GUIDE FOR THE NEWLY DIAGNOSED

Empowering you to make informed decisions and to cope with your emotions after a diagnosis of metastatic breast cancer

presented by:

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

The photographs in this guide show women who have had metastatic breast cancer. We thank all the women who contributed their voices and their experiences to this brochure.
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 to 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 issues in section II. Throughout the guide, you’ll notice the words of women who, like you, know what a metastatic diagnosis means and how one feels. A committee of these women, as well as a committee of medical 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 [lbbc.org](http://lbbc.org) or [mbcn.org](http://mbcn.org). To talk about your questions or emotions with someone facing a similar diagnosis, we encourage you to call LBBC’s Helpline at (888) 753-LBBC (5222).

Warmly,

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

Shirley A. Mertz
President
Metastatic Breast Cancer Network
LIVING BEYOND BREAST CANCER
FREE HELPLINE
(888) 753-LBBC (5222)

METASTATIC BREAST CANCER NETWORK
MBCN.ORG
(888) 500-0370
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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?

Nearly 150,000 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, and know that resources are available to support you throughout your journey. 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 Primary (First) Diagnosis

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. You might prefer to record conversations with your doctor rather than take notes, both for ease and to have a resource for family and friends; 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 become 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, and 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 up to 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

Mainstream media 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 received the best possible treatment for early-stage breast cancer, there remained a chance some cancer cells would survive and cause metastases someday. (To learn more about what causes metastatic breast cancer, see page 14.)

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 women, 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 women 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 41.
Telling Others: Friends, Family and Coworkers

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 to 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 be hesitant 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 even pulling 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 also 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 coworkers 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

“I have been blessed to have had these last three 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

A diagnosis of metastatic breast cancer brings uncertainty and stress to even the best relationships. It can be very challenging for your family, spouse or significant other and 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 his or her 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, it may help to 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” may be helpful because they will likely hear the term. 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. For support resources for family and caregivers, see page 42.
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 than 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 14, and *What Makes Metastatic Breast Cancer Different*, starting on page 15, go into more detail about the biology of metastatic disease. These sections may be useful to you, whether you have a recurrent or primary diagnosis.

For more details on breast cancer basics, visit lbbc.org or download MBCN’s brochure *Get the Facts* at mbcn.org.

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**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, lobular and inflammatory.

**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 produces 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 form of ductal or lobular breast cancer. It 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.

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 protein 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.

Once cancer cells travel away from the breast tissue, they can grow and recur in the areas they reach, depending on that area’s ability to accept the breast cancer cells and the cells’ DNA having changed enough to continue to grow there. Typically, your body will reject or attack things it doesn’t recognize (like germs), but in the case of metastases, 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, the metastasis 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. Systemic therapies (see page 25) like hormonal therapy and chemotherapy 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 course 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 dormant 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 primary breast cancer. They will respond best to treatments designed for breast cancer. 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. Learn more about tests and biopsies on pages 17 and 39.

**What Makes Metastatic Breast Cancer Different**

You may have heard doctors or the media talk about breast cancer as 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 women who undergo treatment and never have to deal with cancer again, but 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, explore the side effects of different treatments. 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 affect your ability to engage in your day-to-day activities.

Treatment for metastatic breast cancer has two main goals: to control the cancer for as long as possible, and to maintain your usual daily activities.

At stage IV it is difficult to fully remove cancer with surgery or medicine because new tumors may appear over time, or cells may become resistant 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.

Being diagnosed with metastatic breast cancer can happen to anyone, at any time. Even stage I cancer can become metastatic, and a woman with stage I disease can find out years after her original treatment ended that the cancer metastasized. The stages are meant only to predict your risk of recurrence.

While the main concern 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 read MBCN’s Diagnosis: Metastatic Breast Cancer, a booklet available in print and online at 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 a wide variety of medical tests. These initial tests help your doctor profile what kind of breast cancer you have, how rapidly it is growing and where it has spread. The information collected is found in imaging, physical exam, laboratory and pathology reports, along with the results of any biopsies or surgeries you have. All this information will be used to make treatment decisions.

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 39.

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 may bring 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, it’s OK to ask your healthcare team why or to 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 elevated. Some providers prefer not to use tumor marker tests because of concerns they are not reliable.

Like any illness, cancer has its own vocabulary. If this is your first diagnosis, it may be helpful to 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 44.

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**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, reduce estrogen levels, or reduce 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+ breast cancer and can be treated with anti-HER2 therapies.

- **Triple-Negative Breast Cancer**: These types of cancers test negative for estrogen and progesterone receptors and human epidermal growth factor receptor 2 (HER2), which means the cancer cells grow without estrogen, progesterone or HER2 proteins present. These cancers do not respond to anti-HER2 or hormonal therapies. Triple-negative cancers usually respond to chemotherapy.
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—breast cancer susceptibility 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.

BRCA testing may give your doctors more information about the breast cancer, and can provide other members of your family information on their chances of developing cancer, too. Knowing your BRCA status may also qualify you for very specific clinical trials.

Your doctor may be more likely to recommend genetic testing if you were diagnosed under age 45, before menopause, with triple-negative breast cancer before age 50, 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 answer or return your phone calls in a reasonable amount of time? Do they listen when you voice your concerns about symptoms or treatments? Do they share your values, or at least respect your beliefs? You may also 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, 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 (PCP). 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 medicine (see page 30), non-medical treatments or 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
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 be focused 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. For a list of treatments now approved or in clinical trials for metastatic breast cancer, see page 40.

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 is also possible to take treatment breaks just 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, you may want to 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 enjoying 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

The most common treatments available for metastatic breast cancer are chemotherapy, hormonal therapy, targeted therapy, surgery and radiation therapy.

Chemotherapy, hormonal therapy and targeted therapies 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 intravenously, or by vein, or orally as a pill taken by mouth.

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. Recent research suggests that removing the original (primary) tumor in those first diagnosed with metastatic breast cancer may lengthen life, especially when the cancer responds to chemotherapy. Upcoming trials will explore surgery for people with primary metastatic disease more fully, so talk to your doctor about new findings.

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 as a secondary treatment that comes 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.

Hormonal Therapies are targeted 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 fewer side effects than chemotherapy. Hormonal therapies were the first targeted therapy, because they target estrogen and progesterone receptors.

Targeted Therapies 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 under study, like PARP inhibitors and anti-VEGF therapies, target specific processes involved in cell and tumor growth. Targeted therapy has the potential to be personalized from person to person. Many types of targeted treatments are in clinical trials.
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.

You may find that 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 cancer type and previous treatments you received. 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 (see page 27). 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 to access the Metastatic Breast Cancer series of guides, and visit 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 on 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 also 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, though 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 each day, 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 (through injection, pill or infusion). The main difference is that you may have more follow-up appointments or tests, which allows the researchers to record your progress and compare it to your peers’.

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 the progress of the cancer. You will always be treated with medicine, either a standard therapy or the therapy under study. Even in placebo-controlled studies, which include an inactive substance, you will not go without active cancer treatment.

If you feel any side effects between appointments, you can 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 ER/PR+, HER2+ or 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 transportation costs and other travel expenses. For resources on low-cost or free hotel rooms, see page 42.

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. Visit lbbc.org for more information, or learn more through the National Cancer Institute database at cancer.gov/clinicaltrials, the Coalition of Cancer Cooperative Groups at cancertrialshelp.org, or clinicaltrials.gov, run by the National Institutes of Health.
“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 complementary 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 treatment, 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. There are 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. Taught in classes, you will learn about physical responses to stress and how to relieve them, and 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 complementary practices. Any additions to treatment, such as herbs, vitamins or supplements, may impact traditional medical therapies. If your doctor is not knowledgeable about complementary approaches or sensitive to your desire to use this in your care, you may want to consider adding an integrative medicine specialist to your healthcare team.
Palliative Care for Well-Being

Throughout your care, you employ many kinds of palliative care, or things you do to 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 associate palliative care with end-of-life care. Though it is true that end-of-life care includes palliative care, you can benefit from it at any stage of breast cancer. Lack of education about and fear of palliative care often keeps women 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 changes that metastatic breast cancer has on your everyday life. Their services include pain management, emotional support, spiritual support and complementary therapies.

Palliative care does not replace regular medical care. But it may help you control the burden of cancer, and its symptoms and side effects: physical, psychological, emotional and spiritual. For more information, please read LBBC’s brochure on Understanding Palliative Care, available free at lbbc.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 you need it. You might even 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, 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. You may be able to take treatment breaks (see page 23) for special activities, like travel or family events.

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 therapies are other options to consider.
Emotional Support may help 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. It may help to 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. For a list of support groups for metastatic breast cancer, visit mbcn.org/support-resources.

- **Peer phone counseling services** allow you to call someone with a metastatic breast cancer diagnosis who has been in treatment like you. When you are first diagnosed, it may be hard to imagine living months or years with metastatic disease. Many people find that speaking to someone who has done just that eases worries. You can reach LBBC’s Helpline at (888) 753-LBBC (5222) 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 doctor’s 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 through listservs that provide news about treatments and upcoming events, such as webinars.
• **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.

“You can learn quite a bit by talking to someone with your diagnosis.” —Carol

**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.

You may want to consider your relationships and decide whether they bring you strength and comfort. Sometimes you may need to make the decision to pull away from relationships that cause you sadness or stress. It is OK to tell people when they’re saying is not helpful. It’s hard for some people to say, “I’m here for you,” and leave it at that.

While metastatic breast cancer will always be with you, you can still embrace a full life that feeds your mind, body and soul. For resources with more information about managing metastatic breast cancer, finding support for yourself or your family, and keeping up-to-date with breast cancer news, visit lbbc.org, mbcn.org, or the websites listed in the resource section (see page 38).

“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, could move us in that direction.

Living with metastatic breast cancer may feel different from day to day. There will be good days, as well as challenging days. But with the support of your care team and loved ones, metastatic breast cancer does not mean you cannot live the life you want. Refer to this guide, lbbc.org, mbcn.org and the resource list at the end of this booklet for more tools and information.

“Live with honesty, faith and hope. There are no givens, but there is always hope. There is always the possibility of tomorrow.” —Cindy
Resources
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 bone, 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-rays. An imaging test generally used to monitor whether treatment is working.
Common Treatments

Hormonal Therapies
Hormonal therapies work to slow or stop the growth of hormone-sensitive breast cancer cells by blocking the function of hormones like estrogen and progesterone, or forcing the body to stop making them. Hormonal therapies include:

- Aromatase inhibitors: anastrozole (Arimidex), letrozole (Femara), exemestane (Aromasin)
- LHRH agonists: goserelin (Zoladex), leuprolide (Lupron)
- mTOR inhibitors: everolimus (Afinitor)
- SERDs: fulvestrant (Faslodex)
- SERMs: tamoxifen, toremifene (Fareston)
- Oophorectomy: surgery to remove the ovaries

Anti-HER2 Therapies
Anti-HER2 therapies target the HER2 gene or HER2 protein that drives abnormal cell growth in HER2 positive cancers. Some block the HER2 protein from within the cancer cell, while others encourage the body’s immune system to attack it. Common anti-HER2 therapies include:

- Trastuzumab (Herceptin)
- Lapatinib (Tykerb)
- Pertuzumab (Perjeta)
- T-DM1 (available in clinical trials)

Cytotoxic Chemotherapies
Cytotoxic chemotherapies are medicines that kill cancer cells by stopping cell growth or cell division, or by interfering with cell DNA, cell parts, or proteins that help them grow. Common cytotoxic chemotherapies include:

- Anthracyclines: doxorubicin (Adriamycin), epirubicin (Ellence), doxorubicin HCl liposome injection (Doxil)
- Taxanes: paclitaxel (Taxol), paclitaxel with albumin (Abraxane), docetaxel (Taxotere)
- Antimetabolites: 5-fluorouracil (5-FU), capecitabine (Xeloda), gemcitabine (Gemzar), methotrexate
- Microtubule inhibitors: ixabepilone (Ixempra), eribulin mesylate (Halaven)
- Platinum-based chemotherapies: cisplatin (Platinol), carboplatin (Paraplatin)
- Vinca alkaloids: vinorelbine (Navelbine)

Other Targeted Therapies
These medicines target other parts of cancer cells and the structures that drive them to grow. Some of these therapies work against blood vessels that feed tumors, stop cells from fixing their own DNA once other treatments damage it, or work against certain enzymes. These targeted therapies include:
Anti-VEGF: bevacizumab (Avastin) (available in clinical trials)
PARP inhibitors: olaparib, iniparib (available in clinical trials)

Other Treatment
If you have bone metastases, your doctor may prescribe bone-building or bone-strengthening medicine to help prevent fractures and pain. These medicines include:
- Bisphosphonates: zeledronic acid (Zometa)
- RANK-ligand inhibitors: denosumab (Xgeva)

Resources for More Information

Information is current as of December 2012 but may change.

Living Beyond Breast Cancer: lbbc.org
Living Beyond Breast Cancer is dedicated to assisting you, whether you are newly diagnosed with metastatic breast cancer or are in ongoing treatment. We are also here for your family members, caregivers, friends and healthcare providers to provide breast cancer information and support. Visit lbbc.org for recent news and resources or to view our Metastatic Breast Cancer series online. To request hard copies, call (610) 645-4567.

In addition to written resources, LBBC provides a Helpline, a peer-to-peer support service staffed by volunteers living with many breast cancer diagnoses. The Helpline can be reached at (888) 753-LBBC (5222).

More information available on lbbc.org or in print:
- Metastatic Breast Cancer Series: Treatment Options for Today and Tomorrow
- Metastatic Breast Cancer Series: Managing Stress and Anxiety
- Metastatic Breast Cancer Series: Understanding Palliative Care

Metastatic Breast Cancer Network: mbcn.org
The Metastatic Breast Cancer Network, a national, patient-led organization, works to raise awareness of metastatic breast cancer within the breast cancer community and public. MBCN encourages women and men living with the disease to raise their voices to demand support, resources and more research for metastatic disease.

MBCN provides education and information to metastatic people and their caregivers. Visit mbcn.org or call (888) 500-0370 to access education, support and advocacy resources.

More information available on mbcn.org:
- Diagnosis: Metastatic Breast Cancer…What does it mean for you?
- Get the Facts Brochure
- Are you living with MBC? Flyer
Advocacy
- Breast Cancer Action: bcaction.org
- Breast Cancer Fund: breastcancerfund.org
- National Breast Cancer Coalition: breastcancerdeadline2020.org
- National Coalition for Cancer Survivorship: canceradvocacy.org
- Patient Advocate Foundation: patientadvocate.org
- Research Advocacy Network: researchadvocacy.org
- Stand Up To Cancer: standup2cancer.org

Caregiving Support
- CarePages.com
- CaringBridge.org
- Lotsa Helping Hands: lbbc.lotsahelpinghands.com
- National Family Caregivers Association: thefamilycaregiver.org

Clinical Trials
- BreastCancerTrials.org
- CCR Clinical Trials at NIH: bethesdatrials.cancer.gov
- CenterWatch Clinical Trials Listing Service: CenterWatch.com
- ClinicalTrials.gov
- ecancertrials.com
- EmergingMed.com
- ENACCT (Education Network to Advance Cancer Clinical Trials): enacct.org
- National Cancer Institute: cancer.gov/clinicaltrials
- Coalition of Cancer Cooperative Groups: cancertrialshelp.org

Family Resources
- Group Loop: grouploop.org (Teens)
- Jack and Jill Late Stage Cancer Foundation: jajf.org (Families)
- Kids Konnected: kidskonnccted.org, (800) 899-2866
- Memories of Love Foundation: memoriesoflove.org
- Men Against Breast Cancer: menagainstbreastcancer.org
- Mommy’s Light Lives On: mommyslight.org
- Mothers Supporting Daughters with Breast Cancer: mothersdaughers.org

Financial Concerns
- Association of Community Cancer Centers: accc-cancer.org
- Brenda Mehling Cancer Fund: bmcf.net (ages 18-40)
- Cancer Financial Assistance Coalition: cancerfac.org
- Centers for Medicare and Medicaid Services: cms.gov
- Joe’s House: joeshouse.org
- Patient Services, Inc.: www.patientservicesinc.org
- Social Security Disability Information: ssa.gov/dibplan/index.htm
General Information and Support
- Abramson Cancer Center of the University of Pennsylvania: Oncolink.org
- American Cancer Society: cancer.org, (800) 227-2345
- Association of Cancer Online Resources: acor.org
- Breastcancer.org
- CancerCare: cancercare.org, (800) 813-4673
- Cancer Support Community: cancersupportcommunity.org, (888) 793-9355
- Healing Circle: healingcircle.com
- Healing Journeys: healingjourneys.org
- SHARE: sharecancersupport.org, (866) 891-2392
- Susan G. Komen for the Cure: komen.org, (877) 465-6636
- Triple-Negative Breast Cancer Foundation: tnbcfoundation.org, (877) 880-8622
- Wellspring Cancer Support: wellspring.ca

Legal Information
- Cancer Legal Resource Center: cancerlegalresourcecenter.org
- cancerandcareers.org

Metastatic Breast Cancer
- AdvancedBC.org
- AdvancedBreastCancerCommunity.org
- BCmets.org
- BrainMetsBC.org
- Living Beyond Breast Cancer: lbbc.org/Audiences/Metastatic-Breast-Cancer, (888) 753-LBBC (5222)
- Metastatic Breast Cancer Network: mbcn.org
- METAvivor: metavivor.org
- MetaCancer Foundation: metacancer.org
- Patient Power: Understanding Advanced Breast Cancer Series: patientpower.info/program/the-treatment-landscape-for-metastatic-breast-cancer

Young Women
- Annual Conference for Young Women Affected by Breast Cancer: c4yw.org
- Stupid Cancer: stupidcancer.org
- Planet Cancer: planetcancer.org
- Sharsheret: sharsheret.org, (866) 474-2774
- Young Adult Cancer Canada: youngadultcancer.ca
- Young Survival Coalition: youngsurvival.org, (877) 972-1011
**Glossary**

**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 trials.** Research studies in people that test how well new medicines and procedures work compared to standard FDA-approved treatments.

**Complementary medicine.** Non-medical treatments or therapies used alongside your medical treatment.

**Duct.** The passageways that carry milk from the lobules to the nipple.

**Ductal cancer.** Cancer that grows in the ducts of the breast as a mass and may later spread through the wall of the duct into other tissues of the breast.

**HER2 protein 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.

**Hospice care.** A palliative care team from many disciplines that offers services to relieve the physical, emotional, social and spiritual burden of a progressive incurable illness.

**Infiltrating or invasive breast cancer.** Cancer that has the ability to spread beyond the breast and nearby lymph nodes.

**In situ cancer.** Cancer that has not invaded the walls of the ducts or acinus. Also called stage 0, or non-invasive, cancer.

**Lobule.** The glands that produce breast milk.

**Lobular cancer.** Cancer that starts in the acinus of the lobule but does not cause scar tissue or form a mass, making it harder to find.

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

Metastasize. 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.

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 you do to 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-controlled studies. Clinical trials in which one group of participants does not receive the treatment being tested so that researchers can compare the new treatment against standard treatments.

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.

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 volunteered their time and expertise for this guide:

Author
Nicole Katze, MA

Living Beyond Breast Cancer Reviewers
Amy Grillo
Janine E. Guglielmino, MA
Elyse Spatz Caplan, MA

Metastatic Breast Cancer Network Reviewers
Joani Gudeman, LCSW, PsyD
Debbie Molis
Katherine O’Brien

Lead Medical Reviewer
William Gradishar, MD
Feinberg School of Medicine
Northwestern University
Chicago, Ill.

Medical Advisory Committee Reviewers
David Euhus, MD
UT Southwestern Medical Center
University of Texas
Dallas, Texas

Betty Ferrell, PhD, MA, FAAN, FPCN
City of Hope – NCI Comprehensive Cancer Center
Los Angeles, Calif.

Roz Kleban, LCSW
Evelyn H. Lauder Breast Center
Memorial Sloan-Kettering Cancer Center
New York, N.Y.

Marie Lavigne, LCSW, OSW-C
Providence Health & Services
Anchorage, Alaska

Kathy Miller, MD
Melvin and Bren Simon Cancer Center
Indiana University
Indianapolis, Ind.
This brochure is designed for education 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.

LIVING BEYOND BREAST CANCER, founded in 1991, is a national nonprofit organization dedicated to empowering all women affected by breast cancer to live as long as possible with the best quality of life by providing educational and support programs and services. Visit lbbc.org for recent news and resources, or call the Helpline at (888) 753-LBBC (5222) for peer support.

METASTATIC BREAST CANCER NETWORK, a national, patient-led organization, works to raise awareness of metastatic breast cancer and encourages women and men living with the disease to raise their voices to demand support, resources and more research. Visit mbcn.org or call (888) 500-0370 to access education, support and advocacy resources.