



# Beyond Pink

SHARING OUR METASTATIC BREAST CANCER STORY

## Understanding Breast Cancer A Focus on Metastatic Breast Cancer and Treatments



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“ Ultimately, I have used this diagnosis to reflect on the blessings in my life and channel those feelings of gratitude into action. I have become a better wife, employee, mother, grandmother, friend, and advocate. I am grateful for my support system and the love of family and friends. I am living more authentically than I was; diagnosis has been life changing in such a positive way! ”

- Gina, living with metastatic breast cancer



Being diagnosed with metastatic breast cancer (MBC) is a life-changing experience. You and your loved ones may feel a range of emotions, such as fear, anger, denial, and uncertainty. The testing, treatments, and decisions patients face can be overwhelming, and there is often a lack of tailored information specific to metastatic breast cancer.

Learning more about metastatic breast cancer and its treatment options may help ease some of these concerns. Taking the time to learn about MBC and the available choices can help patients and families feel empowered, allowing for more involvement with their treatment team to make the best healthcare decisions possible. **In 2021, an estimated 284,200 people (281,550 women and 2,650 men) in the United States will be diagnosed with invasive breast cancer.**

Although MBC is generally not curable, in many cases there may be treatment options for patients to help manage their disease.

This guidebook is intended to help families learn about MBC and available options. It also provides some practical suggestions to help patients cope with the many challenges they may face.

Medical terms are indicated in bold when they first appear in each section and you'll find a glossary for these words at the end of this guidebook.

If you have questions as you read this, write them down in the Notes section located at the back of this book to discuss with your doctor or health care provider at your next visit.

## 10 THINGS

# To Know About Metastatic Breast Cancer: What You Should Know at Diagnosis

**Recurrence of breast cancer continues to be one of the most feared diseases among women.**

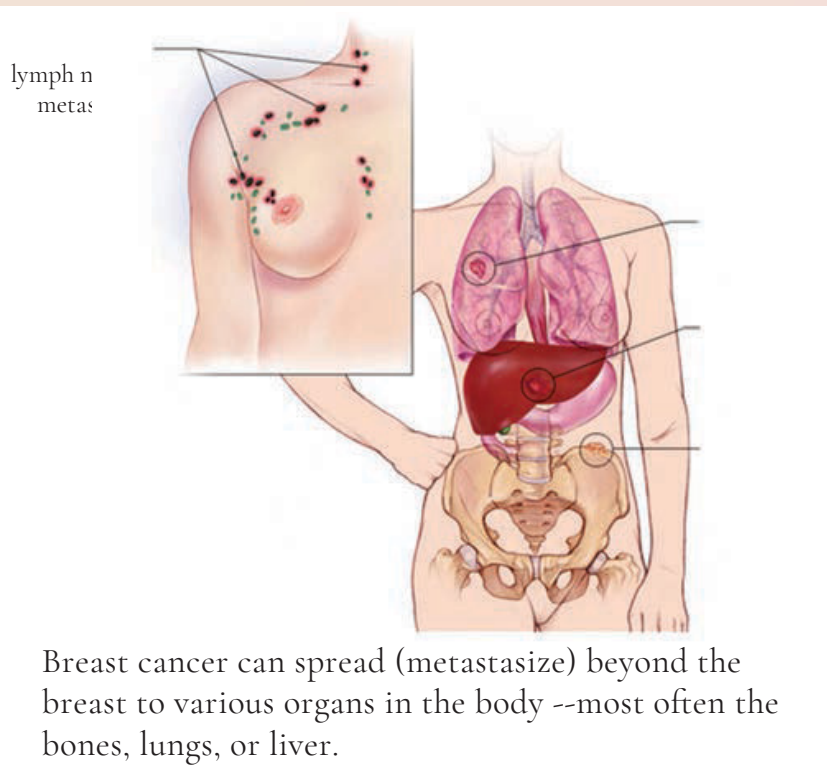
A diagnosis of metastatic breast cancer can come as a shock and be frightening, as it means you'll live with cancer for the rest of your life. But, through active management of the disease, many people are able to live full, productive lives.

**THE FOLLOWING ARE 10 THINGS YOU SHOULD KNOW IF YOU OR  
SOMEONE YOU LOVE HAS BEEN DIAGNOSED WITH METASTATIC BREAST CANCER.**

- 1 Metastatic breast cancer (MBC), also known as stage IV breast cancer, is a form of breast cancer that has spread to other parts of the body (eg, lungs, liver, bones). It may be located in other organs outside of the breast and/or lymph nodes near the breast.
- 2 Breast cancer that has spread to other parts of the body (metastasized) is not the same as cancer of these organs. When cancer spreads to another organ, it retains the characteristics of the original organ, so treatment and chances of remission relate to the primary tumor site.
- 3 It can take a few days or even a couple of weeks to know if you have MBC, as there are a number of tests (eg, scans or biopsies) needed to confirm the diagnosis. While this can be frustrating, knowing the pathology of the disease is critical to help determine the appropriate treatment plan.
- 4 Currently there are four primary molecular subtypes of MBC that have been identified: Luminal A or HR+/HER2- (HR-positive/HER2-negative), Luminal B or HR+/HER2+ (HR-positive/HER2-positive), Triple-negative or HR-/HER2- (HR-negative/HER2-negative), and HER2-positive. In addition to molecular subtype, HR status and levels of HER2 expression may help provide a better understanding of the tumor across the spectrum of HER2.
- 5 Treatment of MBC can be highly personalized based on the tumor type, as well as factors like where and how the cancer has spread, your overall health and experience with prior treatments. The most important thing is to stay focused and determine what you need to do to help inform treatment decisions and determine with your medical team which options may be right for you.
- 6 Breast cancer that has metastasized may not have the exact same characteristics as the original tumor. For example, cancer that was ER+ at diagnosis may now be ER-. This is another reason your treatment may differ from previous breast cancer treatments.
- 7 MBC is a chronic, progressive illness, so it is important to work closely with your medical team to actively manage the disease. The goal for treatment is to help remain stable and slow down the cancer progression, to keep the disease under control while trying to maintain quality of life.
- 8 If you've had a prior diagnosis of breast cancer, it is important to not question your prior treatment decisions or feel guilty about deciding against certain courses of treatment. The most important thing is to stay focused and work with your doctor to determine options that may help manage your disease.
- 9 Do not feel rushed into making decisions about your care. When we are anxious we may not process information clearly, and need time to be comfortable with a treatment decision. Always have thoughtful discussions with your medical team, and do not hesitate if you wish to seek a second opinion.
- 10 It is important for your loved ones to also be educated about the disease, treatment options and what to expect. The more they know, the better they can support you in this journey.



## Understanding Metastatic Breast Cancer



Breast cancer occurs when cells in the breast become abnormal and grow without control. Metastatic breast cancer (MBC), otherwise known as Stage IV breast cancer, is the most advanced stage of breast cancer and means that the cancer has spread from its original location to other parts of the body. While metastatic breast cancer often develops as a recurrence and spread of a previously diagnosed breast cancer, in a small number of cases it can occur in women who have no prior history of breast cancer. This is called “de novo” metastatic disease.

The most common places to which these cancer cells travel are the bones, lungs, or liver. People with MBC can have these cancer cells in just one place or in several areas of the body.

If breast cancer spreads or metastasizes to other body parts, it is still called breast cancer. For example, if breast cancer spreads to the lungs, the cancer in the lung is not lung cancer, but breast cancer that has metastasized.

### Signs and Symptoms

Signs and symptoms of metastatic breast cancer can be similar to other health problems and may include:

- Bone Pain
- Jaundice (yellow skin)
- Bone fractures
- Changes in vision
- Headaches or seizures
- Extreme fatigue/tiredness
- Persistent coughing

Patients with breast cancer should notify their doctor as soon as possible if they experience any new symptoms.

## Common Tests

In people with MBC, various tests could be used to evaluate the disease. Your doctor will determine which of the following tests are needed.

**PHYSICAL EXAM.** The doctor gives the person a complete **physical examination** to better understand how the patient is feeling and the areas that may be of concern.

**BIOPSY.** In many cases, a **biopsy**, which involves removing a small piece of tissue from the suspected tumor or area to determine if characteristics of the cells confirm a cancer diagnosis, confirms the spread of the original cancer (metastasis), or are different from the original cancer.

**BLOOD TEST.** **Blood tests** can check a person's general health and may show the extent to which the cancer has spread.

**CHEST X-RAY.** A **chest x-ray** may be done to see if the breast cancer has spread to other parts of the abdominal cavity.

**ADVANCED GENOMIC TESTING.** **Advanced genomic testing**, also known as Biomarker testing, can help you and your care team learn more about your specific type of MBC and help your doctor determine which options may be right for you. Advanced genomic testing is typically done by testing a tissue sample from your tumor after surgery or biopsy, or, in some cases, with a blood test.

**GENETIC TESTING.** **Genetic testing** can help estimate a person's chance of developing cancer in their lifetime by searching for specific changes, alterations, or mutations, to one's genes. While genetic testing looks at the genes inherited from a person's parents, it's important to note that a mutation can be hereditary (passed down from a parent) or acquired (developed later in life through certain environmental risk factors). Genetic testing may be recommended if you have a family history of breast cancer and may also help inform your treatment options.

**BONE SCAN.** A **bone scan** is used to check for breast cancer that has spread to the bones. During a bone scan, a small amount of low-level radioactive material is injected into the blood. Areas that have changes to the bone attract more of this radioactive material, which may indicate the presence of metastatic cancer.

**MAGNETIC RESONANCE IMAGING (MRI) SCAN.** **Magnetic resonance imaging**, or **MRI**, uses magnet and radio waves instead of x-rays to create an image of the body. The MRI can help doctors examine cancer in the breast or look for cancer that may have spread beyond the breast. In addition, MRI scans are helpful to identify tumor growth in the brain and spinal cord.

**COMPUTED TOMOGRAPHY (CT) SCAN.**

A **computed tomography scan**, also known as a **CT scan**, produces detailed pictures of the body by combining multiple x-ray images. This test is often used to look at organ metastases in the chest and abdomen areas.

**POSITRON EMISSION TOMOGRAPHY (PET) SCAN.**

In some cases, a **positron emission tomography**, or **PET, scan** may also be done. Radioactive material is injected into the blood, and concentrates more in tumor cells than in healthy cells. A special camera detects these areas of increased radioactivity, and this visual information is used to form an image showing where cancer may be present

## Types of Metastatic Breast Cancer

There are different types of MBC, each of which has different characteristics. One of the characteristics is the presence or absence of **hormone receptors**, such as the **estrogen receptor (ER)** and the **progesterone receptor (PR)**.

The human epidermal growth factor receptor 2 (HER2) is another characteristic that is used to determine the type of MBC. About 20% of breast cancers have some level of HER2 amplification - about 10-34% of individuals with breast cancer have high levels of HER2 expression, also known as HER2+. The status of these markers in a tumor is used to inform treatment decisions.

Breast cancer has four primary molecular subtypes, defined in large part by hormone receptors (HR) and other types of proteins involved (or not involved) in each cancer:

- Luminal A or HR+/HER2- (HR-positive/HER2-negative)
- Luminal B or HR+/HER2+ (HR-positive/HER2-positive)
- Triple-negative or HR-/HER2- (HR/HER2-negative)
- HER2-positive

A fifth subtype, known as normal-like breast cancer, closely resembles luminal A.

In addition to molecular subtype, HER2 expression (measured from high to low levels of HER2) may help provide a more complete view of the tumor across the spectrum of HER2.



## Types of Metastatic Breast Cancer (cont'd)

### HORMONE (ER, PR) RECEPTOR-POSITIVE BREAST CANCER

- Hormone receptor (HR)-positive breast cancers have estrogen and/or progesterone receptors and rely upon the hormones estrogen and/or progesterone for growth
- The presence of these receptors helps determine if the cancer may respond to hormonal therapy, a treatment approach that is discussed in the “Treatment Options” section
- The most common area for metastases in people with breast cancer is bone, and bone metastases are more common in women with HR-positive breast cancer
- HR-positive breast cancer occurs in approximately 66% of those with metastatic breast cancer



### Luminal A Tumors:

- Luminal A tumors, the most common molecular type, tend to grow at a slower rate than other cancer types. These are called HR-positive because they're defined by their hormone receptors, specifically as ER-positive and/or PR-positive. A cancer that is ER- and/or PR-positive grows from estrogen and/or progesterone. Drugs that help lower the amount of these hormones may be used in treating this type of breast cancer called a hormonal therapy. Luminal A tumors are associated with the most favorable prognosis.
- Luminal A cancers are also described as HER2-negative. HER2 stands for human epidermal growth factor receptor-2, which is a protein normally produced by the body. From a gene perspective, HER2 plays an important role in cell growth and repair in healthy breast cells. A breast cancer patient with a normal amount of the HER2 protein has HER2-negative cancer.

### HORMONE (ER, PR) RECEPTOR-NEGATIVE BREAST CANCER

HR-negative breast cancer is not affected by estrogen or progesterone. This type is called estrogen receptor-negative or progesterone receptor-negative.

**Approximately 29.9% of MBC patients have HR-negative breast cancer.**

### Luminal B

- In addition to being HR-positive, this subtype was originally characterized clinically as always being positive for HER2, but more recently has been defined by being highly positive for the protein Ki67 (an indicator of a large number of actively dividing cells) and/or HER2. Luminal B breast cancers tend to be of higher grade than luminal A and thus are associated with poorer outcomes.

## Types of Metastatic Breast Cancer (cont'd)

### Triple-negative Breast Cancer

- In this type of cancer, the cells do not contain receptors for estrogen, progesterone or HER2.
- Triple-negative breast cancers have a poorer prognosis than other subtypes, in part because treatment advances have lagged behind other molecular subtypes. These cancers occur at twice the rate in black women compared to white women in the US, and are also more common in premenopausal women and those with a *BRCA1* gene mutation.
- As triple-negative breast cancer is ER-, PR- and HER2-negative, this malignancy cannot be treated with hormone therapy or medications that work by blocking HER2. Triple-negative breast cancer may be treated with chemotherapy, radiation therapy and non-HER2 targeted therapy.

### HER2-positive/HER2-enriched

- One in five invasive breast cancers is HER2-positive, making it one of the more common breast cancer subtypes in the United States. HER2-positive cancers are ER- and PR-negative and human epidermal growth factor receptor 2 (HER2)-positive.
- HER2-positive breast cancer cells carry too many copies of the *HER2* gene, which makes HER2-protein receptors found on breast cells. When they work normally, HER2 receptors control how a healthy breast cell grows, divides and repairs itself. When they proliferate, the receptors tell the cells to divide and grow rapidly and without control. That's because their cells absorb too much of a substance called human epidermal growth factor 2 (HER2) which energizes cell growth. Doctors often test breast cancer tissues for excess HER2-positive genes to inform treatment with certain targeted therapy options, which help block HER2.
- Depending on the cancer's stage, treatment options for HER2-positive breast cancer may include a combination of surgery, radiation therapy, chemotherapy and/or targeted therapy.

### HER2-NEGATIVE BREAST CANCER

In HER2-negative breast cancer, the cancer cells do not have an excess of the protein HER2. Approximately 80% of MBCs are HER2-negative.

# Understanding Changes in Hormone Receptor Status

Because breast cancer can be hormone driven – and the hormones driving the tumor’s growth may change over time, it is important to know your tumor’s hormone status and, based on recommendations from your doctor, consider re-biopsying your tumor periodically to ensure the hormones driving its growth have not changed. Testing your tumor’s hormone receptor status and levels of HER2 expression is known as biomarker testing, which is discussed in the “Biomarker Testing” section.

If your tumor’s hormone status has changed, it is important to speak to your doctor about what this means for your MBC journey and how these changes may impact your current course of treatment.

## Understanding Metastatic Breast Cancer (MBC) and the Hormone Connection

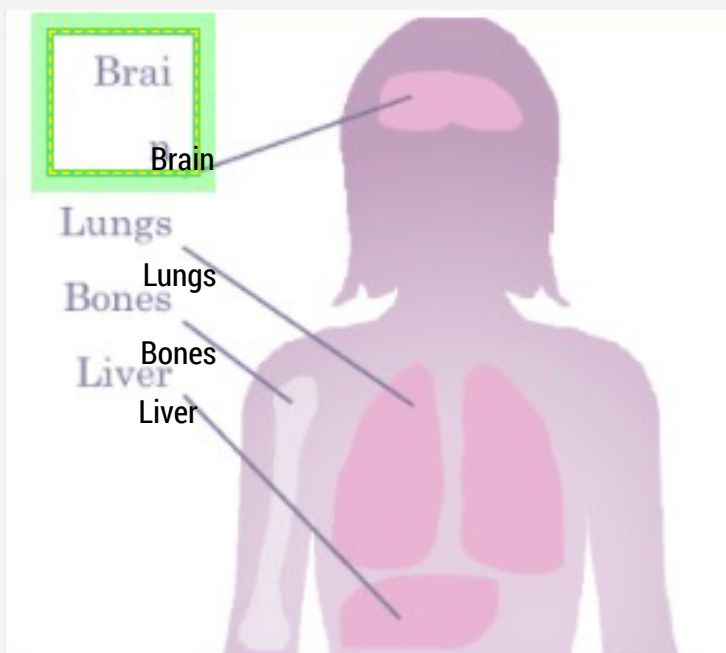
Possible MBC types:

- Luminal A or HR+/HER2-(HR-positive/HER2-negative)
- Luminal B or HR+/HER2+(HR-positive/HER2-positive)
- Triple-negative or HR-/HER2-(HR/HER2-negative)
- HER2-positive

**70%** of Metastases are in the bone

### MBC Classifications That Impact Tumor Growth:

- Hormone Receptor Status
- Levels of HER2 expression



**1 What is MBC?**  
MBC is when breast cancer cells have spread to other parts of the body outside the breast and is most commonly found in the lungs, liver, bones and brain.

**2 How can hormones influence MBC?**  
Breast cancer can be hormone driven and the progression can be directly related to the types of hormone receptors (estrogen or progesterone) present.

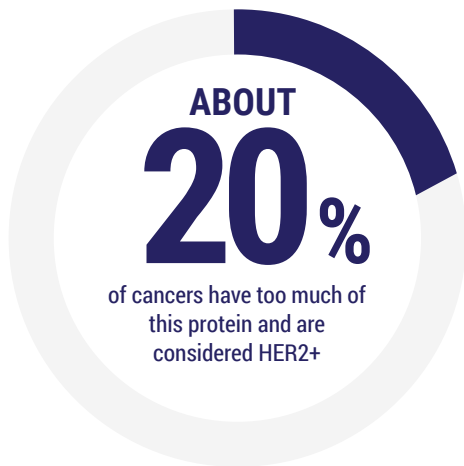
**75% of breast cancers are hormone receptor positive**  
Meaning their growth is fueled by female hormones – EITHER estrogen or progesterone.



**3** What are HER2 and triple-negative MBC?

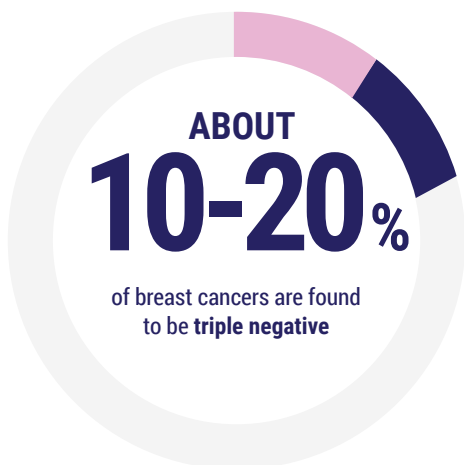
**HER2 (Human Epidermal Growth Receptor 2)**

is a **PROTEIN** that acts as a receptor on the surface of a cell. When HER2 proteins are too high it can stimulate cancer growth.



**TRIPLE-NEGATIVE MBC** occurs when

the tumor tests negative for estrogen and progesterone receptors and HER2 protein. In this case, cancer growth is not supported by hormones nor by the presence of too many HER2 proteins.



**4** Why is it important to know my tumor's hormone receptor status and levels of HER2 expression?

**Knowing Your Tumor's Hormone Receptor Status and Levels of HER2 Expression**

is critical in understanding your breast cancer diagnosis. It is important to work with your medical team to make informed decisions about your treatment options

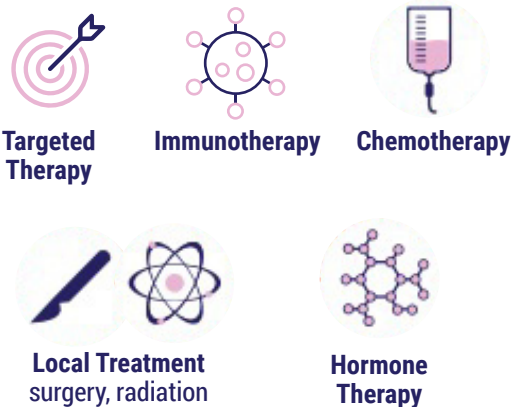


It may be important to re-biopsy the tumor periodically **because it could change over time**

**5** What can I do with this information?

Talk to your medical team to determine what your tumor's HR status means for your MBC treatment journey

**Possible metastatic breast cancer treatment options to discuss with your medical team:**



You may also discuss your eligibility for ongoing clinical trials with your doctor.

## Understanding MBC and the Genetic Connection

Other types of MBC are classified according to the presence of an alteration in genes or a specific trait in the tumor cells. Gene alterations can be hereditary (passed down from a parent) or acquired (developed later in life through certain environmental risk factors). Knowing which type of gene alteration you have, which can be determined with advanced genomic testing, can help your doctor make informed treatment decisions. Genetic alterations that may be present in MBC tumors include:

Alteration Type	Inherited	Acquired
<i>BRCA1 and BRCA2</i>	X	X
<i>EGFR</i>		X
<i>ATM</i>	X	X
<i>BARD1</i>	X	X
<i>CHEK2</i>	X	X
<i>PALB2</i>	X	X
<i>STK11</i>	X	X
<i>PIK3CA</i>		X
<i>mTOR</i>		X
<i>TP53</i>		X
<i>AKT1</i>	X	X
<i>PTEN</i>	X	X
<i>CDHI</i>	X	X
<i>APC</i>		X
<i>NRAS</i>		X
<i>KRAS</i>		X
<i>CDK4</i>		X

## *BRCA1* and *BRCA2*

Breast cancer susceptibility genes 1/2 are human genes that produce proteins responsible for repairing damaged DNA and play an important role in maintaining the genetic stability of cells. While everyone will inherit copies of these genes, an alteration on this gene, either hereditary or acquired, can lead to increased risk of cancer.

*BRCA* gene alterations can be either hereditary (also called germline), meaning you are born with them and they were passed on from your mother or father, or acquired later in life (called somatic alterations).

The alterations in the following genes have also been linked to breast cancer:

### *EGFR*

The epidermal growth factor receptor (EGFR) is a protein that lives on the surface of normal cells and cancer cells. An alteration in the *EGFR* gene is acquired and can drive abnormal cell growth, which can lead to cancer. **Approximately half of all triple negative breast cancers** have cancer cells that make too much *EGFR*.

### *BARD1*

An alteration in one copy of *BARD1* gene **increases the risk of female breast cancer**, including triple-negative breast cancer, as well as other types of cancers such as ovarian cancer.

### *CDK4*

Cyclin Dependent Kinase 4 is a protein coding gene, mediates progression through the G1 phase when the cell prepares to initiate DNA synthesis. ***CDK4* is altered in 1.21% of breast carcinoma patients.**

### *PIK3CA*

*PIK3CA* is a gene that encodes a lipid kinase involved in multiple signaling pathways. These pathways influence cellular functions such as growth, death, and proliferation. **Acquired alterations in this gene are found in 30-40% of all breast cancers.**

### *APC*

The *APC* gene instructs the body in making the APC protein, which acts as a tumor suppressor by keeping cells from growing and dividing too quickly. Alterations in this gene can **lead to breast cancer.**

### *KRAS*

Another type of oncogene that instructs the body to make a protein called K-Ras, which tells cells to grow and divide. **Less than 2% of breast cancers have a *KRAS* alteration.**

## ATM

Instead of activating DNA repair, the defective ATM protein allows alterations to accumulate in other genes, which may cause cells to grow and divide in an uncontrolled way. This kind of unregulated cell growth can lead to the formation of cancerous tumors. Inheriting one abnormal copy of this gene has been linked to a high rate of breast cancer. It has been suggested that women who carry an alteration in the *ATM* gene have an **estimated 20-60% increased risk for breast cancer**. Those with an *ATM* gene mutation are thought to be at increased risk for early-onset breast cancer and bilateral breast cancer.

## STK11

The *STK11* gene (also called *LKB1*) provides instructions for making an enzyme called serine/threonine kinase 11. This enzyme is a tumor suppressor, which means that it helps keep cells from growing and dividing too fast or in an uncontrolled way. People with an inherited alteration in *STK11* gene are at a **greater lifetime risk of developing many different types of cancer**, including breast, ovarian, endometrial, cervical, pancreatic, colorectal, gastric, small intestine, and lung cancer. The lifetime risk for a woman with a *STK11* mutation is about 32-54% compared to 12.5% for an average risk woman.

## PALB2

The *PALB2* gene is called the partner and localizer of the *BRCA2* gene. It provides instructions to make a protein that works with the *BRCA2* protein to repair damaged DNA and stop tumor growth. Alterations in the *PALB2* gene are known to carry a predisposition to developing breast cancer. **The estimated lifetime risk is between 33 and 58%.**

## AKT1

This gene provides instructions for the body to make a protein called AKT1 kinase, which is found in cells throughout the body. It helps **regulate cell growth, division and survival, and also the process by which cells self-destruct when they become damaged**. The *AKT1* gene alteration is seen in cancers including breast, colon and lung.

## CHEK2

*CHEK2* is a tumor-suppressor gene that protects cells from becoming cancerous. People who inherit alterations in the gene are at increased risk for certain types of cancer, thus **risk of developing breast cancer can be increased by 37%.**

## mTOR

A protein found on various types of cells throughout the body, which is produced as a result of instructions from the *mTOR* gene. **When *mTOR* is overactivated due to a genetic alteration, cancer may result.**

## PTEN

The *PTEN* gene helps stop the growth of tumors. It's known as a tumor suppressor. A tumor suppressor gene is like the brakes on a car. It puts the "brakes" on cells, so they don't divide too quickly. Mutations in one copy of the *PTEN* gene can **increase the chance of developing certain types of cancer** in one's lifetime, including breast cancer.

## NRAS

The *NRAS* gene instructs the body to make a protein called N-Ras that is involved in regulating cell division. *NRAS* belongs to a class of genes called oncogenes that, when altered, **can cause normal cells to become cancerous.**

## TP53

**(also known as *p53*):** An alteration in this gene, which helps stop the growth of cells with damaged DNA, is a **rare cause of breast cancer.**

## CDHI

Women with an alteration in this gene have an **increased risk of invasive lobular breast cancer.**



## Understanding Treatment Options

**There are many factors that your doctor may need to consider when making a treatment plan, such as:**

- Type of breast cancer
- Location and size of tumors and if the cancer has spread to other areas of the body
- Previous treatments (if any) and how you responded
- Length of time the person was free of disease after initial therapy
- Symptoms
- Age, overall health, and any other medical conditions
- Individual treatment goals and preferences, such as quality of life and ease of treatment regimen
- Possible side effects of cancer therapy
- Possible changes in the tumor's hormone receptor status

There are different options for the treatment of MBC. If your cancer gets worse, your tumor's hormone receptor status changes or you experience significant treatment-related side effects, your doctor may suggest other treatment options.

Learning about the disease and the treatment options available will help you have a more informed conversation with your doctor. Your own preferences may also play a role in the treatment decision-making process, so be sure to talk to your doctor about your goals and concerns of treatment.



## 8 THINGS

# To Know About Making Treatment Decisions

While metastatic breast cancer remains incurable, current treatments aim to slow down the progression of the disease and potentially help maintain quality of life. Your treatment options will depend on several factors and can change over time, so it's important that you talk with your medical team when making decisions about your care. Below are some tips to help when deciding what's best for you.

## 1 Ask what type of metastatic breast cancer you have

There are several types of metastatic breast cancer (MBC) and it's important to know what kind you have. Metastatic breast cancer can be classified by hormone receptor (HR) status and levels of human epidermal growth factor receptor 2 (HER2) expression. The type you have will help determine your treatment options. Your tumor status can change over time, so retesting your tumor might be considered. Please discuss with your doctor.

## 2 Ask what test(s) can help you learn more about your MBC

Like other cancers, there are several ways that your disease can be evaluated to inform your treatment options and decisions. Some of these include:

- Tumor biopsy
- Blood test
- Bone scan
- Advanced genomic testing
- Chest X-ray
- Genetic tests (including BRCA1/2, ESRm, TP53, or PTEN tests)

## 3 Work with your medical team to determine which treatment plan is right for you

Your doctor will often consider your personal treatment goals and preferences before recommending a treatment plan. These include how many times a day you take the medicine, number of weeks you'll be on treatment, how you respond to treatment and if you have any side effects. Be sure to have an honest and open discussion with your team so you receive the best care.

## 4 Know all of your options

The type of MBC you have will help determine your treatment plan. Treatment decisions and recommendations are personalized so it is important to know all of your options. Some therapies include:

- **Hormonal Therapy:** Standard treatment for many people with HR-positive breast cancer. Treatment blocks the effect of estrogen or progesterone on breast cancer cells and lowers the amount of estrogen or progesterone in the body
- **Chemotherapy:** Drugs that kill rapidly growing cells including cancer cells and some healthy cells
- **Targeted Therapy:** Drugs that target specific tumor types and genetic mutations
- **Immunotherapy:** Drugs that change how the immune system works to better enable it to fight cancer
- **Combination Therapy:** Using two or more methods to treat the cancer
- **Other therapies:** May enhance the effects of other treatments or help minimize side effects such as treatments for bone metastases, surgery or radiation therapy

**5 Ask about the pros and cons of treatment options**

Whether you've just been diagnosed with MBC or have been living with the disease for some time, it helps to know what to expect from your treatment, such as efficacy, side effects and out-of-pocket cost. Take notes during your appointments, and if you're not comfortable with the discussion or the options presented to you, don't hesitate to ask for further explanation or seek a second opinion.

**6 What about combination treatment?**

Some people with MBC may require combination therapy, which involves taking two or more medications at the same time. Therapies approved for combination are given individually and not combined into a single administration. This approach is not recommended for everyone, so be sure to talk with your medical team about which approach may be right for you. Many therapies used in combination therapy may be used alone as monotherapy as well.

**7 What happens if the treatment stops working?**

Responses to cancer treatment will vary for each individual. If your treatment stops working and the cancer continues to grow or returns, your medical team may recommend another type of treatment. However, before that happens, your medical team may order additional testing to determine if your cancer has changed or progressed.

**8 Take an active role in your treatment**

Consistently communicating with your medical team is key to learning more about your disease and ensuring you receive the best possible care. Before each doctor visit, bring questions and notes on how you're feeling on your current treatment. Also, remember to try to achieve your best health through good nutrition, staying active and limiting stress.

**MBC Treatment Classes and Administration Types**

Class	Monotherapy	Combination Therapy
Anthracyclines	X	X
Antimetabolites	X	X
CDK4/6 inhibitors	X	X
Microtubule Inhibitors	X	X
Nonsteroidal aromatase inhibitors	X	X
Estrogen receptor antagonist	X	X
Steroidal aromatase inhibitors	X	X
Taxanes	X	X
HER2- targeted therapies	X	X
HER2+ targeted therapies	X	X
mTOR inhibitors	X	X
PI3K inhibitors	X	X
Antibody-Drug Conjugates	X	X
Immunotherapy	X	X
PARP inhibitors	X	X

## Biomarker Testing

### Treatment Options

Some people with MBC will do very well on a single treatment, while others may require combination therapy. The next few pages provide more information about different treatment options for metastatic breast cancer.

MBC is more likely to respond to certain systemic therapies, such as treatments targeting the hormone receptors, if the estrogen receptor, progesterone receptor, or HER2 status is positive. **Systemic therapy** is medication that travels through the bloodstream to kill or slow the growth of cancer cells.

### Systemic treatment options

Many systemic medications are used to treat MBC, including:

- Hormonal therapy
- Chemotherapy
- Targeted therapy
- Immunotherapy

Some tumors are driven by the presence of unique sets of alterations that have been altered in the environment. These are often called biomarkers.

It may be helpful to think of a “biomarker” like the “thumbprint” of a tumor, and this unique thumbprint can be measured or can convey certain aspects of your tumor that can help guide your treatment plan.

When doctors identify the specific thumbprint of a tumor – its pattern of biomarkers – through biomarker testing, they can often prescribe medicines that are designed to target those specific traits. This testing is typically done by testing a tissue sample from your tumor after surgery or biopsy, or, in some cases, with a blood test. Biomarker testing can help determine which type of MBC you have to help your doctor determine your treatment path.

## Genetic Testing

Differing from biomarker testing, genetic testing looks at the genes inherited from a person’s parents. Some genes are associated with increasing a person’s risk for developing cancer in their lifetime. Importantly, an alteration in one’s genes can be hereditary (passed down from a parent) or acquired (developed later in life through certain environmental risk factors). Genetic testing may be recommended if you have a family history of breast cancer and can also help inform your

treatment options. Genetic testing for hereditary breast cancer can look for alterations in the *BRCA1* and *BRCA2* genes, or your doctor may suggest a multigene panel which looks for alterations across several genes at the same time. Knowing if you have a genetic alteration, either inherited or acquired, is important in informing the appropriate treatment options.



## **Hormonal Therapy**

Hormonal therapy is the main treatment for many women with HR-positive breast cancer. Hormonal therapy, sometimes called endocrine therapy (a term used to describe treatment that adds, blocks, or removes hormones), is a way of treating breast cancer with medication to block the effect of the hormones **estrogen** or **progesterone**, or to lower the level of either of these hormones in the body. Blocking the effects or lowering the levels of these hormones can slow or stop the growth of breast cancer.

Hormonal therapy for breast cancer is NOT the same as hormone replacement therapy, which involves giving estrogen to women to help ease the symptoms of menopause. Hormone replacement therapy should not be used in women who have been diagnosed with breast cancer.

About 50% of all those with HR-positive metastatic breast cancer respond to hormonal therapy. Hormonal therapy may be appropriate if there is a presence of estrogen and/or progesterone receptors in the cancer cells. Your doctor can confirm this by performing a test.

If hormonal therapy worked for you initially but then the cancer spread, you may be given a different type of hormonal therapy. The US Food and Drug Administration (FDA) has approved several different types of hormonal therapies to treat HR-positive MBC.



There are various factors to determine what type of hormonal therapy may be right for you. Knowing if you are premenopausal or postmenopausal will aid your doctor in making a recommendation. Other factors may include:

- Effectiveness and safety of available treatment options
- Type(s) of hormonal therapy previously received
- Previous treatment experience
- Your age and other existing medical conditions
- Your preferences, as well as those of your doctor

You and your doctor may discuss which type of hormonal therapy might be right for you throughout your treatment journey.

### How are hormones made in premenopausal and postmenopausal women?

While women are still menstruating (premenopausal), they have high levels of estrogen that are produced by the ovaries. After menopause, smaller amounts of estrogen are still made in the body by converting a hormone called androgen into estrogen.

### Possible Side Effects

The side effects of hormonal therapy depend on the treatment being used and might include:

- Feeling tired
- Hot flashes
- Mild nausea
- Vaginal dryness or discharge
- Mood swings
- Muscle pain and joint stiffness and/or pain
- Weakened bones

### Possible serious side effects may include:

- Blood clots
- Increased risk of stroke
- Cancer of the uterus
- Loss of bone strength that can lead to **osteoporosis** and bone fractures

Talk to your doctor about any side effects you may experience as there may be options available to help manage the side effects. This is not a complete list of side effects.

### Chemotherapy

Chemotherapy involves the use of drugs to kill cancer cells. These drugs move throughout the body by traveling through the bloodstream and kill any rapidly growing cells, including cancer cells and some healthy cells.

Chemotherapy is used in patients who have:

- HR-negative or triple negative breast cancer
- HR-positive breast cancer, in which:
  - The cancer does not respond to/or has stopped responding to hormonal therapy
  - The person has metastatic disease that threatens the function of vital organs

There are many chemotherapy drugs available. If the cancer worsens during or after treatment with one chemotherapy drug, or if treatment-related side effects are a problem, you may be able to try an alternate drug.

Doctors look at many factors when deciding on the type of chemotherapy to recommend. These factors include:

- How aggressive or fast-growing the cancer is
- The type(s) of chemotherapy the person has already received
- Chemotherapy side effects
- Other medical conditions
- Patient preferences



## What to expect with chemotherapy

Drugs used for chemotherapy come in many different forms. Some are taken by mouth (orally) as pills while others are injected directly into a vein (intravenously) in a doctor's office or clinic. While some people may receive one chemotherapy drug, others may be given a combination.

It may take several hours to undergo chemotherapy at a clinic or hospital. Depending on the type of chemotherapy, you may take medications before the chemotherapy to help prevent or reduce certain side effects, such as nausea.

Chemotherapy is given in cycles, with a pre-determined number of treatments, followed by a break.

- Different chemotherapy drugs have different cycles
- You may not always get the same drug(s) on treatment days
- Taking breaks between cycles may help reduce side effects
- Treatment most commonly lasts for several months

## When chemotherapy may be used

There are several situations in which a doctor may recommend chemotherapy:

- After surgery (adjuvant chemotherapy): This is a type of therapy given to those with no evidence of cancer after surgery. Adjuvant chemotherapy is used to kill cancer cells that may have been left behind after surgery, or that may have spread but can't be recognized with the current tests available. If these cells are allowed to grow, they can create new tumors elsewhere in the body.

- Before surgery (neoadjuvant chemotherapy): This is similar to adjuvant therapy, except the person begins therapy before surgery instead of after. The goal of neoadjuvant chemotherapy is to shrink the tumor so it can be removed with less extensive surgery. By giving chemotherapy before removing the tumor, doctors can also better see how the cancer responds.
- For advanced breast cancer: Depending on the type of MBC, chemotherapy can be the main treatment for some people. Chemotherapy is used either when cancer is diagnosed or after initial therapy. The length of treatment depends upon whether the cancer shrinks, how much it shrinks, and how well the treatment is tolerated.



### Possible side effects

Every person may experience different side effects of chemotherapy drugs and the severity of side effects will vary from person to person.

While possible side effects vary with different chemotherapy drugs, the most common side effects include:

- Low red blood cell count (anemia)
- Extreme tiredness (fatigue)
- Hair loss
- Increased chance of bruising, bleeding, and infection
- Nausea and vomiting
- Low white blood cell count (neutropenia)

### Other possible effects on the body include:

- Diarrhea or constipation
- Changes in appetite
- Gaining or losing weight
- Sore mouth, gums, and throat
- Nerve damage (mainly in the hands and feet), which can cause numbness, pain, burning or tingling, or sensitivity to cold and heat
- Muscle weakness
- Dry and/or discolored skin
- Kidney irritation leading to decreased urination, swelling (edema) of the hands and feet or headache
- Bladder irritation leading to a burning sensation when urinating and increased urinary frequency
- Premature menopause (not having any more menstrual periods) and infertility (not being able to become pregnant)

### More serious side effects might include:

- Long-term damage to the heart, lungs, kidneys, or reproductive organs
- A second cancer (that can show up many years later)

Most side effects are temporary and begin to lessen after treatment ends; however, others may take months or years to go away.

Patients may need to take other medications to prevent or ease these side effects. If side effects are severe, your doctor may temporarily stop or lower the dose of the chemotherapy. Or your doctor may recommend a different chemotherapy medication.

Talk to your doctor about the side effects you can expect and how they can be managed if they occur.

Remember to tell your doctor about any side effects you experience. This is not a complete list of side effects.

Scientists and doctors continue to research and test new ways to treat cancer. Much of their research has focused on gene alteration (mutations) in cells that can lead to the development of cancer. Scientists have been working to develop drugs that target specific genes and associated cancer types. These so-called targeted therapies work differently from traditional chemotherapy or hormonal therapy medications because they affect the genetic changes that cause cancer, and often have different side effects. Targeted therapies block the growth and spread of cancer cells. However, not all tumors have the same targets, which is why it's important to discuss biomarker testing with your care team.

Knowing if you have certain inherited and/or acquired alterations can help you and your healthcare team make informed decisions for your specific type of MBC.



## Targeted Therapy

In HER2-positive MBC, treatment approaches are well-established and defined by use of HER2-directed agents, regardless of HR status. HR status helps define the treatment pathway for patients with HER2-negative MBC.



### The HER2-targeted therapy

The HER2- targeted therapies can be used to treat HER2-positive metastatic breast cancer, and some can be used in combination with chemotherapy, surgery and/or radiation.

These medications target breast cancer cells that make too much of the protein HER2. They work through two primary methods:

- Interfering with HER2 by preventing the breast cancer cell from receiving growth signals
- Blocking signals inside the cell that can lead to cancer growth. Even if your HER2-targeted therapy stops working, you may continue to receive the same therapy or receive an additional HER2-targeted medication. Because each treatment has a different way of working, a new or additional medication may be used alone (as a monotherapy) or in combination with another therapy

### Side effects of HER2-targeted therapy

Some side effects may include nausea, rash, vomiting, diarrhea, and fatigue. Possible serious side effects may include decreased heart function and liver problems, such as hepatitis and elevated liver enzymes.

Talk to your doctor about what side effects you can expect and how you can manage them if they occur.

Be sure to tell your doctor if you experience any side effects while being treated with any of these therapies. This is not a complete list of side effects.

### BRCA1- and BRCA2-gene alteration targeted therapy

Genetic testing for an alteration, such as testing for Breast Cancer susceptibility gene 1 (*BRCA1*) or Breast Cancer susceptibility gene 2 (*BRCA2*) alterations, may be used to guide treatment decisions for people diagnosed with breast cancer. BRCA alterations can be either inherited or acquired. Certain people with MBC who have an

inherited *BRCA1* or *BRCA2* alteration may be appropriate for targeted treatments which work by blocking a protein the cells use to repair damaged DNA.

### Side effects of BRCA1- and BRCA2-gene alteration targeted therapy

Side effects can include nausea, vomiting, diarrhea, fatigue, loss of appetite, taste changes, anemia, thrombocytopenia (low platelet counts), leukopenia (low white blood cell counts), belly pain, and muscle and joint pain. Some side effects may be serious, including bone marrow problems called myelodysplastic syndrome (MDS) or acute myeloid leukemia (AML). Rarely, some people treated with this target therapy have developed a blood cancer, such as myelodysplastic syndrome (MDS) or acute myeloid leukemia (AML).

This is not a complete list of side effects. Talk to your doctor about what side effects you can expect and how you can manage them if they occur. Be sure to tell your doctor if you experience any side effects while being treated with any of these therapies.

### **Other targeted therapies:**

These treatments utilize drugs that target specific tumor types and genetic alterations, including mTOR inhibitors, PI3K, and CDK4/6. These drugs affect genetic changes that cause cancer and often have different side effects.

Side effects of other targeted therapies: Some side effects seen with mTOR inhibitors may include stomatitis, diarrhea, neutropenia, and anemia; with PI3K pathway inhibitors are hyperglycemia, dermatitis and rash, stomatitis, diarrhea, nausea, and fatigue; with CDK4/6 inhibitors are nausea, diarrhea, fatigue, neutropenia, anemia thrombocytopenia (low platelet counts), some of which may be serious. This is not a complete list of side effects. Please speak with your doctor about any side effects you may experience.

### **Immunotherapies:**

Immunotherapies utilize drugs that strengthen or change how the immune system works to better enable it to fight cancer. Immunotherapies act by helping your immune system work harder and more efficiently to attack cancer cells by targeting specific receptors on breast cancer cells and boost your immune system to stop or slow cancer growth as well as spread to other areas of the body.

### **Side effects of immunotherapies:**

Side effects of immunotherapies can include fatigue, cough, nausea, skin rash, poor appetite, constipation, and diarrhea.

### **Infusion reactions:**

Some people might have an infusion reaction while getting these drugs. This is like an allergic reaction and can include fever, chills, flushing of the face, rash, itchy skin, feeling dizzy, wheezing, and trouble breathing. It's important to tell your doctor or nurse right away if you have any of these symptoms while receiving these drugs.

### **Autoimmune reactions:**

These drugs remove one of the safeguards on the body's immune system. Sometimes the immune system starts attacking other parts of the body, which can cause serious or even life-threatening problems in the lungs, intestines, liver, hormone-making glands, kidneys, other organs.

It's very important to report any new side effects to your health care team quickly. If serious side effects do occur, treatment may need to be stopped and you may get high doses of corticosteroids to suppress your immune system.

This is not a complete list of side effects. Please speak with your doctor about any side effects you may experience.

### **Combination therapy**

In the treatment of metastatic breast cancer, combination therapy can refer to the use of two or more medications. There are a variety of medicines that can be used in combination therapy. Talk to your doctor about which treatment regimens may be right for you.



**Additional Treatment Options**

These are additional treatment options that your doctor may recommend to add to your treatment plan:

- Treatments for bone metastases
- Surgery
- Radiation therapy

**Treatments for Bone Metastases**

If breast cancer has spread to the bones, you may experience bone pain and have an increased risk of fracture. Also, some breast cancer treatments may cause bone thinning (osteoporosis).

When someone has been confirmed to have bone metastases, the doctor may recommend any of the following to aid bone health:

- Medications to strengthen bones by decreasing thinning and lower the risk of a bone fracture, minimizing the need for surgery
- Over the counter supplements, in addition to prescribed medications
- Radiation to treat bone pain

**Surgery**

Surgery is relatively uncommon for people with metastatic breast cancer, but it may be used for patients who need symptom relief after initial treatment.

**Radiation Therapy**

Radiation therapy uses x-rays to kill cancer cells. It is often given after surgery to help reduce the chance that the cancer will come back in the breast or nearby lymph nodes. Radiation may also be recommended after surgical removal of the breast (mastectomy) in people either with a cancer larger than 5 centimeters, or when cancer is found in the lymph nodes.

In people with MBC, radiation therapy may be used to help relieve symptoms such as pain, or to improve breathing.

**Possible side effects of radiation therapy**

Side effects of radiation therapy may depend on where the radiation treatment is given. Side effects may continue for several months after treatment is finished. Your doctor may be able to provide recommendations for coping with most common side effects, including:

- Skin irritation, including: redness, tenderness, or sensitivity
- Extreme tiredness

Make sure to tell your doctor if you experience any side effects while undergoing treatment. This is not a complete list of side effects.



## Clinical Trials

Clinical trials are carefully conducted research studies that are done with patient volunteers. They are designed to determine the effectiveness and safety of investigational treatments or procedures. Talk to your doctor to determine if a clinical trial might be an option for you.

Each clinical trial has specific guidelines on patient characteristics that should be included and excluded. The following factors can help determine if someone is appropriate for a given clinical trial:

- Age
- Gender
- Type of disease
- Prior treatments
- Medical history

Before treatments are allowed to be tested in people, researchers must show that the investigational drug works as intended and must apply for approval. If the FDA approves the application, the clinical trial is allowed to move into the next phase of research. In addition, every trial has specific rules determined by the FDA for when and how patients should be monitored, as well as when they will receive medications and at what doses.

Throughout the study, participants will visit the research team to determine if the treatment is working and if the person is experiencing any side effects. Testing of treatments occurs in phases. Most clinical trials are categorized as phases I, II, III, or IV.

**PHASE I TRIALS** are often the first studies to test investigational drugs in people. Phase I trials typically evaluate how an investigational drug should be given and how much of the drug may be given safely. These trials usually involve a small group of otherwise small group of patients.

**PHASE II TRIALS** further test the safety of the drug and begin to measure how well the investigational drug works in a larger group of participants. Trial patients are usually patients with the disease for which the specific medication is being evaluated.

**PHASE III TRIALS** typically compare the safety and efficacy of the investigational treatment with the current standard treatment. Phase III trials often enroll a large number of participants at different sites. These studies are most often used to determine if a medication can be submitted for FDA approval.

**PHASE IV TRIALS** are conducted after a new treatment has been approved by the FDA and is available to be prescribed. These trials typically evaluate the safety and efficacy of a drug over a longer period of time in a larger number of participants.





**It is essential to note that participation in a clinical trial is voluntary.**

Before deciding whether to participate in a clinical trial, it is important to learn about your options.

Discuss pros and cons, including the potential risks and benefits of participation with.

- Your doctor
- Other members of your healthcare team
- Family members

You can find information about current clinical trials at the National Cancer Institute's trial registry, available at <http://www.cancer.gov/clinicaltrials/search>.

There are potential risks and benefits when participating in a clinical trial.

#### **Pros**

- Care provided by leading cancer researchers
- Access to new drugs and interventions before they are widely available
- Close monitoring of your health care and any side effects
- An opportunity to make a valuable contribution to cancer research

#### **Cons**

- Potential side effects of the treatment
- The investigational treatment may not work
- Forgo an opportunity to receive an approved treatment
- Additional tests and doctor visits may be required

## Here are some questions you can ask your doctor to help you better understand clinical trials:

#### **General questions:**

- Is a clinical trial an option for me?
- What types of clinical trials can I join?
- What are the pros and cons of clinical trials?

#### **If you are considering enrolling in a specific trial:**

- What is the purpose of the trial?
- Why do researchers think this investigational treatment might be better than the approved treatments that are already available?
- What are my other options if I don't enroll in the trial?
- What are the possible short- and long-term risks of participating in the trial?
- What kinds of side effects should I expect?

#### **If you are enrolled in a trial:**

- How long will the clinical trial last?
- How and how often will the safety and effectiveness of the investigational treatment be monitored?
- What other kinds of tests, treatments, or doctor's visits are needed or allowed during the trial period?
- What is the cost to participate?
- Does insurance cover the cost of participation?
- Will I be able to continue taking my other medications during the trial period?

# MBC MythBusters

Being diagnosed with MBC is a life-changing experience. People with MBC and their loved ones may feel a range of emotions, such as fear, anger, denial, and uncertainty. The decisions can be overwhelming, and there is often a lack of information specific to MBC. Below we dispel several common myths about MBC.

## MYTH

**MBC is just a more advanced stage of breast cancer and each case is the same.**

There are many types of MBC. Because MBC can be present in many places, each diagnosis will differ in important ways, including what treatment option(s) might work best.

**Those who have been diagnosed with MBC did not treat their initial breast cancer diagnosis aggressively enough, or chose the wrong initial treatment.**

MBC, like other cancers, can be unpredictable. A diagnosis of MBC does not mean the person did anything wrong when deciding on the course of treatment following initial diagnosis. While all treatment options should be discussed with a physician, your loved one should not blame themselves if the disease spreads or returns.

**Because it's an advanced form of breast cancer, MBC is always extremely debilitating.**

Since there is no cure for MBC, people with the disease will be in treatment for the rest of their lives and the goal is to delay the progression of the disease. Through effective management, many people may live active and productive lives.

## MYTH

**All cases of MBC are treated the same way.**

**It is necessary to decide on a course of treatment for MBC immediately and stick with it throughout the full course of treatment.**

**The timeframe in which the disease will progress is similar for everyone living with MBC.**

## FACT

There is no one-size-fits all treatment for MBC; every person and their disease is unique. Treatment choices are determined by cancer type, location and extent of the metastasis, hormone status, levels of HER2 expression, and other factors. Knowing the hormone status and levels of HER2 expression can help better manage your loved one's MBC journey and determine what tests will need to be done, treatment options, and how their body may be affected.

MBC tumors can change over time. Because of this, it is important to work with your loved one's medical team to regularly evaluate the current treatment regimen to make the most informed decisions. There are a variety of available treatment options which may be given alone (monotherapy) or in combination, and may be considered to help slow the spread of the disease and maintain overall quality of life.

MBC is not the same for everyone. Particularly because there is a strong hormone component to MBC, each person's illness experience will be different due to the level of hormones present in the body. A person's overall health status, genetics and other illnesses can also impact the MBC journey.

## Living With Metastatic Breast Cancer

“ I sometimes feel overwhelmed with survivor’s guilt, and I wish that I had one quick answer as to how I deal with this, but sometimes I’m at a loss about what to do. Reaching out to my MBC community is a powerful way to find support. They understand even when I don’t have words to express myself fully. I’m filled with gratitude that I have them in my life. ”

- Linda C., living with metastatic breast cancer

People with MBC face many challenges. These challenges may present issues that affect many parts of their lives, including the physical, psychological, social, and spiritual aspects of their lives. The challenges may be related to various factors, including:

- Disease symptoms
- Changes in relationships with family and friends
- Ability to perform daily activities
- Financial concerns

For many people, working through the psychological aspects of living with MBC may be particularly challenging, as the disease may lead to depression, anxiety, fear, and loss of independence. Loved ones and caregivers also share the burden of many of these issues.





## Coping with Side Effects and Symptoms

Cancer treatment can also affect normal, healthy cells, which can result in side effects. These side effects and symptoms can be different for every person.

Many effects of cancer and cancer treatment can be managed; therefore, it's important to talk to your health care team about any side effects, pain, or discomfort. There are many different types of prescription and over-the-counter treatments that can help manage side effects, including:

- Relieve pain
- Fight infections
- Treat anemia (abnormally low level of red blood cell counts)
- Strengthen bones
- Treat diarrhea
- Relieve constipation
- Reduce nausea and vomiting
- Treat hot flashes
- Treat depression

In addition to standard medical treatments, some complementary treatments may also help you feel better. Examples of complementary treatments include acupuncture or massage therapy. Talk to your doctor first before using any complementary therapies.

### Maintaining Overall Health and Wellness

#### Nutrition

People with breast cancer should do their best to make healthy choices. Good nutrition can help keep your strength up and help you cope with side effects.

Additionally, a healthy diet may help lower the risk of infection. You may wish to talk to a dietitian or nutritionist to help you find a diet that allows you to get enough calories and protein - both of which are important in helping fight infection, as well as forming and maintaining tissues and enzymes. The following tips may be helpful:

- Try different plant-based foods, such as beans and peas, instead of meat, a few meals each week
- Try to eat at least 2½ cups of fruits and vegetables a day, including citrus fruits, dark-green and deep-yellow vegetables

- Choose low-fat milk and dairy products, and limit high-fat foods, especially those from animal sources
- Limit your intake of salt-cured, smoked, and pickled foods

#### Exercise

Staying active may help lessen fatigue, boost energy, and increase appetite. It is important to talk to your doctor if you plan to begin an exercise program. Exercise may help with fatigue and stress. It may also improve mood, self-esteem, and your sense of well-being, while also keeping you at a healthy weight.

#### Relaxation

Meditation, relaxation therapy, and massage may help relieve anxiety and stress. Remember to take time for yourself. You may need to plan ahead for times when you need more rest. Don't be afraid to ask for help and cut back on any extra commitments that may drain your time and energy. Friends and family can help support you with practical things, such as doing chores and arranging transportation for treatment.

#### Getting support

For many people, a diagnosis of metastatic breast cancer triggers a range of emotions—shock, disbelief, fear, anxiety, sadness, anger, and depression.

Talking to family and friends can be a source of comfort and is an effective way of coping. Some people join a support group or online community for breast cancer patients. Groups focusing on certain stages of cancer, such as metastatic disease, can be especially helpful.

You may find that talking to others with metastatic breast cancer eases some of your fears, as they learn how others cope.

Some people find comfort in spirituality. Some may wish to work with a religious leader to help them with their feelings, while others may prefer a mental health professional. Ask your doctor if he or she has any recommendations.

Everyone is different. Take time to find the support that is right for you.

Receiving a diagnosis of metastatic breast cancer (MBC) can be overwhelming, not only for you but also for your friends and relatives who may not know what it means or what to say to show their support. In addition to feeling sad and uncomfortable, your loved ones may find it difficult to talk to you out of fear of upsetting you or of saying the wrong thing.

However, talking to them about your diagnosis is an important part of helping them understand what it means for your daily life, as they can be a vital source of support along your MBC journey. This information is meant to help you and your loved ones talk about your MBC diagnosis, so that together, you can address the challenges of living with this disease.

### **Talking to Your Family About Your MBC Diagnosis**

A cancer diagnosis affects the entire family, not just the person who has the disease. Therefore, you should consider how much you want to share with family and close friends regarding your diagnosis and cancer care.

**Once you've told your family about your diagnosis, you should also take the time to discuss changes to family routines.** It's appropriate to let them know where you may need help with tasks you once handled yourself. Creating an opportunity for open communication can help you and your family make decisions as a team and work together to handle the changes to your family life. At the same time, you and your family should continue participating in enjoyable activities you did before your diagnosis.

**Your family might respond to your diagnosis by trying to "protect" you from upsetting news or events.** Acting as if everything is OK can lead to tension and confusion within the family. If you see such "protective" behavior in your family, gently inform them that "protecting" you makes you feel isolated and you would like to continue to be involved in family discussions. Communicating clearly with your family about how you feel, both physically and emotionally, will help them better understand what you're going through and enable them to provide the support you need.

**Even with the support of your family and friends, you may find it difficult to manage your frustrations and emotions.** While such feelings may be unexpected, they are common responses to a major life change. It's best for you and your family to be honest with each other about what you're all feeling and work together to utilize effective coping strategies such as seeking information about MBC, how to plan for the emotional challenges that will occur during the course of MBC, and accepting the diagnosis. Employing coping strategies that help you understand the diagnosis while also recognizing the demands the illness (ie, change of individual responsibilities, consistent doctor appointments, and/or unpredictable health status that can impact daily activities) will have on the entire family may ease some of your feelings of guilt and frustration.

**It is important to remember that people react differently to the stress of a cancer diagnosis.** It is important to structure sharing information as you are most comfortable to manage emotions and expectations of others while also maintaining control of the discussion. There are no rules about whom to talk to, or when to share information. You may find you are most comfortable breaking the news to your spouse or partner first, followed by other family members and friends. The following tips can help you decide whom you want to talk to about your diagnosis, when to share information and how much information to share:

- Make a list of people that you want to talk to in person
- Ask a loved one or friend to be with you when you share the news
- Set the stage by creating an environment where you are comfortable talking, ie, in your home or other private location
- Decide how much information you would like to share during the discussion and set expectations for others regarding what type of information you are comfortable sharing and how often

Some people are more comfortable using active coping including: seeking social support, accepting the diagnosis, seeking information about the disease and planning how to handle emotions and physical challenges.

On the other hand, others may be more comfortable using avoidant coping such as denial of the diagnosis or thinking there will be a cure, behavioral disengagement or spending more time on other activities, and avoiding discussions of the topic. While no one coping method is correct, the family dynamic can determine which strategies will help the patient and family most effectively. Therefore, it is important to be able to talk to your family about similarities and differences in individual coping styles. Although this may be difficult, it will help you understand each other and ultimately work together.

#### **Talking to Young Children About Your MBC Diagnosis**

If there are young children in your family, you may be worried about how they'll react to the news of your diagnosis.

A child's reaction to a cancer diagnosis often depends on how the adults in their lives are handling the situation. It is important to decide in advance how to talk to young children about your MBC diagnosis. While it's natural for adults to want to shield their children from their own fears and worries, that may not be in the children's best interest. Children often overhear adults discussing subjects not meant for them, even when they don't appear to be listening, and often pick up on their parents' worry and anxiety.

The first step in talking to a young child is to arrange a quiet time when you won't be disturbed. If you have more than one child, talking to them individually can help you tailor the information to each child's level of understanding and will provide you an opportunity to address how each child responds. Some children may not have any questions during the discussion, but you should encourage them to ask questions any time. It is most helpful to give young children truthful information that they can understand by sharing small amounts of information over time and answering their questions in a way that is appropriate. Young children (up to age 8) do not need detailed information, but older children (ages 8-12) and teenagers may want to know more.

Regardless of their age, all children should have the following basic information:

- The name of the cancer (ie, breast cancer)
- Where the cancer is
- Where do you go for treatment and what happens
- How you may feel during treatment and/or physical changes that occur (eg, fatigue, weight changes, hair loss, vomiting)
- How their lives may be affected

**Be prepared to address children's questions and worries.**

## Asking for—and Accepting—Help from Family and Friends

**Allowing your loved ones to help can be an important way for them to cope with your disease.** One of the first questions you may get from a friend or family member is, “What can I do to help?” You may be tempted to say, “Oh, nothing right now. We’re fine.” Maybe you don’t really know what you need, value your privacy, or feel you have all you can handle without having more people around you. However, most people really do want to help. Allowing your loved ones to help and support you makes them feel they’re part of your life.

**Be as specific as possible about the kind of help you need.** For example, tell your friends or relatives when you need a ride to the doctor or find out if they can help with housecleaning, yard work, child care, or grocery shopping.

Even if you do not know what you need, share this information as it will give your loved ones a chance to offer something they can do for you.

**Don’t be surprised if some people don’t offer to help.** They may not be able to help because they have problems of their own, they don’t know how to help you or are afraid due to a past experience.

**If you are comfortable, consider encouraging your loved ones to talk to you about how they’re feeling** so you can work through your feelings together. However, if you’re not ready to hear about how they feel, it’s OK not to ask. It can be hard enough to manage your treatment and deal with how you feel, but do keep in mind they are also experiencing a variety of emotions.

**Sometimes you may not want to accept help from others, talk about your feelings or ask how others feel.** It’s OK not to accept help all the time or to decline a discussion, in a nice way, regarding your illness. This allows you to set your own boundaries about when and under what circumstances you would like help and are willing to discuss your illness.

## What to Avoid

While there are many things you can do to make it easier to talk to friends and family about your MBC diagnosis, there are a few things you may want to avoid:

- Don’t ignore or neglect a friend or relative who may need to open up and talk with you. This may cause them to think you do not care about them
- Don’t ignore your own need to talk with someone. It’s healthy to want to share how you feel. Always remember you are not a burden to your loved ones
- Don’t set up a false front, or a “happy face,” if you don’t really feel that way. While you might want to protect your loved ones by acting as cheerful as possible, it is more helpful if you share your true feelings so they can provide the support you need
- Don’t feel that there is a perfect way to talk or handle your interactions with others. You will find that there are times when you want to talk and other times when you feel that communication is not going very well. Realize that you—and others—are doing the best you can



### **Taking an active role in your treatment**

Communication is an essential part of learning about the disease and understanding treatment options. Determine how much you want to know and how involved you want to be in the decision-making process. While some people want to be actively involved, others are more comfortable with knowing only what is necessary. Here are some tips you and your family may find helpful as you go through the treatment process.

Make the most out of each doctor's visit.

- Prepare for each visit. Write a list of questions and take it to your next visit
- Make a list of the medications you're taking (including over-the-counter medications, vitamins, and herbal supplements), the doses you take, and the number of times a day you take the medications. If you're unsure of any of this information, take the medication bottles with you
- Consider taking a family member or friend with you. They can offer support, help you remember questions you may forget, and may be a second pair of ears
- Ask your doctor to clearly explain anything you don't understand or information you are not comfortable with
- Do not feel rushed into making decisions about your care. Always have thoughtful discussions with your medical team, and do not hesitate if you wish to seek a second opinion
- Share feelings of anxiety and distress with your healthcare team and loved ones. This is not the time to hide concerns or try to see if feelings of anxiety and distress will pass. Talk with your healthcare team and loved ones about ways you can relieve your stress and reduce your fears
- Talk to others going through similar journeys. Connecting with others living with MBC in person or online can be extraordinarily meaningful for both those who are just beginning their MBC journey and for those who have experience and insights to share

“ Make sure you are an active member of your treatment team. Without your input, your team is like a school of fish out water. ”

- Regina, living with metastatic breast cancer



### You and your health care team

Ultimately, your medical team is the best resource to help manage the disease, so it's important to understand which health care professionals (HCPs) you should consider to be a part of your team. These professionals will provide you with services and resources to maximize your health and well-being.

It is important to remember that you are the center of the health care team. When faced with a major decision, you can always decide to get a second medical opinion. Be sure to share your concerns and decisions with everyone involved in your care.

Below are some points you should know when choosing your treatment team:

- Understand who should be on your team. Utilize all resources available to you, such as your primary care physician (PCP), local cancer center, advocacy groups, or oncologist directory (AMA, ASCO), to find the right experts to support your journey
- An effective treatment team includes a variety of professionals. Specialists and HCPs you should consider including on your medical team include a medical oncologist, PCP, nutritionist, mental health professional, physical therapist, pharmacist, surgeon, radiologist and an oncology nurse practitioner
- Your medical oncologist will be responsible for your care and treatment. Consider choosing someone who

specializes in breast cancer and has expertise in treating women with metastatic disease. You may also want to consider choosing member of an established breast care center as this can help streamline your care

- Build a relationship with your team. Good communication between you and your team is essential to having your needs met to your satisfaction

It is very helpful if your entire health care team has the same information. You can help share this information by:

- Asking your oncologist for a treatment summary that includes your medical history and cancer treatment history. A treatment summary can be a useful tool to make sure all your health care providers know your history and the cancer treatments you have had
- Keeping copies of test results and medical records so that you can share them with all members of the health care team

## Metastatic Breast Cancer Story

### Staying on track with treatment

To get the most out of treatment, you need to stick to your treatment plan. Here are some practical suggestions:

- Try not to miss any doctor visits, especially when cancer treatment will be given
- If you take pills, make sure to take them, as prescribed, the same time every day. Some tips for remembering to take medications include:
- Call your doctor if you have side effects. Many side effects may be managed. Do not stop taking your medication on your own without talking to your doctor first
- Taking pills along with meals or other daily events, such as brushing your teeth
- Using special pillboxes that are divided into days of the week. You can find these pillboxes at any pharmacy
- Asking people who are close to you to remind you to take the pills
- Keeping a medicine calendar near your pills, making a note every time you take a dose

### Living with metastatic breast cancer

If you are undergoing IV treatment and/or treatment at an infusion center, make sure to track your appointments closely and stay in touch with your care team. Some tips for remembering your infusion treatment appointments include:

- Maintaining a treatment calendar to ensure your appointments are outlined in one place
- Keeping the phone number and address of the treatment center in a notebook for easy reference
- Asking friends or family to accompany you to treatments

## Dealing with Financial Issues

Paying for treatment can create a financial burden for people with MBC and their families, even for those with insurance. However, it is important not to panic or stop treatment. Talk to your insurance provider or someone at your doctor's office to learn about your benefits and additional resources that can help you pay for treatment.

Many organizations can help those with breast cancer get financial assistance or support services. Some possible sources for information on financial assistance are listed to the right.

For a list of resources by category, download *Dealing with Financial Issues Related to Metastatic Breast Cancer* from the Beyond Pink homepage.

### National Cancer Institute (NCI)

<http://www.cancer.gov/cancertopics/coping/financial-legal>

### American Cancer Society (ACS)

<https://www.cancer.org/treatment/finding-and-paying-for-treatment.html>

### American Association for Cancer Research (AACR)

<https://www.aacr.org/patients-caregivers/cancer/breast-cancer/>

### Cancer Financial Assistance Coalition (CFAC)

<http://www.cancerfac.org/>

### CancerCare

<http://www.cancercares.org/financial>





## Important Questions to Ask Your Doctor

### **Metastatic Breast Cancer**

- What type of MBC do I have?
- Where has the cancer spread?
- Can you describe the tests I will need?
- Based on my type of MBC, what types of therapies should I consider?

### **Changes in Hormone Receptor Status**

- What is my current hormone receptor status?
- What does this change in hormone receptor status mean for my MBC?
- What does this mean for my treatment? Can I stay on my current course of therapy or will I need to start a new therapy?

### **Hormonal therapy:**

- Is hormonal therapy an option for me? Why or why not?
- What type of hormonal therapy should I have? Why?
- When will I start the hormonal therapy?
- How often will I get it?
- How long will I need to take it?

### **Chemotherapy**

- Is chemotherapy an option for me?
- What type of chemotherapy should I have? Why?
- Are there any other chemotherapy options that are appropriate for me?
- Will I receive chemotherapy by mouth or by injection?
- How many cycles of chemotherapy treatments should I have?
- How long will the treatment take?

### **Targeted therapy:**

- Is targeted therapy an option for me? If so, why?
- What type of targeted therapy should I have? Why?
- How will the targeted therapy be given to me?
- How many treatments do I need?
- How long will the treatment take?

### **Immunotherapy:**

- Is immunotherapy an option I should consider?
- What is immunotherapy and how does it work?
- How is immunotherapy different from other treatments?
- How can I help manage the side effects?

### **Surgery:**

- Do I need surgery?
- What can I expect if I do have surgery?
- How long will I take to heal after surgery?
- How long will the procedure take?
- After surgery, what kind of follow-up care will I need?

### **Radiation:**

- Do you think radiation therapy is an option for me? If so, why?
- How many treatments will I need?
- How will the radiation be given?
- Which area(s) of my body will receive radiation?

### **Treatment Side Effects**

- What are the side effects of this therapy?
- Will the side effects last for a long time?
- How can I help manage the side effects?



## Resources

Below are some of the breast cancer organizations with web sites that offer information and helpful resources for people with MBC, family, and friends. They are grouped by the type of service they provide most often, but many organizations offer a variety of services.

This list of resources is provided solely as a convenience. AstraZeneca takes no responsibility for the content of, or services provided by, these organizations and makes no representation as to the accuracy or completeness of any information provided. AstraZeneca shall have no liability for any damages or injuries of any kind arising from the information provided.

### Support and community

#### **American Cancer Society (ACS)**

  [www.cancer.org](http://www.cancer.org) 1-800-ACS-2345

The ACS is a nationwide, community-based, voluntary health organization dedicated to eliminating cancer as a major health problem. In addition to its headquarters in Atlanta, Georgia, the ACS has regional and local offices throughout the country that support 11 geographical divisions.

#### **Association of Oncology Social Work (AOSW)**

  [www.aosw.org](http://www.aosw.org) 1-215-599-6093


The AOSW is a non-profit international organization dedicated to providing psychosocial services to people with cancer, their families, and caregivers. It is the world's largest professional organization entirely dedicated to the psychosocial care of people affected by cancer.

#### **Breastcancer.org**

 [www.breastcancer.org](http://www.breastcancer.org)

Breastcancer.org is a non-profit organization, dedicated to providing the most reliable, complete, and up-to-date information about breast cancer. Its web site provides information on various topics including symptoms and diagnosis, treatment and side effects, and day-to-day matters.

#### **CancerNet (American Society of Clinical Oncology)**

  [www.cancer.net](http://www.cancer.net) 1-888-651-3038



Founded in 1964, ASCO is committed to the principle that knowledge conquers cancer. Together with the Association for Clinical Oncology, ASCO® represents nearly 45,000 oncology professionals who care for people living with cancer. Through research, education, and promotion of the highest quality, equitable patient care, ASCO works to conquer cancer and create a world where cancer is prevented or cured, and every survivor is healthy.

#### **CancerCare**

  [www.cancer.org](http://www.cancer.org) 1-800-813-HOPE

Cancer Care provides free, professional support services and information to help people manage the emotional, practical, and financial challenges of cancer.

#### **Cancer Support Community (formerly known as The Wellness Community)**

 [www.cancersupportcommunity.org](http://www.cancersupportcommunity.org)  
 1-888-793-9355

The Cancer Support Community is an international non-profit organization dedicated to providing support, education and hope to people affected by cancer. One of the largest employers of psychosocial oncology mental health professionals in the United States, CSC offers a menu of personalized services and education for all people affected by cancer.



## **Facing Hereditary Cancer Empowered (FORCE)**

 [facingourrisk.org](http://facingourrisk.org)

FORCE's mission is to improve the lives of families facing hereditary cancer. FORCE accomplishes this mission by providing expert-reviewed information to help people make informed medical decisions. Their supportive community of peers and professionals ensures no one faces hereditary cancer alone. FORCE is a champion, advocating for access to care, and better treatment and prevention options.

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## **Living Beyond Breast Cancer (LBBC)**

  [www.lbbc.org](http://www.lbbc.org) 1-610-645-4567 1-484-708-1550

Living Beyond Breast Cancer provides programs and services to those whose lives have been impacted by breast cancer.

The goal is to provide easily accessible information which is frequently reviewed by the country's leading healthcare experts, community and support that you can trust, and respectful of patients and their situations.

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## **Metastatic Breast Cancer Alliance**

 <http://www.mbcalliance.org/>

Led by advocates, Metastatic Breast Cancer Alliance aims to ensure patients and caregivers are able to access needed care and services, build understanding how MBC differs from early stage breast cancer, and progress research to better quality of patients' lives.

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## **Metastatic Breast Cancer Network**

  <http://mbcn.org/> 1-888-500-0370

Metastatic Breast Cancer Network is a national, independent, nonprofit, patient advocacy group dedicated to helping those living with MBC be their own best advocate. The group provides education on coping with the disease and treatment option information.


## **METAvisor**

 <http://www.metavivor.org/>

The first organization dedicated to funding research for Stage IV breast cancer, METAvisor continues to rally public awareness, awards research grants, and provides much needed support for those living with MBC.

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## **National Comprehensive Cancer Network**

 <https://www.nccn.org/guidelines/guidelines-detail?category=patients&id=22>

NCCN FOUNDATION® is a 501(c)3 organization founded by the National Comprehensive Cancer Network® (NCCN®)—a not-for-profit alliance of leading cancer centers devoted to patient care, research, and education—to empower people living with cancer and advance oncology innovation.



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## **SHARE**

 <https://www.sharecancersupport.org/>


SHARE is a national nonprofit organization that supports, educates, and empowers women affected by breast, ovarian, uterine or metastatic breast cancer, with a special focus on medically underserved communities. Our mission is to connect these women with the unique support of survivors and peers, creating a community where no one has to face breast, ovarian, uterine or metastatic breast cancer alone. SHARE touches lives 190,000 times each year.

## Sharsharet

  [www.sharsharet.org](http://www.sharsharet.org) 866.474.2774

Sharsharet is a national non-profit organization, improves the lives of Jewish women and families living with or at increased genetic risk for breast or ovarian cancer through personalized support and saves lives through educational outreach.

## Susan G. Komen for the Cure

  [ww5.komen.org](http://ww5.komen.org) 1-877 GO KOMEN

Susan G. Komen's mission is simply to save lives and end breast cancer forever by educating, supporting research, offering grants that provide financial and emotional assistance, and advocating better breast cancer policy. Last year, 50,000 families impacted by breast cancer received Komen's social and financial support.

## Tutu Project

 <https://thetutuproject.com/>

The Tutu Project. Bringing cheer and support to breast cancer patients every day. A ride to chemo. Child care. Food in the fridge. A mortgage payment. The Tutu Project helps people with breast cancer get through their day with support for all those things that cancer doesn't care about. All the everyday stuff that suddenly becomes unaffordable – even for people with insurance. And when it seems like getting through the day feels impossible, the Tutu Project is there with a little emotional support too.



## Young Survivor Coalition

  [www.youngsurvival.org](http://www.youngsurvival.org) 1-877-YSC-1011

Young Survival Coalition provides in-person and online educational programs that are designed to reach young women affected by breast cancer, as well as friends, family, medical professionals, caregivers, the breast health community, and the general public. Programs include conferences, online chats, and educational materials.



## Treatment options

### American Cancer Society (ACS)

 <https://www.cancer.org/treatment/treatments-and-side-effects.html>  
 1-800-ACS-2345

For over a century, American Cancer Society has worked to save lives, help people get well and stay well, find cures, and fight against cancer. Cancer research, educational material, advocacy events, and treatment and support options are all part of ACS's contribution to creating a world with less cancer.

### American Society of Clinical Oncology (ASCO)

 <https://www.cancer.net/cancer-types/breast-cancer/%20treatment-options>  
 1-888-651-3038

Founded in 1964, ASCO is committed to the principle that knowledge conquers cancer. Together with the Association for Clinical Oncology, ASCO® represents nearly 45,000 oncology professionals who care for people living with cancer. Through research, education, and promotion of the highest quality, equitable patient care, ASCO works to conquer cancer and create a world where cancer is prevented or cured, and every survivor is healthy.



### Breastcancer.org

 <http://www.breastcancer.org/treatment>

A nonprofit organization dedicated to providing reliable, complete, and up-to-date information about breast cancer. Breastcancer.org strives to help women and their loved ones make the best decisions for their lives.

### Cancer survivorship and education

National Coalition for Cancer Survivorship (NCCS)

  [www.canceradvocacy.org](http://www.canceradvocacy.org) 1-888-650-9127

Born from the desire to replace the words “cancer victim” with “cancer survivor,” National Coalition for Cancer Survivorship (NCCS) has worked for almost 30 years to advocate for quality cancer care. NCCS works with legislators and policy makers to represent cancer patients and survivors to improve quality of care and life after diagnosis.



## Glossary

### A

**ADJUVANT CHEMOTHERAPY** (ADD-joo-vant key-mo-THER-a-pee): additional chemotherapy given after local treatment (surgery, radiotherapy) to lower the risk that the cancer will come back.

**ADRENAL GLAND** (uh-DREE-nul gland): a small gland that makes hormones, which help control heart rate, blood pressure, and other important functions of the body.

**ANALOG** (A-nuh-log): a substance or compound that is artificially made (derived) from a naturally occurring substance or compound.

**ANDROGEN** (AN-droh-jen): a type of hormone that supports the development and maintenance of male sex characteristics.

**ANEMIA** (un-NEE-mee-uh): a condition in which the number of red blood cells is below normal.

**ANGIOGENESIS** (an-gee-o-JEN-i-sis): the formation of new blood vessels, which tumors need to grow and spread. These new vessels carry oxygen and nutrients to the tumor, allowing it to grow. Antiangiogenesis medications stop tumors from growing by blocking formation of new blood vessels.

### B

**BIOMARKER TESTING** (BI -oh marker): Testing a tissue sample from the tumor after surgery or biopsy, or, in some cases, with a blood test, to determine which type of MBC a person has, which can help determine treatment options.

**BIOPSY** (BI-yop-see): a procedure in which a small piece of tissue is removed and then examined for the presence of disease such as cancer.

**BONE SCAN** (bohn scan): a test used to help find cancer metastases in the bone. Bone scans can find abnormal things in the bone such as fractures, infections, or tumors.

**BRCA**: the most common cause of hereditary breast cancer is an inherited alteration in the *BRCA1* or *BRCA2* gene. These genes help make proteins that repair damaged DNA in normal cells. When these genes become damaged (altered), abnormal cell growth can result, which can lead to cancer.

### C

**CAT SCAN** (cat scan): See computed tomography scan.

**CHEMOTHERAPY** (kee-mo-THER-a-pee): a treatment with strong drugs that attack cancer cells but may also temporarily harm some types of healthy cells.

**COMPLEMENTARY MEDICINE** (kom-plah-MEN-tah-ree MED-ah-sin): a type of nontraditional therapy used with, but not instead of, traditional medical treatment. Acupuncture and massage therapy are examples of complementary therapies.

**COMPUTED TOMOGRAPHY SCAN** (kum-pyoot-ed to-MOG-ra-fee scan): also called CT or CAT scan; an x-ray machine test that takes multiple pictures of organs and tissues, and uses a computer to create a detailed image of areas within the body.

**CT SCAN** (See-tee scan): See computed tomography scan.

### D

**DE NOVO** (deh NOH-voh): in cancer, the first occurrence of cancer in the body.

**DISEASE PROGRESSION**: the process in which the cancer worsens or continues to spread in the body. MBC treatment may stop working after a time, even after shrinking the tumor or slowing cancer growth for many years. When this happens, the doctor may recommend new or additional treatments.

### E

**EDEMA** (eh-DEE-ma): swelling caused by excess fluid in body tissues.

**EFFICACY** (EF-uh-cuh-see): effectiveness. In medicine, efficacy refers to the ability of an intervention (such as a drug or surgery) to produce the desired beneficial effect.

**ESTROGEN** (ES-trow-jin): a hormone made by the ovaries, fat tissues, and other places in the body. It causes female sex characteristics and is important in menstruation and fertility. Estrogen may also cause the growth of some breast cancers (ie, those that are estrogen receptor-positive).

**ESTROGEN RECEPTOR** (ES-trow-jen re-SEP-tor): a structure on the inside of various cells in the body, most prominently the breast and uterus. Estrogen receptors are also located in the brain, heart, liver, and bone, in addition to breast and uterus. When estrogen binds to the estrogen receptors, it causes cells to grow.

**G**  
**GENETIC TESTING:** usually conducted with a blood test to determine if someone has inherited alterations passed on by their parents, such as BRCA1 and BRCA2, that make them more likely to get breast cancer.

**GENOMIC TESTING:** testing a sample of a tumor to determine how active specific genes are, and the ways in which they interact with each other, which may affect the behavior of the cancer, such as how likely it is to grow and spread.

**H**  
**HER2** (her two): a protein involved in the growth of normal cells. It is found on some breast cancer cells, as well as on other types of cancer cells.

**HER2-TARGETED THERAPY** (her two TAHR-git-id THER-a-pee): therapy specifically for patients whose breast cancer overproduces the HER2 protein (see targeted therapy).

**HORMONAL THERAPY** (hor-MOWN-uhl THER-a-pee): a way of treating breast cancer that is hormone receptor-positive. Hormonal therapy can be used to block the effect of estrogen and/or progesterone or to prevent the ovaries from producing these hormones. It is different from hormone replacement therapy.

**HORMONE RECEPTOR** (hor-MOWN re-SEP-tor): a structure on the inside of a cell that receives and to which hormones, such as estrogen or progesterone, bind. When these hormones bind to the receptor, the breast cancer cells grow.

**HORMONE RECEPTOR-NEGATIVE** (hor-MOWN re-SEP-tor NEH-guh-tiv): in breast cancer, this means that the tumor cells do not have hormone receptors and, therefore, do not need hormones to grow.

**HORMONE RECEPTOR-POSITIVE** (hor-MOWN re-SEP-tor POZ-i-tiv): in breast cancer, this means the tumor cells have hormone receptors (see hormone receptor above) and need hormones, such as estrogen and progesterone, to grow.

**HORMONE REPLACEMENT THERAPY** (hor-MOWN ri-PLAYS-mu nt THER-a-pee): a treatment that gives estrogen and/or progesterone to women to help ease the symptoms of menopause.

**I**  
**INTRAVENOUS** (in-tra-VEE-nis): in the vein.

**J**  
**JAUNDICE** (JAWN-dis): a yellow discoloration of the skin and/or whites of the eyes. It is caused when the liver cannot get rid of bile and there is too much of a substance called bilirubin in the blood.

**L**  
**LOCAL THERAPY** (LOW-kal THER-a-pee): a treatment directed only at the area where the cancer is, such as surgery or radiation to the breast.

**LYMPH** (limpf): a clear fluid that contains proteins, salts, water as well as white blood cells, which play an important role in fighting infections.

**LYMPH NODES** (limpf nowdz): small, bean-shaped structures located in several places throughout the body, such as the groin, armpit, and neck. Lymph nodes carry lymph (see lymph above) and may play a role in fighting cancer.

**M**

**MAGNETIC RESONANCE IMAGING** (MAG-ne-tik re-SOW-nins IM-i-jing): often called an MRI, this test uses magnetic fields to create clear images of internal body parts, including tissues, muscles, nerves, and bones.

**MENOPAUSE** (MEN-o-pawz): a stage in a woman's life when menstruation stops and the ovaries stop making eggs and the hormones estrogen and progesterone.

**METASTASIS** (me-TAS-tah-sis): a cancer that has spread beyond the original site of the cancer to other parts of the body.

**METASTASIZE** (me-TAS-ta-sayz): what cancer cells do when they break off from the tumor where they started and spread to other areas of the body via the blood and/or the lymph.

**METASTATIC** (met-uh-STAT-ik): something that has spread (metastasized) to other locations.

**MRI**: See magnetic resonance imaging.

**N**

**NEOADJUVANT CHEMOTHERAPY** (NEE-oh-add-joo-vant key-mo-THER-a-pee): chemotherapy given as a first step to shrink a tumor before the local treatment, which is usually surgery, is given.

**P**

**PET**: See positron emission tomography.

**POSITRON EMISSION TOMOGRAPHY** (PO-zi-tron i-MI-shin to-MOG-ra-fee): often called a PET scan, this procedure makes a detailed image of areas in the body and can be used to locate cancer cells. The procedure involves the injection of a small amount of a radioactive material into a vein. Because tumors soak up more of the radioactive material, they can be easily identified.

**POSTMENOPAUSAL** (POWST-men-o-PAW-zal): happening after menopause.

**PREMENOPAUSAL** (PREE-men-o-PAW-zal): happening before menopause.

**PROGESTERONE** (pro-JES-ter-own): a hormone that is important in menstruation and fertility. Progesterone may also affect the growth of some breast cancers (ie, those that are progesterone

receptor-positive).

**PROGESTERONE RECEPTOR** (pro-JES-ter-own re-SEP-tor): a structure on the inside of a cell that receives and to which progesterone binds. When progesterone binds to the progesterone receptor, it causes breast cancer cells to grow.

**PROTEIN** (PRO-teen): an essential component in the body. Proteins form basic structures of the body, such as the skin and hair, and have many jobs that are needed for the body to work normally.

**R**

**RADIATION** (ray-dee-AY-shun) and **RADIOTHERAPY** (RAY-dee-yo-THER-a-pee): x-rays used to treat cancer and the symptoms related to cancer.

**RECEPTOR** (reh-SEP-ter): a molecule inside, or on the surface of, a cell to which a specific substance binds, causing a specific effect in the cell.

**RECURRENCE** (re-KAHR-ins): the return of cancer signs or symptoms after a period during which they could not be detected.

**REMISSION**: remission can be complete or partial. Complete remission occurs when a treatment successfully destroys all tumors that can be measured or seen. Partial remission is when the cancer partly responds to treatment but does not disappear.

**S**

**SIGNALING** (SIG-niling): a process used by cells to control important functions in the body.

**SYSTEMIC THERAPY** (sis-TE-mik THER-a-pee): a treatment given orally or directly into the bloodstream to affect or treat cells all over the body rather than at a specific site. In breast cancer, systemic therapies may include chemotherapy, hormone therapy, and targeted therapy.

## T

**TARGETED THERAPY** (TAHR-git-id THER-a-pee): This treatment specifically attacks the functioning of cancer cells, stopping their growth and spread to other parts of the body.

**TRIPLE NEGATIVE** (TRI-pill NEG-a-tiv): breast cancer cells that do not have estrogen receptors (ER-), progesterone receptors (PR-), or large amounts of the HER2 protein (see HER2).

**TUMOR** (TOO-mor): abnormal tissue caused from cells growing more quickly than normal tissue.







