



Metastatic Navigator

**A YOUNG ADULT'S
GUIDE TO LIVING WITH
METASTATIC BREAST CANCER**

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Introduction



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What is Metastatic Breast Cancer?

Metastatic breast cancer (MBC) is also called “stage IV” breast cancer. It may also be referred to as “mets” or “advanced breast cancer.” MBC is breast cancer that has left the breast and local area around the breast and has been found in other parts of the body, such as the bones, liver, brain and lungs.

Although MBC is not curable, with current advances in treatment, it may be treated on an ongoing basis and lived with for years.

A diagnosis of metastatic breast cancer (MBC) can be devastating. You may have had breast cancer before and know a lot about the disease already. Or, this could be your first cancer diagnosis, which means you have a lot of new information to process.

Perhaps the fact that you know so much adds to your anxiety. You may feel regret about your initial treatment decisions or betrayed by your doctors and your body. You might be concerned about how to disclose, and explain, what this diagnosis means to your family – your partner, your children and/or your parents. These are all normal, common feelings. **Many young adults with MBC have found that having good information, developing a plan of action and getting support from family, friends or other survivors can all be extremely helpful in coping with the disease and the changes it can bring.**

In the early days of an MBC diagnosis, it may be very helpful to speak with those who are living well with the disease. Doing so may help you cultivate a sense of hope. The YSC SurvivorLink program can connect you via telephone with another young adult living with metastatic disease. They can share their experiences, hope and empathy. You may also choose to participate in our Virtual Hangout specifically for young adults diagnosed with metastatic breast cancer. Contact YSC toll free at 877.972.1011 or email support@youngsurvival.org.

Welcome

A Note from Young Survival Coalition

You are not a statistic. You are not your prognosis. You are not your breast cancer. You are a young adult who has been diagnosed with metastatic breast cancer (MBC). Although you may feel afraid or uncertain, Young Survival Coalition (YSC) is here to help.

YSC created the Metastatic Navigator to educate and empower young adults diagnosed with MBC. We want to help you fight the feelings of fear and isolation that accompany such a diagnosis so that you feel connected, supported and hopeful. You may feel like you are the only young adult who has ever been diagnosed with breast cancer, but you are not!

While an MBC diagnosis at any age is life altering, young adults have unique issues and concerns. Inside this Navigator, you'll find easy-to-understand information, questions to ask healthcare providers, a way to track your medical information and helpful tips from young adults who've been down this road.

Take time to look over all the items in this Navigator. If you ever have any questions, comments or want to get involved, contact us at support@youngsurvival.org or call 877.972.1011.

We know this can be an overwhelming time. There is a great deal of information to digest and a wide array of emotions to manage. Go at your own pace, use the information and resources as you need them and, most important, feel free to contact us at any time. We'll help you understand your diagnosis, know your options, advocate for yourself, keep track of everything and know that you are not alone. YSC can also connect you to a trained peer mentor with a similar diagnosis. YSC is here to help you live well with MBC.

Sincerely,

Young Survival Coalition

I'm Like You, Living with MBC

Dear heart,
You are not alone.

This is a chapter of your life that could never be anticipated, never planned for, and there's hardly anything anyone can say to make sense of how you arrived here, holding this guidebook in your hands with questions and fears about your future. Know that you are not alone. Our wish is that these four powerful words will carry you forward in the months and years ahead, and offer you hope as you navigate your way through your new future.

As hard as it is to consider during these early days of diagnosis, I want to assure you there is good news on the horizon and remarkable advances being made in stage IV breast cancer treatment that are changing the landscape of our prognosis. We are starting to use words like "chronic disease" instead of "terminal disease," and we are seeing many, myself included, who are far outliving our initial dire prognosis and rapidly changing the outcome of future statistics.

Our new focus has shifted to finding balance and sustainability for ourselves and our loved ones as we seek to pace ourselves through long-term future treatment. We are coming together in communal support to share our experiences and lean on each other through periods of grief and loss, as well as celebrate moments of thriving in optimistic possibility.

I'm glad you're part of our community, where we are committed in heart and soul to making your journey as comfortable as possible, while helping you navigate through the many questions and fears you're experiencing. Your fellow survivors are your sisters, and we understand the uniqueness of your situation like no one else can.

You are not alone.

In harmony,
Katie Hogan
Stage IV since 2006





Disclaimer

Young Survival Coalition has provided this Metastatic Navigator for educational, informational and community purposes only as a resource to young adults and the people whose lives are affected by breast cancer. For specific answers to questions or concerns, you should consult your healthcare provider, as treatment for each patient varies with individual circumstances. The content is not intended in any way to be a substitute for professional counseling or medical advice. You should not rely upon information found in this publication without seeking the advice of a qualified healthcare provider. YSC does not endorse, recommend or make any warranties or representations regarding any of the materials, products or information provided by organizations referred to in this resource. Always seek the advice of your physician or other qualified health service provider with any questions you may have regarding a medical condition or treatment. Never disregard medical advice or delay in seeking it based on information you have read in this resource.

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GET TO KNOW YSC

Young Survival Coalition (YSC) was founded in 1998 by three young women who were under the age of 35 when diagnosed with breast cancer. They were discouraged by the lack of resources available and the underrepresentation of young adults in breast cancer research. Today, YSC is the go-to organization for young adults facing a breast cancer diagnosis.

Unlike their post-menopausal counterparts, young adults diagnosed with breast cancer face higher mortality rates, fertility issues and the possibility and ramifications of early menopause. YSC strives to educate, empower and connect young survivors, while advocating to increase the number of research studies about breast cancer in young adults.

Headquartered in New York City, YSC is the oldest and largest national organization focused exclusively on the unique needs of young adults affected by breast cancer. Along with its nationwide Face 2 Face networks and vibrant online community, YSC hosts the YSC Summit – the only conference dedicated to the unique issues of young adults with breast cancer. YSC also hosts Regional Symposia, and it produces free educational resources such as the Navigator series, which includes information about every phase of treatment and survivorship, and the online searchable database that connects young adults with organizations based on their location and needs.



YSC programs connect, educate and support young adults affected by breast cancer.



CONNECT TO OTHERS

Find others who know what it's like to face breast cancer at a young age. There are three easy ways to connect:

1. YSC Face 2 Face Networking

YSC Face 2 Face (F2F) peer-led networking groups bring together survivors in your local community. Groups can be based on location, similar diagnosis, interests or even age. To find a YSC F2F group near you or learn how easy it is to start one, visit youngsurvival.org/meet-in-person or call 877.972.1011.

2. YSC Private Facebook Group

Share experiences and information at any time of day or night — even from a smartphone. Connect online 24/7 at youngsurvival.org/forms/ysc-private-facebook-group.

3. YSC SurvivorLink

Get one-on-one peer support from a trained volunteer who shares a similar diagnosis, life experiences or concerns. To be connected or inquire about becoming a trained SurvivorLink mentor, call YSC's toll-free number at 877.972.1011, or email support@youngsurvival.org.



TOOLS YOU CAN USE

YSC offers free resources unique to young adults affected by breast cancer and those who care about them. Resources can be accessed online or mailed.

Knowledge is Power. Visit youngsurvival.org.

It's the most comprehensive resource for and about young adults with breast cancer. Find information on medical research and updates on clinical trials. Read survivor stories. Download fact sheets, learn about upcoming educational offerings and access podcasts on past topics.

ResourceLink

Access hundreds of national and local resources in a searchable online directory at youngsurvival.org/directory. Also, you can call 877.972.1011 or email support@youngsurvival.org for assistance.

Tour de Pink: Connect and Give Back

If you're looking to connect with other young adults affected by breast cancer, while also taking your body back, join us at the life-changing Tour de Pink bike ride. Challenge yourself, support YSC and meet others in this incredible community. Learn more at ysctourdepink.org.

YSC Summit and Regional Symposia

These conferences feature inspirational speakers and special wellness activities. They also include workshops that address concerns for others living with metastatic breast cancer and their co-survivors (relative, partner or friend). You'll have the opportunity to connect with a community of others managing metastatic breast cancer and their co-survivors. Find out more at youngsurvival.org/get-involved/conferences. There are even ways to receive financial support by applying for travel scholarships and fee waivers.

Virtual Programming and Online Chats

YSC offers virtual programming and chat forums for young adults with breast cancer. Past podcasts are available on the Audio and Video Library page of YSC's website. View additional videos and YSC news on YSC's YouTube channel. For more information, visit youngsurvival.org/learn.

Using the Metastatic Navigator

Staying organized during this uncertain time in your life isn't easy, but the more organized you are, the less overwhelming things will seem. As you learn to live with MBC, partner with your healthcare team and discuss treatment options, you will find it helps to have all of your notes, records and information in one place.

This Navigator has information to help you ask the right questions throughout your journey. It also has valuable tools and charts to help you keep track of your information and stay organized. Take the Navigator with you to appointments, especially at first. Use the space provided to take notes and track your medication and side effects.

IF THIS IS YOUR FIRST DIAGNOSIS OF BREAST CANCER: According to a recent publication, the number of young women diagnosed with MBC when they first present with breast cancer is increasing. Any diagnosis of cancer in a young adult is challenging, but being told you are stage IV or have MBC right away can be overwhelming. Because of the new terminology you may be hearing, we recommend that you order a free copy of YSC's "Newly Diagnosed Navigator" at youngsurvival.org/forms/print-resources-order-form. Although not all of it will be relevant, a background on the disease and terminology may be useful to you. Basics such as "what is breast cancer" are not covered in this Metastatic Navigator.

IF THIS IS NOT YOUR FIRST DIAGNOSIS OF BREAST CANCER: Bring copies of your medical records from your prior breast cancer diagnosis/diagnoses, if you have them, to your initial doctors' appointments, especially if you are seeing new doctors. It is important for your doctors to know the details of your prior diagnosis and the treatment you received. Your doctors will likely recommend that one or more areas be biopsied in order to determine whether your cancer has changed since your first diagnosis. For example, it is not uncommon for breast cancer that was estrogen receptor positive at initial diagnosis to return as estrogen receptor negative at the site of metastasis and vice versa.

Some Tips

ASK QUESTIONS. The more you understand, the easier the process will be. Take advantage of your healthcare providers and don't leave your doctor's office until all of your questions have been answered. Try to have another person with you at your appointments. This person can keep track of the questions, make notes and be an extra set of ears when things become overwhelming. You may also want to record your consultation, with your doctor's approval.

Do you have tattoos?

If you have one or more tattoos and your scans or tests suggest possible MBC, especially in your lymph nodes, be sure to mention your tattoos to your doctor. Also insist upon a biopsy to confirm the presence of MBC. Recent reports indicate that tattoo ink can go into the lymph nodes and may appear to be MBC during scans or tests, when it is really not.

OBTAIN COPIES OF EVERYTHING. A folder or binder may be useful. Some key information to ask for:

- Pathology reports
- Biopsy reports
- Scan reports
- Genetic testing
- List of medications
- Clinical trial documents
- Physician consultation reports
- List of appointments
- List of providers

WRITE IT DOWN. You will likely come up with questions and concerns at all times of the day and night. Keep a small notebook or this Navigator with you – at home, work, even next to the bed at night. That way, when a question hits you at 3 a.m., you can write it down and remember it for later.

DON'T GO IT ALONE. Call Young Survival Coalition. We provide a circle of hope and support for young adults with MBC. We are here for you, so no one diagnosed under 40 faces MBC alone – youngsurvival.org or 877.972.1011. While you may have plenty of friends and family, they may not fully understand what you're going through. Our SurvivorLink peer mentoring program and online video support group for MBC can connect you with other young adults living with MBC.

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Diagnosis



Understanding Your Diagnosis

Metastatic Breast Cancer (MBC) is breast cancer that has left the breast and local area around the breast and has been found in other parts of the body. MBC is also called “stage IV” breast cancer. It may also be referred to as “mets.” MBC is sometimes referred to as “advanced breast cancer,” although they are not the same. MBC is advanced breast cancer, but advanced breast cancer also can refer to some stage III cancers that are not MBC.

MBC is more likely to be found in the bones, liver, brain or lungs than other parts of the body, though it can be found elsewhere - including the gastrointestinal and gynecologic organs. Breast cancer that is found in one of these parts of the body is still made up of breast cancer cells and still called breast cancer. Breast cancer metastases, no matter where they are found in the body, typically will respond best to breast cancer treatments.

MBC diagnoses are often found by a symptom – perhaps a recurring pain or cough, shortness of breath, lack of appetite, headaches or an injury. It is also possible to learn of metastases through routine scans.

MBC is generally not curable. Once metastases have been found, treatment becomes focused on stopping or slowing the spread of the cancer for as long as possible. Occasionally the treatments cause the disease to disappear for some period of time. This is called “no evidence of disease” or NED. The goal is to increase length of survival and maintain a good quality of life. Some do far outlive their prognoses, and their disease can be managed with a high quality of life for years.

A small percentage of women with MBC may remain NED indefinitely after treatment. New treatments are being developed all the time, and the hope is that as current treatment stops working, new ones may come along that increase the length of survival. MBC is a disease that must be continually treated but with which a person can live for quite some time. There is reason to be hopeful.



5% to 9% of women who are diagnosed with breast cancer for the first time are diagnosed with MBC.

If you are among this group, in addition to reading about MBC, you may also need to learn the basics of breast cancer. Order a free copy of YSC's "Newly Diagnosed Navigator" for basic breast cancer information at youngsurvival.org/forms/print-resources-order-form.

Tests to Determine Extent of Metastatic Disease and Response to Treatment

To assess the situation at diagnosis, and throughout your treatment, a number of tests will be performed. Initially, these will help to determine where the metastases are located. As you continue your treatment, tests will assess how effective the treatment is at shrinking the cancer or keeping it from growing.

Diagnostic scans are performed to find out if you have MBC and the extent of it. The scans also measure response to treatment or progression of metastatic tumors. If you have been through a diagnosis of breast cancer in the past, you may already be familiar with the different types of scans.

No matter how many times you have been through a scan, there is often anxiety involved in either the process itself or waiting for results – this is normal.

Answering some of the following questions about the process and the time involved may help to lower anxiety. Consider how you would like your scan results communicated to you and if it helps to reduce the amount of time it will take to receive your results. Is a phone call better than waiting for an in-person appointment? Is it okay for your doctor to leave results on a voicemail or send you an email? If you are being scanned right before a holiday, do you want to receive your results beforehand or do you prefer to wait until after the holiday? Can you have a scan in the morning and have the results given to your doctor later that day?

Remember, you are an important part of your healthcare team, and expressing your preferences may help you better manage any anxiety you experience.

Your doctor may be able to do some scans in his or her office area, or you may be sent to a radiology center or hospital for tests. When scheduling additional scans, some doctors

No matter how many times you have been through a scan, there is often anxiety this is a normal reaction.

might encourage you to use the same testing facility or even the same scanning machine. This may increase consistency in your scan reports. It is not always possible to do scans at the same facility as previous scans. If you need to change facilities for any reason, be sure to obtain a copy of your prior scan report and images (usually a CD). Then you can bring it to the new facility, so the radiologist can compare. This can sometimes help avoid confusion and unnecessary biopsies.

You do not need to understand fully how to read your scans, but understanding what they show is helpful. Your scans are normally examined by both a radiologist and your oncologist, and the radiologist will include a report on the findings. Don't be surprised if he or she notes unessential information that doesn't pertain to your diagnosis (for example "unable to visualize the left ovary"). You can often obtain a copy of your scans on a disc, in addition to the paper report and the pictures.

Some of the most typical types of scans and tests used to assess MBC are listed below. Certain scans and tests may have specific instructions (for example, fasting), so be sure to follow your doctor's instructions to prepare for the scan or test.

Bone Scans

Bone scans are used to see if cancer has spread to the bone. In a majority of cases of MBC, the bones are the first area of metastases. Bone scans look at the bones for "hot spots" that may be cancerous/have cancer or are the result of old injuries. The scans give doctors a place to start and help to determine which further tests to do. Bone scans require an injection of a radioactive dye and then waiting for a period of a few hours for the dye to move through the bloodstream before having the scan.

Chest X-Ray

Lung metastases rarely cause pain, but they can cause shortness of breath or a cough that won't go away. A chest x-ray can be used to determine if breast cancer that has spread to the lungs is the cause of these symptoms or if there is a different cause.

CT or CAT Scan

A Computerized Tomography or CT/CAT scan is a more detailed x-ray of the body. A contrast dye is either ingested or injected into the vein. A computer rotates around the body, creating a three-dimensional image of the body. CT scans are usually used to look for metastases in the brain, lungs and liver.

MRI

An MRI (Magnetic Resonance Imaging) machine uses radio waves and a powerful magnet linked to a computer to take three-dimensional pictures of the body. The pictures show if there is cancer in the area of the body that has been scanned. An MRI will require you to lie down in a tube-like machine and can take 40 minutes or more. MRIs are often done both with and without contrast dye. Typically, you will have an IV placed in a vein in your arm before entering the machine. Images will be taken without any contrast dye. Then, contrast dye will be injected through the IV and additional images will be taken. Some people may feel claustrophobic while inside the machine. If this is a concern for you, talk to your healthcare team about how to make the test more comfortable for you.

PET Scan

A Positron-Emission Tomography, or PET scan, monitors glucose use in specific body tissue. Cancer cells use more glucose than normal tissue. Before the scan, radioactive glucose called a “tracer” is injected into a vein. A computer takes images and analyzes where the glucose is being used the most. PET scans may be able to detect cancer that other tests cannot. Certain organs also normally uptake more glucose.

PET CT Scan

A combination of the PET and CT Scans described above, performed at the same time, can present a more detailed image of the presence or extent of cancer in the body. Normal tissue glucose uptake and abnormally high uptake by cancer cells usually appears very different on PET/CT, although on occasion non-cancerous lesions or areas of inflammation may have high uptake.

Blood Tests

There are three different blood tests that may be used to detect breast cancer. The CA 27.29 blood test measures the level of CA 27.29 that may be found in the blood of some individuals with breast cancer. In theory, the level rises as there is more breast cancer in the body. The CA 27.29 test can be helpful in determining if cancer is growing in the body, so it can help doctors know if treatments are working. The CA 27.29 may not be a reliable test in the case of every woman, and the results of the test may fluctuate within a range. For these reasons, the CA 27.29 test is used to determine trends over time and is not typically used as a diagnostic test on its own. Similar tests that may be used are the CA-15-3 and CEA (carcinoembryonic antigen).

Circulating tumor cells (CTCs) may also be measured through a blood test. CTCs are extremely rare in healthy individuals and patients with nonmalignant diseases but are often present in people with metastatic cancer. Some clinical studies indicate the assessment of CTCs can assist physicians in monitoring and predicting cancer progression and in evaluating a patient's response to therapy. Tumor markers may be falsely elevated or they may be normal in patients with metastatic disease. CTC testing and use is still in the experimental stage.

Blood tests such as a comprehensive metabolic panel and a complete blood count (CBC) panel may indicate that breast cancer has spread to the liver and bones. These tests may help your doctor determine how your organs are being affected by your treatments.

Biopsies

Your doctor will want to biopsy, if possible, one or more of the abnormal tissue growths in your body to determine their characteristics (including whether they are malignant or benign), which will aid in making treatment decisions. A biopsy is the surgical removal of all or part of an abnormal tissue growth, using a specific type of needle device or surgery. Most often, image-guided needle biopsies are performed first for suspected mets rather than surgical biopsy. The abnormal tissue growth is then examined by a pathologist. For more information about your pathology report, see page 24.

Genomic Testing

Your doctor may want to perform genomic testing on your tumor to gain a better idea of its subtype and driving mutations in the tumor genes. Understanding the genetic changes or mutations that make up your tumor may help determine which treatments you may benefit from. Genomic testing is sometimes referred to as tumor sequencing. There are various tests available, and your doctor will discuss them with you if they may help with treatment decisions.

Disease Characteristics

It is important to understand the disease characteristics of your breast cancer. Your disease type will determine what treatments will work best against your cancer. While metastases often have the same characteristics of the initial breast cancer, they don't always. Your doctor will likely order a biopsy of the metastases, if it is possible to conduct one, to be sure that the treatments given are right for your specific breast cancer.

Estrogen and Progesterone Receptor Status

Estrogen receptor positive (ER+) and progesterone receptor positive (PR+) breast cancers are stimulated to grow by the hormones estrogen and progesterone. ER/PR+ breast cancer is the most common type of breast cancer, accounting for the majority of breast cancers. These breast cancer types are more likely to metastasize to bones, lymph nodes, pleura and peritoneum. Endocrine treatments either reduce or block hormones that are circulating in the body that can feed a ER/PR+ breast cancer. This slows or stops the growth of the cancer. Ovarian suppression and ablation, which shut down the ovaries temporarily or permanently, is another hormonal therapy that may be used to stop the body's production of estrogen. See pages 39 and 49.

HER2/neu Status

HER2/neu (or HER2) is a protein that is over-expressed in approximately 20% of breast cancers. When too much of this protein is produced, the tumor is considered HER2 positive (HER2+). HER2+ breast cancer is more likely to metastasize to the liver and brain.

There are two ways to check a tumor for HER2 expression. The first is called immunohistochemistry (IHC). It uses an antibody to HER2 to stain cancer cells – cells that have a lot of HER2 protein on their surface will stain strongly for



HER2 expression. With this test, tumors are described by how strongly they express HER2. By IHC, a result of 0 or 1+ is considered negative. A result of 3+ is considered positive. A result of 2+ is considered borderline or “equivocal.”

The second test for HER2 is called fluorescence in situ hybridization (FISH). This test looks at the number of copies of the HER2 gene that cancer cells carry, and compares this to the number of copies of chromosome 17 that the cells carry. Chromosome 17 is where the HER2 gene is located. The result of the FISH test is a ratio of HER2 to chromosome 17 (CEP 17). Normally, cells carry two copies of the HER2 gene and two copies of chromosome 17, so the ratio is 1. If the ratio is 2.2 or higher, the tumor is considered HER2+. A ratio of less than 1.8 is considered negative, and a ratio between 1.8 and 2.2 is equivocal or borderline.

There are currently a number of HER2-targeted therapies that are FDA approved for treatment of breast cancer, and often treatment with these agents is very effective.

Triple Negative Breast Cancer

Cancer that is not ER, PR or HER2 positive is said to be “triple negative.” Triple negative breast cancer is more common in young women, women of color, and women with a BRCA1 mutation. Triple negative breast cancer is almost always treated with chemotherapy, but research into targeted therapies is ongoing. Triple negative breast cancer is more likely to metastasize to the liver, lungs and brain. It has been determined that different subtypes of triple negative breast cancer exist. Some types of triple negative breast cancer that have been identified are androgen receptor positive, basal-like and BRCA-mutated. Current research and clinical trials are examining how these subtypes differ, if different treatments work better for each subtype, and whether the subtype affects prognosis.

Questions to Ask to Better Understand Your Diagnosis

Here are some proposed questions that may help you understand your diagnosis. Not all questions may apply to your situation:

- What is my exact diagnosis?
- Which tests were used to confirm this?
- Where are the metastases?
- How many areas or sites are involved?
- What is already known, and what additional follow-up investigation is required?
- Have the metastases been tested to determine the type of breast cancer they may be?
- Has it been confirmed that this is MBC? Is it the same type I had before? How will the differences change my treatment decisions?
- Has the hormonal status of my breast cancer changed?
- If there are additional tests to take, how will they affect my course of treatment?
- How can I learn more about my particular diagnosis?
- Is genetic testing appropriate to consider given my age at diagnosis or other factors?

Being open with your healthcare team is one way to ensure you get the best care possible. Of course, disclosing sexual orientation or gender identity is always a personal choice, but it can also help improve the healthcare you receive. If you are LGBTQ, and would like to let your healthcare team know, there's a chance you may need to start the conversation. If the subject does not naturally come up during the course of care or your healthcare provider does not ask you directly, bring it up when you feel the most comfortable. Let your healthcare provider know there is something you would like to talk to them about to get the conversation going. If you do not feel supported by your healthcare team, you may wish to seek other physician recommendations from the LGBTQ cancer community. Check out the National LGBT Cancer Network's Provider Database: cancer-network.org/out-and-surviving/.

Your Pathology Reports

Pathology reports are created after a tissue specimen, obtained during surgery or biopsy, is examined under a microscope. Your pathology report can be a major source of information. Familiarizing yourself with this essential piece of your medical history will help you discuss your options with your healthcare provider.

Your pathology report is a collection of information that describes your cancer. Its purpose is to provide your healthcare team with information about a surgical specimen or tissue sample. The information is then used to determine the exact nature of the specimen (cancerous vs. non-cancerous)

and the characteristics of the tissue sample. The description of its characteristics (some of which were discussed above) will give you and your physician(s) information about aggressiveness and possible treatment options. Because your pathology can change from your original or previous diagnosis, your doctor will likely biopsy new sites of metastasis, if it is possible to do so to

determine their characteristics and identify appropriate treatment. For help reading your pathology report, see the Diagnosis section of YSC's "Newly Diagnosed Navigator."

Ask for a copy of your pathology report following biopsy, surgery or at any time. This way, when it is time for a follow-up visit with your surgeon or oncologist, you can be ready to ask questions. Some pathologists are willing to go over the report with the patient. When you get your pathology report, make copies and keep them with your other important medical records. Consider bringing along a copy of your pathology report when consulting with your physicians.

What is a pathologist?

A doctor who identifies diseases and assesses its characteristics by studying cells and tissues under a microscope.

Additional Resources

Here is a partial list of additional resources that may aid your understanding of your diagnosis. For a more complete list, visit YSC's searchable online Support directory at youngsurvival.org/directory.

100 QUESTIONS & ANSWERS ABOUT ADVANCED AND METASTATIC BREAST CANCER, 2ND EDITION

Lillie D. Shockney, RN, BS, MAS and Gary R. Shapiro, MD (Jones & Bartlett Learning, 2012)

By giving both the doctor's and patient's views, this book provides authoritative, practical answers to your questions about the medical, psychological and emotional aspects of MBC.

ADVANCED BREAST CANCER: A GUIDE TO LIVING WITH METASTATIC DISEASE, 2ND EDITION

Musa Mayer (Patient-Centered Guides, 1998)

This book deals honestly with the realities of metastatic disease, yet offers hope and comfort.

BCMETS.ORG

The largest online listserv to offer support and information for women living with MBC, their families and friends.

BRAINMETSBC.ORG

This website offers women with MBC and their families a place to learn about brain metastases from a patient perspective. The information on this website may be viewed in English or Spanish.

THE INSIDER'S GUIDE TO METASTATIC BREAST CANCER, A SUMMARY OF THE DISEASE AND ITS TREATMENTS

Anne Loeser, 2019

The Guide provides science-based information in a format that is easy to understand and includes detailed information about treatment options and side effects. Order online or download on the MBC Alliance website: mbcalliance.org/the-insiders-guide-to-metastatic-breast-cancer.

NATIONAL COALITION FOR CANCER SURVIVORSHIP

[canceradvocacy.org/resources/
pocket-care-guide](https://canceradvocacy.org/resources/pocket-care-guide)

This iPhone app allows you to generate lists of questions to ask your doctor and record the answer, along with a glossary of terms. More information is available at the link above and in the App store.



METASTATIC BREAST CANCER ALLIANCE

mbcalliance.org

The MBC Alliance is a group of breast cancer nonprofits and industry partners seeking to improve the lives of and outcomes for those living with MBC and their families through increasing awareness and education about the disease and advancing policy and strategic coordination of research funding specifically focused on metastasis that has the potential to extend life, enhance quality of life and ultimately to cure the disease.

SAY YES TO HOPE

Survivor Hotline: 877.937.7478 (US only)
info@SayYESToHOPE.org

SayYESToHOPE.org

Focused on liver cancer and other cancers that have spread to the liver, this nonprofit provides treatment information, online and telephone support, and resources.



Decisions

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Making Treatment Decisions

When making treatment decisions, it is normal to feel overwhelmed by all of the new information you are learning about your diagnosis and treatment options.

You should feel empowered to ask questions, gather information on your own, seek second and even third opinions, and generally advocate for yourself and what is important to you.

There are many ways to treat MBC, and even the leading experts may not treat the same breast cancer in the same way. Use these options to your advantage. When offered a treatment recommendation, ask your doctor what information he or she used to make the decision. Is there hard scientific evidence that this is the best possible treatment for your situation?

Treatment plans should be created with an excellent team of specialists. They should take into account your specific breast cancer, the part(s) of the body to which your cancer has metastasized, your treatment history, and what is best for your quality of life, priorities and health status.

Be sure to speak with your doctor about whether there are clinical trials that may be appropriate for you.

Getting Informed

Do your research. Breast cancer treatments change quickly, with new advances occurring regularly. Periodically ask your doctor for an update on treatment changes in the time since your initial diagnosis.

The Internet can be an excellent source of information, but be careful about your sources. The safest way to be sure that you are getting good information is to choose websites that are connected with organizations you know and trust. One major factor in the quality of information on the Internet is how recently it was written or updated. Even well-meaning sources can provide poor or outdated information if they are not able to maintain it. Rely on credible sources only, such as the National Cancer Institute at [cancer.gov](https://www.cancer.gov). Reach out for support and information. Survivors and support groups are often very knowledgeable.

Keep communicating, asking and learning. Join a listserv for women with MBC that focuses on treatment information and the latest research at [bcmets.org](https://www.bcmets.org). Metastatic Breast Cancer Network (MBCN) is an advocacy group dedicated to the unique concerns of women and men living with MBC. Find them at [mbcn.org](https://www.mbcn.org). The Metastatic Breast Cancer Alliance and METAvivor also advocate for more research on MBC at [mbcalliance.org](https://www.mbcalliance.org) and [metavivor.org](https://www.metavivor.org).



Your Healthcare Team

You are the most important part of your healthcare team. You should always feel comfortable asking questions, asking for information to be repeated if you do not understand it and making sure you understand the rationale behind the treatment. As part of your own healthcare team, you are working with your doctors to treat your breast cancer. How you communicate and make decisions with your doctors is important, so make changes if you are not satisfied with how you are receiving information.

Evaluate your medical team. If you have just been re-diagnosed, do you want to see the doctors from your previous diagnosis again, or would you like to take this opportunity to change doctors? How much experience does your team have in treating your type of MBC in young women? How comfortable are you communicating with your healthcare team? How available are your doctors if you need to call or email with questions or concerns? YSC recommends that young women seek care from a comprehensive cancer center or large teaching hospital that has experience in the unique issues and needs of young women. In many cases, you can get a second opinion from a doctor at one of these centers. If it is too far to travel for regular treatment, they will coordinate your care with your local doctors. Search the list of National Cancer Institute (NCI)-designated Cancer Centers at cancer.gov/research/nci-role/cancer-centers/find to find a list of comprehensive cancer centers across the country. Make sure to check your insurance and understand its coverage for out-of-network providers.

There are important things to consider when building a new healthcare team:

- Ask for recommendations from friends you trust, a nurse or doctor with whom you have a good relationship or anyone else who may have some insight.
- Consider communication and working styles, and know what is most important to you. How do you work best? Do you want someone who has a great bedside manner and time for a lot of questions? Some doctors will develop treatment plans and go over them with you so that you can make the ultimate decision, while others will provide you with their decisions. You may prefer either of these methods.

- When possible, include a doctor in your care team who specializes in metastatic breast cancer. Consider seeing someone who can take the time to read up on all the latest treatments in breast cancer and have his or her finger on the pulse of new standards of care, rather than a generalist who may have to keep up with all treatments for many different cancers.

There are several professionals who treat breast cancer and provide support throughout the process. Some important members of your healthcare team are listed below.

Medical Oncologist

The medical oncologist is a physician who will work with you to determine your course of treatment. You will have regular appointments with this doctor. During these appointments, you will discuss how well treatments are working, and you will discuss changing treatments, if necessary. You will also go over the results of any tests that may show how well the treatments are working and discuss changing treatments, if necessary.

Radiation Oncologist

The radiation oncologist is a physician who treats breast cancer with radiation.

Radiologist

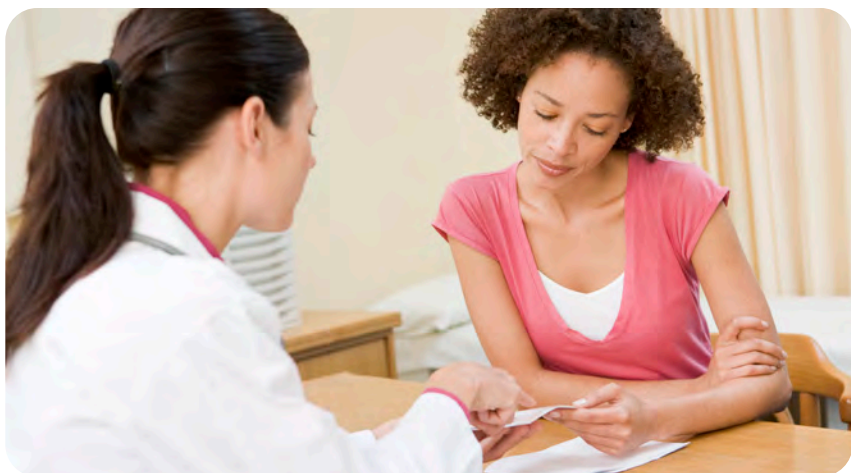
A radiologist is a doctor who reviews and interprets the results of imaging tests like the ones described in the Glossary of this Navigator.

Surgeon or Surgical Oncologist

The surgeon or surgical oncologist is a physician who treats breast cancer with surgery.

Palliative Care Specialist

Palliative care doctors and nurses work with the oncologists treating your breast cancer to manage and treat the symptoms and side effects of your cancer and treatment. They may be able to assist you with managing any pain that you are experiencing.



Genetic Counselors

Genetic counselors will assist your medical team in determining what genetic tests, if any, should be performed to determine whether you have inherited gene mutations that increase your risk of developing cancer. Genetic counselors can also advise on which family members should be evaluated for gene mutations. They will also assist in interpreting the results of genetic testing and can providing counseling to you and your family members.

Oncology Nurse

Oncology nurses are key people in your care, administering chemotherapy and other cancer treatments. The oncology nurse will help educate you about your treatments. He or she can also provide a level of support that doctors may not have time for and answer questions you may have between appointments.

Oncology Social Worker

The oncology social worker helps you with the emotional aspects of cancer, as well as the issues that may come up in daily life, such as financial needs and family issues. The oncology social worker can provide individual or family counseling and may run support groups at the hospital. He or she can be a great resource to guide you through the process and help you resolve issues that develop because of your cancer and treatment.

Others

Depending on where you are receiving your treatment, you may also have other professionals available to help you, including a **nurse practitioner** who may see you if your oncologist or other doctor is unable to do so. Nurse practitioners can do many of the same things as doctors, including prescribing medication. **Nurse navigators** and **patient navigators** also can assist you in coordinating your care and appointments. Ask your medical center who is available as resources to you. Your **primary care physician** should also be kept updated, and he or she can be another source of information, medical care and support. It is also a good idea to incorporate an **individual or family counselor, therapist or psychologist** into your team. It is crucial for young women with MBC to work through feelings related to their diagnosis and any feelings of grief or loss, which will be very different from what early stage breast cancer patients experience. A **nutritionist** can assist you with managing the side effects of cancer treatments, such as loss of appetite and weight loss or gain. The use of an **integrative oncologist**, who combines conventional cancer therapies with evidence-based complementary and alternative therapies, is also becoming more common. See more on complementary therapies on page 59 of this Navigator.

Questions to Ask Your Healthcare Team

Here are some proposed questions that may help. Not all questions may apply to your situation:

- How many young women with MBC have you treated?
- How do you keep up with the latest treatments?
- How can I be sure to get all of my questions answered during appointments? Is it best to bring a list to my appointment or email questions before or afterward?
- How can I get questions answered between appointments?
- On what evidence do you base your treatment decisions?
- Are you open to considering clinical trials?
- Can you tell me more about your palliative care services and will I be assigned a team?

Genetic Testing

Being diagnosed with cancer at a young age can be a significant sign of a possible genetic link.

Genetic testing can identify gene mutations that you have inherited, such as BRCA1 and BRCA2, ATM, CHEK2, PTEN and PALB2 mutations. There may be treatment options available to you based on these mutations. Knowing your inherited gene mutations may help you make treatment decisions and decide on possible steps to reduce the risk of other cancer occurrences.

Genetic counselors will help you determine which genetic tests are appropriate for you and will help you understand the results of your genetic tests. Oncologists and cancer centers can direct you to the genetic counselor affiliated with your facility. Additionally, the National Society of Genetic Counselors offers a directory of genetic counselors by state and specialty. Visit nsgc.org for more information.

Knowing your inherited gene mutations also helps your family members determine their need for genetic testing, earlier screening and risk reduction approaches.

Sometimes it is not possible to collect your full family history. Perhaps you are adopted or do not have contact with certain family members. Share what you do know with your care team or genetic counselor. They will help you to determine next steps.

Additional information on family history and genetic counseling can be found in YSC's "Newly Diagnosed Navigator."

Check out youngsurvival.org for programs and discussions on this topic. Audio files and videos are available.



Treatment

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Understanding Your Treatment Options

Treatments for MBC may be similar to treatments for early-stage breast cancer. Treatments are generally dictated by the characteristics of the breast cancer, such as hormone receptor status or HER2 status, and the location of known metastasis (where the cancer has spread). Treatments for MBC aim to shrink or stabilize the tumors that are found and to prevent new tumors.

In general, metastatic disease will be treated with one therapy after another, continuing with each one for as long as it remains effective. If one course of therapy stops working, there are additional therapies that will be used to try to stabilize the disease. MBC treatments are often referred to as “first-line,” “second-line,” “third-line,” etc.

A first-line cancer treatment is one that is used as an initial treatment for metastatic disease. A second-line treatment is used after a first-line treatment stops working or cannot be used. Third-line treatments are employed only after other treatments have stopped working or cannot be used.

Closely monitoring and changing treatments when necessary may stabilize the disease for a long period of time. Many patients find changing treatments to be stressful and unnerving. That is normal. Have thorough discussions with your oncologist about the benefit of changing treatment at this time, the possible side effects and what to expect. Having as much information as possible can help ease some anxiety.

“With many new treatments coming out faster and faster, many of us are living longer and with better quality of life with MBC than ever before. We are the new stats!”

-Dikla B., MBC thriver

Factors in Treatment Decisions

The two biggest factors in your treatment decisions will be the characteristics of your breast cancer and the location of your metastases.

Characteristics of MBC

The characteristics of your breast cancer will determine the type of treatment that could be effective for you. Examples include hormone receptor status (if your breast cancer is ER and/or PR positive) and HER2 status. Other characteristics of your cancer could determine the success of targeted therapies or immunotherapies.

Treatments for MBC fall into two categories: **systemic treatment** for the whole body and **local treatment** that treats one specific part of the body. Your breast cancer type will determine the systemic treatments you receive. Systemic treatments will treat metastatic disease wherever it is present in the body and include hormonal therapy, targeted therapy, chemotherapy and immunotherapy. The location of your mets will determine the local treatments that you receive, if any. Surgery and radiation therapy are considered local treatments.

First-line therapy for **ER/PR+ MBC** is hormonal therapy (also referred to as endocrine therapy), which will be used as long as possible. Many hormonal therapies are available. In these cases, chemotherapy is typically used only when endocrine therapy stops working. Targeted therapies may be paired with hormonal therapies as a first- or subsequent-line treatment in hormone positive breast cancer. Many pairings of hormonal therapy and targeted therapy are under investigation in clinical trials.

First-line therapy, as well as all subsequent lines of therapy for **HER2+ MBC**, involves the use of targeted anti-HER2 therapies. There are many different anti-HER2 therapies that are available to patients with HER2+ breast cancer, and more are under investigation in clinical trials. HER2+ breast cancers that are also ER/PR+ will also be treated with hormonal therapies. Chemotherapy may be used alongside anti-HER2 therapies, as well.

Typical first-line and subsequent lines of treatment for **TRIPLE NEGATIVE** MBC involve chemotherapy, with multiple single agents and combinations available (although combinations are used less frequently). Multiple clinical trials are currently in process testing targeted therapies and immunotherapies in triple negative MBC.

For all types of metastatic breast cancers, clinical trials give patients the option to try treatments that may be an improvement over the current best practice. Clinical trials may give some access to treatments years before they become approved and widely available. We especially encourage metastatic breast cancer patients with triple negative disease to seek out clinical trials. For more information on clinical trials, see page 52.

Location of MBC

BONE METASTASES are the most common type of breast cancer metastases. Bone mets can cause pain, fractures and high levels of calcium in the blood (hypercalcemia). A list of common bone targeted therapies is on page 50. The purpose of these therapies is to strengthen the bone, delay or prevent breaks, slow bone mets growth, lower the amount of calcium in the blood and alleviate pain. In addition, if the bone mets are causing pain, radiation may be used to lessen the pain. Radiation also helps shrink the mets and improve bone strength. Treatment of broken bones, insertion of a metal rod for a bone at risk of breaking, or injection of bone cement into a fractured vertebra may also be needed.

LIVER METASTASES can occasionally be removed, but usually they are managed with medications to control their growth. If there are relatively few or isolated liver metastases, surgery may be used to remove them. Radiation may also be used. Other options are radiofrequency ablation or cryosurgery. These treatments kill cancer cells with heat and freezing temperatures, respectively. Usually, however, liver metastases are managed with chemotherapy, targeted therapy and/or hormonal therapy, particularly if they are large or there are many of them.

Not all MBC patients will have the same disease course. It will vary greatly depending on the type of breast cancer you have and the location of metastases. What is appropriate treatment for someone else may not be best for you.

Similar to liver metastases, **LUNG METASTASES** can occasionally be removed, but they are more often treated to control growth. Isolated metastases may also be treated with radiation. Lung metastases are also treated with systemic therapies, like chemotherapy, targeted therapy and hormonal therapies, depending on the MBC characteristics.

The number and location of **BRAIN METASTASES** play a role in the decision about how to proceed. If there are relatively few tumors or a large tumor impacting surrounding tissue, surgery or stereotactic radiosurgery (such as Gamma Knife) may be used. Whole brain radiation may be recommended in patients with multiple brain mets, especially if they are large.

The brain is protected from infections and potentially toxic substances by a special network of blood vessels with closely spaced cells. This is called the “blood-brain barrier.” Not all systemic treatments can cross the blood-brain barrier. There is evidence that some already-approved chemotherapeutic drugs, some targeted therapies for HER2+ breast cancer and PARP inhibitors may be able to cross the blood-brain barrier and may be potential treatment options for brain mets.

Some chemotherapies and targeted therapies (alone or in combination) may be able to penetrate the blood-brain barrier. Clinical trials of these treatments are ongoing.

“The best way to deal with MBC is as part of a community filled with nurturing, supportive and helpful souls, including peers who share your experiences, whether they already exist in your social, work, spiritual and family circles or whether you create a new nurturing and supportive network for yourself.”

-Dikla, diagnosed with MBC 17 years ago, at age 32

Systemic Treatments

Systemic treatments treat the whole body to reach all the cancer cells that may exist anywhere in the body. Once breast cancer has spread to one part of the body outside the breast, it is likely that it has spread to other places where it may be too small for any tests to detect. Systemic treatments fall into four categories, which are described in this section.

Which treatments will work for you depends on the type of breast cancer you have. It is important to test at least one metastatic site to identify whether the metastases are the same type of cancer as any previous breast cancer diagnoses. In most cases, the pathology of the cancer will be the same as in an initial diagnosis, but there are instances where the make-up of the cells has changed. For example, a cancer that was ER+ in the past may become ER- at the site of metastasis.

The four categories of systemic treatment are:

Chemotherapy

Chemotherapy drugs are treatments that disrupt cell functions in order to stop the cancer cells from growing and dividing. Chemotherapy is a systemic therapy, which means it affects your whole body, including your cancer cells at your tumor site and those cancer cells that may be circulating throughout your body. It often targets rapidly dividing cells, which makes it effective against cancer cells because they divide more quickly and erratically than normal cells. But chemotherapy may also affect some healthy cells, leading to physical side effects.

There are many chemotherapy drugs that work to treat MBC in different ways. They are commonly grouped into several categories corresponding to how they work in your body and affect cancer cells. The main classes are alkylating agents, anti-metabolites, anti-tumor antibiotics, plant alkaloids and anti-microtubule agents. A list of commonly used chemotherapy agents is included on page 48.

In accordance with National Comprehensive Cancer Network (NCCN)

guidelines, chemotherapies are generally given sequentially, meaning one at a time, although chemotherapy combinations may be used in select patients. This may be the case for patients with high tumor burden, rapidly progressing disease and visceral crisis (severe organ dysfunction). Chemotherapies can also be used in combination with targeted therapy like anti-HER2 therapy in HER2+ breast cancer. Chemotherapy is currently the primary treatment for metastatic triple negative breast cancer.

Not all chemotherapies have the same side effects. Common effects include hair loss, nausea, decreased white blood cell count and risk of infection, as well as mouth sores, absence of menstruation (amenorrhea) and numbness or pain in hands and feet (neuropathy). This can vary within a class of drugs (a group of drugs that acts in a similar way) and with each drug. Note that not all chemotherapies used to treat MBC will cause hair loss, which is a common concern for patients. Talk with your oncologist about your options for managing other potential physical effects of chemotherapy. Not everyone experiences chemotherapy the same way, and not every person will feel the same way. If you have taken a specific chemotherapy before, keep in mind that there may be new treatments to manage side effects that were not available to you in the past.

Hormonal Therapy

Hormonal treatments, also known as endocrine therapies, are systemic therapies that target breast cancers that grow in the presence of estrogen and/or progesterone (ER+ and/or PR+). Hormonal therapy is often the first line of treatment for hormone-positive MBC. If a particular hormonal therapy ceases to be effective, patients will likely be switched to a different one. The various types will be used for as long as possible, until they are no longer effective.

Since hormonal treatment for early stage breast cancer usually continues for five to 10 years, it is possible to be diagnosed with MBC while still undergoing hormonal treatment for a prior early stage breast cancer diagnosis. In that case, your doctor may switch you to a different hormonal treatment.

As a young adult, it is important to know for sure if you are premenopausal or in permanent menopause, because this will determine which hormonal therapies are options for you. The absence of a period is not the same as being in definitive menopause. If you have previously been treated for early stage breast cancer and ceased to have a period following treatment, you may be in a temporary state of menopause. It is important to carefully monitor your menopausal status when using these treatments, if you are not in definitive menopause. Monitoring may include serum testing of levels of the hormone estradiol to help determine your menopausal status.

The goal of hormone treatments is to block estrogen from binding to cancer cells or to decrease the amount of estrogen in your body, since these types of cancer are “fed” by estrogen. Tamoxifen, for example, is a part of a class of drugs known as **selective estrogen receptor modulators (SERMs)** that may be used regardless of menopausal status. SERMs stop estrogen from binding to receptors on breast cancer cells. Two classes of drugs known as **aromatase inhibitors (AIs)** and **selective estrogen downregulators (SERDs)** may be used only in post-menopausal adults or those who have been put into menopause. AIs include Arimidex (anastrozole), Aromasin (exemestane) and Femara (letrozole). These drugs work by blocking the aromatase enzyme and thereby lowering the amount of estrogen made in tissues of the body other than the ovaries. The drug Faslodex (fulvestrant) is a SERD, which binds to the estrogen receptors and blocks estrogen from binding to the receptors. A list of hormonal treatments is included on page 49.

Your doctor may also recommend **ovarian suppression** or **ovarian ablation** as treatment options to lower hormone levels in your body.

It is possible to be put into menopause temporarily through ovarian suppression, which is the process of shutting down the ovaries with an injection of either gonadotropin (GnRH) or luteinizing releasing hormone (LHRH) agonists. A GnRH or LHRH agonist is a hormonal therapy that temporarily puts the body into immediate menopause. This can cause side effects similar to menopause symptoms, such as hot flashes, decreased sexual desire and absence of menstruation (amenorrhoea). Speak to your doctor about how to manage any menopausal symptoms.

Removing your ovaries, also known as ovarian ablation, with a surgical procedure known as oophorectomy will put you into a state of permanent menopause. Oophorectomy may be recommended as a part of your treatment for MBC, or you may choose to undergo ovarian ablation instead of ovarian suppression. Your doctor can help you decide between ovarian suppression and ovarian ablation.

The possible side effects of hormonal therapies vary for the different classes. Tamoxifen may include hot flashes, vaginal discharge, nausea, fatigue, blood clots and depression. AIs may cause joint pain, osteoporosis, hot flashes and fatigue. And fulvestrant may cause nausea, headache and abdominal pain, for example. Ovarian suppression and ovarian ablation will put you into a state of menopause, in which you may experience symptoms of menopause mentioned above. Early menopause will also put you at risk of osteoporosis. Speak to your doctor about how to best manage the side effects of hormonal treatments and menopause.

Targeted Therapies

Targeted therapies are biologic agents that target specific aspects of cancer cells, such as proteins that stimulate cell growth. Targeted therapies only work on tumors that express the specific characteristics that are targeted by the therapy. For example, one that targets a protein that stimulates cell growth will only work if the tumor over-expresses that specific protein. There have been major advancements in targeted therapies in recent years, and it is likely that targeted treatment use will increase in the future. These treatments only work on specific types of breast cancer, so a targeted treatment that works for one person may not work well for another.

Targeted therapies are often used for HER2+ MBC. First-line therapy, as well as all subsequent lines of therapy for HER2+ MBC, will involve the use of **anti-HER2 treatment**. These treatments are typically monoclonal antibodies, which are antibodies that recognize and attach to specific proteins in cancer cells. The most commonly used targeted anti-HER2 therapy today is Herceptin (trastuzumab), which has had a significant impact on survival since its approval for use in metastatic breast cancer. Other anti-HER2 therapies are Tykerb (lapatinib), Perjeta (pertuzumab) and Nerlynx (neratinib). There is also Kadcyla (ado-trastuzumab or T-DM1), which chemically links trastuzumab to a chemotherapy, so that it is not released until it reaches the cancer cell. Many new anti-HER2 therapies are currently being investigated in clinical trials.

A class of targeted therapies called **small molecule inhibitors** is also effective in certain types of breast cancers. Small molecule inhibitors target characteristics of a cancer cell that regulate cancer cell growth and survival. One type of small molecule inhibitors is **cyclin dependent kinase (CDK) 4/6 inhibitors**, which targets CDK 4/6, a type of protein that helps regulate cell cycle progression. CDK 4/6 inhibitors work by stopping cancer cells from growing. Ibrance (palbociclib), Kisqali (ribociclib) and Verzenio (abemaciclib) are examples of CDK 4/6 inhibitors. CDK 4/6 inhibitors are often paired with hormonal therapy as a first-line treatment for hormone positive breast cancer.

A second type of small molecule inhibitors are **mTOR inhibitors**. mTOR inhibitors work by targeting cell growth and survival. The drug Afinitor (everolimus) is an mTOR inhibitor. This type of drug is often used in hormone positive breast cancers.

PARP inhibitors target the PARP enzyme, which is involved in repairing DNA damage in cells. PARP inhibitors work by making it difficult for cancer

cells to repair DNA damage. These targeted therapies have shown promise in patients with genetic mutations such as BRCA1 and BRCA2 mutations, including triple negative breast cancers with such mutations. PARP inhibitors include Lynparza (olaparib), Talzenna (talazoparib) and Rubraca (rucaparib).

A number of clinical trials are currently investigating **antibody drug conjugate (ADC)** therapies for breast cancers, including triple negative metastatic breast cancer. An antibody drug conjugate is a chemotherapy that is paired with an antibody that targets tumor cells expressing certain antigens. Kadcyla (ado-trastuzumab), discussed above, is an example of an ADC that is approved for use in HER2+ breast cancers. Sacituzumab govitecan (IMMU-132) is an ADC being evaluated in clinical trials as a treatment for metastatic triple negative disease.

Targeted therapies tend to have less severe side effects than chemotherapy, but these side effects can still be serious. Some individuals experience low white blood cell counts that put you at risk of infection, anemia, fever and chills, neutropenia (low levels of a type of white blood cell), fatigue, nausea, diarrhea or mouth sores. Some anti-HER2 therapies can cause heart problems. The side effects of targeted therapies will need to be monitored carefully. Speak to your doctor about the risks and benefits of targeted treatments and how to best manage side effects.

A list of common targeted therapies is included on page 48-49.

Immunotherapy

Immunotherapies are treatments that work to help your body's own immune system fight cancer. Immunotherapies can work in a number of ways. For example, they help the immune system recognize that breast cancer cells are harmful and should be destroyed, or recognize breast cancer cells that may be evading detection by the immune system.

Immune checkpoint inhibitors and **cytokines** give the immune system additional tools to help it fight cancer. Immune checkpoint inhibitors work by releasing the "brakes" that keep your immune system from attacking cancer cells. Cytokines are proteins made by your cells that help your immune system fight cancer. One recent clinical trial combined an immune checkpoint inhibitor, Tecentriq (atezolizumab), with the chemotherapy, Abraxane (nab-paclitaxel). Together, they have shown success in triple negative MBC patients whose tumors tested positive for expression of the biomarker PD-L1, which is a checkpoint protein. This immunotherapy/chemotherapy combination has been approved by the FDA for use in metastatic triple-negative breast cancer with immune cells that express the biomarker PD-L1.

Other immune checkpoint inhibitors, such as Keytruda (pembrolizumab) are under investigation in clinical trials.

Some immunotherapies (such as **vaccines** and **adoptive cell therapies**, like CAR T-cell therapies) boost your immune system's ability to respond to cancer. Vaccines can help your body recognize breast cancer cells and respond to them. In CAR T-cell therapy, T cells, which are a type of white blood cell that is an important part of the immune system, are used to fight cancer. Clinical trials of vaccines and adoptive cell therapies for treatment of breast cancer are still in early stages.

Immunotherapy for the treatment of breast cancer is fairly new and a number of treatments are currently under investigation in early-stage clinical trials. Many of the current immunotherapy clinical trials are focused on the treatment of triple negative MBC. Certain characteristics of triple negative MBC may make it more responsive to immunotherapy. It is unclear at this time which immunotherapies will prove to be the most successful in fighting breast cancer. Ultimately, different immunotherapies may be combined with each other or with chemotherapies or targeted therapies to induce the best response.

The side effects of immunotherapy will vary depending on the therapy. Some side effects include fever, chills, fatigue, muscle and joint aches, nausea, trouble breathing and low or high blood pressure. In some cases, immunotherapies may result in the immune system attacking healthy cells along with cancer cells. This may cause problems or damage to various organs or the development of autoimmune disorders.

Speak to your doctor to see if you are eligible for immunotherapy clinical trials. You can find additional information about participating in clinical trials on page 52.

Local Treatments

Local treatments focus on relieving pain or managing disease in one specific part of the body. Sometimes it is not recommended to wait for systemic treatment to relieve pain or stop any danger to an area with metastases – for example, when there are risks to the spine, brain or risk of a bone fracture. In these cases, local treatments can be used to alleviate the pain and discomfort more quickly.

Local treatments may include:

Surgery

Whether this is your first diagnosis of breast cancer or a recurrence, surgery to remove a tumor in the breast may be a part of your treatment. Whether breast surgery has an advantage in MBC treatment is being studied, but currently there is not enough evidence to show a benefit to survival. In some cases, breast surgery will be used to reduce the amount of cancer in an area to reduce pain and discomfort.

Depending upon where your cancer has metastasized, you may need surgery to remove a tumor in another part of your body, if it is possible to do so.

Another type of surgery that may be recommended as a part of the treatment for hormone positive breast cancer is an oophorectomy, which is a surgery to remove the ovaries. Oophorectomy may be recommended for premenopausal patients to lower the amount of estrogen in the body and/or to allow for the use of aromatase inhibitors, which are hormonal treatments that are effective only in menopausal women.

Radiation

Radiation therapy is the use of high-energy X-rays or other particles to kill cancer cells. Radiation is more commonly used than surgery to shrink a tumor in MBC. Radiation may be used if a tumor is in the bone and causing pain or

the risk of a fracture, or (in the case of metastases in the spine) to prevent nerve damage. Radiation may also be used on tumors elsewhere in the body, such as the lungs or liver, to shrink or slow tumor growth or to treat pain.

Radiation can also be used to treat cancer that has spread to the brain. Stereotactic radiosurgery (radiation only to the tumor or tumors) may be used to treat a small number of metastases in the brain. Whole brain radiation may be used to treat a larger number of metastases in the brain. Gamma Knife is a treatment using gamma rays, a type of high-energy radiation that can be tightly focused on small tumors or other lesions in the head or neck so very little normal tissue receives radiation. The gamma rays are aimed at the tumor from many different angles at once and deliver a large dose of radiation to the tumor in one treatment session. Gamma Knife therapy is not a knife and is not surgery.

Other Local Treatments

Although not as common as surgery and radiation, other forms of local treatment can include radiofrequency ablation and cryoablation. Radiofrequency ablation is a nonsurgical treatment that removes cancer cells with heat. It can be used to remove some types of breast cancer metastases. Cryoablation involves the use of a special freezing probe through the skin that kills or weakens cancer cells. Both forms of ablation can be used where there are small, isolated metastases. Additionally, vertebral augmentation, in which bone cement is injected into a fractured vertebra to relieve pain caused by metastasis, may be an option. Vertebral augmentation is done through procedures called vertebroplasty and kyphoplasty.

Questions About Treatment

Here are some proposed questions that may help you understand your treatment options. Not all questions may apply to your situation:

- What types of treatments are recommended for my type of breast cancer?
- Are there local treatments for my metastases?
- Are there any clinical trials I should consider at this time?
- Are there any new targeted treatments being developed that may help my breast cancer?
- Does my menopausal status have an effect on my treatment options?
- Should I consider shutting down or removing my ovaries?

Breast Cancer Drug Information

You will probably hear the names of common drugs by brand name, generic name and class of drug. There are new developments in treatment happening every day. For the most up-to-date information, visit [nccn.org/patients/guidelines/content/PDF/stage_IV_breast.pdf](https://www.nccn.org/patients/guidelines/content/PDF/stage_IV_breast.pdf) for the National Comprehensive Cancer network (NCCN) Guidelines for Patients - Metastatic Breast Cancer or [breastcancer.org/treatment](https://www.breastcancer.org/treatment).

During the course of your research and in discussions with your healthcare team, you may hear branded and non-branded names for various medications. This is because generics (in the case of conventional medications) and biosimilars (in the case of biologic medications) may be available. Generics are chemically identical to the conventional medications they reference. Biosimilars are not identical to the biologic medications they reference, but are similar and are intended to have the same safety and effectiveness.

Drug: Chemotherapy

BRAND NAME	GENERIC NAME	CLASS OF DRUG
Abraxane®	paclitaxel albumin-bound	plant alkaloid; taxane; anti-microtubule agent
Adriamycin®	doxorubicin	anti-tumor antibiotic; anthracycline
Adrucil®	5-fluorouracil [5-FU]	anti-metabolite; alkylating agent
Camptosar®	irinotecan	plant alkaloids
Cytosan®	cyclophosphamide	alkylating agent
Doxil®	doxorubicin liposomal	anti-tumor antibiotic; anthracycline
Ellence®	epirubicin	anti-tumor antibiotic; anthracycline
Gemzar®	gemcitabine	anti-metabolite
Halaven®	eribulin mesylate	anti-microtubule agent
Ixempra®	ixabepilone	anti-microtubule agent
Mexate®	methotrexate	anti-metabolite
Mutamycin®	mitomycin-C	anti-tumor antibiotic
Navelbine®	vinorelbine tartrate	plant alkaloids
Novantrone®	mitoxantrone	anti-tumor antibiotic
Paraplatin®	carboplatin	alkylating agent; platinum
Platinol®	cisplatin	alkylating agent; platinum
Taxol®	paclitaxel	plant alkaloid; taxane, anti-microtubule agent
Taxotere®	docetaxel	plant alkaloid; taxane, anti-microtubule agent
Temodar®	temozolomide	alkylating agent (only for brain mets)
Xeloda®	capecitabine	anti-metabolite

Drug: Targeted Therapies or Biologics

BRAND NAME	GENERIC NAME	CLASS OF DRUG
Afinitor®	everolimus	mTOR inhibitor
Herceptin®	trastuzumab	anti-HER2
Ibrance®	palbociclib	CDK inhibitor
Kiskali®	ribociclib	CDK inhibitor

Drug: Targeted Therapies or Biologics (cont...)

Verzenio®	abemaciclib	CDK inhibitor
none, IMMU-132	sacituzumab govitecan	antibody drug conjugate
Kadcyla®	ado-trastuzumab emtansine	anti-HER2
Lynparza®	olaparib	PARP inhibitor
none, compound ABT-888	veliparib	PARP inhibitor
Talzenna	Talazoparib	PARP inhibitor
Perjeta®	pertuzumab	anti-HER2
Tykerb®	lapatinib	tyrosine kinase inhibitor; anti-HER2
Nerlynx®	neratinib	tyrosine kinase inhibitor; anti-HER2
Tecentriq®	atezolizumab	immunotherapy; immune checkpoint inhibitor
Keytruda®	pembrolizumab	immunotherapy; immune checkpoint inhibitor

Drug: Hormonal Therapy and Aromatase Inhibitor

BRAND NAME	GENERIC NAME	CLASS OF DRUG
Faslodex®	fulvestrant	hormonal
Nolvadex®	tamoxifen	hormonal; can be used in premenopausal women
Arimidex®	anastrozole	hormonal therapy; aromatase inhibitor ; can only be used in menopausal women or with ovarian suppression
Aromasin®	exemestane	hormonal therapy; aromatase inhibitor ; can only be used in menopausal women or with ovarian suppression
Femara®	letrozole	hormonal therapy; aromatase inhibitor ; can only be used in menopausal women or with ovarian suppression

Drug: LHRH Agonist

BRAND NAME	GENERIC NAME	CLASS OF DRUG
Lupron®	leuprolide	hormonal therapy to shut down ovaries
Zoladex®	goserelin	hormonal therapy to shut down ovaries

Drug: Bisphosphonates & Similar

Bisphosphonates are used to reduce bone complications and bone pain in patients whose breast cancer has spread to the bone, and to prevent osteopenia and osteoporosis. They are also used to treat symptoms of cancer such as hypercalcemia (excess calcium in the blood). Side effects may include fever, fatigue and flushing, as well as flu-like symptoms, typically after the first treatment only. Talk with your doctor about how to best reduce the risk of a condition called osteonecrosis of the jaw, which is a rare but serious side effect of bisphosphonates.

BRAND NAME	GENERIC NAME	CLASS OF DRUG
Aredia®	pamidronate	bisphosphonate
Xgeva®	denosumab	RankL (ligand) inhibitor; same purpose as bisphosphonate
Zometa®	zoledronic acid	bisphosphonate
Fosamax®	alendronate	bisphosphonate

* Some of the information above was originally reproduced with the permission of Musa Mayer.

Questions to Ask Your Doctor

Here are some proposed questions that may help you understand your treatment options. Not all questions may apply to your situation:

- How does this drug work?
- How is this drug taken (pill, IV, injection) and are there different forms of the drug?
- What are the common side effects?
- Are there any uncommon but serious side effects I should know about?
- Who do I call if I am concerned about a side effect or symptom? Do I wait until normal business hours or call immediately?
- What are the pros and cons of this treatment?
- How will we know if it's working?
- What are my other options now, and if this drug stops working?
- If chemotherapy is recommended, is there a pill form?



Clinical Trials

When considering clinical trial participation, you will want to understand the main purpose and general design of the trial, what it will require of you and what your rights and protections are. The following is a primer on clinical trials, including terminology, participation and resources.

Why Participate in a Clinical Trial?

A clinical trial is a research study to determine the safety and effectiveness of a drug or treatment that is under investigation. Many clinical trials are investigating a new drug or treatment that is not currently approved for use in patients. Some clinical trials are investigating the use of an already-approved drug or treatment for a new use.

Clinical trials may give you access to a new and promising drug and/or treatment. Often, the only way to access these drugs and treatments is through participation in a clinical trial. **Participation in a clinical trial should be considered as an option at any time during your treatment.** A clinical trial may also provide an opportunity for treatment when all of the approved treatment options have been exhausted.

Clinical trials may increase the amount of attention you have from your medical team. Because clinical trials require a lot of information be kept about side effects and other aspects of the study, you may find that you have more time to discuss your treatments with your medical team.

In addition to the benefits to you of participating in a clinical trial, your participation will also benefit all breast cancer patients. By taking part in a clinical trial, you have an opportunity to add to scientists' knowledge about cancer and to help in the development of improved cancer treatments. Nearly all of the treatments you have available to you are because women who have had breast cancer before you took part in clinical trials.

What is a Clinical Trial?

A clinical trial is a controlled, scientific study to test the safety and effectiveness of a very specific therapeutic intervention. A clinical trial might test a new drug, a different way of administration, an innovative surgical technique or new procedures.

Clinical trials are the only rigorous way to determine if a new drug works, or if a change in treatments or procedures provides additional benefit or fewer side effects. Drug clinical trials are designated as Phase I, II, III or IV.

Phase I	Newly developed drugs always begin human testing in a Phase I trial that typically involves fewer than 50 patients. The primary objective of Phase I trials is to determine if a drug is safe. These studies also evaluate how a drug should be given (e.g. by mouth or injection), how often it should be given and what dose is safe.
Phase II	Phase II trials are somewhat larger, typically enrolling 50-200 patients, and are considered “proof-of-concept studies.” The primary objective of Phase II trials is to determine how well the new drug works. These studies also continue to evaluate a drug’s safety and major side effects.
Phase III	Phase III trials are large and often enroll 200 or more patients across several different medical centers. The main objective of Phase III cancer treatment trials is to determine if the new treatment is better than what is already available. These trials are large enough that any significant medical benefit associated with the new treatment is not likely to be due to chance, and they identify all of the more common side effects and safety concerns. Typically, after a Phase III trial is completed, results are submitted to the FDA for review and either approval or denial as an acceptable treatment option.
Phase IV	Finally, Phase IV trials are conducted to gain additional information about the safety and effectiveness of drugs and other treatments that are already available. They might compare two or more accepted treatment regimens, examine alternative dosing schedules, treat a narrower range of cancer sub-types or enroll a more limited patient sub-population than Phase III trials. Alternatively, Phase IV trials might examine a treatment’s “real-world” safety and effectiveness in a broader patient population than the one selected for earlier phase trials.

Non-Treatment Trials

Non-treatment trials such as observational studies do not involve any interventions; they follow the patient over a period of time to determine treatment outcomes. For example, an outcome or observational study might follow young chemotherapy patients to determine long-term effects on heart health. Participating in a non-treatment trial may increase the amount of monitoring that you receive.

Trial Participation

Clinical trials for new treatments confer both potential benefits and potential risks compared to the usual standard of care. You should carefully consider the personal risk/benefit ratio that you consider acceptable before deciding to participate in a trial. Know that you have the right to withdraw from a clinical trial at any time.

Benefits include the opportunity to receive a new treatment that is not otherwise available and the opportunity to receive a treatment that is potentially better than the standard of care, as well as an increased level of medical attention. Risks include the possibility that the new treatment will be less effective than anticipated or have harmful side effects that are unexpected or worse than those of the standard therapy.

You should always ask how participating in one clinical trial would impact your ability to participate in future clinical trials. Additionally, if a clinical trial requests your tumor block for use in the trial, be sure to discuss with your medical team how this will affect your own care or your ability to participate in future trials.

Prior to enrolling in a trial, you will have the opportunity to learn about the clinical trial and to ask questions of the physician conducting the trial. You will be asked to review and sign a written Informed Consent, which will detail the trial's objectives; potential risks and benefits; design; your rights and protections with respect to safety and privacy; your right to withdraw; and trial funding. Some trials require travel or a significant time commitment. Be sure to ask these questions and consider how those answers fit into your current needs and lifestyle.

Visit [breastcancertrials.org](https://www.breastcancertrials.org) to find trials that may be right for you.

There are institutional safeguards that oversee the safety and ethics of clinical trials. The Institutional Review Board (IRB), comprising professionals from medical, scientific, legal, ethics and patient advocacy backgrounds, reviews all protocols and weighs the potential risks and benefits to participants and to the advancement of medical science.

For some clinical trials for new cancer treatments lacking extensive previous testing in humans, a Data Safety Monitoring Committee (DSMC) will further oversee patient safety. The DSMC is independent and usually includes at least one medical specialist, one statistician and one ethicist. This committee has the power to stop a trial early if the data show high safety risks, suggest no medical benefit or show that a drug is so highly effective that to deprive a comparison group of the treatment would be unethical.

To search the biomedical science literature for recently published trial results, visit the PubMed website at pubmed.gov. Short summaries of research results, if available, are free.

How to Find a Clinical Trial

The Metastatic Breast Cancer Trial Search feature on the breastcancertrials.org website focuses specifically on clinical trials for metastatic breast cancer. The website includes an online, free clinical trial matching portal and also allows you to set up an alert to receive information about newly listed trials that match your situation. Additionally, metastatictrialtalk.org is a related site with carefully selected news and features about metastatic breast cancer research. The site highlights new clinical trials and takes an in-depth look at existing clinical trials.

Additional general information about clinical trials is available through the **American Cancer Society at cancer.org/clinicaltrials**. Finally, you can search information about all clinical trials at clinicaltrials.gov.

Costs to Participate

In many cases, federal law under the Affordable Care Act (ACA) requires health insurers to cover routine costs associated with approved clinical trials. A clinical trial is approved if it is a federally funded or approved study for the prevention, detection or treatment of cancer. The ACA does not affect Medicare, which has slightly different rules for covering clinical trials. In general, Medicare covers the routine costs of patients participating in clinical trials.

Health insurers, Medicare and Medicaid generally do not cover the cost of the treatment or procedure being studied in the clinical trial, but usually the institution or pharmaceutical company sponsoring the trial will cover these costs.

The ACA also prevents insurers from denying a patient's participation in clinical trials or increasing their insurance premium because the insured decides to enroll in a clinical trial.

There are exceptions to federal law requirements to cover the costs of routine patient care. First, health plans that were grandfathered under the ACA do not need to comply with these rules regarding clinical trials. The ACA provisions also do not apply to Medicaid. Therefore, states are not required to cover routine patient care costs through Medicaid, although some states may choose to do so. Finally, health plans are not required to cover the costs of out-of-network doctors or hospitals if the plan does not usually do so.

It is very important to speak with your insurer and the sponsoring organization about what clinical trial costs will and will not be covered. Clinical trials will often have a coordinator who can help you understand what costs are covered.

In addition to questions on coverage of drugs, procedures and services, you should specifically ask the sponsoring organization if any additional out-of-pocket expenses such as the cost of travel, lodging and parking are reimbursed.

Compassionate Use

Not everyone will qualify for clinical trials. For example, a certain treatment history may disqualify you from a clinical trial. However, there are two additional pathways for patients to receive an investigational drug that is not yet FDA-approved. The first pathway is called Compassionate Use or

Expanded Access. Compassionate Use or Expanded Access is a program for patients with serious or immediately life-threatening diseases. Under this program, patients can submit applications through their doctors to the FDA to request access to investigational drugs. For more information, visit [fda.gov/NewsEvents/PublicHealthFocus/ExpandedAccessCompassionateUse/default.htm](https://www.fda.gov/NewsEvents/PublicHealthFocus/ExpandedAccessCompassionateUse/default.htm). The second pathway is through the Right-to-Try Act. This Act covers patients with a life-threatening disease who have exhausted approved treatment options and who are not eligible to participate in a clinical trial for the investigational drug. The main difference between Right-to-Try and Compassionate Use is that FDA permission is not required under the Right-to-Try Act. To initiate a request under Right-to-Try, the patient or the patient's doctor needs to reach out directly to the drug manufacturer. Each company will have its own process and procedures for approving requests.

Questions to Ask About Clinical Trials

Here are some proposed questions that may help you understand your clinical trial options. Not all questions may apply to your situation:

- What is the purpose of the study? What phase is the study?
- Who is sponsoring the study?
- What are my alternatives for treatment? Why should I consider this study over another treatment option (if one is available)?
- Will participating in this trial limit my ability to participate in another trial in the future?
- Will I be required to give my tumor block to the clinical trial and how will that affect my future care and ability to participate in clinical trials?
- Exactly what will my time commitment be?
- What else does the study need from me?
- What are the risks and benefits of this treatment?
- How much is known about side effects that should be expected?
- How long will the study last?
- If the drug is effectively treating my cancer, will I be able to continue on it after the trial is over?

- What will my out-of-pocket costs be to participate? What costs are covered by my insurance or by the sponsor?
- Will costs be covered by the trial or by insurance?
- What happens if I'm harmed by taking part in this study?
- Will I have access to follow-up care after the trial? How would I get it?
- Will the treatment or monitoring cause any pain or discomfort?
- Is there any long-term risk from this treatment that may not show up during the trial?
- Has this study received approval from your hospital's Institutional Review Board (IRB) and the FDA?
- Will there be a safety committee reviewing the data during the trial?

Complementary and Alternative Medicine

Approximately 38% of all American adults introduce some type of complementary and alternative medicine (CAM) into their lives.

The National Center for Complementary and Alternative Medicine defines CAM as a group of diverse medical and healthcare systems, practices and products that are generally not considered part of conventional medicine. Conventional medicine, often called Western or allopathic medicine, is medicine practiced by medical doctors, nurses, physical therapists, psychologists and other medical professionals.

COMPLEMENTARY medicine refers to the use of CAM together with conventional medicine; **ALTERNATIVE** medicine is the use of CAM in place of conventional medicine. **INTEGRATIVE** medicine is the combination of conventional and evidence-based CAM treatments. There are many types of complementary and alternative therapies, including acupuncture, homeopathic medicine, dietary supplements, probiotic therapy, massage, reiki and mind-body therapies such as relaxation, visualization, yoga, qi gong and tai chi.

Many cancer patients explore the use of CAM to help lessen the side effects of cancer treatment, relieve pain and help boost their immune systems. Most medical institutions now recognize the benefits to quality of life complementary therapies can provide, and some centers provide complementary treatment services in-house. **If you decide to use CAM therapies, you should talk to your doctor, especially if you are considering taking supplements or following a special diet.** It is possible that these may have interactions with your treatments. It is also recommended to find a CAM provider who has experience with cancer patients.

Find more information about CAM from the National Cancer Institute at cancer.gov/about-cancer/treatment/cam or 800.422.6237, or from the National Center for Complementary and Alternative Medicine at nccih.nih.gov/health/integrative-health or 888.644.6226. To find CAM practitioners in your area, visit the Society of Integrative Oncology (SIO) website, integrativeonc.org or Oncology Association of Naturopathic Physicians at oncannp.org.



Questions to Ask About Complementary Medicine

- Does this center offer any complementary or integrative therapies?
- Is there any evidence that this CAM treatment may benefit me?
- Is there any evidence that this CAM treatment may cause harm or interfere with conventional treatments?
- Are there any complementary therapies that you recommend or suggest I avoid?
- What are the side effects?
- For CAM practitioners: What is your training or qualifications? Are you certified or licensed by your state (if applicable)?
- Do you treat other cancer patients?
- Will you work with my doctor?

Managing Side Effects

Side effects of treatments are a real and constant reminder of living with MBC. While the impact and severity of some side effects are known, others are less understood and are the subject of ongoing study. Your doctors should offer clear and understandable information about potential side effects. This is an important aspect of treatment that can be overlooked. If you do not feel like you have enough information to start a new treatment, ask your doctor for more details, including a summary of possible side effects.

Learning what side effects to expect from a treatment, and how these side effects can be managed, may lessen their impact. Anticipating the effects of treatment on your daily life can allow you to plan and adjust your work and home activities. For some women, knowing the possible side effects seems to reduce their severity.

Talk with your doctor about what side effects are more tolerable to you. Some common side effects of cancer treatment include hair loss, nausea, vomiting, fever, amenorrhea (loss of menstrual periods), hot flashes, fatigue, insomnia, changes in fingernails and toenails, and cognitive changes (often referred to as “chemo brain”). Another side effect is pain and neuropathy, which is pain and numbness that occurs when chemotherapy affects the nerves, typically in the hands and feet. Emotional effects, such as stress and anxiety, are discussed in the Quality of Life section starting on p. 92.

Not everyone experiences side effects the same way, and what might be intolerable to one person could be acceptable to another. It is important to tailor a treatment plan to your own lifestyle and what you find most important.

Keep track of your side effects and report them to your doctor or nurse. A diary to keep track of side effects can be found in the Keeping Track section of this Navigator on p. 131. Report a side effect to your healthcare provider immediately, if it causes unexpected discomfort or if it is not something

discussed previously. Remember, side effects are not small or trivial, and the ones that cause pain or discomfort are often temporary and can be prevented, treated or lessened.

Pain Management

Pain caused by cancer or its treatment can be emotionally and physically draining. Metastatic cancer can cause pain in the sites of metastases – for example, in the hip, spine or other area. It can cause headaches from brain metastases or pain in the abdomen from metastases to the liver. Pain can also cause increased anxiety, as a constant reminder of the cancer, and a concern that the pain will never go away or will get worse.

Managing cancer pain is an important part of treatment, and you may need to advocate for yourself to be sure that you are getting what you need. Do not worry about sounding like you are complaining to your doctor or nurses. Your healthcare team wants to hear about the pain you are experiencing so they can help manage it and improve your quality of life. If your doctors are having trouble managing your pain in the manner you would like, see a pain specialist. Some patients are afraid of managing their pain because they are worried about becoming addicted to pain medications. However, pain medication addiction is very uncommon in MBC patients.

Similarly, do not worry that reporting side effects of a treatment that is working well could cause your doctor to switch your treatments. Often, there are enough options for alleviating pain that switching treatments would only be done as a last resort.

It may help to keep a diary of your pain. The Health and Side Effects Diary in the Keeping Track section of this Navigator can help you with this. A diary will give your doctor detailed information about the pain you are experiencing. Record where you feel the pain, the intensity of the pain, when it happens, how long it lasts, and what you are doing when the pain starts. Also record what you do to try to alleviate the pain and when you take any pain medication, as well as treatments. Be sure to note how well the pain medication seems to keep the pain in check. Having this information at your next visit will help you and your doctor pinpoint the problem and come up with solutions.

Palliative Care

It is a common misconception that palliative care is only for those with limited life expectancy. This is not the case. Palliative care is available to patients from initial diagnosis throughout treatment. Not all treatment centers have palliative care specialists, so check with your doctor to see if



palliative care is an option where you receive treatment.

Palliative care is a term used to describe the care given to improve a patient's quality of life. It is also called "comfort care" or "supportive care." **Palliative care is for patients at any stage of breast cancer.** Although palliative care is often thought of together with hospice care, the two do not always go hand in hand.

The goal of palliative care is to manage the distressing side effects of a disease or its treatment. Healthcare providers who specialize in palliative care have extensive training in the management of symptoms such as pain, neuropathy, nausea, diarrhea and constipation. They are also skilled in helping patients with psychological, social and spiritual problems related to a disease. The diagnosis of MBC can result in significant distress, which can manifest as heightened anxiety, fear, insomnia and depression. If you are experiencing distress, palliative care can provide much-needed support in addition to the care of your primary medical team.

Taking a Break from Treatment

There may come a time when you have been undergoing treatment for a long time, or your treatment is so greatly impacting your quality of life that you may consider a treatment break. If you feel you need a break, talk with your doctor about whether it is possible for you and how it may affect you over the

long term. Some women may have a break in treatment with minimal impact on overall survival.

Questions to Ask About Side Effects and Pain Management

Here are some proposed questions that may help you understand your side effects and how to alleviate them. Not all questions may apply to your situation:

- With this treatment, what side effects should I expect?
- How can I prevent or prepare for potential side effects?
- Are there treatments available for the side effects I will experience?
- What side effects are considered serious, and when should I call my doctor?
- How should I inform my doctor of any side effects I'm experiencing between appointments?
- What is the best way to manage my pain?
- How long can this medication be expected to manage my pain?
- Will my pain medication make me feel foggy or sleepy or otherwise interrupt my daily activities?
- Are there things that I should not do while taking this pain medication?
- Is there something else that we can do to manage my pain besides medication?
- Do you have a palliative care team?
- Should I see a palliative care specialist?
- Can I take a break from treatment?
- If I take a break from treatment, how will it affect my treatment going forward?

The Decision to End Treatment & Begin Hospice

If treatments have stopped working or become too difficult to endure, your focus and care may shift from cancer treatment to preparing for the end of life. In this case, medical treatment focuses on easing the pain, symptoms and stress of illness, rather than treatment for a cure. Some women may want to continue treatment as long as possible. Deciding to end cancer treatment can be extremely difficult. An additional hurdle may be the prospect of discussing your decision with family members who are not prepared for your change in thinking.

It is best to open the lines of communication on this topic with your family and your doctor early in treatment in order to prevent surprises. You want to have these conversations now before you're in a situation where you can't make a decision for yourself.

Resources and organizations can help patients and families through the transition from active treatment to providing comfort and managing pain until the end of life. Hospice is an excellent source of support for anyone who is no longer undergoing active treatment for cancer.

If you have not already done so, it can also be constructive to think about matters such as a will, financial considerations and the disposition of personal effects. It is always best to consider these issues sooner rather than later. There are several excellent resources for helping patients and families cope with the issues that come up at the end of life. The American Cancer Society has a guide on talking to children about a parent or other loved one's terminal illness: [cancer.org/treatment/children-and-cancer/when-a-family-member-has-cancer/dealing-with-parents-terminal-illness.html](https://www.cancer.org/treatment/children-and-cancer/when-a-family-member-has-cancer/dealing-with-parents-terminal-illness.html).

For additional information on end-of-life matters, see the Legal Issues section on page 85.

What is Hospice?

Hospice focuses on caring, not curing. It is a team approach to medical care, pain management and emotional support customized to the needs and wishes of the patient and her family.

Hospice is usually provided in the patient's home but can also be provided in long-term care facilities. Hospice is typically covered by insurance. Members of the hospice team (primary physician, hospice physician, nurses, home health aides, social workers, therapists, chaplains and trained volunteers) make regular visits to assess the patient and provide care. They are "on call" around the clock, if needed.

The hospice team performs a variety of care and services, including managing pain and other symptoms, assisting with the emotional and spiritual aspects of dying, providing needed medical supplies and drugs, teaching the caregivers how to assist the patient, and providing counseling and support to family and friends. Research has shown that hospice care may actually lengthen life by increasing the quality of time the patient has remaining.

When to call hospice is a frequent question. Typically, it's advisable to call hospice when the decision to end treatment is made, or when it is estimated that the life expectancy of the patient is six months or less. Hospice may be recommended by your physician but can be consulted at any time by the patient or her caregivers. Patients and co-survivors receive the most benefit when hospice is called in earlier, rather than later.

The National Hospice and Palliative Care Organization (NHPCO) CaringInfo provides free resources and information to help people make decisions about end-of-life care and services before a crisis, and it helps people connect with the resources they need, when they need them. Contact them at [caringinfo.org](https://www.caringinfo.org) or 800.658.8898. VITAS Healthcare also provides an online discussion guide for families about hospice: [vitas.com/hospice-and-palliative-care-basics/when-is-it-time-for-hospice/hospice-family-discussion-guide](https://www.vitas.com/hospice-and-palliative-care-basics/when-is-it-time-for-hospice/hospice-family-discussion-guide).

Making the decision to end treatment is a very difficult and emotional one. Surround yourself with supportive family and friends. Connect with counselors, therapists and/or religious leaders. Legacy projects such as scrapbooks, videotaped stories, a written history, cards and letters written for future events to friends or family members may help you pass on your wisdom and memories.



Questions to Ask About Ending Treatment

Here are some proposed questions that may help. Not all questions may apply to your situation:

- How do I know when it's time to consider ending treatment?
- If I stop treatment and change my mind, can I go back on treatment?
- How will my pain be managed if I am not in treatment?
- Will I still be seen by my oncologist if I am not in treatment?
- What does hospice do and what services are generally included?
- How can I talk with my family about this?
- Are there any resources to help my family cope?
- How can I get help to go over my finances and will?
- How can I be sure to have control over the end of my life?
- What are my options for at-home or hospital-based care?

Additional Resources

DEATH WITH DIGNITY

deathwithdignity.org/learn/end-of-life-resources

Death with Dignity National Center believes that end-of-life decisions should be made by the patient in consultation with their healthcare provider and loved ones.

DEATH OVER DINNER

deathoverdinner.org

Death Over Dinner is a movement that encourages individuals to have end-of-life discussions in an environment that fosters warmth and connection—sharing a meal together.

FIVE WISHES

fivewishes.org

Five Wishes is an advanced care planning program.

HOSPICE FOUNDATION OF AMERICA

hospicefoundation.org/Hospice-Care

The Hospice Foundation of America provides information on end of life, hospice care and grief.

THE CONVERSATION PROJECT

theconversationproject.org

The Conversation Project helps individuals discuss their wishes for end-of-life care.

THE LEGACY PROJECT

legacyproject.org/activities/index.html

The Legacy Project offers activities and guides for creating a legacy.



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Keeping Your Records

Keeping track of your personal medical history is a key part of managing your health. Many women find that accessing and organizing their records empowers them to be even more interactive with their healthcare team. Some of the most crucial documents are your pathology reports and any diagnostic test reports you may have received. Have you asked for them yet? Did you know that after every appointment, your doctor makes notes regarding the visit and the next steps? These are also part of your medical file, and you have a right to them.

If your doctor has your medical record, why should you keep a copy yourself?

- Your reports, results and notes help you see the full picture of your diagnosis and care. They also help you to know what questions to ask. You can read them at home, take time to understand them and prepare for your next doctor's appointment.
- Each doctor or facility that sees you has its own separate medical file. Keeping one yourself combines them into a single, more complete record.
- As your treatment progresses, it becomes increasingly difficult to remember when and what procedures, treatments or tests may have been performed. With your records, you don't have to worry about forgetting.
- Keeping your own copy of your medical file makes it easier if you need to get a second opinion or you go to a new facility. You don't have to wait for a file request or for records to be transferred.
- When it comes to filing and managing health insurance, keeping your own records can make all the difference.
- Come tax time, your personal medical file can help you claim the most deductions possible.

What should you ask for and keep?

- Contact information for doctors, nurses or any healthcare provider, as well as resources such as advocacy organizations
- Your personal health history, including surgeries, allergies, hospitalizations and other health problems
- Reports from your diagnoses – any diagnostic tests or biopsies
- Copies of pathology reports, scan reports and laboratory reports
- Dates of diagnoses and treatments
- Office and doctors' notes from each visit
- List of medications
- Any information on clinical trials in which you enroll or are considering
- Treatment information, including drug names and dosages
- Documented side effects or reactions from treatment
- A schedule for and results of follow-up tests

How do you get your records?

- When you see your doctor, ask for a copy of anything new that has been added to your file.
- After any test or procedure, ask that you receive a copy of the report.
- If you are ever hospitalized, ask for a copy of your medical record before you leave (if available).
- Keep copies of medical bills and insurance claims.

If you wait too long before asking for copies, it may be challenging to obtain the information. Doctors may also take 30 days or longer to provide you with copies of medical records, which may put strain on you in the event you urgently need to have a copy of your medical record. Ask for copies as you go along; it will make the process much easier. Use the Keeping Track pages inside this Navigator to organize everything. It will be much easier to find important information if it is all in one place. This may be a good way for someone in your life to help you.

Once you start collecting your records, you will see how much easier it is to be in control of your own care. Having this information can empower you to make the healthcare decisions that are best for you.



Online Medical Records

It is becoming increasingly common for medical practices and hospitals to store their medical records, test reports and doctors' notes online instead of on paper. This should make it easier for you to obtain the records you need, and you may be able to download and save them onto your computer. If your doctor or medical facility uses online medical records, be sure to ask for information on how you can access them.

Records from Prior Diagnoses

If this is not your first diagnosis of breast cancer, and you have copies of records from your prior diagnoses, bring them along to your medical appointments. The type of breast cancer you had previously and the treatments you have already received will help determine how to proceed with your new diagnosis.

Checklist for Your Appointments

- This Navigator
- Questions for your doctor
- List of prescriptions
- Pen or pencil
- Someone else to take notes, or a way to record the appointment

Health Insurance

In order to get the most out of insurance coverage, you need to understand what benefits are covered by your plan and the policies your insurance company has in place, so that you can access as many services as possible. This information may be available on your insurance provider's website or listed within your policy. Ask your employer or the insurance company to provide it, if you do not have a copy.

Often, it's easier to call the member services department at your insurance company directly and ask the following questions:

- Are my intended doctors a part of my insurance plan?
- Do I need pre-approval for a second opinion?
- Can I go out-of-network or out of my plan to obtain care and is it covered?
- How do my out-of-pocket costs and co-pays differ between in-network services/doctors and out-of-network services/doctors?
- Do I need pre-approval for any treatment? If so, when and how do I obtain it?
- What services are covered and to what extent?
- Can I switch doctors?
- Can I choose my own specialists?
- What is my deductible? How is it applied? Is there an out-of-pocket maximum?
- Are there co-pays? For which services and how much?
- Are there expiration or renewal dates to note?
- Is there a required location for me to go for tests, scans or bloodwork in order for them to be covered?
- Do I need referrals before I can go to a specialist? And from whom do I obtain those referrals?
- Are prescriptions covered? Is there any way to reduce my costs such as through a mail-in option?

Do not throw away insurance mail or mail from your doctors. Be sure to look over all literature, documents and bills that you receive from your insurance carrier. It is possible to be billed incorrectly or charged for things that should be covered. Keep track of all bills and all payments, as well as all conversations with your insurance representatives. You may consider scanning these documents and saving them on your computer, organized by provider or dates of service.

This is a great opportunity to involve a friend or family member looking to help. Use a supporter to help you sort through and file your mail and to help you manage a list of your insurance action items.

Insurance companies often have case management departments to help members who have serious chronic illnesses. A case manager can help coordinate medical needs and be a consistent voice as you manage your breast cancer. Ask your member services representative if you are eligible for case management and if she can assign you to a case manager. A patient navigator, nurse or social worker at your cancer center may also be an excellent resource for assistance.

TERM	DEFINITION	EXAMPLE
Co-payment	A set amount you pay per visit	<ul style="list-style-type: none"> • \$25 per office visit • \$100 per ER visit
Usual and Customary Charges (UCC)	Amount generally charged for a procedure in your area. Note that typically you do NOT owe the amount in excess of your UCC. Check with your insurer to confirm.	<ul style="list-style-type: none"> • MD charges \$250 for an office visit • UCC in area \$100 • Health Plan reimburses \$100
Deductible	Amount you have to spend before the health plan pays	<ul style="list-style-type: none"> • \$500 deductible per inpatient hospital stay. After you have paid \$500, the insurer starts paying the balance.
Coinsurance	Your share of the costs of a healthcare service, usually stated as a percentage of the total charges. Generally used for out-of-network services	<ul style="list-style-type: none"> • Your coinsurance is 20% and your MD charges \$100. • Health plan pays 80% • You pay 20% of the \$100

Out-of-Pocket Maximum	Maximum amount you pay for covered services in a plan year/out-of-pocket maximum	<ul style="list-style-type: none"> • Your out-of-pocket maximum is \$6,000. You pay \$6,000 in the first months of the year on co-payments, deductibles and co-insurance. • Your health plan covers all costs of covered care above the \$6,000 already paid for the rest of the plan year.
Yearly or Coverage Maximums	Maximum amount paid for either a benefit or total medical costs annually. The ACA eliminated lifetime benefit maximums for essential health benefits.	<ul style="list-style-type: none"> • Benefit example: \$1,500 maximum paid for durable medical equipment

Questions to Ask

- Who handles questions about health insurance in this office or medical center?
- Will this person help me work with my health insurance company?
- Will this person help me figure out my medical bills to make sure they are correct?
- If an insurance claim is denied, who can help me file an appeal?
- Do you offer any payment plans or charity programs?
- Are there ways to change my treatment schedule, if necessary, to work around my job or child care?
- Where can I get low-cost or free counseling or support to help me cope with my diagnosis?

Medication Cost Questions

- What is my prescription co-pay for this drug?
- Is this prescription a one-time cost, or will it be an ongoing expense?
- Is this medication on my health insurance plan's preferred drug list?
- Can I switch to a less expensive brand-name drug within the same drug class?
- Is there a generic drug available that will have the same effect? Is it less expensive?
- Can we regularly go over my list of medications, to see if there are ways to lower my drug costs?
- For medications to treat side effects, is there an over-the-counter medicine that has the same effect as the prescribed drug? Is it less expensive?
- Are there programs that can help cover the costs of my drug(s) for cancer treatment or side effects?

If You Do Not Have Insurance

If You Do Not Have Health Insurance

Cancer is scary even with the best health insurance. Being without coverage adds another level of stress, but you do have options.

These resources may help:

- The National Breast and Cervical Cancer Treatment Act provides money to pay for treatment for certain uninsured women. Visit the website at [cdc.gov/cancer/nbccedp](https://www.cdc.gov/cancer/nbccedp) and click “contact the program” under the tab on the left to get information about how this program works in your state.
- Seek financial assistance at your treatment center. Some hospitals have patient assistance programs based on financial need to offset the cost of hospital bills. Meet with the hospital financial counselor or patient advocate and explain your situation. Keep records of the date and topics discussed in each conversation. Bring a family member or friend who knows your situation and can help take notes and ask questions.
- Enlist the oncology social worker to help you with your case. The social worker may have information on whether or not you are eligible for Medicaid or Medicare (which can cover individuals with MBC regardless of age) and other public assistance. He or she can direct you to assistance that is available through the hospital or local charities. You may be eligible for food stamps, social security or other benefits. Prepare for your meeting by making a list of questions.
- Inquire about the Hill-Burton Program, a federal program that requires hospitals to provide free or low-cost care to people who cannot pay. Not every hospital provides this program. Contact your hospital or the Hill-Burton Program at 800.638.0742 (800.492.0359 in Maryland) or [hrsa.gov/get-health-care/affordable/hill-burton](https://www.hrsa.gov/get-health-care/affordable/hill-burton).
- Some states have “guaranteed issue” individual health plans that are available regardless of health history. Contact your State Department of Insurance to see what options your state may have.

“We all have the right to a fulfilling and good life and a community of support, and to pursue the life that we want. Don’t hesitate to reach out. We are here to do more than just survive. We are here for each other and we are here to thrive!”

-Dikla B.

- Some pharmaceutical companies have patient assistance programs to provide their drugs to people who cannot afford them. See the listing of phone numbers for these programs on page 92. NeedyMeds, Inc. is a non-profit organization with the mission of helping people who cannot afford to pay for their medications. Check needymeds.com for additional information.
- Be sure to check YSC’s searchable online Support directory (youngsurvival.org/directory) for more financial and insurance resources.

The Affordable Care Act

On March 23, 2010, President Obama signed a law called the “Affordable Care Act,” which required health insurance reforms. This law should make it easier for women diagnosed with breast cancer to get, and keep, health insurance. Key points:

- You cannot be denied health insurance coverage because of a pre-existing condition, including cancer, or be charged more because of your health status.
- Health insurers cannot cancel your coverage if you become sick or are diagnosed with cancer.
- Every state has a high-risk pool to provide coverage for those uninsured for six months or more and who have cancer or other pre-existing conditions.

As healthcare policy evolves, we encourage you to access resources at healthcare.gov and materials from the experts at Triage Cancer (triagecancer.org) to stay abreast of current policy.

The American Cancer Society also has a booklet entitled “The Affordable Care Act: How it Helps People with Cancer and their Families,” which you can request

free of charge by calling 800.227.2345. The American Cancer Society has additional information about the ACA at: <https://www.cancer.org/treatment/finding-and-paying-for-treatment/understanding-health-insurance/health-insurance-laws/the-health-care-law>.

Disability



An MBC diagnosis generally makes one eligible for disability income resources. Employers and government agencies provide these resources.

SOCIAL SECURITY DISABILITY INSURANCE (SSDI) is loss of income protection provided by the United States government to people who have worked long enough, recently enough and paid Social Security taxes. SSDI replaces lost **income** due to a disability that is expected to last at least one year or result in death. Breast cancer qualifies for Social Security Disability benefits if it meets one of the following criteria: inoperable cancer, inflammatory breast cancer, recurrent cancer (except local recurrence controlled by prescribed therapy), or distant metastases from breast cancer. The amount paid out to you is equal to the amount that you would receive if you were age 65. There may be a waiting period prior to receiving SSDI benefits. See the Social Security Disability website at ssa.gov/disability for more information and to apply for benefits.

COMPASSIONATE ALLOWANCE is a program that began in 2008 to speed up the SSDI claim process. Certain disabling conditions, including MBC, entitle you to an expedited review process – typically within three weeks you will receive a disability determination. Medical documentation of your MBC will be necessary. See ssa.gov/compassionateallowances for more information.

SUPPLEMENTAL SECURITY INCOME (SSI) is a federal **income** supplement program designed to help disabled people who have little or no income. SSI is meant to modestly provide cash to meet the basic needs of food, shelter and clothing. If you are eligible for SSI, you will likely qualify for additional benefits provided by your state, including Medicaid, food stamps and other social services. For detailed information on eligibility requirements, visit the SSI website at socialsecurity.gov/ssi/index.htm.

SHORT-TERM DISABILITY replaces part or all of your pay when you are out of work for a short period of time with an illness or injury that is not related to work. For example, if you are undergoing a new chemotherapy regimen that makes it difficult for you to work, you may be eligible for short-term disability. Typically, short-term disability provides a weekly **income** and **insurance** benefit for a period of 13 to 26 weeks.

In five states – California, Hawaii, New Jersey, New York and Rhode Island – and Puerto Rico, short-term disability is a state-mandated benefit. In other states, your employer may offer, and cover the costs of, short-term disability insurance. You can also purchase short-term disability insurance on your own, but it may be expensive and/or exclude short-term disability benefits for any problems associated with your breast cancer.

To take advantage of your short-term disability insurance policy, you should work with your employer to review the terms of your policy. Depending upon the policy, there is sometimes a waiting period for benefits. It is important to remember that your health information is private, and you only need to tell your employer about your disability and if/when you anticipate returning to work. If you are claiming short-term disability, process your claim as soon as possible after you stop working.

LONG-TERM DISABILITY INSURANCE also replaces part or all of your pay when you are out of work with an illness or injury unrelated to work. Typically, long-term disability is offered with short-term disability, but it can be offered or bought as a separate policy. It starts when short-term disability ends. Long-term disability is paid out after you have been unable to work for a period of time and there is a reasonable anticipation that you will not be able to return to work for an extended period of time. As with short-term disability, you should work with your employer to receive your benefits. With long-term disability, it is often the case that the employee pays you long-term disability insurance premium while receiving a portion of your **income**.

MEDICARE is a **federal insurance program** that pays for hospital care, home healthcare, doctors' services and prescription medication. There are three different parts of the Medicare program – Part A (hospital care), Part B (doctors' services) and Part D (prescription drugs). Although Medicare primarily covers people over 65 years old, it also covers people under 65 if they are disabled. If you are covered by Medicare, you may be required to pay a premium, deductible and co-payments. If you are low income, you may be eligible to have your out-of-pocket healthcare costs covered through your state Medicaid program. It is a good idea to ask your Medicare representative if that is an option for you. If you have commercial insurance and are low income, you may still be eligible for Medicaid to cover your out-of-pocket costs. There may be a waiting period before benefits begin.

MEDICAID is a **state assistance insurance program** for low-income people of all ages. Each state has different income and asset requirements to determine eligibility. Patients usually pay no part of costs for covered medical expenses, but sometimes small co-payments between \$5 and \$10 are required for emergency room visits and prescription drugs.

Centers for Medicare and Medicaid Services, often referred to as CMS, have an informative website with numerous resources and an interactive eligibility tool. The toll-free number offers 24-hour service seven days a week. Contact the CMS at 800.633.4227 or [medicare.gov](https://www.medicare.gov).

There are additional financial assistance resources for treatment listed in the Additional Resources section on page 88.

Financial Management and Assistance

A diagnosis of breast cancer can have a significant financial impact even if you have health insurance. Because bills, co-pays, invoices and receipts quickly pile up, it is important to explore ways to proactively manage your medical expenses.

Keep your medical bills and insurance statements. Don't throw anything out. Organize your documents in a file or folder. You may prefer to set up a spreadsheet on your computer to track this information. Keeping track of and organizing your medical bills is a great job to give a friend or family member who wants to help.

There may also be computer and web-based programs available to help you organize and manage medical expenses. If your insurance carrier is United Healthcare, CIGNA or Medical Mutual of Ohio, Quicken Expense Health Tracker is a free tool that may be available to you. This online service is designed to help you understand insurance claims, correct errors, easily make payments, track expenses and prepare medical cost information at tax time. For more information, speak to your insurance company or healthcare provider.

Financial Assistance

Aside from the medical bills that metastatic cancer creates, the loss of income that often accompanies a diagnosis can strain any budget. Seeking help can often involve making many phone calls to agencies and organizations that seem only to lead to more phone calls. However, financial assistance options are available. Try to remain hopeful that you will find assistance, and keep good notes of who you call and what you learn when talking with them.

Keep in mind that the sooner you reach out for help, the better. Do not wait until your resources are gone before asking for help. When seeking financial assistance, think outside the box, and don't limit your requests to funds for medical expenses. For example, if co-pays are breaking your budget, don't just look for money to assist with co-pays. If you can get help with transportation to medical visits, or to access food assistance, you will be more likely to be able to afford your co-pays.

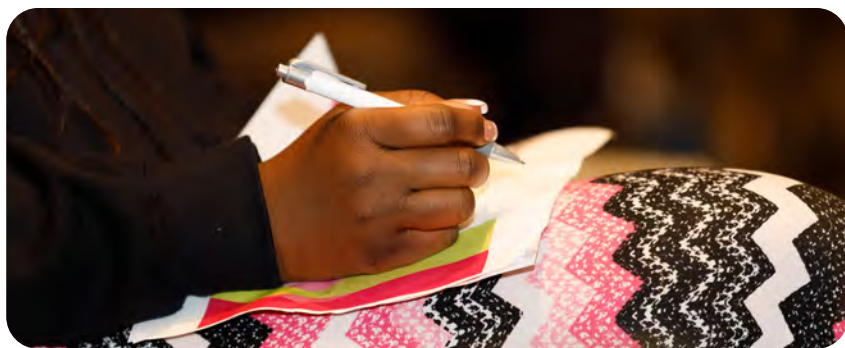
If you have credit cards and need to use them to pay medical bills or household expenses, be careful of getting into credit card debt. Don't wait until you have maxed out your cards to seek help. Creative thinking early on might make a difference in long-term financial planning and peace of mind.

The following organizations can help with financial assistance:

- The **AMERICAN CANCER SOCIETY (ACS)** can provide information on local sources of financial assistance. The ACS website lists many resources that provide financial assistance. To reach your local ACS, contact the national office at 800.227.2345 or visit [cancer.org](https://www.cancer.org).
- The **PATIENT ADVOCATE FOUNDATION CO-PAY RELIEF (CPR)** provides direct financial assistance to qualified patients, assisting them with the prescription drug co-payments their insurance requires. Contact the CPR program at [copays.org](https://www.copays.org) or 866.512.3861.
- **CANCERCARE** provides financial assistance for certain cancer-related costs and co-pays. They also have professional oncology social workers available to help connect patients with additional resources. Visit [cancercare.org/financial_assistance](https://www.cancercare.org/financial_assistance) or contact CancerCare at 800.813.4673 for more information.
- The **UNITED WAY** 2-1-1 program is in place across the country to help those in need. See [211.org](https://www.211.org) or call 703.836.7112 to contact your local United Way office.
- **STUPID CANCER** maintains a list of financial resources here: [stupidcancer.org/get-help/resource-directories/financial-assistance](https://www.stupidcancer.org/get-help/resource-directories/financial-assistance).
- The **SAMFUND AND TRIAGE CANCER** partnered to create Cancer Finances ([cancerfinances.org](https://www.cancerfinances.org)), a toolkit that helps individuals navigate their finances after a cancer diagnosis.

Reach out to **RELIGIOUS ORGANIZATIONS** that you belong to or that are near you. These organizations provide help to their members and people in their community in a variety of ways.

Check out **YOUNG SURVIVAL COALITION'S SUPPORT: SEARCHABLE ONLINE DIRECTORY** for more financial and insurance resources: [youngsurvival.org/directory](https://www.youngsurvival.org/directory).



Here are some questions to ask staff at your medical center:

Transportation Expense Questions

- Is there free or low-cost transportation for patients at the medical center where I will have treatment?
- Are there reduced parking rates for patients at the medical center or doctor's office?
- Is there an organization that can help me pay for transportation to and from treatments and medical appointments?
- If I am traveling a long distance, are there free or reduced-cost hotels or lodging near the treatment facility?
- Does this center provide gas cards?

Family and Living Expense Questions

- If I have trouble paying for basic items, like food or heat, due to the cost of my cancer treatment, are there organizations that can help me?
- Where can I get low-cost or free child or elder care during my treatment?
- Where can I get free or low-cost personal items, such as a wig, if needed?
- Is there an organization that can provide low-cost or free counseling or support to my family?

Triage Cancer (trriagecancer.org) provides education on the various practical matters and legal issues that often impact individuals diagnosed with cancer through conferences, webinars, materials and other resources.

Legal Issues

A diagnosis of cancer can impact many areas of your life, including your legal rights. Many young women feel lost or afraid when it comes to dealing with legal issues. One way to reduce these feelings is to be as organized and prepared as possible.

Laws

There are several laws that can help protect you during your treatment:

HIPAA: The Health Insurance Portability and Accountability Act (HIPAA) helps protect the privacy of a patient's individual medical information, provides patients with access to their medical records, and helps people maintain their health insurance for themselves and their family members when they change, leave or lose a job. Learn more at hhs.gov/hipaa/index.html.

GINA: The Genetic Information Nondiscrimination Act of 2008 (GINA) is designed to prohibit the improper use of genetic information in health insurance and employment. The Act prohibits group health plans and health insurers from denying coverage to a healthy individual or charging that person higher premiums based solely on a genetic predisposition to developing a disease in the future. The legislation also bars employers from using individuals' genetic information when making hiring, firing, job placement or promotion decisions. This means your genetic test results cannot be used against you by a current or prospective employer. GINA does not extend to life insurance, disability insurance or long-term care insurance.

FMLA: The Family and Medical Leave Act (FMLA) requires that covered employers grant an eligible employee up to a total of 12 work weeks of unpaid leave during any 12-month period when the employee is unable to work because of a serious health condition, or when the employee needs to care for his/her spouse, child or parent with a serious health condition. This might allow you to take time off for treatment without worrying about being fired or losing your health insurance coverage. The leave can be intermittent (not all taken at the same time). There are some conditions, however, and it is unpaid. For more information, go to dol.gov/whd/fmla.

ADA: The Americans with Disabilities Act (ADA) “requires employers to provide adjustments or modifications to enable people with cancer to enjoy equal employment opportunities unless doing so would be an undue hardship (i.e., a significant difficulty or expense). Not all employees with cancer will need an accommodation or require the same accommodations, and most of the accommodations a person with cancer might need will involve little or no cost. An employer must provide a reasonable accommodation that is needed because of the limitations caused by the cancer itself, the side effects of medication or treatment for the cancer, or both. For example, an employer may have to accommodate an employee who is unable to work while she is undergoing chemotherapy or who has depression as a result of cancer, the treatment for it, or both.” See eeoc.gov/laws/types/cancer.cfm for more information.

Cancer and Careers is a great resource for those who are experiencing difficulty with their employment because of their MBC or its treatment, or who have employment-related questions. See cancerandcareers.org.

Legal Questions

Here are some questions to ask your nurse or patient navigator about legal issues. Not all questions may apply to your situation:

- Who can I talk with if I have lost income because of my cancer?
- If I have on-the-job difficulties related to my cancer, who can help me understand my legal rights?
- If my caregiver has difficulties at his or her job because of my cancer, who can help us understand our legal rights?
- Where can I find out if my medical and related expenses can be deducted from federal income taxes?

Legal Documents

It is important to ensure that all of your legal documents are up to date. All people over the age of 18 should have legal documents that discuss their decisions and wishes in the event they are unable to make decisions themselves, or to resolve issues at the time of death. Creating these legal documents does not mean that you’ve given up hope or are planning to stop treatment. It is simply a way to plan ahead and give direction long before you’re in a situation where you may not be able to make a decision for yourself.

Identify someone you trust to help you with the legal matters that are important to you. Familiarize them with the location and status of your important paperwork. The following terms can enable you to begin to understand and navigate some of the legal needs you may have and determine the right supporter to help you in this area.

ADVANCE DIRECTIVE: Also known as a healthcare directive, this is a legal document that empowers you to decide and make clear in writing what type of medical care you prefer to receive should you become unable to speak for yourself. A living will and do-not-resuscitate order (DNR) are types of advance directives:

LIVING WILL: a written statement that provides details on a person's wishes concerning medical treatment, to be used when they are unable to express those wishes.

DNR: A request/decision by a patient or someone else acting on his/her behalf that tells a healthcare provider NOT to perform CPR if the patient's heart or breathing stops.

HEALTHCARE AGENT: Also referred to as a healthcare proxy or durable power of attorney for healthcare, this is the person you choose to be your healthcare decision maker if or when you are unable to make these decisions for yourself. It is recommended that you identify and talk with this person about your wishes when you are feeling well. Ensure they understand your priorities and decisions about treatment and medical procedures. Note that laws may vary state by state.

LEGAL GUARDIAN: This is a legally appointed person responsible for making decisions for a minor (child under 18) or a person lacking the mental capacity to make decisions for herself. Laws vary by state, and the determination of a guardianship may take away the parents' right to make decisions about their child's life, but it does not permanently terminate parental rights.

POWER OF ATTORNEY: This legal document grants one person the right to represent another within specific contexts. Circumstances may include your health-related information, legal matters, banking or conducting business on your behalf.

WILL: A will is a legal document outlining what will happen to your estate (your financial assets and property) after death. Without a will, the state in which you live will dispose of your property according to state law.

No matter how much or little you may have, these legal documents are important and can provide peace of mind when facing health challenges.

Your Digital Footprint

Today, much of our lives is chronicled on social media like Facebook, YouTube, and Instagram. But what happens to those accounts and memories when the user passes away? The answer is not entirely clear. Facebook changed its policy and now has a "legacy contact" feature that can allow a person you have previously identified to maintain some aspects of your account after death.

Additional Resources

Here is a partial list of additional resources that may provide assistance. For a more complete list, visit YSC's searchable online Support directory at youngsurvival.org/directory.

AMERICAN CANCER SOCIETY

National Headquarters
250 Williams Street, NW
Atlanta, GA 30303
800.227.2345
cancer.org

A national, community-based organization that provides information and referrals to numerous education, community and patient support services including transportation programs, medical insurance and financial assistance resources.

NATIONAL BREAST AND CERVICAL CANCER EARLY DETECTION PROGRAM (NBCCEDP)

Centers for Disease Control and
Prevention
Division of Cancer Prevention and
Control
800.232.4636
cdcinfo@cdc.gov
cdc.gov/cancer/NBCCEDP

The National Breast and Cervical Cancer Early Detection Program (NBCCEDP) is a federally funded program for low-income U.S. residents. It is designed to provide no-cost cancer treatment as soon as possible after diagnosis.

CANCERCARE, INC.

275 Seventh Avenue, Floor 22
New York, NY 10001
800.813.4673
info@cancercare.org
cancercare.org

CancerCare is a national non-profit organization that provides free professional support services to anyone affected by cancer, including those living with cancer, family, friends and the bereaved. CancerCare programs, including counseling, education, financial assistance and practical help, are provided by trained oncology social workers free of charge.

CANCER LEGAL RESOURCE CENTER

866.843.2572
CLRC@drlcenter.org
cancerlegalresourcecenter.org

The Disability Rights Legal Center's (DRLC) Cancer Legal Resource Center (CLRC) was founded to address the unique legal issues of those diagnosed with cancer. CLRC provides free information and education about cancer-related legal issues to all cancer survivors and caregivers through their national telephone assistance line, and conducts outreach programs and activities within the community to raise public awareness.

CATHERINE H. TUCK FOUNDATION

1266 West Paces Ferry Road NW,
#421
Atlanta, GA 30327
info@catherinefund.org
catherinefund.org/Home.html

The Catherine H. Tuck Foundation provides financial assistance for non-medical expenses like rent, utilities, food and transportation to women diagnosed with breast cancer.

UNITED STATES GOVERNMENT BENEFITS

844.872.4681
usa.gov/benefits

The United States government website listing information on benefit and assistance programs.

THE HEALTHWELL FOUNDATION

P.O. Box 489
Buckeystown, MD 21717
800.675.8416
grants@healthwellfoundation.org
healthwellfoundation.org

The HealthWell Foundation works to reduce financial barriers to care for underinsured patients by providing financial assistance. The Foundation helps eligible individuals with payments for prescription drug copayments, coinsurance, deductibles and other selected out-of-pocket costs.

HILL-BURTON PROGRAM

800.638.0742

800.492.0359 (in Maryland)

hsra.gov/get-health-care/affordable/hill-burton

The Hill-Burton Program provided federal funds to hospitals. Although the program no longer provides funding, there are around 140 health care facilities across the country that are still obligated to provide free or reduced-cost care for those unable to pay for medical care. Eligibility is based on income and family size.

HOPE LODGES (AMERICAN CANCER SOCIETY)

National Headquarters

250 Williams Street, NW

Atlanta, GA 30303

800.227.2345

cancer.org/treatment/support-programs-and-services/patient-lodging/hope-lodge.html

Hope Lodges provide temporary, home-like residences without charge to cancer patients. They facilitate the cancer treatment process by providing an emotionally supportive environment, while reducing the financial burden. Currently, there are more than 30 Hope Lodge locations throughout the United States. Accommodations and eligibility requirements may vary by location, and room availability is first-come, first-served.

MEDICAID (CENTERS FOR MEDICARE AND MEDICAID SERVICES)

800.633.4227

cms.hhs.gov/home/medicaid.asp

The Medicaid Program provides medical benefits to groups of low-income people, some of whom may have no medical insurance or inadequate medical insurance. Although the federal government establishes general guidelines for the program, each state establishes its own Medicaid program requirements. Eligibility for Medicaid depends on the state of residence.

MERCY MEDICAL ANGELS

Patient Travel Referral Program

4620 Haygood Road, Suite 1

Virginia Beach, VA 23455

800.296.1217

757.318.9174

info@nationalpatienttravelcenter.org

patienttravel.org

Mercy Medical Angels Patient Travel Referral Program provides assistance to those who need help with transportation to their medical treatment. The program provides assistance with air travel and ground transportation. For more information, visit their website.

NEEDYMEDS, INC.

P.O. Box 219

Gloucester, MA 01931

800.503.6897

info@needymeds.com

needymeds.com

NeedyMeds provides information on healthcare programs, offers direct assistance and facilitates programs. Their website provides links to

a variety of patient assistance programs that help individuals who can't afford medications and healthcare costs.

PARTNERSHIP FOR PRESCRIPTION ASSISTANCE

pparx.org

Partnership For Prescription Assistance helps connect patients to assistance programs where they can get access to the prescription drugs they need for free or nearly free.

PATIENT ADVOCATE FOUNDATION

421 Butler Farm Road

Hampton, VA 23666

800.532.5274

help@patientadvocate.org

patientadvocate.org

The Patient Advocate Foundation (PAF) provides professional case management services to patients with chronic, life-threatening and debilitating illnesses. PAF case managers serve as active liaisons between the patient and his or her insurer, employer and/or creditors to resolve insurance, job retention and/or debt crisis matters as they relate to the diagnosis. The website also has a state-by-state financial resource guide that provides information about seeking financial assistance for a broad range of needs.

The Patient Advocate Foundation administers the Co-Pay Relief Program, which provides financial support to insured patients who must financially and medically qualify to receive assistance with pharmaceutical co-payments.

ROAD TO RECOVERY (AMERICAN CANCER SOCIETY)

National Headquarters

250 Williams Street, NW

Atlanta, GA 30303

800.227.2345

cancer.org/treatment/support-programs-and-services/road-to-recovery.html

Road to Recovery is an American Cancer Society service program that provides transportation for cancer patients to their treatments and home again. Transportation is provided according to the needs and available resources in each community.

RXASSIST

info@rxassist.org

rxassist.org

RxAssist is a web-based medication assistance resource center. It provides a searchable database of patient assistance programs. You can search the databases by generic or brand drug name or search by the pharmaceutical company name.

TENDER LOVING CARE (AMERICAN CANCER SOCIETY)

800.850.9445

tlcdirect.org

TLC is an American Cancer Society (not-for-profit) catalog and website for women in treatment for cancer. It offers affordable products for women with treatment-related hair loss and for women with breast cancer. Products include wigs, hats, scarves, kerchiefs, turbans and breast forms.

Pharmaceutical Patient Assistance Programs

LYNPARZA (OLAPARIB) **FASLODEX (FULVESTRANT)** **ZOLADEX (GOSERELIN)**

AstraZeneca Pharmaceuticals
AZ&Me Prescription Savings
Program
800.292.6363
azandmeapp.com

IBRANCE (PALBOCICLIB) **TALZENNA (TALAZOPARIB)**

Pfizer
Pfizer RxPathways
844.989.7284
pfizerrxpathways.com
pfizeroncologytogether.com

KEYTRUDA (PEMBROLIZUMAB)

Merck and Co., Inc.
Merck Patient Assistance Program,
Inc.
855.257.3932
merckhelps.com

KISQALI (RIBOCICLIB) **ZOMETA (ZOLEDRONIC ACID)**

Novartis Pharmaceuticals
Novartis Patient Assistance
Programs
800.277.2254
patientassistancenow.com

VERZENIO (ABEMACICLIB)

Lilly Oncology
844.837.9364
[verzenio.com/savings-support/
continuouscare](http://verzenio.com/savings-support/continuouscare)

HERCEPTIN (TRASTUZUMAB) **KADCYLA (ADO-TRASTUZUMAB** **EMTANSINE)** **PERJETA (PERTUZUMAB)** **TECENTRIQ (ATEZOLIZUMAB)** **XELODA (CAPECITABINE)**

Genentech, Inc.
Genentech AccessSolutions
866.422.2377
genentech-access.com/patient.html

LUPRON (LEUPROLIDE)

myAbbVie Assist
800.222.6885
[addbvie.com/patients/patient-
assistance](http://addbvie.com/patients/patient-assistance)

XGEVA (DENOSUMAB)

Amgen
[amgensafetynetfoundation.com/
about.html](http://amgensafetynetfoundation.com/about.html)

Quality of Life



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Improving Quality of Life

During the past 30+ years, breast cancer organizations, advocates and healthcare providers have been working to improve the quality of life for women who are facing MBC. Good quality of life means something different to every woman living with MBC, and achieving it may require a slightly different approach every day. Quality of life is discussed throughout this Navigator; this section will focus on the following:

- Relieving stress and anxiety
- Building a supportive community
- Managing relationships
- Finding meaning
- Special issues and concerns

“When living with metastatic breast cancer, you are most likely facing a lifetime of various treatments. In this scenario, quality of life is everything.”

Kristen M., diagnosed at 31

Relieving Stress and Anxiety

When you are living with MBC, it is normal to experience a certain amount of stress and anxiety. Uncertainty about the future, concerns about pain and fears around the loss of independence are just a few contributing factors. It is important to remember to not blame yourself, but to deal with the symptoms of stress and anxiety head on.

There are many different ways to help relieve stress, and you should explore the strategies that work best for you. You might want to see a licensed therapist, participate in a support group or ask your doctor to prescribe a medication designed to curb anxiety and/or depression. Eliminating things that make you feel anxious while introducing activities that promote a calm, relaxing environment can help reduce your stress level and improve your quality of life. Try one of the following creative or mind-body practices:

- Paint, draw or make a collage or vision board to help creatively express your emotions. You might even want to work with an art therapist to help guide you.
- Write down your thoughts and feelings in a journal, or express yourself through creative writing such as poetry or a short story.
- Take a yoga class or practice in a quiet room at home.
- Meditate or practice mindful, deep breathing.
- Listen to music – whatever kind makes you most happy.
- Take a walk around your neighborhood, in the park or anywhere that connects you with nature.
- Visit a reiki practitioner to balance your energy. Reiki is a Japanese technique for stress reduction, relaxation and healing.

Making time to enjoy the small pleasures life has to offer can also help relieve stress. Eat dinner with your family, meet your girlfriends for coffee, take a bubble bath or do whatever it is you love.

**Admitting you need help
isn't a weakness,
it's a strength.**



If you find that your anxieties, worries or fears are becoming overwhelming and are interfering with your day-to-day activities or sleep habits, talk to your doctor. You may be experiencing symptoms of depression, which is a serious medical condition that needs to be treated professionally. Also speak with your healthcare providers if you are having difficulty sleeping. If relaxation exercises do not work, medication may be recommended, at least for the short term. Appointments with a licensed therapist can also help to relieve your anxieties and fears. It is comforting to be able to speak openly in a safe environment and without fear of judgment.

Recognize Your Limits

Lest it sound as if you should be keeping up with juggling everything you do all the time to enjoy life to the fullest, it is also important to recognize the limitations that come with MBC and its treatment. The demands of treatment usually make it necessary to cut back and be careful not to overdo things, at least during some periods. Recognizing these limits and cutting back can help to reduce disappointments at times when you can't "do it all." It is okay to rest and take time for yourself. Try not to feel guilty when you need to do so. Know that it is imperative to your restoration.

Building a Supportive Community

Maintaining a good quality of life will be easier if you have a solid support system in place. Your supportive community includes the healthcare professionals discussed in the Making Treatment Decisions section on page 27, but it also includes close friends or family who can coordinate help from a larger network of support. Friends often want to help, and it can be beneficial to you and your family, as well as your friends, if you can find a way to focus their support in areas that are useful to you. For example, friends can cook dinner for you and drop it off on nights that you know you won't be feeling well because of treatment.

If you have young children, it may be helpful to coordinate rides to and from school through another parent. In other words, allow one or more friends to coordinate help for you from your larger network of friends. This may help you feel comfortable asking for help, and it will relieve you of the burden of coordinating everyone. There are websites devoted to organizing rides, meals and other help, as well as providing updates to friends. See websites listed on page 106.

We know that not everyone has a traditional family unit. Maybe you are single and living far from friends and family, or maybe you are parenting alone without a structured support network for your children. This can be difficult, but there are resources out there. Don't be afraid to ask your hospital's social worker or local church, synagogue and school about ways you can find financial, childcare or emotional help. Also, sometimes support comes from unexpected places. You may have a trusted co-worker or caring neighbor who can assist with meals or transportation, for example. Most people want to find ways to help, and this removes some of the burden off of you, too.

It is important to remember that most young women do not find all of the



support they need from just family and friends. You may feel that you are the only young woman who is living with MBC, and sometimes your family and friends can't relate. In fact, many others are going through a similar experience.

Building your supportive community of women who are also living with MBC or coping with similar issues can reduce feelings of isolation and increase a sense of hopefulness. Many women, especially young women, find it important to connect with others when facing breast cancer, and they value the friendships made through the breast cancer community.

You can also contact YSC's SurvivorLink peer mentoring program if you would like to be connected directly to another young woman living with MBC. Call YSC's toll-free number at 877.972.1011 or email support@youngsurvival.org.

Support groups exist in many different formats: formal and informal; online; over the phone; in person or on community boards and social media. It's important to find the group that is right for you.

If you do not live in a big city, you may find that there are no in-person groups for you to attend. Through YSC's Face to Face program, you can create your own (youngsurvival.org/meet-in-person) or participate in YSC's online video support group for young adults with MBC. For information, see youngsurvival.org or call 877.972.1011.

Managing Relationships

Relationships with co-survivors (your partner, relatives, children, friends) are important during times of stress. Keeping the lines of communication open will help you feel understood and contribute positively to your quality of life. Try to be open about your disease, how treatments are affecting you and how others can help.

Remember that most young women do not find all of the support they need from just family and friends.

Partners Coping with MBC

A diagnosis of MBC presents a challenge for any relationship; however, resources are available to help you and your partner cope with the emotional difficulties that you will face following this diagnosis. The Internet is a useful place for young adults with metastatic disease and their co-survivors to find support either locally or online.

Talk with your oncology social worker or inquire at your doctor's office. If you have a place of worship, you may find that this is a good source of guidance and support. Visit YSC's searchable online Support directory at youngsurvival.org/directory to find organizations that may be of support to you and your partner.

Find a way to make time for yourselves. You are probably spending time together during doctor visits, running errands or perhaps caring for your children, but couples sometimes forget to take the time to communicate with each other. Make the effort to schedule time when you and your partner can give each other your undivided attention.

Make it clear that you want him or her to feel comfortable expressing his or her emotions. Some co-survivors feel the need to put on a brave face for their partner. However, it may be more helpful if your partner is able to acknowledge his or her own fears. When a co-survivor presents a strong front, it may become more difficult for the patient to open up and communicate honestly.

Encourage your partner to listen to what you are saying. It is common for partners to respond to an illness by trying to act as a “superhero” who knows how to solve every problem. No one can have all the answers when dealing with cancer. Let your partner know that you need to voice your concerns. Encourage your partner to listen without judging or focusing on providing answers or solutions.

Approach physical intimacy with sensitivity. Let your partner know how you feel about sexual intimacy. Your feelings may change throughout the process of diagnosis, treatment and recovery. This may be due to the side effects of treatment, physical and emotional exhaustion or changes in body image. Although sexuality may become more complicated, try to express your needs to your partner regarding your desire for physical closeness and affection.

Supporting Your Parents

No parent expects that his or her child will be diagnosed with breast cancer. Whether a parent is your primary support or not, he or she may have many questions and their own worries. This can be difficult for you to manage, while you manage your own health, so providing external resources is important. Encourage your parent to find his or her own support group, like those through CancerCare. Many also find release in speaking to a close friend or family member. Another great resource is Mothers Supporting Daughters (mothersdaughters.org). Perhaps find those you trust and ask them to check on your parent or take him or her out from time to time. It's also helpful for many families to maintain normalcy. If you and your parents talk on the phone every Sunday or spend your birthday at the the local ice cream shop, keep doing that. Routines and special traditions can help keep relationships strong, even when other parts of your lives feel difficult.

Single and Dating with MBC

Being diagnosed with MBC while single can have its own unique challenges. Single women may not have that one person who can meet many of their physical and emotional needs. Single women with cancer rely on a larger network of friends, parents and other family members for love, help, companionship and support. This can make independent young women feel uncomfortable about being too dependent on friends and family. Some

relationships will be strengthened, but others may be strained, and it's not always possible to predict which direction they will take. Recognize the value of those friends who are truly there for you, and try not to spend a lot of emotional energy on those people who are unable to support you.

If you are still interested in dating, ask your friends and family members if they know of, or can keep their eye out for, someone who could be right for you. Ask a friend to help you get out of the house to a place where there may be opportunities to meet new people—even when you aren't feeling like getting out there.

Dating while coping with MBC brings further challenges. Physical changes may make it hard to feel comfortable in your body, and fatigue and pain can be discouraging. Menopausal symptoms from treatment are common and can cause changes in your interest in sex and arousal.

Sometimes you may feel as if you are the only one who is preoccupied with a major concern. We tend to assume that breast cancer is the “elephant in the room” that no one is talking about. It's possible that the person you are dating isn't sure how to tell you about his or her own “elephant.” To try to take some of the weight off of your shoulders; imagine that the person across from you is wondering how to tell you that he or she is divorced, is infertile, has children from another marriage or has had cancer.

Many single people use online dating to meet someone. Though online dating presents different benefits or challenges, often how you handle sensitive topics (like your diagnosis) would be the same. When and how much you tell a date or potential partner is your decision alone. Just be clear of your own expectations of the process. Are you looking for a casual activity partner, companion or something more serious? If you are looking to move forward with someone and they act negatively or insensitive to your diagnosis, this may be a sign that this person will not provide the support you need.

If you feel you want to date but are having trouble getting started, check in with yourself. Are you experiencing fatigue from a particular treatment? Are your blood counts low? Are you feeling anxious or depressed? It may be necessary to treat these issues before being able to really focus on dating.

Sexual Health and Intimacy

Sexual health and intimacy are important aspects of quality of life, and a diagnosis of MBC does not change this.

A diagnosis of MBC presents a challenge for any patient, whether or not

you are in a relationship. The most important thing to know is that help is available, and resources (either at your doctor's office, cancer center or even online) are available. Visit YSC's searchable online Support directory youngsurvival.org/directory to see if there are any organizations near you.

Sexual health can mean different things to different women, but in general, it includes the way you see and feel about your body, your sense of desire, your state of arousal, sexual activity, orgasm and satisfaction. It can be impacted by how you are feeling emotionally, the way you and your partner (if you have one) are doing as a couple and as individuals, and your current medications and cancer treatments. Sometimes, couples therapy can be helpful in working out the barriers to intimacy and sexual satisfaction that so often come with a diagnosis of cancer.

If there are issues related to your sexual health or intimacy that cause you distress, seek help. Some patients are able to bring this up with their treatment team, while others do not feel comfortable doing so. If you are in the latter group, talk with your nurse or an oncology social worker. After all, if your healthcare providers do not know what you are feeling or experiencing, they cannot begin to help you.

Some women with MBC find barriers to intimacy can be:

- Physical changes that impact body image
- Pain that can make close contact uncomfortable or pain from penetration
- The loss of a breast or breast tissue
- Fatigue, discomfort and hormonal changes that can reduce libido
- Depression and other psychological factors that can emotionally and physically impact sexuality and intimacy in relationships

For partners, some of the barriers may be:

- Concern about causing pain
- Knowing when to approach intimacy and when not
- Anxiety about touching a scar or wondering if it is safe to be intimate while a partner is in treatment (particularly with chemotherapy)

Depending on the issue, medications and other treatments may be available. For those who engage in vaginal penetration, this might include vaginal moisturizers or the use of vaginal lubricants and dilators. Additional treatments may include vaginal estrogen or dehydroepiandrosterone (DHEA), or even 4% lidocaine jelly. Consult your oncologist before using any products that contain estrogen.

Healthcare providers are continually learning more and more about how best to treat the symptoms of sexual dysfunction, and there is no reason why you should not benefit from what they are learning. It is important that intercourse be approached with sensitivity. Although it may have become more complicated, it is still possible. However, the goal should not be completion of any one sexual act but rather the pursuit of pleasure.

Body image is a significant issue for many young women with breast cancer. Scars, the loss of breasts and changes to erogenous zones may all be contributing factors. Weight changes and hair loss can also contribute to feeling unattractive or less than sexy. Women tend to put a great deal of pressure on themselves to try to meet today's standards when it comes to "beauty," even when dealing with the side effects of breast cancer treatment. Remember that feeling sexy is about confidence, and that can only come from within. Your brain is the most important sex organ you have! Take the time to build (or re-build) your self-esteem when it comes to your physical appearance. Get to know your body and its needs, as they may be new or different than before you began treatment.

Try to reconnect with your physical self by getting a massage, taking a yoga or belly dancing class or relaxing in a hot bubble bath. Concentrate on your own well-being and believe that you deserve to be admired, loved and able to experience intimate pleasure.

Beyond medical treatment, communication between partners is crucial. Be honest about what you are going through and let your partner know if you are having sexual difficulties. Encourage your partner to be honest with you, too, and don't be afraid of talking about what the diagnosis of MBC means to you both. Much of this can help improve the sense of intimacy between two people. Practice being intimate without having sex. Being close together without the pressure of an escalation to sex may allow one or both partners to relax and focus on feeling close and connected again. Experts often recommend practicing sexual pleasure with yourself if you are having difficulty being intimate with a partner or if you don't have one.

For women who are not in a relationship, the diagnosis of MBC can bring its own unique challenges. The issues can range from body image concerns to when, if and how to disclose your medical diagnosis to a potential new partner. These are real concerns that should not be underestimated. Again, talking to your medical team or another trusted person can be helpful and provide the support you need when you begin dating.

Helping Children Cope

For many mothers, one of the first reactions to being diagnosed with breast cancer is, “What about my kids?” There is no one right way to help children cope with their mother’s breast cancer because everyone is different. There are general guidelines that can help families meet their children’s unique needs.

Communication

Talking about what is happening is extremely important, but not always easy. It is normal to want to protect children from bad news, but children of all ages tend to be good at picking up parents’ distress, even when parents think they are hiding it well.

Having a clear explanation about what is happening helps children understand that they are not to blame for parents’ worries, and it prevents them from creating explanations for changes that are just plain wrong and sometimes much worse than reality.

Using the word “cancer”

Many parents wonder whether they should mention the word “cancer” to children. They worry that doing so will make children more upset than just saying, “Mommy is sick.” A problem with using only general words like “sick” or “boo-boo on my breast” is that children hear these words applied to themselves when they have colds or scrapes. They can end up feeling confused when you don’t recover as quickly as they do, and they may worry that getting “sick” will be just as hard for them the next time.

Telling children about your MBC diagnosis

The exact words you use to talk with your children will depend on their ages and whether they were aware of an initial diagnosis (if there was one). Children of all ages can benefit from knowing the name of the illness (breast cancer), the type of treatment and how cancer will affect their own day-to-day lives.

Sometimes beginning a conversation with a description of what children may have noticed already can make it easier: “I think you know that I’ve had a few doctors’ appointments lately...we just figured out that I have something called breast cancer. My doctors are going to give me a treatment, called chemotherapy, to help me get better. I will be going to the doctor’s office at the hospital for my medicine every week, and on the days I go, Isabelle’s mom will take care of you until I get home.”

Telling children about your prognosis

Speaking with your children about the likely outcome of your disease is even more difficult. What you tell them and when will vary on a case-by-case basis, depending on the extent of your disease, your current prognosis, and the age and maturity of your children. You may wish to tell them that your cancer is not curable, but that you are in treatment and explain how the treatment helps.

Telling children that you are doing everything you can to be here for them as long as possible can be reassuring. It is not uncommon for children to ask if you will die. Remind them that everyone will die, that we never know exactly when, but that you are here for them now. Being open and honest is one of the greatest gifts you can give your children. Having other family members, clergy or a therapist present for this conversation can help to relieve you of some of the burden and provide support to both you and your children.

Keeping lines of communication open

Once you have told your children about your diagnosis and treatment plan, then what? Check in and keep talking over the following days and weeks. You may have needed to ask your doctors the same questions more than once before the information really sunk in. Your children may need to do the same. Their reactions will change as the news sinks in and your treatment begins, and as routines at home begin to change. It helps to encourage children not to worry alone, and to talk about their concerns and feelings with a loving adult. Questions like, “Are you hearing too much or too little about my cancer?” and “Are there questions (or feelings) you have but don’t want to share with me? Who else could you talk with?” might help start children talking. Parents seem to have a hard time asking about their children’s feelings, perhaps because it is so difficult to see our children feeling sad or scared. Some children believe that sharing their feelings will upset their parents and need to be reassured that speaking with another trusted adult is okay, even if it’s not a parent. Be sure to connect up with your children’s teachers and make them aware of what is happening in their lives currently. Sometimes children will act differently in school when feeling stressed or worried.

The things that upset your children may surprise you, so asking about their feelings can help your family figure out how to work together to lower children’s distress. For example, depending on their age, your children may feel frustrated that they can’t have friends over when you’re not feeling well. They may feel like their house is not their own because so many visitors are stopping by to offer support. They may feel overwhelmed by being asked to “step up to the plate” and help out with housework or care for younger siblings.

A question like, “What bothers you the most about my having cancer?” sends the message that it’s okay for kids to share negative feelings. Your job then is to listen, accept the feelings and see if you can come up with some solutions together. Even if there is no easy solution, listening and even wishing with them that things were different, can help: “I’m glad you told me how sad and angry you are that we won’t be able to go on the vacation we planned this year... we will try to plan another vacation, but I wish that I could magically bring our vacation to us so that we could have the vacation we planned.” Be okay if you receive no answer, especially from teens who may be talking with friends instead of you. Regardless, it is important to keep checking in.

Family therapy or talking with a faith leader can be helpful, especially for discussing hard topics. If you have to be hospitalized, and you know about it in advance, speak with your children about what is happening, what to expect and who will be taking care of them while you are in the hospital. Counseling or support for children may be available through your cancer center or nonprofits such as Cancer Support Community and CancerCare.

Family time

Along with maintaining normal routines, it will help if your children can still enjoy time with you when cancer isn’t the main focus. It can be reassuring to everyone to feel that the good parts of life are carrying on, even in the face of illness. You may find that you have many visits and phone calls from friends and family wanting to check in. This can be hard on children.

You may feel supported by these conversations, but your children more likely will feel uncomfortable and tired of hearing about cancer. It can help to let friends know that while you are with your children, you would prefer not to give updates. Also, set aside some “cancer-free” time at home, including during meals and at your children’s bedtime, when you don’t answer the phone.

Part of preserving your quality of life is to know what milestones are upcoming in the months that lie ahead. It is important that your treatment team be aware of them with the goal that these milestones of significance to you be preserved. This means not starting a new treatment 48 hours before going to your niece’s wedding or attending a family reunion, for example.

Some families feel comfortable choosing a close friend or family member to be in charge of giving updates to everyone else, either by phone or email. Websites such as CaringBridge ([caringbridge.org](https://www.caringbridge.org)) are excellent free tools for keeping everyone updated. One person can also be chosen to organize people who are offering to help your family. Then, when someone asks how he or she can help, and you can’t immediately think of anything, you can

suggest they contact your “Captain of Kindness” so when you need something, they can be asked. LotsaHelpingHands (lotsahelpinghands.com) is another helpful online tool. Don't be afraid to ask for help beyond just meals and rides to your appointments. Housecleaning, yardwork, dog-walking and childcare assistance are all tasks that need to be done and may become harder to manage while you are in active treatment. People want to help – let them!

Risk of Cancer in Children

Many young mothers who are diagnosed with breast cancer are concerned that their children might get cancer in the future. Carrying known inherited genetic mutations, including in BRCA1, BRCA2 and other breast cancer susceptibility genes, can significantly increase the likelihood of being diagnosed with breast and other cancers. While scientists have made great strides in advancing knowledge of genetics in recent years, much remains unknown.

The best way to understand your children's risk of having genetic mutations is to see a genetic counselor and consider testing yourself to see if you carry a genetic mutation. If you are negative, it is less likely that your cancer was caused by a genetic mutation that you could have passed to your offspring. If you are positive, then testing other individuals in your family can be more specific and less expensive, as the testing will focus on looking for the known mutation.

It is generally recommended to wait until children are grown before testing them to determine their own risk. There are exceptions, however, if testing a child will impact their medical management in the near future. For example, ask your counselor about any related mutations found in children and recommended next steps. Children should be able to decide for themselves whether they want to know this information. And because knowledge about genetics advances every year, by the time the children are tested, they will likely receive more valuable information about their individual risk. See the discussion on page 85 about genetic anti-discrimination laws if you or your children test positive for a BRCA1 or BRCA2 mutation.

For more information about helping children cope, visit youngsurvival.org and download YSC's fact sheet, *Helping Children Cope with Breast Cancer*.

Finding Meaning

“Positive” Outlook

Young women living with MBC sometimes feel pressured to cultivate a positive outlook. Well-meaning friends and family members sometimes insist that a positive outlook will enable you to overcome cancer or live longer, but it’s not helpful to add the burden of staying cheerful to someone who is facing MBC.

It is important to find room for all of the emotions you may be feeling. Sometimes you will feel hopeful, and other times you may experience sorrow or despair. This is normal. To ask someone only to be positive denies her the ability to be true to herself and her feelings and face reality head-on.

That said, generally when people feel optimistic and hopeful, they feel better than when they are feeling down, overwhelmed or negative about their situation. It’s important to understand the distinction between trying to have an optimistic outlook to help you feel better versus having a positive attitude in order to beat cancer. There is no scientific evidence that having a positive outlook can guarantee better outcomes for breast cancer. Choosing optimism some of the time may help you better cope with some of the challenges you will face and increase your quality of life.



Special Issues and Concerns

Fertility and Adoption



If you were diagnosed before you started or completed your family, you may be concerned about fertility and/or wondering about adoption. Many of the treatments you are likely to undergo for MBC will impair your ability to have children. In addition, depending on the extent of your MBC and your prognosis, your physician may not recommend pregnancy. If you are interested in learning about your options for a future family, you should discuss this with your

doctors early in your MBC diagnosis. Adoption is generally difficult for cancer patients, and more so for those with MBC. If adoption is something of interest to you, discuss this with your physician and contact local adoption agencies for their insight. State law may impact your options, as well. You can find fertility and adoption resources by visiting YSC's searchable online Support Directory.

Diagnosis during Pregnancy

Breast cancer is the most common form of cancer in women who are pregnant or have recently given birth, occurring in one out of every 3,000 pregnancies. A breast cancer diagnosis during pregnancy requires special considerations and consultation with your physicians. One of YSC's partner organizations, Hope for Two, offers several services including peer support, an international registry and connection to a Maternal Fetal Medicine physician who offers guidance to women and/or their physicians. Learn more at hopefortwo.org. You can also connect with other young women diagnosed during pregnancy on the YSC Discussion Boards.

Additional Resources

Here is a partial list of additional resources that may enhance quality of life. For a more complete list, visit YSC's searchable online Support directory at youngsurvival.org/directory.

In-Person Conferences

YSC SUMMIT AND REGIONAL SYMPOSIA

youngsurvival.org/get-involved/conferences

Held throughout the country, these in-person YSC events educate, support and connect young women diagnosed with breast cancer and their co-survivors. The annual YSC Summit includes special sessions specifically for young adults living with MBC. Symposia are held two or more times a year and focus on wellness.

ANNUAL CONFERENCE FOR WOMEN LIVING WITH METASTATIC BREAST CANCER

lbbc.org/programs-events/educational-programs/conferences

The annual "Living Beyond Breast Cancer" conference provides information updates and support for women of all ages diagnosed with MBC.

Various Susan G. Komen Affiliates throughout the country offer annual conferences and other events specifically for those living with metastatic breast cancer that provide education and support. Visit ww5.komen.org/FindingLocalMBCEvents to find out if there are any upcoming events near you.

Additionally, Metastatic Trial Talk has a "Conference Talk" section on their website, which highlights upcoming conferences relevant to those living with metastatic breast cancer and provides links to view content from previous conferences (metastatictrialtalk.org/category/conference-talk).

Retreats

In addition to the retreats listed in the searchable online Support Directory:

CAMP KEEPSAKE

c/o Cancer Hope Foundation
568 Constitution Avenue, Unit F
Camarillo, CA 93012
805.384.5445
info@cancerhopefoundation.org
cancerhopefoundation.org/programs

Camp Keepsake, a program of Cancer Hope Foundation, is a place where adults with cancer and cancer survivors can go with their family and friends to spend time away from the hectic and often stressful routine of doctor visits and treatments.

CASTING FOR RECOVERY METASTATIC RETREATS

512.940.0246
susan.gaetz@castingforrecovery.org
castingforrecovery.org/stageiv

Casting For Recovery offers a retreat program that combines education and support with the sport of fly fishing. They have a retreat program specifically for those diagnosed with metastatic breast cancer. The retreats are offered at no cost to participants.

FIRST DESCENTS

3001 Brighton Blvd, Suite 623
Denver, CO 80216
303.945.2490
info@firstdescents.org
firstdescents.org

First Descents offers outdoor adventure sports, activities and retreats for young adults (ages 18-39) diagnosed with cancer. No experience is necessary and there are scholarships available.

IMAGE REBORN FOUNDATION (UTAH)

5445 S. Highland Dr., Ste. 5
Salt Lake City, UT 84117
801.679.3065
info@imagerebornfoundation.org

imagerebornfoundation.org/retreat-program

Image Reborn Foundation's renewal retreat program is designed and facilitated by professional staff with experience in addressing the unique concerns of women diagnosed with breast cancer. Each retreat is focused on support and renewal. The retreats are held on the weekend in the mountains outside of Salt Lake City, Utah. Each retreat hosts around 6-8 attendees, and lodging, activities, and meals are covered. They offer specialized retreats for MBC survivors and young breast cancer survivors.

A JOURNEY OF COURAGE AND HOPE FOR COUPLES: A METASTATIC BREAST CANCER RETREAT

Bon Secours Retreat Center
Marriottsville, MD
Contact Lillie Shockney

410.614.2853

shockli@jhmi.edu

hopkinsmedicine.org/avon_foundation_breast_center/news_events/retreats

This breast cancer retreat is designed for women living with breast cancer metastases and their adult daughter, mother, friend or partner who supports them through their breast cancer experience. Free lodging and meals provided. Retreats are open to individuals from across the country. You may also contact the National Breast Cancer Foundation to find similar retreats in your area (nationalbreastcancer.org).

A JOURNEY OF COURAGE AND HOPE FOR WOMEN AND THE WOMEN WHO SUPPORT THEM: A METASTATIC BREAST CANCER RETREAT

Bon Secours Retreat Center
Marriottsville, MD
Contact Lillie Shockney

410.614.2853

shockli@jhmi.edu

hopkinsmedicine.org/avon_foundation_breast_center/news_events/retreats

This breast cancer retreat is designed for women living with breast cancer metastases and their spouse or partner who supports them through their breast cancer experience. Free lodging and meals provided.

KICK CANCER OVERBOARD CRUISES

732.571.1960

kickit@kickcanceroverboard.org

kickcanceroverboard.org/next-cruise

Their mission is to give a FREE cruise to people who have been affected by cancer. It offers them a break for a few days, where the most important question is not how to pay for the next medical bill, but whether to play bingo, get a massage or sing karaoke.

LITTLE PINK HOUSES OF HOPE

2442 Tribek Court

Burlington, NC 27215

336.213.4733

littlepink.org

Little Pink Houses provides free week-long vacations for patients and their families. Their mission is to promote breast cancer recovery by offering opportunities for survivors to reconnect and celebrate life. They believe a cancer diagnosis does not just affect the patient, but the entire family. Every retreat is designed to help families relax, reconnect and rejuvenate during the cancer journey.

STOWE WEEKEND OF HOPE

P.O. Box 604

Stowe, VT 05672

802.387.0379

stowehope.org

For one weekend each spring, the Stowe Weekend of Hope offers an educational and inspirational retreat for cancer survivors and their families in Stowe, Vermont. The Stowe Weekend of Hope provides a low or no-cost opportunity for cancer survivors, their families and caregivers, with access to education, healing, and support throughout the weekend retreat.

Other Resources

AMERICAN PSYCHOSOCIAL ONCOLOGY SOCIETY HELPLINE

866.276.7443

apos-society.org

APOS is a multi-disciplinary professional organization dedicated to the psychosocial aspects of cancer treatment. The APOS helpline assists people with cancer and their caregivers in finding counseling services in their own communities.

CAMP KESEM

10586 West Pico Boulevard, #196

Los Angeles, CA 90064

253.736.3821

campkesem.org

Camp Kesem offers free summer camp to children who have a parent with cancer. Camp Kesem is available in 42 states across the country.

CANCERCARE, INC.

275 Seventh Avenue, Floor 22

New York, NY 10001

800.813.4673

info@cancercare.org

cancercare.org

CancerCare is a national non-profit organization that provides free professional support services to anyone affected by cancer, including those living with cancer, family, friends and the bereaved. CancerCare programs, including counseling, education, financial assistance and practical help, are provided by trained oncology social workers free of charge.

CARINGBRIDGE.ORG

CaringBridge is a non-profit organization that provides free websites that connect family and friends during a serious health event, care or recovery. Authors add health updates and photos to share their story, while visitors leave messages of love and support in the guestbook.

HOLDING TIGHT, LETTING GO: LIVING WITH METASTATIC BREAST CANCER

Musa Mayer (Patient Centered Guides, 1997)

This book offers the stories of 40 women and men as they struggle to come to terms with MBC. It addresses the fact that women with MBC generally go on to live with their disease, often for many years, and that through facing their reality, and gathering information and support, the time they have can be full and meaningful.

JACK & JILL LATE STAGE CANCER FOUNDATION

3282 Northside Parkway, NW, Suite 100

Atlanta, GA 30327

404.537.5253

jajf.org

The Jack & Jill Late Stage Cancer Foundation gives children and their parents an opportunity to spend time together creating memories in the face of the hardships and uncertainties brought on by a late-stage cancer diagnosis.

KIDSKONNECTED

1024 Bayside Dr. #235

Newport Beach, CA 92660

949.582.5443

info@kidskonnected.org

kidskonnected.org

Provides friendship, understanding, education and support for kids and teens who have a parent with cancer.

METASTATIC BREAST CANCER NETWORK

165 West 46th Street, Suite 712

New York, NY 10036

888.500.0370

mbcn@mbcn.org

mbcn.org

Metastatic Breast Cancer Network (MBCN) is a national independent patient advocacy group dedicated to the unique concerns of women and men with MBC. They aim to help those living with stage IV breast cancer be their own best advocate by providing education and information on treatments and coping with the disease.

METAVIVOR

92 Maryland Avenue

Annapolis, MD 21401

818.860.1226

info@metavivor.org

metavivor.org

This advocacy group raises awareness of MBC and the need for more MBC research funding. It also directly funds MBC research.

METASTATIC TRIAL TALK

415.476.5777

metastatictrialtalk@gmail.com

metastatictrialtalk.org

Metastatic Trial Talk (MTT) is published monthly and provides those living with MBC with carefully selected news and information about metastatic breast cancer research and clinical trials. Each issue features information on seven topic areas: research news, conference talk, new trials, personal stories, inside clinical trials, resources and support, and “from the experts.”

THERESA'S RESEARCH FOUNDATION

618.580.0908

josh@theresasresearch.org

theresasresearch.org

Theresa's Research Foundation funds research for MBC in order to provide better treatment options, improve quality of life for those living MBC, and one day lead to a cure. They also hold an annual medical conference for metastatic breast cancer and, in conjunction with the conference, they offer an advocacy program.

Glossary



Glossary

Portions of this glossary have been adapted from the National Cancer Institute (NCI) Dictionary of Cancer Terms. For a complete listing, visit the NCI website at cancer.gov.

A

ADVANCE DIRECTIVE

A legal document that states the treatment or care a person wishes to receive or not receive if he or she becomes unable to make medical decisions (for example, due to being unconscious or in a coma). Some types of advance directives are living wills and do-not-resuscitate (DNR) orders.

ALKYLATING AGENTS

Alkylating agents were among the first chemotherapy drugs developed and are still commonly used today. Alkylating agents form chemical bonds with a cell's DNA and prevent the cell from dividing.

ALTERNATIVE MEDICINE OR THERAPY

Practices used instead of standard treatments. See "Complementary and Alternative Medicine."

AMENORRHEA

The absence or halting of the menstrual cycle in premenopausal women.

ANTHRACYCLINES

A type of antibiotic that comes from certain types

of Streptomyces bacteria. Anthracyclines are used as chemotherapy to treat many types of cancer. Anthracyclines damage the DNA in cancer cells, causing them to die.

ANTIBODY DRUG CONJUGATE (ADC)

A class of targeted therapy drugs, where a very strong chemo drug is attached to an antibody that targets and binds to a specific cancer cell protein or receptor. The chemo is delivered directly to the cancer cell and is not activated until it reaches it.

ANTI-METABOLITES

A type of chemotherapy that blocks enzymes necessary for DNA synthesis.

ANTI-MICROTUBULE AGENTS

A type of chemotherapy that disrupts the ability of a cell to divide.

ANTI-TUMOR ANTIBIOTICS

A type of chemotherapy that acts by binding with DNA and preventing RNA synthesis. Preventing RNA synthesis does not allow a cell to make the proteins necessary for cell

survival, and as a result the cell dies. Anti-tumor antibiotics are not the same as antibiotics that fight bacterial infections.

ANTIBODIES

Special proteins produced by your immune system that help to protect the body from disease.

AROMATASE INHIBITOR

A drug that decreases the amount of estrogen made in the body after menopause. This can slow or stop cancer cells that need estrogen to grow.

B

BENIGN

Not cancerous.

BIOLOGICAL THERAPY

Also known as immunotherapy or biotherapy, this term refers to treatments designed to use the body's immune system (either directly or indirectly) to fight cancer or reduce the side effects of cancer treatment.

BIOMARKERS

A biological molecule found in blood, other body fluids, or tissues that is a sign of a normal or abnormal process, or of a condition or disease. A biomarker may be used to see how well the body responds to a treatment for a disease or condition.

BIOPSY

The removal of a sample of tissue for examination under a microscope to check for cancer cells. Your doctor may want to biopsy sites of metastasis to learn the characteristics of the metastatic tumor(s).

BISPHOSPHONATES

A group of drugs routinely used in the treatment of osteoporosis. In cancer, bisphosphonates may reduce the incidence of

metastasis to the bones and, when cancer has spread to the bones, they may prevent fractures, promote healing and reduce pain.

BLOOD-BRAIN BARRIER

A special layer of the brain that protects it from infection and potentially toxic substances, made up of a network of blood vessels with closely spaced cells. If you have brain metastases, you may hear this term. Not all treatments or chemotherapies are able to get through the blood-brain barrier.

BONE SCAN

An x-ray that looks for signs of metastasis to the bones.

BRCA1 AND BRCA2

Abbreviations for Breast Cancer Genes 1 and 2, located on chromosome 17 and 13, respectively, that help to suppress cell growth under normal circumstances. Individuals with a mutated version of these genes are at increased risk of breast, ovarian or other cancers.

C

CHEMOTHERAPY

Often referred to simply as chemo. The use of drugs to kill cancer cells. Chemotherapy can be taken orally or by needle into a vein or muscle. Chemo enters the bloodstream and travels throughout the body.

CIRCULATING TUMOR CELL (CTC)

Cells that have detached from a primary tumor and circulate in the bloodstream. CTCs are extremely rare in healthy individuals and patients with non-cancer diseases but are often present in metastatic cancer.

COMPLEMENTARY AND ALTERNATIVE MEDICINE (CAM)

Forms of treatment that are used in addition to (complementary) or instead of (alternative) standard treatments, and are generally not considered standard medical approaches. Standard treatments go through a long and careful research process to prove they are safe and effective, but less is known about most types of CAM. CAM may include dietary supplements, megadose vitamins, herbal preparations, acupuncture, massage therapy, magnet therapy, spiritual healing and meditation.

COMPLETE BLOOD COUNT (CBC)

A test to check the number of red and white blood cells and platelets in a sample of blood. Also called blood cell count.

COMBINATION THERAPY

Treatment that utilizes more than one anti-cancer drug at a time.

COMPUTED TOMOGRAPHY (CT) SCAN

A series of detailed pictures of areas inside the body taken from different angles. The pictures are created by a computer linked to an x-ray machine. Also called computerized axial tomography scan, computerized tomography and CAT scan.

CYCLIN-DEPENDENT KINASE (CDK) INHIBITOR

A targeted therapy that targets specific proteins that regulate cell cycle progression.

CYTOTOXIC CHEMOTHERAPY

Anti-cancer drugs that kill cells, especially cancer cells.

D

DO NOT RESUSCITATE (DNR) ORDER

A request/decision by a patient or someone else acting on his/her behalf that tells a healthcare provider NOT to perform CPR if the patient's heart or breathing stops.

E

ENDOCRINE THERAPY

Treatment that adds, blocks or removes hormones. Synthetic hormones or other drugs may be given to block the body's natural hormones to slow or stop the growth of certain cancers (such as breast cancer). Also called hormonal therapy, hormone therapy and hormone treatment.

EPIDERMAL GROWTH FACTOR RECEPTOR (EGFR)

The protein found on the surface of some cells and to which epidermal growth factor binds, causing the cells to divide. It is found at abnormally high levels on the surface of many types of cancer cells, so these cells may divide excessively in the presence of epidermal growth factor. Also called ErbB1 and HER1.

ESTROGEN RECEPTOR POSITIVE (ER+)

This is an indication of whether the individual cancer cells in the tumor express an estrogen receptor, which means that they are receptive and sensitive to estrogen.

ESTROGEN RECEPTOR (ER) STATUS

This refers to whether the tumor is ER-positive or ER-negative. Estrogen receptors allow the hormone estrogen to attach to the cell and fuel the cancer cell's growth.

F

FLUORESCENCE IN SITU HYBRIDIZATION (FISH)

A type of lab test to detect a protein called human epidermal growth factor receptor-2 (HER2). If too much of this protein is produced, the tumor is considered HER2+. The FISH test will give a result of positive (HER2 is over-expressed) or negative.

G

GAMMA KNIFE THERAPY

A treatment using gamma rays, a type of high-energy radiation that can be tightly focused on small tumors or other lesions in the head or neck so very little normal tissue receives radiation. The gamma rays are aimed at the tumor from many different angles at once and deliver a large dose of radiation to the tumor in one treatment session. Gamma Knife therapy is not a knife and is not surgery. Gamma Knife is a registered trademark of Elekta Instruments, Inc.

GENES

Basic unit of heredity; genes are made up of DNA. Everyone has two copies of each gene, one inherited from each parent.

GENETIC TESTING

A form of medical testing that looks for changes or alterations

H

HEALTHCARE PROXY

A type of advance directive that gives a person (such as a relative, lawyer or friend) the authority to make healthcare decisions for another person. It becomes active when that person loses the ability to make decisions for him or herself.

HUMAN EPIDERMAL GROWTH FACTOR RECEPTOR 2 (HER2/NEU)

A protein involved in normal cell growth. It is found on some types of cancer cells, including breast and ovarian. Cancer cells removed from the body may be tested for the presence of HER2/neu to help determine the best type of treatment.

HORMONE RECEPTOR

A protein that binds a specific hormone to a cell. The hormone receptor may be on the surface of the cell or inside the cell.

HORMONAL THERAPY

See "Endocrine Therapy."

HYPERCALCEMIA

Accelerated loss of calcium from bones, leading to a condition where the level of calcium in the bloodstream is above normal.

I

IMAGING

Any one of a variety of radiologic techniques, including x-ray, mammography and MRI, used to produce a clinical image. Imaging is used to visualize the breast tissue or other parts of the body in order to detect any visible, suspicious masses.

IMMUNOHISTOCHEMISTRY (IHC)

A type of laboratory test used by pathologists to examine a tissue specimen and determine if cancer is present and, if so, what type of cancer it is. For example, IHC can be used to determine if a breast cancer is HER2+.

IMMUNOTHERAPY

A treatment that uses the body's own immune system to fight cancer.

INFORMED CONSENT

A process in which a person is given important facts about a medical procedure or treatment, a clinical trial or genetic testing before deciding whether to participate. It also includes informing the patient when there is new information that may affect his or her decision to continue. Informed consent includes information about the possible risks, benefits and limits of the procedure, treatment, trial or genetic testing.

L

LIVING WILL

A written statement that provides details on a person's wishes concerning medical treatment, to be used when they are unable to express those wishes.

LYMPH

The clear fluid that travels through the lymphatic system and carries cells that help fight infections and other diseases. Also called lymphatic fluid.

LYMPH NODE

A rounded mass of lymphatic tissue. Lymph nodes filter lymph (lymphatic fluid), and they store lymphocytes (white blood cells). They are located along

M

lymphatic vessels. Also called lymph gland.

MAGNETIC RESONANCE IMAGING (MRI)

A procedure in which radio waves and a powerful magnet linked to a computer are used to create detailed pictures of areas inside the body. These pictures can show the difference between normal and diseased tissue. Magnetic resonance imaging makes better images of organs and soft tissue than other scanning techniques, such as computed tomography (CT) or x-ray. It is especially useful for imaging the brain, the spine, the soft tissue of joints and the inside of bones.

MALIGNANT

Cancerous.

METASTASES

The plural of "metastasis."

METASTASIS

The spread of disease from one organ or body part to another. All cancerous tumors have the ability to metastasize.

METASTATIC BREAST CANCER

Cancer that has spread outside the breast to other parts of the body. Metastatic breast cancer may spread to organs or sites such as the liver, lungs, bone, brain or others.

MONOCLONAL ANTIBODY

A type of protein made in the laboratory that can bind to substances in the body, including tumor cells. There are many kinds of monoclonal antibodies, and each is made to

find one substance. Monoclonal antibodies are being used to treat some types of cancer and are being studied in the treatment of other types. They can be used alone or to carry drugs, toxins or radioactive materials directly to a tumor.

MTOR INHIBITOR

A targeted therapy that blocks a protein called mTOR, which helps control cell division.

MUTATION

A gene mutation is a permanent alteration in the DNA sequence that makes up a gene, such that the sequence differs from what is found in most people. Hereditary mutations are inherited from a parent and are present throughout a person's life in virtually every cell in the body. Acquired (or somatic) mutations occur at some point during a person's life and are present in only certain cells, not in every cell in the body. A mutation can also be referred to as a pathogenic or likely pathogenic variant.

N

NEUROPATHY

A nerve problem that causes pain, numbness, tingling, swelling or muscle weakness in different parts of the body. It usually begins in the hands or feet and gets worse over time. Neuropathy may be caused by some cancer treatments such as chemotherapy. Also called peripheral neuropathy.

NO EVIDENCE OF DISEASE (NED)

A term used to describe the apparent lack of visible cancer in the body. A treatment for MBC may cause NED, at least for a period of time.

O

OLIGOMETASTASIS

MBC that is in only one or a limited number of sites.

OOPHORECTOMY

Surgical removal of one or both ovaries.

OSTEONECROSIS

Condition when some non-cancerous bone cells die off in a way that is not normal.

OSTEOPENIA

Condition where there is less bone density or bone mass than normal; can lead to osteoporosis.

OSTEOPOROSIS

A condition that is marked by a decrease in bone mass and density, causing bones to become fragile.

OVARIAN SUPPRESSION

The use of surgery, chemicals or radiation on the ovaries to halt their functioning and thereby "shut off" the menstrual cycle.

P

PALLIATIVE CARE

Care given to improve the quality of life of patients who have a disease. This is for all stages of disease and is NOT hospice. The goal of palliative care is to prevent or treat as early as possible the symptoms of a disease, side effects caused by treatment of a disease, and psychological, social and spiritual problems related to a disease or its treatment.

PATIENT NAVIGATOR

Individual who assists patients in navigating their care and treatment by assisting them with scheduling appointments, answering questions related

to test results and providing guidance in decision making across the continuum of care.

PERITONEUM

The layer of tissue that lines the abdomen.

PLANT ALKALOIDS

Plant alkaloids are chemotherapy treatments derived from plants. They are a class of chemicals. Both the vinca and taxane alkaloids act as anti-microtubule agents.

POLY ADP-RIBOSE POLYMERASE (PARP) INHIBITOR

A type of targeted therapy that interferes with a cancer cell's ability to repair itself. PARP inhibitors are currently in clinical trials for patients with inherited gene mutations, such as BRCA1 and BRCA2 mutations.

POSITRON EMISSION TOMOGRAPHY (PET) SCAN

A procedure in which a small amount of radioactive glucose (sugar) is injected into a vein, and a scanner is used to make detailed, computerized pictures of areas inside the body where the glucose is used. Because cancer cells often use more glucose than normal cells, the pictures can be used to find cancer cells in the body.

PROGESTERONE RECEPTOR NEGATIVE OR NORMAL (PR-)

A tumor that is not progesterone-receptor-positive.

PROGESTERONE RECEPTOR POSITIVE (PR+)

An indication of whether the

cancer cells in the tumor express a progesterone receptor, which means they are receptive and sensitive to progesterone, a hormone that regulates important functions in a female.

PROGESTERONE RECEPTOR (PR) STATUS

This refers to whether the tumor is PR-positive or PR-negative. Progesterone receptors allow the hormone progesterone to attach and activate the cell.

PROGNOSIS

A prediction of the likely outcome of a disease.

PROGRESSION

The course of a disease, such as cancer, as it becomes worse or spreads in the body.

RADIATION THERAPY

The use of high-energy radiation from x-rays, gamma rays, neutrons, protons and other sources to kill cancer cells and shrink tumors. Radiation may come from a machine outside the body (external-beam radiation therapy), or it may come from radioactive material placed in the body near cancer cells (internal radiation therapy).

RANKL (LIGAND) INHIBITOR:

A type of drug that works to prevent the development of osteoclasts, which are cells that break down bone (bone resorption). RankL Inhibitors are used to prevent osteoporosis and also to treat metastasis to the bones.

R

RECURRENCE OR RECURRENT CANCER

Cancer that comes back, usually after a period of time during which the cancer could not be detected. The cancer may come back to the same place as the original tumor or to another place in the body.

SECOND-LINE TREATMENT

The term used to describe the second type of treatment used, after the first-line treatment was not successful or could not be tolerated by the patient.

SIDE EFFECT

A problem that occurs when treatment affects healthy tissues or organs. Some common side effects of cancer treatment are fatigue, pain, nausea, vomiting, decreased blood cell counts, hair loss and mouth sores.

STANDARD OF CARE

Treatment that experts agree is appropriate, accepted and widely used. Healthcare providers are obligated to provide patients with the standard of care. Also called best practice and standard therapy.

STEREOTACTIC RADIOSURGERY (SRS)

A type of external radiation therapy that uses special equipment to position the patient and precisely give a single large dose of radiation to a tumor. It is used to treat brain tumors and other brain disorders that cannot be treated by regular surgery. It is also being studied in the treatment of other types of cancer. Also called radiation surgery, radiosurgery and stereotaxic radiosurgery.

TARGETED THERAPY

Targeted cancer therapies are treatments that target specific characteristics of cancer cells, such as a protein or an enzyme, or the formation of new blood vessels that might allow the cancer cells to grow in a rapid or abnormal way. Targeted therapies are generally less likely than chemotherapy to harm normal, healthy cells.

TAXANES

A type of chemotherapy drug that blocks cell growth by stopping mitosis (cell division). Taxol and Taxotere are two taxanes commonly used in breast cancer chemotherapy.

TUMOR

An abnormal mass or a lump of extra tissue. A tumor may be benign (noncancerous) or malignant (cancerous).

TYROSINE KINASE INHIBITOR

A targeted therapy that blocks the action of enzymes called tyrosine kinases that are involved in cell signaling, growth and division.

S

T



Keeping Track

My Pathology and Diagnosis	121
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My Pathology and Diagnosis

Use this form to record information about initial diagnosis of metastatic breast cancer.

CHECK TYPE(S) OF TEST PERFORMED

Please note: Not every test is applicable to every situation/diagnosis.

BONE SCAN CAT SCAN MRI PET

GENETIC TESTING: BRCA1_____ BRCA2_____

MUGA:_____%

TUMOR MARKERS: CA 15-3, CA 27-29 OR CA-125_____

BIOPSY

OTHER TESTING_____

Medication Log

MEDICATION	DOSAGE	PRESCRIBED BY	START DATE	END DATE	PURPOSE

MEDICATION	DOSAGE	PRESCRIBED BY	START DATE	END DATE	PURPOSE

MEDICATION	DOSAGE	PRESCRIBED BY	START DATE	END DATE	PURPOSE

MEDICATION	DOSAGE	PRESCRIBED BY	START DATE	END DATE	PURPOSE

Health and Side Effects Diary

Use these pages to note how you are feeling on specific days during your treatment. This may help you see patterns in side effects and make you better able to explain issues to your healthcare provider.

MY PAIN SCALE: Grade your pain using the scale below. A value of 1 is minimal pain. A value of 10 is the most pain you have ever experienced.

NO
PAIN

0 - 1 - 2 - 3 - 4 - 5 - 6 - 7 - 8 - 9 - 10

MOST PAIN YOU
HAVE EVER
EXPERIENCED

DATE	DAYS SINCE LAST TREATMENT	WHAT TREATMENT?	PAIN SCALE	SIDE EFFECTS

DATE	DAYS SINCE LAST TREATMENT	WHAT TREATMENT?	PAIN SCALE	SIDE EFFECTS

DATE	DAYS SINCE LAST TREATMENT	WHAT TREATMENT?	PAIN SCALE	SIDE EFFECTS

DATE	DAYS SINCE LAST TREATMENT	WHAT TREATMENT?	PAIN SCALE	SIDE EFFECTS

DATE	DAYS SINCE LAST TREATMENT	WHAT TREATMENT?	PAIN SCALE	SIDE EFFECTS



Notes

“Strength does not come from physical capacity.
It comes from an indomitable will.”

-Mahatma Gandhi



877.972.1011

youngsurvival.org

 /youngsurvivalcoalition

 @YSCBuzz

 YSC YoungSurvival