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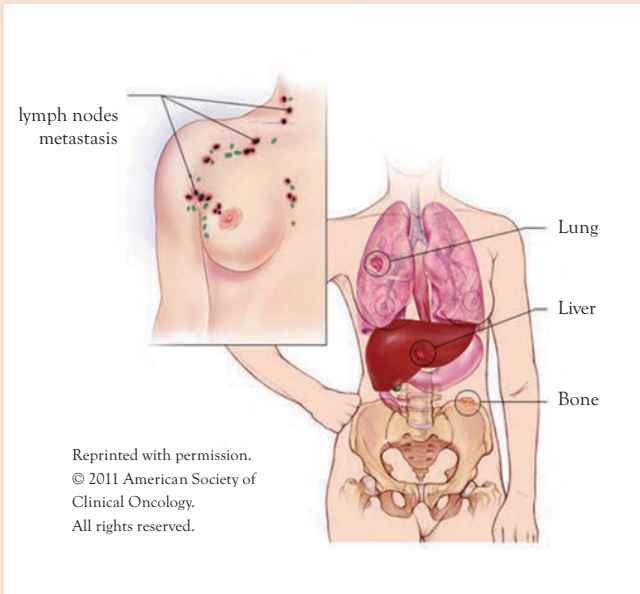


# Beyond Pink

SHARING OUR METASTATIC BREAST CANCER STORY

## Treatments for MBC

Learning about your disease and treatment options will help you make informed decisions with your doctor. There are many factors that your doctor may need to consider when developing a treatment plan. Some patients with MBC will do very well on a single treatment, while others may require combination therapy. Your treatment plan may depend on the type of MBC you have – based on hormone receptor (HR) status and the levels of human epidermal growth factor receptor 2 (HER2) expression – as well as your personal treatment goals and preferences. Treatment options include:



- **Hormonal Therapy:** Standard treatment for many people with HR-positive (HR+) breast cancer that blocks the effect of estrogen or progesterone on breast cancer cells and lowers the amount of estrogen or progesterone in the body, which can slow down or stop the growth of the cancer.
- **Chemotherapy:** Drugs that kill rapidly growing cells, including cancer cells and some healthy cells. There are many chemotherapy drugs available, so if the cancer worsens during or after treatment, or if treatment-related side effects are a problem, patients may be able to try an alternate drug. Chemotherapy can be used to treat HR-negative (HR-) and triple-negative MBC (mTNBC), and in some people who have HR+ disease.
- **Targeted Therapy:** This is a cancer treatment that uses drugs to target specific genes and proteins that are involved in the growth and survival of cancer cells. These drugs work differently from traditional chemotherapy or hormonal therapy medications because they affect the genetic changes that cause cancer, and often have different side effects.
- **Immunotherapy:** Drugs that strengthen or change how the immune system works to better enable it to fight cancer. Immunotherapies act by helping your immune system work harder and more efficiently to attack cancer cells by targeting specific receptors on breast cancer cells, and boost your immune system to stop or slow cancer growth as well as spread to other areas of the body.
- **Combination Therapy:** Using two or more methods to treat the cancer. Therapies approved for combination are given individually and not combined into a single administration. There are a variety of medicines that can be used in combination therapy. Talk to your doctor about which treatment regimens may be right for you.

## Additional Treatment Options

There are some additional medicines your doctor may recommend that may enhance the effects of other treatments or help prevent side effects.



- **Treatments for bone metastases:** If breast cancer has spread to the bones, patients may experience bone pain and have an increased risk of fracture. Also, some breast cancer treatments may cause bone thinning (osteoporosis). When a patient has been confirmed to have bone metastases, the doctor may recommend any of the following to aid bone health:

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

- **Surgery:** Surgery is relatively uncommon for patients with metastatic breast cancer but may be used in certain instances.

- **Radiation therapy:** Radiation therapy uses x-rays to kill cancer cells. It is often given after surgery to help reduce the chance that the cancer will come back in the breast or nearby lymph nodes. Radiation may also be recommended after surgical removal of the breast (mastectomy) in patients either with a cancer larger than five centimeters, or when cancer is found in the lymph nodes. In patients with metastatic breast cancer, radiation therapy may be used to help relieve symptoms such as pain, or to improve breathing.





## Responses to Treatment Vary for Each Patient

If your treatment stops working, your medical team may recommend another type of treatment. However, before that happens, your medical team may order additional testing to help determine if your cancer has changed or progressed.

## Managing Side Effects

Whether you've just been diagnosed with MBC or have been living with the disease for some time, it helps to know the potential side effects to expect from treatment. Following are some of the most common side effects associated with MBC treatment and some tips on how to manage them with your doctor. This is not a complete list of side effects. Please speak to your doctor about any side effects you may experience, and how to help manage these side effects. Always be sure to consult with your medical team before trying any tips.



## Hot Flashes

One of the most common side effects of hormonal treatment, hot flashes, are associated with the hormonal changes within your body. These changes can be caused by menopause and/or medication. There are some prescription medicines that treat hot flashes. It may also help to avoid certain triggers including:

- Alcohol
- Caffeine
- Hot tubs
- Smoking
- Hot food
- Diet pills
- Saunas
- Stress
- Spicy food
- Hot rooms
- Hot showers

## Joint Pain

Joint and muscle pain may come from your treatment, other medical conditions or other medications you're taking. The pain may go away over time as your body adjusts. For persistent pain, you can try:

- OTC medications
- Swimming
- Prescription treatments
- Strength building exercises
- Heat
- Yoga
- Massage

## Nausea and Vomiting

Common side effects during MBC treatment, which may be caused by specific cancer treatments, the use of certain pain medications, or anxiety. Talk to your doctor about what options may be right for you.



## Decrease in Bone Mass

Weakening of the bones, also known as osteoporosis, causes an increased risk of bone fractures. It may be caused by some MBC treatments or a drop in estrogen due to menopause. A bone density test can measure bone loss. To help reduce your risk:

- Eat a balanced diet rich in calcium and vitamin D
- Engage in weight-bearing exercise, such as walking
- Avoid smoking and excessive alcohol consumption

## Weight Changes

Some MBC treatments may cause you to lose or gain weight. Keep a journal to monitor your weight and eating patterns, and discuss any concerns with your treatment team. Your team may recommend:

- Supplementing your diet with extra protein and calories
- Consulting a dietician or nutritionist for specific recommendations
- If you're gaining weight, lowering the fat content and/or calorie count of your daily diet
- Starting a program of regular, moderate exercise for further weight reduction.





## Vaginal Dryness

Cancer therapy may cause vaginal dryness, leading to discomfort and more difficult or painful intercourse. There are numerous OTC water-based vaginal lubricants or moisturizers available that may help. Petroleum jelly should be avoided, as it may increase the risk of vaginal yeast infections.

## Fatigue

Treatment-related fatigue can be physically, emotionally, and mentally draining and impact quality of life. Unlike normal tiredness that is relieved by rest, exercise, or a good night's sleep, treatment-related fatigue can leave you feeling “wiped out” and make it hard to concentrate, even after getting plenty of rest. To help manage fatigue:

- Stay aware of your energy levels and pace yourself accordingly
- Listen to your body
- Carve out “windows of opportunity” for important activities
- Get checked for anemia
- Ask your treatment team for recommendations

## Lymphedema

The build-up of extra lymph fluid in tissues that often occurs after surgery or certain MBC treatments. Fluid build-up from lymph nodes under your arms can cause arm or hand swelling, a tight or heavy feeling in the arm, and difficulty with daily tasks. Lymphedema can be managed by:

- Elevating the affected arm
- Seeking professional massage or physical therapy for the affected arm
- Exercising gently
- Wearing a compression sleeve to help fluid drain from the affected arm

## Possible Side Effects of Radiation Therapy

Side effects of radiation therapy may depend on where the radiation treatment is given. While side effects usually lessen in time, they may continue for several months after treatment is finished. The most common are skin irritation (redness, tenderness, or sensitivity) and extreme tiredness. Make sure to tell your doctor if you experience any side effects while undergoing treatment.

## Possible Side Effects of Immunotherapy

Different types of immunotherapy may cause different kinds of side effects. Some of the most common side effects of immunotherapy may include skin changes, such as redness, dryness, or blistering and flu-like symptoms. It is important to discuss all side effects with your doctor. Many side effects may go away when treatment ends, but some effects may last beyond the treatment period.



## To Know About Metastatic Breast Cancer

Being diagnosed with metastatic breast cancer can come as a shock and be frightening, and often results in questions such as “How will I manage a cancer I will have for the rest of my life?” While this question can be difficult to answer, it is important to know that you are not alone in answering it.

### BELOW ARE 10 THINGS YOU SHOULD KNOW TO HELP ACTIVELY MANAGE YOUR METASTATIC BREAST CANCER

- 1 Actively participate in treatment discussions** and ask your doctor to explain anything you do not understand or information with which you are not comfortable.
- 2 Involve your full treatment team.** Your healthcare team is made up of various healthcare professionals. Be open and honest about your symptoms and treatment side effects. Cancer affects people differently, and no one can predict your individual experience.
- 3 Know your tumor’s hormone receptor status and ask what it means for your treatment plan.** Breast cancer can be hormone driven—and the progression of MBC can be directly related to the types of hormones. Knowing what drives tumor growth allows you and your medical team to identify and select appropriate treatment options. You may also want to have a re-biopsy done periodically to see if your tumor’s hormone receptor status has changed.
- 4 Consider taking a family member or a friend to your appointments** to offer support, to help you remember questions you want to ask and/or to take notes for you to review at a later time.
- 5 Share feelings of anxiety and distress with your healthcare team and loved ones.** This is not the time to hide concerns or try to see if feelings of anxiety and distress will pass. Talk with your healthcare team and loved ones about ways you can relieve your stress and reduce your fears.
- 6 Learn how treatments might affect sexual desire or activity.** Breast cancer and treatments can cause fatigue, discomfort, pain, and other side effects—all of which may decrease sexual desire. Talk with your healthcare team about what to expect and how to handle these side effects, and be open and honest with your partner about what you’re feeling and what you need from them.
- 7 Stay active and exercise when you can.** Take walks as you feel up to it and/or seek an exercise program designed for cancer patients within your community. Staying physically active can help to keep your body strong and may improve your sense of well-being; be sure to talk to your doctor before you begin an exercise program.
- 8 Maintain a healthy diet.** Consider speaking with a nutritionist to find a diet that works for you. Good nutrition may help you keep up your strength and handle the side effects of treatment.
- 9 Talk to others going through similar journeys.** Dealing with cancer can be emotionally and physically draining. Connecting with others living with metastatic breast cancer in person or online can be extraordinarily meaningful for both those who are just beginning their MBC journey and for those who have experience and insights to share.
- 10 Continue to participate in activities you enjoy.** Having a routine can help you focus on activities that bring you joy. Whether it is a daily routine or something you do only once a week, a routine can help you maintain good habits and provide structure during times of uncertainty when so many other aspects of life seem out of control.

## Questions to Ask Your Doctor About Treatment Options

- What type of treatment(s) should I have? Why?
- When will I start the treatment?
- How will the treatment be given to me?
- How often will I get it?
- How long will I need to take it?
- What are the side effects and how can I manage them?



## Clinical Trials

Clinical trials are carefully conducted research studies that are done with patient volunteers. They are designed to determine the effectiveness and safety of new treatments or procedures. Each clinical trial has specific guidelines on patient characteristics that should be included and excluded. The following factors can help determine if a patient is appropriate for a given clinical trial:

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

Every trial has specific rules determined by the US Food and Drug Administration (FDA) for when and how patients should be monitored, as well as when they will receive medications and at what doses. Throughout the study, patients will visit with the research team to determine if the treatment is working and if the patient is experiencing any side effects. Talk to your doctor to determine if a clinical trial might be an option for you.

## Clinical Trial Phases

- **PHASE I TRIALS** are often the first studies to test a new drug in people. Phase I trials typically evaluate how a new drug should be given and how much of the drug may be given safely in a small group of patients (20 to 80).
- **PHASE II TRIALS** further test the safety of the drug and begin to measure how well the drug works in a larger group (100 to 300) of patients. Participants are usually patients with the disease for which the specific medication is being evaluated.
- **PHASE III TRIALS** typically compare the safety and efficacy of the new treatment with the current standard treatment. Phase III trials often enroll a large number of patients (1,000 to 3,000) at different sites. These studies are most often used to determine if a medication can be submitted for FDA approval.
- **PHASE IV TRIALS** are conducted after a new treatment has been approved by the FDA and is available to be prescribed. These trials typically evaluate the safety and efficacy of a drug over a longer period in a larger number of patients.

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



## Choosing Your Treatment Team

Your medical team is the best resource to help manage the disease, so it's important to understand which health care professionals (HCPs) you should consider to be a part of your team. Following are 10 things you should know when choosing your treatment team.

- 1** The first step is to **understand who should be on your team**. Utilize all resources available to you, such as your advanced care practitioner, local cancer center, advocacy groups, oncologist directory (AMA, ASCO) or medical insurance carrier, to find the right experts to support your journey.
- 2** **An effective treatment team includes a variety of professionals**. Specialists and HCPs you should consider including on your medical team include a medical oncologist, advanced care practitioner, nutritionist, mental health professional, physical therapist, pharmacist, surgeon, radiologist and an oncology nurse practitioner.
- 3** **Your medical oncologist will be responsible for your care and treatment plan**. Consider choosing someone who specializes in breast cancer and has expertise in treating patients with metastatic disease.
- 4** **Do your research on potential providers** to ensure you are comfortable with their experience and style. Talk with others who have been treated by these doctors, ask for recommendations and research their background and areas of expertise through online searches and professional society recommendations (e.g., National Consortium of Breast Centers).
- 5** **Consider choosing members of an established breast center program** that is part of the National Cancer Institute (NCI). This can help to streamline your care as they offer many services “under the same roof” including: seminars or workshops by a counselor or nurse that teach strategies to empower patients to actively manage their care, patient and family education (e.g., informational materials, support groups, counseling), testing and analysis services, urgent care needs and emotional support.
- 6** **Identify a primary point of contact**, which could be your medical oncologist, a nurse practitioner or patient navigator. This person will work closely with you to help ensure everyone on your team has the same information about your treatment plan and is aware of your needs.
- 7** **Build a relationship with your team**. Good communication between you and your team is essential to have your needs met to your satisfaction. Share how you want to receive information and ask questions. Also, learn how your team is communicating with each other to ensure you feel confident that you are receiving the best possible care.
- 8** **Actively participate in your treatment discussions and learn as much as you can about MBC**. If you don't understand what your doctor is telling you, ask questions until you do.
- 9** **Talk openly with your medical team about how your current course of treatment may be affecting you and how you are feeling**. This will help determine if you need any additional tests or if changes need to be made to your current course of treatment.
- 10** **Talk to others going through similar journeys**. Sharing your experiences and getting advice from others living with the disease can help you better manage your MBC experience, including personal experience with doctors, advice on how to discuss uncomfortable topics and where to find information about the disease.