

METASTATIC BREAST CANCER:

A Guide to Shared Decision-Making for Patients



KEY WORDS TO KNOW

Care Team | A multidisciplinary group of specialists who collaborate to treat metastatic breast cancer while maintaining your quality of life. These specialists often include medical oncologists, nurses, nurse navigators, radiation oncologists, and surgeons, but may also include caregivers or family members chosen by the patient.

Comprehensive Cancer Center | Refers to facilities designated by the National Cancer Institute, indicating a high standard of excellence in cancer research and treatment. They provide a wide range of services, including clinical trials, advanced treatment options, and support for patients and their families.

Cost of Care | The total financial impact of receiving healthcare. This includes medical bills, insurance premiums, and the complexity of navigating insurance transitions (like changing insurance), as well as other costs that affect daily life.

Financial Counselor | A professional on the hospital staff who helps you navigate the “business” side of being a patient, like insurance navigation, assistance programs, and budgeting.

Healthcare Power of Attorney or Healthcare Proxy | The person responsible for making medical decisions on your behalf if you’re unable to do so yourself.

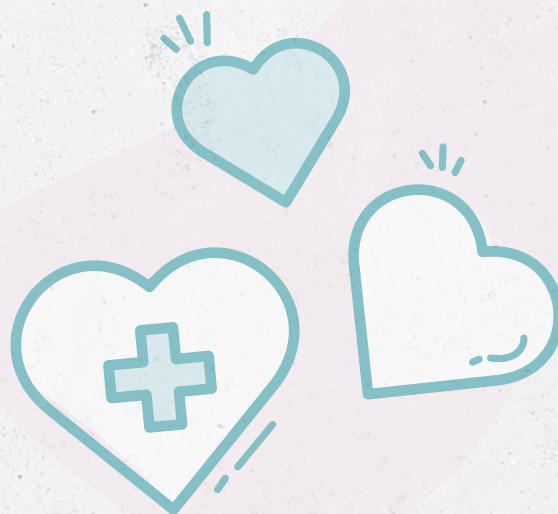
Out-of-Pocket Costs | The portion of medical expenses that you are responsible for paying yourself, which are not covered by insurance.

Peer Support | Connects you with people who also have a metastatic breast cancer diagnosis for social and emotional support. This can be one-on-one or in a group setting. It can also take place in person or virtually.

Self-Advocacy | Your ability to effectively communicate your needs, ask questions, and represent your own interests to ensure you receive the best possible care.

Shared Decision-Making | A collaborative process where you and your healthcare providers work together to make medical decisions. It balances a provider’s medical expertise with your values, preferences, and lifestyle.

Skilled Communication | Using tools to become an active partner in your healthcare. Ensuring your medical team understands your life and you understand their medicine.





A diagnosis of metastatic breast cancer (mBC) can bring a flood of information, emotions, and decisions—often all at once. Treatment options may change over time, and there is rarely a single “right” path forward. Care extends far beyond the pharmacy or the hospital: it encompasses the language used, the costs incurred, and the respect shown for the patient’s voice.

What matters most is that care decisions reflect not only the best available medical evidence, but also your values, priorities, and goals for living well.

This guide is designed to support shared decision-making between you and your healthcare team.

It means working together to understand your options, weigh potential benefits and side effects, and consider how each choice fits into your life. It recognizes that you are the expert on your own experiences, and that your voice is essential in every decision about your care.

Whether you are newly diagnosed with metastatic breast cancer or navigating a

new phase of treatment, this guide offers questions, tools, and space for reflection to help you prepare for meaningful conversations with your clinicians. Its purpose is not to tell you what to choose, but to help you make informed decisions that feel right for you—now and as your needs evolve.

You are not alone in this process. This guide is here to help you feel informed, supported, and empowered as you navigate decisions about your care.

Know Your Moves



Shared decision-making is *about you feeling empowered* to say yes, no, or not yet.



CASE STUDY 1 | ANGELA

Angela is 61 years old and living with metastatic breast cancer. Since her diagnosis, her main goal has always been to stay in control of her own life.

As her cancer changed, so did her options. At one point, her medical team suggested much more aggressive treatment. While this plan made sense medically, it came with harsher side effects and meant spending more time at the clinic. Angela thought about her life outside the hospital; she wanted to keep working, take care of her children, and feel like herself.

While Angela weighed her options, she faced a lot of outside pressure. Family members urged her to “fight harder,”

and friends suggested treatments she “had to try.” Even some providers seemed to expect her to choose the most aggressive path.

However, during a follow-up visit, Angela spoke up to her **care team**. She explained that she wanted to choose a less intensive treatment because it better aligned with her goals, even if it meant a smaller chance of a long-term benefit. Her oncologist listened, respected her reasoning, and confirmed that the final decision was hers to make.

Once her choice was respected, Angela felt a sense of relief. She wasn’t “giving up.” She was choosing a path that fit her priorities.

TIPS FOR TALKING WITH YOUR CARE TEAM

Here are some ways to prepare for and participate in your medical appointments.

Speak Up

- Ask your healthcare provider to explain things in simple terms | “Can you explain that without complex medical terms?”
- Repeat back what you heard | “So what I’m hearing is...”
- Ask about all your options | “What are the other choices I have?”
- Be honest about your concerns | “I’m worried about the side effects because...”

Helpful Questions

- “What are the side effects, and how will they affect my daily life?”
- “What happens if I choose not to do this treatment?”
- “How much time will this take each week?”
- “Is there a less intensive option?”
- “What would you do if I were your family member?”

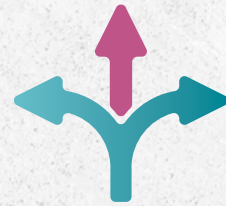
Stand Up for Yourself

- You can say | “I need more time to think about this.”
- You can say | “This doesn’t feel right for me.”
- You can say | “I want to try a different approach.”
- You can ask for a second opinion

Remember

Good healthcare providers want you to ask questions. They want to understand what matters to you. If you feel rushed or unheard, it’s okay to speak up or find a healthcare provider who listens better.

Know Your Moves



You should always be the ultimate decision-maker. Healthcare providers and families are there to provide information and emotional support, but they should not override your voice.





CASE STUDY 2 | TANYA

Tanya is a 45-year-old woman living with metastatic breast cancer. During her treatment, Tanya learned that some of the hardest moments came not from test results, but from the words her **care team** used to explain them.

Early after her metastatic diagnosis, Tanya remembers hearing phrases like “there’s nothing more we can do” and “this is no longer curable.” The healthcare providers meant well, but the words they chose left her feeling dismissed and hopeless.

Months later, Tanya transitioned to a new oncology team. At her first visit, the oncologist reviewed her history carefully and said, “While this cancer can’t be cured, there are many things we can do together to treat it, manage

symptoms, and support the life you want to live.” Tanya felt the shift immediately: the facts were the same, but the framing was different.

As treatment decisions arose, the care team paid attention to how information was delivered. Options were explained in plain language, without complex medical terms or judgment. Instead of being told what she “should” do, Tanya was asked what mattered most to her. Her care team treated her with respect and made her feel like a partner in her care. This helped Tanya feel empowered, even when facing difficult news.

This approach changed how Tanya experienced her care. She felt invited into the conversation rather than spoken over.

/// TIPS FOR MAKING YOUR VOICE HEARD

Language is a powerful tool. It is okay to set boundaries on how and when you receive information.

Phrases to Use When You Feel Unheard

- “I need you to explain why you are recommending this treatment versus other options.”
- “I am not comfortable with that plan. Let’s discuss alternatives.”
- “I need to pause and process this information before moving forward.”

What to Look for in Good Communication

- Healthcare providers who ask about your goals and priorities.
- Information shared without rushing.
- Space for you to ask questions and express emotions.
- Respect for your role as the decision-maker.

Red Flags in Communication

- Feeling rushed or dismissed.
- Medical terms without explanation.
- Being told what you “should” do without discussion.
- Absolute statements that leave no room for questions.
- Feeling like your concerns don’t matter.
- Avoiding or minimizing discussions on cost.

i Know Your Moves



Words matter. The way healthcare providers share information can either shut down conversations or open them up. The right words help patients understand their choices, know their role, and hold onto hope.





CASE STUDY 3 | DENISE

Denise is a 52-year-old woman living with metastatic breast cancer in a rural community. The nearest **comprehensive cancer center** is more than two hours from her home. While her diagnosis was overwhelming, the day-to-day challenges she faced were just as hard.

Denise has limited insurance coverage, and her plan comes with a lot of **out-of-pocket costs**. Each oncology visit requires taking a full day off work, arranging transportation, and paying for gas, meals, and sometimes lodging. Over time, these costs continued to add up and began to influence her care decisions. Denise started to delay appointments and postpone scans and imaging. Her treatment discussions were shaped not only by medical recommendations, but by what felt realistically possible.

During one visit, Denise admitted to her oncologist that travel was becoming too much. She worried that asking for alternatives would make it seem like she wasn't trying hard enough or didn't care about getting better. Instead, her care team listened.

Together, they explored options that could bring care closer to home. Some follow-up visits were shifted to telehealth. Labs and imaging were coordinated through a local facility. The team reviewed treatment options aligned with Denise's medical needs while reducing the frequency of long-distance travel. A social worker helped her apply for transportation assistance.

For the first time, Denise felt that her care plan fit her real life. **Shared decision-making** became meaningful because her challenges were openly recognized and addressed.

//// TIPS FOR NAVIGATING ACCESS CHALLENGES

Here are some strategies you can use when facing access challenges.

Talk Openly About Your Barriers

- Tell your **care team** about challenges with transportation, time off work, or costs. | Be specific: “I can’t afford to miss work twice a week” or “The gas costs are adding up.”
- Don’t wait until you’ve missed appointments. Speak up early.

Ask About Alternatives

- “Can some of my appointments be done by video or phone?”
- “Is there a clinic closer to home where I can get labs or scans?”
- “Are there treatment options that require fewer trips?”
- “Can appointments be bundled together on the same day?”

Get Help With Financial and Practical Support

- Ask to speak with a social worker or patient navigator.
- Ask about: transportation assistance programs, lodging assistance, financial aid for treatment costs, prescription assistance programs.
- Many hospitals have **financial counselors** who can help you understand costs before treatment starts.
- Ask about charity care programs at your hospital.

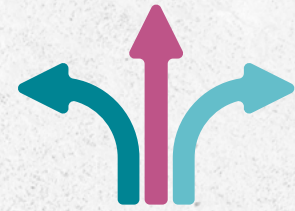
When to Speak Up

- You’re missing appointments because of cost or distance.
- You’re choosing between treatment and paying bills.
- You’re skipping medications because of cost.
- Your care team doesn’t seem to understand or care about your barriers.

Remember

Your care plan should fit your real life. If barriers exist, speak up. Options and resources are often available.

i Know Your Moves



Access is not evenly distributed. Where you live, your insurance, your income, and your support system can all affect how, and whether, you can get the care your healthcare providers recommend.





CASE STUDY 4 | KEISHA

Keisha is a 42-year-old woman living with metastatic breast cancer. While her medical team provided excellent care, she often felt alone in ways that appointments and treatments could not fix. Friends wanted to help but didn't always understand. Family members tried to stay positive. But this made it hard for Keisha to share her fears or worries.

After starting a new treatment, Keisha's nurse mentioned a **peer support** program that connected people living with metastatic breast cancer. At first, Keisha was hesitant. She wasn't sure she wanted to hear other people's stories or be reminded of what lay ahead. But she agreed to try a virtual peer support group.

In her first session, Keisha heard someone describe the same things she felt: worry before scans, exhaustion from treatment,

and frustration when people didn't understand. For the first time since her diagnosis, she didn't feel like she had to explain herself. The words, emotions, and experiences were shared.

Through peer connections, Keisha learned practical strategies for navigating side effects, preparing for appointments, and asking clearer questions of her care team. Just as importantly, she gained confidence.

Over time, Keisha began to speak up more during medical visits, sharing her goals and concerns with greater clarity. She also became an advocate beyond her own care. She participated in patient advisory panels and shared her story to help improve systems that affect others living with metastatic disease.

TIPS FOR FINDING AND USING PEER SUPPORT

Here are some ways you can connect with peer support and make the most of these connections.

Finding Peer Support

- Ask your care team if they know of peer support programs.
- Look for programs through cancer support organizations like CancerCare or Cancer Support Community, your hospital or cancer center, national organizations focused on your specific cancer type, online communities and forums.
- Consider different formats | In-person support groups, virtual/online groups, one-on-one peer mentoring, social media communities, phone-based support.

Choosing the Right Group

- Look for groups specific to metastatic cancer (not just general cancer support).
- Consider groups focused on your age, cancer type, or life situation.
- Try a few different groups. It's okay if the first one isn't the right fit.
- Ask if there's a facilitator who can guide discussions.

Getting Started

- It's okay to just listen at first. You don't have to share right away.
- Remember that everyone was new once.
- You can share as much or as little as you're comfortable with.
- It's normal to feel emotional during or after meetings.

Questions to Ask in Peer Support

- "What questions do you ask your healthcare providers?"
- "How do you talk to family about what you need?"
- "What do you wish you'd known earlier?"

Using What You Learn

- Take notes on helpful tips or strategies and try one new approach at a time.
- Share useful information with your care team.
- Remember that what works for others might not work for you, and that's okay.

Remember

Peer support is not a replacement for medical or mental healthcare, but it fills a unique need. Other patients understand your experience in ways that even the best healthcare providers and most loving family members cannot. You deserve that connection and understanding.

Know Your Moves



Connection matters. **Peer support helps patients feel less alone,** learn from shared experiences, and find their voice in their own care.



CASE STUDY 5 | MARIA

Maria is a 34-year-old woman living with metastatic breast cancer. Since her diagnosis, treatment has become a constant part of her life: appointments, scans, medications, and time away from work. What her care team didn't immediately see was the growing money problems that came with her illness.

Maria's health insurance plan had high **out-of-pocket costs**. She also worked part-time. She began struggling to pay for copays, transportation, and lost wages from missed work. To make ends meet, she delayed refilling medications and skipped some follow-up visits. She didn't mention it to her care team at first. Like many patients, she thought she had to handle the money problems on her own.

During a routine visit, her oncologist asked not only how treatment was going, but how Maria was managing overall. That simple question opened the door. Maria shared that

she wanted to continue treatment but was afraid she couldn't afford it. She admitted that financial stress was affecting her ability to follow the care plan they had created together.

Instead of moving on, the care team stopped to help. They acknowledged that money concerns are a real part of cancer care. These concerns deserve the same attention as side effects or lab results. Together, Maria, her oncologist, a social worker, and a **financial counselor** made a plan. They explored financial assistance programs, adjusted where services were delivered to lower costs, and reviewed treatment options with both medical benefit and affordability in mind. Just as important, they agreed to keep the conversation going.

With support in place, Maria was able to stay on treatment and felt less anxious about the future. More than that, she felt heard.

TIPS FOR DEALING WITH FINANCIAL BURDENS OF TREATMENT

Open Communication with Your Care Team

- **Be Honest About Financial Concerns** | Don't hesitate to discuss financial worries with your oncologist or care team.
- **Ask Questions** | Inquire about the costs associated with different treatment options and any available financial assistance.

Utilize Financial Counseling Services

- **Request a Financial Counselor** | Ask your healthcare facility if they have financial counselors who can help navigate costs.
- **Explore Assistance Programs** | Look into foundations or organizations that provide financial aid for cancer patients.

Stay Informed About Your Insurance

- **Understand Your Policy** | Familiarize yourself with your insurance coverage, including deductibles, copays, and out-of-pocket maximums.
- **Check for In-Network Providers** | Ensure that you are using in-network hospitals and specialists to reduce costs.

Adjust Treatment Plans as Needed

- **Discuss Affordability** | Work with your care team to evaluate treatment plans that balance clinical benefits with cost.
- **Consider Alternative Options** | Ask about generic medications or clinical trials that offer reduced costs.

i Know Your Moves



When *patients are empowered to speak, and care teams are prepared to listen*, better, more equitable cancer care becomes possible.

QUESTIONS TO ASK YOUR FINANCIAL COUNSELOR

- What financial assistance programs are available for my treatment?
- Can you help me understand my insurance benefits and costs?
- Are there any payment plans or options to manage out-of-pocket expenses?
- What resources can I use to find affordable medications or therapies?
- How can I access support for transportation or other non-medical costs?

The Breast Cancer Resource Directory,

developed by the Patient Advocate Foundation, offers trusted guidance for those navigating breast cancer or metastatic breast cancer. This user-friendly tool helps you find financial aid and support services that match your unique needs.

Simply select options from each drop-down that best match your needs and to generate a customized list of national and regional programs focused on improving access to care and easing financial stress. There's no limit to how many searches you can perform.

View the directory at www.patientadvocate.org/breastcancerresources

Patient Advocate Foundation's

Co-Pay Relief Program exists to help reduce the financial distress patients and their families face when paying for treatment. We believe that no patient should go without life-changing medications because they cannot afford them.

Find out more at www.copays.org

COLLABORATIVE CARE APPOINTMENT WORKSHEET

MY TOP 3 PRIORITIES

(For example: maintaining the ability to work, attending a specific event, minimizing side effects).

1. _____

2. _____

3. _____

MY LEARNING STYLE

(I want numbers/stats vs. I want the big picture).

MY TEAM

My Medical Lead/**Healthcare Proxy** _____

My **Financial Counselor** _____

My Emotional Support Person _____

WHAT TO DO NEXT FOLLOWING DIAGNOSIS OR TREATMENT CHANGES

INTRODUCTION TO SELF-ADVOCACY

Self-advocacy means understanding your needs, speaking up for yourself, and partnering with your care team to make decisions that reflect your values, goals, and lived experience.

1. Remember, You Are the Expert on Your Life

You know your body, your experiences, and what matters most to you.

- Share how treatments affect your daily life
- Speak up when something does not feel right
- Ask for care that aligns with your goals and priorities

Your voice is important.

2. Understand Your Diagnosis and Care Plan

You have the right to information you can understand. You can ask:

- Can you explain this in plain language?
- What does this mean for me right now?
- What are the goals of my treatment?
- What should I expect next?

It is okay to ask questions as many times as you need.

3. Prepare to Speak Up

Preparing ahead of time can make it easier to advocate for yourself. Before appointments:

- Write down your questions and concerns
- Identify your top priorities for the visit
- Track symptoms, side effects, or changes

You may want to bring:

- A notebook or phone for notes
- A trusted person for support

4. Ask for What You Need

Advocating for yourself includes asking for help and support. You can ask for:

- More time to make decisions
- Referrals to specialists or support services
- Help with side effects, pain, or symptoms
- Emotional, financial, or practical support

You deserve care that supports your whole life.

5. Know Your Rights and Options

You have choices in your care. You have the right to:

- Be treated with respect
- Seek a second opinion
- Understand risks and benefits of treatments
- Decline or change a treatment plan

Self-advocacy includes making informed choices that feel right for you.

6. Address Barriers Early

Barriers can make care more challenging, but support is available. Common barriers include:

- Transportation or distance to care
- Cost or insurance challenges
- Work or caregiving responsibilities
- Emotional stress or fatigue

Let your care team know so they can help connect you to resources.

7. Build a Support Network

You do not have to advocate alone.

Support may include:

- Family or friends
- **Peer support** groups
- Patient navigators or social workers
- Advocacy organizations

Connecting with others can strengthen your confidence and resilience.

8. Be Kind to Yourself

Self-advocacy is a skill that takes time.

- It is okay to feel overwhelmed
- You do not have to do everything at once
- Every step you take matters

You are doing the best you can. Your voice matters. Your experience matters. Your choices matter.

SKILLED COMMUNICATION TIPS FOR SHARED DECISION-MAKING

You are the expert on your life, your values, and your goals. These tools are here to support your voice in care decisions.

1. Prepare Before Appointments

Preparing ahead of time can help you get the most out of each visit. Before your appointment, consider:

- What are my top 1–3 concerns right now?
- What symptoms or side effects are most affecting my daily life?
- What decisions do I need to make soon?

Helpful tools:

- Write questions down and bring them with you
- Bring a notebook, phone, or trusted person to help take notes
- Ask for information in plain language if something is unclear

2. Ask Clear, Direct Questions

You have the right to understand your care. Examples of helpful questions:

- What are my treatment options right now?
- What are the benefits and risks of each option?
- How might this treatment affect my quality of life?
- What happens if I choose to wait or try something different?

It is okay to ask the same question more than once.

3. Share What Matters Most to You

Your values and goals should guide decisions. You may want to share:

- Your priorities (e.g., symptom control, time with family, work, independence)
- Concerns about side effects, costs, or logistics
- Cultural, family, or spiritual factors that influence your choices

You can say: “What matters most to me right now is...”

4. Take Time to Decide

You do not have to make every decision immediately. It is okay to:

- Ask for time to think
- Involve family or caregivers
- Seek a second opinion
- Ask for written information to review later

You can say: “I need some time to think about this before deciding.”

5. Address Barriers Openly

Barriers are real—and talking about them helps your care team support you. Consider discussing:

- Transportation challenges
- Cost or insurance concerns
- Emotional stress or fatigue
- Difficulty following a treatment plan

You can ask: “Who can help me with this?”

6. Remember, You Are a Partner in Your Care

Good communication is a two-way conversation.

- You deserve respect, honesty, and empathy.
- Your questions and preferences matter.
- **Shared decision-making** means your voice counts.

Your voice matters. Your experience matters. Your choices matter.

CONVERSATIONS ABOUT THE COST OF CARE

Financial concerns are a normal and important part of your healthcare journey. You deserve information, support, and transparency.

1. Know That it is Okay to Talk About Cost

Talking about the **cost of care** will not affect the quality of your treatment. You have the right to:

- Ask questions about costs
- Understand your insurance coverage
- Explore financial assistance options

You are not alone, and help is available.

2. Prepare Before Appointments

Preparing ahead can make cost conversations easier. Before your visit, consider:

- What costs worry me most right now?
- Have my insurance, job, or income changed?
- Do I need help paying for medications, transportation, or household bills?

Bring:

- Insurance cards and recent bills (if available)
 - A list of medications
 - Notes or questions about costs
-

3. Identify Who Can Help

You do not have to manage financial concerns alone. Ask to speak with:

- A **financial counselor** or billing specialist
- A social worker or patient navigator
- A patient assistance or charity care representative

You can say: "I would like help understanding the cost of my care."

4. Ask Clear Cost-Related Questions

Clear questions help your care team better support you. You may ask:

- What will this treatment or test cost me?
- What will my insurance cover?
- What are my **out-of-pocket costs**?
- Are there lower-cost options or alternatives?
- Who can help me understand my bills?

It is okay to ask for explanations in plain language.

5. Address Common Barriers

Many people feel uncomfortable discussing cost. These feelings are valid. Common concerns include:

- Fear of being judged
- Worry that care will be affected
- Feeling embarrassed or overwhelmed

Remember: discussing cost helps your care team support you better.

6. Explore Support and Assistance

There may be help available beyond your medical team. Support may include:

- Insurance or Medicaid navigation
- Copay or medication assistance programs
- Transportation, grocery, or utility support
- Nonprofit or community resources

Ask for written resources or referrals when possible.

7. Take Notes and Follow Up

Cost conversations often happen over time.

- Write down names, phone numbers, and next steps
 - Ask who to contact if bills change or new questions arise
 - Keep copies of bills and explanation of benefits (EOBs)
-

8. Remember, You Deserve Transparency and Support

Cost is part of your care. You deserve:

- Honest information
- Respectful conversations
- Support in navigating financial challenges

Your health and well-being come first.

ACKNOWLEDGMENTS

Community Partners

Facing Our Risk of Cancer
Empowered (FORCE)

Fannie Lou Hamer Cancer Foundation

Los Angeles Alliance for
Community Health & Aging

University of Illinois Cancer Center

VCU Massey Comprehensive
Cancer Center

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