

DIAGNOSIS: Metastatic Breast Cancer...

What Does It Mean For You?

A diagnosis of metastatic breast cancer can be frightening and overwhelming. It is understandable to experience a range of emotions when you are first diagnosed.

This brochure will provide you with up-to-date facts and some answers to frequently asked questions.

Today, more and more women and men with metastatic breast cancer are living longer, meaningful and productive lives. While the search for a cure continues, rest assured that metastatic breast cancer can, at times, be effectively controlled for extended periods of time with ongoing treatment.

1 Am I going to die?

This could well be your first question when you are confronted with a diagnosis of metastatic breast cancer, especially if you have gone through a previous breast cancer diagnosis and treatment.

Though you may be concerned by statistics you have heard, keep in mind that every individual is unique. Because statistics are based on the general population, they do not reflect the experience of any one individual. Each person brings to the table a unique set of characteristics that influence her or his experience with breast cancer, including tumor type, site of metastases, and personal health history.

2 What does it mean that the cancer has metastasized?

Metastasis refers to the spread of the cancer to distant organs. When the cancer does so, it is known as metastatic disease.

In about 6% to 10% of all breast cancer patients, the cancer has spread to distant organs and is classified as Stage IV at the time of the first diagnosis. In the majority of patients with metastatic breast cancer, the metastasis is diagnosed after a cancer has already been treated at an earlier stage.

3 Where can breast cancer metastasize to?

Breast cancer can spread to different parts of the body, most commonly to the bones, the lungs and the liver. Sometimes, other organs are involved. (Breast cancer that spreads to any of these sites is not the same as cancers that originate in them.)

4 What are my treatment options?

Treatment options include chemotherapy, targeted therapies, and sometimes radiation and surgery.

Targeted therapy

Years ago, the treatment for breast cancer was based on a “one size fits all” concept. When diagnosed, most people received the same chemotherapies.

Now, treatment can be more individualized. New ways of testing cancer cells for specific biomarkers – indicators of tumor behavior – allow your doctor to choose the best available treatments for your unique cancer type.

If your cancer cells are found to be hormone responsive, the hormones estrogen and progesterone that exist naturally in our bodies can actually fuel your cancer. This is commonly referred to as **ER-positive (ER+) or PR-positive (PR+)** status.

If your tumor is ER+ and/or PR+, you may not only benefit from traditional chemotherapy, but also from targeted, hormonal therapies. These therapies may include drugs such as tamoxifen, which blocks estrogen after it is produced from binding to the estrogen receptor; aromatase inhibitors, which interfere with the production of estrogen; fulvestrant (Faslodex™), which destroys the estrogen receptor (only temporarily), or other agents that may be developed in the future.

If you are pre-menopausal, you may benefit from a reduction in estrogen production through ovarian suppression using monthly injections. Surgical removal of the ovaries (oophorectomy) may also be recommended.

5 What do the categories HER2-positive and triple negative mean?

HER2 is a protein that acts as a receptor on the surface of the cancer cell. It also acts as a fertilizer, causing the cancer cells to reproduce. All breast cancer cells have some **HER2** receptors, but 20-30% of patients have breast cancers with many extra copies of this protein. If your tumor has extra **HER2**, your cancer can be classified as **HER2-positive**.

You may be treated with trastuzumab (Herceptin™), a targeted therapy that can block the **HER2** receptor. Usually, trastuzumab is administered along with chemotherapy. Or you may be treated with newer targeted therapies, such as lapatinib (Tykerb™), which inactivates both the **HER2** receptor and the related HER1 receptor, or with other agents that may become available in the future.

Some cancers are classified as all three at the same time: **ER+**, **PR+** and **HER2+**.

Your cancer could also be classified as **triple negative**, meaning that it would not express these three markers and would not be responsive to the above targeted therapies (hormone therapies and anti-HER2 agents) but would be most effectively treated with chemotherapeutic agents. Chemotherapy, a systemic therapy that interrupts cell growth and division, can be given orally or intravenously. In addition, clinical trials are analyzing the benefits of new agents to fight triple negative disease.

6 How long will I be on treatment?

Treatment will be lifelong and is intended to provide symptom relief, good quality of life, and prolonged progression-free survival. Remember, treatment that stabilizes tumor growth, even without shrinking or eliminating it, effectively controls the disease, and this is considered a positive outcome.

7 How will I be monitored?

Imaging tests, ranging from CT scans and MRIs to bone scans and PET scans, may be used to monitor changes in the size and location of the breast cancer metastases and to assess your response to therapy. Sometimes, blood tests measuring tumor markers, such as CA15-3, CA 27-29, and carcinoembryonic antigen (CEA), can provide clues to the clinical behavior of breast cancer.

While tumor markers can be indicative of tumor behavior, most oncologists do not recommend changing treatment based on tumor markers alone.

8 Why does the treatment for metastatic disease seem “less aggressive” than treatment for early-stage disease? Everything feels less urgent, despite a much more serious prognosis. Why is that?

Treatment of early-stage disease focuses on curing the breast cancer and therefore tends to be immediate and aggressive. In contrast, because there is no cure for metastatic breast cancer at this time, treatment focuses on controlling the disease and permits a more measured, long-term approach to therapy. This allows for more conservative treatment that reduces the incidence of adverse side effects.

9 Should I get a second opinion?

As mentioned previously, there are many treatment options. You might want to speak with another oncologist and/or someone from a major cancer center in your area to clarify the possibilities. Your doctor is likely to welcome your decision to get a second opinion.

10 How can I manage pain and other symptoms caused by cancer and its treatments?

The management of pain should be included in your cancer treatment. Sometimes, by shrinking the tumor itself, pain is reduced. A number of drugs are currently available to control pain, and new products are expected to be available in the future. In addition, various complementary therapies may be helpful, including yoga, meditation, acupuncture, physical therapy and others.

You might want to contact the following organizations for additional information about pain management:

American Academy of Pain Management

www.aapainmanage.org
1-209-533-9744

American Pain Foundation

www.painfoundation.org
1-888-615-7246

Cancer Care

www.cancercare.org
1-800-813-4673

11 Will I have to change my lifestyle?

Any change in your lifestyle will depend on your symptoms and your treatment regimen. Many people continue living in the same way as they did before receiving their diagnosis – continuing to work, exercise, and generally enjoy life. Others may make minor or more major adjustments until they find their own comfort level.

12 How can I maximize my relationship with my doctor?

You might find, as many individuals do, that gathering information about the disease and its treatment helps you formulate the questions you want to ask. You might also find it useful to prepare a written list of your questions before meeting with your doctor. It can help to bring someone with you to your doctor's appointment to listen and help you remember the details.

13 What is the role of a social worker?

A social worker can help you ride the emotional ups and downs that may accompany your diagnosis. Social workers can help you navigate the healthcare system and assist you in finding resources for help with home care, financial issues, childcare, transportation, and other concerns.

14 Should I tell my friends and family that I have stage IV breast cancer? What should I tell them?

Just as your lifestyle adjustments depend on your individual needs, your decision to discuss your disease with your friends and family depends on your situation. Usually, however, it is best to inform your family and friends that you have stage IV breast cancer and what this means. They are likely to understand and be supportive, and this can be helpful to you.

15 How do I determine if a clinical trial is appropriate for me?

There are a number of websites that list clinical trials and help clarify their appropriateness for different individuals.

Speak with your doctor first, and then check out the following organizations:

National Cancer Institute Clinical Trials Website

www.cancer.gov

1-800-4-cancer

American Cancer Society Clinical Trials Matching Service

www.cancer.org

1-800-303-5691

Breast Cancer Trials

www.breastcancertrials.org

415-476-5777

This publication was written and produced by the **Metastatic Breast Cancer Network (MBCN)**, a national, independent, nonprofit patient advocacy group dedicated to the unique concerns of the women and men living with metastatic breast cancer.

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MBCN is THE proactive voice in the metastatic breast cancer community, helping patients and healthcare professionals recognize that with the help of new treatments we are living longer and more productive lives than ever before. MBCN is fighting for treatments to extend life, making metastatic breast cancer a truly chronic disease.

To join MBCN or get further information, visit our website, www.mbcn.org or phone 888-500-0370.

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