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Beyond Pink

SHARING OUR METASTATIC BREAST CANCER STORY

Supporting Your Loved Ones on Their Journey with MBC: A Guide for Caregivers

If someone you care about has been diagnosed with metastatic breast cancer (MBC), your tasks probably extend beyond helping with day-to-day activities. Your most important job may be providing them with emotional support, including talking and listening. Research has shown that people living with cancer who have strong support systems tend to adjust better to the life changes that cancer brings, have a more positive outlook, and often report a better quality of life. This resource is meant to provide guidance on how you can show support for someone you care about, and practice good self-care, as you both experience the many challenges and feelings that arise along the MBC journey.

The first step in helping your loved one is to learn all that you can about the disease.



What Is MBC

Metastatic breast cancer, 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 MBC often develops as a recurrence of a previously diagnosed breast cancer, in a small number of cases it can occur in people with no prior history of breast cancer.

Types of MBC

There are different types of MBC, each with different characteristics. One of the characteristics is the presence or absence of hormone receptors. The human epidermal growth factor receptor 2 (HER2) is also used to determine the type of MBC. The status of these markers in a tumor is important in helping inform the treatment approach.

Hormone Receptor-Positive MBC

Some breast cancer tumors rely upon the hormones estrogen and/or progesterone for growth. These are called hormone receptor-positive breast cancers. If the cancer does not rely on these hormones, it is known as hormone receptor-negative.

There are different types of MBC that are dependent on the presence or absence of hormone receptors:

- Estrogen receptor positive (ER+): This means the cancer cells have estrogen receptors and the cancer is fueled by estrogen.
- Estrogen receptor negative (ER-): This type does not depend on estrogen for growth.
- Progesterone receptor positive (PR+): The cancer cells have progesterone receptors and the cancer relies upon progesterone for growth.
- Progesterone receptor negative (PR-): This type does not depend on progesterone for growth.

HER2-Positive MBC

In HER2-positive MBC, the cancer cells make too much of the protein HER2, which can cause breast cancer cells fueled by HER2 to grow. About 20 percent of those with MBC have HER2-positive breast cancer.

Triple Negative MBC

Triple negative MBC occurs when the tumor tests negative for estrogen, progesterone and HER2 protein. In this case, cancer growth is not supported by hormones nor by the presence of too many HER2 proteins. About 15% of MBC is triple negative, and this type is more common in younger patients.

Genetic Alteration Types

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:

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:

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

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.**

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.

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.**

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 an *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%.**

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%.**

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 for developing certain types of cancer** in one's lifetime, including breast cancer.

TP53

(Also known as p53): An alteration in this gene, which helps stop the growth of cells with damaged DNA, is the **most frequent in breast cancer (30% of all breast cancers)**. The role of the *TP53* gene in the management of breast cancer remains unclear.

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.

mTOR

A protein found in 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.**

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.**

CDHI

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

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.



FACT

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 management, many people may be able to live active and productive lives.

MYTH

All cases of MBC are treated the same way.

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, HER2 status, and other factors. Knowing the hormone and HER2 status may 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.

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

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.

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

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.

Understanding Disease Progression

Whichever type of MBC your loved one has, their 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. The treatment options depend on many factors, including location of the cancer, prior treatments, the person's age, general health and treatment preferences, including their desire to continue receiving treatment.



Providing Care and Support to Your Loved One

No matter how much support you can give, your loved one's journey with MBC will be difficult at times. They may experience setbacks with their disease, as well as side effects from medications. Feelings of anger and discouragement are common, and sadness and confusion may worsen. Don't take it personally if your loved one takes out their emotions and frustrations on you or others. Ideas to provide support during these difficult times include:

- Remind them that they don't have to face this journey alone and encourage them to lean on you when needed
- Try to understand what your loved one is going through—by listening or offering to lend a hand with chores and errands
- Don't act like a cheerleader, or try to make them feel good when they're feeling bad. Instead, allow your loved one to express anger, frustration, and any other feelings
- Stay in touch. Schedule regular check-ins to demonstrate your support. Call at times that work for your loved one's schedule, and visit as often as your schedule allows

Since you may not be able to complete all of these tasks alone, organize friends and neighbors to help. You may also want to consider asking for assistance researching information or to be the contact person who updates friends and family. Depending on the type of treatment your loved one is on – whether they require infusions or oral therapies, your needs as a caregiver may be different. Take the time to seek the support and care that you need, specific to your situation, and if one support system isn't working for you, try not to get discouraged. There are many support services out there – ask your loved one's care team for additional recommendations or read the Resources section of the Understanding MBC guide.



Communicating with Your Loved One

It can be very difficult for you and your loved one to talk about an MBC diagnosis. When you do communicate, take some time to assess how much or how little they want to talk about the disease. Below are some tips for interacting with your loved one throughout your shared journey.

Be a Sounding Board and Focus on Their Needs

- Try putting aside your own feelings and practicing active listening
- Try not to judge, make light of the situation, or change the way your loved one feels or acts. Sometimes it's OK not to say anything, but let them know you are there for them and offer a hug or other sign of affection
- Ask open-ended questions to help keep the conversation going, such as, "What are you feeling?" Try to avoid questions that may get a one-word response

- Be prepared to hear anything. Your loved one may be thinking about death or may tell you they're afraid. If they share these types of feelings, you don't have to reply, but you should acknowledge how they feel and ask if there is anything you can do to help
- Gear the conversation to your loved one's attention span so they don't feel overwhelmed or guilty if they want to end the discussion or change the subject

Offer to Participate in Treatment Discussions

A major role for a caregiver can be helping make treatment decisions, which may come with many strong emotions. While these decisions can be difficult, you can help by talking through various options to help your loved one actively manage their disease in partnership with their medical team.



Supporting Your Loved One When Talking About an MBC Diagnosis With Children, Friends and Family

One of your most important caregiver roles is helping your loved one talk with close friends and family about their diagnosis. A good place to start may be helping them decide whom to talk to, when and how much information to share. The following tips can help with these decisions:

- Help them make a list of people they want to talk to in person
- Help make another list of people that you (or someone else) may contact with the news of your loved one's diagnosis, if they are not comfortable
- Offer to be present when they share the news with others for moral support
- Encourage your loved one to be clear with family and friends about what type of information they want to share about their disease and how they feel. This approach can help others better understand and provide the appropriate support
- Encourage them to be honest with friends and family about what they're going through

If your loved one has children, unless you're asked to be there, let your loved one handle these conversations. However, you can still help them figure out what and how much to tell their children. Keep in mind that:

- Young children (up to age 8) don't need a lot of detailed information, but older children may want to know more. The most important issue for children of any age is their own sense of security and safety
- Remind your loved one that their children are probably very worried about them

- Above all, help ensure the children get a balanced point of view, emphasizing that cancer is a serious disease but there is a team of medical professionals helping their mom or dad
- Encourage your loved one to choose a time when they're feeling fairly calm to talk to their children
- Reassure your loved one that it's OK for children to cry, and to see their parents cry sometimes
- Your loved one can help their children cope by encouraging them to share how they feel, and by reassuring them that they will always be loved and cared for no matter what



Helping Your Loved One Seek and Accept Help

Some people find it hard to accept help, even when they need it. Don't be surprised or hurt if they resist; just continue to offer your support. There are several ways you can assist your loved one to accept help:

- Provide emotional support through your presence
- Offer practical ideas on what you can do to help. If needed, insist they select one specific chore for you to complete
- Remind them that allowing others to help can be an important way to help family/friends to cope with your loved one's disease



The Importance of Self Care

Adjusting to Your Loved One's Diagnosis

It's common for caregivers to put aside their own feelings and needs when they learn someone they love has been diagnosed with MBC, but this is hard to sustain long-term. This is a very emotional time for everyone, so consider finding ways to deal with stress, distress, and sadness that you may experience. Be aware of when you may be experiencing these feelings and take action to address your needs. Signs can include:

- Feeling overwhelmed
- Getting sick more than usual
- Feeling impatient or forgetful
- Withdrawing from others or activities you enjoy
- Prolonged tiredness
- Difficulty sleeping

Caring for Your Mind and Body

Caring for your own needs is vital so that you have the strength to be there for your loved one. After all, just as someone with MBC should not spend all of their time thinking about their illness, neither should you spend every minute thinking about or being a caregiver. Even as you put your loved one's needs first, you still need to:

- Find nice things you can do for yourself, whether it's a massage or call with a friend, or that others can do for you, to help you cope with your thoughts and feelings
- Connect regularly with friends or other family members and develop your own support network
- Keep up with your own checkups, screenings, and other medical needs
- Take your medications as prescribed. Ask your doctor for extra refills to reduce trips to the drug store, or find out if your grocer or pharmacy delivers
- Eat healthy meals, exercise and get enough rest. If your loved one is in the hospital or has long doctor's appointments, bring healthy food from home. Playing soft music or doing breathing exercises may help you fall asleep. Try running, walking or swimming for 30 minutes daily to keep yourself fit



Dealing With Difficult Feelings

As a caregiver, you are going through cancer along with your loved one. As your loved one is managing their MBC, things can become challenging. It is not unusual for the caregiver's emotional health to be impacted, with feelings of depression, anxiety or even helplessness, because what is happening to your loved one is not something you can control. If you are experiencing these feelings, it is important to:



- Be honest with yourself about the fact that you cannot do everything
- Set realistic limits on what you can and can't do, and don't be afraid to reach out to others for help. Asking for help does not make you weak or selfish; it's essential to maintain your mental and physical well-being
- Plan and make time to do things that you enjoy away from the house, such as a social outing with a friend, an outside hobby that gives you a sense of accomplishment, or taking a walk
- Make an effort each day to talk about something other than your loved one's illness and your caregiver role
- Accept that you will likely make some mistakes. Try not to blame yourself and remember the things you have done well. Include other family members and your loved one in important decisions
- Consider joining a support group with other caregivers. This may help you see things in a new light and give you new insights or coping tips. Support groups can meet online, in person or over the phone. Find one that best suits your needs
- If you find that your feelings of sadness or hopelessness are constant or you're neglecting your own health, seek professional help