FRANKLY SPEAKING ABOUT CANCER

Coping with Metastatic Breast Cancer



When you have metastatic breast cancer (MBC or mBC), every day can bring a new challenge. You may feel scared, worried, depressed, or overwhelmed. Emotional ups and downs are normal. On some days, you're not sure how you're going to get through this.

Metastatic describes cancer that has spread to another part of the body. Metastatic cancers are usually more aggressive and harder to treat. Having metastatic breast cancer means that cancer treatment is likely to be part of your life from here forward.

This fact sheet describes concerns common to people with metastatic breast cancer, and offers ways to regain control and help you maintain the best possible quality of life.

CANCER SUPPORT COMMUNITY

GILDA'S CLUB WORLDWIDE

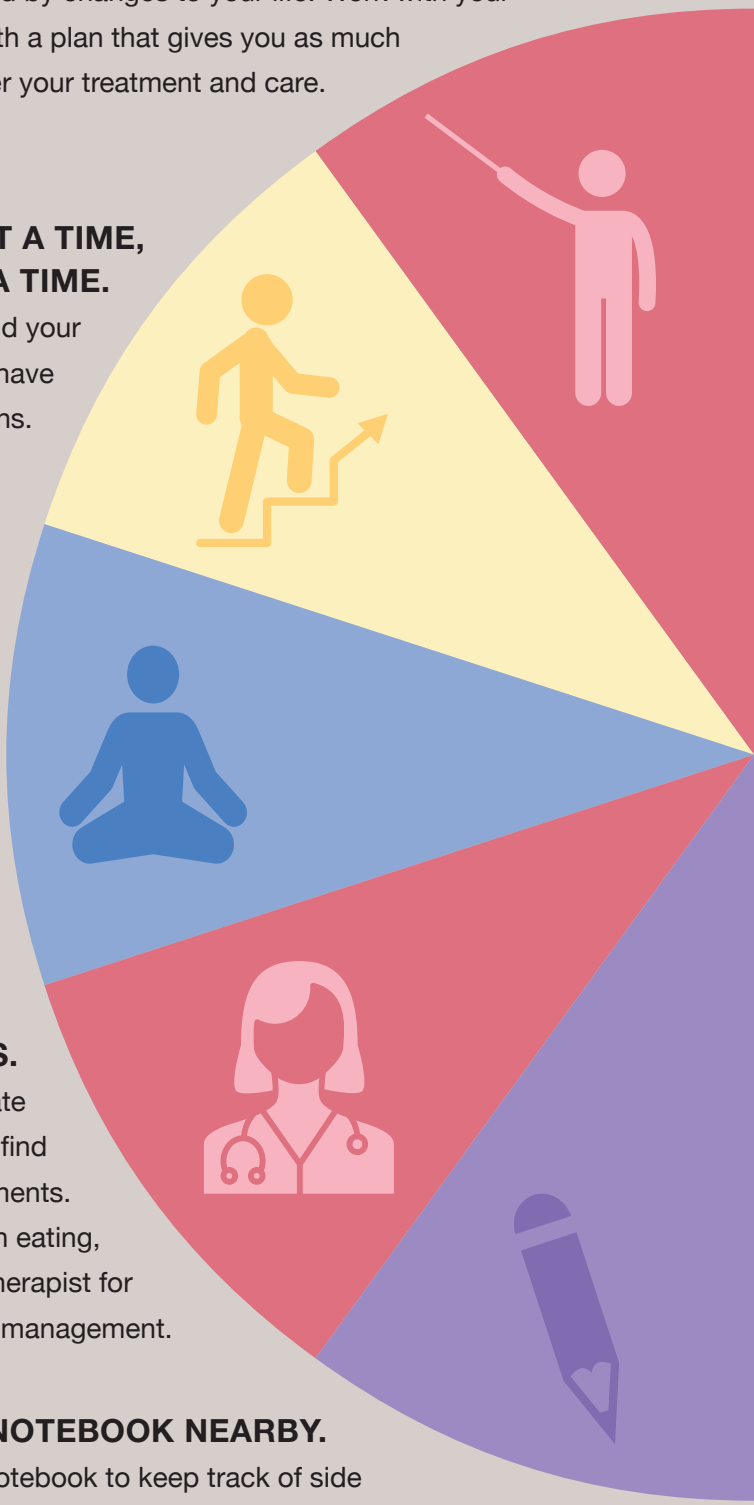
10 TIPS FOR LIVING WELL WITH

FIND WAYS TO FEEL IN CHARGE OF YOUR LIFE.

You may feel frustrated by changes to your life. Work with your medical team to come up with a plan that gives you as much control as possible over your treatment and care.

TAKE ONE STEP AT A TIME, AND MAKE ONE DECISION AT A TIME.

If life feels overwhelming, take small steps to find your best path. Talk, listen, and learn. In time, you will have the information you need to make good decisions.



LEARN TO RELAX AND FIND A NEW PERSPECTIVE.

Be aware of your feelings and find ways to stay calm. Focus on activities you enjoy. Try to find humor in each day. Spend time alone if you need.

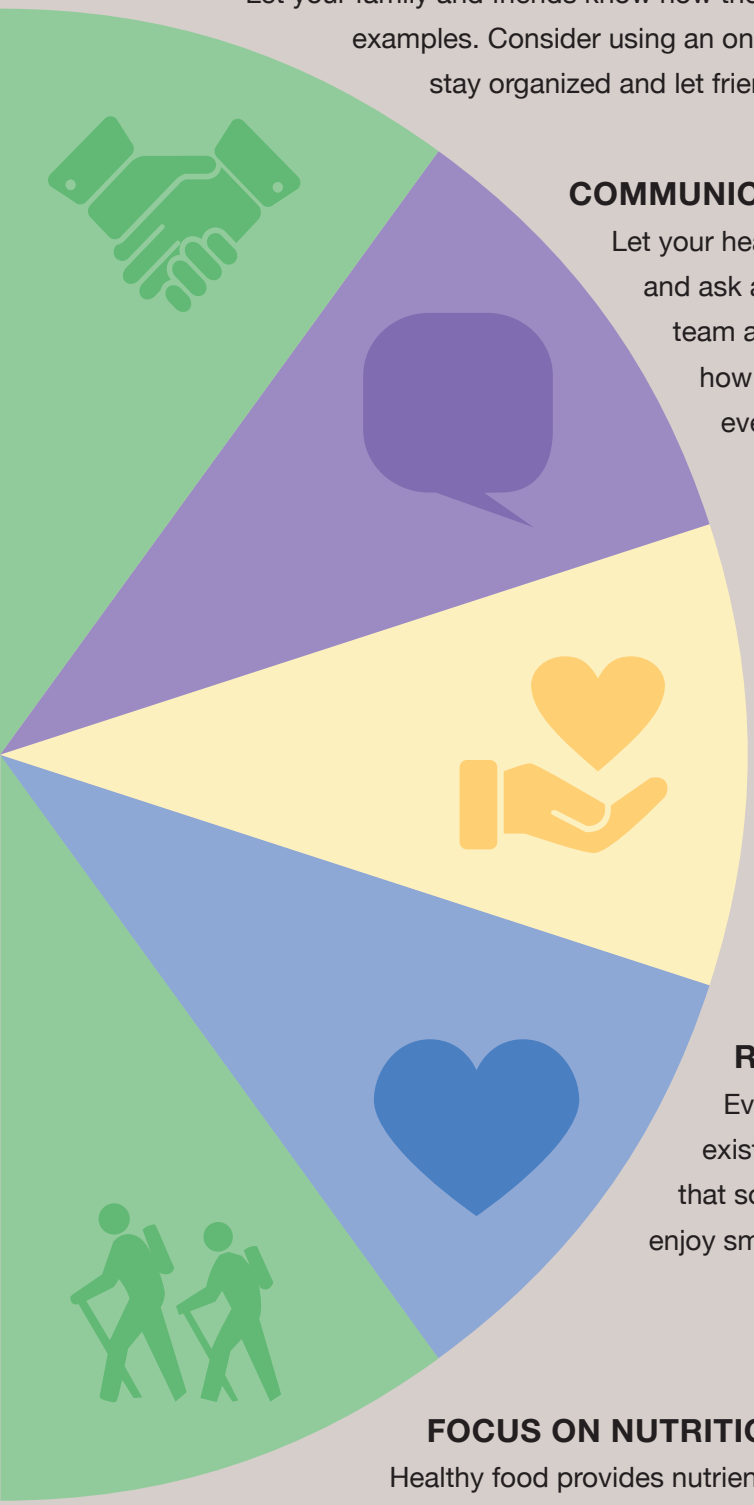
GET HELP FROM SPECIALISTS.

Expand your health care team to include a patient advocate and specialists. A patient advocate can help you find resources, manage insurance, and prepare legal documents. Other useful specialists include a nutritionist to help with eating, a psychologist for emotional distress, a physical therapist for weakness, and a palliative care specialist for symptom management.

KEEP A NOTEBOOK NEARBY.

Use a notebook to keep track of side effects, take notes when you talk with your health care team, and remember financial or insurance details.

METASTATIC BREAST CANCER



ASK FOR SUPPORT AND ACCEPT HELP WHEN IT IS OFFERED.

Let your family and friends know how they can support you. Offer specific examples. Consider using an online schedule or MyLifeLine.org to stay organized and let friends know what's needed.

COMMUNICATE WITH YOUR HEALTH CARE TEAM.

Let your health care team know how you feel. Ask questions and ask again if you don't understand the answers. Tell your team about **your** goals for treatment. Be sure they know how your treatment and symptoms are affecting your everyday life.

REACH OUT TO OTHERS WITH METASTATIC BREAST CANCER.

It's comforting to talk with people who understand what you're going through. Try to connect with others through the internet or a local support group.

REMEMBER THAT HOPE IS POSSIBLE.

Even if cure is unlikely, many treatment options exist. Hope can make each day a little better. Accept that some days will be better than others, but try to enjoy small moments and do things that make you smile.

FOCUS ON NUTRITION AND EXERCISE.

Healthy food provides nutrients to help your body. Exercise can lift your spirits, boost your energy, and reduce stress. Even minor efforts can help you feel better.

Coping with Treatment

Everyone approaches cancer treatment differently. Some people gear up for battle while others feel hopeless or fearful. Those who start strong can lose momentum over time.

Try to maintain a positive attitude. Some days will be harder than others. Identify ways to feel more in control. Be sure to:

FIND A HEALTH CARE TEAM YOU TRUST.

Your cancer experience depends in part on your relationship with your health care team. It's easier to talk openly with a doctor you trust. If you have not found a team you trust, keep looking. Getting a second opinion can help you learn more and feel more in control.

LEARN ABOUT YOUR CANCER.

In order to make decisions, you will need to learn about metastatic breast cancer and its treatment. Ask questions until you understand the answers. Don't trust everything you read online.

MAKE INFORMED DECISIONS.

Making treatment decisions is a big part of a cancer experience. Discuss options with your health care team as well as trusted friends and family. CSC's Open to Options® program (see page 8) can help you get the information you need to make decisions.

Use the discussion tool found on page 7 to talk with your health care team. The goal is to work with your team to find treatments that allow you to live as well as possible and achieve your goals.

Managing Side Effects and Symptoms

The side effects of treatment can be a lot to handle. There will be good days and bad days. Focus on helping yourself feel better today. It's important to remember:

- Side effects are not the same for everyone. It can help to talk with others who have had the same treatment. But keep in mind that your experience may be different. You may not experience all or even most side effects associated with a treatment.
- Different treatments can have different side effects. Ask about possible side effects and how they can be managed for every drug or treatment you consider.
- Many side effects can be treated. Keep track of changes and when they occur. Describe them to your health care team, and ask what you can do to feel better. Reporting is critical because your team only knows what you tell them.
- If side effects become too unpleasant, ask if there is another drug or treatment you can try.

More information on how to cope with specific side effects can be found at: www.CancerSupportCommunity.org/cancer-treatment-side-effects.

Lifestyle Changes

Coping with changes to daily life can be difficult for you or the people around you. As new routines or family roles are established, your career or work life may be affected. You may miss activities you

can no longer do. Managing your health care may consume much of your time.

Getting used to a "new normal" is challenging but important. The sooner you accept where you are now, the better chance you have to find solutions, comfort, and enjoyment in your life. Be thoughtful about how you spend your time. Prioritize people and activities that are meaningful to you.

"I attend the MBC group as often as my energy and schedule allows, it helps to be with others going through this journey. I have enjoyed yoga, the luncheons and especially the art class. It's crucial to have a home away from home where everyone understands and doesn't need you to explain."

—Sheila B.,
metastatic breast cancer patient

EVERYDAY HEALTH

It's hard to be positive when you don't feel well. A healthy diet, exercise, and the right amount of rest can help you feel better, have more energy, and stay hopeful. Try to make healthy living a part of your daily life. Set realistic goals for each day.

EAT HEALTHY

Nutrition is important even when you don't feel hungry. Try to limit alcohol and eat a healthy, balanced diet. If you are too tired to cook, keep healthy snacks around.

EXERCISE AND BE ACTIVE

If you have trouble getting motivated, ask a friend to exercise with you. Start by taking a walk or trying a yoga class. Set a goal to do something active you enjoy for 10 to 30 minutes most days.

RELAX

Calm yourself with deep breathing, journaling, meditation, exercise, or creative activities.

Many people with cancer experience a loss of energy or fatigue. You may have trouble getting around due to mobility issues or pain. If you experience these symptoms, talk with your health care team about how to manage them and stay active without feeling worse.

GETTING SUPPORT

The Cancer Support Helpline counselors can be reached toll-free at (888) 793-9355 or via live chat, Monday through Friday, 9:00 a.m.–9:00 p.m. ET

CANCER SUPPORT HELPLINE
888-793-9355

Emotional Support

Whether you have faced cancer before or this is your first time, you need support. It may take a while to find the support that is right for you, but don't give up.

Where to turn for support:

- Talk with an oncology social worker, therapist, or spiritual advisor.
- Call a cancer support line.
- Attend a metastatic breast cancer support group.
- Participate in online chat groups and discussion boards.
- Talk with trusted friends or family members.
- Advocate for support, services, and research to help people with metastatic breast cancer.

CONSIDERING A SUPPORT GROUP?

Many people benefit from the sharing and bonds developed in a group. A support group can help you feel less alone and learn from the experiences of others. If possible, try to find a group specifically for metastatic breast cancer.

Depression and Anxiety

It is normal to feel sad, but if you routinely find it difficult to get out of bed or draw pleasure from life, you may be depressed. Tell your doctor right away if sadness or worry dominate your day. Depression and anxiety are treatable. Treatment can improve your quality of life and help you cope with cancer.

Coping with the Cost of Care

Cancer can be expensive. The cost itself can be a burden, as can concern over its long-term impact. It's never too early to start to think about the cost of care.

You may feel uncomfortable discussing money or the cost of treatment with your health care team. Even though it's hard, starting open conversations early can help you in the long term. Ask for help from a trusted friend or family member, patient navigator, or social worker. As you think ahead, consider:

- Medical expenses, including prescription drug co-pays
- Missed time from work or a time when you won't be able to work
- How caregiving may affect the earnings of a partner or other family member
- Childcare or transportation expenses

If you are not sure how to get started, call the Cancer Support Community Helpline at 888-793-9355 or look for more information at www.CancerSupportCommunity.org/cost.

Preparing for Your Doctor's Visit—A Worksheet

IF YOU HAVE Metastatic Breast Cancer (MBC), this 2-page worksheet can help you talk to your health care team about symptoms, treatment options, side effects, and getting the emotional and practical support you need. It is normal to worry, but there are steps you can take to prepare for your doctor's visits and to take an active part in making decisions about your treatment.

Tips for Taking Control

Know what kind of breast cancer you have. Ask your doctor, is it?

- Hormone (estrogen and progesterone) receptor positive
- HER2 (human epidermal growth factor receptor 2) positive
- Triple negative (not estrogen, progesterone or HER2 positive)

Knowing your cancer type will help determine your treatment options. Remember you can get a second opinion about your options at any point.

- Write down your questions before each doctor's visit.
- Take someone with you to appointments for support and an extra set of eyes and ears.
- Tell your health care team about any symptoms, side effects, or concerns you have.

Preparing for Your Doctor's Visit

Talk about what is important to you. Here are some suggestions to think about before your next appointment.

- What are you most worried about today?
- What are you most worried about in the future?
- How are you feeling today? Better or worse than your last appointment?
- If you are feeling either better or worse, what has changed?

Below are some of the things people with MBC may experience as shared by members of our Cancer Experience Registry. Think about how often they affect you. Talk to your health care team about how best to manage them.	Rarely	Sometimes	All the Time
Feeling very tired			
Pain			
Difficulty thinking clearly or remembering			
Feeling anxious or depressed			
Swelling or hardness in your arm			
Shortness of breath			
Nausea/vomiting			
Weight loss or gain			
Loss of sexual desire or problems with intimacy			
Others:			

How are cancer or treatment-related side effects interfering with your life?	Rarely	Sometimes	All the Time
Work (unable to work, unable to do tasks, missing work)			
Sleep			
Social relationships			
Sexual relationships			
Unable to do activities I normally enjoy			
Eating and/or exercise			
Unable to do daily activities (get dressed, prepare meals, manage finances)			
Others:			

SETTING GOALS FOR TREATMENT

When you talk to your doctor about your treatment options, ask what the goal is. Also, think about your own values and tell your doctor what is important to you. Your goals may change over time.

Physical Health and Well-being	*What do you want to be able to do?*
Family and Social Relationships	*What's going on in the lives of others that is important to you?*
Work	*Do you want to continue working? Can you adjust your schedule or responsibilities?*
Financial	*Do you have concerns about how to pay for your care? (insurance, co-pays, parking, other)*
Other	*What else is important to you?*

GETTING SUPPORT

Think about who in your life is a helping presence. It might be your spouse or partner, friends, faith community, support group, or co-workers. Make a list of specific ways they can help. Ask your health care team about resources for social, emotional, and practical support. Let them know about your concerns.

Open to Options

OPEN TO OPTIONS™ CAN HELP

For help in developing your own set of questions to ask your doctor, schedule an Open to Options appointment. You will talk to a trained specialist who will work with you to clarify and prioritize your questions for your time with your doctor. To learn more about this and other programs offered by the Cancer Support Community, call our toll free Helpline at 1-888-793-9355 or go to www.CancerSupportCommunity.org

Relationships

Cancer affects relationships. Loved ones may have different ways of coping with your diagnosis.

Worry and stress can add strain, but changes can be positive, too. Relationships may grow stronger and connections deeper. You cherish time together more. People can prove to be more dependable than you expect.

Metastatic breast cancer brings special challenges. Friends may comment that you look well, even when you feel your worst. Others may be more familiar with treatable forms of breast cancer. You may find yourself explaining metastatic breast cancer.

Try to be honest and open with friends and family about your situation, feelings, and needs. Accept support. This can be hard if you are the caretaker within your community. Most importantly, find the people who will be there for you and lift you up when needed.

Sexual Intimacy

Sexuality can be an important part of who you are and how you relate to others. You may find fatigue, worry, discomfort with your body, or the side effects of treatment lower your interest in sexual activity.

If you have concerns, talk with your health care team. They may be able to treat symptoms or side effects that interfere with intimacy, or refer you to resources that can help.

Be open with your partner about how you are feeling. Sex and intimacy can be achieved in many different ways. Gentle touching, holding hands, kissing, and hugging can help you feel closer and more connected.

If You Are Young

A cancer diagnosis can be especially hard to accept when you are young. You may be just getting started in life, figuring out what you want to do, or enjoying early career success. You may be excited about a relationship, relishing your independence, or actively looking. Perhaps you have children or are planning a family. Whatever your situation, cancer doesn't fit in.

Young women with metastatic breast cancer have unique concerns. Cancer can affect relationships, fertility, sexuality, and body image. You may feel alone.

Connecting with people in a similar situation can help. Use the resources on the back page

> *"It's so important to turn to your family and friends and let them know how you are feeling. You can't do everything. You're not Super Woman anymore"*
>
> *—Karen, metastatic breast cancer patient*

or ask your health care team to recommend support groups or put you in touch with other women with metastatic breast cancer who are your age or at a similar stage of life.

Talking with Kids

It's important to tell your children that you have cancer. If they aren't yet adults, you need to do it in a way they will understand. Refer to CSC's *Frankly Speaking About Cancer: What Do I Tell the Kids* for specific advice for different age groups. (www.CancerSupportCommunity.org/Kids) With children of any age, focus on what to expect, and reassure them that you love them and they will be taken care of.

Looking Ahead

Every day is a new day. Find hope in people and activities you enjoy. Focus on things to look forward to—a visit from a friend, a special event, or the next episode of a favorite television show.

Keep working to strengthen your life. Connect with friends and family who can support you. Build community through a hobby, activity, religion, work, neighborhood, or support group.

The future may be uncertain but you will feel stronger and more in control if you face it prepared, knowing what is most important to you. Steps you take now can help you regain control and feel more secure.

For example, take time to get your legal papers in order. Talk to a social worker about the documents you need to help ensure that your medical and end-of-life needs are met.

As you do so, you may start to think about what you have accomplished, overcome, or how you want to be remembered. Consider writing or keeping a journal. Life legacy activities let you tell your story or record wishes in writing, audio, or videotape. Reflecting on your life can be a powerful way to spend time and leave memories behind for loved ones.

"My life has not stopped because I've been diagnosed with metastatic breast cancer. I pace myself, yet I am passionate about pursuing my dreams. I consider the cancer aspect of my life as a chronic condition a—'thorn in my side'—but it will never define who I am as a woman."

—Khadijah,
metastatic breast cancer patient



MARGARET Z.

Shortly after the birth of her third child, 37-year-old Margaret saw a doctor for what she thought was a breastfeeding infection. The appointment turned into a series of tests, resulting in a diagnosis of metastatic inflammatory breast cancer. Margaret started chemotherapy a week later. She later had a mastectomy to prevent recurrence and continues to take hormone therapy. She is fortunate to be what oncologists call an “exceptional survivor.” Today, Margaret’s children are 10, 13, and 16. She and her husband have been married for 21 years. Routine check-ups and three-week cycles of Herceptin® have kept Margaret from returning to work. Instead, she volunteers with Living Beyond Breast Cancer and develops children’s books about cancer for families. Margaret also runs three or four times a week. “Being active has made all the difference. It is something from my life before cancer. When I’m running and forget that I’m a cancer patient, that is the best moment of the day.” Also vital is the support she receives from others. “It’s been really important to me to have solid people to talk to. It’s provided me a sense of hopefulness. Depression is a huge part of this disease. I encourage others to seek out support and talk about their experience. I can’t imagine holding it in and doing it all myself.”

Metastatic Breast Cancer Information, Survivorship & Support

BreastCancerTrials.org • 415-476-5777 • www.breastcancertrials.org

Cancer and Careers • 646-929-8023 • www.cancerandcareers.org/en

Living Beyond Breast Cancer • 888-753-5222 • www.lbbc.org

Metastatic Breast Cancer Network • 888-500-0370 • www.mbcn.org

Young Survival Coalition • 877-972-1011 • www.youngsurvival.org

Patient Advocate Foundation • 800-532-5274 • www.patientadvocate.org

Cancer Support Community Resources

The Cancer Support Community's (CSC) resources and programs are available free of charge. To access any of these resources below, call 888-793-9355 or visit www.CancerSupportCommunity.org

Cancer Support Helpline® Whether you are newly diagnosed with cancer, a longtime cancer survivor, caring for someone with cancer, or a health care professional looking for resources, CSC's toll-free Cancer Support Helpline (888-793-9355) is staffed by licensed CSC Helpline Counselors available to assist you Mon-Fri 9am - 9pm ET.

Open to Options® If you are facing a cancer treatment decision, this research-proven program can help you. In less than an hour, our trained specialists can help you create a written list of specific questions about your concerns for your doctor. Appointments can be made by calling 888-793-9355, visiting www.CancerSupportCommunity.org or by contacting your local CSC or Gilda's Club providing this service.

Cancer Experience Registry® The Registry is a community of people touched by cancer. The Registry works to collect, analyze, and share information about the experience and needs of patients and their families. To join, go to www.CancerExperienceRegistry.org.

Frankly Speaking about Cancer® CSC's landmark cancer education series provides trusted information for cancer patients and their loved ones. Information is available through publications, online, and in-person programs.

Grassroots Network CSC's Cancer Policy Institute provides updates on policy issues that impact the health and well-being of cancer patients and survivors. Join the Network to make your voice heard by federal and state policy makers. www.CancerSupportCommunity.org/join-our-movement.

Services at Local CSCs and Gilda's Clubs Almost 50 locations plus 120 satellite locations around the country offer on-site support groups, educational workshops, and healthy lifestyle programs specifically designed for people affected by cancer at no cost to the member.

The Living Room, Online Here you will find support and connection with others on discussion boards, a special space for teens, and personal web pages to keep your family and friends up-to-date.

THIS PROGRAM WAS MADE POSSIBLE THROUGH A CHARITABLE GRANT FROM:

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This booklet is available to download and print yourself at www.CancerSupportCommunity.org/metastatic-breast-cancer. For print copies of this booklet or other information about coping with cancer, visit Orders.CancerSupportCommunity.org.

The Cancer Support Community and its partners provide this information as a service. This publication is not intended to take the place of medical care or the advice of your doctor. We strongly suggest consulting your doctor or other health care professionals to answer questions and learn more.

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