

METASTATIC BREAST CANCER SERIES

Guide for the Newly Diagnosed



LIVING BEYOND
BREAST CANCER®

mbcn | METASTATIC
BREAST CANCER
NETWORK
EDUCATING • EMPOWERING • ADVOCATING

Fill out our online survey today for a chance to win a \$50 gift card!

Tell us what you think of the *Metastatic Breast Cancer Series: Guide for the Newly Diagnosed*.

Thank you for helping Living Beyond Breast Cancer improve our programs and services.

[CLICK HERE TO COMPLETE OUR SURVEY](#)



Dear Friend:

Whether this is your first breast cancer diagnosis or you have had breast cancer before, learning you have metastatic breast cancer is likely to be overwhelming. This booklet is designed to provide you with the information and support necessary to help you make informed decisions about your treatment and to manage your emotions during the first few months after a metastatic diagnosis.

Living Beyond Breast Cancer and the **Metastatic Breast Cancer Network** worked together to create this resource to assist you in becoming your best advocate. Our organizations have a deep appreciation for the many challenges you may face as you cope with the disease. Not only will you find sections designed to help you understand the tests and treatments that you may undergo, but also you will find sections addressing the impact that metastatic breast cancer can have on your emotional well-being.

If this is your first diagnosis, you may want to learn more about breast cancer in general. If this is a recurrence, you'll want metastatic breast cancer specifics. We cover both in section 2. Throughout the guide, you'll notice the words of people who, like you, know what a metastatic diagnosis means and how it feels. A committee of these women, as well as a committee of healthcare professionals, helped LBBC and MBCN provide the information you find in this brochure.

Living Beyond Breast Cancer and the Metastatic Breast Cancer Network are here to help you get the information you need to navigate a breast cancer diagnosis. For more information, visit lbcc.org or mbcn.org. **LBBC's Breast Cancer Helpline** connects you to a trained volunteer who has been diagnosed with breast cancer for emotional support, guidance, and hope. Complete our online match form at LBBC.ORG/HELPLINE or call us at **888-753-5222** to tell us about yourself and the kind of support you are seeking.

Warmly,



Jean A. Sachs, MSS, MLSP
Chief Executive Officer
Living Beyond Breast Cancer



Shirley A. Mertz
President
Metastatic Breast Cancer Network

LBBC Breast Cancer Helpline

LBBC.ORG/HELPLINE

888-753-5222

Metastatic Breast Cancer Network

MBCN.ORG

888-500-0370

SECTION 1

UNDERSTANDING YOUR DIAGNOSIS	7
Coping With Your Diagnosis	7
Managing a Metastatic Breast Cancer Diagnosis From the Start	8
Managing a Recurrent Diagnosis	10
A Note on Personal Research and Statistics	11
Telling Others: Friends, Family, and Co-workers	11
A Note on Spouses, Significant Others, and Children	12

SECTION 2

UNDERSTANDING METASTATIC BREAST CANCER	15
Breast Cancer Basics	15
How Breast Cancer Metastasizes	16
What Makes Metastatic Breast Cancer Different	17
Understanding New Terms and Your Pathology Report	19
Knowing the Cancer's Subtype	20
A Note on BRCA Genetic Testing	21
Creating a Healthcare Team You Trust	21
A Note on Second Opinions	22

SECTION 3

UNDERSTANDING TREATMENT OPTIONS	25
Common Treatment Options	27
Clinical Trials and Your Treatment	28
Integrative and Complementary Approaches to Care	30
Palliative Care for Well-Being	31

SECTION 4

MAINTAINING YOUR EVERYDAY WELL-BEING	33
Improving Your Daily Life	33

SECTION 5

LOOKING TOWARD THE FUTURE	37
--	----

SECTION 6

RESOURCES	39
Organizations That Can Help	39
Tests to Expect	41
Words to Know	42

UNDERSTANDING YOUR DIAGNOSIS



Understanding your diagnosis

Learning you have metastatic breast cancer can be overwhelming. Right now you may be feeling and thinking many things all at once, and life may feel out of your control. It is natural to ask: Who can help me? What happens next? What do I do now?

About 168,300 people — women and men — are living with metastatic breast cancer in the United States. What was once a rarely discussed disease is getting more public attention through the efforts of people with metastatic breast cancer who work to educate the public and to advocate for more treatments to extend lives. With the help of organizations like Living Beyond Breast Cancer and the Metastatic Breast Cancer Network, people with metastatic breast cancer are finding that they, like you, are not alone.

Metastatic breast cancer is life changing, and managing the disease will now be part of your daily life. Rest assured that advances in research and treatment have made it possible for many to live longer, more fulfilling lives than in the past. The disease varies from person to person and your treatment experiences will be unique.

“I will live the rest of my life as a cancer patient, but I have comfort knowing that I do not travel this road alone.” — SANDRA

COPING WITH YOUR DIAGNOSIS

No matter how familiar you are with breast cancer, the next few days, weeks, and months will likely be challenging. You'll hear new medical terms, undergo many diagnostic tests, and meet medical professionals you may not have needed in the past. Adapting to ongoing treatment may take time, but there are many ways to prepare.

It is understandable to feel many emotions all at once. People facing a serious diagnosis often feel anger, loss, confusion, and fear. There is no right way to feel. Your emotions are a product of your situation, your personality, and your personal coping style. These feelings may change throughout your treatment as you confront new challenges.

Some people find it helpful to share feelings with friends, family, or others living with metastatic breast cancer. Others may seek out support groups or individual counseling.

“It took me a while to digest the indefiniteness of a metastatic diagnosis. But once I understood, I accepted my reality and was able to continue to start living in the moment. That is the challenge.” — NAZNEEN

Whatever your reactions, allow yourself to experience them. Know that resources are available to support you. A metastatic diagnosis comes with different worries at different times. No one expects you to be strong, brave, or together all the time. No one expects you to handle this alone.

“Allow yourself to grieve. Don’t try to be the strong person all the time. There’s a lot of pressure to be that inspirational person and be the perfect cancer patient who doesn’t complain. But you have to be true to yourself.” — KIM

MANAGING A METASTATIC BREAST CANCER DIAGNOSIS FROM THE START

Hearing you have breast cancer is difficult news, but your emotions may be intensified when you learn that it has **metastasized**, or spread to areas of the body outside the breast or nearby lymph nodes. Along with the shock of diagnosis, you are given a great deal of unfamiliar medical information.

It may help to write notes during all your appointments. Knowing as much as you can about your situation may empower you. When you have your first meeting with your doctors, you may want to take someone with you — a trusted, reliable friend or family member — who can take notes or record what you discuss. You may want a way to review the important information you’ll receive.

In fact, you might want to keep a running list of all medicines you take, tests that you have, and symptoms and side effects you experience. Your personal notes may help you remember questions that you have for your doctors. If you prefer to record conversations with your doctor rather than take notes, let your provider know.

“Make it a practice to keep a journal of visits with questions, answers, tests, appointments, and treatments. It will come in handy in the future.” — CAROL

Your doctors might also recommend resources to you. Information about metastatic breast cancer can be found online as well. If you turn to online resources, be aware of how reading those resources makes you feel. If they cause more anxiety or stress, you may want to stop reading or ask someone you trust to do research for you.

“Every breast cancer patient should educate themselves about their particular type of cancer and seek out a doctor who will offer them personalized treatment.”— SHIRLEY

It is common to be overwhelmed by the amount of information available and the differences between sources. As you find resources that you trust, make a list for the future. Keeping a personal or online journal may provide an outlet for anxiety. It also makes a great record of concerns you may wish to discuss with your doctors and other support professionals.



MANAGING A RECURRENT DIAGNOSIS

No matter how long it's been since you had breast cancer, finding out that the cancer has metastasized may bring feelings of shock, disbelief, anger, betrayal, and sadness. You may also feel guilty, or believe that you or your doctors could have done something differently to prevent the cancer's return.

You are not alone. Researchers believe that between 20 and 30 percent of people first diagnosed with early-stage disease will develop metastatic disease.

“It’s OK to feel what you are feeling. Allow yourself the same compassion you would offer a good friend. Be realistic about who can handle the emotions and fears you may need to share.”— NANCY

News coverage tends to focus on stories of survivorship, and to praise people who appear to have “fought their battle” with breast cancer, heroically and successfully. The lack of public awareness of metastatic breast cancer can leave you feeling isolated, misunderstood, and unsupported.

Even with the best treatments for a primary breast cancer, it is possible for the cancer to return later. There was always a chance for recurrence, even if that chance was very small. Regular tests or noticing symptoms might have helped you and your doctors find the metastasis earlier, but research shows that finding metastatic breast cancer early does not change the outcome. **You are not to blame.** Even if you had the best possible treatment for early-stage breast cancer, there remained a chance some cancer cells would survive and cause metastases someday.

It is normal to feel that you’ve lost trust in your doctors or treatments, or to be angry with your medical team or yourself. As you learn more about your diagnosis and your treatment options, these feelings may fade. Don’t rush yourself. Allow time to make sense of the news and to feel your feelings.



A NOTE ON PERSONAL RESEARCH AND STATISTICS

When you're faced with questions like *What are my chances?* and *How long do I have?*, a statistic might seem like good, concrete information. But statistics are not personalized to your specific situation.

Statistics are recorded to help researchers understand how metastatic breast cancer affects large groups of people, not individuals. In the research setting, these numbers help show how the disease acts, what medicines it reacts to, and other issues that help doctors work toward developing treatments. Average percentages often reflect thousands of people in research done sometimes years ago — but never just one, today. **You are not a statistic.**

In a similar way, doing online research about your diagnosis and its symptoms and side effects may heighten worry and anxiety. It's important to listen to yourself and be aware of when to stop reading. It may be helpful to consider your research a jumping-off point to talk with your doctors, not a definite example of what will happen to you. Your healthcare team can speak to your specific concerns.

Start with trusted online sources from hospitals or from government, nonprofit, or academic institutions. As you read, keep in mind that every person is different. No one else's experience will match your own.

For a list of trusted resources, see page 39.

TELLING OTHERS: FRIENDS, FAMILY, AND CO-WORKERS

Talking with others about your diagnosis can be a great source of comfort, but for some it can also be very stressful. Finding the right time *for you* is important. It is OK to want to wait until you make sense of the diagnosis yourself before you tell others.

“Telling people is highly personal. Sometimes you have to work it out within yourself before you open the doors to let everyone else in.” — ANN

You may feel more comfortable sharing the news after you've done your own research and talked with your doctors. Who you tell and when you tell them is a personal choice. You may find that telling one or two people is best in the beginning, or you may want to tell as many people as you can. Take this step in the way that is most comfortable for you.

Writing down what you want others to know about your situation may help you say what you want to say more clearly. The words you use may bring about powerful emotions for all of you.

It may not be possible to predict other people's reactions. At a time when you need comfort, you may find yourself comforting others. The thought of disrupting the lives of your family and friends, or fear about how they will respond, may make you wary of telling everyone or anyone. Remember, though, that the people closest to you are sometimes the best support system.

Keeping a group of supportive and caring people in your life may help you cope with metastatic breast cancer. As you go through treatment, you may benefit from the support of having someone with you at appointments to take notes, to drive you to and from treatments, or to help with daily chores when you don't feel up to it.

Those around you may feel more at ease when they can be helpful, so don't hesitate to tell people what you need. Doing so may help you conserve energy for what you want to enjoy most.

Many will want to be there for you, but some may surprise you by the way they react to your news. Some may even pull away. Your friends and family may need time. They may feel sad, angry, scared, or confused. Sometimes people want to help, but don't know what to do or say. Some people just will not respond in a supportive or sensitive way. Most of the time, insensitive remarks or reactions are grounded in the other person's fear and discomfort.

It may be helpful to plan ahead for how you want to respond to insensitive reactions. It may be as simple as saying you prefer to discuss your situation with your medical team, or changing the subject. It's also fine to be direct. Consider saying, "This is not helping me right now." If someone is not helpful to you, it is OK to set boundaries.

At work, you have a right to privacy. You don't have to give out personal information if you don't want to. Since you may see your co-workers every day, carefully consider who, if anyone, you want to tell about your diagnosis. Decide if sharing the news may disrupt your day-to-day work life or expand your support network.

If you need to take time off for treatment, use disability benefits, or change your work hours, you will be required to disclose some information to your human resources representative. For more information on career concerns and the Family Medical Leave Act (FMLA), visit lbcc.org or mbcn.org.

“I have derived enormous strength and healing from the embrace of a circle of friends and loved ones, reminding my family that we are not making this journey alone. In African cultures where I work, illness belongs to an entire community. When one person is sick, everyone heals together.”— POLLY

A NOTE ON SPOUSES, SIGNIFICANT OTHERS, AND CHILDREN

A diagnosis of metastatic breast cancer brings uncertainty and stress to even the best relationships. It can be very challenging for your spouse or significant other and your children.

Openly discussing your feelings, worries, and fears with the people closest to you may help you maintain your relationships. Keep in mind that your partner will have their own worries and concerns and will need time, comfort, and support. It can be very hard to tell children about your diagnosis. Though not telling them may seem best at first, children of all ages often pick up on the stress and emotions of their parents or may overhear conversations. Not telling them may leave them confused and anxious.

With very young children, explain in simple terms that you are sick and you are working with doctors to feel better. With children who are old enough to follow what adults are talking about, using the word cancer will be helpful because they will hear it out in the world. Talking about cancer with your children may also help them understand that they did not somehow make you sick. If your treatment has side effects like hair loss, let your children know you will lose your hair, but that you will still be you.

You are the best judge of what your children can understand and process. Depending on age and developmental stage, children can respond to the news with a wide range of reactions, which will change over time. For more information about talking with children of all ages, visit lbbc.org and see the resources on page 40.

“I have been blessed to have had these last 3 years and look forward to many more, science willing. I am grateful for the support I have received from my friends. The sense of feeling cared about is extremely healing.”— JO



UNDERSTANDING METASTATIC BREAST CANCER



Understanding metastatic breast cancer

If this is your first cancer diagnosis, understanding the disease will help you talk with your healthcare providers. This section gives you a basic understanding of breast cancer, how it metastasizes, and how metastatic breast cancer is different from early-stage disease.

The first section, Breast Cancer Basics, briefly describes breast cancer, some types of breast cancer, and how doctors interpret and use stages. The following sections, How Breast Cancer Metastasizes, starting on page 16, and What Makes Metastatic Breast Cancer Different, starting on page 17, go into more detail about the biology of metastatic disease. These sections may be useful to you, whether the cancer has returned, or metastatic breast cancer is your **primary diagnosis** — your first diagnosis of breast cancer.

For more details on breast cancer basics, visit lbbc.org or mbcn.org.

BREAST CANCER BASICS

Though we refer to it as simply breast cancer, like many diseases, breast cancer comes in several types that grow and respond to medicines differently. All breast cancers start in the tissues of the breast, when breast cells grow out of control. This happens because of a **mutation** (error) in cell DNA that causes them to reproduce without stopping, making the cells become **malignant**, or cancerous. The most common types of breast cancer are ductal and lobular.

Ductal cancers begin by growing in a mass inside the **ducts** of the breast, the passageways that carry milk from the lobules to the nipple. They later spread through the wall of the ducts into the fat and fibrous tissue of the breast. When a ductal cancer travels through the wall, it causes a fibrous tissue reaction around itself, forming a scar that leads to a well-defined mass.

Lobular cancers start in the **acinus** of the **lobule**, the structure within the glands that produce breast milk. Unlike ductal cancer cells, lobular cancer cells spread through the wall of the acinus into the fat and fibrous tissues of the breast but do not collect scar tissue. They can sometimes grow without forming a mass, making them harder to find.

Inflammatory breast cancer is an aggressive but uncommon form of breast cancer. It can be ductal or lobular. It develops when cancer cells block the lymph vessels in the skin of the breast, causing it to be red, swollen, and tender.

When breast cancer cells invade the wall of the milk duct or acinus, they are called **invasive** or **infiltrating**. These cancers have the ability to spread beyond the breast and nearby lymph nodes to the armpit, neck, or chest, through lymphatic channels or through the bloodstream.

Doctors put breast cancer into five stages: stage 0, which is considered **non-invasive** (in situ) and stays within the ducts or lobules, and stages I through IV. All cancers above stage 0 are considered invasive cancers. Stages are based on tumor size, lymph node involvement, and whether the cancer has spread beyond the breast and nearby lymph nodes to other parts of the body. When cancer is metastatic, the cancer has traveled away from the breast and lymph nodes to other parts of the body, such as the bones, lungs, liver, or brain. Though cancer at any stage can become metastatic, **metastatic cancer** is the term used to refer to **stage IV** cancer.

Breast cancer is also broken down by subtype. Subtypes are determined by the cancer cells' reaction to the hormones estrogen and progesterone, usually recognized by the presence of hormone receptors in the cells (referred to as **hormone receptor status**), or too much of the HER2 protein, called the **HER2 status**. Your doctor will also note how the cancer grows (in a sheet or in a mass) and the **proliferation index**, which tells what percentage of the cancer cells are actively dividing.

Knowing the subtype can help you and your doctors determine the best course of treatment for you. Many targeted medicines have been and are being developed for specific subtypes.

All subtypes of breast cancer can become metastatic.

HOW BREAST CANCER METASTASIZES

When breast cancer metastasizes, the cancer cells enter the lymphatic channels or the bloodstream and spread to lymph nodes or other organs of the body.

Breast cancer cells can travel away from the breast and get into the bloodstream fairly easily, but only a select few can survive and grow in other organs. Typically, your body will reject or attack things it doesn't recognize (like germs), but in the case of metastasis, cancer cells seem familiar enough that different areas of the body allow them to grow. The most common locations of breast cancer metastases are the liver, bones, lungs, and brain.

If you had breast cancer before, this new diagnosis may be referred to as **recurrent disease**. In this case, some of the primary cancer cells survived the treatments you may have had after your early-stage diagnosis. Therapies that treat the whole body, called systemic therapies (see page 27), aim to eliminate cancer cells in the breast as well as those that may have already started traveling to other parts of the body. But in some cases, those cells escape the treatment and begin to grow later.

Many doctors have researched the process of metastasis, but to date no one can predict how long cancer cells will be inactive before they begin to grow and can be detected.

Even though the cancer cells spread to a different area of the body, your doctors will still treat them as breast cancer. Being diagnosed with bone metastasis is not the same as being diagnosed with bone cancer. Under a microscope, the cancer cells still look the same as breast cancer cells. Though they are growing at a distant site, these cells have many of the same mutations and a similar genetic makeup to the cells that caused the cancer in the breast. If you had early-stage breast cancer before, your doctor may decide to do a biopsy to ensure the tumor cells remain similar to those at your original diagnosis.

If this is your first cancer diagnosis, it is possible your doctors discovered you have breast cancer because you had symptoms in a different area of your body, like your bones. Your doctors were able to make the diagnosis because breast cancer cells remain breast cancer cells, no matter where they are.

Your doctors should run tests to make sure that the cancer cells from the metastatic site are the same as your primary diagnosis (if you had one). They will adjust your treatments if necessary, for the best results possible.

WHAT MAKES METASTATIC BREAST CANCER DIFFERENT

You may have heard that breast cancer is a disease that can be treated and then ends. At the end of treatment for your first diagnosis, maybe you felt your experience was over. Perhaps your doctors mentioned the chance of recurrence, but it sounded unlikely.

There are many people who undergo treatment and never have to deal with cancer again. A metastatic breast cancer diagnosis is different because it means you will actively deal with breast cancer for the rest of your life.

With metastatic breast cancer, the goal of treatment is to shrink or weaken the cancer, manage your symptoms and side effects, and prevent the cancer from spreading further. Changes in treatment are made as the cancer grows or spreads to new places in your body. You and your doctors will talk regularly about **progression**, the growth of tumors or spread of cancer, and **regression**, decreases in tumor size or the cancer's reach. When one treatment stops working, you and your doctors will look at new options.

When talking with your doctor, ask about treatment side effects. Maintaining your usual daily activities and being able to participate in the things you enjoy are essential to your overall well-being. It may be helpful to talk openly with your medical team about how symptoms and side effects impact you every day.

Treatment for metastatic breast cancer has two main goals: to control the cancer for as long as possible, and with the highest quality of life possible.

At stage IV it is difficult to fully remove cancer with surgery or medicine because new tumors may appear over time, or cells may stop responding to different treatments. While metastatic breast cancer is not considered curable, it is possible to experience periods where tests show no evidence of disease, often called **NED**. While reaching NED may not always be possible, it is likely that you will have periods when the cancer does not grow. This is called **stable disease**.

Being diagnosed with metastatic breast cancer can happen to anyone, at any time. Even stage I cancer can become metastatic. Years after completing treatment, someone with stage I cancer may learn the cancer is back and is now metastatic. The stages are meant only to predict your risk of recurrence.

While the main goal is choosing the treatment path that will get rid of tumors and outlying cancer cells in the most effective way, you and your doctors may also want to think about what you are willing to try and what you aren't, so that you continue living the way you want to live.

For more information on metastasis and what it means for you, please visit lbcc.org and mbcn.org.

“Every day I wake up remembering that I have metastatic breast cancer. That will never change. What I am hoping to help change is the general misconceptions that are floating around the world of pink. I want to help change the fact that metastatic breast cancer is not curable. I want to be a part, if even a small part, of helping to find a cure.”— BARB



UNDERSTANDING NEW TERMS AND YOUR PATHOLOGY REPORT

In the time leading up to and after your diagnosis, you will have many medical tests. These initial tests help your doctor see what kind of breast cancer you have, how rapidly it is growing, and where it has spread. The information collected is part of your **pathology report**, a profile of all of your test results that helps doctors determine your treatment path.

It's important to get copies of all test results, including imaging, for your own record-keeping. Having them on hand may make things easier if you get a second opinion or need to change doctors. If possible, get a copy of your pathology report from your first diagnosis. Should you repeat tests now, your doctor can compare your earlier pathology report to your current one to see if the cancer has changed. Between 15 and 20 percent of metastatic cancers have different pathology traits than at early-stage diagnosis. It is important to ask for a new biopsy to confirm your breast cancer type so the treatment you receive matches your current diagnosis.

Throughout treatment you will have tests to help you and your healthcare team assess the success of your treatment plan and make changes, if needed. Your doctor may request blood tests, bone scans, x-rays, CT scans, MRIs, and PET scans. Tests are chosen based on where the cancer has spread. Learn more about tests on page 41.

Many doctors now do a **confirming biopsy**, a biopsy on the metastatic site to find out if the cancer cells are estrogen or progesterone receptor-positive or HER2-positive. A **biopsy** tests a sample of tissue taken from the affected site, or a lump or tumor removed with surgery. Doctors sometimes assume the cancer cells in the metastatic site have the same features as those in the breast, but current research suggests that sometimes the traits of cells change.

A confirming biopsy brings you the comfort of knowing more about your diagnosis, as well as better targeting your treatment. It will show your healthcare team whether the cancer became sensitive to certain hormones or has too much of a certain kind of protein. Though it's rare, it is possible that a confirming biopsy will find that what looks like breast cancer metastasis is something else, such as a **benign** (not harmful) growth or another disease.

If your diagnosis was not confirmed by biopsy, ask your healthcare team why it was not, or request one. In some cases, such as in brain or bone metastasis, the location may make biopsy difficult, so your doctors will rely on scans, symptoms, and blood work to confirm your diagnosis instead.

Your doctor may also order a **blood marker test** or **tumor marker test**, a test that looks for specific proteins or tumor cells circulating in your blood. The proteins and tumor cells are small pieces that break off the cancer and enter the bloodstream, making it possible to find them with a blood test. In some cases, doctors use blood marker tests to help with diagnosis, but more often they are used to monitor disease progression. In some cases a biopsy will confirm a metastatic diagnosis even when blood markers are not at high levels. Some providers prefer not to use tumor marker tests because of concerns they are not reliable.

Like any illness, cancer has its own vocabulary. Keep a running list of terms you want defined to help you make sense of everything. Don't be afraid to ask your doctor, nurse, or other medical professional to explain what they mean more clearly. For a list of words used in this guide, see page 42.

KNOWING THE CANCER'S SUBTYPE

As researchers have learned more about breast cancer, treatment and research options have become tailored to specific types. Your pathology report will include the type of cancer you have, and whether it is a single type or a combination of types. In some cases, the subtype of cancer may change if the cancer is recurrent. Retesting now will give you and your doctors important information to help you make informed decisions about treatment. The known subtypes are:

- **Hormone receptor-positive or negative (ER+/- or PR +/-):** Cancer cells that grow in response to certain hormones test positive; those that do not test negative. In some cases, hormone-sensitive cancers respond to medicines called hormonal therapies, which block estrogen from binding to cancer cells, lower estrogen levels, or lessen the number of estrogen receptors on the cells. In other cases, the cell will have high levels of estrogen receptors but few or no progesterone receptors, where in a normal cell there are high levels of both. Tumors that are ER+ but PR- may be more aggressive and less sensitive to hormonal therapies. Tumors that are both ER+ and PR+ usually respond to hormonal therapies. Any hormone sensitivity makes you a candidate for hormonal therapy.
- **Human epidermal growth factor receptor 2-positive or negative (HER2 +/-):** The HER2 protein is part of normal cell growth, but in some cancer cells the amount of HER2 proteins is too high. This is called HER2-positive breast cancer and can be treated with anti-HER2 therapies.
- **Triple-negative:** These types of cancers test negative for estrogen and progesterone receptors and for HER2. This means the cancer cells grow without estrogen, progesterone, or HER2 proteins present. These cancers do not respond to hormonal or anti-HER2 therapies. Triple-negative cancers usually respond to chemotherapy and other types of treatment.



A NOTE ON BRCA GENETIC TESTING

If you come from a family with a history of breast or ovarian cancer, genetic counseling and testing to identify mutations in your **BRCA1** or **BRCA2 genes** may give you more insight into your diagnosis. The BRCA genes are known tumor suppressors, or genes that make proteins that help control cell growth. When inherited with a mutation, the BRCA genes can increase the chances of developing breast and ovarian cancer in families.

Knowing your BRCA status may qualify you for certain kinds of anti-cancer treatments. It can also give your doctors more information about the breast cancer and provide members of your family information about their chances of developing cancer in the future.

Your doctor may be more likely to recommend genetic testing if you were diagnosed under age 45, with triple-negative breast cancer under age 60, have a strong family history of breast or ovarian cancer, or are of Ashkenazi Jewish heritage.

CREATING A HEALTHCARE TEAM YOU TRUST

After a diagnosis of metastatic breast cancer, it is important to build or find a healthcare team you trust will get you the care you need to live well. Your healthcare providers will support you over a long period, so it is important you feel comfortable. They should listen to your concerns.

The most important part of trusting your healthcare team is being able to communicate with them in the way that is most comfortable for you. You may want many questions answered, or you may feel more at ease following the doctor's suggestions. When building your healthcare team, consider what matters to you. Will your doctors respond to you in a reasonable amount of time? Do they listen when you voice your concerns about symptoms or treatments? Do they share your values, and respect your beliefs? You may want to add new professionals to your team, such as a palliative care specialist (see page 31) with expertise on pain and symptom management, or a cancer doctor who specializes in breast care.

If you already have a healthcare team from a past diagnosis, it is OK to reconsider who you want to care for you. You can do this at any time.

Sometimes, health insurance providers limit the medical professionals you may see or require you go to a specific treatment center that already has healthcare teams in place. Still, you are always entitled to a second opinion. Talk to your insurance company case worker if you have one, or ask to speak to someone who can tell you which professionals and institutions are covered by your healthcare plan. Your cancer center may also offer specialized registered nurse case workers, nurse or patient navigators, or oncology social workers who can assist you further.

Some of the professionals you may see include radiologists, pathologists, surgical oncologists, medical oncologists, radiation oncologists, and primary care physicians (PCPs). Oncology and surgical oncology nurses, social workers, psychotherapists, chaplains, and physical therapists may play a role in your care. They will help you with care before and after treatments, with your and your family's emotional needs, and with finding resources for support and advice.

If you think you may be interested in **complementary and integrative therapy** (see page 30), non-medical therapies used alongside your medical treatment, you may consider adding a complementary/integrative care expert to your team.

A NOTE ON SECOND OPINIONS

A second opinion may bring a fresh perspective and shed light on new treatment ideas. Or, if you feel like you are not getting the information you need, a second opinion may help you find someone more suited to you and your situation.

Your doctor should support you if you wish to seek a second opinion. Your original physician will likely communicate with your second opinion doctor to determine the best treatment possible for you.

Even if the second opinion is the same or similar to the first, getting one may give you confidence that you are on the right path, with the right team helping you. When you go for a second opinion, consider taking a list of questions to help you get the most out of your appointment. Sometimes people decide to change care providers as a result of a second opinion.

“It’s important to read and talk to friends, family, and other women with metastatic disease before the second opinion. They can help you form questions to ask.”—BONNIE







Understanding treatment options

The goal of treatment in metastatic breast cancer is to prevent or slow progression of the disease while easing symptoms and treatment side effects. Your healthcare team will focus on enhancing your overall well-being while working to reduce the amount of cancer in your body.

Because metastatic breast cancer is treatable but not curable, it is important to realize that at times, treatments may not seem as aggressive as those given for early-stage breast cancer. This is because treatment for early-stage breast cancer is short-term, with the goal of getting rid of all of the cancer, while treatment for metastatic breast cancer relieves symptoms over the long-term.

If you were treated for breast cancer in the past, it is unlikely you will get the same medicine you received for early-stage disease. The cancer cells may have built a resistance to those medicines, or the treatments may be too toxic to your body to use more than once. In most cases, a diagnosis of metastatic disease means an entirely new course of treatment.

In metastatic breast cancer, treatments will change over time as the cancer adapts to and builds resistance against therapies. Typically, a treatment is used until the cancer progresses. Then your healthcare team will suggest a new course of treatment. It is hard to predict how long a specific treatment may work in any person. Some treatments work for many years, while others need to be changed more often.

In addition to the methods available to treat all stages of breast cancer, many new FDA-approved treatment options are available only to people with stage IV breast cancer. Your doctor can tell you about them and their availability for you. Your doctors may also speak with you about clinical trials (see page 28), which offer access to treatments under study for metastatic breast cancer.

In some cases, you and your doctor can schedule **treatment breaks** for special events, like weddings or vacations, where it might be hard to get treatment or the side effects may disrupt your life. It also is possible to take treatment breaks to give your body a rest from treatment and side effects. If you think you may need or want a treatment break, talk with your healthcare team as early as you can.

10 QUESTIONS TO ASK ABOUT TREATMENT

Managing metastatic breast cancer is as much about living your life as it is about treating the cancer. When making treatment decisions, ask these questions:

1. What are the benefits of this treatment?
2. What are the short-term side effects?
3. What are the long-term side effects?
4. How is the medicine given?
5. How long does it take to receive treatment?
6. Will this medicine make me feel sick and prevent me from doing my daily activities?
7. What can I do to make sure I can continue to do the things I love while I take this medicine?
8. What side effects mean I should call you immediately?
9. Why do you believe this treatment is the best option for me?
10. If this treatment doesn't work, or makes me feel too sick, what are my other options?



COMMON TREATMENT OPTIONS

There are several common types of treatment approved for metastatic breast cancer.

These are hormonal therapy, targeted therapy, chemotherapy, immunotherapy, surgery, and radiation therapy.

Hormonal therapy, targeted therapy, immunotherapy, and chemotherapy are **systemic**, meaning they travel through the bloodstream and treat the whole body. Surgery and radiation therapy are **local**, only affecting cells in and around tumors. Most treatments will be given either by vein or as a pill taken by mouth.

- **Hormonal therapies** are targeted, systemic treatments used to treat hormone receptor-positive breast cancer. In hormone-sensitive metastatic breast cancer, hormonal therapies are often the starting point for treatment. They are the most effective approach for this type of cancer and have different side effects than chemotherapy. Hormonal therapies were the first targeted therapy, because they target estrogen and progesterone receptors.
- **Targeted therapies** are systemic treatments that attack specific proteins or genes on or within cancer cells that help the cells grow. Targeted therapies include medicines that treat HER2-positive metastatic breast cancer. Others target specific processes involved in cell and tumor growth, such as CDK 4/6 inhibitors and PARP inhibitors. Targeted therapy has the potential to be personalized from person to person.
- **Immunotherapy**, a systemic therapy, uses the body's defense system to fight cancer. These medicines make the immune system stronger, and help it focus on the parts of cancer cells that look different from normal, healthy cells. Once the immune system sees these differences, it is more likely to recognize the cancer as something harmful to the body, and to attack it. Immunotherapy is available to people with certain types of metastatic breast cancer.
- **Chemotherapy**, a systemic therapy, is given by infusion into a vein or **access port** or is taken as a pill. It kills rapidly dividing cells in order to slow or stop the growth of cancer. An access port, sometimes called a port-a-cath, is a small device under the skin that allows access to your veins. Another option is a **PICC line** (peripherally inserted central catheter), a long, flexible tube inserted into a vein in the arm that gives access to larger veins. In many cases, chemotherapy will be given after your first line of treatment, to help prevent the cancer from growing again. Together with your doctor, you will consider the physical and emotional side effects of chemotherapy. Depending on the type of cancer you have, your age, and treatments you've had in the past, your doctor may advise for or against chemotherapy.
- **Radiation therapy**, a local therapy, works to damage cancer cells in specific areas of the body. In metastatic breast cancer, radiation therapy is used to shrink tumors, ease pain, and improve your quality of life. It is sometimes used to treat brain tumors in metastatic breast cancer.
- **Surgery**, a local treatment, can sometimes ease or prevent symptoms and side effects at the original or metastatic site (for example, the brain). If one or a few metastatic sites remain stable over time, surgery may be used to remove the disease. Clinical trials are more fully exploring the use of surgery to remove the primary tumor in people with metastatic disease, so talk with your doctor about new findings.

There are many options for the order, frequency, and combination of treatments. Some medicines work better when combined with other treatments as a combination therapy, while others may be taken one after the other. When you take only one medicine at a time, this is referred to as single-agent therapy. Your doctor's recommendation will be based on many factors, such as the type of cancer, guidelines for treatment, past treatments you received, and other conditions you have. You may want to ask if combining medicines or taking them in a certain order changes the side effects or makes them stronger.

You might also choose to get your treatment through a clinical trial. If you think you may be interested in a clinical trial, talk to your doctor early in your care so you have more options.

Each treatment has its own side effects. For more information, visit lbbc.org and mbcn.org.

CLINICAL TRIALS AND YOUR TREATMENT

Your doctor may suggest you receive treatment through a **clinical trial**, a research study that tests how well new medicines and procedures work in people. Clinical trials either compare standard FDA-approved treatments to new treatments, or study new therapies. All of today's standard therapies were once part of clinical trials.

If you have not taken part in a clinical trial before, you might worry that doing so will make you a "guinea pig." This is a common fear. In reality, the researchers who run clinical trials are working to prove their treatment is effective and safe. They want you to be as well as possible. There are many laws and regulations in place to safeguard participants in clinical trials.

Clinical trials are not a last resort. If your providers suggest one, it doesn't mean they have given up. Sometimes it's better to enroll in a study *before* you try other standard treatments, because some trials only include people who have not taken certain medicines in the past. Joining a clinical trial before you try other treatments may give you more options over a longer period.

When you enroll in a clinical trial, you usually won't be expected to go to a lab and remain there during treatment. You may have to travel to a different clinic or work with a different doctor. Some trials require you stay in a hospital or visit a doctor's office more often but this is information you will have upfront, before you enroll. Typically, your treatment experience won't be much different than usual. Most new medicines are available in the same forms as traditional medicines, either through injection, infusion, or pills. The main difference is that you may have more follow-up appointments or tests, which allow the researchers to record your progress and compare it to those getting a different treatment.

There are three trial phases in which you may be able to take part.

● **Phase I trials** test a medicine or method in a small number of people because little is known about the risks and benefits of the treatment. Those who choose to participate have usually tried other treatments that no longer work, or they have not been helped by standard treatments in the past. The goals are to find out how to give the new treatment, how much to give, and what the side effects are. Phase I trials are generally not disease-specific and people with other types of cancers may participate as well.

● **Phase II trials** test the new treatment in a slightly larger group of people with a specific disease. The goals are to see if it is effective in treating that specific disease and to evaluate side effects and their severity. The method and dose determined in the phase I trial is used during treatment.

● **Phase III trials** test medicines in very large groups of people after they have been studied in phase I and phase II trials. By now, doctors already know how effective the treatment should be and what side effects might occur. These trials compare the new treatment to standard treatments to find risks and benefits and give guidance to medical professionals.

During your treatment in a clinical trial, a team of doctors and nurses will talk with you regularly about any discomfort or side effects you experience and how you feel overall, as well as watch for growth of the cancer. You will always be treated with medicine, either a **standard therapy**, a treatment that is accepted by providers as proper therapy for a type of disease and is widely used by healthcare professionals, or the therapy under study added to standard therapy. This is even true in studies that include a **placebo**, an inactive substance sometimes given with a standard therapy. **You will never go without at least standard active cancer treatment.**

If you feel side effects between appointments, contact your trial doctors or nurses to report the symptoms and talk about methods to relieve them. You or your doctor can choose to withdraw you from the trial at any time. You are not required to complete it. Though you have the freedom to leave a trial, remaining a participant helps researchers maintain a stable group and gives them a better chance of understanding the therapy under study.

A clinical trial gives you access to treatments that may be effective but are not yet approved by the FDA. Many trials are designed to treat specific kinds of breast cancer. Ongoing and upcoming trials are focused on metastatic breast cancer and seek people with hormone receptor-positive, HER2-positive, and triple-negative cancers. Other studies are testing how treatments already in standard use for other types of cancer work in breast cancer, and seek FDA approval from the results.

Sometimes clinical trials cost little for participants, which may make it possible for you to get treatments that are expensive or that aren't routinely covered by your insurance. In other cases, you may still need to pay for parts of treatment that you would have received without participating, like routine check-ups. Taking part in some clinical trials may involve extra costs for transportation, travel, or child or elder care. For resources on low-cost or free hotel rooms, see page 40.

To learn more about clinical trials, talk to your doctors. Because trials focus on very specific types of breast cancer, guidelines to enroll are strict and may be based on your prior treatments, type of cancer, age, and other factors.

LEARN MORE

Visit lbcc.org or mbcn.org to use the Metastatic Breast Cancer Trial Search tool. You can also learn more at one of the websites listed on page 40.

“The road gets hard and knocks us down, but the important thing is not letting it keep us down. We have to brush ourselves off and stand up again and muster up the courage and energy to fight one more round.”—DANA

INTEGRATIVE AND COMPLEMENTARY APPROACHES TO CARE

Today, many programs and cancer centers offer treatment plans that integrate traditional medicine with integrative care practices to fully support your physical, emotional, and spiritual wellness. By caring for the whole person, integrative treatment plans can strengthen your body, ease your mind, bring you calm, or even help you discover what is most important to you.

Many services comprise complementary therapy, so search for activities that center and empower you. Every person is unique, so what might give you a physical and spiritual release might be different for someone else. These are some common practices to complement your traditional treatments:

- **Exercise** helps keep the body strong and muscles relaxed. Certain types, like yoga, have been shown in studies to have healing benefits in breast cancer by reducing fatigue and stress and improving sleep.
- **Nutrition** can help you maintain a strong and well-nourished body. During treatment, good nutrition prepares your body for medicines and for healing over time.
- **Mind-body practices** use the mind to calm stress and anxiety. They include yoga, hypnotherapy, meditation, visualization, and music and art therapy.
- **Meditation and mindfulness exercises** combine meditation, yoga, and awareness of the body. These practices can teach you about your body's physical responses to stress, how to relieve that stress, and help you strengthen your body through light exercise.
- **Body work therapies** focus on physical sensation as a source to relieve pain and tension. They include therapeutic massage, acupuncture, and acupressure.
- **Chinese and herbal medicines** are natural supplements that are believed to target the buildup of toxins and regulate the flow of fluids and energy in the body. The medicines are herbal combinations created to treat the source of the cancer.

Talk with your providers about your interest in integrative practices. Any additions to treatment, such as herbs, vitamins, or supplements, may impact traditional medicines. If your doctor is not knowledgeable about complementary approaches or sensitive to your desire to use this in your care, consider adding an integrative medicine specialist to your healthcare team.

For more information, download our brochure *Managing Stress and Anxiety* at lbcc.org.

PALLIATIVE CARE FOR WELL-BEING

Throughout your treatment, your healthcare providers employ **palliative care** or supportive care, things that ensure you are living in a way that enhances your everyday activities. These measures include complementary practices that center you or strengthen your body against treatment side effects, traditional medicines that manage pain, and activities that support your emotional, physical, social, and spiritual well-being. Managing pain due to surgery is considered palliative care, even though your providers may not have used that term.

Many people think palliative care is the same as end-of-life care. Though it is true that end-of-life care includes palliative care, you can benefit from palliative care at any stage of breast cancer. Lack of education about and fear of palliative care often keeps people from using it, even though palliative care could provide important benefits that may impact your daily life.

A palliative care team made of doctors, nurses, social workers, and other professionals may help you cope with the effects that metastatic breast cancer has on your everyday life. Their services include pain management, emotional support, spiritual support, and complementary therapies.

Palliative care is a supplement to regular medical care. It does not replace it. But it may help you control the burden of cancer, and its symptoms and side effects: physical, psychological, emotional, and spiritual.

LEARN MORE

For more information on palliative care, visit lbbc.org, mbcn.org, or getpalliativecare.org.





Maintaining your everyday well-being

Living well with metastatic breast cancer means different things to different people. But living well and living fully are very possible. From the day of your diagnosis forward, you may make small and large changes to your habits, routines, and activities to address the challenges of living well with metastatic disease.

There may be times you fear for the future, or lose confidence in your body and in the people who support you. These are normal responses to managing ongoing illness and grieving the small and large losses metastatic breast cancer can cause. Let yourself experience these emotions. You are not alone. Ask for help if and when you need it. You might decide to seek out others living with metastatic breast cancer. Many people gain great strength from talking with those who share in the experience.

“Slow down and listen to your body. It’s a matter of knowing how treatment will affect you. Don’t eliminate living by any means.” — CINDY

As much as caring for yourself is about controlling the cancer medically, another part of living with metastatic disease is feeling in charge of your everyday well-being. Knowing what makes life meaningful to you may help you as you choose medical treatments. Ask yourself: Will a certain treatment prevent me from doing the things I enjoy? Is the cost of losing that activity high or low? Everyone is different, so you may choose a treatment that others turn down — and that’s OK. Talk to your doctor about your goals.

IMPROVING YOUR DAILY LIFE

Your everyday well-being, often called **quality of life**, can be broken down into four parts: physical, emotional, social, and spiritual. Finding a balance in each may help you care for yourself.

🔴 **Physical support** helps you maintain physical strength, flexibility, and wellness. Simple exercises like walking, as well as more strenuous exercise like yoga or weight lifting, help you reconnect with your body, improve your mood, and make you feel better physically. Your care team can help you with a regular exercise plan.

➤ **Palliative care** (page 31) and **pain management** are also key to maintaining good physical support. Therapeutic massage, pain medicine, and complementary and integrative therapies are other options to consider.

🔴 **Emotional support** helps you cope with the stresses and anxieties of living with metastatic breast cancer. At times, you might feel disconnected, isolated, or uncertain about the future. Consider taking part in programs or support services, like counseling, psychotherapy, or support groups. You might take classes or join clubs that support your interests. These activities may help you connect with others and offer you ways to cope with your emotions and stay engaged in things you enjoy.

- **Counseling and individual therapy** offer you the chance to voice concerns you keep to yourself in a safe, nonjudgmental setting. Many people withhold fears or worries to avoid upsetting or burdening others. A counselor or therapist is someone outside your usual life you can talk to. If you begin to feel overwhelmed by your diagnosis and the changes in your life, seek support right away. Don't be afraid to try a few different providers. It may take time to find the right therapist for you.
 - **Support groups** provide a place to meet and talk with others coping with breast cancer. Talking with people in similar situations may help ease isolation and foster understanding. Support groups are also a good way to learn about new resources. Not everyone feels comfortable in every support group. Much depends on the people in the group. If you want a support group but the first one you try doesn't meet your needs, seek out another. Decide what kind of peers you want in your group, such as people with the same diagnosis as you, people your age, or a group open to people with all kinds of metastatic cancer.
 - **Peer counseling services** allow you to talk to someone with a metastatic breast cancer diagnosis like you. When you are first diagnosed, it may be hard to imagine living months or years with metastatic disease. Many people find that talking to someone who has done just that eases worries. You can reach **LBBC's Breast Cancer Helpline** at **888-753-5222** or **lbcc.org/helpline**. Or, refer to the Metastatic Breast Cancer Network's website, mbcn.org, for a list of available telephone resources.
- 🔴 **Social support** provides connection to maintain a healthy emotional life. Having friends, family, or peers for emotional support, as well as a social life outside of cancer, may help you feel happy and enjoy a full life.
- **Scheduling time with family and friends** helps you make sure you get to see the people most important to you. There may be times when treatment schedules and doctors' appointments get in the way, so making dates can help your relationships stay on track.
 - **Joining an online community** offers active, 24/7 communication with people living with metastatic breast cancer. These forums may be very helpful if you live in a remote place, have a busy schedule, or simply feel more comfortable talking about your challenges online. Many breast cancer organizations offer email newsletters with news about treatments and upcoming programs.
 - **Attending workshops, conferences, and classes** offered by breast cancer organizations and hospitals can help you learn about new treatments and clinical trials, or get your questions answered. They also allow you to meet and network with others living with metastatic breast cancer. Many are available free or with scholarships
- 🔴 **Spiritual support** may help you find a sense of calm, peace, or deeper faith. If you are a spiritual or religious person, your diagnosis may have left you feeling disappointed, angry, or uncertain. Talking with a religious leader or a spiritual counselor may help you explore your feelings. Spirituality is different for everyone, and comes in the form of traditional religious practices as well as devotion to an activity or purpose, such as community service or art.
- **Church and prayer groups** are available at many cancer centers, hospitals, and churches, and may even focus on metastatic cancer.
 - **Spiritual counseling or guidance** is offered by both traditional religious institutions and holistic wellness centers.

These activities may also help you find calm:

- **Volunteering** for a breast cancer or other organization may give you a new sense of purpose, or give you a break from thinking about breast cancer.
- **Personal activities** like art, music, sports, or writing can be a great outlet for stress, and offer you time alone to process news, decisions, or emotions.

After a metastatic breast cancer diagnosis, some people reconsider their relationships. The truth is that some people find it hard to say “I’m here for you,” and leave it at that. Some don’t know when they are being unhelpful. It’s OK to let them know, or to decide to take a break or walk away from relationships that don’t work for you now.

While metastatic breast cancer will always be with you, you can still embrace a full life that feeds your mind, body, and soul.

“I’ve learned my time is a precious commodity. I’ve also learned that quality of life is extremely important, especially when quantity of life is unknown.”—JEN





Looking toward the future

Researchers continue to seek new medicines and therapies for metastatic breast cancer. Over several decades, scientists have learned a great deal about how individual cancer cells and their parts grow and divide. The more they learn, the better doctors can target individual cancers in individual people.

Your doctors may refer to metastatic breast cancer as a **chronic condition**, a disease that progresses over a long period of time, like diabetes or heart disease. Everyone has different reactions to the use of this term to describe metastatic disease. Making metastatic breast cancer a chronic condition is the goal of much current research. Though this is not a reality today, progress, in the form of individualized and targeted medicines, is moving us in that direction.

Living with metastatic breast cancer may feel different from day to day. There will be good days, as well as hard ones. But with the support of your care team and loved ones, metastatic breast cancer does not mean you cannot live the life you want.

“Live with honesty, faith and hope. There are no givens, but there is always hope. There is always the possibility of tomorrow.”—CINDY





Resources

Information is current as of June 2021 but may change.

ORGANIZATIONS THAT CAN HELP

Living Beyond Breast Cancer [LBBC.ORG](https://www.lbbc.org)

Living Beyond Breast Cancer is a nationwide nonprofit and leader in the metastatic breast cancer community. For 30 years, we've offered emotional, practical, and trusted information, as well as a community of support to people diagnosed with all stages of breast cancer.

- ❏ Our events, virtual live programs, and on-demand content will help you plan for treatment, cope with your diagnosis, manage finances, and more. [LBBC.ORG/METASTATIC](https://www.lbbc.org/metastatic)
- ❏ Hear from experts across the country and connect with other people impacted by metastatic breast cancer at our annual **Conference on Metastatic Breast Cancer**.
- ❏ Join our two private Facebook groups to connect with other people diagnosed with breast cancer, share resources, and receive peer support.
 - [BREAST CANCER SUPPORT FOR ALL AGES, ALL STAGES](#)
 - [BREAST CANCER SUPPORT FOR YOUNG WOMEN](#)
- ❏ Reach out to our Breast Cancer Helpline to get connected with a trained volunteer who is living with metastatic breast cancer for emotional support, guidance, and hope.
 - [888-753-5222 | LBBC.ORG/HELPLINE](https://www.lbbc.org/helpline)
- ❏ Become a Hear My Voice Advocate to raise awareness about the realities of MBC, and to help other people in your community living with stage IV breast cancer make empowered decisions too. [LBBC.ORG/HEARMYVOICE](https://www.lbbc.org/hearmyvoice)

Metastatic Breast Cancer Network [MBCN.ORG](https://www.mbcn.org)

The Metastatic Breast Cancer Network is a national, independent, nonprofit, all volunteer patient advocacy group dedicated to the unique concerns of the women and men living with metastatic breast cancer. We strive to help those living with stage IV breast cancer be their own best advocate through providing education and information on treatments and coping with the disease.

MBCN:

- ❏ **EDUCATES** patients about metastatic breast cancer treatments and how to cope with the disease; Educates the public about the differences between early and advanced stage disease.
- ❏ **EMPOWERS** patients to use their stories and voices to bring attention to the needs of metastatic breast cancer patients and to use their knowledge to participate more fully with their healthcare provider
- ❏ **ADVOCATES** for focused research to find more targeted therapies to lengthen the lives of patients and make metastatic breast cancer truly a chronic disease like diabetes or HIV/AIDS

Visit [mbcn.org](https://www.mbcn.org) or call (888) 500-0370 (voicemail) to access education, support, and advocacy resources.

CAREGIVING SUPPORT

- Caregiver Action Network: caregiveraction.org
- CaringBridge: caringbridge.org
- Lotsa Helping Hands: lotsahelpinghands.com

CLINICAL TRIALS

- BreastCancerTrials.org
- CancerConnect: news.cancerconnect.com
- centerwatch.com
- ClinicalTrials.gov
- emergingmed.com
- Metastatic Breast Cancer Trial search:
lbbc.org/metastatic-trial-search or mbcn.org/clinical-trials-finder
- NCI: cancer.gov/clinicaltrials
- NCI Center for Cancer Research: ccr.cancer.gov

FAMILY RESOURCES

- Jack and Jill Late Stage Cancer Foundation: jajf.org
- Men Against Breast Cancer: menagainstbreastcancer.org
- Mothers Supporting Daughters with Breast Cancer: mothersdaughters.org
- Parenting with breast cancer: lbbc.org/parenting

FINANCIAL CONCERNS

- Association of Community Cancer Centers: acc-cancer.org
- Cancer Financial Assistance Coalition: cancerfac.org
- Centers for Medicare and Medicaid Services: cms.gov
- Healthwell Foundation: healthwellfoundation.org, 800-675-8416
- Joe's House: joeshouse.org
- Patient Access Network (PAN) Foundation: panfoundation.org, 866-316-7263
- Patient Services, Inc.: patientservicesinc.org
- The Pink Fund: thepinkfund.org, 877-234-7465
- Social Security Disability Information: ssa.gov/dibplan/index.htm

BREAST CANCER INFORMATION AND SUPPORT

In addition to Living Beyond Breast Cancer and the Metastatic Breast Cancer Network, here are some other helpful organizations:

- Abramson Cancer Center of the University of Pennsylvania: oncolink.org
- American Cancer Society: cancer.org, 800-227-2345
- BreastCancer.org
- CancerCare: cancercare.org, 800-813-4673
- Cancer Support Community: cancersupportcommunity.org, 888-793-9355
- Healing Journeys: healingjourneys.org
- Metastatic Breast Cancer Alliance: mbcalliance.org
- Metastasis Research Society: metastasis-research.org
- METAvivor: metavivor.org
- SHARE: sharecancersupport.org, 844-275-7427
- Susan G. Komen: komen.org, 877-465-6636

- Theresa's Research Foundation: theresasresearch.org
- Triple Negative Breast Cancer Foundation: tnbcfoundation.org, 877-880-8622
- Wellspring Cancer Support: wellspring.ca

LEGAL INFORMATION

- Cancer and Careers: cancerandcareers.org
- Cancer Legal Resource Center: cancerlegalresourcecenter.org
- Triage Cancer: triagecancer.org

YOUNG WOMEN

- Livestrong: livestrong.org/we-can-help/young-adults
- Rethink breast cancer: rethinkbreastcancer.com
- Sharsheret: sharsheret.org, 866-474-2774
- Stupid Cancer: stupidcancer.org
- Tigerlily Foundation: tigerlilyfoundation.org
- Young Adult Cancer Canada: youngadultcancer.ca
- Young Survival Coalition: youngsurvival.org, 877-972-1011

TESTS TO EXPECT

Biopsy. A test in which a small amount of tissue is taken from your body so a pathologist can look at it under a microscope.

Blood marker or tumor marker test. A blood test to look for proteins that tumors produce or tumor cells that have entered the bloodstream, to see if cancer has spread to other parts of the body.

Bone scan. An imaging test performed by a radiologist to see if cancer spread to bone.

BRCA1 or BRCA2 genetic testing. Blood tests to look for mutations of the BRCA genes, which may show that a family is at higher risk for breast cancer.

Confirming biopsy. A biopsy to see if cancer cells have changed since primary diagnosis.

CT (Computerized Axial Tomography) scan. Sometimes called a CAT scan, three-dimensional x-ray images to look at organs like the bones, liver, lungs, brain, and lymph nodes.

Mammogram. An imaging test to assess breast tissue when there are no symptoms of breast cancer.

MRI (Magnetic Resonance Imaging). An imaging test that uses magnet and radio waves to create cross-sectional images of specific areas of the body.

PET (Positron Emission Tomography) scan. Usually ordered after diagnosis, a PET scan takes images of the whole body to identify cancer cells and where they may have spread.

Ultrasound. An imaging test that uses high-frequency sound waves to create images of the inside of the body, and to see if a mass is solid or full of fluid.

X-ray. An imaging test generally used to monitor whether treatment is working.

WORDS TO KNOW

Access port. A small device implanted under the skin that allows access to your veins; sometimes called a port-a-cath.

Acinus. A structure within the glands that produce breast milk.

Benign. Not harmful.

BRCA1 or BRCA2 genes. Breast cancer susceptibility genes. Mutations on the BRCA genes can increase the risk for developing cancer.

Chronic condition. A disease that progresses over a long period, like diabetes or heart disease.

Clinical trial. Research study that tests how well new medicines and procedures work in people.

Complementary and integrative therapy. Non-medical therapies used alongside your medical treatment.

Ducts. The passageways that carry milk from the lobules to the nipple.

Ductal cancers. Cancers that grow in the ducts of the breasts as masses and may later spread through the wall of the duct into other tissues of the breast.

HER2 status. The measure of how much of the HER2 protein is present in cancer cells.

Hormone receptor status. The measure of hormone receptors on cancer cells.

Inflammatory breast cancer. An aggressive form of breast cancer that is diagnosed less often than other types. It develops when cancer cells block the lymph vessels in the skin of the breast, causing it to be red, swollen, and tender.

Invasive or infiltrating breast cancer. Cancer that has the ability to spread beyond the breast and nearby lymph nodes.

Lobule. The glands that produce breast milk.

Lobular cancers. Cancers that start in the acinus of the lobule but do not cause scar tissue or form masses, making them harder to find.

Local therapy. Medicines and treatments that affect cells in and around tumors.

Malignant. Cancerous.

Metastasized. Spread beyond the breast or nearby lymph nodes to distant areas of the body.

Metastatic cancer. Cancer that has spread to distant areas of the body, and a term used to refer to stage IV cancer.

Mutation. An error in cell DNA that causes breast cells to reproduce without stopping.

NED. A period where tests show no evidence of disease.

Non-invasive. Cancer that stays within the ducts or lobules of the breast. Also called in situ or stage 0 cancer.

Palliative care. Things that ensure you are living in a way that enhances your everyday activities, such as complementary practices to center you or strengthen your body, pain management medicines, and emotional, physical, social, and spiritual support.

Pathology report. A profile of all of your test results that helps doctors determine your treatment path.

PICC line. A thin, flexible tube inserted into a vein in the arm and into a larger vein in the body, used to give chemotherapy medicine.

Placebo. An inactive substance sometimes given with a standard therapy during a clinical trial.

Primary diagnosis. The first diagnosis of breast cancer.

Progression. The course of a disease. In cancer, the growth of tumors or spread of the disease.

Proliferation index. A number that shows what percentage of the cancer cells are actively dividing at a given time.

Quality of life. Everyday well-being.

Recurrent disease. Cancer that has come back.

Regression. Decreases in the tumor size or spread of cancer.

Stable disease. Periods when the cancer does not grow.

Stage IV. See **Metastatic cancer.**

Standard therapy. A treatment that is accepted by providers as proper therapy for a type of disease and is widely used by healthcare professionals.

Systemic therapy. Medicines and treatments that treat the whole body by traveling through the bloodstream.

Treatment breaks. Short breaks in treatment that allow for rest or for special events like weddings or vacations.

Many thanks to these individuals who contributed their time and expertise for this guide.

AUTHOR

Nicole Katze, MA

LIVING BEYOND BREAST CANCER REVIEWERS

Amy Grillo

Janine E. Guglielmino, MA

METASTATIC BREAST CANCER NETWORK REVIEWERS

Shirley Mertz

LEAD MEDICAL REVIEWER

William Gradishar, MD

Feinberg School of Medicine

Northwestern University

Chicago, Illinois

MEDICAL ADVISORY COMMITTEE REVIEWERS

Medical Oncology

Kathy Miller, MD

IU Simon Comprehensive Cancer Center

Indiana University

Indianapolis, Indiana

Oncology Nursing

Evelyn Robles-Rodriguez, DNP, APN, AOCN

MD Anderson Cancer Center at Cooper

Camden, New Jersey

Oncology Social Work

Roz Kleban, LCSW

Evelyn H. Lauder Breast Center

Memorial Sloan-Kettering Cancer Center

New York, New York

Marie Lavigne, LCSW, OSW-C

Katmai Oncology Group

Anchorage, Alaska

Palliative Care Specialist

Betty Ferrell, MSN, PhD

City of Hope – NCI Comprehensive Cancer Center

Los Angeles, California

Research

Danny R. Welch, PhD

University of Kansas Cancer Center
Kansas City, Kansas

Surgical Oncology

David Euhus, MD

Johns Hopkins Hospital
Baltimore, Maryland

CONSUMER ADVISORY COMMITTEE REVIEWERS

Terrie Bradford Barnes, Shreveport, Louisiana

Nancy Janes, Alberta, Canada

Nazneen Lotia, Chicago, Illinois

Carol Miele, Albrightsville, Pennsylvania

Kim Thayer, Portland, Oregon

Ann Wiley, Cary, North Carolina

We dedicate this guide to Katherine O’Brien, Ginny Knachmuhs, and Joani Gudeman, LCSW, PsyD, of the Metastatic Breast Cancer Network. We honor and remember all our past contributors.



LIVING BEYOND BREAST CANCER®

LIVING BEYOND BREAST CANCER is a nationwide nonprofit and leader in the metastatic breast cancer community. For 30 years, we've offered emotional, practical, and trusted information, as well as a community of support to people diagnosed with all stages of breast cancer. Reach out to our Breast Cancer Helpline to get connected with a trained volunteer who is living with metastatic breast cancer for emotional support, guidance, and hope.

888-753-5222 | [LBBC.ORG/HELPLINE](https://www.lbbc.org/helpline)



METASTATIC BREAST CANCER NETWORK is a national, independent, nonprofit, all volunteer patient advocacy group dedicated to the unique concerns of the women and men living with metastatic breast cancer. We strive to help those living with stage IV breast cancer be their own best advocate through providing education and information on treatments and coping with the disease. **Visit [MBCN.ORG](https://www.mbcn.org) or call (888) 500-0370 (voicemail) to access education, support, and advocacy resources.**

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

© 2021 Living Beyond Breast Cancer, 4th edition.

Who is the MBC Alliance?

- Largest coalition of breast cancer organizations in the U.S. with ongoing collaboration
- More than 100 volunteers from 49 member organization plus 30 individual members - many of whom are living with MBC

The mission of the MBC Alliance is to improve the lives of, and outcomes for, those living with metastatic breast cancer and their families through increasing awareness and education about the disease and advancing policy and strategic coordination of research funding - specifically focused on metastasis - that has the potential to extend life, enhance quality of life and ultimately... to cure.

www.mbcalliance.org



MBCconnect
PATIENT POWERED. RESEARCH DRIVEN

YOU can help accelerate metastatic breast cancer research and get potential matches with clinical trials.



Learn more at
www.mbccconnect.org



Metastatic Breast Cancer
MBCalliance➤
together we are stronger than the disease

NONPROFIT MEMBERS



NONPROFIT SUPPORTERS

Canadian Cancer Survivor Network The Cancer Cough Foundation

Certain activities of the Alliance are supported by the unrestricted financial contributions of the following member organizations:

PREMIERE



SUSTAINING



SUPPORTING



Membership as of April 2021

FOUNDING MEMBERS



LIVING BEYOND BREAST CANCER®

METS.LBBC.ORG

Living Beyond Breast Cancer is a national nonprofit organization that seeks to create a world that understands there is more than one way to have breast cancer. To fulfill its mission of providing trusted information and a community of support to those impacted by the disease, Living Beyond Breast Cancer offers in-person experiences and on-demand emotional, practical, and evidence-based content.

Nearly 30 years since its inception, the organization remains committed to creating a culture of acceptance—where sharing the diversity of the lived experience of breast cancer fosters self-advocacy and hope.

For more information, visit **LBBC.ORG** or call **855-807-6386**.