

METASTATIC BREAST CANCER  
DIAGNOSIS, TREATMENT DECISIONS  
AND ONGOING CARE

# BEING YOUR OWN BEST ADVOCATE



A diagnosis of advanced or metastatic breast cancer can be complex and frightening. But you CAN get the excellent care you deserve. Here are some tips for taking charge of your treatment.

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## DIAGNOSIS: THE BASICS

Metastatic Breast Cancer (MBC) is not one disease. You need to know and understand what kind of metastatic breast cancer you have so you know what treatment is appropriate. Your pathology report is generally the starting point for treatment decisions.

### FOUR ESSENTIAL RIGHTS:

- 1.** You have a right to know how your diagnosis was made in language you understand. Ask questions until you are clear about the diagnosis including where you have metastasis and the extent of your metastasis.
- 2.** Ask your doctor to explain what subtype of metastatic breast cancer you have. Subtypes are determined by what is making your cancer grow. For example, when cancer cells are fueled by the hormone estrogen, the subtype is called **estrogen positive cancer**; when there is too high an amount of a protein called HER2 in the cancer cells, the subtype is called **HER2 positive breast cancer**, if the cancer cells do **not** use estrogen, progesterone, and the HER2 protein to grow, the subtype is called **triple negative breast cancer** .
- 3.** You have a right to timely explanations of imaging tests and/or blood tests. Why is the test being done and what information will it provide? How often will this test be repeated? You have a right to copies of the results of every imaging and blood test. Keep these records together for future reference.
- 4.** You have a right to ask questions. For each appointment, write down three or four concerns and/or questions. Questions can relate to your current treatment, symptoms such as pain, inability to sleep, something you did not understand from the last appointment and so on.



## TREATMENT DECISIONS

Every treatment has potential good and bad effects (toxicities). It's important to know what your quality of life will be. Will the treatment mean changes for your family and work life? Can you continue your regular daily activities?

### TAKING CHARGE OF YOUR TREATMENT

- You should be told why a treatment is being recommended as well as the treatment's potential benefits and harmful effects. How well has this treatment worked for other patients who have your kind of metastatic breast cancer?
- Weigh your options. Talk with others who have taken the treatment (your doctor may refer you to such patients) and research the treatment on a reputable website. Take the time you need to be comfortable with your decision.
- Report any treatment symptoms to your doctor or nurse. You are not "complaining," but rather helping your doctor give you good care. Sometimes a dose may be adjusted or medications given to relieve your symptoms. If you need a little break from treatment, ask your doctor.
- If your doctor wants to add something to your treatment, stop your treatment, or switch treatments, he or she should clearly explain why. You should have a chance to ask questions. Do you understand the goals of each suggested change? If you disagree, tell your doctor.
- Ask how you will know if a treatment is working. What tests will be used? Some patients also like to ask what the next treatment might be if the treatment fails to reduce the metastasis or keep the disease stable (no additional progression).



## SECOND OPINIONS

If your disease progresses after treatment, sometimes it is helpful to get a second opinion. Some patients also seek a second opinion when they are first diagnosed.

A doctor giving a second opinion will start by reviewing your treatment records, especially your pathology report. When you see the doctor, he or she will ask you to tell your treatment story in your own words. How were you diagnosed? What have you done to date? How are you doing? After talking to you, the doctor will conduct an exam. At the end of the appointment, the doctor will give you his or her thoughts on your treatment.

### HOW TO GET ANOTHER OPINION

- Inform your doctor you intend to get a second opinion. People seek second opinions all the time—your doctor will not take it personally!
- Consider calling the nearest comprehensive cancer center to find a second opinion doctor. Tell the center you have metastatic breast cancer. Cancer centers are used to such calls and they can tell you how to set up an appointment, get your records and so on. Remember: You want an independent opinion—therefore, look beyond your current doctor's practice.
- All of your records, including biopsies, pathology reports, scan results, blood test results, etc., belong to you. Typically there is a form to sign indicating you want these results sent to another healthcare provider directly—often times with no cost to you. Sometimes there will be a cost if you want to personally receive all these records at one time.



## YOU ARE IN CHARGE OF YOU...

If you do not trust your healthcare provider, chances are you will not do as well as someone who does. It can be upsetting to make any kind of change to your routine. But you are worth it!

### IT MIGHT BE TIME FOR A NEW DOCTOR IF:

- Your doctor is always rushed and does not answer your questions or concerns.
- Your doctor does not explain your diagnosis, your imaging results, or suggested treatment in terms that you can understand—even when you have let the doctor know you don't understand what he or she is saying.
- Your doctor says “Because that was my decision” when you ask why a test or treatment is being ordered.
- Your doctor gets angry when you tell him or her you want a second opinion.
- Your doctor doesn't listen when you talk about pain, anxiety, sleep problems or sexual issues.
- Your doctor doesn't let you have your say.



## ADVICE FROM PATIENTS LIVING WITH MBC

MBCN has compiled the following suggestions from people living with metastatic breast cancer:

- Insist on a biopsy of your cancer--not only at the time of diagnosis, but also at the time of each progression. Sometimes, the biology of your breast cancer can change, and that change could impact the kind of treatment you should receive.
- Bring someone with you to your appointment who can be “a second set of ears” or who can take notes for you. Consider using your smart phone (with permission) to record the visit.
- During a second opinion, you may discover another doctor who explains things better than your current doctor.
- If your doctor does not bring it up, ask if you could benefit from a clinical trial.
- Learn as much as you can about your disease and all the options available.
- Join an online or in person support group for people with metastatic breast cancer.
- To cope with anxiety, get counseling.
- Stay as active as possible.
- View good nutrition as good complimentary medicine for your disease.
- Seek out survivor stories, disease information and sources of support at MBCN’s website: [mbcn.org](http://mbcn.org).