



**Just Diagnosed with
Breast Cancer...**
Now What?

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Just Diagnosed with Breast Cancer...

Now What?



Hearing the words, “You have breast cancer,” changes everything in a moment. Many aspects of life suddenly look and feel different as you begin to accept such a profound diagnosis and start to wonder what the future may hold. In the beginning, there’s a lot of new information to take in: new vocabulary, new doctors and specialists, different treatment options, and a new way of living. It’s normal to feel overwhelmed.

We created this guide with newly diagnosed patients and their loved ones in mind, to help answer some basic questions about breast cancer, the doctors and specialists who may comprise your care team, the meanings of some new words you may hear at your appointments, and resources that can help support you and your loved ones as you embark on this new journey.

We hope that you find this information helpful and encouraging. Remember that NBCF is here for you at every step of your breast cancer journey. While the eBook will not contain all the information you may need, please reach out to help@nbcf.org or visit nbcf.org at any time for additional help and support.



Breast Cancer Basics

A breast cancer diagnosis comes with a lot of medical jargon and words that may not be familiar to someone who doesn't have a background in medicine. Here is a list of common terms to know when you are first diagnosed with breast cancer.

Glossary of Common Breast Cancer Terms (in alphabetical order)

- **Benign:** A tumor that is not cancerous or malignant.
- **BRCA:** An abbreviation for "BRest CAncer" gene mutation. There are two types of BRCA gene mutations that have been found to impact a person's chances of developing breast cancer: BRCA1 and BRCA2.
- **Biopsy:** A medical test that removes a sample of tissue or fluid from a suspicious area. The removed sample is examined in a laboratory to check for the presence of cancer or other abnormalities.
- **Chemotherapy:** A cancer treatment method that uses a combination of drugs to either destroy cancer cells or slow down the growth of cancer cells. Chemotherapy is a systemic therapy, meaning that the drugs travel in the bloodstream throughout the entire body. Chemotherapy can be given in the form of an IV (infusion) therapy or as an oral (pill) therapy. The method of receiving the treatment is unrelated to its effectiveness.
- **Chemo brain:** A common term used by cancer patients and survivors to describe the potential side effects of chemotherapy, including brain fog, cognitive impairment

or dysfunction, or thinking or memory problems that can occur during and after cancer treatment.

- **Dense breasts:** Breast tissue with a high concentration of fibroglandular tissue. Dense breast tissue is a [risk factor](#) for developing breast cancer and can make mammograms more difficult to read.
- **Docetaxel:** A type of chemotherapy called a taxane. Docetaxel is often used to treat breast, lung, prostate, stomach, and head and neck cancers. It works to stop the growth of cancer cells by blocking cell division.
- **Ductal carcinoma in situ (DCIS):** An early and non-invasive type of breast cancer where abnormal cells have been found in the lining of the breast milk ducts, where the abnormal cells have not spread outside of the ducts. DCIS is [Stage 0](#) breast cancer, meaning that the cancer is non-invasive and has not spread beyond the original site of the cancerous growth.
- **Grade:** Breast cancer cells are assigned a level, or a grade, after they are removed from the breast and studied in a lab. A cancer's grade is used to help predict the outcome (prognosis) of the disease and to determine what treatments might work best. The assigned grade (Grade 1-3) is based on how much the cancer cells look like normal cells.
 - » **Grade 1 (low):** The cancer is slower-growing and less likely to spread.
 - » **Grade 2 (intermediate):** The cancer is growing faster than a Grade 1 cancer but slower than a Grade 3 cancer.
 - » **Grade 3 (high):** The cancer is faster-growing and is more likely to spread.
- **Herceptin:** A drug that can be used to treat HER2-positive breast cancer that is early-stage, advanced-stage, or metastatic. The chemical name for Herceptin is trastuzumab.

- **HER2:** HER2 stands for “human epidermal growth factor receptor 2.” HER2 proteins are found on the surface of breast cells and are involved in normal cell growth. If a person’s HER2 protein levels are higher than usual, or overexpressed, it can cause cancer to grow and spread more quickly.
 - » **HER2-positive and HER2-low:** If breast cancer cells have abnormally high levels of HER2 proteins, the breast cancer is considered HER2-positive (elevated levels of HER2 proteins) or HER2-low (slightly elevated levels of HER2 proteins). HER2-positive and HER2-low breast cancers can cause the cancer cells to multiply and spread more quickly. HER2-positive and HER2-low breast cancers are primarily treated with biologic targeted therapy, such as Herceptin.
 - » **HER2-negative:** If breast cancer cells do not have elevated levels of HER2 proteins, the breast cancer is considered HER2-negative. HER2-negative breast cancer is not treated with biologic targeted therapy. Depending on the size of the tumor, hormone receptors, and other factors, it might be treated with chemotherapy.
- **Hormonal therapy:** A type of drug therapy that keeps breast cancer cells from receiving or using the natural female hormones in the body (estrogen and progesterone) which they need to grow. Hormonal therapy also blocks the ability of healthy breast cells to receive hormones that could stimulate breast cancer cells to regrow in the form of recurrence of the breast cancer within the breast or elsewhere in the body. Hormonal therapy is not considered an applicable treatment for triple negative breast cancer.
- **In situ:** Latin for “in the original place.” The earliest stage of cancer is called “carcinoma in situ,” or “cancer in the original place,” meaning it has not spread from the original location.

- **Inflammatory breast cancer (IBC):** A rare and aggressive type of breast cancer, IBC occurs when cancer cells infiltrate the skin and lymph vessels of the breast. IBC is harder to diagnose than other types of breast cancer and tends to occur in younger women. It also spreads more quickly than other types of breast cancer. IBC is classified as Stage 3 breast cancer since it includes cancer of the skin of the breast. If the cancer has spread outside of the breast and skin to other organs of the body, it is classified as Stage 4 breast cancer.
- **Infusion:** The slow injection of a substance into a vein or tissue. Chemotherapy, biologic targeted therapy, and immunotherapy are generally delivered through an infusion, or an injection of the drugs into the body.
- **Invasive ductal carcinoma (IDC):** Invasive breast cancer where abnormal cancer cells that began forming in milk ducts have spread beyond the ducts into other parts of the breast tissue. IDC is the most common type of breast cancer, making up 70-80% of all breast cancer diagnoses.
- **Invasive lobular cancer (ILC):** Invasive breast cancer that begins in the lobules (milk glands) of the breast and spreads to surrounding normal tissue. It can also spread through the blood and lymph systems to other parts of the body. ILC is the second most common type of breast cancer, accounting for 12-15% of breast cancer diagnoses.
- **Lobular carcinoma in situ (LCIS):** LCIS is not breast cancer. It is a condition where abnormal cells are found in the lobules of the breast. The atypical cells have not spread outside of the lobules into the surrounding breast tissue. LCIS is a marker for increased risk of getting breast cancer in the future. Someone with LCIS found on a breast biopsy might be followed in a high-risk clinic as well as receive a hormonal therapy drug, like Tamoxifen, to reduce their risk.

- **Lumpectomy:** A surgical treatment for breast cancer in which the primary breast cancer tumor and a margin of healthy tissue around the tumor is removed, but not the entire breast itself. Lumpectomy may be used in conjunction with other treatments, such as chemotherapy or radiation.
- **Lymphedema:** A chronic condition that is caused by a disruption or damage to the normal drainage pattern in the lymph nodes. It most often causes swelling of the arm, but it can also affect the breast, chest, and sometimes even the legs. Removing the axillary lymph nodes as part of breast cancer treatment increases your risk for developing lymphedema.
- **Malignant:** A tumor that is cancerous.
- **Mammogram:** Used for the early detection or the diagnosis of breast cancer, a mammogram is an x-ray of the breast that allows a qualified specialist to examine the breast tissue for any suspicious areas.
- **Mastectomy:** A surgical treatment for breast cancer in which tissue is removed from one or both breasts. Mastectomy may be used in conjunction with other treatment options, such as chemotherapy or radiation. There are different types of mastectomies:
 - » **Total simple mastectomy:** Surgical removal of the entire breast, including the breast tissue, nipple, areola, sentinel lymph node, and breast skin.
 - » **Skin-sparing mastectomy:** Surgical removal of the breast tissue, nipple, areola, and sentinel lymph node. This type leaves the breast skin intact for surgical breast reconstruction.
 - » **Nipple-sparing mastectomy:** Surgical removal of the breast tissue like the skin-sparing mastectomy but also preserves the nipple and areola.
 - » **Modified radical mastectomy:** Surgical removal of

the entire breast, nipple, areola, and axillary lymph nodes, but often leaves the chest wall intact.

- » **Double (or bilateral) mastectomy:** Surgical removal of both breasts.
- » **Unilateral mastectomy:** Surgical removal of one breast.
- » **Preventative (or prophylactic) mastectomy:** Surgical removal of both breasts before cancer has developed. Those at high genetic risk for breast cancer may choose to have a preventative mastectomy to reduce their risk of developing breast cancer in the future.
- **Metastatic breast cancer:** Classified as Stage 4 breast cancer, metastatic breast cancer (MBC) occurs when breast cancer has spread, or metastasized, to other parts of the body, such as the lungs, liver, bones, or brain. Although MBC is not curable, it is treatable, with more and more women living longer by managing the disease as a chronic illness with a focus on quality of life as a primary goal.
- **Palliative care:** Specialized medical care that focuses on the management of symptoms or side effects that are disruptive to a patient's quality of life. It is designed for those who have a serious, life-threatening, or terminal illness but does not replace the patient's primary treatment. The goal of palliative care is to either restore or preserve quality of life.
- **PET scan:** Positron emission tomography, or PET scan, is an imaging test that uses a radioactive substance, called a tracer, to check for the spread of breast cancer throughout the body. The tracer helps identify areas that may not be visible on an MRI or CT scan.
- **Prognosis:** A doctor's prediction of the course and outcome of a medical condition, such as cancer.
- **Radiation:** A type of breast cancer treatment that uses high-energy rays to kill cancerous cells. It affects cells only in the part of the body receiving the radiation.

- **Reconstruction:** Surgery to recreate the breast(s) after mastectomy. Some types of reconstruction use breast implants, while others may use fatty tissue from your own body (such as the stomach, buttocks, or inner thigh) to form a breast. Reconstruction may be performed at the same time as a mastectomy or may occur months or years later.
- **Recurrence:** When breast cancer returns after completion of initial treatments.
 - » **Local recurrence:** Breast cancer returns in the same breast as the original tumor.
 - » **Regional recurrence:** Breast cancer returns near the original site, in lymph nodes in the armpit or collarbone.
 - » **Distant recurrence:** Breast cancer returns or spreads away from the original tumor to other parts of the body, such as the bones, lungs, liver, or brain. Metastatic breast cancer (MBC), or Stage 4 breast cancer, is a distant recurrence of breast cancer.
- **Red devil:** Chemotherapy drug doxorubicin is commonly referred to as the “red devil” due to its distinctive red color and because it may cause serious side effects, such as hair loss, nausea, and vomiting, in patients.
- **Stage:** Breast cancer stage is based on the size and location of the primary tumor and whether or not it has spread. There are multiple stages of breast cancer:
 - » **Stage 0:** The earliest stage of breast cancer. Stage 0 is non-invasive, meaning it hasn’t spread outside of its original location in the breast tissue, and is highly treatable when detected early.
 - » **Stage 1:** The earliest stage of what is considered

invasive breast cancer, meaning the cancer is no longer contained in its original location because it has spread to, or invaded, other areas of the body. Stage 1 breast cancer is considered early-stage, localized cancer and is highly treatable and survivable.

- » **Stage 2:** The breast cancer is growing, but it is still contained in the breast or growth has only extended to the nearby lymph nodes. Stage 2 breast cancer has two groups—Stage 2A or Stage 2B—depending on the size and location of the cancerous growth.
- » **Stage 3:** The breast cancer has extended beyond the immediate region of the tumor and may have invaded nearby lymph nodes and muscles, but has not spread to distant organs. Although this stage is considered to be advanced, there are a growing number of effective treatment options.
- » **Stage 4:** The cancer has spread, or metastasized, to other areas of the body, such as the brain, bones, lungs, or liver. Stage 4 breast cancer is also known as metastatic breast cancer.
- **Tamoxifen:** A hormone therapy drug that can prevent the original breast cancer from returning and can also help prevent the development of new breast cancers in the other breast or elsewhere in the body in the future. It is usually taken for a time period of 5 years after treatment for breast cancer.
- **Targeted therapy:** Also called biologic targeted therapy, a breast cancer treatment method that uses drugs to target specific proteins on cancer cells that may help them grow or spread. Targeted drugs work to destroy or slow down cancerous cell growth.

- **Thriver:** A term commonly used by metastatic breast cancer patients to describe themselves. “Thriver” is often used instead of “survivor” in the MBC community.
- **Triple negative breast cancer (TNBC):** A type of breast cancer in which the three most common types of receptors known to fuel most breast cancer growth—estrogen, progesterone, and the HER2/neu gene—are not present in the cancer tumor. Hormone therapy is not effective for TNBC, with the preferred treatment option being chemotherapy.
- **Tumor:** A mass of abnormal tissue. A tumor can be benign (non-cancerous) or malignant (cancerous).
- **Ultrasound:** A scan that uses penetrating sound waves that do not affect or damage the tissue and cannot be heard by humans. Ultrasound is used to investigate a suspicious area detected in the breast.

Use the space below to write down any new words or terms that you want to keep track of.



Breast Cancer Treatment Team

The list below will help explain what a typical breast cancer treatment team of doctors, nurses, and specialists may look like. Not all patients will need the services of every specialist listed.

Who's on Your Treatment Team?

Medical Oncologist

A medical oncologist is a doctor who specializes in the field of cancer. Your medical oncologist will be your primary source of care and information regarding medications, including chemotherapy (if deemed necessary), other treatment options, such as hormonal therapy or biologic targeted therapy, lab tests and results, managing side effects of treatment, and results of treatment. Your medical oncologist and their team of oncology nurses will be with you throughout your breast cancer journey.

Surgical Oncologist

A surgical oncologist is a surgeon who specializes in removing cancerous tumors through surgery. They will also discuss with you the order in which treatments should be done. Your surgical oncologist will collaborate with your medical oncologist to determine the best course of treatment and surgical options for your type of cancer.

Radiation Oncologist

A radiation oncologist is a doctor who specializes in treating cancer through using radiation therapy. Not every cancer patient will need radiation as part of their treatment plan. If you do need radiation therapy, the radiation oncologist and their team will guide you through the radiation treatment process.

Plastic Reconstruction Surgeon

A plastic reconstruction surgeon is a surgeon who

specializes in the reconstruction of the breasts, through surgery, after cancer removal surgery (mastectomy) or other therapy. Not all individuals will need or want breast reconstruction surgery as part of their breast cancer treatment journey.

Genetic Counselor

A genetic counselor is a medical professional who specializes in medical genetics and evaluates risks a patient may have for a genetic link to cancer. They will be able to evaluate your family history of breast cancer, conduct genetic testing, and/or review your medical history to help assess your risk and the potential risk of other family members. Not every patient will need or want the services of a genetic counselor. Ask your treatment team, including your oncologist and surgeon, if they recommend genetic counseling in your case.

Patient Navigator

A patient navigator is an individual such as a nurse, social worker, community health worker, or other healthcare professional, who can help guide patients through and around the barriers in the complex cancer care system. These barriers to care can include things like the cost of treatment and other financial concerns, such as missed time from work, being uninsured, fear surrounding your diagnosis or treatment, misinformation surrounding the disease, or language barriers. Many patients even consider their patient navigators their “lifelines” as they undergo breast cancer treatment.

NBCF supports patient navigators at many of our partner hospitals throughout the nation. Visit nbcf.org/patient-navigation to search for an NBCF-funded patient navigator at a partner facility near you. If there is not an NBCF partner hospital or facility in your area, call your local hospital and ask to speak to a social worker, patient navigator, or nurse navigator. This person will know about the availability of resources in your area. For additional questions, you can reach out to NBCF at help@nbcf.org.

Breast Cancer Treatment Options

There are several treatment options currently available for breast cancer. The best course of treatment for you will depend on the type and stage of breast cancer you have. Below is a list of some of the most common breast cancer treatment options. This is not an exhaustive list, and all breast cancer treatment options and details should be discussed with your care team.

Types of Treatment

Surgery



Surgery is the most common treatment for breast cancer. Breast cancer surgery involves removing the tumor and nearby margins of tissue. Surgical options may include lumpectomy, mastectomy, radical mastectomy, and breast reconstruction. Surgery is often used in conjunction with other types of treatment, such as chemotherapy. Learn more about breast cancer surgery options in the free Breast Cancer Surgery eBook.

Chemotherapy



Chemotherapy treatment uses a combination of drugs to either destroy cancer cells or slow down the growth of cancer cells. Chemotherapy is a systemic therapy, meaning that the drugs travel in the bloodstream throughout the entire body. There are several types of chemotherapy drugs available. Patients often report side effects such as fatigue, nausea, and hair loss from chemotherapy.

Radiation



Radiation uses high-energy rays to kill cancerous cells. It is targeted at only one area of the body and affects only the cells in the area being targeted. Radiation is often used after cancer surgery to ensure the cancer does not return to the affected area.

Hormonal Therapy



Hormonal therapy is a type of drug therapy that keeps breast cancer cells from receiving or using natural female hormones (estrogen and progesterone), which they need to grow. Hormonal therapy also blocks the ability of healthy breast cells to receive hormones that could stimulate cancer cells to regrow, or recur, within the breast or elsewhere in the body.

Targeted Therapy



Targeted therapy uses drugs to target specific proteins in cancer cells that may help them grow or spread. Targeted therapy drugs work to destroy or slow down cancerous cell growth.

Breast Cancer Treatment Side Effects

No matter the course of treatment chosen by you and your care team, most patients are likely to experience breast cancer treatment side effects. Treatment side effects can vary widely from person to person. Some may experience mild side effects that cause little interruption to daily life, while others may experience more severe side effects that impact their daily lives. Always discuss any new or worsening side effects with your care team.

Resources: From Diagnosis to Treatment to Recovery

NBCF is committed to helping women at every step of their breast cancer journey, from diagnosis and treatment to recovery and survivorship. To that end, we have created dozens of helpful resources, available for free to all patients, caregivers, and loved ones. Below are several key resources that you may find helpful as you begin your breast cancer journey.

Emotional Care and Support

HOPE Kit

A HOPE Kit is a tangible expression of hope, providing comfort and encouragement to women undergoing breast cancer treatment. Each HOPE Kit is filled with thoughtfully selected items to not only brighten a patient's day, but also ease some of the side effects caused by treatment. Each HOPE Kit contains:

- Fuzzy socks
- Drink tumbler
- Tea
- Clean beauty product
- Unscented lotion
- Lip balm
- Face mask
- Hard candy
- Two special products (varies)
- HOPE journal & pen
- Inspirational bracelet
- Educational resources



Visit nbcf.org/hopekit to request a HOPE Kit for yourself or a loved one in treatment for breast cancer.

Support Group

Having the support of others experiencing the same thing as you can be an important part of the breast cancer journey. Research has shown that taking part in a support group,

where you both give and receive help, is an effective way to reduce the stress and anxiety that can come with a breast cancer diagnosis. Seeking support can come at various stages of the journey for patients. Don't be concerned if you don't feel like joining a support group right away, but know that it is an option that can make a big difference, if and when you need it.



NBCF offers in-person and virtual support groups for breast cancer patients and survivors. Visit nbcf.org/supportgroup to learn more and join an NBCF support group.

Educational Resources

NBCF offers dozens of free educational resources, eBooks, and guides that provide information on early detection, breast cancer stages and treatment, survivor support, and healthy living. Visit nbcf.org/about-breast-cancer to access these free resources.