

# FRANKLY SPEAKING ABOUT CANCER

## Metastatic Breast Cancer





# Table of Contents

Prologue: How to Use this Book.....	2
Chapter 1: You are Not Alone .....	4
Chapter 2: What is Metastatic Breast Cancer? .....	10
Chapter 3: Treatment Planning .....	14
Chapter 4: Managing Symptoms and Side Effects.....	26
Chapter 5: Coping with Metastatic Breast Cancer .....	42
Chapter 6: Advance Care Planning.....	58
Glossary .....	62
<i>Preparing For Your Doctor's Visit</i> worksheet .....	66
Resources .....	69

## How to Use This Book

This book has a lot of information about living with **metastatic\*** (*meh-tuh-STAY-tik*) breast cancer. It may be too much to take in all at once. Feel free to use this book as a guide, and refer to its content as you need it.

You may have opened this book because you have a specific question or concern. Take a look at the Table of Contents or use this guide to find the information you need more easily.

IF YOU ARE...	GO TO...
Newly diagnosed and want to learn how you can take control of your care	Pg. 4, Chapter 1, You are Not Alone
Confused about the different types of metastatic breast cancer	Pg. 10, Chapter 2, What is Metastatic Breast Cancer?
Looking for a doctor or health care team Having trouble talking with your health care team about your goals	Pgs. 15-21, Chapter 3, Step 1 and 2
Trying to choose between treatments or find out what treatments are right for you	Pgs. 21-24, Chapter 3, Step 3 and 4
Starting a new treatment	Refer to our <i>Treatment for Metastatic Breast Cancer</i> booklet in the back pocket of this book.
Looking to learn more about specific side effects: <ul style="list-style-type: none"> <li>• Bone loss and weakness, pg. 40-41</li> <li>• Cognitive changes (chemo-brain), pg. 33</li> <li>• Constipation, pgs. 30-31</li> <li>• Depression, pg. 40</li> <li>• Diarrhea, pg. 30</li> <li>• Eating problems, pg. 32</li> <li>• Fatigue, pgs. 39-40</li> <li>• Hair loss, pgs. 35-36</li> <li>• Hot flashes, pg. 37</li> <li>• Insomnia, pg. 33</li> <li>• Low blood counts, pgs. 32-33</li> <li>• Lymphedema, pg. 35</li> <li>• Mouth sores, pg. 31</li> <li>• Nail and skin changes, pgs. 36-37</li> <li>• Nausea and vomiting, pgs. 28-29</li> <li>• Pain, pg. 40</li> <li>• Peripheral neuropathy, pg. 34</li> <li>• Vaginal dryness and discharge, pg. 38</li> </ul>	Chapter 4, Managing Symptoms and Side Effects
Feeling alone or having trouble talking with family and friends	Pgs. 44-46, Chapter 5, Coping and Support



IF YOU ARE...	GO TO...
Feeling alone, anxious, depressed Concerned about a loved one with metastatic breast cancer	Pgs. 46-47, Chapter 5, Stress, Anxiety, and Depression Pg. 49, Chapter 5, Support for Caregivers
Young and coping with metastatic breast cancer	Pg. 48, Chapter 5, If You Are Young
Parenting while facing metastatic breast cancer	Pgs. 53-54, Chapter 5, Helping Children and Teens Cope
Worried about work or career	Pgs. 55-57, Chapter 5, Work
Worried about health care costs or insurance Information on disability, medicare, and social security pg. 50	Pg. 57, Chapter 5, Financial Concerns
Want to make sure your legal documents are in order	Pg. 58-60, Chapter 6, Advance Care Planning
Unsure of a medical term you've heard	Pgs. 62-65, Glossary
<i>Preparing For Your Doctor's Visit</i> worksheet	Pgs. 66-68

## HOW TO GET THE MOST OUT OF THIS BOOK

You may find this book or others like it hard to read. It may be too difficult emotionally. Or maybe the words or thoughts don't sound like you.

As you read, think, and talk about cancer you will hear words used to describe the attitude you may or should have. Some of them will sound about right. Some won't fit at all. The ones that ring true for you may not be the same as the ones that are meaningful for someone else.

Each person's cancer or cancer caregiver experience is their own, and there is no one set of perfect words to describe how everyone feels. Try to focus on the information being provided, and ignore the words that don't speak to you.

Think, instead, about how you are going to make each day better for yourself, and what you can do to live the best life you can. Many people have been where you are and many are there right now. You are not alone.

## IN THIS CHAPTER:

- 10 Tips For Living Well with Metastatic Breast Cancer
- Learning to Live with Metastatic Breast Cancer

# 1

## You Are Not Alone

You or a loved one has been diagnosed with **metastatic\*** breast cancer. This may be your first experience with cancer. Or you may have had cancer before. Either way, this is a difficult and emotional time.

This book was written for you. It will help answer your questions, prepare for what's next, and provide resources so you can face tomorrow with confidence and hope. People with metastatic breast cancer, their loved ones, doctors, nurses, health educators, and counselors contributed to this book. They shared their knowledge, stories, fears, wishes, and advice to support you.

This book can be a resource for you now and in the future. Read for what is important to you today. Refer back as different questions arise.

Living with metastatic breast cancer is challenging. But there are steps you can take to make the journey a little easier. These steps may help

you feel more in control and ready to move forward. Never be afraid to hope, just remember what you hope for may change.

There are about 155,000 people living with metastatic breast cancer in the United States. Thanks to recent advances in research and treatment, people are living longer and with greater well-being than ever before.

About 5 to 10 percent of people diagnosed with breast cancer for the first time are diagnosed with stage IV (4), also referred to as **de novo metastatic breast cancer**.<sup>\*</sup> Others develop metastatic breast cancer as a **recurrence**<sup>\*</sup> (or return) of a previous breast cancer. In this case, it has spread beyond the breast and lymph nodes under the arm to other places in the body, like the liver, lungs, bones, or brain.

About 1 percent of breast cancers occur in men. Like women, their breast cancer may be found early or it may be found after it has spread beyond the breast.

“When you’re first diagnosed, you feel like you’re alone and going to die. Through meeting people in support groups, it gives you more hope.” —Jeana



<sup>\*</sup>These words are explained in the glossary on page 62

# 10 TIPS FOR LIVING WELL WITH

## 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 the right decisions for you.

## PAY ATTENTION TO WHAT YOU NEED

Be aware of your feelings. Focus on activities you enjoy. Try to find humor in each day. Seek out people who help you feel relaxed or happy. Spend time alone if you need. Some days you may not know what you need, and that's okay too. Be kind to yourself.

## BE YOUR OWN BEST ADVOCATE

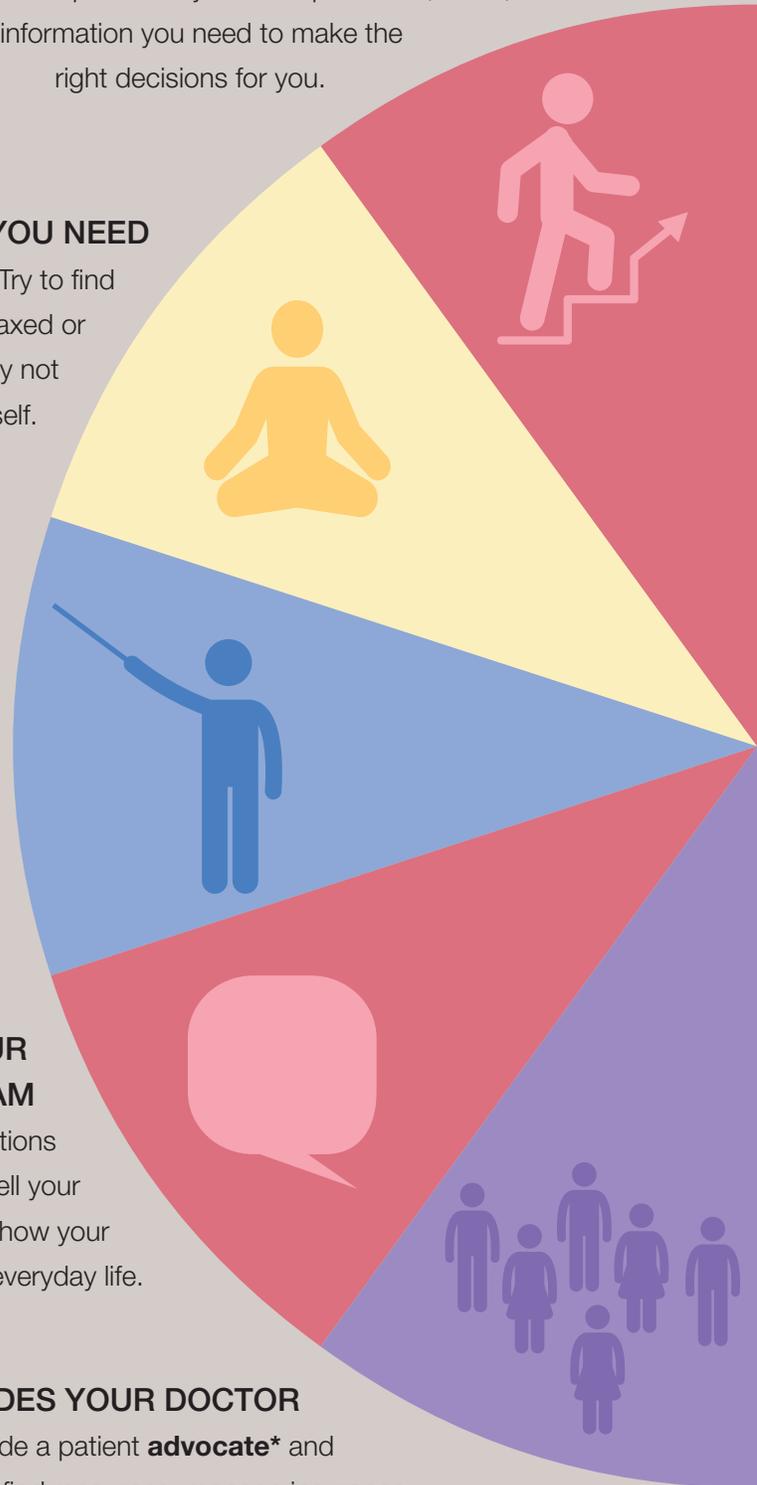
You may feel frustrated by changes to your life. Talk with your medical team and your family and friends. Work together to come up with a plan that gives you as much control as possible over your treatment and care.

## COMMUNICATE EFFECTIVELY 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.

## GET HELP FROM OTHERS, BESIDES YOUR DOCTOR

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.



# METASTATIC BREAST CANCER

## 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.

## 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 online or in a local support group.

## ASK FOR SUPPORT AND ACCEPT HELP WHEN IT IS OFFERED

Let your family and friends know how they can support you. Be specific if you can. Consider using an online schedule such as **MyLifeLine.org** to stay organized and let friends know what's needed.

## 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.

## Learning to Live with Metastatic Breast Cancer

Being diagnosed with metastatic breast cancer may feel like an immediate death sentence. It isn't. Although some people do not respond to treatment, many more are able to live well for months or years. Even though there is no cure, there are ways to slow down how fast the cancer grows or spreads. New treatments make it possible for many people to live longer and better.

Metastatic breast cancer will always require some type of treatment. When one treatment stops working, usually another can be tried. Try to learn more about your disease. By being well informed, you will feel more comfortable talking with your doctors and more confident in the decisions you make together.

The thought of living with cancer for the rest of your life can be scary and overwhelming. It's normal to feel afraid. Find ways to cope and recharge if you are feeling discouraged or worried. Try to do things every day that help you feel better physically, emotionally, or spiritually. Find events to look forward to, and work with your health care team to figure out how to feel your best when it's most important to you.

You may hear sad stories about other people's experiences with cancer. Or you may see discouraging statistics. But you are not a statistic. Statistics apply to groups, and

each person is unique. Many people like you get up each day and work with their health care team to develop a plan to maintain the best quality of life for the longest time possible. This book is designed to give you the tools and support to do just that.

“Recently, I went back and read my journal entry from the beginning. I was really, really scared, and I'm scared now. And even though my doctors and others could say that there is life after the diagnosis, I wish somehow emotionally I could have felt that a little sooner. But again, it's that unknowing-ness of it. I think it's just part of living with metastatic breast cancer.” — Ruth

Ruth  
3-year MBC survivor



## IN THIS CHAPTER:

- Definition of Metastatic Breast Cancer
- Types and Subtypes of Metastatic Breast Cancer
- Biomarkers and Biomarker Testing
- Genetic Testing
- Key Questions to Ask Your Doctor About Your Diagnosis

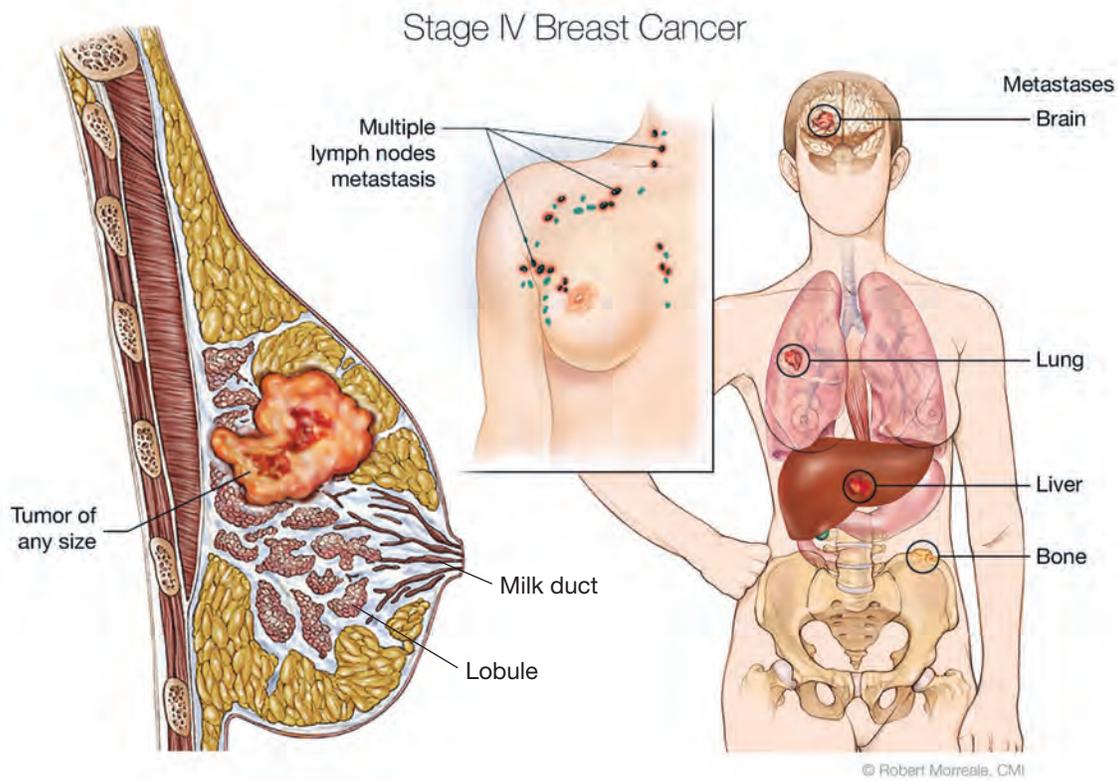
# 2

## What is Metastatic Breast Cancer?

Cancer is a condition in which cells grow and divide without stopping. Cancer interferes with normal, healthy cell growth. Instead of dying, old or damaged cells survive. New cells form when they are not needed. In some cases, they form growths called tumors.

Cancer cells invade and destroy normal, healthy tissue. They can also spread from their original site to other parts of the body. This process is known as metastasizing. The word **metastatic\*** describes cancer that has spread. Cancers are named for the place in the body where they begin (the **primary site\*** or **primary cancer\***), not where they spread.

Breast cancer starts in the **ducts\*** or **lobules\*** of the breast. Metastatic breast cancer means that breast cancer has spread to other parts of the body. It is also called stage IV (4) breast cancer. When breast cancer spreads, it most commonly spreads to the bones, lungs, liver, and brain.



Metastatic breast cancer can be a new cancer. Or it can be the return of a prior breast cancer. If you have breast cancer for the first time and it has already spread, it is called ***de novo metastatic breast cancer***.\*

Even though the cancer may be in a different part of the body, it is still breast cancer. This is true even if your breasts were removed. This means that breast cancer treatments, not treatments for other cancers, will work best.

\*These words are explained in the glossary on page 62

## Learning to “Speak Cancer”

Members of your health care team may use words you don't understand when they talk about your diagnosis and treatment. Some of these words may sound familiar and others may be completely new. You may feel like you are learning a new language or are back in science class again.

Use the glossary at the end of this book to look up words. Ask questions. Your health care team may not always remember to speak slowly or use simple words. It's okay to remind them. It is their job to explain cancer to you in a way that you understand, even if it means drawing pictures or translating into another language. Keep asking until it makes sense to you.

## Understanding Your Diagnosis

A complete diagnosis usually takes more than one doctor's visit. It may involve scans, blood tests, and a **biopsy**.\* Your doctor will work with a team to figure out whether this is breast cancer or another kind of cancer, the type and subtype of breast cancer you have, and the places in your body it has spread.

If you had breast cancer in the past, your doctor will confirm whether it is the same type of breast cancer as before. Breast cancer that has spread to another part of the body is still breast cancer. The site(s) where the cancer has spread may affect your treatment options.

## BREAST CANCER TYPES

Your health care team will want to know as much about your cancer as possible to be able to recommend the best treatment options for you. One of the first things they will look at is the type of breast cancer you have. The most common forms are **invasive ductal\*** and **invasive lobular\*** breast cancers. **Inflammatory breast cancer\*** is less common. Make sure to ask your doctor any questions about your specific breast cancer type.

## BREAST CANCER SUBTYPES/BIOMARKER TESTING

It is also important to understand the subtypes of breast cancer. Your doctor will do this by testing for **biomarkers**.\* These are signs in your blood or tissue that help describe your cancer. The subtype will determine your treatment options.

### ■ **Hormone Receptor-Positive\***

**(HR+) Breast Cancer:** Breast cancer can be **estrogen receptor-positive (ER+)\*** and/or **progesterone receptor-positive (PR+)\***. This means that hormones play a role in the growth and spread of the cancer. These breast cancers are often treated with anti-estrogen **hormone therapy**.\*

### ■ **HER2-Positive Breast Cancer:**

Breast cancer can be **HER2/neu positive (HER2+)\***. This means that a protein called human epidermal growth factor receptor 2 (HER2) is present in the cancer. HER2 helps control the rate at which cancer cells grow. HER2+ cancer may be treated with **targeted therapy**.\*

### ■ Triple-Negative Breast Cancer:

Breast cancers that do not test positive for either hormone or HER2 are described as triple negative. There are fewer treatments that work well for this kind of breast cancer. More research is being done.

### GENETIC TESTING

Your health care team also may recommend genetic testing. This is likely if you are young, have a family history of breast or other cancers, or have triple-negative breast cancer. Genetic testing looks for changes in **genes\*** passed down through your family. Two well-known ones are BRCA1 and BRCA 2. This information may affect your treatment options.

Find out which **biomarkers\*** your tumor has been tested for. Ask if there are any other tests that can help determine the

treatment that might be best for your cancer. More on treating cancers with certain **biomarkers\*** can be found in our *Treatment for Metastatic Breast Cancer* booklet in the back pocket of this book.

### BREAST CANCER IN FAMILIES

Breast cancer can run in families, through changes (mutations) in genes, such as BRCA1 and BRCA2.

Researchers study families to try to find effective ways to prevent and treat cancer. If you think breast cancer may run in your family, talk with your health care team about genetic testing. You may be able to help future generations in your family by getting tested.

For more information on genetic testing, visit **[www.CancerSupportCommunity.org/cancer-hereditary](http://www.CancerSupportCommunity.org/cancer-hereditary)**.

## QUESTIONS TO ASK YOUR DOCTOR ABOUT YOUR DIAGNOSIS

- What is the exact name of the kind of breast cancer I have?

---

- Is it the same type of breast cancer as my previous breast cancer?

---

- Are there other biomarker tests (such as ER, PR, HER2, BRCA, and Ki-67), scans, or biopsies that should be done to help decide what treatment I should have?

---

- Do you have a suggestion for where to go or someone to see for a second opinion?

---

\*These words are explained in the glossary on page 62

## IN THIS CHAPTER:

- Choosing a Health Care Team
- Getting a Second Opinion
- Members of the Health Care Team
- Communicating with Your Team
- Understanding the Goals of Treatment
- Choosing the Right Treatment For You
- Learn More About What Treatments Are Available Now in our *Treatment for Metastatic Breast Cancer* booklet, in the Back Pocket of this Book

# 3

## Treatment Planning

There are different approaches for treating metastatic breast cancer. Treatment may involve **hormone therapy**,\* **chemotherapy**,\* or **targeted therapy**.\* Other treatments may help with symptoms or side effects. Many people with metastatic breast cancer receive their treatment through a clinical trial. You can learn more about specific treatments available in our *Frankly Speaking About Cancer: Treatment for Metastatic Breast Cancer* booklet. This is located in the back pocket of this book.

## Understanding Treatment Planning

The process of learning about treatment options and choosing one is called treatment planning. You will be asked to make choices at the beginning of treatment and again along the way. As you consider your options, you may talk with family, friends, and members of your health care team. Here are some steps you can take to feel more in control and better able to make decisions that are right for you.

## Tips for Taking Charge of Your Care

### STEP 1: FIND THE RIGHT HEALTH CARE TEAM FOR YOU

Your health care team includes the doctors, nurses, and other professionals who will provide you with medical care and support. Living with metastatic breast cancer typically means a lot of doctors' visits and ongoing treatment. You need a health care team you can trust.

You may have already met with a medical oncologist. They may be someone you saw in the past or a new doctor. You may know that this doctor is the right person to treat your metastatic breast cancer. If you are not sure, it's important to talk to another doctor and get a second opinion. Even if you like your doctor, it's a good idea to review the questions in the pages that follow. You want to make sure that you have the right doctor to treat your cancer.

Where you go for treatment is a very personal choice. Here are some important questions to ask yourself when choosing your health care team:

- **Past relationships.** If you had breast cancer before, would you like to see the same doctors? Do they listen and take your needs and concerns into account? Do you trust them? If you aren't sure, it's a good idea to meet with someone else, or more than one doctor, as a comparison. Even after meeting with other doctors, you can choose to continue with your original doctor.
- **Recommendations.** Is there a doctor or nurse you trust who can recommend a medical oncologist for you? Do you have a friend, colleague, or relative you trust who has had a good experience with a doctor they can recommend?
- **Expertise.** Is your doctor a general oncologist or a breast cancer specialist? Do they attend medical conferences and keep up with breast cancer research? Advances in treatment happen quickly. Try to find someone who is up-to-date on the latest research.
  - Ask how they stay current.
  - Ask about their experience treating metastatic breast cancer with the same subtype as yours.

Try to find a doctor who treats metastatic breast cancer with the same subtype as yours. You may have more options at a

hospital with an active research program, such as an NCI-designated comprehensive cancer center. If there are none near you, consider visiting one for a second opinion before you start or change treatment. Refer to the next page for resources and tips to help you find a doctor.

■ **Communication style.** Do you want a doctor who tells you all of your options and leaves the final decision up to you? Or do you want someone who doesn't go into detail and just tells you what they think is the best thing to do? Think about which approach works better for you. Once you have chosen a doctor, let them know when they are explaining things well or if you would like them to explain things differently.

■ **Approach to treatment.** Some doctors recommend many tests and combined treatments, while others prefer a less aggressive approach. The decision is yours, but it is important for you to understand the choices. Be sure to:

- Ask each doctor you meet about all of your options for treatment, including taking part in a clinical trial.
- Ask about the goal of each treatment option.
- Be clear about *your goals*. Let them know what is important to you and what helps you feel good about life. Ask if the treatment they are recommending will be the best to meet your goals.

■ **Getting a second opinion.** Many people find that it helps to get a second or even third opinion from another oncologist or cancer center. Some doctors even encourage it. Doctors have different experiences with treatments. Talking with other doctors can help you make a decision or confirm your current treatment plan. A second opinion can:

- Help you feel more confident that you are getting the best possible care.
- Be especially helpful when one treatment stops working and you're looking for the next one to try.
- Give you some new options for treatment or management of side effects.



“My doctor encouraged me to get a second opinion. He told me to get two or three. It was very reassuring to know that he had my best interests in mind.” — Amanda

## WHEN YOU DON'T HAVE MANY OPTIONS FOR HEALTH CARE

It may be hard to find a doctor. You may be limited by geography, insurance, or finances. As a first step, make sure that you have done a thorough search. There may be a doctor or hospital you haven't heard about. Try these websites to find a doctor:

- **AMERICAN SOCIETY OF CLINICAL ONCOLOGY:**  
**[www.cancer.net/find-cancer-doctor](http://www.cancer.net/find-cancer-doctor)**
- **NATIONAL CANCER INSTITUTE-DESIGNATED CANCER CENTERS:**  
**[www.cancer.gov/research/nci-role/cancer-centers/find](http://www.cancer.gov/research/nci-role/cancer-centers/find)**

If you can't find a doctor nearby or have chosen a doctor who has not treated metastatic breast cancer very often, here are some things you can do to ensure that you receive the best possible care:

- Learn about metastatic breast cancer. Read this book or use other resources at the end of this book. Ask questions. Your doctor may not be able to answer them on the spot. Try to find a doctor who will look for information and resources to learn as much as possible about your disease and how to treat it.
- Ask your doctor where to go for a second opinion. Does your doctor know another doctor at an NCI cancer center? Maybe there is someone you could see once who could consult on your case?
- Call or email the closest NCI-designated cancer center. Ask if they have a visiting oncologist who comes to your area occasionally. Ask how you can get to see this doctor. Some hospitals have telemedicine services that could be useful to you or your doctor.
- Find out if you are eligible for any clinical trials. More information about getting treatment through a clinical trial is in the clinical trials section of the *Treatment for Metastatic Breast Cancer* booklet in the back pocket of this book.
- Call or email a cancer organization listed at the end of this book for advice.
- Build your own health care team. Work with your doctor to find other resources and care team members. (See the next few pages for who might be on your team.)

**Refer to chapter 6 for more information on insurance, benefits, and the cost of care.**

■ **Availability of Clinical Trials.** Some treatments with the best chance of success may be available only through clinical trials. But not all treatment centers offer clinical trials. And not all centers have the same clinical trials. Be sure to ask:

- About local clinical trials that might be right for you.
- If they are willing to refer you to other clinical trials.

This information may help you choose your treatment team. (Refer to the Clinical Trials section of our *Treatment for Metastatic Breast Cancer* booklet in the back pocket of this book for more information on clinical trials.)

■ **Geographic location.** Think about travel that might be needed for treatment. How will you get there? How often will you need to go? Are you able

to travel farther if it means getting better care? In some cities, nonprofit organizations provide housing or host families for people being treated at a local hospital.

■ **Insurance.** Your choice of doctors may be limited by your insurance. Check with your insurance provider and your doctor to make sure your care will be covered. Ask about appointments, tests, and treatments. If you do not have health insurance, see page 71 for a list of government and nonprofit organizations that can help or refer to CSC's *Coping with the Cost of Care* booklet: [www.CancerSupportCommunity.org/cost](http://www.CancerSupportCommunity.org/cost).

■ **Urgent care needs.** Is the medical oncologist available for urgent care needs? Does this doctor work with a team? Who is available to answer questions during off hours?



## KEY MEMBERS OF YOUR HEALTH CARE TEAM

Each member of your health care team will take care of you in a different way. Your team may include a:

- **Medical oncologist** - diagnoses and treats cancer. They will oversee your treatment. Try to find a breast cancer specialist (at least 50% dedicated to breast cancer treatment).
- **Primary care physician** - still see this doctor for regular check-ups and non-cancer-related issues like diabetes, hypertension, or asthma.
- **Oncology nurse practitioner (NP) or Oncology physician assistant (PA)** - can diagnose and treat medical problems and prescribe medicine. They may see you with your doctor or independently. This may be the person you contact with urgent questions or concerns.
- **Oncology nurse** - a registered nurse (RN) who specializes in cancer. Often they administer treatments and other medicines. They can help you understand your cancer diagnosis and treatment. They can be a good source of information and support.
- **Surgical oncologist** - if surgery is recommended, look for a surgeon who specializes in that surgery. Ask how many times they have done that operation.
- **Radiation oncologist** - will manage any radiation treatments.
- **Radiologist** - oversees the scans used to diagnose and monitor you, including ultrasound, x-ray, **MRI,\* CT scan,\* bone scan,\*** and **PET scan.\***
- **Palliative care specialist** - helps manage symptoms, pain, and side effects.
- **Oncology social worker** - can provide counseling. They can also help you with financial, transportation, and home care needs.
- **Psychologist/psychiatrist** - both can provide mental health care to support you before, during, or after treatment. A psychiatrist can also prescribe medicine.
- **Nutritionist/registered dietitian** - they can help find foods to eat or ways to eat them to get the nutrients you need. Look for a registered dietician (RDN) who has experience working with people with cancer.
- **Patient/nurse navigator** - can help you talk with your health care team, help set up appointments, and help you get financial, legal, and social support.
- **Physical therapist or rehabilitation medical therapist** - can help treat discomfort that interferes with daily life. Some are certified in cancer.
- **Oncology Pharmacist** - a pharmacist with special training in cancer medicines. They can teach you about drugs and how they interact. They can help you manage side effects. They also may help you find co-pay assistance or discounts.
- **Chaplain** - can offer emotional and spiritual support. You also may find support from clergy outside of hospital.

\*These words are explained in the glossary on page 62

## STEP 2: LEARN HOW TO WORK WITH YOUR TEAM: COMMUNICATION IS KEY

You've chosen your health care team. The next step is to make sure that you work with them in a way that is most helpful to you. In order to get the best possible care, it is important to maintain open communication. You want to be able to report on how you feel. You also want to understand enough about your cancer to help make treatment decisions that match your goals. Here are some tips for communicating with your health care team:

- ✓ Keep a running list of questions to bring to office visits. Write down questions as they come to you so you don't forget later.
- ✓ Bring a friend or family member to appointments. It can be hard to take in all the information by yourself. Take notes, or ask the person with you to take notes.
- ✓ Ask about the best way to get your questions answered. Should you bring a list to every office visit? Do they prefer email? Do you need to schedule an extra appointment if your list is very long? Find out who to contact with questions and concerns between visits. Write down phone numbers and email addresses in the same book where you take notes and keep track of symptoms and side effects.



“I told my doctors who I am as a person and how I understand material. They know to ask me questions when I’m quiet.” —Felicia

- ✓ Ask questions until you are sure you understand. You deserve to get your questions answered in a way that makes sense to you. It's okay to ask the same question again. Tell your doctor if you need something described in a different language or format. For example, you can ask your doctor to draw a picture or compare what they are talking about to something you already know.

✓ ALWAYS tell your team about:

- Any side effects or symptoms. This is especially important for those that make you uncomfortable or interfere with your daily activities. They can help only if they know what's bothering you.
- Any natural treatments you are taking. This includes herbs, vitamins, supplements, or other complementary treatments. They may interfere with some cancer drugs. Your doctor can tell you what is safe to take, what isn't, and what is known or unknown about the various treatments.
- Medicines prescribed by any other doctor for other health conditions. Your doctors need to be aware of what you are taking. Communicate with each other about your care.

✓ ALWAYS make sure your treatment goals are known and honored.

A patient navigator can also help you communicate with your health care team. Ask if your treatment center has patient navigators.

Take a look at the worksheet, *Preparing for your Doctor's Visit* on pages 66-68 for questions to ask.

## DOCTOR-PATIENT RELATIONSHIP

You need to have a positive relationship with your doctor. Ideally, you will work together as a team. Try to find a doctor who will be your partner in helping you achieve the best health possible. It may take a little work to get there. Use the worksheet on pages 66-68 to start a conversation with your doctor. Try to explain your hopes, goals, and concerns. Be as open and honest as possible.

If you feel like your doctor doesn't respond to your concerns or answer your questions, consider seeking a second opinion. If it is helpful, refer to the patients' bill of rights provided by your hospital or medical practice to understand your rights.

## STEP 3: UNDERSTAND THE GOALS OF TREATMENT

The goal of treatment for metastatic breast cancer is to slow or sometimes stop the growth of the cancer cells. The idea is to keep the cancer from spreading for as long as possible. While there is no cure for metastatic breast cancer, there are ways to manage the disease for months or years.

This is very different from early stage breast cancer (stages 0-3). Early stage breast cancer is treated with multiple forms of treatment. Surgery is usually the first step. After breast cancer has spread to other parts of the body, treatment needs to focus on the whole body. These whole body treatments are called **systemic therapies**.\*

\*These words are explained in the glossary on page 62

Some of the drugs are the same. But the approach and number of treatments are different. If you had breast cancer before, you probably had a set number of treatments. Going forward, you may receive an unlimited number of treatments for as long as the drugs are controlling or shrinking the cancer.

The treatment plan may sound too simple. Or, you may be disappointed that surgery is no longer an option or a priority. It is important to have a realistic understanding of the situation so you can make better decisions.

There are many treatments for metastatic breast cancer. The number is growing every year. Researchers discover new treatments, test them in clinical trials, and offer them to patients. Each person's cancer is different. Responses to treatment vary from patient to patient. No one treatment or series of treatments is best for everyone. People often try different treatments, staying with one for as long as it is working.

“My surgery was scheduled then canceled after the doctor found that the breast cancer was metastatic.” —Ruth

## STEP 4: CHOOSE THE RIGHT TREATMENT FOR YOU

As you start to learn about possible treatments, you will be asked to make decisions. Some of the information may be hard to hear, and these conversations might feel overwhelming at times. Work with your health care team to understand the options and think about what is important to you.

Before recommending a specific treatment, your doctor will consider, among other factors:

- The type and subtype of breast cancer you have
- The treatment you have already had
- The drug's potential side effects.

As you consider treatments, be sure to:

- Ask questions. Learn about the different treatments. Find out why one might work better for you than another.
- Ask about the goal of each recommended treatment.



- Ask about possible side effects. Work with your health care team to find the best ways to manage your side effects.
- Ask about receiving treatment through a clinical trial.
- Talk with family, friends, and your health care team as you consider your next steps.
- Seek support.
- Consider getting a second or even third opinion. Talking with another doctor can help you better understand your disease and how to treat it.
- Use our *Preparing For Your Doctor's Visit* worksheet (pgs. 66-68). Review it before each visit to decide the most important questions to ask your health care team. ([www.CancerSupportCommunity.org/metastatic-breast-cancer](http://www.CancerSupportCommunity.org/metastatic-breast-cancer))
- Tell your health care team about your goals and what you hope to get out of treatment.
- Tell your health care team about special events in the coming weeks or months that are important to you. They may be able to arrange a “drug holiday” so that you can feel as well as possible at the time of the event.

## Treatment Options

There are different approaches for treating metastatic breast cancer. Treatment may involve **hormone therapy**,\* **chemotherapy**,\* or **targeted therapy**.\* Other treatments may help with symptoms or side effects. Many people with metastatic breast cancer receive their treatment through a clinical trial.

- **Hormone Therapy:** the use of drugs that block hormones that are driving cancer growth
- **Chemotherapy:** the use of drugs to destroy or damage fast-growing cells like cancer cells so they cannot divide and multiply
- **Targeted Therapy:** the use of drugs that work by targeting specific changes in some cancer cells that helps them grow, divide, and spread
- **Treatment through a clinical trial:** studies that test new approaches to treating cancer

### WANT MORE HELP TALKING TO YOUR HEALTH CARE TEAM?

If you are facing a cancer treatment decision, CSC's Open to Options® research-proven program can help. Our Open to Options® team can help you create a list of questions for your doctor. Call 1-888-793-9355 to make an appointment or to find a local CSC or Gilda's Club near you.



\*These words are explained in the glossary on page 62

Supportive care is also an option used to mainly **relieve symptoms** of metastatic breast cancer and **not treat the cancer itself**. There are three different approaches:

- **Surgery:** Which is used to remove a mass that is causing pain. It may not remove all of the cancer from the body, but it may help you feel better.
- **Radiation therapy:** Involves high-energy x-rays that can be used to shrink tumors, relieve pain, and improve your daily life.
- **Palliative (supportive) care:** When you and your health care team discuss what can help provide you relief from illness-related symptoms at the same time of treatment. This includes your team of doctors, nurses, social workers, and other specialists. **Palliative care\*** is different from **hospice\*** or end-of-life treatment.

To learn more about specific treatment options and supportive care for metastatic breast cancer, please refer to our booklet: *Treatment for Metastatic Breast Cancer*. This can be found in the back pocket of this book.



Margaret  
10-year MBC Survivor



## IN THIS CHAPTER:

- Tips for Coping with Side Effects
- Side Effects of Cancer Treatment and How to Manage Them:
  - Nausea and vomiting, pgs. 28-29
  - Diarrhea and constipation, pgs. 30-31
  - Mouth sores and difficulty eating, pgs. 31-32
  - Low blood counts, pgs. 32-33
  - Cognitive changes and insomnia, pg. 33
  - Peripheral neuropathy, pg. 34
  - Lymphedema, pg. 35
  - Hair loss, nail, and skin changes, pgs. 35-36
  - Skin rashes and hand-foot syndrome, pgs. 36-37
  - Hot flashes and vaginal dryness and discharge, pgs. 37-38
- Side Effects that may be Symptoms or Both:
  - Fatigue and depression, pgs. 39-40
  - Pain, bone loss, and weakness, pg. 40

# 4

## Managing Symptoms and Side Effects

Coping with the side effects of treatment can be one of the hardest parts of having cancer. It can be scary to read through long lists of possible side effects. This can be especially upsetting when you think about being in treatment off and on for the rest of your life.

## Things To Keep In Mind

As you prepare to start treatment, take the time to learn about the side effects of the treatment you are considering. There may be steps you can take or choices you can make to help make treatment a little easier. Keep in mind:

- **You probably won't have all the side effects or symptoms listed here.** These lists can seem endless. They are long because they include every possible side effect for many different drugs. You are unlikely to get all or even most of the items on these lists. Every treatment has different side effects, and every person has a unique response to treatment.



“You need to remember to tell your health care team everything, no matter how small. That’s the only way they can help.” — Jeana

- **Your health care team can help manage your symptoms and side effects.** Your health care team can help with symptoms and side effects. Discuss possible side effects with them before you begin treatment. Know what may happen and how side effects will be managed. Ask if there is anything you can do or take in advance to prevent or lessen side effects. Ask to talk with a palliative care specialist if one is available. Work with your team to develop a plan for controlling any problems that interfere with daily life. This is not the time to be heroic or suffer in silence.
- **Your health care team only knows what you tell them.** Report any change you notice as soon as you notice it. Often, side effects can be successfully managed, but your team needs to know about them. Tell them about anything you intend to use to manage side effects. This includes over-the-counter drugs, herbs, vitamins, or visits to complementary or alternative health care providers.
- **You can benefit from new ways to prevent or treat side effects.** In the last few years, new treatments have been found for nausea, diarrhea, inflamed throat, heartburn, hot flashes, and other common side effects. Even if you suffered from these side effects in the past and did not have effective treatments, you might find that better treatments are available now.

■ **You are not alone.** Other people have been through the same treatment and may have had the same side effects. Support groups, hotlines, and online groups for people with metastatic breast cancer are great places to get practical advice from others who have found ways to live well with metastatic breast cancer and cope with symptoms and side effects. Remember that side effects vary from person to person. Support is also available from your health care team. Oncology social workers, patient navigators, and hospital chaplains may be available to you at no charge.

## Side Effects and Tips for Coping

This list includes common side effects people get from many different drugs. Reading through the whole list right now probably will not be helpful. Instead, use this list as a reference as you hear about or have side effects. Keep in mind that you cannot tell how well a treatment is working by the side effects you have.

### NAUSEA & VOMITING

Cancer treatment can cause nausea and vomiting. Ask your doctor if the drug you'll be getting is likely to cause these side effects. Even with drugs known to cause nausea, individual experiences vary a lot. If you expect to feel nausea, talk to your doctor and prepare. There are many

treatments that can help prevent, reduce, or eliminate nausea and vomiting. Even if you had these side effects before, your reaction may be different this time. Newer medicines, not available at the time of your original diagnosis, may better help control the problem.

Different types of nausea are treated with different medicines.

■ **Acute nausea** occurs within the first 24 hours after treatment. Drugs are injected or given in pill form. You can take medicine before chemotherapy to help prevent or reduce this type of nausea. There are many treatments. Examples include:

- Aprepitant (Emend<sup>®</sup>) – This drug helps prevent both acute and delayed nausea and vomiting.
- Dexamethasone (Decadron<sup>®</sup>) – A steroid that may be given in combination with anti-nausea medicine.
- Ondansetron (Zofran<sup>®</sup>) – This drug may be given before treatment or prescribed to take at home after. It also comes in a dissolvable form for people who have difficulty swallowing.
- Palonosetron (Aloxi<sup>®</sup>) – This drug works for three to five days. It is a good choice if delayed nausea is likely.
- Prochlorperazine (Compazine<sup>®</sup>) – This is prescribed to take at home after treatment.



When Felicia's nausea was too much to

bear, her doctor insisted that Felicia find a food she could tolerate. After many trials, she was able to eat frozen applesauce with a straw, and later boiled egg noodles and low-fat boiled chicken. This was her diet for quite a while.

- **Delayed nausea** occurs two or three days after chemo and can last for days or even weeks. Some of the medicines used to treat acute nausea may help prevent or reduce delayed nausea as well. In addition, olanzapine (Zyprexa<sup>®</sup>) has been found to decrease nausea and increase the appetite. It can also be helpful for treating low-grade nausea caused by liver metastases.\*
- **Anticipatory nausea** can occur before chemo. It may be triggered by a smell that reminds you of treatment. Younger people may be more likely to get this side effect. Relaxation exercises can help prevent it. Ask about meditation

or guided visualization. If it lasts, a medicine for anxiety like lorazepam (Ativan<sup>®</sup>) can be helpful. Preventing nausea at the start of chemotherapy is the best way to avoid this problem. Talk to your doctor to make sure you are receiving the best anti-nausea medicines for your chemo treatment.

There are also lifestyle changes and eating choices that can help reduce or prevent nausea and vomiting. They include:

- **Eating smaller meals more frequently.** Small servings can be easier to take and help reduce nausea. Aim for six small meals per day to avoid an empty stomach. An empty stomach can make nausea worse. If you can, avoid being around cooking smells.
- **Choosing bland, low-fat foods.** Try plain pasta or rice. Limit fried, greasy, spicy, or fatty foods. Visit [www.CancerSupportCommunity.org/TreatmentRecipes](http://www.CancerSupportCommunity.org/TreatmentRecipes) for recipes to help with nausea.
- **Avoiding hot foods.** Choose foods that are room temperature or cold.
- **Drinking liquids.** Drink water, coconut water, 100% juice, or chamomile or ginger teas.
- **Staying relaxed.** Some relaxation strategies can help with nausea prevention. They include meditation, breathing exercises, hypnosis, guided imagery, music therapy, **acupuncture**,\* and acupressure.

\*These words are explained in the glossary on page 62

## DIARRHEA

Some drugs may irritate the lining of the stomach or intestines. This can cause diarrhea or watery stools. If this happens, try to stay hydrated. Carry a water bottle. Drink 8 to 10 glasses of fluid per day. Good drinks are water, sports drinks, broth, or other liquids that contain electrolytes. Avoid drinks with caffeine.

Changes to your diet may help too. Try to avoid a lot of spices, dairy, and fried foods. The BRAT (bananas, rice, applesauce, dry white toast) diet is recommended. Visit [www.CancerSupportCommunity.org/TreatmentRecipes](http://www.CancerSupportCommunity.org/TreatmentRecipes) for recipes that can help manage diarrhea. Check with your doctor before using any over-the-counter anti-diarrheal medicines, like Imodium<sup>®</sup> or Kaopectate<sup>®</sup>. Diarrhea can cause skin to become irritated or painful. Avoid this by keeping the rectal area clean and dry. Use A&D ointment to soothe and protect the skin. Do not take any laxatives or stool softeners without talking to your doctor.

When you need to go out, ask about restrooms in advance. Learn where they are located and, if possible, their condition. Travel with toilet paper and wipes if needed. Avoid public transportation or other situations where you may not be able to get to a bathroom easily. Carry an extra set of clothing when possible.

## CONSTIPATION

Constipation occurs when you are unable to empty your bowels. It causes swelling, significant pain, and sometimes anxiety anticipating the pain. Ask your health care team if the drugs you are taking can cause constipation. There may be changes you can make or medicines to have on hand that can prevent or ease the impact of constipation. Drinking lots of fluids and walking, stretching, or yoga can help relieve symptoms. These food tips may be helpful as well:

- ✓ Choose high fiber foods, such as whole grains, fruits, vegetables, nuts, and beans.

“My doctors rotated my anti-nausea meds so that they would work better. Taking dissolvable Zofran<sup>®</sup> helped me a lot when I was out and food smells started to make me nauseous. I wouldn’t necessarily be able to eat, but I could sit through dinner without getting sick.”

— Chris, cancer patient

- ✓ Try prunes and other dried fruits and juices, such as prune or apple juice.
- ✓ Drink hot beverages, such as herbal tea or decaffeinated coffee.
- ✓ If you are having gas and bloating, avoid “gassy” vegetables like cabbage, broccoli, cauliflower, peas, corn, or beans.

## **MOUTH SORES**

Some people develop painful areas or sores in their mouth as a result of cancer treatment. Your chance of getting mouth sores depends on:

- The type of treatment you receive
- Your history of cold sores or oral herpes; and
- Potential sources of bacteria in the mouth.

There are no specific drugs to prevent mouth sores. But, there are some prescriptions that can help relieve your discomfort. It may help to keep the mouth moist and healthy through frequent rinsing with water or alcohol-free mouthwashes. Let your health care team know if sores are very painful or make it hard to eat or drink.

Follow these food tips for mouth sores and mouth pain.

Choose foods that help soothe the mouth, including:

- ✓ Cold foods, such as popsicles, frozen fruit, and ice cream.
- ✓ Soft, mild foods, such as cottage cheese, smoothies, and yogurt.
- ✓ Well-cooked, soft meals such as potatoes, macaroni and cheese, casseroles, stews, ravioli in white sauce, and ground meats.

Avoid foods that could irritate the mouth, including:

- ✓ Acidic or spicy foods, such as citrus fruits, tomatoes, peppers, and vinegar.
- ✓ Crunchy or hard foods, such as crusty bread, pretzels, and chips.
- ✓ Hot foods—choose room temperature or cold instead.
- ✓ Alcohol and carbonated drinks.

Other tips for mouth sores and mouth pain:

- ✓ Suck on ice chips when you have mouth pain.
- ✓ Drink through a straw to avoid sore spots.
- ✓ Use a baking soda rinse before and after meals.

**More hints and recipes to help you cope with eating side effects can be found at [www.CancerSupportCommunity.org/TreatmentNutrition](http://www.CancerSupportCommunity.org/TreatmentNutrition).**

## DIFFICULTY EATING

Mouth sores, stomach distress, and changes in taste can make eating difficult. Getting enough nutrition can help you feel better and have more energy. If you are having trouble eating, talk with your health care team. A nurse, dietician, or nutritionist may be able to help. Pay attention to your weight and let your team know if it gets too low. A palliative care doctor may have advice too. If your weight drops too much, they may suggest an appetite stimulant such as megestrol acetate (Megace®). Refer to [www.CancerSupportCommunity.org/TreatmentNutrition](http://www.CancerSupportCommunity.org/TreatmentNutrition) for more tips and recipes.

## LOW BLOOD COUNTS

### Neutropenia

Chemotherapy reduces blood cells, especially the white blood cells that fight infection. Low white blood cell count results in neutropenia (*noo-troh-PEE-nee-uh*), which puts you at a higher risk for infection. Let your doctor or nurse know right away if you develop a fever, sore throat, burning with urination, or rash during chemo treatment. You may have an infection that requires treatment with antibiotics. It is important to treat it right away to prevent ending up in the hospital.

There are medicines—called growth factors—that can help prevent neutropenia. Your doctor may recommend:

- Filgrastim (Granix®, Neupogen®, Zarxio®) is a white cell growth factor. It

is given as an injection daily for approximately a week or until your white blood cells reach a safe level.

- Pegfilgrastim (Neulasta®, Fulphila™) is a growth factor that helps increase the number of white blood cells in your body. It is given as an injection once a day after each chemo cycle. Pegfilgrastim is available in an on-body device to avoid a return visit to the doctor.

### Anemia

Chemotherapy, or sometimes the breast cancer itself, can cause low red blood cell (hemoglobin) counts. This causes **anemia**.\* You may feel tired, short of breath, or dizzy. Sometimes a blood transfusion can help restore iron and ease symptoms.

If your red blood counts continue to be low after blood transfusions, your doctor may prescribe a growth factor such as epoetin alfa (Procrit®), erythropoietin (Epogen®), or darbepoetin (Aranesp®).

## TIPS TO HELP MEMORY AND CONCENTRATION

- Make lists of important things to do
- List your schedule in a calendar
- Carry a notebook with you to jot down things you need to remember
- Exercise your brain with puzzles or by learning something new
- Improve your focus through relaxation techniques and/or meditation

These medicines help stimulate the production of red blood cells. Ask your doctor about the risks and benefits before taking drugs like these.

## **COGNITIVE CHANGES ("CHEMOBRAIN")**

People with cancer often find that their brain seems to work differently. You may be forgetful or mildly confused, have trouble concentrating, or have difficulty finding the right words or multi-tasking. People have commonly referred to this experience as "chemobrain." Doctors are not sure what causes it, and there is no simple treatment.

There are things you can do to help cope. Talk with your health care team about the problems you are having. These same symptoms can be signs of anxiety or depression so it's especially important to report them. They also may be linked to aging or lower estrogen. Try to be as specific as possible so that your team can help you figure out what is going on and manage it.

It is also a good idea to tell the people around you so that they can support you. Coping strategies like writing things down and making lists, focusing on one thing at a time, maintaining routines, eating well, and getting even a small amount of exercise can help you feel more on top of things.

## **INSOMNIA**

Insomnia is the inability to get enough sleep to feel rested. This can significantly affect your ability to feel well and to cope with daily activities. For some people going through cancer treatment, disruption in sleep can be one of the most distressing side effects they face. Feeling too tired or fatigued from cancer treatment and having sleep problems sometimes go hand in hand. Here are some tips that can help you cope with insomnia:

- ✓ Work with your health care team to address underlying sources of insomnia, such as pain, anxiety, or medication.
- ✓ Develop a sleep routine. Go to bed and wake up at the same time each day.
- ✓ Start a bedtime ritual, such as reading or taking a bath, to signal to your body that it is time for sleep.
- ✓ Avoid caffeine, alcohol, and tobacco, especially at night.
- ✓ If you are hungry at bedtime, eat a light snack.
- ✓ Exercise regularly, preferably more than two to three hours before bedtime.
- ✓ Sleep in a quiet, dark room that is not too hot or cold.
- ✓ Medications are sometimes used to treat insomnia in the short-term if other approaches do not work.

## PERIPHERAL NEUROPATHY

Peripheral **neuropathy\*** (*peh-RIH-feh-rul noor-AH-puh-thee*) occurs when chemotherapy damages the nerves, usually in the hands and feet. It may start with tingling or numbness. It can develop into ongoing discomfort or pain. Neuropathy can decrease your ability to sense temperature change. You may have neuropathy if you have trouble:

- Picking up small objects
- Opening jars
- Buttoning small buttons
- Doing computer work
- Feeling the ground when you are walking

“Peripheral neuropathy made me depressed. It gave me respect for the power of pain, and greater respect for people with chronic pain. I had to learn to manage life through pain. I don’t wear heels anymore, and I don’t stand as much.” — Felicia

Tell your doctor right away if you feel tingling, numbness, or pain in your hands or feet. Early treatment is key to reducing these side effects, preventing injuries, and feeling better.

Neuropathy tends to occur more with taxane drugs than with other forms of chemotherapy. It also may occur with platinum-containing compounds and certain microtubule inhibitors. Refer to our *Treatment for Metastatic Breast Cancer* booklet in the back pocket of this book for more information on these drug families.

While there are no treatments to reverse peripheral neuropathy, there are medicines, such as duloxetine (Cymbalta<sup>®</sup>) that can help with pain and burning. Neuropathy can become permanent if it goes on for a long period of time. If it becomes too burdensome, your doctor may suggest lowering the dose of, or taking a break from, chemotherapy.

These tips may help you manage neuropathy better:

- ✓ Prevent falls by walking slowly, using handrails, and wearing supportive shoes.
- ✓ Be cautious when using sharp objects or cooking.
- ✓ If you have trouble sensing temperature change, be careful with hot objects and hot water.
- ✓ Avoid drinking alcohol, which, even in small amounts, can make neuropathy worse.

## LYMPHEDEMA

**Lymphedema\*** is swelling that is caused by a buildup of fluid beneath the skin. Cancer and cancer treatment can damage or remove lymph nodes, which lead to lymphedema. In breast cancer, you are most likely to get it in your arm. Lymphedema can develop soon after treatment, or appear weeks, months, or even years later.

Talk with your healthcare team if you notice any swelling in your arm or on the side where you had surgery or radiation. Ask them whether manual lymph drainage or compression garments could help you.

There is no sure way to prevent lymphedema, but it can help to take special care of your arm. Use these tips to help prevent and manage lymphedema:

- ✓ Maintain a healthy weight.
- ✓ When possible, avoid shots, needles, finger sticks, blood pressure checks, or blood draws in the at-risk arm.
- ✓ Keep the skin of the at-risk arm clean and gently moisturized.
- ✓ Make sure the at-risk arm gets proper circulation.
- ✓ Lift the arm above the heart occasionally.
- ✓ Wear loose-fitting clothing. Avoid tight clothing and jewelry around the affected area.

- ✓ Avoid heavy lifting, rigorous movements or too much pressure on the affected arm.
- ✓ Exercise. Work with a lymphedema specialist or physical therapist to develop a safe exercise program.
- ✓ Limit time in extreme temperatures, such as very hot showers. Avoid saunas, hot tubs and the use of ice or heating pads in affected areas.
- ✓ Try to avoid injury and infection to the affected arm.
- ✓ If you use a breast prosthesis, choose one that is lightweight.
- ✓ Take special precautions when traveling—ask for guidance from a lymphedema specialist.
- ✓ Watch for even a slight increase in size or swelling of the arm, hand, fingers, chest wall, or trunk. Tell your health care team if you notice these symptoms.

## HAIR LOSS

Hair loss is one of the most well-known side effects of cancer treatment. It does not happen to everyone. Some chemotherapy drugs can cause hair loss in some people. Hair loss is also called alopecia (*ab-loh-PEE-shuh*). When it occurs, hair loss usually happens 10 to 21 days after the first treatment. You may lose the hair on your head, body, or around your eyes.

\*These words are explained in the glossary on page 62

Ask your health care team if you are likely to lose your hair and, if so, when. Knowing the timing will help you prepare. By planning ahead, you may feel more control over hair loss and your cancer. Some people choose to:

- Get a short haircut. While hair loss can be upsetting, some women find their new hairstyles empowering. For example, some women who get “buzz” haircuts before chemo say they feel a new lightness and freedom. They like the simpler, easier-to-manage hair.
- Shop for a wig. You may find comfort in choosing one that looks like you. Or, you could try a new look. Wigs are often partially covered by insurance. Ask your doctor about a prescription for a “cranial prosthesis.”
- Select a stylish head covering. Find a scarf, hat, or turban that looks good and feels comfortable. Use this as an opportunity to be more creative and adventurous in your look. If it is cold where you live, cover your head to keep warm.
- Hold a “coming out” party to prepare for losing your hair. Friends bring or make hats and scarves.
- Hold a festive “shaving party” to cut off your hair before it falls out. This can be a way to help children feel more comfortable with your hair loss.

- Donate long hair to a nonprofit organization that accepts hair for a good cause.
- Ask your doctor about prescribing a cooling cap system to prevent hair loss. They are costly and not yet covered by all insurance companies.

Most of all, do whatever feels right to you. The more you prepare for losing your hair, the easier it will be if and when it happens. Nonetheless, when hair loss occurs, it can be upsetting. Be kind to yourself and allow time and space to cope with this loss. Reach out for the support you need.

## NAIL AND SKIN CHANGES

Some types of chemotherapy, particularly Taxotere<sup>®</sup>, can cause changes in the fingernails and toenails. Nail changes can look like a fungus. The nail turns yellow or green and thickens. The nail may lift up off the nail bed. It may fall off. In most cases, nail changes are not serious enough to warrant a break from the chemotherapy. You may need extra roomy shoes to avoid painful pressure on affected toenails. If you notice nail changes, check for the cause before starting any type of fungal or other skin treatment. What looks like fungus may actually be a chemo side effect.

## SKIN RASHES AND SENSITIVITIES

Skin rashes are a side effect of some **targeted therapies**.\* Ask about this side effect before you start treatment. Try to

have medicine on hand and know how to use it in case a problem occurs. If a rash becomes severe or painful, talk with your health care team right away. Rashes must be treated to avoid infection.

Chemotherapy and radiation can also cause sun sensitivity. Use these tips:

- ✓ Try to stay out of the sun between 10 am and 4 pm.
- ✓ Use sunscreen with SPF 30 or higher.
- ✓ Wear sunglasses and hats; cover as much skin as possible.
- ✓ Radiation can cause skin changes. Talk with your doctor about how to protect your skin and treat any reactions that occur.

## HAND-FOOT SYNDROME

Hand-foot syndrome is a side effect of certain **chemotherapy\*** and **targeted therapy\*** drugs. If you find you have redness, swelling, peeling, blisters, pain, burning, or sensitivity to touch, you may have hand-foot syndrome. It is important to report these symptoms to your health care team right away. You want to prevent them from getting worse or interfering with cancer treatment. You may be able to prevent or ease the symptoms of hand-foot syndrome. Avoid heat and hot water. Use ice packs and cold water to cool your hands and feet. Avoid rubber gloves, tight shoes, harsh chemicals, or anything else that causes rubbing or irritation.

## HOT FLASHES

Hot flashes are a side effect of **hormone therapy.\*** Some drugs are more likely to cause hot flashes, and some women are more sensitive than others. In general, women who take aromatase inhibitors (Arimidex<sup>®</sup>, Femara<sup>®</sup>, or Aromasin<sup>®</sup>) have fewer or less severe hot flashes than women on tamoxifen.

If hot flashes become uncomfortable, you may find relief with medicine or lifestyle changes.

## LIFESTYLE CHANGES THAT MAY HELP MINIMIZE HOT FLASHES

- Avoid spicy foods, alcohol, and smoking.
- Avoid saunas and hot baths or showers.
- Wear layered clothing, preferably cotton.
- Exercise.
- Use deep, slow abdominal breathing techniques.
- Try **acupuncture\***—some people find that this can help relieve a number of their symptoms. Talk to your health care team first. **It isn't always covered by insurance.**

\*These words are explained in the glossary on page 62

Medicines used to treat hot flashes include:

- Venlafaxine (Effexor<sup>®</sup>)
- Gabapentin (Neurontin<sup>®</sup>)
- Clonidine (Catapres<sup>®</sup>, Kapvay<sup>®</sup>)
- Megestrol acetate (Megace<sup>®</sup>)
- Fluoxetine (Prozac<sup>®</sup>) and paroxetine (Paxil<sup>®</sup>)

These drugs take time before they work against hot flashes. Don't give up if your hot flashes don't go away within a few days. Wait approximately two weeks to see if the drug is working for you.

You may hear that natural remedies, such as black cohosh or phytoestrogens (estrogen from plants), can help with hot flashes. So



“It’s hard to know if something is a symptom, a side effect, or just aging.” —Ruth

far, there is little to no science behind these claims. Also, phytoestrogens (products that mimic estrogen in the body) are not recommended for women with breast cancer. **Talk with your doctor about any drug or natural treatment before taking any other drugs while on hormone therapy.\***

## VAGINAL DRYNESS AND DISCHARGE

Hormone treatments can cause vaginal dryness or discharge. This may affect your comfort and your sex life. Some remedies include hormones that may interfere with treatment for breast cancer. Ask your health care team about safe treatments that might help with dryness, such as:

- Lubricants and moisturizers
- Low-dose local, prescription, hormone treatment (small pill inserted in the vagina)

There are also other more invasive treatments available. Be sure to ask your health care team about what may work best for you.

You also may experience vaginal discharge. If it bothers you, you can:

- Bathe daily and wear clean, cotton underwear.
- Avoid douches and sprays.
- Wipe from front to back.

More information on sexuality and intimacy can be found on pages 54-55 of chapter 5 in this book.

## YOUR SEX LIFE

Cancer treatment can lower your libido and affect your sex life in other ways. Talk with your health care team about any changes you notice. It's also important to talk openly with your partner about how you're feeling. Refer to chapter 5 for more information on sexual side effects and intimacy.

## Side Effects That May also be Symptoms

Some changes you notice may be side effects of treatment or symptoms of cancer. Or, they may be something else entirely. Talk with your health care team regularly about any concerns you have.

## FATIGUE

Fatigue is tiredness that interferes with daily activities, and does not respond well to rest. You may have low energy, drowsiness, or feel tired all the time. Most people with metastatic breast cancer have fatigue at some point during treatment.

It can be hard to figure out what causes fatigue. It may be a side effect of treatment or of medication used to manage treatment side effects, or a symptom of the cancer itself. It also can be caused by poor sleep, common to people who are treated with endocrine therapies. Fatigue also can be a symptom of depression.

Let your health care team know if you think you have fatigue. They will ask questions to

rule out other causes such as low thyroid activity, **anemia**,\* or electrolyte abnormalities.

If fatigue is related to treatment, you may be able to take a break or switch to another treatment. Talk with your doctor about the best options for you. Many people find that fatigue gets better and energy returns within a few weeks or months after treatment.

Whatever the cause of the fatigue, there are lifestyle changes you can make to improve your energy level:

- **Recognize your limits.** Save your energy for the activities you value most. If you know you get tired in the afternoon, make time for a short nap. Try not to nap late in the day as this could affect your ability to get a good night's sleep.
- **Ask for help when you need it.** Instead of using up your energy on chores, grocery shopping, or cooking, ask your family, friends, or neighbors for help with these things. Save your energy for more meaningful activities.
- **Try to get a little bit of exercise every day.** This is one of the most effective ways to prevent and treat fatigue. Try to do some regular exercise, such as walking, yoga, or tai chi. Talk to your doctor or nurse before beginning an exercise program. Too much can also cause fatigue. Keeping a balance is important.

\*These words are explained in the glossary on page 62

- **Get professional help.** Mental health treatment, such as cognitive behavioral therapy, may be able to help with fatigue.

## DEPRESSION

Fatigue can be related to depression. Depression is a mental health condition marked by mood changes, ongoing sadness, and crying. There are treatments that work well for depression. Here are some questions to help figure out if your fatigue is caused by depression:

- Are you having crying spells that seem to come out of nowhere that you can't control?
- Have you lost interest in the things in your life that used to be pleasurable?
- Have you stopped looking forward to events and occasions that used to be joyful for you?
- Do you still look forward to things but then get so tired that you find it hard to participate?

For more information on depression, see “Stress, Anxiety, and Depression” on pages 46-47.

## PAIN

Pain can be a symptom of metastatic breast cancer or a side effect of treatment. There are many ways to manage pain. You do not have to suffer in silence. Work with your health care team to find the best pain management treatments for you. Ask to see someone who specializes in palliative care.

Many people with cancer worry about getting addicted to pain medicines. Or, they fear that pain medicines won't work later if used early on. Talk with your health care team about any concerns you have.

Untreated pain can lead to fatigue or other symptoms. The right amount of pain medicine is the amount that controls most or all of the pain, most or all of the time.

Some people find it helpful to have two different pain medicines:

- **Long-acting pain medicine** ensures that there's some pain medicine in the body all the time.
- **Short-acting pain medicine** for when you need an extra boost that will give you relief within 30 minutes or so of taking it.

There are many options for both types of pain medicine. Different drugs and combinations work best for different people.

## BONE LOSS AND WEAKNESS

Bone loss or weakness can be caused by cancer in the bones, **hormone therapy**,\* or early menopause. These symptoms may be brought on by surgery or other treatments. Ask your doctor about bone density testing (a DEXA scan).

Depending on the results of your DEXA scan, your doctor may suggest that you:

- Take a bone strengthening medicine.
- Get more calcium and vitamin D, either through food or vitamins.



Mary Lou  
5-year MBC survivor

- Avoid activities with a high risk of injury, like skiing or horseback riding.

A bone strengthening medicine also may be recommended if cancer has spread to your bones (bone metastases). Your doctor may prescribe zoledronic acid (Zometa<sup>®</sup>) or denosumab (Xgeva<sup>®</sup>). These drugs help prevent the bones from losing calcium; this decreases the risk of fractures. A different kind of scan will be done to see how the medicine works and make sure that you are not at risk for fracture.

If you have a fracture or are at risk, there are procedures that can be used to strengthen the bones from the inside. In some cases, your doctor may recommend radiation therapy to help with bone pain. They may also recommend a surgical procedure in which a type of cement is injected into weak or fractured bones to strengthen them.

For more information on bone loss and bone metastases, see [www.CancerSupportCommunity.org/bone-health](http://www.CancerSupportCommunity.org/bone-health).

## TIPS FOR DEALING WITH SYMPTOMS AND SIDE EFFECTS

- When reading lists of side effects, keep in mind that not everyone experiences every side effect. Everyone has a unique response to treatment.
- Many side effects can be treated. Know what to look for. Keep track of changes and when they occur.
- Report side effects to your team. They only know what you tell them. Tell your doctors and nurses how you're feeling to get the best possible relief.
- If the side effects of one treatment are too hard to take, ask if you can take a break from it or try another.
- Talk to other people with cancer who have had similar experiences.

## IN THIS CHAPTER:

- Getting Support
- Coping with Feelings
- Support for Caregivers
- Telling Family Members
- Helping Children and Teens Cope
- Dating
- Work and Insurance

# 5

## Coping with Metastatic Breast Cancer

Metastatic breast cancer brings change. Change may affect any or all aspects of your life – work, relationships, or how you spend your time. What was once important to you may be different now. Treatment takes time and energy. Taking care of yourself physically and emotionally is a key concern. Relationships become more important.

As you try different treatments, your expectations for the future may change. You may have extended periods in and out of treatment. You may not know what to expect. Living with uncertainty may be one of the hardest things to accept.

Even if things are uncertain, you can find joy. Focus on what's important to you. Have hope – even for small things, like enjoying a favorite food again or looking forward to spending time with a friend. Hopes can become short-term goals. They can give you energy to keep going, even when you are feeling down.

This chapter covers many aspects of coping, including support, relationships, talking with the kids in your life, and issues affecting young women. It also addresses the practical realities of living with cancer.



“You need to readjust your thinking, and develop a new skill set as you move forward. Accept that this is what you’re going to be living with. Accept the inexplicable.”

—Felicia

## ACCEPTING SUPPORT

When you talk with people who have metastatic breast cancer, they will tell you about the importance of accepting support. Cancer takes physical and emotional energy. You will have days when you feel okay but others when you can't do much at all. There will be emotional ups and downs. You will have to adapt to what some describe as the "new normal." All of this can be a lot to absorb. **You owe it to yourself to get the help you need.**

"Being alone is a position we all experience. Deciding to be alone when there is support is a choice. If you feel alone or you are alone, call a support person." — Felicia

Support takes different forms and can serve different purposes. One day you may need someone to help with laundry or pick up your kids. On another, you may want a walking companion or company while you await a test result. At times, you may want help dealing with more serious fears, worries, anger, or despair.

If you are a person who always helps others, it can be difficult to ask for support. This is often true for women who tend to be caretakers. The people who rely on you may be scared or angry. They may resent that you are less available for them. They may try to deny that there's anything wrong with you. You may feel like you have to justify yourself or support others, when you most need support for yourself.

Try to find the people who are able to be there for you when you need them. They may be family members, close friends, neighbors, co-workers, or acquaintances. You may be surprised to see who comes through with a meal, helping hand, or shoulder to lean on.

If you have a friend who is interested in organizing others to help you on chemo weeks or other tough times, let them. You will benefit from the support, and they will like feeling useful. Websites, such as **[www.MyLifeLine.org](http://www.MyLifeLine.org)**, can help with this.

Many people find therapists, social workers, religious counselors, support groups, and helplines to be good sources of comfort and advice. They can be very helpful for dealing with the initial shock of diagnosis. Religion or spirituality can be a great source of comfort for many people. Refer to the resources section at the end of this book for a list of organizations that offer support.

It's important to remember that no two people deal with these situations in exactly the same way. What worked for your

cousin, neighbor, or colleague might not work for you. It may take a while to find the support or help you need. Keep trying until you do.

## **IS A SUPPORT GROUP RIGHT FOR YOU?**

Support from others who are dealing with metastatic disease or other types of cancer can be a source of comfort, strength, and hope. Support groups can help you handle depression, anxiety, or the shock of diagnosis. They can offer valuable information and resources.

“When you’re first diagnosed, you feel like you’re alone and going to die. Meeting people in support groups gives you more hope. By letting people help you, it helps them deal with the situation as well.” —Jeana

## **TO GET THE SUPPORT YOU NEED, YOU CAN:**

- Talk one-on-one with an oncology social worker, therapist, or spiritual advisor. [Ask about Managing Cancer and Living Meaningfully (CALM), a psychological program shown to help people with advanced cancer.]
- Talk to friends or family members.
- Join a face-to-face metastatic breast cancer support group.
- Participate in an online community for people with metastatic breast cancer, chat groups, or discussion boards.
- Take part in community or faith-based activities.
- Attend an educational program for people with metastatic breast cancer.
- Advocate for support, services, and research to help people living with metastatic breast cancer.
- Keep a journal.
- Exercise your mind and body through meditation or yoga.

You can also reach out to one of the support organizations listed in the back of this book. Or ask your doctor, nurse, or social worker to connect you with support services in your area.

## Benefits of support groups:

- They can help reduce the three biggest stressors associated with cancer: *unwanted isolation, loss of control, and loss of hope.*
- Participants report a decrease in depression, an increased zest for life, and a new attitude toward their illness.

There are different kinds of support groups. If possible, try to find one for people with metastatic breast cancer. If this is not possible, look for one for people with any kind of metastatic cancer. You may try more than one group before finding one that is right for you. It may be helpful to speak with a social worker or the group leader when considering a support group. They may be able to match you with a group that has the right dynamic for you.

You also may find support over the phone or on the internet. These support groups

can help people deal with depression and cope with pain. These can be a good option if you are more comfortable online or on the phone, do not feel well enough to leave home, or live in an area where there are no in-person support groups. Groups dedicated to metastatic breast cancer can be a great source of support.

## STRESS, ANXIETY, AND DEPRESSION

Many people with metastatic cancer have some pretty overwhelming feelings. When you are first diagnosed, it is normal to feel shocked or alone, angry, anxious, or feel a



## WHY ME? WHY NOT ME?

When you have cancer, it is normal to wonder why this happened to you or to feel like, somehow, you could have prevented cancer. As you connect with others who have metastatic breast cancer, you may find that you respond better to treatment, perhaps even better than people who are younger or appear healthier. Some people can feel guilty when they compare their response to others. One of the best ways to honor someone who is not faring as well is to appreciate what you have and live the best life you can.

“You come across many people with metastatic breast cancer who don’t make it. You wonder why them and not me. There’s no answer.” — Amanda

sense of despair. Sometimes crying and expressing your sadness can help get you through the tough emotions.

Other times, you may feel so bad that you lose interest in things that used to make you happy. You may want to stay in bed all day, and avoid friends and family. If you start feeling this way, you may be suffering from depression.

Depression and anxiety can make it difficult for you to cope with symptoms and treatment, and can affect your well-being. There are many effective treatments for these conditions.

The first and most important step in treating depression is to acknowledge it and ask for help. See page 40 in chapter 4 for a list of questions to ask yourself and discuss with your health care team to see if you may be depressed. Important points to remember about depression:

- **Tell your doctor if you have overwhelming feelings of depression, fear, or anxiety.** Your health care team can help you deal with these feelings, and help you cope better with your cancer.
- **Getting treated for depression or anxiety can make a huge difference in your daily life.** It can make it easier for you to deal with cancer. It will allow you to rediscover joy and pleasure in your everyday life.

## BODY IMAGE CONCERNS

Cancer and cancer treatment can change how you look. You may lose or gain weight, lose your hair, or grapple with scars or the loss of your breasts. There may be times that you look in the mirror and don't recognize yourself.

These changes can be upsetting, and make you feel self-conscious. It may take a while for you to feel comfortable with your body again but it is possible. You can rebuild your confidence and feel better about yourself and your body.

There are programs that aim to help people feel better about the changes they've undergone as a result of cancer. Refer to the resource list which begins on page 69 for more information.



“The hardest part is waiting for the other shoe to drop. Will cancer show up on a test or scan?” —Ruth

## IF YOU ARE YOUNG

Women and men of all ages are affected by metastatic breast cancer. Finding out you have metastatic breast cancer 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 for someone. Perhaps you have children or were hoping to start a family. Whatever your situation, cancer doesn't fit in.

Cancer can affect relationships, sexuality, and body image. You may feel alone, especially if you are single. Being in treatment may make you feel old. A Saturday night recovering from chemo isn't how you imagined spending time at this stage of life. You may find yourself thinking about your own mortality. For young women, these side effects can be particularly devastating:

- Early-onset menopause
- Infertility
- Sexual problems such as vaginal dryness or decreased libido
- Concerns about body image related to hair loss, weight gain, and body scars

There are actions you can take that may help minimize or even prevent some of these side effects. For example, vaginal lubricants and dilators may help with some sexual concerns. Refer to pages 38-39 in chapter 4 for more information.

If you have children at home, their needs may be foremost on your mind. Refer to pages 53-54 for more information on helping children and adolescents cope.

For all of these concerns, connecting with people in a similar situation can help. Use the resources at the end of this book 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.

## EVERYDAY HEALTH

It's hard to be positive when you don't feel well. Research shows that a healthy diet, exercise, and the right amount of rest can help you feel better, have more energy, and stay hopeful. Try your best to make healthy living a part of your daily life.

If this is new to you or sounds challenging, start slowly. Pick one aspect of healthy living to focus on. Set realistic goals. Tell friends or family members what you are doing and ask for their support.

If symptoms or side effects make eating or moving difficult, talk with your health care team. Tips on healthy eating and coping with eating problems are available at [www.CancerSupportCommunity.org/TreatmentNutrition](http://www.CancerSupportCommunity.org/TreatmentNutrition). A dietician or nutritionist may be able to help you identify foods you are able to eat that provide the nutrition you need. If pain or fatigue interferes with movement, your team may be able to help with this as well.

## SUPPORT FOR CAREGIVERS

Caregivers help or arrange help for people who are ill or disabled. This can take different forms. It might involve physical care or emotional support. Some caregivers assist with money matters, insurance, household chores, rides, or making appointments. Caregivers may or may not live with the person. Caring for someone who has cancer is not easy. People who do so need support and help.

Caregiving can be a full-time job. A caregiver with another job may miss days of work or have trouble getting work done. Some caregivers take unpaid leave, turn down promotions, or lose benefits. It can be very stressful to care for someone and worry about keeping your job at the same time.

Caregivers are often very focused on their loved one. They may neglect their own health and well-being. It is important for caregivers to take care of themselves. Many caregivers benefit from support groups. They can talk about emotional issues, share concerns, obtain help, and feel less alone. To learn more, visit [www.CancerSupportCommunity.org/Caregivers](http://www.CancerSupportCommunity.org/Caregivers).

### Respite Care

Respite care is short-term, temporary relief to caregivers who are providing full-time support to an ill loved one. Respite care offers intensive care for people in their homes. This gives the caregiver an opportunity to take a break. It is often a positive experience for everyone involved.

You can contact a respite care organization when you need time away. To find a program or learn more, visit [www.archrespite.org](http://www.archrespite.org).



“As a caregiver, we also have to think about ourselves. Felicia may not know this, but there may be times that I really can’t answer her call at that time, because I could be going through something. But when I am mentally, physically, emotionally, and spiritually prepared, I’m calling her and giving her what it is that I can give.”

– Vicki, long distance caregiver for Felicia

## RELATIONSHIPS

Having metastatic breast cancer is likely to change the way you relate to loved ones and how they relate to you. People 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 may cherish time together more. People can prove to be more dependable than you expect.

At the same time, friends may comment that you look well, even when you feel your worst. Others may be more familiar with treatable forms of breast cancer and misunderstand your situation. You may get tired of explaining metastatic breast cancer.

One of the most important things you can do to maintain relationships is to communicate openly with your family and friends. Be honest about your diagnosis, feelings, and needs. Let them know how treatment is affecting you. Accept support if you need it. Most importantly, find the people who will be there for you and lift you up when needed.

### Telling Family Members

People facing cancer often worry about how their family and friends are coping with the changes that cancer often brings into our lives. A diagnosis of cancer will almost certainly change the way you relate to your loved ones and the way they relate

to you. Remember that these relationship changes can be positive. Many people find that relationships become more meaningful and deeper.

You hope and expect that your family members and friends will be your greatest source of support. But even loving families and well-meaning friends can add to the stress of learning to be a cancer survivor. Sometimes you continue to try to be a protector and caretaker, even when you long for some care for yourself.

Cancer survivors often comment that others simply do not understand how draining treatment can be on all levels—physically, psychologically, emotionally. This is often why people affected by cancer find it difficult to ask for and receive help. Attending support groups, couples workshops, family counseling, educational programs, and religious retreats are very helpful for finding new ways to cope and communicate.

One of the most important things you can do to stay connected to family and friends is to be open and honest in how you are feeling and ask them to do the same. People often don't know what to say so they may say the wrong thing or nothing at all. Here are some tips to help the conversation:

- ✓ Tell them honestly about your diagnosis, how the disease and treatment might be affecting you, and how they can and cannot help you.



## SARAH – TALKING TO KIDS

When Sarah was first diagnosed with breast cancer, she had a lot of anxiety about telling her three young children. “I over-prepared. They don’t need to know about the biological basis of cancer,” the former science teacher jokes.

In retrospect, Sarah understands, “The conversation has to be all about them. Don’t over-worry. It doesn’t have to be a long conversation. It should be very concrete and address how their lives might change.” In Sarah’s case, this meant a change in after-school routine.

Sarah acknowledges that it is helpful to prepare enough to calm kids’ fears and address the things they might be thinking. For example, Sarah says it’s important to tell children that “nothing they did caused this.”

- ✓ Let them know if it's okay to ask you questions or if something they are doing is adding to your stress and anxiety. Be specific about what you need when people offer help.
- ✓ Your network of support—your relationships at home, at work and elsewhere—make a difference in your life. These relationships can contribute to feelings of anger, sadness, and loneliness; or feelings of comfort, love, and support.
- ✓ There are times when it can be beneficial for a couple or the whole family to sit down with a cancer counselor to talk about relationship or family issues related to the diagnosis and treatment. Your oncologist, oncology social worker, or local community support organization should be able to provide you with a list of qualified professionals in your area. You may want to check with your insurance company to determine what services and providers are covered under your plan.



“With metastatic cancer, I think it was really hard for the kids to understand that the cancer isn’t going to go away. Coming to terms with that was really hard, and there were emotional ups and downs. I’ve been really thankful for the CSC children and teen support group and parent support group, because through that they have met other kids that they can talk to that actually understand. I think our kids really have gotten a lot out of it.”

—Jeana

## Helping Children and Teens Cope

If you have children, you may question what you should and should not tell them about your cancer diagnosis. You may want to protect them. But children sense and know more than adults often give them credit for. They may overhear telephone conversations, pick up on their parents' anxiety, blame themselves, and fear the worst if they are given no information.

It's important to tell your children that you have cancer, and to do it in a way they will understand. Younger children (up to about eight years old) will not need a great deal of detailed information. Older children and adolescents will need to know more. 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](http://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. Keep in mind:

- Unusual behavior may be your child's way of showing how upset they are.
- Children's fears of what might happen are likely to be far worse than the real situation.
- Uncertainty or not knowing may be more difficult for them to cope with than the truth.

## TIPS FOR TALKING WITH CHILDREN

- Provide accurate information about cancer in a way your children can understand. It's okay to use the word "cancer" and to tell them where the cancer is located on your body.
- Make sure that your children understand that cancer is no one's fault. This did not happen because of anything they, their siblings, or you did. Some children need to hear often that your illness is not their fault.
- Provide information about how cancer treatment may affect your children's lives. Tell them about changes to their schedule, childcare plans, or day-to-day household roles and responsibilities.
- Let children know if you expect any changes to your appearance, such as hair loss or weight loss.
- Reassure children that they will be taken care of. Remind them that they are loved, supported, and cared for.

**Refer to Parenting Resources on page 71 for more information.**



- They may want to help. Allow your children to participate in your care. Give them age-appropriate tasks such as bringing you a glass of water.

Teenagers may feel conflict or guilt. They want to get away and become independent but may feel a pull to be at home to help or provide support. They may feel isolated or lonely. When talking with teens about your cancer diagnosis, it is important to acknowledge their feelings and reassure them that they are not alone. Support groups or other forms of peer support can be very helpful for teenagers.

## **DATING WITH METASTATIC BREAST CANCER**

Dating with metastatic breast cancer can be scary. You may look or feel differently. You may be unsure of how and when to tell

someone about your cancer, and worried about how they will respond. Talk with others about your concerns. When you are on a date, try to focus on the moment.

## **Sexuality and Sexual Intimacy**

Sexuality can be an important part of who you are and how you relate to others. For some people, a good sex life is key to enjoying life. Cancer can cause physical and emotional symptoms that interfere with sexuality. You may find that fatigue, worry, discomfort with your body, or the side effects of treatment lower your interest in sex. You may not feel sexy. You may wonder how metastatic breast cancer and treatment will affect your future sex life.

The first step in getting help is to talk about it. This can be hard for many people. Keep these tips in mind:

- ✓ Talk with your health care team. The more you share, the more they can help you or refer you to someone who can. They may be able to suggest or prescribe treatments for physical symptoms.
- ✓ If you have a partner, talk with them about how you feel. Work together on how to deal with times you may not be “in the mood.” It is important to communicate with each other. These conversations can also help you become closer. If it’s hard to talk about it, you may find couples therapy to be helpful.
- ✓ Remember that there are many different ways to have sex and feel sexual. If you are struggling, find other ways to be intimate. Use your imagination and be creative!
- ✓ You can feel intimacy in many different ways. Gentle touching, holding hands, kissing, and hugging can help you feel closer and more connected to another person.
- ✓ Other people with metastatic breast cancer may have tips to share. If you feel uncomfortable bringing up sex in a support group, ask the leader privately to raise the topic. You probably are not the only person with questions or concerns.
- ✓ If sex is important to you, and it’s not getting better, you may want to seek help from a sex therapist or sexual health specialist.

Information on managing vaginal dryness, vaginal discharge, and other sexual side

effects can be found on page 38 in chapter 4.

## WORK

The decision to keep working when you have metastatic breast cancer is a personal one. There is no one right answer. Work can be a source of support. But it can also be a source of stress. Even a desk job may be too physically or mentally demanding.

If you continue working, talk with your boss or human resources office about leave time, disability benefits, and job flexibility. Are there parts of your job you can do from home? Cancer is a disability, so you may be eligible for benefits and accommodations for people with disabilities.

Many people with metastatic breast cancer eventually leave their jobs. This can be difficult too. Even if you don’t love your work, you may not be ready to resign, especially if you need the money, or you are not sure what you will do without work. Whatever your job has been, it is a part of your identity.

Your outlook may change after you leave your job. You may find that there are many meaningful and enjoyable ways to spend time. People with metastatic breast cancer who contributed to this book talked about writing, cooking, quilting, spending time with family, speaking to groups about women’s health, and even racing dragon boats. If you have worked for a long time, you may like having time to rest and just watch television.

These are tough decisions. Give yourself space to think, and find support for whatever choice you make.

“I cried when I realized I had to leave my job. I had been there for 20 years. I wasn’t able to do the job I liked and didn’t know what I would do now. I’ve had to learn to grieve different kinds of losses as a result of the disease.”

—Felicia

## WORK-RELATED LAWS

For many people, even with good support and medical care, a big concern remains: What will all of these treatments cost? What if I have to stop working? How will I get or keep health insurance coverage? What if I don’t have health insurance? How will treatment be covered? Do I have short or long term disability insurance through my work? If not, how will I pay the bills if I need to take unpaid leave from work? These federal laws provide some protections and benefits for people with cancer and their loved ones:

- **The Americans with Disabilities Act (ADA)** protects people with health problems, including cancer, from discrimination. Under the ADA, if you are still able to perform the essential functions of your job, your employer has to make reasonable accommodations for you. For example, they may allow flextime when you have doctors’ appointments. The ADA only applies to employers with 15 or more employees.
- **The Family and Medical Leave Act (FMLA)** applies to companies with 50 or more employees. It allows you (the person with cancer) and your family members to take up to 12 weeks of unpaid leave with health insurance. There is also intermittent FMLA. This allows you to take additional days off as needed for treatments or doctors’ appointments if you have a chronic medical condition. Your job will be protected.
- **Vocational Rehabilitation Act of 1973** ensures that people with cancer can get job retraining if they seek a different kind of work than they did before cancer. State government agencies can help with this process.

The government agency that oversees these laws is the **Equal Employment Opportunity Commission (EEOC)**. If you have any questions about workplace laws, they have a toll-free number that many people find very helpful: 800-669-4000.

People with metastatic breast cancer are also eligible for **Medicare** and automatically qualify to receive disability from the Social Security Administration. To be eligible and earn **Social Security Disability Benefits (SSDI)**, you must have been employed within the last 10 years and not able to work due to your disability. To receive **Supplemental Security Income (SSI)**, you must have little or no income available. No employment history is needed.

Once you are approved for SSDI and SSI, there is a five month waiting period in order to start receiving benefits. Once you have received SSDI benefits for two years, you are eligible for Medicare coverage. People with metastatic breast cancer do not need to wait to be 65 and older to apply for Medicare.

If you and your health care team expect that you will be out of work for at least one year due to cancer treatment, you should apply for SSDI as soon as possible. The sooner you apply, the sooner you will receive assistance if you are eligible. You can apply for benefits by calling the toll-free Social Security number, 800-772-1213, or go online at [www.socialsecurity.gov](http://www.socialsecurity.gov).

## **INSURANCE AND MEDICAL COSTS**

Cancer treatment can be costly. There are medical expenses, the loss of your or your partner's income due to cancer, and the emotional toll that worries about money may bring. One of the most important things you can do is discuss the cost of cancer

treatment with your health care team.

Start to talk with your team about the cost of care from day one. As treatments are discussed, ask if they are covered by your insurance. Find out if there is a social worker or financial counselor who can answer questions about cost, insurance choices, or coverage.

If you have health insurance, call your insurance provider to learn more about your coverage. If you get your insurance through work, you can also talk with your human resources department or supervisor.

As of the time of the writing of this book, the **Affordable Care Act** offers two important protections for people with cancer. First, you cannot be denied coverage by an insurance company because of your illness (a pre-existing condition). Second, insurance companies can no longer set annual or lifetime limits to healthcare.

If you do not have insurance or if your insurance does not cover a certain treatment, help may be available. Reach out to government programs and nonprofit organizations that offer advice and support. Ask your health care team about drug discount programs and advocacy organizations that provide support. (See Resources for more information.)

For more information about managing the financial challenges of a cancer diagnosis, visit [www.CancerSupportCommunity.org/cost](http://www.CancerSupportCommunity.org/cost).

## IN THIS CHAPTER:

- Advance Care Planning
- Legal Plans
- Coping with End-of-Life
- Hospice
- Finding Closure
- Checklist on Advance Care Planning

# 6

## Advance Care Planning

When you learn you have a life-threatening illness, you may start to think about death and your future. This may be the first time that this has come up for you or your family. You may begin to think about what you will need or want to achieve in the months or years ahead.

It is normal for people with cancer to want to discuss the possibility of death. It is just as normal not to want to discuss this possibility. Often, family members have a difficult time with these conversations even when the person with cancer wants to talk about it. They may fear that you are “giving up.” This is not always the case. If possible, try to have these discussions when you are healthy and strong as part of the coping process. The goal is to make thoughtful decisions and be as prepared as possible.

See our Resources section which begins on page 69 for help if you are not sure how to start talking to your family and friends.

## What Advance Care Planning Means to You

Living with metastatic breast cancer can lead you to think about making end-of-life decisions. This is a step anyone (not only cancer patients) should take in making sure their wishes are met and that the proper legal documents are in place in helping you maintain control.

It can be helpful to talk about your wishes with loved ones. Think about what you might need. What do you want to achieve in the weeks, months, or years ahead? Try to have open and honest communication with your doctor and your family. This can help you maintain control over this time. It can give you a chance to accomplish goals or put closure on matters that might give you a sense of peace.

Some people find comfort or satisfaction in writing about their cancer experience.

“Legacy writing” is a way to tell your story and carry on your legacy. Legacy projects can also be created digitally. They can be as simple as making a few videos or audio recordings of yourself with a smartphone. Legacy projects can help you and your loved ones cope with your illness. Look in the library or online for more information on legacy writing. The prompts for writing can also be used as prompts for what to say in videos. One nonprofit that helps you create legacy video is Life Chronicles [www.lifechronicles.org](http://www.lifechronicles.org).

## Advance Care Legal Plans

If you have not already, you may want to think about your end-of-life plans. Ensuring that legal documents exist can help you maintain control. People with cancer often report a feeling of relief when these tasks are out of the way.

Here are some key documents to prepare to guarantee that your end-of-life wishes are honored.

- **Will** – a document that plans for the distribution of your property and money. You will be asked to identify legal guardians for your children under the age of 18. You will also need to make plans for your pets. The executor of your estate is a trusted person you appoint to help carry out your wishes.
- **Living will or advanced directive** – a document that details your wishes about medical treatment if a time should come when you can no longer say what you want. Most states honor a **living will\*** prepared in advance. However, the laws vary by state.
- **Health care proxy or medical power of attorney** – a document that allows you to name a trusted person to make decisions about your medical care if you cannot do so yourself. In many states, this person is authorized to speak for you any time you are unable to make your own medical decisions, not only at the end of life.

\*These words are explained in the glossary on page 62

- **Financial power of attorney** – this document names a trusted person who is able to make financial decisions and payments for your health care needs if you are unable to do so yourself. You may want to name two different people as your medical and financial power of attorney. This can ensure that there are no potential conflicts of interest when decisions about your care need to be made.
- **Do Not Resuscitate (DNR) Order** – an order that your doctor writes on your chart if you do not want “heroic measures” taken in the event of a cardiac or respiratory arrest. This is used if you stop breathing or your heart stops working and you aren’t revived right away. The order says that you do not want to be put on machines that will keep your body alive even though you’re unconscious. It is very important to think about this issue and discuss it with your family and doctor before you get seriously ill.
- **Out of hospital DNR** – This DNR serves the same purpose as the one above but you keep copies of it. It can be provided to emergency services workers. States have different laws around this. Look into the laws of the state(s) where you live and spend the most time.

Think carefully about who is most likely to follow your advanced directive. Sometimes a spouse or close family member is too emotionally involved for this responsibility.

Discuss these decisions with family members, supportive friends, clergy, and health care providers. It will lessen confusion and help everyone feel more comfortable with your decisions. Be sure your medical power of attorney or proxy has access to the signed directives and that your doctor has a copy as well.

## Coping with End-of-Life

When cancer is described as terminal, it means that it cannot be cured and is likely to cause death within a limited period of time. If you are at this stage and active treatment has stopped, it is normal to feel a wide range of emotions such as anger, denial, fear, sadness, and even acceptance.

To the best that you can, talk openly and honestly with your family and your health care team about your feelings. These conversations can help you maintain a sense of control. They also may provide an opportunity for you to accomplish certain goals or achieve meaningful closure.

During this time, it is important to take care of yourself. Find enjoyment and comfort where you can. Ask for pain medicine and other treatments to help manage symptoms and side effects. The goal is to feel as comfortable as possible. Eat when you feel like it, and let your loved ones know if eating is making you feel uncomfortable. If you have questions or need support, talk to members of your health care team. Even if you are not in active treatment, these people can still be helpful.

## Hospice

**Hospice\*** can provide care and comfort to people affected by cancer at the end-of-life. Hospice care can be provided in your home. It can also take place at a hospice facility. Trained nurses are on call 24 hours a day. A hospice team is available to meet your physical and emotional needs, as well as the emotional needs of your family.

Ask your health care team about hospice early in your treatment. Find out when and how hospice may be a useful part of your care. Many people are referred to hospice later than they could be. This means that they and their families miss the opportunity to benefit from everything hospice has to offer.

## Finding Closure

There are ways to bring closure on life that can help you feel more at peace. They may involve relationships, personal goals, or spirituality. If treatment is no longer working, you may want to think about steps you can take to complete your life.

This is the time to tell people who are important to you how you feel. Say thanks to those who have supported you. Ask for and offer forgiveness if needed. Reach out to people you want to see or talk to again to say goodbye. You may want to meet with a clergy person or spiritual leader.

There may be events, hopes, and dreams which you hope to fulfill in the future. They may be planned for months or years away, or still imagined. Knowing or anticipating that you may not be there may be very hard for you or loved ones to accept. You may find solace in thinking creatively about how to fulfill these hopes in less traditional ways, such as leaving letters or video for loved ones to read or watch on future milestone days. You can express pride, give advice, or share loving words. Writing these messages and storing them in a safe place may be fulfilling for you. Receiving them may be gratifying for the people who love you. See [Advance Care Planning Resources](#) on page 71. Also talk to your oncology social worker, counselor, or clergy member for help finding closure.

### ADVANCE CARE PLANNING CHECKLIST

- Have I discussed advance care planning with my family and health care team?
- Have I documented my wishes in a legally suitable format?
- Have I legally chosen someone to make medical decisions for me in case I cannot do so myself?
- When was the last time I reviewed all of my documents that detail my wishes?
- Do my loved ones and health care team have a copy and know where my documents are?

# Glossary

**Acupuncture** – The technique of inserting thin needles through the skin at specific points on the body to relieve or control pain and other symptoms. It is an ancient Chinese medical procedure (a type of complementary and alternative medicine). Some people affected by breast cancer find it useful in controlling nausea and other side effects of treatment.

**Advocate** – A person who provides support and information to, in this case, people with cancer. Advocates participate in the cancer community in many different ways.

**Anemia** – A condition in which the number of red blood cells in the body is below normal. Some patients affected by breast cancer experience anemia as a side effect of their treatments.

**Angiogenesis** (*AN-jee-ob-JEH-neb-sis*) – Blood vessel formation. Tumor angiogenesis is the growth of blood vessels from surrounding tissue to a solid tumor. This is caused by the release of chemicals by the tumor.

**Biomarker** – A biological marker found in cells or tissues that is a sign of a normal or abnormal body process, or of a condition or disease.

**Biopsy** – The removal of cells or tissues for examination by a pathologist to see whether cancer is present. The pathologist may study the tissue under a microscope or perform other tests on the cells or tissue.

**Biosimilar** (*BY-ob-SIH-mib-ler*) – A biological drug that is very similar to another biological drug that is approved by the FDA but may be made in a different way or from different substances.

**Bone Scan** – A method of imaging using a radioactive tracer that looks for cancer or other changes in the bone.

**Chemotherapy** – Treatment with drugs to stop the growth of rapidly dividing cancer cells.

**Combination therapy** – The use of more than one form of treatment at the same time.

**Complete response (CR)** – When treatment removes all signs of cancer; does not necessarily mean that you are cured.

**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 CAT scan.

**De novo metastatic breast cancer** – Breast cancer that has already spread by the time of first diagnosis.

**Duct** – In the breast, the milk ducts are thin tubes that carry milk from the lobules to the nipple.

**Ductal breast cancer** – Cancer that begins in the lining of the milk ducts of the breast.

**Estrogen receptor-negative (ER-)** – Breast cancer cells that do not grow in the presence of the hormones estrogen.

**Estrogen receptor-positive (ER+)** – Breast cancer cells that grow in the presence of the hormones estrogen.

**Gene** – Unit of heredity that passes traits or other characteristics from parent to offspring. Genes are pieces of DNA.

**HER2/neu or HER2** – Human epidermal growth factor receptor 2. The HER2/neu protein is involved in the growth of breast cancer cells.

**HER2-negative (HER2-)** – Breast cancer cells that have the expected amount of the HER2/neu protein.

**HER2-positive (HER2+)** – Breast cancer cells that have too much of the HER2/neu protein.

**Hormone receptor-negative (HR-)** – Breast cancer cells that do not grow in the presence of the hormones estrogen or progesterone.

**Hormone receptor-positive (HR+)** – Breast cancer cells that grow in the presence of the hormones estrogen or progesterone.

**Hormone therapy** – Treatment that adds, blocks, or removes hormones. For breast cancer patients, this therapy is given to slow or stop the growth of cancer.

**Hospice** – End-of-life care given after treatment has been ended; focuses on making the patient and family members comfortable and supported.

**Immunotherapy** – Cancer treatment that works by boosting the body's natural immune response.

**Inflammatory breast cancer** – A type of breast cancer where the breast looks red and swollen and feels warm.

**Invasive ductal carcinoma** – Breast cancer that begins in the lining of the milk ducts and spreads to nearby tissue. From there, it can also spread to other parts of the body. This is the most common form of breast cancer.

**Invasive lobular carcinoma** – Breast cancer that begins in the milk glands (lobules) and spreads to nearby tissue. From there, it can also spread to other parts of the body.

**Living Will** – A legal document that details your wishes about medical treatment if a time should come when you can no longer express those wishes.

**Lobule** – In the breast, a gland that makes milk.

**Lobular breast cancer** – Cancer that begins in the milk glands of the breast.

**Lymphedema** (*LIM-fub-DEE-muh*) – A side effect of some cancer treatment that causes swelling in the lymph nodes, often in the arms or legs.

**Maintenance therapy** – Lower intensity therapy given after first-line therapy to delay the return of cancer.

**Metastasis** (*meh-TAS-tuh-sis*) – The spread of breast cancer from one part of the body to another. A tumor formed by cells that have spread is called a “metastatic tumor” or a “metastasis.” The metastatic breast tumor contains cells that are like those in the original (primary) breast tumor. More than 1 metastasis are called metastases.

**Metastatic** (*meh-tuh-STA-tik*) – Having to do with metastasis. Having to do with the spread of cancer from its original location to another part of the body.

**MRI** (magnetic resonance imaging) – 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. Also called nuclear magnetic resonance imaging (NMRI).

**Multimodality or combination therapy** – The use of more than one kind of treatment at the same time.

**Neuropathy** (*noor-AH-pub-thee*) – A condition marked by sometimes severe discomfort in the nerves that can be a symptom of cancer or side effect of cancer treatment.

**No evidence of disease (NED)** – When there is no longer any visual signs of breast cancer on diagnostics tests like CT scans or PET Scans. This does not mean that all breast cancer is gone from the body. It just means that it may be too small to see with our current methods of imaging.

**Osteoporosis** (*OS-tee-oh-pub-ROH-sis*) – A condition that is characterized by a decrease in bone mass and density, causing bones to become fragile. Some breast cancer treatments put women at higher risk for developing osteoporosis.

**Palliative care** (*PA-lee-uh-tiv kayr*) – A medical specialty that focuses on symptom management and quality of life.

**Pathologist** – A doctor who specializes in diagnosing specific diseases by examining cells and tissues under a microscope.

**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 breast cancer cells often use more glucose than normal cells, the pictures can be used to find cancer cells in the body.

**Precision Medicine** – Often used interchangeably with personalized medicine, uses information about genes and cells to determine a course of treatment. Sometimes called personalized medicine.

**Primary site or primary cancer** – The area where the cancer begins. In breast cancer, the primary site is the breast, even if the cancer spreads to other areas of the body.

**Progesterone receptor-negative (PR-)** – Breast cancer cells that do not grow in the presence of the hormone progesterone.

**Progesterone receptor-positive (PR+)** – Breast cancer cells that grow in the presence of the hormone progesterone.

**Recurrence** – Return of a previous cancer.

**Specialty pharmacy** – A pharmacy that offers additional services and resources, often related to cancer or other chronic illnesses.

**Systemic therapy** – Treatments that travel through the bloodstream to reach the whole body, not just a specific organ or body part.

**Targeted therapy** – Drugs that work by altering or targeting a specific cellular or genetic characteristic or process.

**Tumor markers** – Measure different proteins in the blood which can sometimes indicate if a treatment is working. Examples of tumor markers include CA-15-3 (breast cancer) and CEA (ovarian, lung, breast, pancreas, and gastrointestinal tract cancers). Also called biomarker.

# Preparing for Your Doctor's Visit



## 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:			

Download additional copies of this worksheet at [www.CancerSupportCommunity.org/metastatic-breast-cancer](http://www.CancerSupportCommunity.org/metastatic-breast-cancer).

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

## 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 66].
- These are interfering in my life in the following ways [fill in your answers from the top of page 67].
- 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 67]
- 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](http://www.CancerSupportCommunity.org/cost)**.

# Resources

## Cancer Support Community Resources

The Cancer Support Community's (CSC) resources and programs are available free of charge. Call 888-793-9355 or visit [www.CancerSupportCommunity.org](http://www.CancerSupportCommunity.org) for more info.

**Cancer Support Helpline®** — Have questions, concerns or looking for resources? Call CSC's toll-free Cancer Support Helpline (888-793-9355), available in 200 languages Mon - Fri 9am - 9pm ET.

**Frankly Speaking about Cancer®** — Trusted information for cancer patients and their loved ones is available through publications, online, and in-person programs.

**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](http://www.MyLifeLine.org).

**Open to Options®** — Need help making a cancer treatment decision? Our trained specialists can help you create a list of questions to share with your doctor. Make an appointment by calling 888-793-9355 or by contacting your local CSC or Gilda's Club.

**Services at Local CSCs and Gilda's Clubs** — With the help of 170 locations, CSC and Gilda's Club affiliates provide services free of charge to people touched by cancer. Attend support groups, educational sessions, wellness programs, and more at a location near you. [www.CancerSupportCommunity.org/FindLocation](http://www.CancerSupportCommunity.org/FindLocation).

**Cancer Experience Registry®** — Help others by sharing your cancer patient or cancer caregiver experience via survey at [www.CancerExperienceRegistry.org](http://www.CancerExperienceRegistry.org).

**Grassroots Network** — Make sure your voice is heard by federal and state policy makers on issues affecting cancer patients and survivors by joining our Network at [www.CancerSupportCommunity.org/become-advocate](http://www.CancerSupportCommunity.org/become-advocate).

## Metastatic Breast Cancer Information and Support

### Cancer Support Community

Offers free support groups at affiliates across the country or online, free healthy lifestyles groups, educational programs, literature, and resources.

888-793-9355 • [www.CancerSupportCommunity.org/metastatic-breast-cancer](http://www.CancerSupportCommunity.org/metastatic-breast-cancer)

### American Cancer Society

800-227-2345 • [www.cancer.org](http://www.cancer.org)

Provides local support, resources, and information for all cancer types.

### Look Good Feel Better

<http://lookgoodfeelbetter.org>

A public service program that teaches beauty techniques to people with cancer to help them manage the appearance-related side effects of cancer treatment.

### Cancer.net

888-651-3038 • [www.cancer.net](http://www.cancer.net)

Provides timely, oncologist-approved information to help patients and families make informed health care decisions from the American Society of Clinical Oncology.

### CancerCare

800-813-4673 • [www.cancercare.org](http://www.cancercare.org)

Offers toll free telephone and online support groups, literature, and resources for cancer patients.

### Living Beyond Breast Cancer

888-753-5222 • [www.lbbc.org](http://www.lbbc.org)

Connects people with trusted breast cancer information and a community of support.

### **Metastatic Breast Cancer Network**

888-500-0370 • [www.mbcn.org](http://www.mbcn.org)

A patient-led advocacy organization that educates, advocates, and empowers.

### **Young Survival Coalition**

877-972-1011 • [www.youngsurvival.org](http://www.youngsurvival.org)

Offers support and resources to young women with breast cancer, including an online video support group for young women with metastatic breast cancer.

## Caregiver Resources

### **Arch National Respite Network and Resource Center**

703-256-2084 • <https://archrespite.org/us-map>

Connects caregivers with respite services.

### **Metastatic Breast Cancer Info Center Caregiver Resources**

[www.mbcinfocenter.com/mbc-caregiver-resources](http://www.mbcinfocenter.com/mbc-caregiver-resources)

Resources for caregivers of people with metastatic breast cancer.

## Resources to Find a Doctor or Clinical Trial

### **American Society of Clinical Oncology**

[www.cancer.net/find-cancer-doctor](http://www.cancer.net/find-cancer-doctor)

Allows you to search for a cancer doctor by geography and/or specialty.

### **BreastCancerTrials.org**

415-476-5777 • [www.breastcancertrials.org](http://www.breastcancertrials.org) and <https://metastatictrialtalk.org>

Provides information on clinical trials for breast cancer and metastatic breast cancer.

### **Cancer Support Community's Clinical Trials Resources**

800-814-8927 • [www.CancerSupportCommunity.org/ClinicalTrials](http://www.CancerSupportCommunity.org/ClinicalTrials)

[www.CancerSupportCommunity.org/metastatic-breast-cancer-trial-search](http://www.CancerSupportCommunity.org/metastatic-breast-cancer-trial-search)

### **National Cancer Institute Clinical Trials Resource**

800-422-6237 • [www.cancer.gov/clinicaltrials](http://www.cancer.gov/clinicaltrials)

Get more information on and search for cancer clinical trials.

### **National Cancer Institute-Designated Cancer Centers**

[www.cancer.gov/research/nci-role/cancer-centers/find](http://www.cancer.gov/research/nci-role/cancer-centers/find)

Find the cancer research center nearest you.

## Complementary and Alternative Medicine (CAM) Resources

### **Annie Appleseed Project**

(561) 749-0084 • <https://annieappleseedproject.org>

Provides information on CAM practices and their role in cancer treatment.

### **National Center for Complementary and Integrative Health**

888-644-6226 • <https://nccih.nih.gov>

Provides information on CAM practices and their role in cancer treatment.

### **National Cancer Institute's Office of Cancer Complementary and Alternative Medicine**

240-276-6595 • <https://cam.cancer.gov>

Provides information on CAM practices and their role in cancer treatment.

## Employment, Financial, Insurance, and Legal Resources

### Cancer and Careers

646-929-8023 • [www.cancerandcareers.org/en](http://www.cancerandcareers.org/en)  
Educates and empowers people with cancer to thrive in the workplace.

### Cancer Legal Resource Center

866-843-2572 • [www.disabilityrightslegalcenter.org/cancer-legal-resource-center](http://www.disabilityrightslegalcenter.org/cancer-legal-resource-center)  
Provides free and confidential information and resources on cancer-related legal issues to cancer patients, survivors, and their families.

### Centers for Medicare and Medicaid Services

800-633-4227 • [www.cms.gov](http://www.cms.gov)  
Call to find out if you are eligible for government health insurance programs.

### Equal Employment Opportunity Commission (EEOC)

800-669-4000 • [www.eeoc.gov](http://www.eeoc.gov)  
Oversees workplace and disability laws and protects workers' rights.

### Healthcare.gov

[www.healthcare.gov](http://www.healthcare.gov)  
Offers information about health insurance options available through the U.S. government.

### Patient Access Network Foundation

866-316-7263 • [www.panfoundation.org](http://www.panfoundation.org)  
Provides assistance to underinsured patients. Patients or a member of their medical team can apply online or over the phone.

### Patient Advocate Foundation

800-532-5274 • [www.patientadvocate.org](http://www.patientadvocate.org)  
Offers assistance to patients who need specific help with insurance, insurance coverage, job retention, debt crisis matters, and other practical matters affecting people with cancer.

### Social Security Administration

800-772-1213 • [www.ssa.gov/medicare](http://www.ssa.gov/medicare)

### Triage Cancer

424-258-4628 • [www.triagecancer.org](http://www.triagecancer.org)  
Provides education on the practical and legal issues related to cancer.

## Resources for Young Women

### Livestrong Fertility

855-844-7777  
[www.livestrong.org/we-can-help/livestrong-fertility](http://www.livestrong.org/we-can-help/livestrong-fertility)  
Helps people with issues related to becoming a parent with cancer.

### Living Beyond Breast Cancer's Young Women Initiative

888-753-5222 • [www.lbbc.org/young-womens-initiative](http://www.lbbc.org/young-womens-initiative)  
Support and resources for women diagnosed before age 45.

### Young Survival Coalition

877-972-1011 • [www.youngsurvival.org](http://www.youngsurvival.org)  
Resources, connections, and outreach for young women with breast cancer.

## Parenting Resources

### Camp Kesem

[www.CampKesem.org](http://www.CampKesem.org)

### CancerCare for Kids

[www.CancerCare.org/children](http://www.CancerCare.org/children)

### Children's Treehouse – Climb Program

[www.ChildrensTreehousefdn.org](http://www.ChildrensTreehousefdn.org)

### Kids Connected

[www.KidsConnected.org](http://www.KidsConnected.org)

### Marjorie E. Korff PACT

(Parenting at a Challenging Time) Program

617-724-7272 • [www.mghpact.org](http://www.mghpact.org)  
Provides parent guidance consultations to parents with cancer and their partners.

### Talking to Kids and Teens About Cancer

[www.CancerSupportCommunity.org/Kids](http://www.CancerSupportCommunity.org/Kids)

## Advance Care Planning Resources

### The Conversation Project

<https://theconversationproject.org/>

### Death Over Dinner

<https://deathoverdinner.org>

### Johns Hopkins University Resources for People with Metastatic Cancer

<https://youtu.be/g1B4d4QQWHM>

<https://youtu.be/daYihwstRpM>

### Life Chronicles

805-682-3411 • [www.lifechronicles.org](http://www.lifechronicles.org)  
Creates video recordings that capture thoughts, memories, or leave a legacy.

## Acknowledgments

We'd like to extend a special thank you to the patients and caregivers who participated in focus groups, interviews, surveys, photos, and videos. Their generosity in sharing their experiences shaped the development of this program.

### ADVISORY BOARD

Shirley Mertz, Metastatic Breast Cancer Network  
Devon McGoldrick, Lilly Oncology  
Kirsten Norslien, LPC, MS, NCC, Gilda's Club Madison, WI  
Maggie Nicholas-Alexander, Young Survival Coalition  
Catherine Ormerod, MSS, MLSP, Living Beyond Breast Cancer  
Lidia Schapira, MD, Stanford University  
Lillie Shockney, RN, BS, MAS, ONN-CG, Johns Hopkins University  
Jordan Hill, PharmD, BCOP, West Virginia University

Photography by Ed Cunicelli.

### ABOUT THE CANCER SUPPORT COMMUNITY

The Cancer Support Community (CSC) is a global non-profit network of 175 locations, including CSC and Gilda's Club centers, health-care partnerships, and satellite locations that deliver more than \$50 million in free support services to patients and families. In addition, CSC administers a toll-free helpline and produces award-winning educational resources that reach more than one million people each year. Formed in 2009 by the merger of The Wellness Community and Gilda's Club, CSC also conducts cutting-edge research on the emotional, psychological, and financial journey of cancer patients. In addition, CSC advocates at all levels of government for policies to help individuals whose lives have been disrupted by cancer. In January 2018, CSC welcomed Denver-based nonprofit MyLifeLine, a digital community that includes more than 40,000 patients, caregivers, and their supporters that will enable CSC to scale its digital services in an innovative, groundbreaking way.

For more information, visit [www.CancerSupportCommunity.org](http://www.CancerSupportCommunity.org)  
So that no one faces cancer®

### FRANKLY SPEAKING ABOUT CANCER: METASTATIC BREAST CANCER PROGRAM PARTNERS:



FRANKLY SPEAKING ABOUT CANCER: METASTATIC BREAST CANCER  
WAS MADE POSSIBLE WITH THE GENEROUS SUPPORT FROM:



Novartis

New treatments for Metastatic Breast Cancer are being developed. For the most recent and up-to-date version of our *Treatment for Metastatic Breast Cancer* booklet, visit [www.CancerSupportCommunity.org/metastatic-breast-cancer](http://www.CancerSupportCommunity.org/metastatic-breast-cancer) to download and print yourself. To order a print copy, visit [Orders.CancerSupportCommunity.org](http://Orders.CancerSupportCommunity.org) or call 888-793-0355.



[www.CancerSupportCommunity.org](http://www.CancerSupportCommunity.org)

888-793-9355

This book and treatment booklet are available to download and print yourself at [www.CancerSupportCommunity.org/metastatic-breast-cancer](http://www.CancerSupportCommunity.org/metastatic-breast-cancer). For print copies or other information about coping with cancer, visit [Orders.CancerSupportCommunity.org](http://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 professionals to answer questions and learn more.

©February 2019. Cancer Support Community. All Rights Reserved