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# Caregivers of Women Living With Metastatic Breast Cancer

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CancerCare

*Learn about:*

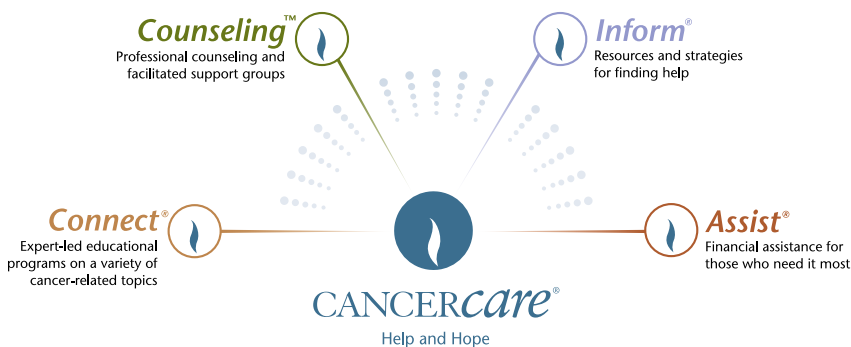
- Living with metastatic breast cancer
- Challenges and rewards of caregiving
- Taking care of yourself while caregiving
- Working with a support team



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Help and Hope

## The *CANCERcare*® Constellation of Services



CancerCare's services are provided free of charge to anyone affected by cancer

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CancerCare is a national nonprofit organization that provides free, professional support services to anyone affected by cancer: people with cancer, caregivers, children, loved ones, and the bereaved. CancerCare programs—including counseling, education, financial assistance, and practical help—are provided by trained oncology social workers and are completely free of charge. Founded in 1944, CancerCare provided individual help to more than 97,000 people last year and received nearly 2.1 million visits to its websites. For more information, call 1-800-813-HOPE (4673) or visit [www.cancercares.org](http://www.cancercares.org).

### Contacting CancerCare

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#### Services

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If you are a health care professional interested in ordering free copies of this booklet for your patients, please use the online order form on our website, [www.cancercares.org](http://www.cancercares.org), or call 1-800-813-HOPE (4673).

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# Caregiving for a woman with metastatic breast cancer can present many challenges and rewards. Help is available to you in this important role.

**If you provide help and support** for a woman living with **metastatic breast cancer**, you are considered a **caregiver**. Caregivers can include spouses or partners, family members, or friends.

Living with metastatic breast cancer presents many challenges for both the woman who is diagnosed and her loved ones. As a caregiver, you may watch your loved one go through physical, emotional, social, and spiritual changes. Seeing her go through this experience can be challenging and even stressful.

In this booklet we'll talk about ways to help your loved one with metastatic breast cancer while taking care of yourself, and how to get the support you need in your role as a caregiver.

## Overview of Metastatic Breast Cancer

Metastatic breast cancer is cancer that has spread beyond the breast and **lymph nodes** in the neck and armpit to another part of the body. The most common places that breast cancer cells might spread to are the bones, lungs, liver, and brain. Most women who develop metastatic breast cancer have already been treated for their original breast cancer with some combination of surgery, radiation, chemotherapy, or anti-

estrogen treatments. But these treatments were not successful, and breast cancer cells either returned or continued to grow.

Today, women with metastatic breast cancer have more treatment options than ever before. For women whose breast cancer is fueled by hormones, a treatment for metastatic breast cancer can be **hormonal therapy**—use of medications that prevent the female hormone estrogen from promoting cancer growth. Hormonal therapies can shrink tumors and/or prevent them from growing for months to years. Other options include chemotherapy and/or a number of newer medications called **targeted treatments**. These treatments zero in on different cancer cell mechanisms: those that promote growth and division of cancer cells and those that supply blood to tumors. Rather than killing both healthy and unhealthy cells, as chemotherapy does, targeted treatments attack cancer cells primarily, sparing healthy tissues and causing less severe side effects.



Although there is no cure for metastatic breast cancer, many diagnosed women live full lives for many years. In large part, this has been made possible by clinical trials, which have enhanced the quality and lengthened the lives of women with metastatic breast cancer.

## Caregivers' Many Roles

Caregivers play many different roles. For instance, some caregivers keep track of their loved one's medications. Others drive them to medical appointments or help with household tasks, such as cooking and taking care of children. Many caregivers also provide emotional support.

# The Importance of Clinical Trials

There's no question that clinical trials have led to advances in cancer treatment, creating a brighter future for people with cancer. Clinical trials in metastatic breast cancer help us learn the worth of new treatments and find ways to improve the quality of life of women with this diagnosis. For this reason, doctors and scientists urge women with metastatic breast cancer to learn about available trials.

Here are a few things you should know:

- Often, patients who take part in clinical trials gain access to and benefit from new treatments.
- Before someone participates in a trial, he or she will be fully informed as to the risks and benefits of the trial.
- No patient receives a placebo (inactive pill) if there is a standard treatment available for the disease. Most trials are designed to test a new treatment against a standard treatment to find out whether the new treatment has any benefit.
- Patients can stop taking part in a clinical trial at any time for any reason.

With metastatic breast cancer, there may be peaks and valleys in the caregiving experience. For example, when a loved one is first diagnosed, there is often a flurry of activities, usually related to gathering information on treatment options and resources. Once your loved one's condition stabilizes, things may not be so hectic. If the person is then diagnosed with metastatic breast cancer, new caregiving roles may arise.

In general, caregiving tasks fall into three categories: medical, emotional, and practical help.

## HELPING WITH MEDICAL MATTERS

When caring for a woman living with metastatic breast cancer, many caregivers provide help with medical matters. If you are the caregiver for a loved one, ask her to what extent she would like you to be involved. Some women prefer their caregivers to take an active role. Here are some of the ways you can do that:

- Learn about her diagnosis and possible treatment options. CancerCare® offers free Telephone Education Workshops and publications that present the latest treatment and coping information. (Other resources for reliable information are listed on page 16.)
- With your loved one's permission, become familiar with her doctor or nurse and talk to them about your concerns.
- Create a list of questions to take to medical appointments with your loved one.
- Bring a notebook or tape recorder so you can keep track of the doctor's answers and refer to them later.
- Find out if there are any special instructions you should be aware of, such as changes in your loved one's diet or tips for coping with treatment side effects.



If you need to speak with the health care team without your loved one present, find out about the rules of the **Health Insurance Portability and Accountability Act (HIPAA)**. This law requires patients to sign consent forms before doctors or other health care professionals can share information about their medical treatment.

## Some Questions to Ask the Doctor

- What are the goals of this treatment?
- How long will the treatment last?
- Do you have any written information about this treatment?
- What are the side effects of this treatment?
- Are there any ways to help manage any side effects?
- How do we know if a side effect is severe enough to call you?
- Are there any other treatment options?
- Are there any clinical trials we should be aware of?
- What is the best way to let you know when we have questions about the treatment?

If you need help managing some of your loved one's medical needs, ask your doctor or hospital social worker about local **home health agencies**. Under certain circumstances, these organizations can send a nurse, health aide, or physical therapist to the home to help.

### **PROVIDING EMOTIONAL SUPPORT**

When caring for a woman with metastatic breast cancer, it's important to let her talk about her feelings. For instance, she may express concerns about separation from family or having unfinished tasks. Here are some of the things you can do:

- Be willing to listen, even when it may be difficult. Many people are tempted to say, "You will be fine," partly as a way to cope with their own anxiety. But just by being there, you help relieve your loved one's feelings of isolation or loneliness. Listening is one of the most important skills of a caregiver. Remember, you don't have to offer solutions or play "cheerleader." Just lend a caring ear.



- Respect your loved one's decisions about her care and her life. Even if you are in a position to share decision making, ultimately it is her body and spirit that are facing cancer and its treatment. Similarly, it's important to let her decide what roles she would like to continue to have in the family and to choose the areas where she wants your help.
- Talk to your loved one about whether additional support is needed. Oncology social workers and nurse practitioners help women with cancer and their families through particularly difficult periods. CancerCare® offers free counseling from professional oncology social workers on staff.

### HELPING WITH PRACTICAL TASKS

Many caregivers help women living with metastatic cancer by taking on practical tasks, such as running errands and helping with household chores. Offer your help in concrete terms. Instead of saying, "Let me know if you need anything," suggest something specific such as, "I'd be happy to pick up your prescription."

Because metastatic breast cancer can also place a strain on a family's budget, caregivers often have to help manage financial issues as well. Fortunately, there are many resources available to help caregivers do this:

- Ask your loved one's health insurance company to assign a **case manager** who can explain what services and treatment an insurance policy does and doesn't cover. The manager can also explain any **out-of-plan benefits** that the policy may offer.
- See if your loved one's hospital or medical center employs a financial counselor who can help with hospital bills.
- Speak with a social worker about what help might be available to you and your loved one. These professionals can direct you to government agencies that, by law, provide aid for people with cancer (such programs are called **entitlements**). They can also refer you to other resources in

## Keeping Track of Important Papers

Helping your loved one cope with cancer can involve keeping records and paperwork in order. It's helpful to keep these important documents in one place in case questions arise:

- Copies of medical records
- Prescription information
- Income-related records
- Disability insurance
- Long-term care insurance
- Pensions
- Social Security
- Veterans benefits
- Bank statements
- Wills



your community that provide assistance. Most hospitals have social workers on staff. Help is also available from oncology social workers at CancerCare®.

- For many people, expensive cancer medications pose a financial challenge. If this is the case for your loved one, contact the Partnership for Prescription Assistance, listed among the resources on page 16. They can refer you to one or more of the over 475 programs that help people in need get medications for free or at low cost. CancerCare can also help you manage financial challenges (see page 11).

## Coping With the Challenges of Being a Caregiver

Research has shown that caregiving is often rewarding for both the person with cancer and his or her caregiver. For example,

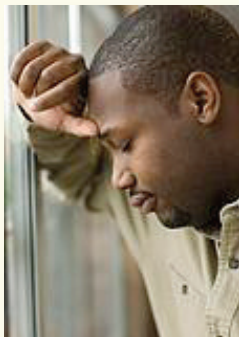
caregivers often find new strengths or talents they didn't know they had, such as advocating for their loved one or managing finances. Plus, spending more time with a loved one who needs your help can lead to a closer relationship with that person. However, caregiving can also present many challenges. Many caregivers report that their caregiving responsibilities sometimes feel like a full-time job, and research has shown that the physical and mental health of caregivers may be affected when caring for someone with a chronic illness. For example, caregivers may experience greater fatigue or trouble sleeping, saying "I can't shut my mind off." Caregivers may experience great sadness, distress, or even depression.

Sometimes, caregivers tend to put their own needs and feelings aside. But if you are a caregiver, it is important that you take time for yourself. People with metastatic breast cancer have many needs. They may need more of you than you can give. It's alright

## Could It Be Depression?

If you are taking care of a woman living with metastatic breast cancer, it's important that you talk to your doctor about your challenges and experiences. Being a caregiver may lead to feelings of sadness or distress, and sometimes these feelings can turn into depression. But help is available. If you are experiencing the following symptoms for more than two weeks, talk to your doctor:

- Feeling overwhelmed or helpless
- Crying all the time
- Not being able to enjoy things
- Difficulty concentrating
- Trouble sleeping
- Upset stomach
- Weight loss or weight gain
- Thoughts of hurting yourself



to take a break or ask for help when you need it. There are many community and national organizations, religious institutions, and volunteer organizations that can provide support or extra help to give you time to take care of yourself.

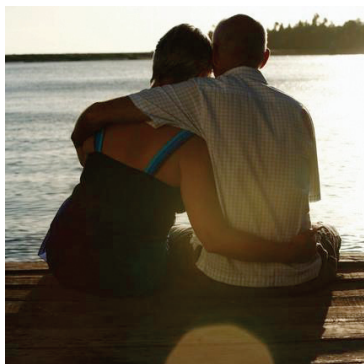
There are also many practical things you can do to take care of yourself. Not only will this help you feel your best, but it will also allow you to continue providing help and support to your loved one as she copes with metastatic breast cancer.

Here are some things you can do for yourself:

- **Plan a few minutes each day just for yourself.** Take time to do something you enjoy, even if it's as simple as taking a walk around your neighborhood or spending a little time on the computer. Doing something enjoyable can provide relief.

- **Create a peaceful atmosphere for both yourself and your loved one.**

Calm surroundings help ease the strain of caregiving. For example, you might find it relaxing to listen to soft music together, light a scented candle, or just sit together. If you both feel comfortable with it, physical contact such as hugging, kissing, or holding hands can also be soothing.



- **Allow yourself to experience and accept your feelings.** Caring for a woman living with metastatic breast cancer triggers a wide range of emotions, some of which may be difficult. For example, it's normal to feel angry about the situation sometimes. It's not unusual for spouses, siblings, adult children, or partners of women with metastatic breast cancer to have feelings of helplessness. If that happens to you, it's vital to remember that you don't have to solve all the problems. You just have to be there to

listen and love. Recognize that your feelings are normal, and ask for support if they ever feel overwhelming.

## Working With the Support Team

As we discussed in the previous pages, it's perfectly normal to feel sad or frustrated about your loved one's situation. But, there are many things you can do to take care of yourself as a caregiver. You can also turn to these resources for additional support:

**Oncology social workers** provide emotional support for people with cancer and their loved ones. They can help you cope with the challenges of caregiving and guide you to resources. CancerCare® offers free counseling from professional oncology social workers on staff who understand the challenges that caregivers face. We can work with you one-on-one to develop strategies for coping.

**Support groups** Many support groups are available for caregivers of women with metastatic breast cancer. Support groups can reduce the feeling that you are alone in your role as a caregiver. These groups provide reassurance, suggestions, insight—a safe haven where you can share similar concerns with your peers in a supportive environment. At CancerCare, caregivers of people with cancer and their families can take part in support groups in person, online, or on the telephone.

**Financial help** is offered by a number of organizations, including CancerCare, to help cover the cost of medications, transportation to treatment, child care, or help needed around the home. CancerCare can also refer you to other resources in your community that can provide assistance.

**To learn more about how CancerCare can help, call us at 1-800-813-HOPE (4673) or visit us online at [www.cancercare.org](http://www.cancercare.org).**

# Frequently Asked Questions

**Q Do you have any tips on how caregivers can best communicate with their loved one's health care team?**

**A** First, you should check with your loved one who has cancer to make certain she is comfortable with your asking questions. Sometimes caregivers are so eager to get information, they tend to forget that the person with cancer is sitting right next to them. It's also a good idea for caregivers to introduce themselves to the health care team at the start of the relationship. In this way, doctors and nurses understand why the caregiver is getting involved in the conversation.

To help you remember key information, take a notebook to appointments and write things down. If a doctor or nurse says something you don't understand, be sure to stop and ask him or her to explain. Because there are a number of ways to treat metastatic breast cancer, keeping track of the various options can be confusing.

**Q I have been caring for a sister with metastatic breast cancer for several years. I want to get away for a couple days, but I feel guilty leaving her. Is that normal?**

**A** Absolutely. Caregivers often feel that by taking a break, they are depriving the person they're caring for of time and consideration. This can be particularly difficult for women caught in the "sandwich generation," where they are taking care of their own families as well as taking care of a parent or sibling. Sometimes they feel guilty, thinking "I'm not spending enough time with either group." But when a caregiver takes

care of herself, she can do a better job of taking care of someone else. Caregivers need to learn to give themselves permission to have time away without feeling guilty. This can be refreshing and restore balance to the life of a caregiver. Even just scheduling a time to be alone each day—to walk around the neighborhood, read a book, or listen to music—can help caregivers “recharge their batteries.”

**Q Our mother has always loved cooking and hosting large family gatherings for the holidays. Now that she has metastatic breast cancer, our whole family is worried about how she will cope with the fact that she can't carry out many family traditions. How can we help her?**

**A** It would be perfectly natural for your mother to feel sad about this, especially if she has looked forward to doing so many things for her family on the holidays. Talk with your mother about how you and your siblings can help “redesign” the holiday so that she delegates tasks to everyone who can pitch in. Together you can create some new family traditions that honor your mother, perhaps planning a special dinner that you bring to her. In this way you can get other members of the family involved, bringing everyone closer together.

# Glossary

**caregiver** Any person who helps a family member or loved one during his or her illness.

**case manager** A specialist who works for a health insurance company or other types of agencies. Case managers help clients access the resources and services they need.

**entitlements** Government programs that give financial and other aid to people who fall into specific groups, such as people with cancer.

**Health Insurance Portability and Accountability Act (HIPAA)** A law that gives patients greater access to their own medical records and more control over how their health information is used.

**home health agencies** Organizations or agencies that provide medical and day-to-day care for patients living at home. Home care providers manage tasks such as giving medications, monitoring vital signs, assisting with a patient's personal care like bathing and dressing, and even cooking and cleaning.

**hormonal therapy** Use of medications that prevent the female hormone estrogen from promoting cancer growth.

**lymph nodes** Small, bean-shaped collections of cells that help the body to defend itself from potentially harmful cells, such as bacteria and cancer cells. Lymph nodes under the arm are called *axillary nodes*.

**metastatic breast cancer** Breast cancer that has spread beyond the breast and lymph nodes in the neck and armpit to another part of the body.



**out-of-plan benefits** Insurance coverage for medical services received from doctors who are not in your insurance network. Out-of-plan benefits differ from plan to plan.

**targeted treatments** These drugs zero in on different cancer cell mechanisms: those that promote growth and division of cancer cells and those that supply blood to tumors. Rather than killing both healthy and unhealthy cells, as chemotherapy does, targeted treatments attack cancer cells primarily, sparing healthy tissues and causing less severe side effects.

# Resources

**CancerCare** 1-800-813-HOPE (4673) / [www.cancercares.org](http://www.cancercares.org)

**Advanced Breast Cancer Community**  
[www.advancedbreastcancercommunity.org](http://www.advancedbreastcancercommunity.org)

**AdvancedBC.org** [www.AdvancedBC.org](http://www.AdvancedBC.org)

**American Cancer Society** 1-800-227-2345 / [www.cancer.org](http://www.cancer.org)

**Breast Cancer Network of Strength**  
1-800-221-2141 / [www.networkofstrength.org](http://www.networkofstrength.org)

**Cancer.Net** [www.cancer.net](http://www.cancer.net) (patient information from the American Society of Clinical Oncology)

**Living Beyond Breast Cancer** 1-610-645-4567 / [www.lbbc.org](http://www.lbbc.org)

**Men Against Breast Cancer**  
1-866-547-6222 / [www.menagainstbreastcancer.org](http://www.menagainstbreastcancer.org)

**Metastatic Breast Cancer Network**  
1-888-500-0370 / [www.mbcnetwork.org](http://www.mbcnetwork.org)

**National Cancer Institute** 1-800-422-6237 / [www.cancer.gov](http://www.cancer.gov)

**National Coalition for Cancer Survivorship**  
1-888-650-9127 / [www.canceradvocacy.org](http://www.canceradvocacy.org)

**Partnership for Prescription Assistance**  
1-888-477-2669 / [www.pparx.org](http://www.pparx.org)

**The Wellness Community**  
1-888-793-9355 / [www.thewellnesscommunity.org](http://www.thewellnesscommunity.org)

**Young Survival Coalition** 1-877-972-1011 / [www.youngsurvival.org](http://www.youngsurvival.org)

## To find out about clinical trials:

Coalition of Cancer Cooperative Groups / [www.CancerTrialsHelp.org](http://www.CancerTrialsHelp.org)

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



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The information presented in this patient booklet is provided for your general information only. It is not intended as medical advice and should not be relied upon as a substitute for consultations with qualified health professionals who are aware of your specific situation. We encourage you to take information and questions back to your individual health care provider as a way of creating a dialogue and partnership about your cancer and your treatment.

All people depicted in the photographs in this booklet are models and are used for illustrative purposes only.

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When one word changes your world,

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makes all the difference



With CancerCare,  
the difference comes from:

- Professional oncology social workers
- Free counseling for you and your loved ones
- Education and practical help
- Up-to-date information

Our trusted team of professionally trained oncology social workers provides free counseling, education and practical help for you and your loved ones.



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Help and Hope

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**[www.cancercares.org](http://www.cancercares.org)**