FOURTH EDITION

FRANKLY SPEAKING ABOUT CANCER

Metastatic Breast Cancer

People with cancer who actively *participate* in thei
care along with their health care team will *improve*
quality of *their lives* and may enhance the possibili
recovery. People with cancer who *actively* participa
their care along with *their health* care team will im
the *quality* of their lives and may *enhance* the poss

CANCER SUPPORT COMMUNITY
A Global Network of Education and Hope

Dedicated to all the people with metastatic breast cancer who shared their stories, experiences and wisdom to make this guide possible.

Table of Contents

CHAPTER 1 / EMPOWER YOURSELF 1

CHAPTER 2 / UNDERSTANDING METASTATIC BREAST CANCER 5

CHAPTER 3 / TREATING METASTATIC BREAST CANCER 11

CHAPTER 4 / MANAGING SYMPTOMS AND TREATMENT SIDE EFFECTS 37

CHAPTER 5 / QUALITY OF LIFE CONSIDERATIONS 53

CHAPTER 6 / RESOURCES AND GLOSSARY 67

The purpose of this guide is to help you find the information and support you need and to help you, together with your loved ones and health care team, make the best decisions for your health and your future. It is our hope that the information in this guide will serve as a valuable tool in helping you and your loved ones better understand metastatic breast cancer and some of the aspects of managing the disease upon initial diagnosis and beyond.

We believe that with a better understanding of the disease and treatment options, you will be able to regain a sense of control, alleviate some feelings of isolation and, most importantly, find a renewed sense of hope.

Empower yourself

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

— Khadijah

CHAPTER 1 / **EMPOWER YOURSELF** 1

You are not alone 2

The empowerment approach 3

Living with metastatic breast cancer 4

1 Empower yourself

Living with metastatic breast cancer may be the biggest challenge you will ever face. Never be afraid to hope, just remember what you hope for may change. Perhaps you hope for disease and symptom control; for peace in your relationships; for good communication with your doctor.

Throughout your cancer experience, your perspective on what's important to you is likely to shift. You may discover a "new normal" in how you feel about yourself and in your relationship with others.

While living with metastatic breast cancer can be difficult, understand there are actions you can take to help you feel more in control of your experience every step of the way.

YOU ARE NOT ALONE

According to the National Cancer Institute, approximately 5% of women diagnosed with breast cancer for the first time are diagnosed with stage IV, metastatic breast cancer. And, some women who are initially diagnosed with early breast cancer later experience a distant recurrence, or metastasis, which means the cancer has spread beyond the breast and lymph nodes under the arm and now affects other organs, like the liver, lung, bones or brain. About 1% of breast cancer also occurs in men. Similar to women, it may be found after it has already spread or it may be found early and have the potential to recur later.

Thanks to recent advances in research and treatment, hundreds of thousands of people are living with metastatic breast cancer right now. They are living longer and with a better quality of life than ever before.

THE EMPOWERMENT APPROACH

Being *empowered* is about choosing to adopt a series of actions, behaviors, and attitudes that can help improve your quality of life.

Taking a patient-empowered approach is about recognizing the importance of caring for your entire well-being and taking action to ensure the best quality of life possible with cancer.

Choosing to be empowered is not a single monumental decision, but a series of small, incremental choices that help you regain a sense of control over your treatment and your life in general.

The mission of the Cancer Support Community is to ensure that all people impacted by cancer are empowered by knowledge, strengthened by action, and sustained by community.

Don't be afraid to ask a question — there are no stupid questions — and don't be afraid to get a second opinion.

Don't let some doctor talk you out of it. If you feel more comfortable, get that second opinion and feel comfortable in the treatment you are receiving rather than just accepting it. Be a part of your treatment process. It's empowering to be proactive!

— Penny

LIVING WITH METASTATIC BREAST CANCER

It is hard to think of metastatic disease as a chronic disease, but it is becoming more and more like that as the years go by for women living with mets.

— Susan

Being diagnosed with metastatic breast cancer feels to many like an immediate death sentence, but it isn't. New breast cancer treatments are making it possible for most people with metastatic disease to keep the cancer under control for months and years after diagnosis.

It's true there is no cure for metastatic breast cancer, however the progression of disease may be slowed or disease may stop growing for periods of time with treatment. Researchers are working hard to find new treatments to stop cancer growth and potentially cure metastatic breast cancer.

Metastatic breast cancer is a chronic, progressive disease that will always require some type of treatment, but for some people, living with metastatic breast cancer has become a way of life. While it cannot be completely eliminated, treatments can keep metastatic breast cancer under control for months and sometimes years. And when one treatment stops working, another one can usually be tried. Still, the thought of living with cancer for the rest of your life can be scary and overwhelming. It's normal to feel afraid when you're diagnosed with metastatic breast cancer. But there is hope.

By being well informed about the disease and its treatment, you may be able to more effectively manage your disease over an extended period of time. In addition, by developing constructive ways to better address your emotional, social and spiritual needs, you can take back control and live well, not just despite the disease, but also because of it.

Many people like you get up each day and, in partnership with their health care team, develop a strategy to maintain the best quality of life for the longest amount of time possible. This guide is designed to give you the necessary tools to be Patient Active in managing the disease, your emotions and your life.

Understanding metastatic breast cancer

It's really important to understand the disease and to educate yourself. It's a matter of what this disease is, how it impacts you, and being able to communicate with your health care provider.

— Elaine L.

CHAPTER 2 / **UNDERSTANDING METASTATIC BREAST CANCER**.....5

Diagnosing metastatic breast cancer 6

Key issues to discuss with your doctor about a metastatic breast cancer diagnosis 10

2 Understanding metastatic breast cancer

Metastatic breast cancer is cancer that has spread from the place where it first developed, in the ducts or lobules of the breast, to a different part of the body. It is also called Stage IV breast cancer.

It is very important to remember that even though the cancer may be in a different part of the body, and even though you may have had your breast or breasts removed, it is still breast cancer. This means that breast cancer treatments — not treatments for bone, lung, or other cancers — will be the most effective in treating it.

If you've never had breast cancer before and you were initially diagnosed with metastatic disease, you have cancer in the breast and in other parts of the body. Remember that breast cancer treatments will work for the cancer, no matter where it is. If you find this confusing, or if you don't understand why you're getting breast cancer treatment for cancer that has spread to another part of the body, it's OK to ask your doctor or nurse to explain this further.

DIAGNOSING METASTATIC BREAST CANCER

If you have a history of breast cancer and you develop cancer in a different part of the body, your doctors will do tests to determine whether it is breast cancer that has spread, or a new cancer in another area of the body. These tests not only look to confirm that it is breast cancer that has spread, but for special characteristics of the breast cancer, such as estrogen, progesterone, and HER2/neu.

If breast cancer is estrogen/progesterone (ER/PR) positive it means that hormones are one of the main fuel sources of the cancer cell. If the cancer is HER2/neu (HER2) positive then it means that the cells have extra receptors on them that control the rate that the cancer cell grows.

Cancer cells that are not primarily fueled by estrogen or progesterone and do not have extra HER2/neu receptors are called triple negative. These characteristics and types of breast cancer all have unique ways of behaving in the body.

The information that your doctor learns from these tests helps to determine what type of treatment you should receive. If it is breast cancer that has spread, then treatments for breast cancer will be used to treat it. If it is a different cancer that started in another part of the body, such as the bone or lung, then treatments for that particular type of cancer will be used.

The most common sites for breast cancer metastases (places where breast cancer spreads to) are the bones, lungs, liver and brain.

A diagnosis of metastatic breast cancer can evoke many difficult emotions, including shock, anger, and sadness. These are all normal reactions.

It's extremely important to allow yourself to experience all your feelings, in order to help you move forward and take an active role in your treatment.

When I received the news I feared, and the realization that this is now my reality, I was numb. It was too big for me to wrap my brain around. I was totally numb.

— Nancy

The first step is to recognize your emotions and know that it's OK to feel this way.

Here are just some of the difficult feelings many people deal with when faced with a metastatic breast cancer diagnosis, and some important thoughts to keep in mind to help you deal with some of these feelings:

I don't want to die.

A diagnosis of metastatic breast cancer is not always an immediate death sentence. Many people live with the disease for many years with a reasonably good quality of life thanks to advances in breast cancer treatments. Still, even if you know this, the uncertainty of not knowing if or when the disease will progress can be devastating. There are ways to cope with the uncertainty while continuing to maintain an active and satisfying lifestyle.

How will I tell my family?

Telling loved ones, especially young children, about a cancer diagnosis can be extremely stressful. This is one of the first things many people worry about when diagnosed with metastatic breast cancer. Once everyone knows what you're facing, you can work together to figure out the ways of coping that are best for you and your family.

My doctor was insensitive when s/he gave me the news of my diagnosis. I don't think s/he understands how devastated I am.

It's normal to feel angry at the bearer of the bad news that you have metastatic disease. It's also normal for health care professionals to feel extremely uneasy about giving that news to anyone. There's anxiety and discomfort on both sides — yours and your doctor's. It's important to remember that neither you nor your doctor caused your cancer or caused it to recur. Researchers are still trying to understand why some cancers recur and others do not.

If you feel anger toward your doctor and feel you cannot build a trusting relationship with him or her, find another doctor. If you generally get along well, but you're upset or uncomfortable with how he or she told you about the diagnosis, it's important to acknowledge your feelings and then move on. Sharing this feedback with your doctor can actually help him or her understand the communication style that works best for you.

You have to keep moving forward and trust that the next step will push you further in the positive direction where you want to go.

— Judit

If my doctor had taken me seriously when I complained about back pain months ago, we would have caught this earlier.

Again, it's normal to think that somehow, someone—especially your doctor—should have been able to prevent this from happening, or at least find it at an earlier stage. Doctors would like nothing better than to be able to prevent every breast cancer from metastasizing, or spreading.

Unfortunately, there are some breast cancers that spread no matter what treatments you get to try to prevent recurrence and no matter how diligent you and your doctors are about follow-up.

This is not an easy concept to understand. It may help to ask your oncologist or nurse to talk about this with you.

It must have been all the stress I've been under that made the cancer come back.

Aside from blaming someone else, many people blame themselves when they find out they have metastatic breast cancer. It is common to ask yourself what you could have done differently to prevent this from happening or what may have been different if you had sought medical attention sooner. But, most likely, there is nothing you could have done to prevent this from happening. And there is no body of evidence connecting stress to cancer, so go easy on yourself.

It's OK to take a look at what is most stressful in your life and try to reduce that stress, especially now that you're dealing with metastatic disease. But it is not helpful to try to second-guess what you could or could not have done in the past. Some cancers have a tendency to spread and there's nothing anyone has found so far that can stop them.

Try to stop blaming yourself if this has been an issue for you, and start eliminating the things that make you anxious, while adding activities and experiences that give the most meaning to every day of your life.

The Cancer Experience Registry is designed to help people impacted by cancer, particularly those living with metastatic breast cancer, to share their story, to learn about the experiences of others and to help transform the cancer experience. People who participate are connected to a network of support and resources. Findings from the Registry help us all better understand the social and emotional needs of people living with cancer and improve the ways in which care is delivered. Join today at *CancerExperienceRegistry.org*.

KEY ISSUES TO DISCUSS WITH YOUR DOCTOR ABOUT A METASTATIC BREAST CANCER DIAGNOSIS

Is it breast cancer?

If you had breast cancer in the past and develop cancer in one of the common sites for metastases (bones, liver, lungs, or brain), your doctor may suspect that it's breast cancer that has recurred. He or she will most likely recommend a series of tests, including a biopsy, to find out for sure. A biopsy can also provide information that may help with treatment decisions after diagnosis.

Is it the same type of breast cancer as my earlier breast cancer?

If tissue is available from your initial breast cancer, the tissue from the new biopsy can be used as a source of comparison. If many years have passed since your initial diagnosis and tissue from the initial cancer is not available for comparison, there are still ways to tell what type of cancer it is, based on what the cells look like under a microscope, as well as newer types of biochemical testing.

Is it a different type of cancer, called a "second primary"?

If you had breast cancer and develop cancer in an area of the body that is not common for metastases, or if there are other reasons to suspect that this might be a new cancer, your doctor will recommend a biopsy and other tests to determine what type of cancer it is so that you will get the most appropriate treatment.

Is it OK to get another opinion?

If you have any questions or concerns about your diagnosis, you may feel better getting a second opinion. Many people feel better and more in control of their situation when they have talked with other experts about their disease. Then, as they proceed with treatment, they feel more confident that they have explored every possible option to receive the best available care.

In the event you get two different treatment recommendations it is reasonable to see a third physician as a "tie breaker." Seeing more than three physicians is rarely helpful though and often only serves to delay treating your breast cancer.

It's so important to have a good relationship with your oncologist. That you can bounce ideas off of him/her and that you are treated like you are part of the decision-making process is crucial. And if you don't feel comfortable in the decision-making process, then it's time to change doctors.

— Kim

Treating metastatic breast cancer

CHAPTER 3 / TREATING METASTATIC BREAST CANCER 11

Choosing your health care team 12
Key members of your health care team 13
Communication is key 15
Treatment options for metastatic breast cancer 16
Supportive care 30
Complementary, Integrative and Alternative Medicine (CAM) 32
Choosing the right treatments for you 33
Treatment questions to discuss with your doctor 34

3 Treating metastatic breast cancer

Living with metastatic breast cancer typically means a lot of doctor appointments and ongoing treatment.

You have to be brave and speak up to your doctors if you have questions or concerns. I've experienced people who think we're whiny or babies. I think we're brave every time we show up for the next treatment, the next scan, the next visit.

— Elaine B.

You need a health care team you can trust. Maybe you have a wonderful doctor who has been following you since your initial diagnosis. Maybe you don't like the one you have and want to switch. It's important to remember that how well you get along with your health care team depends a lot on your personal preferences.

It's also important to remember that you can get a second opinion which may allow you to feel confident that you are getting the best possible care. It may be most helpful to get a second opinion when one treatment stops working and you're looking for the next one to try. Consulting with another breast cancer expert might give you some new ideas.

CHOOSING YOUR HEALTH CARE TEAM

Remember that this is a very personal choice, and a doctor who's right for one person may be completely wrong for another. Here are some important things to consider in choosing your health care team:

Past relationships. If you had early stage breast cancer, would you like to continue seeing the same doctors? Or do you feel you can't communicate well with your old doctors and would like to find somebody new?

Recommendations. Is there a doctor or nurse you trust who can recommend a good 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? Is he or she someone who attends medical conferences and keeps up with the latest breast cancer research? With metastatic disease, you may feel it's especially important to find someone who is up to date on all of the latest advances in breast cancer research and treatment.

Type of communication. Do you want a doctor who tells you about all your options and leaves the final decisions up to you? Or do you want someone who doesn't go into too much detail and just tells you what he or she thinks is the best thing to do? Once you determine how much or how little information you would like from your health care team, it's important to share this information with them.

Approach to treatment. Some doctors recommend many tests and combined treatments, while others prefer a less aggressive approach. Since there is no research to show that one approach is better than the other, you should be comfortable with the approach you and your doctor take.

Geographic location. Are you willing and able to travel to a well-known center that may not be near your home? Is the expense and inconvenience of this type of travel worth it to you? Or is there a local hospital with a competent medical team that already knows you and is easy for you to access and interact with?

Type of institution. Is it important to you to be treated at a large medical center with specialists in every medical discipline? Or do you prefer a smaller center specializing exclusively in cancer treatment?

Availability of clinical trials. Would you consider participating in scientific studies on metastatic breast cancer treatment? If you're interested, is this an important consideration for you in choosing where you get treated? Would you be willing to travel to a center where studies are available even if it's far from your home?

A big part in choosing my health care team was feeling good about the quality of care I would receive. My husband and I loved the facility, because it was a comprehensive cancer center. It has a nutritionist, pharmacist, social workers, and counselors. I feel comfortable there.

— Ginny M.

Insurance coverage. In some cases, your choice of health care professionals may be limited to a list of those covered by your insurance plan. Check with your insurance provider and your doctor to make sure the appointments, tests, and treatments you will receive are covered. If you do not have health insurance, see p. 67 for a list of government and nonprofit organizations that can help.

KEY MEMBERS OF YOUR HEALTH CARE TEAM

Remember also that different members of your team will be taking care of you in different important ways. The following are some of the key health care professionals who will be treating you:

Medical oncologist. This is the doctor who will most likely help you decide what course of medical treatment to follow. You'll have regular appointments with this oncologist to see how you're doing. He or she will tell you what tests you need and the results, and will monitor how you respond to your treatment. When a treatment you're taking stops working, your medical oncologist will discuss the next best options for you to consider.

It's extremely important that you tell your oncologist if you're having any side effects or symptoms that are interfering with your everyday activities. In many cases, there are things the doctor can recommend to help prevent or minimize those effects before they become permanent or debilitating.

Talk with your doctor about any medications, supplements, or complementary treatments you may already be receiving or are interested in trying out so that together, you can develop the most appropriate course of treatment for you.

Oncology Nurse Practitioner. Your medical oncologist may work closely with a nurse practitioner (NP) or advanced practice nurse. This is a nurse with advanced schooling and training who is able to diagnosis and treat medical issues and prescribe medications when needed. The NP may see you with your medical oncologist or independently to assess your symptoms and the effectiveness of your treatment.

Radiation oncologist. If you have radiation therapy, this is the doctor who will manage your radiation therapy treatments. Your radiation oncologist works closely with other members of your health care team to develop the most appropriate treatment plan for you and to monitor the radiation's effectiveness.

Without my breast health coordinator, I don't know what I would have done. She has helped me so much with communicating with my doctors and navigating the health care system. She has been a life saver.

— Jordan

Oncology nurse. Your oncology nurse is a registered nurse (RN) who specializes in dealing with individuals with cancer. An oncology nurse can have various roles, but most often he or she is the health care professional who administers treatments and supportive care medications, and is responsible for helping you understand your cancer diagnosis and treatment.

Many people find their oncology nurses to be invaluable sources of information and support. This is the person you can talk to about the questions you have and what the best way is to get them answered. If you have questions between appointments, you may find it useful to get in touch with your nurse. He or she can answer many questions you might have, convey other questions to your oncologist and get back to you with answers. You should tell your nurse about any side effects or symptoms that are bothering you. He or she, together with the medical oncologist, can help find ways to relieve the symptoms. He or she might also have helpful hints learned from other patients who have gone through similar experiences.

Oncology social worker or counselor. This is a person who is knowledgeable about cancer and the social and emotional effects of the disease and its treatment. The social worker or counselor can provide individual, group, or family counseling, help you navigate the health care system, and help to mobilize valuable resources related to financial, transportation and home care needs. Many medical oncologists have oncology social workers who work with their patients. If they don't bring it up themselves, ask your oncologist or nurse to refer you to a qualified oncology social worker.

Primary care physician. When you're dealing with treatment for metastatic breast cancer, it's easy to forget that you still need to get regular physicals and other routine exams to monitor for and manage non-cancer related issues. So it's important to continue seeing your primary care physician. Your primary care doctor will also want to know how you're doing with your treatments for metastatic breast cancer, and keep an eye on any symptoms of distress or anxiety that you might have.

Patient navigator. Many hospitals and clinics now offer the assistance of a patient navigator. A patient navigator may be an oncology nurse or social worker, or it can be a trained layperson. A navigator is available to assist you on the journey through the health care system, identify members of your health care team, explain terms, and more.

COMMUNICATION IS KEY

Once you have a medical team in place, the most important thing you can do to make sure you're getting the best possible care is to maintain open and honest communication.

Here are some tips for communicating effectively with your health care team:

- Keep a running list of questions to bring to your appointments.
- Ask your team what the best way is to get your questions answered: Should you bring your list to every appointment? Would it be easier to get answers by email? Do you need to schedule an extra appointment if your list is getting especially long?
- Know that you deserve to get your questions answered, so don't be shy to ask again—and again—until you're satisfied.
- Bring someone along to appointments with you. It can be hard to take it all in by yourself. A family member or friend may be able to help remember anything you might forget.
- Take notes, or ask someone close to you to come with you and take notes, to make sure you remember what the doctor said.
- ALWAYS, ALWAYS tell your doctor or nurse if you're experiencing any side effects or symptoms that are making you uncomfortable or interfering with your activities. Your doctor can only help if he or she knows what's bothering you.
- ALWAYS, ALWAYS tell your doctor about any herbs, vitamins, supplements, or other complementary treatments you might be taking. Some supplements can lower the effectiveness or interact "negatively" with some anti-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.

Don't be afraid to speak your mind or get on your doctors' nerves. Tell them everything you're feeling. Because they can't help you if they don't know what's wrong. That's what they're there for.

— Laura

- ALWAYS, ALWAYS tell your doctor about any medications prescribed by any other doctor for other health conditions. It's critical for your doctors to be aware of what each is prescribing for you, and for them to communicate with each other about your care.

TREATMENT OPTIONS FOR METASTATIC BREAST CANCER

The goal of treatment for metastatic breast cancer is to slow or sometimes stop the growth of the cancer cells to keep the cancer from spreading for as long as possible. This means that the treatments may not get rid of the cancer completely, but they may stop it from growing, or slow its growth, for months and sometimes even years. If tests or symptoms show that one treatment is no longer working, there will usually be others from which to choose.

The number of treatment options for metastatic breast cancer is continually increasing, and there's no single treatment or series of treatments that's best for everyone. Every person's cancer is different, which means that response to treatment can vary from patient to patient.

This also means that you might get different opinions from health care professionals about the best course of treatment. It can be helpful to get a second, or even a third opinion, until you have enough information to make treatment decisions that you feel are right for you.

You may have heard of or even received some of the treatment options when you were first diagnosed with breast cancer. However, some of the options available today may be new treatments. The treatment of metastatic breast cancer is continually improving as science makes advances. New treatments and treatment combinations are being discovered by researchers, tested in clinical trials, and offered to patients.

It can feel overwhelming to choose a treatment. Your medical oncologist will help you weigh the options and make the best possible choices, taking into consideration your lifestyle, work situation, and other quality of life issues.

Remember that everyone responds differently to different types of treatment. What causes serious side effects for someone else may have few or no side effects for you. That's why it's so important to tell your health care team how you're feeling and how the treatments are affecting you.

The next several pages discuss common treatments for metastatic breast cancer.

Chemotherapy

This type of treatment kills cells in the body that are dividing and growing rapidly. These include cancer cells, but may also include cells related to hair and nail growth, bone marrow cells, and cells in the digestive system. This is why chemotherapy sometimes causes side effects in those parts of the body.

You may get one type of chemotherapy at a time (single-agent therapy) or several drugs in combination (combination therapy). You may also get chemotherapy in combination with other types of treatment. Most chemotherapy treatments are given intravenously (through a needle in a vein), but some are available in pills or by injection. For more details, see the table on the next three pages.

Chemotherapy is typically given in cycles: you receive it for a certain period of time on specific days and during certain weeks. Depending on the type of chemotherapy, there may be a rest period of one to three weeks before your next cycle begins. These rest periods do not decrease the effectiveness of the treatment; they give your body a chance to recover from some side effects.

The type of chemotherapy recommended for you depends on types of chemotherapy you may have already received, the type of breast cancer you have, side effects you may experience, and other factors your doctor will discuss with you.

QUESTIONS TO ASK YOUR DOCTOR ABOUT CHEMOTHERAPY

- What type of chemotherapy do you recommend for me?
- Why do you think this type of chemotherapy would be better for me than others?
- Do you recommend taking chemotherapy in combination with another type of treatment?
- What are some common side effects of the chemotherapy you're recommending?
- What can be done to help manage side effects?
- What's the best way to tell you if I experience side effects?
- Will I get the chemotherapy intravenously (through a needle in a vein) or orally (in a pill)?
- Will I need a port (a small device placed under the skin to make it easier to get intravenous treatments)?
- How will we know if the chemotherapy is working?
- How long will I have to take the chemotherapy?
- Is there a clinical trial involving chemotherapy that you think might be beneficial for me?

TABLE 1 / CHEMOTHERAPY TREATMENTS FOR METASTATIC BREAST CANCER

TYPE OF TREATMENT	BRAND & GENERIC NAMES	POSSIBLE SIDE EFFECTS *Remember that not everyone gets all of these side effects. It is also important to note that each drug does not cause all of the listed side effects.*	HOW TREATMENT IS GIVEN	IMPORTANT THINGS TO KNOW
Anthracyclines	• Adriamycin® (doxorubicin) • Doxil® (doxorubicin HCl liposome injection) • Ellence® (epirubicin)	• Nausea • Vomiting • Hair loss • Increased risk of congestive heart failure • Low blood counts and risk for infection, fatigue, and bleeding • Mouth sores • Redness, pain, and swelling of the hands and feet (Hand-foot syndrome) with Doxil	Intravenous drug given weekly or every two to four weeks	• This type of chemotherapy can be very effective in controlling metastatic breast cancer. • It is not usually recommended for women with previous heart problems. Tests are used to evaluate heart functioning. • After receiving a certain total amount of this type of medicine the risk for heart problems becomes too high and you may have to switch to a different treatment or receive an additional medication to help protect the heart.
Taxanes	• Taxotere® (docetaxel) • Taxol® (paclitaxel) • Abraxane® (paclitaxel in albumin-bound particles)	• Neuropathy (numbness, tingling or pain in hands and feet) • Low blood counts and risk for infection, bleeding and fatigue • Hair loss • Fluid retention • Nail and skin changes • Dry eye, or loss of natural tears • Risk of allergic reaction • Flu-like symptoms • Joint pain • Weakness	Intravenous drug given weekly or every two to three weeks	• The taxanes can be very effective in controlling metastatic breast cancer. • As with all treatments, report any side effects to your medical team right away. SPECIFIC **Taxol** • You should get a steroid medication before taking Taxol to lower the risk of allergic reaction during infusion. **Taxotere** • You should get a steroid medication before the infusion and to take at home after the infusion. This decreases swelling that may occur in the body from this medication. **Abraxane** • This is the same chemotherapy agent as Taxol but is mixed in a different preservative for administration. Abraxane may be used for people who have had an allergy to Taxol before or for patients who are unable to take steroids before their chemotherapy.

TABLE 1 / CHEMOTHERAPY TREATMENTS FOR METASTATIC BREAST CANCER (continued)

TYPE OF TREATMENT	BRAND & GENERIC NAMES	POSSIBLE SIDE EFFECTS *Remember that not everyone gets all of these side effects. It is also important to note that each drug does not cause all of the listed side effects.*	HOW TREATMENT IS GIVEN	IMPORTANT THINGS TO KNOW
Platinum-containing compounds	• Platinol® (cisplatin) • Paraplatin® (carboplatin)	• Low blood counts • Thinning or brittle hair • Loss of appetite or weight • Diarrhea • Nausea and vomiting • Neuropathy (numbness, tingling or pain in hands and feet) • Less common side effects include kidney impairment and hearing loss	Intravenous drugs given weekly to every three weeks	• These drugs are increasingly being used for triple negative breast cancer.
Anti-metabolites	• Xeloda® (capecitabine) • Fluorouracil (5-FU) • Gemzar® (gemcitabine)	**Xeloda** • Mild nausea • Hand-foot syndrome with redness, pain and swelling • Diarrhea • Mouth Sores **Fluorouracil** • Mild nausea • Hand-foot syndrome with redness, pain and swelling • Diarrhea • Mouth Sores **Gemzar** • Mild to moderate nausea and vomiting • Fatigue • Diarrhea • Skin rash • Low blood counts, especially platelets (which help clotting) • Allergic pulmonary reaction	**Xeloda** • Oral pills taken two times per day for a specified amount of time followed by one week off. Dose schedule can be modified if needed. **Fluorouracil** • Intravenous (IV) bolus which is over a very short period of time. • Continuous IV infusion over a specific number of days. **Gemzar** • Intravenous drug given weekly for three weeks followed by one week of rest. Dose schedules may vary.	• These chemotherapy treatments can be very effective in controlling metastatic breast cancer. • These are given when other medicines have stopped working. • Hand-foot syndrome, if it develops, can get so uncomfortable that your doctor may recommend reducing the dose to alleviate the discomfort while maintaining the medicine's effectiveness. If the discomfort continues with lower doses of the medicine, you may need to switch to a different treatment. It is very important to tell your doctor or nurse as soon as you have pain, blistering, cracking, or redness in your hands or feet. SPECIFIC **Fluorouracil** • This is an IV form of Xeloda. For a continuous IV infusion, patients must have a port, or other type of permanent IV, in order to receive this medication. Patients go home with a special, small pump that administers the medication.

TABLE 1 / CHEMOTHERAPY TREATMENTS FOR METASTATIC BREAST CANCER (continued)

TYPE OF TREATMENT	BRAND & GENERIC NAMES	POSSIBLE SIDE EFFECTS *Remember that not everyone gets all of these side effects. It is also important to note that each drug does not cause all of the listed side effects.*	HOW TREATMENT IS GIVEN	IMPORTANT THINGS TO KNOW
Microtubule Inhibitors	• Navelbine® (vinorelbine) • Ixempra® (ixabepilone) • Halaven® (eribulin)	• Mild to moderate nausea and vomiting • Constipation • Diarrhea • Neuropathy (numbness, tingling or pain in hands and feet) • Pain at the tumor site after infusion • Low blood counts – anemia, risk for infection and bleeding • Fatigue • Hair loss • Allergic reactions (itching, rash, difficulty breathing)	**Navelbine** • Intravenous drug given weekly **Ixempra** • Intravenous drug given once every three weeks **Halaven** • Intravenous drug given weekly for the first two weeks of a three week cycle	SPECIFIC **Navelbine** • Generally well tolerated and can be very effective in controlling metastatic breast cancer. • In many cases, there is no hair loss. • This may cause pain in your veins. If you experience this you may want to talk to your doctor about having a port placed. **Ixempra** • Approved for use in cancers that do not respond to treatment with anthracyclines, taxanes, and Xeloda. • It's given alone or with capecitabine. **Halaven** • It is indicated for use only after two other chemotherapy regimens (including a taxane and an anthracycline) have been tried. • This may cause a drop in your white blood cells which can put you at risk for infection. Your doctor may want you to use a shot to help boost your white blood cells with this medication.
Antibody-Drug Conjugates	• Kadcyla® (Ado-Trastuzumab Emtansine)	• Low blood counts – anemia, risk for infection, or risk for bleeding • Neuropathy (numbness, tingling, or pain in hands and feet) • Diarrhea • Abnormal liver function tests • Mild nausea	Intravenous drug given once every three weeks	• This is a combination of Herceptin (trastuzumab) and a chemotherapy drug. You should not receive additional Herceptin with this medication.

Hormonal therapy

Hormonal treatments are used for hormone receptor-positive (estrogen and/or progesterone receptor positive) breast cancers. These are cancers that are stimulated to grow by estrogen. Hormonal therapy lowers the amount of the hormones that reach the cancer, thereby slowing or stopping the cancer's growth.

Hormonal therapies are primarily pills that are taken once a day, however they may also be in the form of injections that are given into the muscle. See the table on the next two pages for more details. In pre-menopausal women, it may also be beneficial to block the estrogen that is still being made by the ovaries. This may be done with medications or by surgically removing the ovaries.

If your initial cancer was hormone receptor-positive, a biopsy will be done, and the cancer tissue will be sent to a laboratory where it will be tested.

QUESTIONS TO ASK YOUR DOCTOR ABOUT HORMONAL THERAPY

- Do I have the type of breast cancer that may respond to hormonal therapy? If yes, what type of hormonal therapy do you recommend for me?
- Why do you think this type of hormonal therapy would be better for me than others?
- Do you recommend taking hormonal therapy in combination with another type of treatment?
- What are some common side effects of the hormonal therapy you're recommending?
- What can be done to help manage side effects?
- What's the best way to tell you if I experience side effects?
- How is the hormonal therapy given?
- How will we know if the hormonal therapy is working?
- How long will I have to take the hormonal therapy?
- Is there a clinical trial involving hormonal therapy that you think might be beneficial for me?

TABLE 2 / HORMONAL TREATMENTS FOR METASTATIC BREAST CANCER

TYPE OF TREATMENT	BRAND & GENERIC NAMES	POSSIBLE SIDE EFFECTS *Remember that not everyone gets all of these side effects. It is also important to note that each drug does not cause all of the listed side effects.*	HOW TREATMENT IS GIVEN	IMPORTANT THINGS TO KNOW
Selective Estrogen Receptor Modulators (SERMs)	• Tamoxifen® (nolvadex) • Fareston® (toremifene)	• Hot flashes • Vaginal discharge • Leg cramps • Slight increased risk of uterine cancer • Slight increased risk of blood clots • Slight increased risk of cataracts • Other menopausal symptoms	Daily pill	• SERMs work for both pre- and post-menopausal women with hormone receptor-positive cancer. • They block hormone receptors on the breast cancer cells so the hormones cannot stimulate the cancer to grow. • SSRIs, a type of antidepressant medicine, may lower the effectiveness of tamoxifen. If you're taking an SSRI (for example, Prozac® or Paxil®), talk to your doctor about whether or not this might affect your response to Tamoxifen.
Aromatase inhibitors	• Arimidex® (anastrozole) • Femara® (letrozole) • Aromasin® (exemestane)	• Hot flashes • Vaginal dryness which can lead to pain with sexual intercourse • Other menopausal symptoms • Decrease in bone density and increased fractures • Pain in joints and soft tissue • Joint stiffness • Increased cholesterol	Daily pill	• Aromatase inhibitors work only for post-menopausal women with hormone receptor-positive breast cancer, and are being studied in premenopausal women who have had menopause induced by treatment. • They have different side effects than Tamoxifen. For example, they do not increase the risk of uterine cancer or blood clots, but they are associated with weaker bones, so they may not be appropriate if your bones are already weak (a condition called osteopenia or osteoporosis). • Your doctor may order a test to evaluate your bone health. If your bones show signs of weakening, or if you already have osteopenia or osteoporosis, bone-strengthening medicine is typically prescribed.

TABLE 2 / HORMONAL TREATMENTS FOR METASTATIC BREAST CANCER (continued)

TYPE OF TREATMENT	BRAND & GENERIC NAMES	POSSIBLE SIDE EFFECTS *Remember that not everyone gets all of these side effects. It is also important to note that each drug does not cause all of the listed side effects.*	HOW TREATMENT IS GIVEN	IMPORTANT THINGS TO KNOW
Selective Estrogen Receptor Down Regulators (SERDs)	• Faslodex® (fulvestrant)	• Hot flashes • Other post-menopausal symptoms including vaginal dryness which could lead to pain with intercourse, tendency to gain weight and some degree of joint stiffness • Reactions (such as pain, redness, or swelling) at the injection site	Injection given every two weeks for the first three doses, then every four weeks	• This type of treatment is effective for post-menopausal women with hormone receptor-positive breast cancer. • It is typically used after other hormonal treatments have stopped working.
Luteinizing hormone-releasing hormones (LHRH) and gonadotropin-releasing hormone (GnRH) agonists	• Zoladex® (goserelin acetate) • Lupron® (leuprolide)	• Hot flashes • Other post-menopausal symptoms including cessation of a menstrual period, vaginal dryness which could lead to pain with intercourse, tendency to gain weight and some degree of joint stiffness	Injection given every one to three months	• This type of treatment is for premenopausal women with hormone receptor-positive breast cancer. • These drugs act by shutting down hormone production in the ovaries (ovarian ablation). This significantly lowers the amount of estrogen in the body that can cause hormone receptor-positive breast cancer to grow. • This can also be done by surgically removing the ovaries.

Targeted therapies

One of the most exciting areas in cancer treatment today is the expanding area of targeted therapies. These drugs target and block specific cell pathways that enable cancer cells to grow. Some are available currently and many more are being developed and tested in clinical trials. These treatments are helping scientists and doctors personalize treatment plans so that they are more effective at treating each individual's type of cancer. You may get targeted therapy alone or in combination with other treatments, like chemotherapy.

Herceptin® (trastuzumab), Perjeta® (pertuzumab), and Tykerb® (lapatinib) work against cancer cells that have too much of the HER2 (also called HER2/neu) protein. To find out whether the cells in the metastasis have too much HER2 protein, your oncologist may recommend that a test be done on the tissue from your original biopsy. Talk to your doctor about the HER2 status of your cancer and how this might affect your treatment choices.

A new medication, Kadcyla® (Ado-Trastuzumab Emtansine), is a combination of both chemotherapy and the targeted agent, Herceptin®. This medication was known for many years as TDM-1 when it was being studied on clinical trials. This drug provides both chemotherapy benefits as well as anti-HER2 benefits at the same time. This drug is the first of its kind to combine the two methods of treating cancer into one medication.

Another type of targeted agent that is being used more in breast cancer are mTor inhibitors. This class of drugs changes the cancer cells' ability to grow by altering some of its proteins. These agents are used with other antic-cancer drugs to make them more effective. An example of an mTor inhibitor is Afinitor® (everolimus) which is given with Aromasin® (exemestane) for individuals with ER/PR positive breast cancer. There are other drugs in this class which are also being studied on clinical trials but are not yet FDA approved.

QUESTIONS TO ASK YOUR DOCTOR ABOUT TARGETED THERAPY

- Are there any targeted therapies available for my type of breast cancer?
- Why do you think this type of targeted therapy would be better for me than others?
- Do you recommend taking targeted therapy in combination with another type of treatment?
- What are some common side effects of the targeted therapy you're recommending?
- What can be done to help manage side effects?
- What's the best way to report to tell you if I experience side effects?
- How is the targeted therapy given?
- How will we know if the targeted therapy is working?
- How long will I have to take the targeted therapy?
- Is there a clinical trial involving other targeted therapies that you think might be beneficial for me?

There are standard protocols when you are initially diagnosed with a primary cancer. But when it becomes metastatic, it is much more individualized, and it is almost as much of an art as a science, so you can get widely varying opinions.

— Wanda

TABLE 3 / TARGETED THERAPIES FOR METASTATIC BREAST CANCER

TYPE OF TREATMENT	BRAND & GENERIC NAMES	POSSIBLE SIDE EFFECTS *Remember that not everyone gets all of these side effects. It is also important to note that each drug does not cause all of the listed side effects.*	HOW TREATMENT IS GIVEN	IMPORTANT THINGS TO KNOW
Anti-HER2 monoclonal antibody	• Herceptin® (trastuzumab) • Perjeta® (Pertuzumab)	• In most cases side effects are mild. • Common side effects include flu-like symptoms such as fever, chills, and muscle aches. • Heart damage is a rare but serious possible side effect, especially in older women or those who have had prior anthracycline (a type of chemotherapy) treatment. • Patients may also experience diarrhea and rash.	Intravenous drug given weekly or every three weeks	• This targeted therapy works against cancer cells that have too much HER2 protein (about 25% of all breast cancers are in this category). • It can be very effective at controlling metastatic breast cancer with few to no side effects. • Side effects often lessen after the first treatment. • Heart functioning is evaluated before treatment as well as during and after treatment.
Dual tyrosine kinase inhibitor	• Tykerb® (lapatinib)	• Side effects include rash, diarrhea and fatigue.	Oral pills taken once a day on an empty stomach	• Approved for use in combination with Xeloda, for treating HER2-positive metastatic breast cancer that is no longer responding to Herceptin. • Targets both the EGFR (HER1) and HER2 receptors. • It is very important to take this medication 1 hour before eating or 2 hours after eating.

TABLE 3 / TARGETED THERAPIES FOR METASTATIC BREAST CANCER (continued)

TYPE OF TREATMENT	BRAND & GENERIC NAMES	POSSIBLE SIDE EFFECTS *Remember that not everyone gets all of these side effects. It is also important to note that each drug does not cause all of the listed side effects.*	HOW TREATMENT IS GIVEN	IMPORTANT THINGS TO KNOW
mTor inhibitors	• Afinitor® (everolimus)	• Mouth sores, rash, irritation of the lining around the lungs, diarrhea, fatigue	• A pill taken once a day with Aromasin (exemestane). • It is best to take this medication at the same time every day. Never crush this medication or take if the tablet is broken.	• Light can change the effectiveness of this medication. Do not remove from the foil packet until you are ready to take it. • Do not take this medication with grapefruit, grapefruit juice, or St John's Wort. • Antifungal medications, like nystatin, may make this medication stronger or worsen the side effects of this medication. • Make sure to let all of your doctors know you are taking this.
Antibody-Drug Conjugates	• Kadcyla® (Ado-Trastuzumab Emtansine)	• Low blood counts – anemia, risk for infection, or risk for bleeding • Neuropathy (numbness, tingling, or pain in hands and feet) • Diarrhea • Abnormal liver function tests • Mild nausea	• Intravenous drug given once every three weeks	• This is a combination of Herceptin (trastuzumab) and a chemotherapy drug. You should not receive additional Herceptin with this medication.

Clinical Trials

A clinical trial is a research study that evaluates promising new treatment options. A cancer patient can participate in a clinical trial immediately after being diagnosed, or, if appropriate, after they have undergone previous treatments. Clinical trials offer access to new treatments available only in a research setting, and patients often benefit from the close monitoring provided as part of a clinical trial.

Clinical trials may test standard cancer treatment in combination with a new treatment element, a new drug to treat cancer, or how we manage the side effects and emotions related to cancer and cancer treatments. Participation in a clinical trial helps researchers to develop new and better treatments for cancer.

QUESTIONS ABOUT CLINICAL TRIALS TO DISCUSS WITH YOUR DOCTOR

- What exactly does the new treatment do to fight the cancer?
- How will my clinical trial treatment differ from standard treatment?
- How is treatment administered and where?
- What is known about the side effects of this drug? How will my safety be monitored?
- How do the possible risks and benefits of this trial compare with other treatment options?
- Will I have to pay for any part of the trial such as tests or the study medication?
- What is my health insurance likely to cover? Who can help answer any questions from my insurance company or health plan?
- Will I be accepted if I have no health insurance?
- Will there be any travel, housing, or childcare costs that I need to consider while I am in the trial?

Everyone who participates helps to build information about the disease and its treatment for future generations. This does not mean that clinical trials are for everyone. But they can be a very good option as they offer the possibility of getting a treatment that may prove to work better than the current standard of care.

In order to participate in a clinical trial, participants must sign an "informed consent" form to show that information about the new treatment, risks and benefits, alternative treatment options and any costs have been fully explained. An informed consent document also explains that participants can withdraw from participating in the trial at any time without compromising their medical care, among other patient rights.

Keeping an open mind about clinical trials will allow you to explore options and decide if there's a trial that may be right for you. It is important to ask your doctor about clinical trials that may be available to you.

TO LEARN MORE ABOUT CLINICAL TRIALS

Your health care team can provide you with information about clinical trials available at your treatment center. If you want to search more widely for clinical trials, the following resources have more information:

- **National Cancer Institute**
  800-422-6237
  www.cancer.gov/clinicaltrials
- **National Institute of Health**
  301-496-4000
  www.clinicaltrials.gov
- **Cancer Support Community's Clinical Trials Matching Service**
  800-814-8927
  www.cancersupportcommunity.org
- **BreastCancerTrials.org**
  415-476-5777
  www.breastcancertrials.org

I was followed more closely by my doctors when I was on a clinical trial than had I received the standard of care treatment only. I feel that I got the best care possible when I was on a clinical trial.

— Loretta

SUPPORTIVE CARE

Surgery. Surgery to remove a breast mass in a person initially diagnosed with metastatic breast cancer is a treatment question that is currently being studied closely by researchers. Some doctors believe that removing the breast mass can improve survival. Ask your doctor for more information.

If you have a mass in the breast or somewhere else in the body that is causing significant symptoms and can easily be removed, surgery may be an option. This may include a mass in the lung, liver, or brain. The surgery may not remove all of the cancer from the body, but it can make you feel better if the mass is causing pain or discomfort.

Radiation. These type of treatments are often a better option than surgery for shrinking large masses that are causing significant pain and/or other symptoms. Radiation is most frequently used with tumors in the bone when they are causing pain or risk of fracture.

As with surgery, the radiation may not kill all of the cancer cells, but it can make you feel better if the cancer is causing pain or discomfort. It can also prevent, manage, or stabilize fractures due to cancer involving the bone and help control tumors in the lymph nodes and also other areas.

Unfortunately, radiation to the bone can also affect non-cancerous cells in the bone marrow, increasing your risk for infections, anemia, and bleeding disorders. If your doctor recommends radiation, be sure to talk to him or her about the potential benefits and drawbacks of this type of treatment.

Palliative care. For people living with metastatic breast cancer, preserving a healthy quality of life can be an important goal of treatment. Palliative care is a medical specialty that focuses on preserving quality of life for those living with a chronic or life-threatening disease.

Important features of palliative care include:

- Provides relief from pain and other illness-related symptoms.
- Incorporated into one's treatment plan at ANY stage of one's disease, including the point in time right after a cancer diagnosis has been made.
- Utilized in combination with other therapies, such as chemotherapy or radiation which aim to prolong survival.
- Offers support to both patients and their families to guide them towards meaningful coping throughout the course of the disease.
- Will likely enhance the quality of life and may positively impact survival outcomes.

THE DIFFERENCE BETWEEN PALLIATIVE CARE AND HOSPICE

Some people confuse palliative care with hospice. While both palliative care and hospice focus on quality of life for patients and their families, there are distinctions between the two.

Hospice focuses specifically on end-of-life care. It is used when active treatment has ceased. Hospice provides comfort to the patient and the patient's family.

For more information on hospice, see page 64 of this book.

COMPLEMENTARY, INTEGRATIVE AND ALTERNATIVE MEDICINE (CAM)

Today, many cancer treatment centers combine standard therapy with a broad range of other treatments that are considered complementary in an approach.

Complementary therapy refers to supportive methods that are used to complement, or add to, medical treatments. Examples of complementary therapies include music, art therapy, massage, acupuncture, Reiki therapy, or relaxation exercises. Researchers are working to scientifically prove the effectiveness of several complementary therapies. For example, a panel of scientists concluded that acupuncture is effective in treating nausea due to chemotherapy, and can also relieve pain and fatigue in some patients.

Integrative therapy or integrative medicine refers to the combined offering of conventional and complementary therapies. An integrative approach may be used to control pain, relieve anxiety, and improve quality of life. For example, you might consider a proven complementary therapy for nausea in addition to standard anti-nausea drugs. Complementary cancer treatments, however, are not substitutes for proven standard therapies to treat metastatic breast cancer.

Alternative therapy refers to treatments that are promoted as options to be used instead of conventional medical treatment. *So far, there is no alternative therapy for metastatic breast cancer that has been scientifically tested and found to be effective.*

As with all types of treatment for metastatic breast cancer, it's important to remember that what works for one person might not necessarily work for you.

Many complementary methods can be used safely along with standard treatment. However, some herbal supplements have been found to actually interfere with the success of chemotherapy agents.

I didn't like yoga. So I asked myself: what do I really need? Music. I've always been a music person. I look for music all the time. I used to love musicals. So I bought DVDs and invited friends over to watch. That made me a more passionate person. Any time I feel stressed I still put them on.

— Francine

If you are interested in learning more about CAM, it may be a good idea to talk with your doctor so that together, you can find the best combination of treatments for you.

For questions about complementary and alternative therapies, contact **The National Center for Complementary and Alternative Medicine** at *www.nccam.nih.gov* or **The National Cancer Institute's Office of Cancer Complementary and Alternative Medicine** at *www.cancer.gov/cam*

CHOOSING THE RIGHT TREATMENTS FOR YOU

The goal of treatment for metastatic breast cancer is to keep the cancer under control while maintaining the best quality of life possible. If one treatment is not working properly or is causing too many side effects, there may be others from which to try.

Selecting from the many available treatments can seem overwhelming. It's good to take some time to learn about your choices and consult with your health care team before beginning treatment. There is no single right answer — you will probably find that there are a number of treatment approaches to choose from. Unfortunately, metastatic breast cancer eventually becomes resistant to each treatment. At which point, you and your doctor can explore and select another of the many available treatment options.

Learning as much as possible about the different treatment options, and discussing them with your health care team, will help you feel confident that you are making the right decisions for you.

HELP WITH MAKING TREATMENT DECISIONS

Open to Options™ is a free telephone or in-person counseling program provided by trained professionals at the Cancer Support Community. It empowers you to communicate your concerns clearly and create a list of questions for your doctor that will help you address your specific needs. Call 1-888-793-9355 to schedule an appointment.

THINGS YOU AND YOUR DOCTOR MAY CONSIDER TO HELP SELECT THE BEST TREATMENT FOR YOU

- Where the cancer is located in your body
- Your age and overall health
- What treatments you've had in the past
- What medications you're taking now
- Whether you're pre- or post-menopausal
- Whether the cancer is hormone receptor- positive or -negative
- Whether the cancer is HER2-positive or Triple Negative
- Whether you have other conditions or diseases that affect your ability to tolerate certain treatments
- What your wishes are regarding further treatment

TREATMENT QUESTIONS TO DISCUSS WITH YOUR DOCTOR

Which treatment should be given first?

The answer to this question will depend on many of the factors discussed in the previous section.

Generally, if the cancer is hormone receptor-positive, you may decide to try a hormonal therapy first, before trying chemotherapy.

Trying hormonal therapy first may be a good approach because these therapies generally cause fewer side effects than chemotherapy, and they can be just as effective as chemotherapy at controlling your cancer. If your breast cancer is not hormone receptor-positive your doctor may then discuss using an oral chemotherapy first. You and your oncology team will decide together on the best approach.

Should I take a single treatment or a combination?

Again, the answer to this question depends on many factors which are different for every person.

Generally, you and your doctor may decide to start with a single treatment first, before trying any combinations of treatments. This may be a good approach because one treatment usually causes fewer side effects than a combination of treatments. However, if your cancer is HER2-positive, you will always receive Herceptin®, as part of a combination treatment.

In some situations, your doctor may suggest a combination chemotherapy treatment, and they will discuss with you why it's appropriate for you at that time. Hormonal therapies can be just as effective, but changes in the size of the cancer may be more subtle.

Again, you and your oncology team will decide together on the best approach.

When should I switch from one treatment to another?

Your oncologist will most likely continue your current treatment as long as it is working and the side effects are manageable.

You may hear about newly available treatments that are very effective. This does not mean you should switch to them right away. They will be available if or when the treatment you're on stops working for you.

Remember, it's up to you to tell your health care team if you're experiencing unpleasant side effects or symptoms. Your doctors and nurses have no way of knowing how you're feeling on any given treatment if you don't tell them.

You may want to call your doctor or nurse to report side effects and not wait until your next appointment. This way you can have your concerns addressed in a timely manner and get recommendations that may be helpful. Most side effects can be controlled with strategies your oncology team recommends. However, if you are having severe side effects despite multiple attempts to relieve them, a particular treatment may not be the right one because it is seriously disrupting your quality of life.

Always tell your health care team how you're feeling and what level of discomfort you may be experiencing with treatment. Your doctors and nurses can help you weigh the benefits of the treatment versus any side effects it might be causing. Together you can determine if it's time for a different treatment.

How do I know when a treatment is working?

One of the toughest things about having metastatic breast cancer, aside from ongoing treatment, is the frequency of testing needed to keep track of the disease. Worrying about test results is a difficult part of having this disease.

There are different tests that are used to monitor metastatic breast cancer, including physical exams, blood tumor markers, X-rays, MRI, bone scans, CT (or CAT) scans and PET scans. Tumor markers measure different proteins in the blood which can sometimes indicate if a treatment is working. The reliability of these tests vary from patient to patient though and are only meant to be used with diagnostic tests and your doctor's clinical judgment.

You live from scan to scan and that's an unfortunate reality of the disease.

— Loretta

In addition to those tests, there are also newer diagnostic tests that doctors can use to monitor the level of cancer in your blood, and in some cases determine the effectiveness of a particular treatment. Ask your health care team if one of these diagnostic tests is appropriate for you.

Will I ever be able to take a break from treatment?

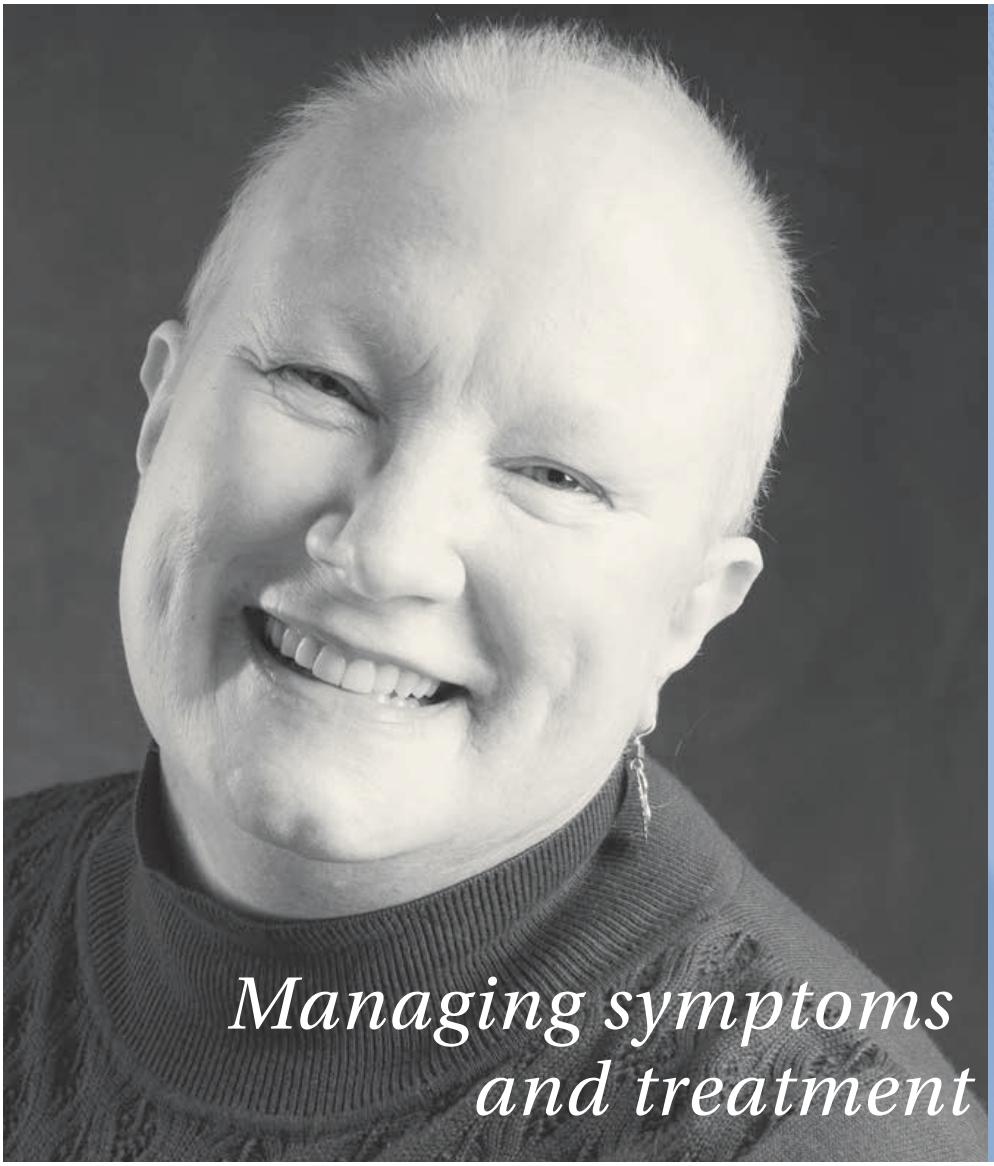
Treatment for metastatic breast cancer is generally continued as long as it's working to keep the cancer under control. In some cases your oncologist may decide to offer you a break from treatment, particularly chemotherapy, if your disease is well controlled and you are having troublesome side effects.

Even if your oncologist does not bring this up, it doesn't mean you can never take a break. Depending on the type of treatment, how long you've been on it, and how your cancer is doing, you may decide with your doctor to take off a few weeks or more. You might have a special vacation planned, an important family event to attend, or a milestone to celebrate. Or you might just want a little time without constant treatment and accompanying side effects.

If you feel you need or want a break from treatment, discuss the options with your doctor as soon as possible. Talking to your doctor in advance will make it easier to plan for breaks without too much disruption to your overall treatment plan.

IMPORTANT POINTS TO REMEMBER ABOUT DIAGNOSTIC TESTS

- Different tests can be useful in determining whether cancer is responding to treatment. Combining the information from CT and MRI scans with measurement of tumor markers in the blood, as well as other blood tests, can help give your health care team a complete picture that aids in planning the best treatment for you.
- Discuss with your doctor what tests are right for you. If you have any questions or doubts about the tests you're getting, or how the test results are interpreted, ask questions or get a second opinion.
- Get the support you need while waiting for test results. Waiting for results or getting the news that a treatment is no longer working can be an extremely stressful and upsetting time. Do you need time alone? Would this be a good time to find a support group or talk to a professional counselor? Do you need someone to be with you when you call or go in to the doctor's office for results? Let your loved ones know what would be most helpful to lower the anxiety and stress of waiting for test results.



Managing symptoms and treatment side effects

You don't have to go through pain and torture. There are things to do about different chemo side effects, and you should be assertive with your doctor so that you can get the right kind of care.

— Mary

CHAPTER 4 / MANAGING SYMPTOMS AND TREATMENT SIDE EFFECTS 37

Managing treatment side effects 40

Managing problems that could be side effects, the disease, or both 48

4 Managing symptoms and treatment side effects

When it comes to side effects, it's extremely important to relay everything you're experiencing to your doctor. There may be a solution or it may lend critical information for your care.

— Ginny M.

Knowing that you'll be receiving treatment for metastatic breast cancer for the rest of your life can be an upsetting thought, especially if you've had unpleasant side effects from treatment in the past. It can be frightening to read through long lists of potential side effects and symptoms. As tough as it may seem, try to remember that there is hope. Every individual has a unique response to treatment and every treatment has different side effects. You will not experience every side effect listed in this guide. If you have a side effect, your symptoms may be mild. It's important to know that there are things you can do that can help alleviate some of the symptoms of side effects.

Hair loss did not bother me a bit when it resulted from the adjuvant setting (Adriamycin five years ago). I almost looked at it as (presumed temporary) battle scars in the fight to rid myself of this disease. Now that I am in permanent treatment, it's tough dealing with something like hair loss as one never knows how permanent it will be.

— Kim

Here are some things to keep in mind to make the thought of ongoing treatment a little less distressing:

Advances in preventing or treating side effects are being made all the time. In the last few years, new treatments for nausea, diarrhea, inflamed throat, heartburn, hot flashes, and other common treatment side effects have been found. 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 probably won't have all the side effects or symptoms listed here. Reading about side effects can be overwhelming because the list may seem endless. Remember that the lists are long because they include every possible side effect for many different drugs. But most of the items on the list are not experienced by everyone who receives each treatment.

Your health care team is there to help manage your symptoms and side effects. Your health care team is available to help control your symptoms and side effects. Before treatment begins, ask if there are any proactive approaches to prevent side effects from occurring. Does your doctor or nurse recommend any strategies to decrease the severity of side effects if they do occur? Work with your team to develop a plan for managing and controlling any symptom or side effect that interferes with your daily life. This is not the time to be heroic and suffer in silence.

Your health care team expects you to report honestly on how you're feeling so they can make any necessary changes to help you feel better. It is important to discuss with your health care team any strategies you intend to use to manage side effects, particularly if they involve use of medications, including those purchased over the counter, herbal

or nutritional supplements, or visits to complementary or alternative health care providers.

You are not alone. Others have been through these treatments and some have probably experienced the same types of side effects that you may have. Support groups, hotlines and online message boards for people with metastatic breast cancer are great places to get practical advice from others who have found helpful ways to live well with metastatic breast cancer and cope with symptoms and side effects. If you do choose to use these resources, it is important to still remember that side effects and their severity vary from person to person.

Support is also available from your health care team. Oncology social workers, nurse navigators and hospital chaplains may be available to you at no charge.

TIPS FOR DEALING WITH SYMPTOMS AND SIDE EFFECTS

- When reading long lists of side effects, remember that not everyone experiences every side effect.
- You don't have to suffer in silence. Tell your doctors and nurses how you're feeling to get the best possible relief.
- If one treatment is causing unpleasant side effects despite multiple efforts to alleviate them, ask if you can take a break from it or try another.
- Talk to others who have had similar experiences.

CANCER SUPPORT HELPLINE
888-793-9355

CSC's toll free **Cancer Support Helpline** (1-888-793-9355) is here to help you or your loved ones. Staffed by licensed CSC Call Counselors available to assist you Mon-Fri 9 am-8 pm ET. Our Call Counselors have been specially trained to answer your questions and link you to valuable information.

MANAGING TREATMENT SIDE EFFECTS

Hair Loss

Some types of chemotherapy cause hair loss and some don't. You may have already experienced hair loss in the past and dread having your hair fall out again. Or you may be worried about having it happen for the first time.

Many report that the best way to deal with hair loss from chemotherapy is to be prepared. Ask your doctor or nurse if the type of chemotherapy you'll be receiving will cause your hair to fall out. If hair loss is expected, knowing when it will begin can help you prepare.

There are steps you can take so that when hair falls out, it won't feel as big of a change. You may want to consider getting a shorter haircut or shopping for a wig. While hair loss can be devastating, some women find their new hairstyles to be empowering. For example, women who have had "buzz" haircuts before chemotherapy have reported feeling a new lightness and freedom with their simpler and easier-to-manage hair. In planning ahead, you are more likely to experience a greater sense of control over hair loss and your overall cancer experience.

You can also feel prepared by selecting head coverings that feel comfortable. Some women prefer scarves, hats and turbans, while others choose wigs that match their previous hair color and style. Some women use this as an opportunity to be more creative and adventurous by selecting a wig that creates an entirely new look. Do whatever feels right to you.

The more you prepare for losing your hair, the easier it will be if and when it actually happens.

Nonetheless, when hair loss occurs, it is usually quite upsetting. Be kind to yourself and allow time and space to cope with this loss. Reach out for the support you need.

It may also help to know that wigs are often partially covered by insurance. If you are interested, ask your physician about a prescription for a "cranial prosthesis."

Nausea & Vomiting

Chemotherapy can cause nausea and vomiting. Even those drugs that are associated with nausea cause varying degrees of this particular side effect in different people.

Ask your doctor if the type of chemotherapy you'll be receiving is likely to cause nausea and/or vomiting.

If it is, or if you know from past experience that you're likely to feel nauseated after chemotherapy, there are many available treatments that may help prevent, reduce, or eliminate these side effects. Remember also that even if you had nausea and/or vomiting previously, your reaction this time may be different. Newer medications, not available at the time of your original diagnosis, may now be available to help control these symptoms.

There are several types of nausea resulting from chemotherapy and your doctor should order the anti-nausea medicines that work best for your treatment:

Acute nausea occurs within the first 24 hours after a chemotherapy treatment. You can get medication even before the chemotherapy is administered to help prevent or reduce this type of nausea. Effective treatments include, but are not limited to:

- Zofran® (ondansetron)
- Kytril® (granisetron)
- Aloxi® (palonosetron)

Some drugs given for acute nausea, like Aloxi, work for a long period of time (three to five days). This drug is a good choice if delayed nausea is anticipated.

These are often given in combination with a steroid medicine like Decadron® (dexamethasone), and sometimes with Ativan® (lorazepam), a drug that decreases anxiety. Emend® (aprepitant), a newer medication which helps prevent both acute and delayed nausea and vomiting, may also be given.

Your doctor may also prescribe anti-nausea medications for you to take at home after chemotherapy treatments. Compazine® (prochlorperazine), Zofran (ondansetron), and Reglan® (metoclopermide) are anti-nausea drugs that are often prescribed for use at home. In addition to these medications, which come in pill form, Zofran also comes in a dissolvable form that melts under the tongue. This can be helpful if you don't like to swallow pills or find you are too nauseous to swallow them.

Delayed nausea occurs two or three days after getting chemotherapy and can last for days or even weeks. There are several medications that can be effective in reducing or preventing this type of nausea:

- Emend® (aprepitant), a pill, is taken by mouth prior to and for several days after chemotherapy to prevent the onset of nausea. Emend® is also available in an IV form (fosaprepitant) to be taken prior to a chemotherapy treatment.
- Using gradually decreasing doses of a steroid medication like Decadron® for the first few days can help prevent delayed nausea.
- As with acute nausea, taking Compazine® (prochlorperazine) or Ativan® (lorazepam) at home can also help with delayed nausea.
- Zyprexa® (olanzapine), a medicine originally developed to treat different forms of mental illness, has been found to decrease nausea and increase appetite. It can also be helpful for treating low-grade nausea caused by liver metastases.

Anticipatory nausea can occur prior to a chemotherapy appointment. It may also be triggered by a certain odor you associate with your chemotherapy or radiation therapy appointments. Younger people are often more at risk for anticipatory nausea. Relaxation exercises including meditation

or guided visualization can help relieve symptoms associated with this type of nausea. If this type of nausea persists despite these techniques a medication for anxiety, like Ativan (lorazepam) is something that can also be helpful. Preventing nausea from the very beginning of chemotherapy treatment is the best way to avoid this problem. It's a good idea to talk to your doctor to make sure you are receiving the most appropriate anti-nausea medicines for your chemotherapy treatment.

There are also lifestyle changes and nutritional approaches that can help reduce or prevent nausea and vomiting. These include:

Eating smaller meals more frequently. Especially when you're at higher risk for feeling a little sick to the stomach, sitting down to a big, full dinner can be a daunting task. Smaller servings can seem more manageable and help reduce the nausea. Eating six small meals each day can help by reducing serving size and not allowing your stomach to ever get completely empty. An empty stomach may increase your chance for nausea in the first few days following chemotherapy treatment. Also, you may want to avoid cooking smells to reduce nausea.

Avoiding highly spiced and high-fat foods. These tend to increase rather than decrease nausea. Blander foods are better if you're feeling queasy.

Diarrhea

Some drugs used for breast cancer may cause diarrhea or watery stools due to irritation of the lining of the stomach or intestines. It is important to stay hydrated by drinking 8-10 glasses of fluid per day. Good fluids are water, Gatorade, or other fluids that contain electrolytes such as other sports drinks. It is important to avoid caffeinated drinks.

It may be helpful to modify your diet if you are experiencing diarrhea as well. Avoiding a lot of spices, diary, and fried foods may be helpful. Using a BRAT diet, or diet made up of bananas, rice, applesauce, and dry white toast is also suggested. It is important to check with your doctor before using any over-the-counter anti-diarrheal medications, like Imodium or Kaopectate.

During episodes of diarrhea the skin can become irritated or painful. Keep the rectal area clean and dry. You may also use A&D ointment to sooth and protect the skin. If you are taking any laxatives or stool softeners it is important to stop and call your doctor.

Mouth Sores

Some individuals on treatment develop painful areas or sores in their mouth as a result of their treatment. The development of these areas depends on many factors such as the type of treatment, any history of cold sores or oral herpes, and other potential sources of bacteria in the mouth. There is no specific way to prevent mouth sores, however using alcohol-free mouthwashes

and rinsing the mouth frequently does help to keep the area moist and healthy. If the sores in your mouth are painful or make you not want to eat or drink it is important to call your doctor.

Low Blood Counts (neutropenia and anemia)

Chemotherapy treatments cause the lowering of all blood cells, particularly the white blood cells that are part of the immune system. With lower white blood cell counts, you are at a higher risk for getting infections.

For this reason, it's extremely important that you let your doctor or nurse know right away if you develop a fever or other symptoms such as sore throat, burning with urination, or rash during chemotherapy treatment. This could be a sign of infection, and may require antibiotic medications. Early intervention for infections is important to try and prevent the need for a hospitalization.

There are medications—called growth factors—that can lower the risk of neutropenia with chemotherapy. Depending on the type of chemotherapy you receive and its risk for neutropenia, your doctor may recommend you take growth factor medications along with the chemotherapy.

Neulasta® (pegfilgrastim) 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 chemotherapy cycle. Neupogen® (filgrastim) is also a white cell growth factor, but it is given as an injection daily for approximately a week or until your white blood cells reach a safe level.

Chemotherapy, or sometimes the breast cancer itself, may also cause your red blood cell counts, or your hemoglobin, to become low. If your counts become very low it could cause symptoms such as fatigue, shortness of breath, or dizziness. Sometimes a blood transfusion can be helpful. If your red blood counts continue to be low despite blood transfusions your doctor may want to consider the use of a growth factor called Procrit® or Epogen® (erythropoietin) or Aranesp® (darbepoetin). This type of medicine helps stimulate the production of more red blood cells in your body.

NOTE: A warning was added to the labels of Procrit, Epogen and Aranesp in 2007, and updated in 2008, based on results from clinical trials. The warning says that this type of medicine "shortened overall survival and/or increased the risk of tumor progression or recurrence in some clinical studies in patients with breast, non-small cell lung, head and neck, lymphoid, and cervical cancers."

This does not mean that you can never take these medicines to increase red blood cell counts. It does mean that they must be used very cautiously. Talk to your doctor about the potential risks and benefits of taking this type of medicine. You may also be asked to sign a special consent form.

Cognitive Changes ("chemo brain")

Many people with metastatic breast cancer report experiencing what is commonly referred to as "chemo brain," one of the side effects of chemotherapy. Research has shown that chemotherapy treatment can affect how your brain functions, especially your short-term memory and sometimes concentration, as well as learning new information and multi-tasking.

Sometimes these are also signs of anxiety or depression, so it's important for you to talk to your doctor or nurse about them.

Unfortunately, there is no simple treatment to relieve these symptoms in the short-term. The good news is that: a) you're not alone in feeling this way—there is scientific evidence that you're not just imagining things, and b) there are things you can do to improve your memory and concentration. Some techniques that people find helpful for managing this side effect are to avoid distractions, write events down or post reminders, and maintain routines.

If you're having difficulty concentrating or remembering things and think it might be related to your treatment, talk to your doctor or nurse. This is a new area that researchers are investigating, so hopefully in the future we will know more about how breast cancer treatment affects brain functioning and how memory and concentration can be improved.

TIPS FOR IMPROVING MEMORY AND CONCENTRATION

- Make lists of important things to do
- Record your schedule in a personal 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 meditation practices

Neuropathy

Neuropathy occurs when chemotherapy damages the nerves, usually in the hands and feet. It may start with a tingling or numbness and can also develop into ongoing discomfort or pain. Neuropathy can also decrease your ability to sense temperature change.

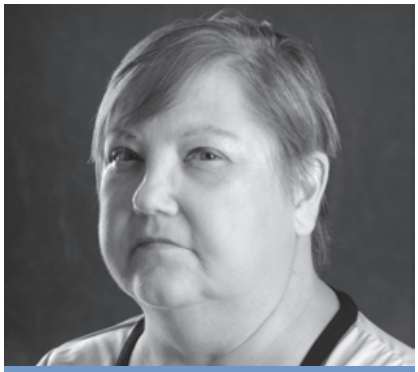
If you have trouble picking up small objects, opening jars, buttoning small buttons, doing computer work or have trouble feeling the ground when you are walking, you may be experiencing neuropathy.

Neuropathy tends to occur more with the taxane chemotherapy medications Taxol® (paclitaxel) and Taxotere® (docetaxel) than with other types of chemotherapy. It may also occur with platinum-containing chemotherapy medications Platinol® (cisplatin), Paraplatin® (carboplatin) and a type of chemotherapy called vinca alkaloids such as Navelbine® (vinorelbine).

So far, there are no treatments to reverse peripheral neuropathy (numbness, tingling, or burning in the fingers and toes), but there are medications that can help with pain and burning. These medications may include Lyrica® (pregabalin) or Neurontin® (gabapentin). If neuropathy goes on for a long period of time, it can become permanent.

If neuropathy becomes a problem for you, your doctor might suggest it is time to reduce your dose or take a break from chemotherapy. Tell your doctor right away if you feel tingling, numbness, or pain in your hands or feet. Early intervention is the key to reducing these side effects, preventing injuries such as burns or falls, and to feel better.

There are steps you can take to manage life better with neuropathy. If you are experiencing numbness in your feet, prevent falls by walking slowly, using handrails and wearing supportive shoes. If your hands are affected, be cautious when using sharp objects or when cooking. If you have trouble sensing temperature change, be careful with hot objects and hot water. Also, consuming alcohol—even in small amounts— can make neuropathy worse, so you may want to avoid it.



I experienced neuropathy. It was the weirdest feeling. I had to get used to driving and walking. With time, I learned to adjust to these changes.

— Loretta

Nail Changes

Some types of chemotherapy, particularly Taxotere® (docetaxel), can cause changes in fingernails and toenails. Nail changes can look like a fungus, with the nail becoming thicker and taking on a yellow or greenish color. It can get uncomfortable if the nail lifts up off the nail bed and keeps getting pulled away. And for some people the nail may completely fall off.

In most cases, nail side effects are not serious enough to warrant a break from the chemotherapy. But it can be so uncomfortable that you may need to find extra roomy shoes to avoid painful pressure on affected toenails.

If you're experiencing nail changes, be sure to check what the cause is before starting any type of fungal or other dermatological treatment. What looks like fungus may actually be a chemotherapy side effect.

A little humor about hot flashes (though they really are not funny!). I was teaching fourth grade during my first chemotherapy, and a little girl came up to me, she was the one designated to be the messenger, 'Mrs. Axler,' she seriously said, 'we had a conference with all the girls and we think you have malaria. In the Little House on the Prairie books, when they get hot and cold and sweat they have malaria. We think you should go to the nurse.'

— Susan

Hot Flashes

Some hormonal therapies cause more hot flashes than others, and some women are more sensitive than others. In general, women who take aromatase inhibitors (Arimidex®, Femara®, or Aromasin®) tend to report fewer or less severe hot flashes than women on Tamoxifen®.

For anyone experiencing uncomfortable hot flashes, the good news is that recent research has pointed to some effective ways of minimizing this unpleasant side effect.

Medications for easing hot flashes include:

- Antidepressants (for example, Effexor® (venlafaxine). When you take antidepressants for hot flashes, you usually take lower doses than the ones commonly used to treat depression. It is important to note that some studies suggest that the antidepressants Prozac® (fluoxetine) and Paxil® (paroxetine) can interfere with the activity of Tamoxifen and probably should not be used for hot flashes in women with breast cancer.
- The anti-seizure medication Neurontin® (gabapentin) has also shown promise in several clinical trials. Interestingly, one clinical trial has shown that the combination of an antidepressant plus Neurontin® does not seem to be better than Neurontin® by itself. So, if you find that antidepressants are not working, ask your doctor about switching to Neurontin®, and tapering off of the antidepressant.

With these medications, it's important to realize that it takes time before they begin working against hot flashes. Don't give up if your hot flashes don't go away in a few days. Wait approximately two weeks to see if they're working for you.

- Megace® (megestrol acetate) can be very effective in treating hot flashes, but may make them worse before they improve. Megace® is associated with a

risk for developing blood clots, as well as increased appetite and weight gain. For these reasons, your doctor may recommend other treatments first.

- The blood pressure medicine clonidine can decrease the sweating and rapid heart rate that sometimes accompany hot flashes. But it can make some women feel sluggish and lethargic. If your blood pressure is typically on the low side, this may not be an option for you.

Many claims have been made about various complementary or alternative therapies like black cohosh or phytoestrogens as treatments for hot flashes. So far, there has been little scientific evidence to support these claims. Additionally, phytoestrogens (products that mimic estrogen in the body) are not recommended for women with breast cancer.

ALWAYS tell your doctor if you want to try any alternative or complementary therapies.

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—this can help with many symptoms and side effects
- Deep, slow abdominal breathing techniques may decrease the severity of hot flashes
- Try acupuncture—some people find that this can help relieve a number of their symptoms; make sure you talk to your health care team first.

Sexual Side Effects

Sexuality can be an important part of who you are and how you relate to others. Many treatments for metastatic breast cancer may affect your sexual function, which can be difficult to face.

Hormonal treatments can cause vaginal dryness and/or discharge and can lower your libido. These are side effects that may be difficult to talk about—for both you and your doctor. Some doctors have little training or experience in discussing sexuality. As tough as it may seem, it is important for you to bring up sexual side effects that concern you with your doctor.

As with all side effects, you don't have to suffer in silence. If you don't want to tell your doctor, talk to your nurse about what you're experiencing and get helpful advice on how to make things better. Others going through the same treatment will probably have helpful tips as well. Remember to ask your doctor about any type of remedy or

treatment you might want to try as some remedies for vaginal dryness may include estrogen or progesterone which may be contraindicated because of your breast cancer.

In general, lubricants can help with vaginal dryness and make vaginal intercourse more pleasurable. Sometimes, your doctor might feel comfortable prescribing low dose vaginal estrogens if your symptoms are severe and they feel it is appropriate for you. The most important thing to do, however, is talk to your partner about how you're feeling, and work together on how to deal with times when you are or are not in the mood for physical intimacy. For information on enhancing intimacy, turn to page 60 of this book.

While metastatic breast cancer and its treatments can cause certain side effects, not everything you experience is necessarily related to your cancer and its treatments. Be sure to communicate with your health care team regularly about any health concerns you may have.

MANAGING PROBLEMS THAT COULD BE SIDE EFFECTS, THE DISEASE, OR BOTH

Most people with metastatic breast cancer experience some form of fatigue, which can have many different causes. Having breast cancer can decrease your energy and make you feel less energetic than you felt before cancer. Chemotherapy, hormonal therapy, targeted therapies and radiation therapy can all make you feel tired or weak. It is also possible that the psychological or emotional effects of living with metastatic cancer can cause fatigue and a reduction in your energy levels. Additionally, treatments used to minimize side effects like nausea or hot flashes can have their own side effects, including fatigue.

It's important to try to figure out what's causing the symptoms. If fatigue is related to treatment, and impacting your ability to perform your regular activities, you might be able to take a break or switch to another treatment. Together with your doctor you can discuss the best options for you.

After taking Xeloda® for a couple of months, I developed Hand-foot Syndrome. When I told my doctor, he suggested switching my treatments so that I could get the relief I needed. It's always a good idea to talk to your doctor about your side effects so that you can find the treatment that's right for you.

— Elaine L.

Fatigue & Insomnia

Fatigue is tiredness that interferes with your functioning and does not respond well to rest. When you're fatigued, you may have low energy, drowsiness, or just feel tired all the time. Many describe this differently, but almost everyone feels it at some time or another during breast cancer treatment.

It's often difficult to know if the fatigue is from the disease itself, from various therapies that you're taking for the disease, or from medications that may be used to alleviate symptoms or side effects.

If your red blood cell counts are low (a condition called anemia), you may be feeling tired because the cells in your body aren't getting enough oxygen. In this case, you may benefit from taking growth factors that help your body make more red blood cells to carry oxygen to your other cells. But this only works for fatigue caused by anemia. For more information on growth factors, see p. 43.

Whatever the cause of the fatigue, there are lifestyle changes you can make to improve your energy levels and participate in the activities that are most important to you:

- **Recognize your limitations.** 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 household chores or grocery shopping, ask your family, friends, neighbors, or support group members for help with these things so you can take care of yourself and save your energy for more meaningful activities.
- **Try to get a little bit of exercise every day.** One of the most effective approaches to preventing and treating fatigue is exercise. Doing regular exercise, such as walking, yoga, or tai chi can help prevent and manage fatigue during treatment. Talk to your doctor or nurse before beginning an exercise program. Remember that fatigue can be caused by doing too much as well as too little. Keeping a balance is important.

When I found out about my cancer diagnosis, I started feeling anxious and irritable. I can't do the same things I used to be able to do, and this was tough for me to accept. My doctor told me I was experiencing symptoms of depression. I started taking medication to relieve my symptoms, and it's really helped. It's truly important to keep your doctors up-to-date on how you're feeling throughout your cancer experience so you can get the help you need.

— Madeline

Depression

Fatigue and insomnia (not being able to fall asleep) can also be related to depression – a psychological condition associated with mood changes and feelings of sadness and crying. There are some very effective treatments for depression that may help to improve your energy level and quality of life.

Here are some questions to ask yourself and discuss with your doctor to figure out if your fatigue or insomnia may be related to 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?
- Or 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 p. 57.

Pain

One of the symptoms of metastatic breast cancer, as well as a side effect of some treatments, is pain. The most important thing to remember is that you do not have to suffer from pain in silence! There are many effective ways to manage pain, and your health care team can help find the best pain management treatments for you.

Many people with cancer are fearful of getting addicted to pain medicines, or worry that pain medicines won't work later if they use them early on. These are both misconceptions. It is important to treat pain effectively, since untreated pain can lead to fatigue and 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.

For many people, it helps to have two different pain medicines:

1. **Long-acting pain medicine** ensures that there's some pain medicine in the body all the time, and
2. **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, and different types and combinations work best for different people.

If you are experiencing pain, talk to your doctor about effective treatments that can help to relieve symptoms.

Bone Loss and Bone Metastases

Significant bone loss or bone weakness may be the result of cancer that has spread to the bone. Bone loss can also be caused by some types of breast cancer treatment, especially the hormonal treatments called aromatase inhibitors (see p. 22). Early menopause brought on by surgical or medical treatments may also cause bone loss.

Not all metastatic patients are followed with bone density testing. If you're taking an aromatase inhibitor, your health care team may monitor your bone health with tests called DEXA scans. They will recommend that you take in enough calcium and vitamin D, either in your diet, or with the addition of calcium supplements. Depending on the results of your DEXA scan, your health care team may also recommend that you take a bone strengthening medicine or that you avoid certain activities with a high risk of injury, like skiing or horseback riding.

If you have metastatic cancer in your bones, your doctor may also want you to take a bone strengthening medication called Zometa® (zolendronic acid) or Xgeva® (denosumab). These medications help prevent the bones from losing calcium and decrease the risk of fractures. A different kind of scan will be done to assess your response to treatment and to be sure there is no risk for fracture.

If tests show that you have a fracture or that certain bones are at a high risk for fracture, there are procedures that can be used to strengthen the bones from the inside. In some cases radiation therapy may be used or a treatment by an international radiologist called kyphoplasty may be performed. In this procedure a type of cement is injected into weak or fractured bones to strengthen them.

Talk to your doctor if you have questions about managing bone loss and bone metastases. See the next page for potential drugs you may be prescribed to help.

TABLE 4 / TREATMENTS FOR MANAGING SIDE EFFECTS AND THE DISEASE

ISSUE	POSSIBLE CAUSE/S	TREATMENT AND/OR PREVENTION OPTIONS
Acute nausea and/or vomiting	• Chemotherapy	• Zofran® (ondansetron) • Aloxi® (palonosetron) • Decadron® (dexamethasone) • Ativan® (lorazepam) • Kytril® (granisetron) • Emend® (aprepitant) • Compazine® (prochlorperazine)
Delayed nausea and/or vomiting	• Chemotherapy	• Emend® (aprepitant and fosaprepitant) • Decadron® (dexamethasone) • Zyprexa® (olanzapine)
Hot flashes	• Hormonal treatment • Treatment-Induced Menopause	• Effexor® (venlafaxine) • Neurontin® (gabapentin) • Clonidine • Paxil® (paroxetine) • Megace® (megestrol acetate)
Low red blood cell counts	• Chemotherapy	• Procrit® (erythropoietin) • Aranesp® (darbepoetin) • Epogen® (erythropoietin)
Low white blood cell counts	• Chemotherapy	• Neupogen® (filgrastim) • Neulasta® (pegfilgrastim)
Fatigue	• Anemia from chemotherapy • Chemotherapy • Other treatments • The cancer itself	• Procrit® (erythropoietin) • Aranesp® (darbepoetin alfa) • Epogen® (epoetin alfa)
Depression or distress	• Some treatments • Stress of cancer and its treatment	• Antidepressant medications • Anti-anxiety medications • Cognitive therapy
Pain	• Chemotherapy, radiation • The cancer itself	• Nonsteroidal anti-inflammatory drugs (NSAIDs) • Opioids
Bone loss	• Hormonal treatment	• Bisphosphonates (Aredia®, Zometa®) • RANK Ligand Inhibitors (Xgeva®)

Quality of life considerations

When you have cancer, you don't focus on what's happened. Rather, you look forward to what is to come and what will be – that's called survival.

— Madeline

CHAPTER 5 / QUALITY OF LIFE CONSIDERATIONS 53

Is a support group right for you? 55
Depression and emotional distress 57
Relationships 58
Young women and metastatic breast cancer 58
Sexual intimacy 60
Helping children and teens cope 61
Managing career and financial concerns 62
Planning for end-of-life 63
Cancer Support Community's resources for support 66

5 Quality of life considerations

When you learn that other women have metastatic breast cancer, it feels comforting to know that there are others with the same burden; you are not alone.

— Ginny M.

One of the hardest things to face when you're diagnosed with metastatic breast cancer is the overwhelming mental and emotional turmoil you may be experiencing. Who can you turn to for help in dealing with your fears, worries, anger, despair and other difficult feelings?

The answer is different for every person, but there's one thing that's the same for everyone: You need help now, and you deserve to be helped and supported.

For many women, it can be especially difficult to ask for help because women often find themselves in the helping and supporting roles.

In addition, when the people who rely on you are faced with your diagnosis, they may get scared or angry themselves. They may resent the fact that you're not as available for them, they may become paralyzed with fear and be unable to help, or they may try to deny that there's anything really wrong with you.

You need to find those people who are able to be there for you when you need them. It might be family members or close friends. Or it might be neighbors, co-workers, or casual acquaintances who offer a helping hand, an ear to listen or shoulder to cry on.

Many people find professional therapists, religious counselors, support groups and help lines to be good sources of comfort and advice, especially for dealing with the initial shock of diagnosis. For a list of organizations that offer support, see pp. 67-68.

Religious faith and/or spirituality can be another great source of comfort for many people.

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.

The key word for me is faith. You must believe in something or someone, so have faith in God.
— Geraldine

TO ACCESS SUPPORT YOU CAN:

- Talk one-on-one with an oncology social worker, therapist, or spiritual advisor
- Attend religious services
- Participate in a face-to-face metastatic breast cancer support group
- Participate in online chat groups and discussion boards
- Advocate for support, services and research to help people living with metastatic breast cancer
- Talk to friends or family members with whom you feel comfortable
- Keep a journal
- Exercise your mind and body through meditation or yoga

Contact the **Cancer Support Community, Living Beyond Breast Cancer, Metastatic Breast Cancer Network**, or **Young Survival Coalition** listed in the back of this booklet to access some of these services; or ask your doctor, nurse or social worker to connect you with support services in your area.

IS A SUPPORT GROUP RIGHT FOR YOU?

Support from others who are dealing with metastatic disease, or even dealing with other types of cancer, can be a true source of comfort, strength and hope.

Over the last 25 years, research has shown that support groups help reduce the three most significant stressors associated with cancer: *unwanted aloneness, loss of control and loss of hope*. Research conducted at the Cancer Support Community has shown that people in support groups, either in person or online, report a decrease in depression, an increased zest for life, and grow a new attitude toward their illness. Support groups can help you deal with depression and anxiety. Some people say that support groups help them with the trauma they feel from their diagnosis, as well as with managing pain.

In the Living Beyond Breast Cancer surveys of nearly 750 women living with metastatic breast cancer (2005 and 2008), 77% of the women said they felt that support groups were important to them. These women said they went to support groups, either in person or online, in order to:

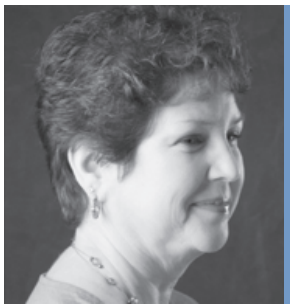
- Learn about the experiences of others
- Get information and emotional support
- Feel less alone
- Get help managing side effects and anxiety
- Find out about available resources

Family and friends don't always know what to say. They're there and they care but they don't always know what to do. I get a lot of support from groups like this, helping other women who are trying to navigate life with metastatic disease. We all understand what it's like.

— Elaine B.

Join a patient advocacy group such as **Metastatic Breast Cancer Network** whose mission is to raise awareness of how metastatic breast cancer differs from early stage disease, to educate patients to become their own best advocates and to work for more metastatic research and treatments to make metastatic breast cancer a truly chronic disease like HIV-AIDS or diabetes. Visit Metastatic Breast Cancer Network at *www.mbcn.org*

There are different kinds of support groups that might help you. Some are mixed diagnosis and include individuals dealing with different types of metastatic cancer. Other support groups might be only for women with metastatic breast cancer. Some people with metastatic disease who turn to support groups for help find that if the group is not intended specifically for participants with metastatic breast cancer, it may not be as helpful to them. By trying out different support groups, you can find what is most comfortable for you. If you are unsure of what support group may be a good fit for you, it may be helpful to speak with a social worker or the group facilitator before joining. They may be able to match you with a group that has the right dynamic for you.



It's so important to turn to your family and friends and to let them know how you're feeling. You can't do everything. You're not Super Woman anymore.

— Karen

In addition to face-fo-face support groups, people may prefer to access support over the phone. Online support groups are also available and have been shown to help people with breast cancer reduce their depression and cope with pain. An online support group might be a good option for you if you prefer being online rather than face-to-face, if you do not feel well enough to go to a face-to-face group, or if you live in an area where there are no face-to-face support groups. Web sites with discussion boards or listservs dedicated to women with metastatic disease can also be a great source of support for women with this disease.

For more information and support contact **Living Beyond Breast Cancer** at *www.lbbc.org* or call 888-753-5222.

DEPRESSION AND EMOTIONAL DISTRESS

When you find out you have metastatic breast cancer, it is normal to feel shocked or alone or to feel a sense of despair.

Sometimes crying and expressing your sadness can be enough to get you through the tough emotions that can come with a diagnosis of metastatic breast cancer. But sometimes you may feel so bad that you lose interest in the things that used to make you happy. You may feel like staying in bed all day, and stop reaching out to friends and family.

If you start feeling this way, you may be suffering from depression. It's important to know that some people feel depressed for the first time after a diagnosis of cancer, while others arrive at cancer with a history of depression. Many people with metastatic cancer face some sort of emotional distress. Depression and emotional distress can make it difficult for you to cope with symptoms and treatment, and can seriously affect your quality of life. Thankfully, there are many effective treatments for this condition.

The first and most important step in treating depression is to acknowledge it and to ask for help. See p. 50 for a list of some questions to ask yourself and discuss with your health care team to see if you may be depressed.

Important points to remember about depression:

- **It's important to tell your doctor if you have feelings of depression and emotional distress.** Your health care team is there to help you cope with these feelings, and to do everything they can to help maintain the best possible quality of life for you.
- **Getting treated for depression can make a huge difference in your quality of life.** Treating depression will make it easier for you to deal with cancer, and will allow you to rediscover joy and pleasure in your everyday life.

TIPS TO COPE WITH DEPRESSION

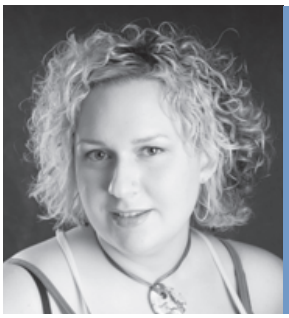
- Talk openly to trusted friends and family members about your feelings and fears.
- Make an appointment with a counselor, therapist or psychiatrist to help cope with your thoughts and feelings.
- Ask your doctor about medications that can help.
- Focus on living in the moment.
- Use relaxation techniques such as deep breathing to reduce your body's release of hormones that may trigger a sensation of anxiety.

RELATIONSHIPS

A diagnosis of metastatic breast 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 are often positive ones, representing an ongoing evolution in the way you and your loved ones relate and communicate with one another.

One of the most important things you can do to sustain and nurture those meaningful relationships is to communicate with your family and friends about how you're feeling. Tell them honestly about your diagnosis, how the disease and treatment might be affecting you, and how they can and cannot help you.

YOUNG WOMEN AND METASTATIC BREAST CANCER



One of the toughest things about being young and living with this disease is dealing with the body image issues that come along with it. I felt horribly disfigured after having a bilateral mastectomy. It's been tough adjusting to my new body.

— Jordan

Women of all ages, including young women, are affected by metastatic breast cancer. Breast cancer accounts for almost 15% of all cancers in people ages 15-39 years old. Compared to older women, when a young woman is diagnosed with breast cancer, it is more likely to be in the advanced stage or will likely recur.

Due to their phase in life, young women encounter certain issues surrounding relationships, fertility, and sexuality, that may not be as relevant or as powerful in older women. For young women, who may be thinking of starting a family or entering a romantic relationship, the side effects of certain cancer treatments can be devastating.

Side Effects of Cancer Treatment Include:

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

However, there are actions you can take that may help minimize or even prevent some of these potential side effects. There are vaginal lubricants and dilators that can aid in making sexual intercourse more comfortable and pleasurable.

As a result of these difficult transitions, the quality of life of many young women with metastatic breast cancer can often be negatively impacted. In turn, it is normal to experience feelings of sadness, grief, and loneliness. However, it can be helpful to know that there are many other women who are going through a similar experience. In a 2011 CSC and YSC-sponsored survey of 90 young women with metastatic breast cancer, over 60% of participants reported the following concerns:

- managing changes in sexuality
- managing fatigue and sleep habits
- maintaining health during and after treatment
- parenting during treatment and childcare

In addition, almost half of participants indicated a desire to connect with other young women with metastatic breast cancer.

To connect with other young women living with metastatic breast cancer, contact **Young Survival Coalition** at *www.youngsurvival.org* or call 877-972-1011.

When I was diagnosed with metastatic breast cancer at 28, my doctor advised me to join a support group. So I told myself I would go and try it out. When I walked in the room, it was full of older women. And here I am at 28, walking in and they said, 'What are you doing here? You're too young.' I really wanted to connect with other women my age, and eventually found the Young Survival Coalition, which has been great.

— Amanda

SEXUAL INTIMACY

Sexuality is closely linked to who you are, how you feel about yourself, and how you relate to others. Maintaining a healthy sexual identity is important to ensuring a good quality of life.

A diagnosis of metastatic breast cancer is likely to bring up questions for you about your sexual well-being and intimate relationships. Be sure to bring up any questions or concerns you have about your body and related sexual function when working with your health care team. As uncomfortable as it may be, it is important to communicate your feelings or concerns about your sexual relationship with your partner. Sometimes, these conversations can be highly beneficial, resulting in strengthened intimacy and a sense of closeness between couples. Some people find couples therapy or sex therapy to be helpful in strengthening relationships and enhancing sexual intimacy.

Remember that sexuality is more than intercourse. It comprises all the feelings and actions associated with loving and caring for someone. If you are experiencing challenges with sexual intercourse, find other ways to be sexual—use your imagination and be creative! Gentle touching, holding hands, kissing, and hugging are just some of the ways you can express love and be intimate. If you still struggle with intercourse due to side effects of your treatment or other challenges in connecting with your partner you should speak with your physician or nurse. There are specialists who may be able to help you manage these challenges.

> *One of the hardest side effects for me to deal with is being intimate with my now fiancé. I never thought I would lose that part of me. It's tough.*
>
> — Amanda

FOR MORE INFORMATION ON SEXUAL INTIMACY PLEASE VISIT:

- **LBBC's Guide to Understanding Sex and Intimacy**
  www.lbbc.org/Understanding-Breast-Cancer/Guides-to-Understanding-Breast-Cancer
- **NCI's Sexuality and Reproductive Issues Page**
  www.cancer.gov/cancertopics/pdq/supportivecare/sexuality
- **Sexual Health**
  www.sexualhealth.com
- **fertileHOPE**
  www.fertilehope.org
- **Pure Romance**
  www.pureromance.com

HELPING CHILDREN AND TEENS COPE

If you have children, you are likely to question what you should and should not tell them about your cancer diagnosis. You may think it's a good idea not to talk much about your cancer with your children, to protect them from emotional upset. However, keeping cancer a secret often causes more harm than good. Children are often much more intuitive than we realize, even at a young age; they may overhear telephone conversations, pick up their parents' anxiety, blame themselves, and fear the worst if they are given misinformation or no information at all.

For more information on talking with children and teens about cancer, visit **CancerCare** at *www.cancercare.org* or visit **Group Loop** at *www.grouploop.org*, Cancer Support Community's online community for teens affected by cancer.

TIPS FOR COMMUNICATING WITH CHILDREN

- **Accurate, age-appropriate information about cancer is very helpful for your children.** It's okay to use the word "cancer" and to tactfully tell them where the cancer is located on your body. Be sure to clarify with your children that cancer is no one's fault.
- **Provide concrete information about how your cancer treatment plan may affect your children's lives.** Tell your children if any changes in your day-to-day roles and responsibilities may be expected, or if they should expect changes in their schedule as well. Also, you may want to prepare your children for any anticipated physical changes that may result from your treatment (i.e. hair loss, weight loss, etc.)
- **Allow your children to participate in your care.** Give them age-appropriate tasks such as bringing you a glass of water or an extra blanket.
- **Reassure children that they will be taken care of.** With the impact of a cancer diagnosis on a family, it is important to reassure children that they are loved, supported and cared for.

If you have teenage children, consider that adolescence marks a period of exploration and self-discovery. Teens often strive to become more independent from their family, and indirectly, may feel isolated, anxious, or possibly self-conscious if they have a parent or guardian who has cancer. When talking with teens about your cancer diagnosis, it is important to acknowledge their feelings and reassure them that they are not alone.

MANAGING CAREER AND FINANCIAL CONCERNS

Getting the support you need, finding a good health care team, and deciding on a treatment plan are all important tasks when you're diagnosed with metastatic breast cancer. But for many people, even with good support and medical care, an over-arching concern remains: What will all of these treatments cost? What if you have to stop working? How will you secure continuing health insurance coverage? What if you don't have health insurance? How will your treatments be covered?

Three 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. Also, under the ADA, if you are still able to perform the essential functions of your job, your employer is obligated to make reasonable accommodations for you, such as 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, and allows you as the person with cancer as well as family members to take up to 12 weeks of unpaid leave with health insurance. There is also intermittent FMLA which allows you to take additional days off as needed for treatments or physician appointments if you have a chronic medical condition while still protecting your job.
- **Vocational Rehabilitation Act of 1973** ensures that people with cancer may be eligible for 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 the enforcement of these laws is the **Equal Employment Opportunity Commission (EEOC)**. If you have any questions about legal protections in the workplace, they have a toll-free number that many people find very helpful: 800-669-4000.

Women with metastatic breast cancer may also receive disability benefits from **Medicare** (if you're over 65) and/or the **Social Security Disability Insurance (SSDI)** program. See p. 67 for contact information.

In addition, there are advocacy groups that offer legal and financial help for people with breast cancer. You'll find a list of these on p. 67.

For more information about managing the financial challenges of a cancer diagnosis, order a free copy of Cancer Support Community's *Frankly Speaking About Cancer: Coping with the Cost of Care*, by visiting *cancersupportcommunity.org*

PLANNING FOR END-OF-LIFE

End-of-Life Legal Plans

At some point during your cancer treatment, it is natural that you may question and consider your end-of-life plans.

Ensuring that legal documents exist, including a will, a living will (advanced directive), and a power of attorney, will help to maintain a sense of control and provide peace as you live with cancer. Note that in some cultures, oral communication about end-of-life wishes takes precedent over the written word.

Here are some key documents that you may want to consider preparing to guarantee that your end-of-life wishes are honored.

Living will or advanced directive — a document that details your wishes about medical treatment if a time should come when you can no longer express those wishes. Most states honor a living will prepared in advance; however, the laws related to living will vary by state.

Medical power of attorney — a document that allows you to appoint a trusted person to make decisions about your medical care if you cannot make decisions yourself. In many states, the person you appoint is authorized to speak for you any time you are unable to make your own medical decisions, not only at the end of life.

Financial power of attorney — this document identifies a trusted person who is able to make financial decisions and payments for your health care needs in the event you are unable to do so yourself. It is often suggested that your medical and financial power of attorney are different people to ensure that there are no potential conflicts of interest in making decisions about your care or needs.

Do Not Resuscitate (DNR) Order — an order that your doctor writes on your chart if you determine you do not want "heroic measures" taken in the event of a cardiac or respiratory arrest. This means that if you stop breathing or your heart stops working and you aren't revived right away, you do not want to be hooked up to 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.

Think carefully about who is most likely to follow the wishes you express in an advanced directive. Sometimes a spouse or close family member is too emotionally involved for this responsibility. Discussing these decisions with close family members, supportive friends, spiritual advisors, and health care providers will minimize confusion and help everyone involved feel more comfortable with whatever decisions they make.

Be sure your medical power of attorney or proxy has access to the signed directives and that your oncologist has a copy as well.

What End-of-Life Means to You

Living with metastatic breast cancer can lead you to think about what end-of-life means to you. Some people find it helpful to plan and communicate their wishes with their loved ones. People often anticipate what they might need and want to achieve in the weeks, months, or years ahead. Open and honest communication with your doctor and your family can help you to maintain control over this time and provide you the opportunity to accomplish certain goals, or put closure on matters that might give you a sense of peace.

Some people participate in writing about their cancer experience, which is called "legacy writing" or videotaping their story, as a way to carry on their legacy. These exercises may be able to help you and your loved ones cope with your cancer journey.

Resources that provide support with legacy writing and videotapes include:

- **Life Chronicles**
  Lifechronicles.org
- **Life with Cancer**
  Lifewithcancer.org

Hospice

Hospice care is one of the most useful resources that can provide care and comfort to people affected by cancer at the end-of-life. Hospice care can be provided in your home, or at a designated Hospice facility, with specially trained nurses 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. There are many misconceptions about what Hospice is, when it should be discussed, and what it is for. Asking your health care team about Hospice early in your treatment is important to understanding when and how it may be a useful part of your care.

I have an eight-year-old granddaughter and I don't really know how much to tell her and what not to tell her. She gets worried about me. Sometimes she says, 'I don't want you to die, I want you to live a long time.' And then yesterday, she said 'Well, when you are in a wheelchair, I will bring a puppy dog in to sit on your lap.' She said, 'You will like that, won't you?'

— Rose

Our lives change all the time. The difference between the good changes and the bad changes is choice. We weren't given the choice. But once you know this part of your life, you have to stay strong and say, Okay, this is what I'm going to do. Maybe you can't do something that you used to be able to do. Maybe there's something that you've never tried, and you've got to go for it. You may fail. But it brings everything into focus. What's important, and what's not important.

— Jordan

CANCER SUPPORT COMMUNITY'S RESOURCES FOR SUPPORT

Cancer Support Community's resources and programs below are available at no charge.

Cancer Support Helpline®

CANCER SUPPORT HELPLINE 888-793-9355

Whether you are newly diagnosed with cancer, a long-time cancer survivor, or are caring for someone with cancer, CSC's TOLL-FREE Cancer Support Helpline (1-888-793-9355) is staffed by licensed CSC Call Counselors available to assist you Mon-Fri 9 am-8 pm ET. Our Call Counselors have been specially trained to answer your questions and link you to valuable information.

Affiliate Network Services

Over 50 locations plus more than 100 satellites around the country offer on-site support groups, educational workshops, yoga, nutrition, and mind-body programs specifically designed for people affected by cancer. For a full list of affiliate locations, visit the Cancer Support Community website or call us at 1-888-793-9355.

Open to Options™

Open to Options

Free one-on-one decision counseling is available with licensed mental health professionals who can help you process information about your situation, and formulate a list of specific questions for your oncologist. Appointments can be made by calling 1-888-793-9355 and by visiting the CSC website to contact an affiliate providing the Open to Options service.

Cancer Experience Registry

CANCER EXPERIENCE REGISTRY
METASTATIC BREAST CANCER

The Cancer Experience Registry is designed to help people impacted by cancer, particularly those living with metastatic breast cancer, to share their story, to learn about the experiences of others and to help transform the cancer experience. People who participate are connected to a network of support and resources. Findings from the Registry help us all better understand the social and emotional needs of people living with cancer and improve the ways in which care is delivered. Join today at *CancerExperienceRegistry.org*.

The Living Room, online

Cancer Support Community's "The Living Room" offers much of the same programming available at each CSC affiliate. On CSC's website you will find online support groups, discussion boards and social networking, "build your own website" services, and education materials.

To access these services, visit *www.cancersupportcommunity.org*

These services are made available with generous contributions from CSC supporters.

Resources and glossary

It's important to believe in yourself and to make the right decision for you at the moment.

— Judit

CHAPTER 6 / RESOURCES AND GLOSSARY 67

Resources 67

Guide to medical terms 69

6 Resources and glossary

RESOURCES

Help with Financial & Legal Concerns

The Air Care Alliance
888-260-9707
www.aircareall.org

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

CancerCare
800-813-4673
www.cancercare.org

Centers for Medicare and Medicaid Services
800-633-4227
www.cms.gov

Corporate Angel Network
866-328-1313
www.corpangelnetwork.org

Disability Rights Legal Center
866-843-2572
www.disabilityrightslegalcenter.org/cancer-legal-resource-center

Equal Employment Opportunity Commission
800-669-4000
www.eeoc.gov

Healthcare.gov
www.cms.gov

LawHelp.org
www.LawHelp.org

National Breast Cancer Coalition and Fund
800-622-2838
www.breastcancerdeadline2020.org

National Coalition for Cancer Survivorship
888-650-9127
www.canceradvocacy.org

Needymeds
800-503-6897
www.needymeds.org

Partnership for Prescription Assistance
888-477-2669
www.pparx.org

Patient Access Network
866-316-7263
www.panfoundation.org

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

Patient Advocate Foundation Co-Pay Relief
866-512-3861
www.copays.org

Survivorship A-Z
www.survivorshipatoz.org/cancer

U.S. Social Security Administration
800-772-1213
www.ssa.gov

Resources & Support

Advanced Breast Cancer Community
www.advancedbreastcancercommunity.org

AdvancedBC.org
www.advancedbc.org

American Cancer Society
800-227-2345
www.cancer.org

BCMets.org
www.bcmets.org

BreastCancer.org
www.breastcancer.org

Cancer Support Community
888-793-9355
www.cancersupportcommunity.org

FORCE: Facing Our Risk of Cancer Empowered
866-824-7475
www.facingourrisk.org

IBC Support
www.ibcsupport.org

Imerman Angels
312-274-5529
www.imermanangels.org

LIVESTRONG Foundation
855-220-7777
www.livestrong.org/cancersupport

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

malecare
212-673-4920
www.malecare.org

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

Susan G. Komen®
877-465-6636
http://ww5.komen.org/Default.aspx

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

Clinical Trial Information

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

Cancer Support Community's Clinical Trials Matching Service
800-814-8927
www.cancersupportcommunity.org

National Cancer Institute
800-422-6237
www.cancer.gov/clinicaltrials

GUIDE TO MEDICAL TERMS

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.

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 – 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.

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.

CT (computed tomography) 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 computed axial tomography (CAT) scan.

Duct – In medicine, a tube or vessel of the body through which fluids pass.

Growth factor – A substance made by the body that functions to regulate cell division and cell survival. Some growth factors are also produced in the laboratory and used in biological therapy.

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 – Breast cancer cells that have the expected amount of the HER2/neu protein.

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

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

Hormone receptor-positive – Breast cancer cells that grow in the presence of the hormones estrogen or progesterone.

Immune system – The complex group of organs and cells that defends the body against infections and other diseases.

Insomnia – Difficulty in going to sleep or getting enough sleep. Insomnia is a potential side effect of some breast cancer treatments.

Metastasis – 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.

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).

No evidence of disease – 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 – 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.

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

PET (positron emission tomography) 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.

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.

Tai chi – A form of traditional Chinese mind-body exercise and meditation that uses slow sets of body movements and controlled breathing. Tai chi is done to improve balance, flexibility, muscle strength, and overall health.

Tumor markers – Measure different proteins in the blood which can sometimes indicate if a treatment is working. Examples of tumor markers include CA-125 (ovarian cancer), CA-15-3 (breast cancer) and CEA (ovarian, lung, breast, pancreas, and gastrointestinal tract cancers). Also called biomarker.

CONTRIBUTORS & EDITORS

Erica Fischer-Cartlidge, MSN, RN, CBCN
Clinical Nurse Specialist
Memorial Sloan-Kettering Cancer Center

Lidia Schapira, MD
Gillette Center for Breast Cancer
Massachusetts General Hospital
Associate Professor of Medicine
Harvard Medical School

Jen Sinclair, LPC
Program Director
Cancer Support Community Greater Lehigh Valley

George W. Sledge, Jr., MD
Professor of Medicine and Pathology
Chief of Oncology
Stanford School of Medicine

DESIGN AND PHOTOGRAPHY

Erin Haslinger Design
Suzanne Kleinwaks Design
Jason Gardner Photography
Laurie Beck Peterson Photography
Bridgett Thompson Photography

A special thanks to the Cancer Support Community of Central New Jersey for hosting a focus group and photo shoot.

Cancer Support Community's *Frankly Speaking About Cancer: Metastatic Breast Cancer* program consists of this educational booklet, a clinically facilitated workshop and online content, at no cost. To order this book or other free materials of the highly acclaimed *Frankly Speaking About Cancer* series, please visit our website at **www.cancersupportcommunity.org** or call us toll-free at **888-793-9355**.

Cancer Support Community

The mission of the Cancer Support Community (CSC) is to ensure that all people impacted by cancer are empowered by knowledge, strengthened by action and sustained by community. In 2009, The Wellness Community and Gilda's Club joined forces to become the Cancer Support Community. The combined organization, with more than 50 years of collective experience, provides the highest quality social and emotional support for people impacted by cancer through a network of more than 50 licensed affiliates, over 100 satellite locations and a vibrant online community, touching more than one million people each year.
www.cancersupportcommunity.org | 888-793-9355

Living Beyond Breast Cancer

To connect people with trusted breast cancer information and a community of support. The goal of LBBC is to help women take an active role in their ongoing recovery or management of the disease, regardless of stage of disease, educational background, social support, or financial means.
www.lbbc.org | 888-753- 5222

Metastatic Breast Cancer Network

The Metastatic Breast Cancer Network (MBCN) is a national, independent, patient-led, nonprofit advocacy group dedicated to the unique concerns of the women and men living with metastatic breast cancer. We strive to help those living with stage IV breast cancer be their own best advocate through providing education on treatments and coping with the disease. MBCN is fighting for treatments to extend life making metastatic breast cancer a truly chronic disease, as the search for the cure continues.
www.mbcn.org | 888-500-0370

Young Survival Coalition

Young Survival Coalition (YSC) is the premier global organization dedicated to the critical issues unique to young women who are diagnosed with breast cancer. YSC offers resources, connections and outreach so women feel supported, empowered and hopeful.
www.youngsurvival.org | 877-972-1011

CANCER SUPPORT COMMUNITY
A Global Network of Education and Hope

Cancer Support Community and our 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 another health care professional to answer questions and learn more.

© 2013 Cancer Support Community. All rights reserved.

LIVING BEYOND BREAST CANCER LBBC.ORG

mbcn METASTATIC BREAST CANCER NETWORK
EDUCATING • EMPOWERING • ADVOCATING

YSC YOUNG SURVIVAL COALITION
Young women facing breast cancer together.

THIS PROGRAM WAS MADE POSSIBLE WITH CHARITABLE CONTRIBUTIONS FROM:

Celgene

Eisai

NOVARTIS ONCOLOGY

People with cancer who actively *participate* in thei
care along with their health care team will *improve*
quality of *their lives* and may enhance the possibili
recovery. People with cancer who *actively* participa
their care along with *their health* care team will im
the *quality* of their lives and may *enhance* the poss