

Look inside for details on accessing alternative options and Federal workplace protections.

# Metastatic Breast Cancer Guide



Breast cancer can happen to anyone, regardless of whether they are old or young, male or female, or whether or not they have high or low risk factors. Breast cancer is considered *Metastatic*, or Stage 4, when there is evidence cancer cells have spread to areas outside the breast or nearby lymph nodes. Metastatic breast cancer patients are likely to have symptoms that affect other organs of the body, including the bones, lungs, liver or brain, where the cancer cells grow and multiply.

Metastatic breast cancer patients along with their caregivers face complex medical situations with accompanying financial challenges, intricate treatment decisions, long-term workplace and employment concerns and many other unique issues. While metastatic breast cancer cannot be cured, it *can* be treated and managed allowing the patient many quality years of life ahead. This guide is designed to provide practical advice to patients and their loved ones as they live with a metastatic breast cancer diagnosis.

*This guide delivers expert advice specifically for Metastatic Breast Cancer patients to help avoid common insurance and care barriers.*



## Engaging With Your Medical Team

**W**hen faced with a metastatic breast cancer diagnosis or a recurrence of breast cancer, there are many aspects to consider during your wellness journey, such as available treatment options and utilizing a proactive strategy to reduce insurance barriers.

***As a metastatic patient, you will likely start to hear numerous new medical and technical clinical terms. To help make sense of your situation, consider these tips when discussing your treatment:***

- Write down your questions before your visit. List the most important ones first to ensure they are answered, and write down the answers in case you forget.
- If you don't understand what the healthcare team is recommending, ask to speak with an oncology nurse to discuss your concerns.
- Consider electronically recording the visit so you or a family member can refer to it later.
- Bring someone with you to your appointment. They can ask questions you may not think of and help you take notes.

- Ask your provider to show you diagrams or drawings that may help increase your understanding.

***Learn more about your treatment team by asking the following questions:***

- How many metastatic breast cancer patients do you treat each year?
- What has been your experience with the results of this treatment?
- How will my treatment affect my daily activities?
- How do you stay up to date on the latest treatment options and medical advances?
- Do you enroll patients into clinical trials should I want to participate in one?
- Who do you recommend I see for a second opinion?
- Would you consider having genomic testing done on my tumor?



## Potential Insurance Complications with Chemotherapy

Many new medications are available orally offering the patient the option for home-centered treatment. However, for treatment such as chemotherapy, which is offered both with intravenous infusion and oral pills, each form may be categorized differently by the insurance company. For example, intravenous chemotherapy is normally covered under the medical benefit of your insurance plan, while oral medications are covered through the prescription benefit of your insurance plan. If you are prescribed the oral form, this means you are responsible for your drug pharmacy co-pay before you can pick up your prescription.

If you and your oncologist determine that oral chemotherapy is your best treatment option, you may find it challenging to afford the high out-of-pocket expenses. Explore co-payment assistance programs or other financial assistance options.

## Understanding Treatment Options



**M**ost treatment for metastatic breast cancer works to prevent or slow the disease progression while easing symptoms and managing treatment side effects. There are several forms of treatment for metastatic breast cancer patients. Your treatment history and response to therapy will determine the type of treatment your doctor may recommend.

*If you have been diagnosed with metastatic breast cancer, call your insurance company and enroll in a case management program. Charged with coordinating your care, case managers bridge the gap between you, your medical providers and the insurance company, tackling any healthcare roadblocks you may encounter.*

**Hormone Therapy** – prevents cancer cells from receiving estrogen, thus halting their growth. This is usually the first treatment option for hormone receptor-positive patients.

**Targeted Therapy** – designed to attack a certain molecular agent or pathway responsible for cancer development.

**Radiation Therapy** – targets the tumor to kill the cancer cells and can provide relief from the pain associated with the cancer.

**Chemotherapy** – treatment that attacks all cells indiscriminately in the hope of reducing the growth of rapidly dividing cancer cells. Available intravenously or via pill form, this treatment can be prescribed alone or in combination with other treatment.

**Surgery** – a provider manually removes the tumor and its surrounding tissue from your body. Two types of common breast cancer surgery are called “lumpectomy” and “mastectomy.” Surgery is frequently no longer a viable treatment option alone during the metastatic stage because the cancer has spread beyond the confines of the breast.

# Qualifying for Government Benefits

## Social Security Disability Insurance (SSDI)

Immediately upon diagnosis of metastatic breast cancer (stage IV), you are eligible to apply for disability benefits under the Compassionate Allowances program. The program is intended to expedite the processing of Social Security Disability Insurance (SSDI) and Supplemental Security Income (SSI) claims for applicants whose medical conditions are so severe that their conditions are known to meet the Social Security's definition of disability. Decisions are usually expedited depending on how quickly you submit the requested information and medical documentation arrives from your doctor.

In most cases, after 24 months of receiving SSDI benefits, you are eligible for Medicare insurance benefits regardless of age.

*Compassionate Allowance speeds the application and disability designation; however, even when found disabled by SSDI, you will not begin to receive your disability checks until the beginning of the sixth month after your disability date.*

## Supplemental Security Income (SSI)

SSI is a separate governmental program that provides benefits to people who are disabled and have very little income and assets. SSI provides monthly payments to low-income individuals who do not qualify for SSDI because they have either never worked or who have insufficient credits on their earnings record. If you qualify for SSI benefits in most states, you are also eligible for Medicaid benefits.



***Request the PAF guide on Maintaining Eligibility for Insurance for more information on benefits and protections.***



## Federal Workplace Protections Critical to Employed Metastatic Breast Cancer Patients

The **Family and Medical Leave Act (FMLA)** exists to help patients maintain employment and employer-based health insurance benefits while being treated for serious illness. This protection allows you to take up to 12 weeks of unpaid leave from work related to your diagnosis and be eligible to return to work. You must provide documentation from a physician that supports the request for leave and provide this to your employer. Once approved, leave can be taken in one large block, or a few hours at a time. FMLA is calculated and recorded annually and can be renewed the following year if a qualifying medical condition continues.

It is important to know that not all employers are required by law to offer FMLA leave. Consult with your human resources department about your company policy.

Employers have the right to require that you use any available paid vacation and sick time before you are allowed to take unpaid FMLA leave. When you return to work, your employer must return you to your original position or an equivalent job with the same pay, benefits and other employment terms.

FMLA also protects caregivers and family members who assist you during your journey, and provides them the option for protected leave to support you during your medical journey.

The **Americans with Disabilities Act (ADA)** protects the privacy of metastatic

breast cancer patients and provides an avenue to request accommodations that support your ability to remain in the workforce.

Under the ADA law, employers cannot inquire whether you have cancer or any other medical condition upon interview or during the hiring process. ADA also protects your privacy if you do share your medical information at a later point to your employer, as your employer may not share this information with unauthorized colleagues.

Once employed, the ADA also allows patients the right to request an accommodation related to your treatment. Examples of reasonable accommodations include the ability to take periodic breaks or have access to a private area to take medication, the ability to have a modified work schedule or shift change, the ability to leave for doctors appointments, permission to work from home, modified work environment temperature or permission to use work telephone to call doctors and coordinate care.

If you have exhausted the 12 weeks of leave allowed under FMLA, and you are not yet ready to return to work, ADA provides another avenue to request extended leave as an accommodation.

Additional provisions specific to cancer patients may be found at the Equal Employment Opportunity Commission website: <http://www.eeoc.gov/laws/types/cancer.cfm>.

## Addressing Areas of Your Care that May be Hard to Face



### **Maintaining comfort and trust in your medical team**

It is important to be comfortable when speaking with your healthcare team. If you are not getting the information you need, you dislike the doctor, your doctor is in an inconvenient location or you are not satisfied with what you are being told, you may want to consider finding a new physician. The doctor-patient relationship has been shown to be critical to overall patient outcomes, so do not feel awkward or embarrassed if you want to seek another provider.

### **Discussing costs with your doctor**

If you find it challenging to pay for your treatment, discuss financial concerns with your treatment team. Being honest about any anxiety related to cost with your doctor may open up a dialogue that ultimately allows you to connect with additional options.

There are financial assistance programs available to assist with your medication and treatment co-payments through nonprofit organizations or through your medication's manufacturer. If you are employed, you may be able to recover some costs through a flexible savings or health savings account that can accompany your health insurance plan. You may also find a list of grant or financial assistance programs on breast cancer support websites that can help.



### **Legal paperwork relevant to patients**

**Advanced Directives**, also known as living wills, are a set of written instructions that communicates your treatment preferences to your healthcare team and family members in a situation where you are incapable of making the decision. This assures that your wishes are carried out and relieves some of the decision-making burden from your loved ones. You do not need to have an advanced directive to authorize a “do not resuscitate” (DNR) order in your medical record, but you will need to make this known to your medical providers in order for it to be documented.

**Power of Attorney** is a document that gives someone the authority to handle all financial, legal and/or health affairs if you are unable to do it for yourself. You need to trust the person you select is both able and willing to perform these duties during these critical and emotional times. Be sure that you discuss your wishes with them in detail and alert them of this documentation so that they are prepared to execute your choices.

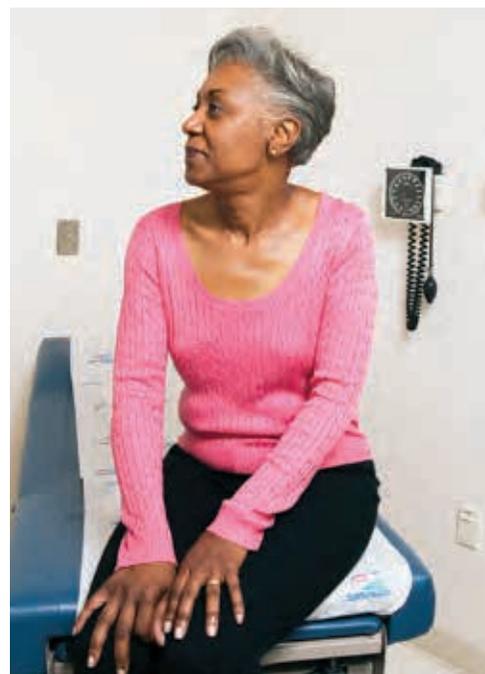
You can also designate a **Medical Power of Attorney** to someone to make medical decisions for you without giving them the authority to handle your financial or legal affairs.

These distinctions are relevant during the period you are receiving medical care. Unless otherwise documented, these powers will expire at the time of your death and will not carry over to allow decisions related to your estate and burial.

### **Beyond active treatment**

The goal of **Palliative Care** is to focus on quality of life during long-term medical care. Palliative care can be given alongside any other forms of active treatment you are receiving to treat your cancer, and be relevant at any point in your treatment journey. The palliative care team helps manage symptoms or side effects you may encounter during treatment.

Palliative care may be covered under the hospice benefit, standard medical benefits of your insurance plan, or contained within long-term care insurance plans.



Inquire about out-of-pocket responsibilities before you agree to receive services. Palliative is distinctly different than hospice care, although it is frequently confused with other end-of-life services.

**Hospice Care** is available to those whose life expectancy is six months or less. Hospice care focuses on maintaining comfort when there are no curative treatments available or when you make the personal choice not to continue treatment. Care is available at home or in a care facility. Hospice staff members are there to support you and your family members with your preferred end-of-life care. Hospice teams provide medical care, emotional support and spiritual resources to people in the last stages of a terminal illness. Hospice benefits are available under most insurance policies. The hospice benefit usually includes all services, medications and equipment necessary to treat the hospice diagnosis.

*Breast cancer can happen to anyone, regardless of whether they are old or young, male or female, or have high or low risk factors.*

## Vocabulary to Know

### **Monoclonal Antibody:**

A type of protein made in a laboratory to bind to a particular substance in the body, including cancer cells. They can be used alone or to carry drugs, toxins or radioactive materials directly to cancer cells.

### **Mutation:**

Any change in the DNA sequence of a cell. Mutations can be harmful, beneficial or have no effect. Certain mutations may lead to cancer or other diseases.

### **Progesterone Receptor:**

A protein found inside some cancer cells that are dependent on progesterone to grow. Also called PR.

### **Relapse or Recurrence:**

A return of cancer after treatment or after a period of time during which the cancer cannot be detected.

### **Targeted Therapy:**

A type of treatment that uses drugs and antibodies to attack specific types of cancer cells with less harm to normal cells. Some targeted therapy blocks the action of certain enzymes, proteins or other molecules involved in the growth and spread of cancer cells. These treatments can be given alone or in combination with chemotherapy.

### **Triple Negative:**

This cancer tests negative for estrogen, progesterone and the HER2 protein. These tumors are not responsive to current targeted therapies, although they usually respond well to chemotherapy.

### **Tumor Response:**

The shrinking of a tumor following treatment.

## Vocabulary to Know

### Adjuvant Therapy:

Treatment given after removing the cancer with surgery.

### BRCA:

Breast Cancer susceptibility genes make proteins that help control cell growth. If you have a family history of breast or ovarian cancer genetic testing can identify your chances of developing those cancers.

### Estrogen Receptor:

A protein found inside some cancer cells that is stimulated by the hormone estrogen and is dependent upon estrogen to grow. Also called ER.

### Expanded Access:

A program started by the FDA that allows certain promising investigational therapies to be made available to people with serious or life-threatening illnesses without other treatment options, before being formally approved for use.

### Food and Drug Administration (FDA):

An agency in the federal government responsible for ensuring drugs, medical devices, and equipment are safe for use in the United States.

### Gene Therapies:

Therapies that alter the genetic structure of a tumor cell, making them more susceptible to either the immune system or chemotherapy.

### Hormonal Therapy:

Treatment that adds, blocks, or removes hormones. To slow or stop the growth of breast cancer, synthetic hormones or other drugs may be given to interfere with the body's ability to stimulate the growth of breast cancer cells.

### Human Epidermal Growth Factor Receptor 2 (HER2):

A protein that controls how cancer cells, grow, divide and repair themselves. HER2 positive indicates that your cancer may respond to targeted hormonal therapies.

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## Options to Access Alternative and Emerging Treatment Options



Researchers today are discovering new treatment options that target specific genetic changes in cancer cells. These new protocols can provide you and your physician the ability to customize treatment based on your unique tumor type and genetic mutations. This method has also been found to reduce exposure to ineffective or less effective treatment protocols.

**Clinical Trials** – Clinical trials offer the ability to access an emerging treatment option otherwise unavailable outside of the trial. Clinical trials are conducted in a series of steps, called phases and many times contain medication that has shown promising results in research.

A clinical trial may require travel so it is important to consider transportation, lodging and food expenses. Some clinical trials will cover those expenses but only if requested by the patient. If you are working while accessing treatment via clinical trials, consider activating any workplace protections you may be eligible for, including protected leave under the Family Medical & Leave Act and applying for short- and long-term Disability benefits to protect your income during extended absences from work.

**Accessing Investigational Drugs** - If you do not qualify for a clinical trial, you may consider requesting treatment through an “Expanded Access” program (also known as “compassionate use”).

This option allows patients access to effective investigational drugs that are in Phase 3 or beyond of the clinical trial stage. Although these treatment options may not yet have been approved by the Food and Drug Administration, to access, there must be reasonable evidence that the risk of the drug is not greater than the risk from the disease and that the drug will prolong survival or improve your quality of life.

In this situation, your insurance may not cover the cost of the treatment or drugs to address any side effects. You may find it helpful to discuss treatment options and financial obligations with your insurance company or case manager if considering an Expanded Access program.

## Genetic and Genomic Testing



Incorporating knowledge specific to the individual genetic makeup in your body as well as your exact cancer as part of your treatment plan can be highly beneficial and lend itself to more informed and targeted decisions on care. This concept, called “personalized medicine” is a rapidly developing field of treatment within the cancer community. The “Genetic” and “Genomic” terms are very similar but actually refer to different types of information.

*Under provisions of the Affordable Care Act, new health plans are required to pay for genetic counseling and genetic testing for women who have a demonstrated high risk of having the BRCA gene.*

**Genetic Testing** is performed on blood or tissues of an individual to identify abnormalities or alterations in your genes that, if present, can identify

your risk for developing a particular disease or type of cancer. This analysis of your individual DNA can detect inheritable genes and chromosomes that have been found to be linked to a higher risk for hereditary disorders. For example, a defective BRCA (breast cancer) gene increases the odds that you will be susceptible to breast or ovarian cancer over the course of your life. Genetic testing can be done on patients of all ages or who do not show any signs of illness. If a gene mutation is positively identified, it does not mean that the patient will definitely be affected by the condition.

**Biomarker Testing** may be completed with genetic testing. Biomarkers refer to the molecules found in all blood or tissues and that can be measured to indicate an abnormal condition or disease. Depending on the specific biomarker, this genetic testing can be used to identify risk of a disease, early detection through screening or even help diagnosis a specific cancer type.

**Genomic Testing** is done on a cancer tumor itself and looks for specific mutations that are present within the cancer cells. Results can provide valuable information on how your specific cancer cell is behaving, and this information can be used to match

treatment found effective against reducing or killing that cellular behavior. Many times genomic testing also identifies ineffective treatment options that can be avoided by your doctor. Talk to your insurance company for coverage details about whether your plan will cover genomic testing related to your breast cancer. If your insurance company will not cover the testing, reach out to the manufacturer of the test to inquire about the availability of financial assistance to help cover the cost.



## Helpful Resources



**Advanced BC.org**  
[www.advancedbc.org](http://www.advancedbc.org)

**BC Mets.org**  
[www.bcmets.org](http://www.bcmets.org)

**Breast Cancer Trials**  
[www.breastcancertrials.org](http://www.breastcancertrials.org)

**BreastCancer.org**  
[www.breastcancer.org](http://www.breastcancer.org)

**Cancer and Careers**  
[www.cancerandcareers.org](http://www.cancerandcareers.org)

**Cancer Care**  
[www.cancercare.org](http://www.cancercare.org)

**Cancer Connect**  
[www.cancerconnect.org](http://www.cancerconnect.org)

**Cancer Support Community**  
[www.cancersupportcommunity.org](http://www.cancersupportcommunity.org)

**FORCE: Facing Our Risk of  
Cancer Empowered**  
[www.facingourrisk.org](http://www.facingourrisk.org)

**Know Your Breast Cancer**  
[www.knowyourbreastcancer.com](http://www.knowyourbreastcancer.com)

**Lazarex Cancer Foundation**  
[www.lazarex.org](http://www.lazarex.org)

**Living Beyond Breast Cancer**  
[www.lbbc.org](http://www.lbbc.org)

**Men Against Breast Cancer**  
[www.menagainstbreastcancer.org](http://www.menagainstbreastcancer.org)

**Metastatic Breast  
Cancer Network**  
[www.mbcn.org](http://www.mbcn.org)

**METAvivor**  
[www.metavivor.org](http://www.metavivor.org)

**My BC Team**  
[www.mbcnetwork.org](http://www.mbcnetwork.org)

**National Cancer Institute**  
[www.cancer.gov](http://www.cancer.gov)  
[www.cancer.gov/clinicaltrials](http://www.cancer.gov/clinicaltrials)

**National Underinsured  
Resource Directory**  
[www.patientadvocate.org/  
underinsured](http://www.patientadvocate.org/underinsured)

**Nueva Vida**  
[www.nueva-vida.org](http://www.nueva-vida.org)

**Patient Resources, Inc.**  
[www.patientresource.com/  
Metastatic\\_Breast.aspx](http://www.patientresource.com/Metastatic_Breast.aspx)

**Pink Link Breast Cancer  
Social Network**  
[www.pink-link.org](http://www.pink-link.org)

**SHARE**  
[www.sharecancersupport.org](http://www.sharecancersupport.org)

**Sharsheret**  
[www.sharsheret.org](http://www.sharsheret.org)

**Sisters' Network**  
[www.sistersnetworkinc.org](http://www.sistersnetworkinc.org)

**Susan G. Komen**  
[www5.komen.org](http://www5.komen.org)

**Triple Negative Breast  
Cancer Foundation**  
[www.tnbcfoundation.org](http://www.tnbcfoundation.org)

**Triple Step Toward The Cure**  
[www.triplesteptowardthecure.org](http://www.triplesteptowardthecure.org)

**Young Survival Coalition**  
[www.youngsurvival.org](http://www.youngsurvival.org)



## Caring for Your Emotional Side

**L**earning that you have metastatic breast cancer can be an overwhelming experience – one that leaves you feeling numb, frightened, vulnerable and alone even when you are surrounded by family and friends.

**This is a time where you need to put yourself first. Metastatic breast cancer is treatable even if not curable. Become informed about all of your treatment options, and have a clear head when you are making decisions regarding how you want to proceed.**

It's important to know that feeling stressed and anxious is normal. Talking to someone may be the first step in helping you live well with metastatic breast cancer. You may feel like you should stay strong but it is also important for you to find people who have experience in what you are facing, can comfort you and are available to share their story. Trying to carry this burden alone while pretending everything is fine is not a good idea and can impact your overall health.

Be honest with your treatment team about any emotional strains and how you are feeling, as there may be support services directly provided by your cancer treatment center and available to help you and your family members. Another option is to take advantage of counseling benefits available through your insurance plan, as this may be a way to express yourself without feeling a burden of sharing with those affected personally by your diagnosis. And lastly, there are many cancer organizations that offer emotional support, including in-person support groups, one-on-one 24/7 phone support, connection to a mentor or fellow survivor, or online disease-specific forums to guide you through the process.