation therapy.

A **genetic counselor** is trained to talk with you about your family history of cancer and whether you may be a candidate for genetic testing for an inherited mutation. These tests look for inherited mutations in your DNA that can increase the risk for breast cancer. Ask your doctor about whether genetic counseling may be right for you.

A **reproductive endocrinologist** is an expert on **fertility**, the ability to have children. Premenopausal women who want to have children, and whose treatment options impact the ability to get pregnant in the future, can be referred to a reproductive endocrinologist for fertility preservation options. Treatments that can affect fertility include chemotherapy and hormonal therapy.

A **plastic or reconstructive surgeon** reshapes or rebuilds the breast after surgery.

A **primary care physician** provides you with your regular medical care and may manage your care with your other doctors.

A **medical oncology nurse** is a registered nurse with special training in the medical and emotional needs of people with cancer. Oncology nurses provide care in many ways, giving anti-cancer treatments that include chemotherapy and targeted therapy, as well as monitoring hormonal therapy and immunotherapy side effects. They may work in the infusion or treatment area, the medical oncology clinic, or with the radiation or pain management departments.

A **surgical oncology nurse** is a registered nurse with special training in the surgical treatment and emotional needs of people with cancer. Surgical oncology nurses work with surgery teams to provide education and coordination before and after surgery. This may include information about breast **reconstruction** options, **lymphedema**, physical therapy, post-surgical garments, or other issues that may arise for people undergoing breast cancer surgery.

A **nurse practitioner** or **NP** has advanced education that allows them to participate in direct medical care. In some states, NPs can practice independently. In other states, they work with your medical oncologist, surgeon, or radiation oncologist. NPs can prescribe medications and refer to support services to help manage side effects.

A **social worker** or **counselor** talks with you and your family about your emotional needs and helps you find support services.

A **financial counselor** helps you and your family manage treatment costs and find financial resources.

A **physician assistant** or **PA** is a licensed healthcare provider who can diagnose and treat cancer with a doctor's oversight. PAs can order tests, assist with surgery, and prescribe medicine.

A **patient navigator** is a nurse, social worker, or other individual who helps you and your loved ones quickly get to the medical team you need to start treatment. A navigator may be the first person you talk to after a cancer diagnosis.

A **physical therapist** performs and teaches exercises to help you maintain strength before starting treatment and to improve recovery.

When you start treatment, ask which doctor will coordinate your care. If you have questions, you should be able to contact your main doctor, even if you just want to ask which person to call.



# Making sense of your pathology report

The **pathology report** is one of the most important documents you will receive. It contains a profile of the cancer's characteristics, prepared by a specially trained doctor called a pathologist. After a breast biopsy or surgery, the pathologist studies the removed breast tissue in the lab. Your doctors then use the results in the report to recommend treatments for you.

Your doctor will give you a copy of this report and add the report to your medical record. After a biopsy, this report will contain some of the test results that inform your treatment plan. When you have a final, **definitive surgery** (lumpectomy or mastectomy) that results in a surrounding cancer-free area of tissue (negative margins), more information will be added to your pathology report to guide the rest of your treatment plan.



Your pathology report will include some or all of this information:

The **anatomic site**, or where the tumor was located.

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The **gross description** of the tissue, or what the pathologist saw when looking at the tissue with the naked eye.

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The **diagnosis**, which may include:

- Whether the cancer is noninvasive (ductal carcinoma in situ, or DCIS) or invasive (ductal or lobular carcinoma or less common cancers such as **inflammatory breast cancer**)
  - The **size**, measured in millimeters (mm) or centimeters (cm)
  - The **tumor grade**, sometimes called histologic grade, which describes what invasive cancer cells look like when compared with normal cells
  - The **mitotic rate**, or how quickly the cancer cells are dividing
  - Whether there is **lymphovascular invasion**, meaning cancer cells have entered the lymph channels in the breast (if this is not mentioned, then there is none)
  - **Hormone receptor status**, or whether the cancer cells have receptors (proteins) that attach to estrogen (**estrogen receptor-positive** or -negative) or progesterone (progesterone receptor-positive or -negative)
  - **HER2 status**, or whether the cancer has too many copies of the HER2/neu gene, which means the cancer has too much of a growth-fueling HER2 protein
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After your definitive surgery, the report will include:

- The tumor **margin**, or whether the tissue surrounding the removed cancer is free of cancer cells
- The lymph node status, or whether cancer cells are in lymph nodes closest to the cancer (the sentinel node or nodes) or underarm lymph nodes (axillary nodes)
- The cancer **stage**, which describes the cancer's extent and behavior

This is not a complete list of all the potential information in a pathology report. To learn more, visit [lbbc.org/pathreport](https://lbbc.org/pathreport).

You may see many unfamiliar words on your pathology report. Ask your doctor or nurse to explain what they mean. It is OK to keep asking questions until you understand the results and what they may mean for you.

## 10 QUESTIONS TO ASK YOUR DOCTOR ABOUT YOUR PATHOLOGY REPORT

1. Is the cancer invasive or noninvasive?
2. What stage is the breast cancer? How large is it?
3. Is it a ductal or a lobular cancer?
4. Has the cancer traveled to my lymph nodes? If yes, how many nodes are affected?
5. Has the cancer traveled elsewhere in my body?
6. Is the cancer estrogen receptor-positive (ER+) or progesterone receptor-positive (PR+)?
7. What is the HER2 status of the cancer?
8. Did the surgeon remove all the cancer from my breast?
9. Besides the main site of the cancer, do I have cancer or other problems in other parts of my breast?
10. Are there areas of concern in my healthy breast?

### A note on treatment goals

Depending on the stage of the cancer and your personal needs, you may set a variety of goals for your treatment. For example, if you have a stage 0, or DCIS, diagnosis, your treatment goals may be to have the tumor removed and reduce the risk of a future invasive cancer. If the cancer is metastatic, your treatment goal may be to get rid of as much cancer as possible and maintain your quality of life. Discuss your treatment goals with your healthcare team.

It's important to talk honestly with your healthcare team about what you want and need from treatment.

Let them know if you're concerned about side effects, how a treatment could impact your day-to-day activities, or your long-term risk for the cancer coming back.

# How doctors figure out the cancer stage

Stage describes the extent of the cancer. Doctors use the **TNM system** to assign a stage to the breast cancer. Each letter in the TNM system is assigned a number to show the size of the original tumor and how far the cancer has spread.

## T

**T stands for tumor.** The T stage is determined by the size of the tumor and whether it has affected the skin over the breast or the muscle beneath the breast. T includes these categories for breast cancer:

- **TX** means the size of the tumor can't be determined.
- **T0** means there is no evidence of a primary tumor.
- **Tis** means the cancer is in situ (DCIS, LCIS, or Paget disease of the breast with no tumor mass).
- **T1** tumors are 2 centimeters or less across.
- **T2** tumors are larger than 2 centimeters but less than 5 centimeters across.
- **T3** tumors are larger than 5 centimeters across.
- **T4** cancers have spread into the **chest wall** or skin, and can include inflammatory breast cancer.

## N

**N stands for lymph nodes.** The N stage is determined either by:

- The number of lymph nodes in the armpit, called **axillary lymph nodes**, that have cancer.
- The number of nodes near the **breastbone** in the center of the chest, called **internal mammary lymph nodes**, that have cancer.
- The number of nodes in the base of the neck near the **collarbone**, called **supraclavicular lymph nodes**, that have cancer.

N includes these categories for breast cancer:

- **NX** means that it can't be determined whether the cancer is in nearby lymph nodes.
- **N0** means cancer has not traveled to nearby lymph nodes.
- **N1** means cancer is in one to three armpit lymph nodes, in lymph nodes near the breastbone, or in both.
- **N2** means cancer is in four to nine armpit lymph nodes, in the lymph nodes near the breastbone, or in both.
- **N3** means cancer is in 10 or more armpit lymph nodes, or in the lymph nodes near the collarbone, or in lymph nodes near the breastbone, or in some combination of these.

## M

**M stands for metastasis.** The M stage is determined by whether the cancer has traveled from the breast and nearby lymph nodes to another area in the body. M includes these categories for breast cancer:

- **MX** means it can't be determined whether or not the cancer has metastasized.
- **M0** means the cancer hasn't metastasized.
- **M1** means the cancer has metastasized to another part of the body, such as the bones, lungs, liver, or brain.

The TNM system, hormone receptor status, HER2 status, and cancer grade help determine the stage, a number between 0 and IV. Stages 0 to III are considered **early-stage** breast cancers. **Metastatic breast cancer**, also known as stage IV breast cancer, has traveled away from the breast and nearby lymph nodes to other parts of the body.

It's important to know that "advanced" breast cancer can mean metastatic breast cancer, but it can also refer to locally advanced breast cancer. Locally advanced breast cancer has spread to areas near the breast, which could include lymph nodes, skin, or the chest wall, but not to other locations in the body.

## THE FIVE MAJOR BREAST CANCER STAGES

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**STAGE 0** breast cancer is noninvasive. Ductal carcinoma in situ, or DCIS, is stage 0 breast cancer. It is confined to the ducts of the breast.

In stages **I through III**, the breast cancer has not spread to any distant organs such as the bones, lungs, or liver.

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**STAGE I** breast cancers are invasive. This means that the cancer has broken through the ducts or lobules into surrounding breast tissue. Stage I breast cancers are 2 centimeters or smaller in size. Usually, these cancers have not traveled to the lymph nodes. Stage I breast cancer falls into two groups: stages IA and IB.

**Stage IA** breast cancers are usually small tumors of 2 centimeters or less, and the cancer has not spread to the lymph nodes or beyond the breast to any other organs.

**Stage IB** breast cancer includes these situations:

- There is no evidence of a breast tumor, but there are small areas of cancer in the axillary lymph nodes measuring at least 0.2 millimeters but no larger than 2 millimeters.
- There is a breast tumor of 2 centimeters or less across, and there are small areas of cancer in the axillary lymph nodes measuring at least 0.2 millimeters but no larger than 2 millimeters.

**STAGE II** breast cancers are invasive. They fall into two groups: stages IIA and IIB.

In **stage IIA** breast cancers:

- There is no evidence of a breast tumor, but cancer is in one to three axillary lymph nodes or internal mammary lymph nodes.
- There is a breast tumor of 2 centimeters or less and there is cancer in one to three axillary lymph nodes or internal mammary lymph nodes.
- There is a breast tumor measuring 2 to 5 centimeters, with no cancer in the lymph nodes.

**Stage IIB** breast cancers can be:

- A breast tumor measuring between 2 and 5 centimeters and cancer cells in one to three axillary or internal mammary lymph nodes
- A breast tumor measuring more than 5 centimeters and no cancer in the lymph nodes, or cancer smaller than 0.2 millimeters is found in the lymph nodes

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**STAGE III** breast cancers are invasive. They fall into three groups: stages IIIA, IIIB, and IIIC.

In **stage IIIA** breast cancers:

- There is no evidence of a tumor, or there is a tumor of any size and cancer is found in four to nine axillary lymph nodes, or the cancer has caused the internal mammary lymph nodes near the breastbone to become enlarged.
- The tumor is larger than 5 centimeters across and there is cancer in one to three axillary lymph nodes or internal mammary lymph nodes.

In **stage IIIB** breast cancers:

- The tumor may be of any size and has grown into the skin or the chest wall.
- Cancer may be in zero to nine axillary lymph nodes.
- Cancer may be in one or more internal mammary lymph nodes.
- The cancer may be inflammatory breast cancer, which includes rapidly developing symptoms such as breast swelling, warmth, redness, and/or an orange peel look on the breast skin.

**Stage IIIC** breast cancers may be small, medium, or large, or doctors may not be able to find a tumor in the breast, but instead find cancer in the chest wall or on the breast skin. These cancers may be:

- In the axillary lymph nodes and internal mammary lymph nodes
- In the supraclavicular (collarbone) lymph nodes
- Inflammatory breast cancer

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**STAGE IV** breast cancers are metastatic, which means the cancer has traveled away from the breast to other organs in the body such as the bones, liver, lungs, or brain. If you have this diagnosis, LBBC has unique resources for you, including the *Metastatic guide for the newly diagnosed*. For more information, visit [lbbc.org/mets](https://www.lbbc.org/mets).

# Treatment basics

There are two parts to breast cancer treatment: local therapy and systemic therapy.

- The goal of **local therapy** is to treat cancer in the breast and nearby lymph nodes. Local therapies include surgery (lumpectomy or mastectomy) and radiation. These therapies are sometimes offered in combination with each other. In other cases, surgery alone is enough.
- The goal of **systemic therapy** is to get rid of any invasive breast cancer cells that may have traveled away from the primary breast tumor to other parts of the body. Systemic therapies include chemotherapy, targeted therapy, hormonal therapy, and immunotherapy.
- Treatment given after surgery is called **adjuvant therapy**. It works to reduce the risk of **recurrence**. Treatment given before surgery is called **neoadjuvant therapy**, sometimes used to shrink a tumor before surgical removal.

You and your healthcare team will work together to find the most effective treatments for you.





# Local treatments

Local treatments aim to remove the cancer in the breast and lymph nodes. In breast cancer, local treatments are surgery and radiation therapy.

## Surgery

Almost everyone diagnosed with breast cancer will have some kind of surgery. The goal of surgery is to remove the cancer from the breast. There are two types of cancer-removing breast surgery: breast conservation and mastectomy.

In **breast conservation**, the surgeon performs a **lumpectomy** (also called a partial mastectomy or segmental lumpectomy), which is followed by radiation treatment to the remaining breast tissue. Lumpectomy removes the tumor from your breast, along with a rim of normal tissue, called the

margin. The surgery must remove all the cancer from your breast. Because cancer often cannot be seen, sometimes it may take additional surgeries to remove it all.

Not everyone can have breast conservation surgery. In general, for breast conservation surgery to be successful, the tumor needs to be less than 5 centimeters in diameter and be in only one area of your breast. Also, your breast must be large enough for the surgery to leave enough tissue for a good cosmetic result. You must be able and willing to receive radiation therapy.

If you cannot have breast conservation because of the size or extent of the tumor and breast conservation is important to you, you may be able to get chemotherapy, hormonal therapy, or targeted therapy before surgery to shrink the tumor, called neoadjuvant therapy. Neoadjuvant therapy is standard

treatment for several types of invasive breast cancer and for inflammatory breast cancer.

In some cases, your surgeon may recommend a **mastectomy**, or removing the entire breast. This is done for a variety of reasons, including personal choice, multiple tumors in different parts of the breast, tumors in the nipple area, previous breast cancer in the same breast, large tumors, or aggressive tumors. A mastectomy may also be recommended if you are not a candidate for radiation therapy because of pregnancy, past radiation in the same area, or difficulty lying flat to receive treatment. Some people at high risk of recurrence or developing a new breast cancer may choose to have both breasts removed. This is called a double mastectomy, bilateral mastectomy, preventive mastectomy, or prophylactic mastectomy. Ask your doctor about all your options.



In making your decision, remember there is no right answer—just the best one for YOU.

### LUMPECTOMY OR MASTECTOMY?

In some cases, a person has the option of lumpectomy or mastectomy. Studies show that lumpectomy followed by radiation therapy works as well as mastectomy in treating early-stage breast cancers.

In making your decision, remember there is no right answer—just the best one for you. Weigh the medical issues and your concerns about your quality of life. If your doctor recommends one surgery over another, ask why. Is keeping your breast the most important thing to you? Are you willing and able to have weeks of radiation therapy after a lumpectomy? Will you live with constant worry of the cancer returning if you don't have a mastectomy? These aren't always easy questions to answer. Talk things through with people you know and trust. You can also reach out to peers for support by joining our community at [lbbc.org/community](https://lbbc.org/community).

### IS THERE CANCER IN THE LYMPH NODES?

If you have an invasive cancer, your surgeon will need to look at the lymph node or nodes closest to where the cancer was found—the sentinel node—to check for cancer cells that may have traveled there. The sentinel node is often in the underarm area, or axilla. This surgery, called a sentinel node biopsy, will usually be done at the same time as your breast surgery. The results will help you and your treatment team learn the stage of the cancer and figure out what treatments you need in addition to surgery and radiation.

If there is no cancer in the sentinel node, it is likely no more lymph nodes will be removed. If cancer is found, your surgeon may remove more lymph nodes, either at the time of your sentinel node biopsy or later. The additional lymph nodes are taken from under the arm in an **axillary lymph node dissection** surgery. It's important to know that compared with sentinel node biopsy, axillary dissection brings a higher risk of side effects such as lymphedema.

Lymphedema occurs when extra lymph fluid gathers in the tissues, causing swelling of the arm or hand. Lymphedema can be an uncomfortable possible **side effect** of any lymph node surgery or radiation to the lymph node area. There are ways to reduce the risk of lymphedema, and ways to manage it if it occurs. Learn more by visiting our side effects section at [lbbc.org/side-effects](https://lbbc.org/side-effects).

Before surgery, ask whether you will have a sentinel lymph node biopsy or axillary dissection. Ask why one surgery is recommended over the other, and ask about the risks for short- and long-term side effects.

## Breast reconstruction surgery

If you have a mastectomy, you may choose to have breast reconstruction, or surgery to rebuild your breast.

There are many types of reconstructive surgery, and you can choose to have your breast rebuilt at the time of your mastectomy or even months or years later. Techniques include implant surgery and surgery using tissue from your abdomen or another part of your body to rebuild the breast.

Another option is to use a **prosthesis**, an artificial breast form that fits into your bra, instead of having reconstructive surgery. A prosthesis helps you keep a breast shape when you wear clothes.

Some women choose not to have reconstruction or wear a prosthesis. This is called going flat and involves a surgery called aesthetic flat closure. You have options, and you can take your time to decide which one makes most sense for you and your lifestyle. For more information, visit [lbbc.org/treatments](http://lbbc.org/treatments).





## Radiation therapy

Radiation treatment is another local therapy. In early-stage breast cancer, the goal of **radiation therapy** is to kill any cancer cells that may remain after cancer removal surgery. Radiation therapy can reduce the risk of breast cancer coming back in the same place (**local recurrence**). When radiation is given after surgery as part of the primary treatment, it is called adjuvant therapy. In metastatic breast cancer, radiation therapy can slow cancer growth or relieve pain from breast cancer that has spread to other parts of the body.

Radiation treatment is very effective against cancer in the specific area to which it is directed, but it will not treat cancer in other areas of the body. Because it is a local treatment, the side effects of radiation are related to the area where the treatment is given. It is unlikely to cause side effects elsewhere. You will not be radioactive

during radiation therapy. You don't need to worry about exposing family members to radiation.

### HOW DOES RADIATION WORK?

Radiation focuses the power of high-energy x-rays on areas where cancer cells may remain, such as the tissue left after surgery to your breast and nearby lymph nodes. The sites for radiation treatment vary and depend on where the cancer was found. You may receive radiation to part of your breast, your whole breast, the chest wall, the area above your collarbone, or under your arm.

### HOW DO I KNOW IF I NEED RADIATION?

You will meet with a radiation oncologist, a doctor who specializes in treating cancer with radiation. This doctor will talk with you about your medical history and your diagnosis of breast cancer, and how radiation may be helpful.

If you have a lumpectomy, you may also have radiation treatment. If you have a mastectomy, you may not need

radiation. To determine if you need radiation after mastectomy, your doctor will look at the size of the tumor and whether cancer traveled to the lymph nodes or other areas such as the muscle below your breast or your skin.

### HOW IS RADIATION GIVEN?

Usually, radiation is given from outside your body by external beam. But sometimes the radiation source can be placed temporarily inside the breast.

### WHAT HAPPENS AT TREATMENT?

Radiation treatment must be very precise. To find the right places to give radiation, your doctor may order a **CAT** (or CT) **scan**. This special x-ray takes pictures of the inside of your breast from many different angles. Then, to make sure the exact same spot is always radiated, a radiation therapist will give you tiny tattoos—about the size of the top of a pin—on the areas to be radiated. This is done under your doctor's supervision. If you do not want the tattoos or cannot have them for any reason, talk with your doctor about options.

Several days to a week later, you will begin treatments. How long radiation treatment takes depends on the kind of treatment you receive.

The standard treatment is **whole breast radiation**, given by external beam 5 days a week for 3 to 5 weeks. Each treatment takes about 15 minutes. The final 1 to 2 weeks may include a **boost**, an extra dose of radiation given over several days, to the area where you had surgery. **Hypofractionated whole breast external beam radiation**, another option, takes 3 to 4 weeks, and radiation oncologists prefer this option over others.

**Partial breast radiation** treats only the part of the breast where the tumor was found.

Whole and partial breast radiation therapy can be given using external beam radiation techniques, such as:

- **3D conformal radiation (3D-CRT)**, which uses 3D imaging to direct photon beams, or x-rays, toward the whole breast or just part of the breast
- **Intensity-modulated radiation therapy (IMRT)**, which can focus more intense doses of radiation to parts of the area where the tumor was, reducing the impact on healthy tissue
- **Proton therapy**, which delivers a beam of proton particles, not x-rays, to a targeted area

These and other techniques can be used to treat early-stage breast cancer as well as areas of metastatic breast cancer spread.

Partial breast radiation can be given by external beam in the ways described, or it can be delivered internally. One internal radiation technique is called **brachytherapy**, in which a surgeon places an applicator or catheters (hollow, flexible tubes) in the cavity where the tumor was found, and small seeds containing radiation are inserted for a short time. Treatment is typically given two times per day for a week. These treatments may take up to a half hour. Your healthcare team removes the applicator or catheters when treatment is complete. Another internal technique is **intraoperative radiation therapy (IORT)**, in which one large dose of radiation is given during lumpectomy surgery. This technique is still being studied and is not widely available.

If you are interested in partial breast radiation, explore the risks and benefits with your doctor.

### WHAT ARE THE SIDE EFFECTS?

Fatigue is a common side effect of radiation treatment. Because the impact of radiation therapy builds up, your fatigue may increase later in your treatments. Expect to feel tired in the last few weeks of treatment, and plan time for naps and resting.

The skin on or near the radiated area may become dry, sore, red, blistered, or scaly. Ask your radiation nurse and radiation oncologist for ideas to keep your skin moist and comfortable.

Radiation after breast reconstruction surgery can change how the reconstructed breasts look. If your treatment plan includes radiation therapy and breast reconstruction, it is important to discuss this with your plastic surgeon and radiation oncologist.

Heart damage can be a long-term side effect of radiation therapy if treatment is on the left side, closer to the heart. A technique called Deep Inspiration Breath Hold, or DIBH, can minimize the heart's radiation exposure.

External radiation increases your risk for developing lymphedema, rib **fractures**, and some rare cancers. Discuss all the benefits and possible side effects with your doctor.

Learn about different radiation therapy techniques, DIBH, side effects, and more at [lbbc.org/treatments](https://www.lbbc.org/treatments).





## Systemic treatments

### A NOTE ON HORMONE RECEPTOR STATUS AND HER2 STATUS

It's important to know the breast cancer's hormone receptor status and HER2 status because it helps you and your care team select precise, effective treatments based on these unique features. Many systemic treatments are available to treat:

- **Hormone receptor-positive breast cancer:** The cancer has protein receptors for estrogen and/or progesterone.
- **HER2-positive breast cancer:** The cancer overexpresses the HER2 protein.
- **Triple-negative breast cancer (TNBC):** The cancer tests negative for hormone receptors and HER2 receptors.

The systemic treatments for breast cancer are chemotherapy, targeted therapy, hormonal therapy, and immunotherapy. If your healthcare team recommends a systemic treatment, it will be based on your pathology report and other test results. This includes tumor size, how fast the cancer is growing, and whether cancer has traveled to nearby tissues or lymph nodes. Treatment options are also based on hormone receptor status and HER2 status. Healthcare professionals use this information to categorize the cancer into specific groups known as molecular subtypes. You can learn more about molecular subtype groups at [lbbc.org](http://lbbc.org).

**Genomic tests**, or tumor biomarker tests, look at tumor cells for more details about the traits of the cancer, how likely it is to return, and how effective chemotherapy and hormonal therapy might be. These tests are done on a tissue sample removed during surgery. Some of these tests

include Oncotype DX, MammaPrint, the Breast Cancer Index test, EndoPredict, and Prosigna.

If genetic testing for an inherited mutation is recommended, the results can help inform whether certain systemic targeted therapies might be helpful.

Each person's treatment plan is unique. Some people may have one treatment option, while others may have a choice of several equally effective options. Your healthcare team will look at other factors including your age, overall health, and lifestyle as you decide on a plan. Treatment can also be given through a **clinical trial**, which evaluates new therapies and compares new treatments to current ones. Read about clinical trials on page 35 of this guide.

As you're weighing options, talk with your care team about why each treatment is recommended, and why one treatment might work better than another. Ask about potential side effects and how to manage them.

# Chemotherapy

**Chemotherapy** is systemic treatment that kills quickly dividing cells, including cancer cells and some healthy cells throughout the body. This can cause side effects such as hair loss and mouth sores, although not everyone experiences every side effect.

## HOW DO I KNOW IF I NEED CHEMOTHERAPY?

Your doctor will recommend chemotherapy if there is a high risk of the cancer coming back outside the breast or if the cancer has traveled outside the breast already. Chemotherapy is given for large tumors, cancer in the lymph nodes, and tumors with features that make them aggressive. Genomic or tumor biomarker testing can determine if chemotherapy may be helpful.

## WHAT IF I HAVE A CHOICE ABOUT CHEMOTHERAPY?

If you have a choice about whether to have chemotherapy, explore the pros and cons with your doctor. Ask about your risk of recurrence with or without chemotherapy, and ask about short- and long-term side effects. Consider your current health and how chemotherapy could impact your day-to-day life.

## HOW IS CHEMOTHERAPY GIVEN?

Chemotherapy can be given as an infusion through a vein or by taking a pill. It can be given before or after surgery.

Chemotherapy after surgery, or adjuvant chemotherapy, usually starts about a month after surgery, once you have had time to heal. Chemotherapy before surgery, also called neoadjuvant chemotherapy, can be an option to shrink a very large tumor so that surgeons can more easily remove it, or to see if it's possible to have a lumpectomy instead of mastectomy. Neoadjuvant chemotherapy can also help your care team understand how well the cancer is responding to treatment. If one type of chemotherapy doesn't shrink the cancer, it helps doctors decide what medicine to try next.

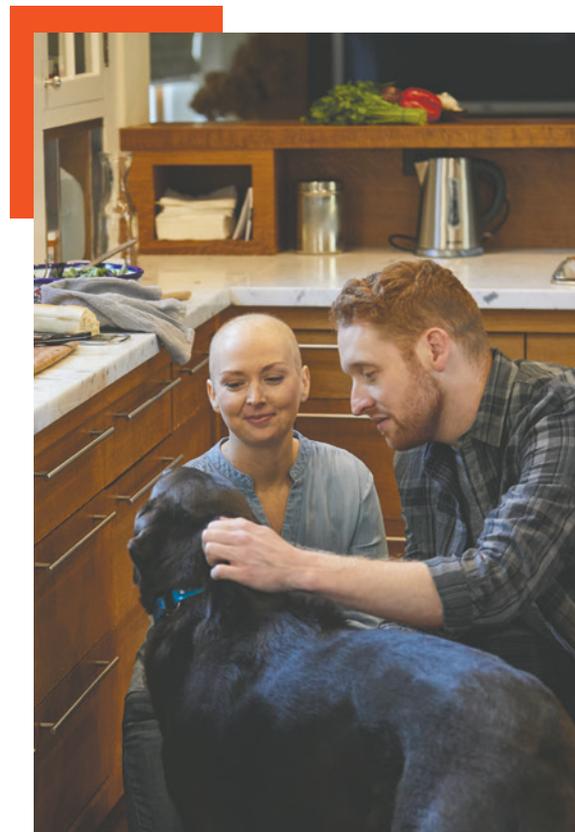
There are many different chemotherapy medicines. These may be given alone, called **single-agent therapy**, or together, called **combination therapy**. Some chemotherapy medicines do a better job treating the cancer when they are given together. If chemotherapy is recommended for you, you and your doctor will decide on an effective plan based on the cancer's traits and your treatment goals.

Chemotherapy is often given in 2- to 3-week cycles. Infusion chemotherapy might be given for a few hours at your cancer center one day a week,

or every other week, for a few weeks at a time. Chemotherapy in pill form may be taken at home one or two times a day for a short period, such as 2 weeks, followed by a period of recovery time before resuming.

For early-stage breast cancer, chemotherapy may be given for 3 to 6 months. In metastatic breast cancer, the length of treatment is based on how effective it is and how manageable the side effects are.

If chemotherapy is given through an IV in your arm or hand, it can irritate small veins, so some surgeons recommend inserting a port. A port is a small device placed under skin in the chest that allows easy access to veins. Once you complete treatment, the port is removed.



## CHEMOTHERAPY SIDE EFFECTS

Because chemotherapy affects all dividing cells, it sometimes damages fast-growing, healthy cells, such as hair cells, blood cells, and cells that line the digestive tract. This can cause side effects such as hair loss, mouth sores, anemia, fatigue, and diarrhea.

### Some common chemotherapy side effects are:

**Anemia**, or a lower number of red blood cells than normal. Anemia can make you feel tired, weak, or short of breath. Take good care of yourself by getting plenty of rest, drinking 8 to 10 glasses of water daily, keeping protein in your daily diet, and doing light exercise when you can. In severe cases of anemia, a blood transfusion is sometimes needed.

**Hair loss** is a side effect of some, but not all, chemotherapies. Anthracycline- or taxane-based chemotherapy usually causes hair loss all over the body. Some treatments cause hair thinning, and others do not impact the hair at all. If hair loss is a risk with your recommended chemotherapy treatment, there are many ways to manage it:

- **Scalp-cooling technology** used during chemotherapy may reduce how much hair you lose, and for some, prevent hair loss. Results can vary. Talk with your doctor if you are interested in scalp cooling and to find out if it's available in your area.
- You may find it helpful to **cut or shave your hair** so you can feel more control over when you lose it and the way you look before it falls out.
- If you decide a **wig** may be right for you, and you'd prefer a wig that matches your natural hair, shop for one before chemotherapy starts so you can get a close match. Wig shopping before treatment can also reduce the stress of finding a wig once hair starts to fall out.
- **Scarves or hats** are another option.

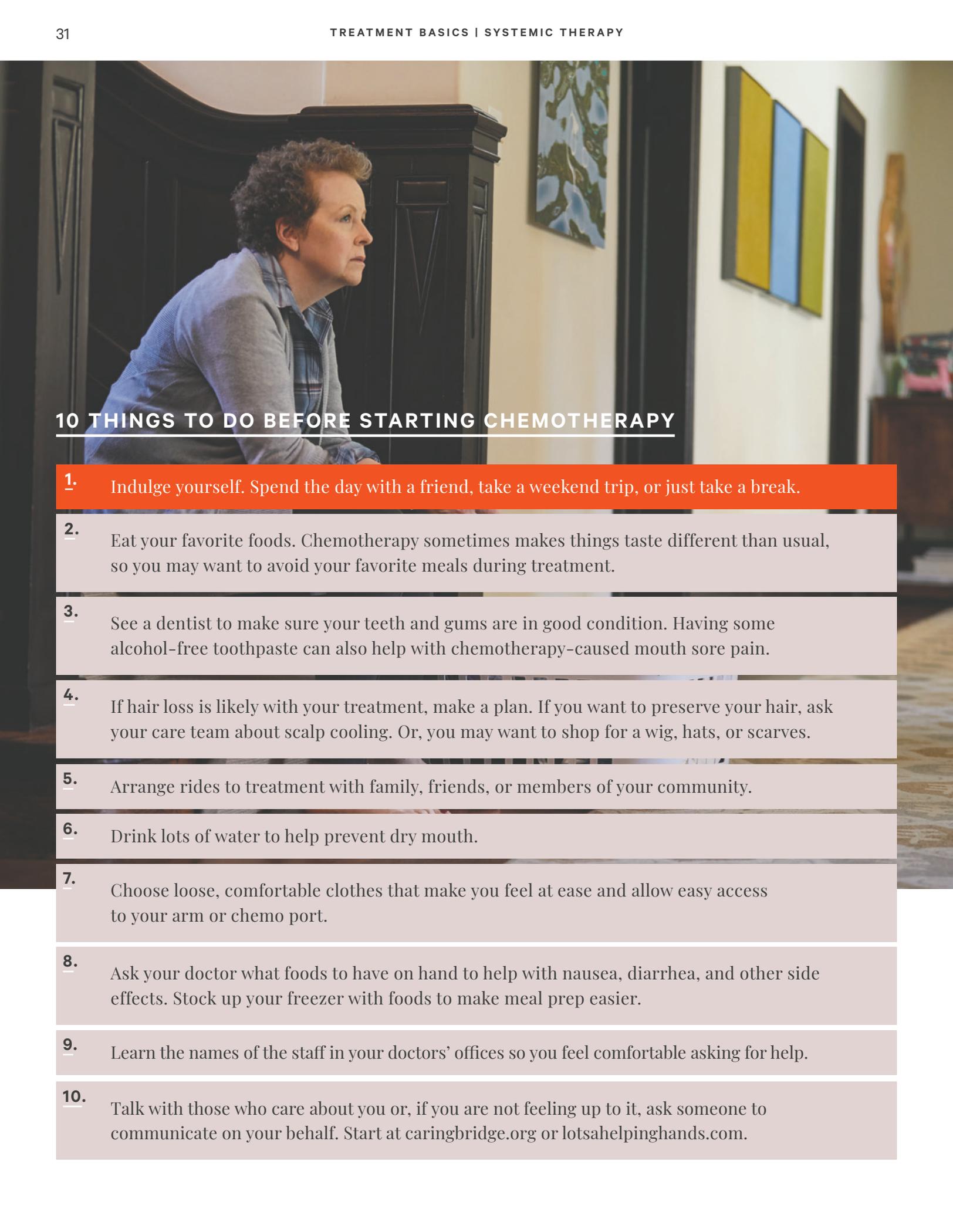
Taking control of hair loss before it happens helps many people get through treatment. Choose whatever is comfortable for you.

**Nausea.** Your care team will likely prescribe medicine to prevent nausea. These medicines can be very effective when taken as prescribed.

**Infection.** Talk with your team about ways to protect yourself, such as washing your hands often with soap and water. If you develop a fever, call your doctor immediately. If tests show a low **white blood cell** count, your care team may recommend medicines called **growth factors** to help prevent infection.

If the idea of chemotherapy feels scary to you, you're not alone. But the truth is, while some people do have challenges with chemotherapy, others manage quite well. Many people continue to work, and others report feeling only mild discomfort. Each person has a unique response. If you feel uncomfortable during treatment, there are many ways your healthcare team can help you. Let your doctors and nurses know about any concerns before you start treatment. Ask which side effects could occur with the chemotherapy you will receive.

To learn more about chemotherapy and side effect management, visit [lbbc.org/chemo](http://lbbc.org/chemo).

A woman with short, curly brown hair is sitting on a dark wooden piano in a living room. She is wearing a light blue sweater over a plaid shirt and is looking off to the side with a thoughtful expression. The room has a white wall with a framed abstract painting and a doorway leading to another room.

## 10 THINGS TO DO BEFORE STARTING CHEMOTHERAPY

1. Indulge yourself. Spend the day with a friend, take a weekend trip, or just take a break.
2. Eat your favorite foods. Chemotherapy sometimes makes things taste different than usual, so you may want to avoid your favorite meals during treatment.
3. See a dentist to make sure your teeth and gums are in good condition. Having some alcohol-free toothpaste can also help with chemotherapy-caused mouth sore pain.
4. If hair loss is likely with your treatment, make a plan. If you want to preserve your hair, ask your care team about scalp cooling. Or, you may want to shop for a wig, hats, or scarves.
5. Arrange rides to treatment with family, friends, or members of your community.
6. Drink lots of water to help prevent dry mouth.
7. Choose loose, comfortable clothes that make you feel at ease and allow easy access to your arm or chemo port.
8. Ask your doctor what foods to have on hand to help with nausea, diarrhea, and other side effects. Stock up your freezer with foods to make meal prep easier.
9. Learn the names of the staff in your doctors' offices so you feel comfortable asking for help.
10. Talk with those who care about you or, if you are not feeling up to it, ask someone to communicate on your behalf. Start at [caringbridge.org](http://caringbridge.org) or [lotsahelpinghands.com](http://lotsahelpinghands.com).



## Targeted therapy

**Targeted therapies** are medicines that treat cancer by recognizing a specific feature of a cancer cell and attaching to the cell to destroy it. There are several different kinds of targeted therapy used to treat early-stage breast cancer.

Targeted therapies for hormone receptor-positive breast cancer include **CDK 4/6 inhibitors**. These therapies target proteins on the cancer cells to slow the cancer's growth. There are many other targeted therapies under study for this type of breast cancer.

**Targeted therapies for HER2-positive breast cancer are:**

- **Monoclonal antibodies** include drugs that target the HER2 protein, such as trastuzumab (Herceptin).
- **Tyrosine kinase inhibitors** target proteins called tyrosine kinases that signal cancer cells to grow. An example is neratinib (Nerlynx).

- **Antibody drug conjugates** pair a chemotherapy with a targeted therapy to deliver the chemotherapy directly to the cancer cell. One example is adotrastuzumab emtansine (Kadcyla).

**Targeted therapies for some triple-negative breast cancers are:**

- **PARP inhibitors** target an enzyme that repairs cancer cell DNA in people who have tested positive for a BRCA mutation and have breast cancer. An example is olaparib (Lynparza).

There are other medicines in these drug classes approved only for metastatic breast cancer. You may be able to access them by getting treatment through a clinical trial.

Targeted therapies may be given before surgery, after surgery, or both. They can be given by vein or by mouth as a pill. Learn more about all types of targeted therapies, including possible side effects and ways to manage them, at [lbbc.org/treatments](http://lbbc.org/treatments).

## Hormonal therapy

Some breast cancers rely on the hormones estrogen and progesterone to grow and survive. These breast cancer cells have proteins called hormone receptors. Your pathology report will say whether the breast cancer is estrogen receptor-positive, progesterone receptor-positive, both, or neither (hormone receptor-negative).

**Hormonal therapy** targets cancer cells that have estrogen and progesterone receptors. Some hormonal therapies, such as **tamoxifen** and **fulvestrant** (Faslodex), prevent estrogen signals from reaching cancer cells and telling them to grow. Other medicines, called **aromatase inhibitors**, prevent the body from making any estrogen or progesterone.

In general, aromatase inhibitors are given for 5 years as a daily pill. Some studies have shown that 10 years of tamoxifen may benefit some women more than the past standard of 5 years.

Another option supported by recent research is to take tamoxifen for up to 5 years, followed by 5 years of an aromatase inhibitor.

For premenopausal women (women who still have menstrual periods) with hormone receptor-positive breast cancer, tamoxifen is usually recommended. Aromatase inhibitors are only approved to treat hormone receptor-positive breast cancer in postmenopausal women.

There are also other ways to stop the ovaries from making estrogen:

- **Ovarian suppression** medicines are given by injection and can be taken alone or with other treatments for hormone receptor-positive breast cancer. In some cases, premenopausal women can take aromatase inhibitors if they are also taking ovarian suppression medicines.
- **Oophorectomy** is surgery to remove the ovaries, permanently stopping the ovaries from making estrogen. It's important to know that this surgery causes immediate and permanent menopause.

### **SIDE EFFECTS OF HORMONAL THERAPY, OVARIAN SUPPRESSION, AND OOPHORECTOMY**

With all these treatments, the most common side effects are hot flashes, fatigue, difficulty sleeping, night sweats, and vaginal dryness. Aromatase inhibitors cause joint pain and muscle aches in about half of women who take them.

There can also be these serious side effects:

- Tamoxifen can bring a slight increased risk of endometrial (uterine) cancer.
- Fulvestrant can cause higher liver enzymes, which can sometimes lead to liver damage.
- Aromatase inhibitors can increase the risk of osteoporosis, bone breaks, and high blood cholesterol.
- Both tamoxifen and aromatase inhibitors carry an increased risk of blood clots and stroke.

If your healthcare team has recommended hormonal therapy, ovarian suppression, or oophorectomy for you, let them know if you have any history of heart problems or other medical conditions. Tell them about any other medicines or supplements you are taking. Talking with your doctor about the risks, benefits, and side effects of each treatment can help you decide what's best for you.

Learn more at [lbbc.org/treatments](https://lbbc.org/treatments).

## Immunotherapy

Immunotherapy is the use of medicines to help the body's own immune system recognize and destroy cancer cells. There is one immunotherapy currently approved by the FDA to treat certain types of breast cancer: pembrolizumab (Keytruda). Pembrolizumab can be given with chemotherapy to treat early-stage triple-negative breast cancer that has a high risk of coming back; for these cancers, pembrolizumab is given before and after surgery.

Immunotherapy medicines are usually given with chemotherapy through an IV infusion into a vein every few weeks.

Immunotherapy side effects can include fatigue, body aches, fever, and stomach upset. Immunotherapy can also affect healthy cells in any organ system, such as the lungs, kidneys, colon, or reproductive system. If immunotherapy has been recommended for you, talk with your healthcare team about what to expect and ways to manage side effects. You can learn more about immunotherapy at [lbbc.org/treatments](https://lbbc.org/treatments).

## Complementary and integrative medicine

Complementary and integrative medicine (CIM) helps many people manage some of the side effects that come with standard cancer treatment. CIM includes therapies such as acupuncture, massage, mindfulness-based stress reduction (MBSR), journaling, creative arts, and yoga.

Some complementary therapies have been shown to decrease nausea, pain, anxiety, and depression. Complementary therapies are used in addition to—not instead of—traditional

medical treatments. Ask your care team if complementary therapies are available at your cancer center or in your community.

Some complementary therapies can interfere with medical treatment, so talk with your doctor about any potential interactions. For more information, visit [lbbc.org/complementary](https://lbbc.org/complementary).



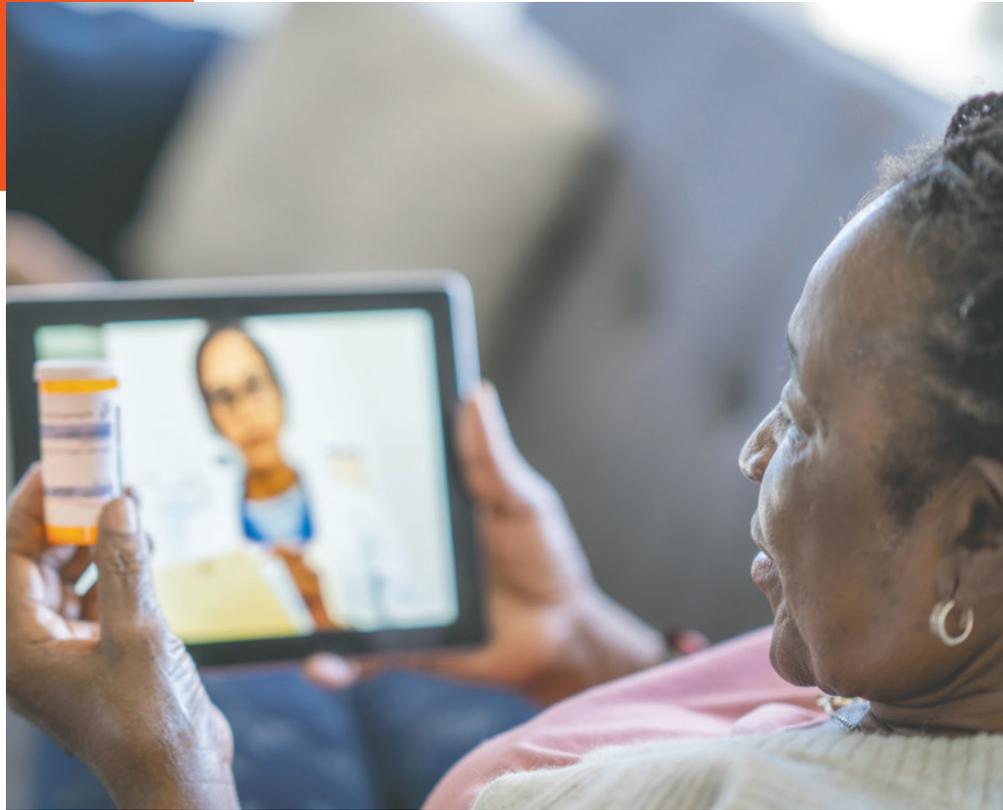
Complementary therapies are used in addition to—not instead of—traditional medical treatments.



## Clinical trials

A **clinical trial** is a research study that tests the safety and effectiveness of new treatments. These new therapies or combinations of therapies may work better than the standard treatment, or they may be as effective but have fewer side effects. Participating in a clinical trial may allow you access to these treatments before they become widely available. Clinical trials generally do not involve extra out-of-pocket costs to participants.

Each clinical trial explains the requirements to join, such as your diagnosis details and any past treatments you had. An **Institutional Review Board**, made up of health professionals and laypeople, reviews the safety and ethics of each trial to protect the rights of participants according to federal and state laws.



Clinical trial participation is voluntary. If you decide to join a trial, the trial team will take you through a process called **informed consent**, telling you the risks and benefits of the study. You will be given an informed consent document that explains all parts of the study, including the treatment options, tests, side effects, risks, and benefits. During the trial, information is reported to a **Data and Safety Monitoring Board**, an independent group not involved with the trial.

Through clinical trials, new and possibly more effective breast cancer treatments are being developed all the time. You always have the option to ask about joining a clinical trial at any point in your treatment.

## Should you get a second opinion?

Getting a second opinion can be helpful in a few ways. It can confirm your diagnosis, allow you to talk with another doctor about treatment options, and give you peace of mind about your decisions.

While it's normal to feel a sense of urgency to make decisions, in most cases, breast cancer is not an emergency and there is time to get a second opinion if you want one. Ask your doctor how much time you may take before starting treatment.

Most private and public insurance plans cover a second opinion. You can find a second opinion doctor by asking your current doctor for a referral or by visiting websites of other hospitals or cancer centers near you. Most healthcare professionals will be comfortable if you let them know you want a second opinion. If not, consider finding a new doctor for your treatment.

## Making treatment decisions

Deciding on a treatment plan can mean many conversations with your healthcare team, loved ones, and others who've been treated for breast cancer. It can also mean taking time to read about options.

No matter what your situation is, think about both your medical and emotional needs. Ask yourself: Does one treatment work better for my lifestyle? Is one more effective against the cancer? How much risk am I willing to tolerate for the benefit of the treatment?

Make an appointment with your doctor and ask to discuss what it may be like to undergo each possible treatment, step by step. Bring someone with you to take notes. Ask questions until you feel you understand your options. Use our "10 Questions to ask your doctor about treatment" list on page 37.

If you have other questions but aren't sure how to ask them, or if you just want to talk more about your experience, contact LBBC's Breast Cancer Helpline at [lbbc.org/community](https://lbbc.org/community).



Ask yourself:  
Does one treatment work better for my lifestyle? Is one more effective against the cancer? How much risk am I willing to tolerate for the benefit of the treatment?

## 10 QUESTIONS TO ASK YOUR DOCTOR ABOUT TREATMENT

1. Why are you recommending this treatment for me?
2. What are the benefits and risks of this treatment?
3. What are the possible short-term and long-term side effects of this treatment?
4. Can I take part in any clinical trials?
5. When will the treatment start, how often will I have it, and how long will it last?
6. How can I expect to feel during treatment and in the weeks afterward?
7. Will I need to take time off from work or make any work accommodations during treatment?
8. How will I know if the treatment is working?
9. How effective is this treatment?
10. Are there other treatments for me to consider? What are the pros and cons of those treatments?





The help to get you through

# tomorrow

Many people feel a sense of relief after making their initial treatment decisions and choosing a healthcare team. Others feel anxiety or fear. Your feelings are reasonable responses to having your life turned upside down by a diagnosis of breast cancer.

A good next step is thinking about the kind of support you want around you. During your initial treatment, you will be busy with doctors' appointments, procedures, tests, and follow-up visits. Which friends or family members make you feel safest and most comfortable? Who can you count on if you need a hand or if you just want someone to listen? Will you

want some time alone to gather your thoughts? Does anyone close to you have medical experience or personal experience with breast cancer? Sometimes these people have special understanding and can help you.

## Asking for help

Most of us are used to caring for others, whether that means earning money to support our families, managing a busy household, or giving emotional support. However you look at it, breast cancer puts many of us in the unfamiliar position of asking others for help.

No one expects you to be superhuman while you are getting cancer treatment. Accepting support can allow you the energy to focus on your health and well-being. Give yourself permission to ask for help—even if it makes you feel a little uncomfortable.

Help means different things to different people, so think about what it means to you. Maybe you want help with practical tasks, such as running errands, cooking meals, or paying bills.

Help can also mean having someone to take you to doctors' appointments or reach out to family and friends with updates about your treatment.

And help can be having someone to spend an hour with you talking about something other than cancer treatment.

Many people will want to help you, and giving them something to do will make them feel useful. Be specific about what you want—and what you don't want—so you will get what you need.

## **10 TIPS FOR GETTING GOOD SUPPORT**

- 1.** Surround yourself with good listeners.
- 2.** Be as open as you can about what you are thinking and feeling. Some people may be afraid to ask.
- 3.** Avoid people who make you feel uncomfortable.
- 4.** Ask other people who had breast cancer about resources that they found helpful. Join one of LBBC's online groups at [lbbc.org](http://lbbc.org) to get peer support.
- 5.** If you're not feeling heard, let people know when you need them to listen. Say, "I need you to sit down, look at me and listen to me for a few minutes so I know you're hearing what I'm saying."
- 6.** Be specific about what you need.
- 7.** Be specific about what you don't need. If people try to do something for you that you would rather do yourself, let them know. If you want to talk about something other than cancer, let them know.
- 8.** Talk with people who put you at ease—a partner, friend, or healthcare provider—and ask for tips on asking for help.
- 9.** If someone starts to tell you stories or give you advice you don't want to hear, ask the person to stop. Don't be afraid to be blunt. Say, "Please stop. This is not helpful to me."
- 10.** Contact our Breast Cancer Helpline at [lbbc.org](http://lbbc.org) or toll-free at (888) 753-5222 and talk with someone who has had breast cancer about how they asked family and friends for help.





## Where to find support

Sometimes it helps to have support outside of family and friends. If you are looking for this kind of support, your treatment center is a great place to start. Let your doctors, nurses, or nurse or patient navigator know how you're feeling, and ask to speak with an oncology social worker or counselor.

If you feel comfortable in groups, ask your oncology nurse or social worker to recommend a support group. If you prefer talking with someone alone, ask to be referred to a licensed mental health professional—a social worker, psychologist, counselor, or psychiatrist.

Some people find great comfort in religious or spiritual communities such as churches, synagogues, temples, or mosques. And if you're a member of a volunteer group or community organization, it's very possible that

there are others in the group whose lives have been touched by breast cancer. Letting people in your groups know about your situation can result in extra support.

Sometimes you just want to talk with someone who knows what you are going through. Ask your healthcare team for the names of breast cancer groups that can connect you directly with people affected by breast cancer. We invite you to join one of our online communities and to connect with our Breast Cancer Helpline at [lbbc.org/community](https://lbbc.org/community).

LBBC and other breast cancer organizations offer many other ways for you to meet people. At LBBC, we offer in-person experiences and on-demand emotional, practical, evidence-based content on our website, [lbbc.org](https://lbbc.org). Many groups offer a variety of programs, and you can choose the ones that best meet your needs and fit your personality.

No one expects you to be superhuman while you are getting cancer treatment. Accepting support can allow you the energy to focus on your health and well-being.



# LIVING your life

## BEYOND BREAST CANCER

Breast cancer treatment affects many areas of your life, both physically and emotionally. It can disrupt plans, family life, work, and finances. It can also impact the most private parts of life, including relationships with partners, parents, friends, coworkers, and yourself. It can change sexual intimacy and the ways you and your partner communicate. And it can affect the way you feel about your body.

These life changes start with your diagnosis, but they do not always end with your last treatment. People who have not had cancer may not understand this. Some people expect your life to go “back to normal” or return to the way it was before your diagnosis. That will be the case for some people. But for many others, breast cancer changes their

outlook and perspective in different ways. Physical recovery after active treatment ends can take 6 or more months, and many different feelings can come up during this time.

## How LBBC can help

LBBC seeks to create a world that understands there is more than one way to have breast cancer. It’s normal to feel concerned about your long-term health or emotional well-being. Some people experience sadness, or a sense of lost control because the period of active treatment is over. Many people who’ve been treated for cancer worry that cancer could return. You are finding a new normal—integrating a history with breast cancer into your

whole life experience. Allow yourself the time, space, and support you need.

Even if your treatment has ended, LBBC is still here for you. We are committed to sharing the diversity of the lived experience of breast cancer. If you are having difficulties or just want to talk, contact our **Breast Cancer Helpline** at [lbbc.org](https://lbbc.org) or toll-free at **(888) 753-5222**. All volunteers have had breast cancer, so they know what you are going through. Together, we can help you put breast cancer into context—and help you learn how to live with, and beyond, your experiences with it.



## **10 TIPS TO LESSEN STRESS AND ANXIETY**

- 1.** Surround yourself with supportive people. This is not the time to take care of the “difficult” people in your life.
- 2.** Maintain a healthy lifestyle. Sleep well, eat well, and exercise, even when you don’t feel like it. Go for a walk, do some stretches, or ride a bike.
- 3.** Ask your doctor about trying a complementary therapy such as acupuncture or meditation.
- 4.** Write your thoughts and feelings in a notebook or a blog. Send it to people who want to know how you’re doing so you don’t have to say the same things over and over again.
- 5.** Take an arts-and-crafts or adult education class to immerse yourself in something unrelated to breast cancer.
- 6.** Keep a schedule, either your regular one or a new one. Keep up with your normal activities as much as possible.
- 7.** Wear clothes that make you feel comfortable and good about yourself. Some people feel better when they put on a little makeup or a piece of jewelry.
- 8.** Get professional help if you want it. See a family therapist with your children, a social worker or counselor, or a psychotherapist.
- 9.** Volunteer for a breast cancer organization or other group unrelated to cancer.
- 10.** Find and talk with others who have had breast cancer, through friends or your hospital. At [lbbc.org](http://lbbc.org), you’ll find a range of resource and support options, including links to LBBC’s online groups to get peer support.



# Resources

Living Beyond Breast Cancer is here for you, no matter what your stage of treatment or recovery. These organizations can help you and your loved ones find more information and support.

## Financial

**CancerCare**

(800) 813-4673  
cancercares.org

**Forward4Tobi**

(847) 894-6650  
forward4tobi.org

**HealthWell Foundation**

(800) 675-8416  
healthwellfoundation.org

**Living Beyond Breast Cancer Fund**

(855) 807-6386  
lbbc.org/fund

**PAN Foundation**

(866) 316-7263  
panfoundation.org

**The Pink Fund**

(877) 234-7465  
pinkfund.org



## People of color

### Asian and Pacific Islander

#### American Health Forum

(415) 954-9988

apiahf.org

### The Chrysalis Initiative

(800) 929-4979

thechrysalisinitiative.org

### Dia de la Mujer Latina

(281) 489-1111

diadelamujerlatina.org

### For the Breast of Us

breastofus.com

### Intercultural Cancer Council and Caucus

iccnetwork.org

### Native American Cancer Initiatives, Inc

(303) 838-9359

natamcancer.org

### Nueva Vida

(202) 223-9100

nueva-vida.org

### Sisters Network

(866) 781-1808

sistersnetworkinc.org

### Touch, the Black Breast Cancer Alliance

(443) 758-1924

touchbbca.org

## Specific cancer diagnoses and situations

### HEREDITARY

facingourrisk.org

### INFLAMMATORY BREAST CANCER

eraseibc.org

ibcresearch.org

### LYMPHEDEMA

#### LymphedIVAs

(866) 411-3482

lymphedivas.com

#### LymphNotes

LymphNotes.com

### Lymphology Association of North America

(773) 756-8971

clt-lana.org

### National Lymphedema Network

(800) 541-3259

lymphnet.org

### MALE BREAST CANCER

hisbreastcancer.org

mbcglobalalliance.org

### METASTATIC BREAST CANCER

mbcn.org

metavivor.org

mbcalliance.org

mbcbrainmets.org

projectlifembc.com

theresasresearch.org

twistedpink.org

### PREMENOPAUSAL

livestrong.org/we-can-help/fertility-  
services

rethinkbreastcancer.com

tigerlilyfoundation.org

youngsurvival.org

### TRIPLE-NEGATIVE BREAST CANCER

tnbcfoundation.org

## Support & information

### American Cancer Society

(800) 227-2345

cancer.org

### Cancer Support Community

(888) 793-9355

cancersupportcommunity.org

### CancerCare

(800) 813-4673

cancercares.org

### CancerConnect

(208) 727-6880

cancerconnect.com

### FORCE: Facing Our Risk of Cancer Empowered

(866) 288-7475

facingourrisk.org

### Imerman Angels

(866) 463-7626

imermanangels.org

### Livestrong

(855) 220-7777

livestrong.org

### Living Beyond Breast Cancer

(888) 753-5222

lbbc.org

### SHARE

(844) 275-7427

sharecancersupport.org

### Sharsheret

(866) 474-2774

sharsheret.org

### Susan G. Komen

(877) 465-6636

komen.org

### Triage Cancer

(424) 258-4628

triagecancer.org

### The Tutu Project

(201) 785-7974

thetutuproject.com

### Young Survival Coalition

(877) 972-1011

youngsurvival.org

## Words to know

**Adjuvant therapy.** Treatment given after removing the cancer with surgery.

**Anemia.** A lower number of red blood cells than normal. Can cause fatigue and shortness of breath.

**Axillary lymph node dissection.**

Surgery to remove lymph nodes under the armpit to check for cancer.

**Axillary lymph nodes.** The lymph nodes in the armpit.

**Biopsy.** Taking a tissue sample from the breast and looking at it under a microscope.

**Bone scan.** Imaging test that uses a small amount of radioactive substance to look for cancer in the bones.

**Breastbone.** Long, flat bone in the center of the chest wall. Attached to the collarbone and first seven ribs. Also called the sternum.

**Breast cancer.** Any of several types of cancers that start in the ducts, lobules, or other tissues of the breast.

**CAT scan.** A test that takes a series of three-dimensional pictures of organs, including the bones, liver, lungs, brain, and lymph nodes. Also called CT scan or computerized tomography scan.

**Chemobrain.** Problems with thinking and short-term memory after cancer treatment.

**Chest wall.** The muscles, bones, and joints that make up the area between the neck and abdomen.

**Chest x-ray.** Test that takes a picture of the lungs, heart, airways, blood vessels, and bones in the chest and upper back.

**Collarbone.** One of two bones at the base of the front of the neck. The collarbone connects the breastbone to the shoulder blades. Also called clavicle.

**Combination therapy.** Two or more medicines given together.

**Definitive surgery.** Final surgery that results in negative (cancer-free) margins. Also known as curative surgery.

**Distant recurrence.** Cancer that has spread to areas far away from where it first started. See recurrence.

**DNA.** The information that makes up the genes of a cell.

**Ductal carcinoma in situ (DCIS).** See in situ.

**Ducts.** Passageways that carry milk from the lobules in the breast to the nipple.

**Early-stage.** Breast cancer that has not traveled outside the breast or axillary lymph nodes.

**Estrogen receptor-positive.** Breast cancer that has some levels of estrogen receptors that stimulate the cancer to grow. See hormone receptor-positive.

**Fertility.** A person's ability to have children.

**Fractures.** Breaks, usually in a bone.

**Genetic testing for an inherited mutation.** Tests that look for inherited mutations in the DNA that may increase the risk of breast cancer.

**Genomic tests.** Tumor biomarker tests that look at groups of genes in cancer cells to see whether they are present, absent, or too active. Genomic tests help guide treatment decisions.

**Grade.** A score that describes how abnormally the cancer cells behave and look compared to healthy breast cells.

**Gross description.** A written description of what the pathologist sees with the naked eye when looking at cancerous tissue.

**Growth factors.** Medicines that boost the production of blood cells. Often used for white blood cell growth to help fight infection.

**HER2-positive.** A term that describes cancer cells that make too much of a protein called HER2. HER2 controls how cancer cells grow, divide, and repair themselves.

**Hormone receptor-positive.** A term that describes cancer cells that receive signals telling them to grow in the presence of estrogen or progesterone, natural hormones in the body.

**Infiltrating.** See invasive.

**Inflammatory breast cancer.** A type of breast cancer in which the breast may appear red and swollen and feel warm. Inflammatory breast cancer cells block lymph vessels in the skin.

**In situ.** In the place where it started. Ductal carcinoma in situ (DCIS) means the breast cancer stays inside the ducts of the breast. People with DCIS are at increased risk of developing invasive cancers.

**Internal mammary lymph nodes.** Lymph nodes near the breastbone.

**Intravenous.** Given by vein.

**Invasive.** Cancer that grows outside the ducts or lobules of the breast and invades nearby tissues. This type of breast cancer has the potential to travel outside the breast to other parts of the body.

**Lobules.** Glands that make breast milk.

**Local recurrence.** The return of cancer in the site where it started. See recurrence.

**Local therapy.** Treatments that kill the cancer in the place where it started. Examples are surgery and radiation treatment.

**Lymph nodes.** Small, bean-shaped structures containing lymphatic fluid and white blood cells that filter bacteria and waste from the body.

**Lymphedema.** A condition in which too much lymph fluid collects in tissues and causes swelling.

**Malignant.** Cancerous.

**Mammogram.** An x-ray photograph to look for breast cancer and other problems in the breast.

**Margin.** A rim of healthy tissue around a breast tumor.

**Metastatic.** When cancer travels outside the ducts or lobules of the breast to the lungs, liver, bones, or brain. Metastatic breast cancer is also known as stage IV breast cancer.

**Mitotic rate.** How quickly cancer cells are dividing.

**MRI.** A test that uses magnets and radio waves to take pictures of part of the breast. Also called magnetic resonance imaging.

**Mutation.** A change or alteration in a cell's genetic information. As the cell makes more copies of itself, the copies will also have the change.

**Neoadjuvant therapy.** Treatment given before removing the cancer with surgery.

**Noninvasive.** Cancer that stays inside the ducts or the lobules of the breast. Also see in situ.

**Oncologist.** A doctor with special training in cancer.

**Partial breast radiation.** Treatment that delivers radiation to only the part of the breast where the tumor was found.

**Pathology report.** A report that describes the cells and tissues of a cancer, based on looking at them through a microscope.

**PET scan.** A test that looks for cancer throughout the body. Also called positron emission tomography.

**Port.** A small device, surgically inserted under the skin, that gives doctors easy access to veins to take blood or give medicine. Also called mediport or port-a-cath.

**Prosthesis.** An artificial breast that fits into a bra.

**Radiation therapy.** Treatment that directs high-energy x-rays to a specific part of the body to kill cancer cells or slow their growth.

**Reconstruction.** Surgery to rebuild the breast.

**Recurrence.** When breast cancer comes back after treatment. It can come back in the same place (local recurrence) or in a place far away from where it started (distant recurrence).

**Scalp cooling.** A therapy that involves cooling the scalp during chemotherapy treatments to prevent or manage hair loss.

**Sentinel lymph node biopsy.** Surgery to check for cancer in the first lymph nodes in the armpit where cancer is likely to travel.

**Side effect.** A consequence of treatment. Examples are fatigue, nausea, and dry mouth.

**Single-agent therapy.** When one medicine is given at a time.

**Stage.** A term that helps describes the extent of cancer in the body based on size and presence of cancer in the lymph nodes and if the cancer has spread to other places.

**Supraclavicular lymph nodes.** The lymph nodes above the collarbone.

**Systemic therapy.** Treatments that travel through the blood to kill cancer throughout the body. Examples are chemotherapy and targeted therapy.

**Triple-negative.** A term that describes a breast cancer cell that tests negative for estrogen receptors, progesterone receptors, and HER2 receptors.

**Tumor grade.** See grade.

**Ultrasound.** A test that uses high-frequency sound waves to take pictures of areas inside the body.

**Vessels.** Small, hollow tubes that carry cells or fluids, such as blood, to different places inside the body.

**White blood cells.** Cells that protect you from infection.

**Whole breast radiation.** Treatment that delivers radiation to the whole breast.







Living Beyond Breast Cancer is a national nonprofit organization that seeks to create a world that understands there is more than one way to have breast cancer. To fulfill our mission of providing trusted information and a community of support, we offer on-demand emotional, practical, and evidence-based content that is meaningful to those newly diagnosed, in treatment, post-treatment, and living with metastatic disease.

For over 30 years, Living Beyond Breast Cancer has imparted wisdom and connection via conferences, events, a peer-to-peer helpline, and more. Today, we remain committed to creating a culture of acceptance—where sharing the diversity of the lived experience of breast cancer fosters self-advocacy and hope.

This brochure is designed for educational and informational purposes only, as a resource to individuals affected by breast cancer. The information provided is general in nature. For answers to specific healthcare questions or concerns, you should consult your healthcare provider, as treatment for different people varies with individual circumstances. The content is not intended in any way to substitute for professional counseling or medical advice.

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