Preparing for Your Doctor's Visit

CANCER SUPPORT COMMUNITY | GILDA'S CLUB WORLDWIDE

A WORKSHEET FOR PEOPLE WITH METASTATIC BREAST CANCER

If you have **Metastatic Breast Cancer**, complete this worksheet to help you talk with your health care team about symptoms, treatment options, side effects, and getting the emotional and practical support you need.

TIPS FOR TAKING CONTROL

- Know what kind of breast cancer you have and where in your body it spread.
- Ask your doctor about your cancer biomarkers. The key biomarkers for breast cancer are the hormones estrogen (ER) and progesterone (PR), and the protein HER2. Knowing which combination of these biomarkers you have can help you understand your treatment options.
- Take someone with you to appointments for support and an extra set of eyes and ears. If your loved one can't be there in person, consider trying a video call on your phone or computer.
- Ask questions until you understand what is being said. Ask for information in a different language or a different format. You can ask your doctor to draw you a picture or compare it to something you already know.
- Write down your questions before each doctor's visit. Keep a journal to take notes during your visit.
- Talk to your health care team or financial navigator about ways to manage treatment costs.
- Consider getting a second opinion. You can get a second opinion at any point.

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
Fatigue, weakness, or falling			
Joint pain, muscle aches, or cramps			
Difficulty thinking clearly or remembering			
Feeling anxious, overwhelmed, or depressed			
Nausea, diarrhea, vomiting, or mouth sores			
Weight loss or gain			
Loss of sexual desire or problems with intimacy			
Others:			

How often are cancer or side effects interfering with your life?	Rarely	Sometimes	All the Time
Work/school/home (unable to go to work/school or do daily tasks)			
Unable to do activities I normally enjoy, such as traveling			
Confidence/self-image			
Sleep			
Social relationships			
Sexual relationships			
Eating and/or exercise			
Others:			

THINK ABOUT YOUR TREATMENT & PERSONAL GOALS

When you talk to your doctor about your treatment options, ask about the goals of the treatment and how each treatment might affect the goals that you have for your life. If you choose not to receive treatment, think about your goals for the care that you receive. Possible goals may be to live as long and as well as possible, contribute to progress by taking part in research, make it to a special event/milestone, or find cutting edge treatments. Let your health care team know about your treatment and personal goals.

Physical Health and Well-Being	*What is most important for you to be able to do?*
Family and Social Relationships	*What's going on in the lives of others that is important to you?*
Work/School	*Do you want or need to continue working? Can you adjust your schedule or responsibilities?*
Community/ Involvement	*Are you getting the support you need from your community? Are you able to stay active/ involved in your community?*
Other	*What else is important to you?*

PREPARING FOR YOUR NEXT HEALTH CARE VISIT

If you are feeling either better or worse today than at your last appointment, let your health care team know what has changed.

Write down your concerns before each doctor's visit. Below are some suggested questions. Concentrate on the issues that are most important to you.

- Can you explain my test results to me?
- Are there any other tests I should be having right now?
- What side effects might I expect, and how can I prepare for them?
- What side effects should I let you know about?
- The symptoms and side-effects that are affecting me the most are: [fill in your answers from page 1].
- These are interfering in my life in the following ways [fill in your answers from the top of page 2].
- What can we do to manage these symptoms?
- Could palliative care help manage my symptoms and side effects? Can you refer me to a palliative care specialist?
- My top goals for treatment are: [fill in your answers from the bottom of page 2]
- Is the treatment that I am currently on the best treatment for me to meet these goals?
- What other treatments are available to me? Are there any new treatments or clinical trials that may be right for me?
- Are there treatments or drugs that work as well but would cost me less?
- How can I manage treatment costs? Is there a financial navigator that I can talk with?
- What's the best way to get in touch with you during office hours and after hours/on weekends?

GETTING SUPPORT

Think about people in your life who can help. It might be your spouse or partner, adult children, friends, faith community, support group, or co-workers. Make a list of the specific ways each of them can help (childcare, meal prep, housework, transportation, laundry, etc.). Consider using MyLifeLine.org to help you stay organized and let friends know what you need. Ask your health care team about resources for social, emotional, physical, and practical support.

If you search for information online, make sure that you are using trusted websites. Turn to the back page for a listing of trusted organizations. CSC and many of these organizations have helplines, online discussion boards, and more ways to seek support from others who have MBC.

FINANCIAL RESOURCES

Even with health insurance, treatment is expensive. Keeping up with costs can be overwhelming. However, there are many resources that can help. Talk with your health care team and your pharmacist about the cost of your treatment. Ask your doctor to refer you to an oncology social worker, financial counselor, or nonprofit organization for help managing the financial issues and costs. Ask if there are prescription assistance programs that can help cover all or part of the cost of your medications. The more you know about your specific treatment plan, the more you can help to reduce unexpected costs. To learn more about ways to manage the cost of treatment, visit: www.CancerSupportCommunity.org/cost.

Financial Support Resources

Cancer Financial Assistance Coalition • www.cancerfac.org
CancerCare • 800-813-4673 • www.cancercare.org/financial_assistance
Cleaning For a Reason • 877-337-3348 • www.cleaningforareason.org
Good Days • 877-968-7233 • www.mygooddays.org
HealthWell Foundation • 800-675-8416 • www.healthwellfoundation.org
Patient Advocate Foundation • 800-532-5274 • www.patientadvocate.org/help.php

Other MBC Information & Support

BreastCancerTrials.org • 415-476-5777 • www.breastcancertrials.org
Living Beyond Breast Cancer (LBBC) • 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

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 long-time 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 9 am - 9 pm 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.

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.

MyLifeLine CSC's private, online community allows patients and caregivers to easily connect with friends and family to receive social, emotional, and practical support throughout the cancer journey and beyond. Sign up at www.MyLifeLine.org.

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 voices heard with federal and state policy makers. www.CancerSupportCommunity.org/join-our-movement.

Cancer Experience Registry® The Registry is a community of people touched by cancer. The primary focus of the Registry is on collecting, analyzing, and sharing information about the experience and needs of patients and their families. To join, go to www.CancerExperienceRegistry.org.

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For more information and resources, please visit the CSC Metastatic Breast Cancer page at www.CancerSupportCommunity.org/metastatic-breast-cancer.

Share your experience and make your voice heard. Join the Cancer Experience Registry and participate in the special community of people facing metastatic breast cancer at www.CancerExperienceRegistry.org.

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