



WE HAVE METASTATIC BREAST CANCER.

**WHAT ACTIONS CAN WE TAKE TO
REALIZE
THE BEST POSSIBLE OUTCOMES?**

SHIRLEY A. MERTZ, MA, JD

PRESIDENT, METASTATIC BREAST CANCER NETWORK

A FOUNDER OF THE METASTATIC BREAST CANCER ALLIANCE

MBC STATISTICS

- Estimates in 2020 were that 168,000 US women live with MBC. We don't know the exact figure because recurrences aren't counted—only the first diagnosis.
- 6% of MBC diagnoses are De Novo; others represent recurrences.
- MBC is present among older & younger women; men; African American, LatinX, and Asian individuals; women & men from the LGBT communities

ALL PERSONS, WHEN FIRST DIAGNOSED, SHARE COMMON FEELINGS

- Shock, anger, terror, disbelief, loss of control
- The mental challenges of dealing with an incurable disease can be as difficult as the challenges of treating the disease. Some describe MBC as a roller coaster ride they can't get off of.
- Comments from family, friends, work colleagues, etc. often show a lack of understanding of MBC. Such comments can hurt.

Early Stage versus Metastatic Breast Cancer

Early-Stage Breast Cancer

Metastatic Breast Cancer

Location of disease	Confined to breast ducts and lobes and adjacent lymph nodes	Most common to bones, brain, liver, lungs
Number of cases	All cases counted	Counted only if De Novo
Stage of disease ¹	0, I, II, III	IV
Threat to life	Only if untreated	Incurable but treatable
Treatment goal	Curative	Control disease and maintain quality of life
Treatment length	Limited	For rest of patient's life
5-Year survival rate ²	Local 99%; Regional 86% ³	28% women and 22% men
Research dollars ⁴	93% of all breast cancer research dollars	7% of all breast cancer research dollars

BREAST CANCER IS NOT ONE DISEASE

- **MBC is complex because it travels to different sites in the body. The cancer may begin in ducts or lobes**
- **Survival statistics are based on others in similar situations, but they are not you.**
- **You are a STATISTIC OF ONE!**
- **Your subtype will impacts treatment choices**

SUBTYPES-NAMED AFTER WHAT MAKES THE CANCER CELLS GROW

1-HORMONE RECEPTOR POSITIVE BC - (Fueled by Estrogen-receptor and/or Progesterone-receptor.)

There are 2 types:

- **Luminal A** breast cancer is estrogen-receptor and/or progesterone-receptor positive, HER2 negative, and has low levels of the protein Ki-67, and are low-grade, growing slowly and have the best prognosis.
- **Luminal B** breast cancer is estrogen-receptor and/or progesterone-receptor positive, and either HER2 positive or HER2 negative with high levels of Ki-67. Luminal B cancers generally grow slightly faster than luminal A cancers and their prognosis is slightly worse.

2-HER2 ENRICHED BREAST CANCER

- **HER2-enriched** breast cancer is fueled by an abundance of the HER2 neu protein and can be also hormone positive. HER2-enriched cancers tend to grow faster than luminal cancers, but they are often successfully treated with targeted therapies aimed at the HER2 protein.

3-TRIPLE NEGATIVE (BASAL) BREAST CANCER

- TNBC is hormone-receptor negative and HER2 negative. It is more common in women with *BRCA1* gene mutations and is more common among younger and Black women.

HOW CAN YOU STAY UP-TO-DATE ON YOUR SUBTYPE?

- Using **Google**, create a request for an alert about “metastatic breast cancer” information or the name of your subtype. Emails will result.
- **Attend MBC Conferences, virtually or in person.** Examples: Komen MBC Impact Series, San Antonio Breast Cancer Conference, MBC Conference by Theresa’s Foundation, etc
- **Review Websites** such as Komen; BreastCancer.org; Susan Love;
- **Listen to Webcasts** that provide info on targeted topics or updates from breast cancer conferences (SABCS)—Komen, SHARE, LBBC, etc
- **Project LEAD**--a course by the National Breast Cancer Coalition

The background is a solid blue gradient. In the corners, there are decorative white line art elements resembling circuit boards or neural networks, with lines and small circles connecting them.

**AN IMPORTANT FIRST DECISION AFTER YOU HAVE
BEEN INFORMED YOU HAVE MBC IS:**

“WHO WILL YOU SELECT AS YOUR ONCOLOGIST?”

A good decision will require research & thought.

YOU NEED A CARING, KNOWLEDGEABLE ONCOLOGIST

- A **Breast Oncologist** will explain your diagnosis, subtype and recommend treatments. To find the right one,
 - > Don't just rely on friends' recommendations—do some research
 - > Does he/she specialize in treating MBC?
 - > Does he/she treat a high volume of MBC patients?
 - Does he/she participate in clinical research?
- Example of how a poor decision can affect you

OTHER MEMBERS OF THE MEDICAL TEAM

A SURGICAL ONCOLOGIST uses surgery to remove tumors and perform biopsies—a tiny piece of tissue removed from a tumor for testing

A RADIATION ONCOLOGIST treats patients with radiation therapy for pain or to remove oligometastatic tumors (2-5 small lesions)

NURSES (Registered, Advanced Practice, Nurse Navigator)- help with education, support, lab work, toxicities, etc.

A PRIMARY CARE DOCTOR addresses conditions other than cancer—blood pressure, diabetes, heart disease, skin lesions, etc.

YOU NEED A GOOD TEAM RELATIONSHIP WHERE:

- *Respect and trust are shared values*
- *Good communication exists between you & the team*
- *The team answers questions in language you understand*
- *You can openly share concerns about your treatment or how you are feeling mentally*
- *The team understands your values and your treatment goals*

SHARE YOUR TREATMENT GOALS

- You & your doctor need to be in agreement about your care
- How aggressive do you want treatment to be? Or do you want less aggressive treatment with fewer side effects?
- If in pain, pain control may be your number one concern
- The effects of treatment will impact you and your family issues. Sleep issues & low energy impact QOL.
- You can change your mind about your treatment choices or plan. Share that with your doctor.

WHAT SIGNS INDICATE IT MIGHT BE TIME TO THINK ABOUT A DIFFERENT DOCTOR?

- Your doctor is **always rushed** and does not answer your questions
- Your doctor **does not explain things** in language you understand
- When you ask why a test is being ordered, your doctor says, “Because that is my decision.”
- During appointments, your doctor focuses on the computer, not you
- Your doctor rarely asks about your treatment side effects, pain, anxiety, sleep problems, etc. at appointments



MEDICAL IMAGING AND BLOOD TESTS ARE IMPORTANT:

1. PROVIDE INFORMATION ABOUT YOUR UNIQUE MBC

2. INDICATE HOW YOU ARE RESPONDING TO TREATMENT



WHEN YOU MEET WITH YOUR MEDICAL TEAM, PAY ATTENTION TO TESTS THAT ARE ORDERED

- **A tissue biopsy of a MBC lesion begins your diagnosis**
- **Biopsies are important in MBC because they reveal the cancer's molecular characteristics in a pathology report**
- **Size, hormone receptors, signs of spread, growth rate**
- **New biopsies over time may indicate your subtype has changed. That is very important information.**



**TWO OTHER TESTS HAVE BECOME IMPORTANT
IN TREATMENT DECISIONS FOR MBC**

Genetic Testing & Genomic Sequencing

They are part of what is called

PRECISION MEDICINE





PRECISION MEDICINE FINDS THE RIGHT TREATMENT FOR THE RIGHT PATIENT AT THE RIGHT TIME

GENETIC TESTING – a blood test can reveal mutations (changes) in the genes you have inherited from your mother and/or father that can contribute to cancer. BRCA1, BRCA2



- The test can gauge family members' risk for breast cancer**
- The test reveals “germline mutations” that can suggest a new MBC treatment or your eligibility for a clinical trial**

WITH GENOMIC SEQUENCING:

- A sample of your tumor is biopsied
- **SOMATIC MUTATIONS** are identified and can reveal why your tumor is growing
- You may qualify for a new treatment or Clinical Trial
- The “right” treatment may be identified for your cancer & help avoid toxicities of “wrong” treatments



**ASK YOUR ONCOLOGIST IF YOU
SHOULD HAVE A
GENETIC TEST AND/OR
GENOMIC SEQUENCING TEST**



OTHER IMPORTANT TESTS INCLUDE SCANS: PET SCANS, CT-SCANS, MRI'S, BONE SCANS, ETC

- **Scans will determine the extent of your disease**
- **Scans will also gauge your response to treatments**
- **Ask that the results be clearly explained. Get a copy of the results. Share with your primary care doctor. Issues other than cancer may be present.**

BE INVOLVED IN THE SELECTION OF TREATMENTS

- Educate yourself about *standard treatments* for your subtype
- Read the booklet of NCCN guidelines for MBC at nccn.org. 31 cancer centers have agreed on the Standard of Care for MBC
(National Comprehensive Cancer Network)
- If your doc suggests more than one treatment, ask about the *benefits* and *toxicities* of each treatment and possible outcomes
- Ask how a treatment might help achieve your goals of treatment:
Control of MBC Spread; Shrinkage of Mets; Comfort and QOL
- Consider how the toxicities might affect you, your family, work, etc

SPEAK UP ABOUT TOXICITIES YOU EXPERIENCE

- After you begin a new treatment or later into the treatment, report uncomfortable symptoms to your doctor or nurse

You are NOT complaining, but rather seeking good care.

- Doses of treatment can be adjusted and/or other meds given for particular toxicities. Treatment is not automatically stopped because of toxicities as some believe.
- If your doctor wants to add something to your treatment; stop treatment; or switch treatments, question “why.”
- If you feel you want other opinions, consider a 2nd opinion

SECOND OPINIONS



- Do not ask a doctor in the same practice for a second opinion
- Ideally, get a second opinion at a NCI-Designated Cancer Center
- 2nd opinions can address progressions or treatment concerns
- A form can direct that your records be sent to the 2nd doctor
- After reviewing your records, meeting you to hear your story, doing a physical exam--the 2nd opinion doctor will share his/her opinion
- Does the 2nd opinion confirm the 1st doctor's opinion or suggest a new approach? You have decisions to make. Consider a 3rd opinion?

PARTICIPATION IN A CLINICAL TRIAL IS ALSO A TREATMENT OPTION

- Trials are studies that often compare a new treatment with a FDA approved treatment OR a new class of treatments
- Enrolling in a trial does NOT mean you have run out of treatment options
- If your oncologist does not bring up clinical trials, ask about them
- An excellent source of finding clinical trials on your own is:
Metastatic Trial Talk.org The site provides other MBC info.



WHILE WE CAN'T CONTROL OUR CANCER CELLS, EACH DAY WE CAN CHOOSE TO:

- STAY ACTIVE—walking, biking, practicing yoga, etc
 - LISTEN TO FAVORITE MUSIC to calm you
 - GOOD NUTRITION --nuts, vegetables, fruits, and green tea
 - Seek a PSYCHOLOGIST OR SOCIAL WORKER to cope with anxiety, depression, or relationships impacted by your diagnosis
 - Practice GRATITUDE, MEDITATION, BREATHING techniques
 - CONNECT WITH OTHERS to learn how they thrive, cope, with MBC
- 
- 

SUMMARY: WHAT HAS BEEN SHARED



- KNOW YOUR MBC SUBTYPE, HOW IT IS TREATED, AND STAY INFORMED
- SELECT A DOCTOR THAT YOU RESPECT, TRUST, AND ALLOWS YOU TO HAVE A VOICE IN YOUR TREATMENT. 2nd OPINIONS CAN BE HELPFUL.
- STRIVE TO UNDERSTAND THE RESULTS OF YOUR PATHOLOGY TESTS, YOUR SCANS, AND BLOOD TESTS
- BE INVOLVED IN THE SELECTION OF YOUR TREATMENTS, INCLUDING EXPLORING CLINICAL TRIALS THAT MIGHT BE APPROPRIATE FOR YOU
- TEND TO YOUR MENTAL & PHYSICAL WELL-BEING AND YOUR QOL



KNOWLEDGE IS POWER. BE INVOLVED IN YOUR CARE.

MAINTAIN HOPE

*"Of all the forces that make for a better world,
None is so powerful as hope. With hope, one can think,
One can work, one can dream. If you have hope,
You have everything."*



The background is a blue gradient with decorative white circuit-like lines in the corners. The lines consist of straight segments and small circles, resembling a stylized electronic circuit.

Thank you for the privilege of
your time!

shirley.a.mertz@gmail.com

QUESTIONS?