Fourth Edition

Advanced Breast Cancer

A TREATMENT GUIDE FOR PATIENTS AND THEIR FAMILIES

WHERE INFORMATION EQUALS HOPE

Published in partnership with AVON BREAST CANCER CRUSADE

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CHANGING THE LIVES OF BREAST CANCER PATIENTS AND THEIR FAMILIES

Since 1992, the Avon Breast Cancer Crusade has been helping to provide quality breast cancer care to people across the country, regardless of their ability to pay.

This means more women have had access to screening and diagnostic services, education, counseling, and nutrition programs. We not only help those who are at risk or diagnosed with breast cancer today, but also fund research into finding better treatments for tomorrow.

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### I think your mindset might just make the difference between living life on your own terms and living in fear from this disease.

~ Shannen Chavez

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**Advanced breast cancer is** breast cancer that has spread beyond the breast, chest wall and nearby lymph nodes, such as the liver, lung, bone or distant lymph nodes. Advanced breast cancer is most often diagnosed when an earlier stage breast cancer returns or recurs months or even decades later, but it can also be identified at initial diagnosis.

This guide explores Stage IV (also called metastatic) breast cancer and discusses triple-negative breast cancer and inflammatory breast cancer. Additionally, while Stage III cancers are considered locally advanced and are treated with curative intent, some of the information provided for metastatic disease may be helpful for people with this diagnosis. Because a cure is not yet available for Stage IV breast cancer, the goal is to identify the treatment that works best for each patient. Ongoing advances in research are resulting in treatments that enable many people with advanced breast cancer to live longer and with a better quality of life than ever before.

When you’re faced with an advanced breast cancer diagnosis, knowledge is empowering. This guide is filled with valuable resources that will help you better manage your disease. Read on to learn more about the types of advanced breast cancer, recommended treatments, side effects and clinical trials, along with helpful tips and support resources for you, your caregiver and your loved ones.

**DEVELOPMENT OF METASTASIS**

Stage IV breast cancer is also called metastatic or advanced breast cancer. When breast cancer spreads, it typically lands in the bones, liver, lungs or brain. Where a cancer starts, or its primary site, often plays a role in where it will metastasize, or spread. Most cancer cells that break free from the original tumor are carried in the blood or lymph until they get trapped in the next “downstream” organ or set of lymph nodes. Once the cells are there, they either die or start new tumors. This is why breast cancer often spreads to lymph nodes in the underarm but rarely to lymph nodes in the groin.

Metastasis is often found during follow-up appointments or during evaluation of symptoms such as bone pain, persistent cough or shortness of breath. An advanced breast cancer diagnosis is made when new cancerous lesions are discovered far from the primary site. Although the cancer has spread to another part of the body, the cancer is still considered breast cancer and will be targeted with the breast cancer treatments you decide on with your doctor.

**STAGING**

Staging determines the extent of the cancer based on the size of the original tumor and if it has spread (see Figures 1 and 2, page 4). The staging system used for most cancers is called TNM staging and was developed by the American Joint Committee on Cancer (AJCC) (see Tables 2 and 3, page 4).

Once advanced breast cancer is diagnosed, the AJCC also recommends testing for estrogen and progesterone receptors (ER and PR) and human epidermal growth factor receptor-2 (HER2):

- **Estrogen receptor (ER)** - if ER receptors are present in your cancer cells, they may receive signals from estrogen that promote their growth.
- **Progesterone receptor (PR)** - if PR receptors are present in your cancer cells, they may receive signals from progesterone that promote their growth.
- **Human epidermal growth factor receptor 2 (HER2)** - a protein found on the surface of breast cells that normally helps control how a healthy breast cell grows, divides and repairs itself. In about 25 percent of breast cancers, this gene makes too many copies of itself, resulting in the breast cells growing and dividing in an uncontrolled way.

Your cancer will respond to types of treatment differently depending on the presence of ER, PR and HER2, so this information is critical in helping your doctor recommend the type of treatment best for you (see Table 1).

Most patients with metastatic breast cancer have HER2-negative (HER2-) breast cancer. If your HER2- breast cancer is also hormone receptor-positive (ER+ and PR+), the most common treatment is hormone therapy, but chemotherapy and targeted therapy also are options. If you have ER+, PR+ or HER2+ breast cancer, your doctor may recommend medicines to shrink, slow or stop the cancer cell growth.

**LESS COMMON TYPES OF BREAST CANCER**

A triple-negative breast cancer (TNBC) diagnosis means that the tumor tests negative for the estrogen receptor (ER-), progesterone receptor (PR-) and human epidermal growth factor (HER2-). As a result, TNBC does not respond to the hormone or targeted therapies typically used to treat advanced breast cancer, so chemotherapy is the only treatment option. Because of this, TNBC can be more difficult to treat, as the average length of time that tumors respond to chemotherapy is shorter than for other types of breast cancer.

More about TNBC:
- About 10 to 20 percent of breast cancers are triple-negative.
- TNBC is more common in younger women or those of African/African American descent.
- There is a higher chance of carrying an inherited mutation in BRCA1 (BR stands for BReast, CA stands for CANcer). Gene mutations are associated with a family risk of breast and ovarian cancers. It is recommended that all patients with TNBC under age 60, even without a family history of cancer, be tested for BRCA 1 and 2. If you are unsure whether you carry the BRCA1 gene, talk with your doctor about genetic testing, as it can help identify treatments that will be most successful for you.

TNBC is an ongoing focus of intensive research for patients with and without the BRCA1 mutation. Triple-negative cancers have a very high level of DNA damage. To develop treatments that repair DNA damage, researchers are evaluating targeted drugs such as poly(ADP-ribose) polymerase (PARP) inhibitors.
family of enzymes needed for a type of DNA repair. Clinical trials are providing enough positive findings to encourage ongoing research, and other targeted and combination therapy drugs also are being evaluated. When you discuss treatment options with your doctor, ask about available clinical trials that you may be eligible for (see page 7).

Inflammatory breast cancer (IBC) is a rare and very aggressive disease in which cancer cells block the lymph vessels in the skin. Named because the breast often looks red or inflamed and feels warm, IBC also may give the breast skin a thick, pitted appearance that resembles an orange peel.

Most inflammatory breast cancers are invasive ductal carcinomas, which means they developed from cells that line the milk ducts of the breast and then spread beyond the ducts. IBC progresses rapidly and is always staged as at least Stage III B (locally advanced) when first diagnosed because the breast cancer cells have metastasized into the skin. If it has spread to the lymph nodes, surrounding tissues or other body parts, it is diagnosed as Stage IV. The advanced stage of IBC, along with its tendency to grow and spread quickly (sometimes in a matter of weeks or months), makes it more challenging to treat than most other types of breast cancer.

IBC accounts for about 1 to 5 percent of all breast cancers. Some experts believe it actually may be more common, but diagnosing it can be difficult because of its atypical symptoms. Breast lumps are not common, and IBC might not show up on a mammogram. Additionally, the swelling and tenderness often lead to a misdiagnosis of mastitis, an infection of the breast tissue that is accompanied by breast pain, swelling, warmth and redness.

More about IBC:
• IBC is more common and is diagnosed at a younger age than other types of breast cancer. It is also diagnosed at a younger age in African American women (average age, 52 years) than in Caucasian women (average age, 57 years). Obesity is also a risk factor.
• Treatment usually includes a combination of chemotherapy drugs, surgery and radiation therapy. Inflammatory breast tumors are frequently hormone receptor-negative, which means that hormone therapy may not be an effective strategy.
• Like other types of breast cancer, IBC can occur in men, but it is usually diagnosed at an older age (after 67 years) than in women.

Because IBC is rare, patients are encouraged to take part in clinical trials for access to the most leading-edge treatments. To learn more about clinical trials and where to find information about available trials, see page 7. (See OVERVIEW/STAGING, page 4)

### Advanced Breast Cancer in Men

Breast cancer in men is a rare disease that occurs when malignant cells invade the breast tissue. Although breast cancer can be diagnosed in men at any age, the average age at diagnosis is between 65 and 70 years.

Even though men have less breast tissue than women, making a lump easier to feel, men may ignore breast changes or not report them to their doctor because they don’t realize they are at risk. As a result, breast cancer in men is often diagnosed at a late stage. That delay in diagnosis can allow the cancer to spread to lymph nodes under the arm or around the collarbone, even before the original tumor in the breast tissue is large enough to be felt.

Most breast cancers in men are hormone receptor-positive, meaning that the growth of cancer cells is stimulated by estrogen and/or progesterone. Typical treatments for hormone receptor-positive cancers include the following:
• Surgery to remove the tumor
• Chemotherapy to kill the cancer cells
• Hormone treatment to stop cancer cell growth
• Radiation treatment to help reduce the risk of recurrence, relieve symptoms and avoid complications from areas of metastases

Because so few men are diagnosed, fewer clinical trials have studied breast cancer in men than in women, but researchers are investigating ways to treat the disease in men. Most treatments for men are modeled on treatments for women because the disease tends to respond similarly in both men and women. Talk with your doctor about each type of treatment, potential side effects and clinical trials so you can make an informed treatment decision.

### Male Breast Anatomy

<table>
<thead>
<tr>
<th>TABLE 1</th>
<th>RECEPTOR AND TREATMENT RESPONSE</th>
</tr>
</thead>
<tbody>
<tr>
<td>Receptors</td>
<td>Likely treatment response</td>
</tr>
<tr>
<td>ER+ and/or PR+, HER2-</td>
<td>Typically responds to hormone (anti-estrogen) therapy</td>
</tr>
<tr>
<td>ER+ and/or PR+, HER2+</td>
<td>Typically responds to hormone therapy and anti-HER2 drugs (targeted therapies)</td>
</tr>
<tr>
<td>ER-/PR-, HER2+</td>
<td>Typically does not respond to hormone therapy, typically will respond to anti-HER2 drugs</td>
</tr>
<tr>
<td>ER-/PR-, HER2- (triple-negative)</td>
<td>Typically treated with chemotherapy, as response to hormone therapy and anti-HER2 drugs is unlikely</td>
</tr>
</tbody>
</table>

Overview

- **Lymph nodes**
- **Ribs**
- **Fatty tissue**
- **Areola**
- **Nipple**
- **Muscle**
- **Ducts**

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**TABLE 2**

<table>
<thead>
<tr>
<th>Category Definition</th>
<th>Tumor (T)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Tx</td>
<td>The tumor cannot be assessed.</td>
</tr>
<tr>
<td>T0</td>
<td>No evidence of primary tumor.</td>
</tr>
<tr>
<td>Tis</td>
<td>Known as carcinoma in situ, the tumor has not started growing into the breast tissue.</td>
</tr>
<tr>
<td>T1</td>
<td>Tumor is 2 centimeters (about ¾ inch) or less.</td>
</tr>
<tr>
<td>T1mi</td>
<td>Tumor is 1 millimeter or less.</td>
</tr>
<tr>
<td>T1a</td>
<td>Tumor is larger than 1 mm but not more than 5 mm (0.5 cm).</td>
</tr>
<tr>
<td>T1b</td>
<td>Tumor is larger than 5 mm but not more than 10 mm (1 cm).</td>
</tr>
<tr>
<td>T1c</td>
<td>Tumor is larger than 10 mm but not more than 2 cm.</td>
</tr>
<tr>
<td>T2</td>
<td>Tumor is larger than 2 cm but not more than 5 cm (almost 2 inches).</td>
</tr>
<tr>
<td>T3</td>
<td>Tumor is larger than 5 cm.</td>
</tr>
<tr>
<td>T4</td>
<td>Tumor may be any size but has grown into the chest wall and/or to the skin.</td>
</tr>
<tr>
<td>T4a</td>
<td>Tumor extends into the chest wall.</td>
</tr>
<tr>
<td>T4b</td>
<td>The skin shows the presence of one or more of the following: edema (swelling), ulceration (a sore, painful area where the breast skin/tissue is breaking down), or satellite skin nodules (additional tumor cell masses) in the same breast.</td>
</tr>
<tr>
<td>T4c</td>
<td>Signs of both T4a and T4b are present.</td>
</tr>
<tr>
<td>T4d</td>
<td>Breast is red, swollen and warm, indicating inflammatory carcinoma.</td>
</tr>
</tbody>
</table>

**Nodes (N)**
- Nx: Lymph nodes cannot be evaluated.
- N0: No metastasis or micrometastasis* found in any lymph nodes.
- N1: Micrometastases* are found in lymph nodes (more than 0.2 mm but no more than 2 mm). Cancer cells have spread to 1 to 3 axillary lymph nodes (nodes under the arm), with at least one metastasis of more than 2 mm (0.2 cm).
- N1a: Cancer cells have spread to internal mammary lymph nodes (nodes on either side of the sternum [breastbone]), not detected by physical exam or imaging.
- N1b: Cancer cells have spread to 1 to 3 axillary lymph nodes and to internal mammary lymph nodes.
- N2: Cancer cells have spread to 4 to 9 axillary lymph nodes.
- N2a: Cancer cells have spread to clinically detected internal mammary lymph nodes but not to axillary lymph nodes.
- N2b: Cancer cells have spread to clinically detected internal mammary lymph nodes.
- N3: Cancer cells have spread to 10 or more axillary lymph nodes OR to the infraclavicular lymph nodes (nodes under the clavicle [collarbone]).
- N3a: Cancer cells have spread to clinically detected internal mammary lymph nodes and 1 or more axillary lymph nodes.
- N3b: Cancer cells have spread to supraclavicular lymph nodes (nodes above the clavicle).

**Metastasis (M)**
- M0: Cancer has not spread to other parts of the body (beyond the breast and local lymph nodes).
- cM0i(+) : There is no evidence of cancer spread, but deposits of tumor cells can be detected at the microscopic or molecular level in the blood, bone marrow or other nodal tissue.
- M1: There is clinical evidence that cancer has spread to other parts of the body.

*Refers to a small cluster of tumor cells, no larger than 2 millimeters.


**TABLE 3**

<table>
<thead>
<tr>
<th>STAGES OF BREAST CANCER</th>
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<tr>
<td>Stage</td>
</tr>
<tr>
<td>-------</td>
</tr>
<tr>
<td>IIIA</td>
</tr>
<tr>
<td>IIIB</td>
</tr>
<tr>
<td>IIIC</td>
</tr>
<tr>
<td>IV</td>
</tr>
</tbody>
</table>

**FIGURE 1**

**STAGE IIIA BREAST CANCER**
- Tumor may be any size

**FIGURE 2**

**STAGE IV METASTATIC BREAST CANCER**
- Tumor may be any size

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Once you feel educated about your options, consider seeking a second opinion from another doctor who has experience treating late-stage breast cancer. Different opinions about the best treatment plan may exist, and it is important to make an informed decision. Regardless of which path you choose, palliative care, which helps relieve symptoms and side effects, should be a part of your discussion.

**TYPES OF TREATMENT**

**Hormone therapy**

Hormone therapy, also known as endocrine therapy, is the primary choice to treat tumors that are ER+ or PR+. The ER+/PR+ designation means that the cancer cells are stimulated to grow by exposure to the female hormones estrogen and/or progesterone. Hormone therapy acts to shrink tumors by either lowering the amount of estrogen in your body or blocking estrogen to slow or stop the growth of cancer cells.

Many types of hormone therapy drugs are available (see Table 1). Your doctor will work with you to determine which drug or combination of drugs may work best for you. Previous treatment(s) and your menopausal status are two factors that will influence your doctor’s treatment recommendation. Patients are typically continued on hormonal therapy as long as the cancer is not growing and being tolerated well. If the tumor grows, other hormonal options may be available. Sometimes, chemotherapy may be recommended either initially or after progression. Also, certain hormonal therapies are sometimes given in combination with biological therapies.

**Chemotherapy**

Chemotherapy is a treatment option if your cancer cells are triple negative (ER-, PR- and HER2-) or if hormone therapy is unsuccessful. Chemotherapy is also usually given with anti-HER2 biological therapies for HER2+ breast cancer. Chemotherapy is typically given as a single drug (see list above right) or in cases of more rapidly growing, very symptomatic or higher burden of tumor, as a combination of two drugs. Your doctor will discuss the potential side effects of different chemotherapy drugs with you so you can weigh the advantages and disadvantages of this type of treatment. For some Stage III breast cancers, ovarian suppression with endocrine therapy may be recommended. As long as the cancer does not grow, or the side effects are tolerable, then treatment is continued. However, if the tumor grows or side effects are too severe, then another chemotherapy option may be discussed.

**Targeted therapy**

Targeted therapy strives to slow the progression of metastatic disease by pinpointing and blocking the genes, proteins or other substances that contribute to the growth and development of cancer cells. With this type of treatment, your doctor “targets” a drug to your specific receptor status. Targeted therapy is typically used for HER2+ breast cancer, with the anti-HER2 agents usually combined with chemotherapy. Other targeted agents are sometimes used in combination with hormonal therapy for ER+ or PR+ breast cancer (see Table 2, page 6). There are currently no approved targeted drugs for triple-negative breast cancer.

A class of drugs currently being explored is poly (ADP-ribose) polymerase (PARP) inhibitors. PARP is an enzyme that cancer cells use to repair DNA damage. PARP inhibitors are designed to disable those enzymes and enzymes damaged by chemotherapy. PARP inhibitors also promote cancer cell death and make cancer cells more sensitive to other chemotherapy agents, increasing the effect of chemotherapy drugs.

**Surgery**

Surgery, the primary treatment for early-stage breast cancer, is used less often to treat advanced breast cancer because the cancer cells have spread to more than one site. Surgery is sometimes used in conjunction with other treatments to enhance quality of life (not cure the disease).

**Radiation therapy**

Radiation therapy is commonly used for brain metastases — either focused on one or several areas for smaller tumors (known as stereotactic radiation, or gamma knife), or to the whole brain. Other sites, such as the bone, can be treated if there are symptoms that don’t respond to medical therapy.
RESISTANCE TO TREATMENT

Resistance occurs when breast cancers that were responding to therapy begin to grow again. Resistance may be caused by several factors; sometimes it occurs after a particular type of drug therapy or long-term use of a drug, and sometimes a tumor may be naturally resistant to systemic therapy. The promising news is that if disease progresses during treatment, alternative treatments with a different drug may be an option.

Overcoming drug resistance is a focus in breast cancer research. Scientists are studying different drug combinations, developing new drugs and evaluating the order in which drugs are given (sequential treatment).

PALLIATIVE CARE

Pain, fatigue, nausea and neuropathy are common side effects you may experience from your treatments or the cancer itself. Unmanaged pain can affect your ability to function, your appetite, your sleep and your mood, all of which can have a substantial effect on your quality of life. Ask your doctor about palliative care early on to help manage symptoms, as this has been shown to improve not only quality of life, but even length of life.

Often mistaken for hospice care, palliative care accompanies your regular treatment and provides physical and emotional relief. The doctors, nurses, social workers, psychiatrists, dietitians and chaplains who make up your treatment team will work with you to improve your quality of life, which will also benefit your caregivers and loved ones.

IMMUNOTHERAPY

This treatment, also called biologic therapy, is still in the early experimental stage for breast cancer treatment. This approach uses the body’s own immune system to fight cancer cells. Important clinical trials are ongoing with promising early responses.

The immune system naturally protects the body by attacking germs, but cancer cells have a unique ability to withstand those attacks and to dampen the immune system. Immunotherapy focuses on combining the body’s natural defenses and works to block the immune-dampening mechanisms (known as “checkpoints”) with drug therapy to stop or slow the subsequent growth of cancer cells. Something that separates immunotherapy from traditional treatments is its “memory”—its ability to remain effective for long intervals far beyond the end of treatment.

Cancer vaccinations have been an ongoing topic of research for decades, but scientists have yet to develop one that is effective for breast cancer, especially when advanced disease is already present. Vaccinating patients with no cancer or early-stage breast cancer to prevent metastatic disease currently is being explored.

Successes in treating melanoma and lung cancer with immunotherapy have encouraged scientists to continue studying ways to treat advanced breast cancer with immunotherapy.

CHOOSING THE RIGHT PATH FOR YOURSELF

Undergoing continuous treatment can take a toll on you. You may reach a point where you feel you need a break, or you might be enjoying a good quality of life and choose to forgo treatment for a while. Talk with your doctor to ensure you understand the pros and cons of interrupting your treatment plan, even for a short time.

You will receive input from your doctors, nurses, family members and friends, but remember—the decisions are yours to make. Weigh the pros and cons of treatments, their corresponding side effects and how they fit into your idea of a good quality of life. Keep in mind that the treatment you choose initially may need to be adjusted depending on how your body responds and the progression of the disease. Unfortunately, there is no instruction manual.

If you reach a time when you choose to stop treatment altogether, talk with your doctor about your feelings. If you make that difficult decision, you are strongly encouraged to investigate hospice care, where efforts are focused on managing symptoms and supporting the patient and family, but not using cancer therapies. Hospice care can take place at home or in a hospice center and offers physical, emotional and spiritual support for you and your loved ones.

CLINICAL TRIALS

Clinical trials are research studies that explore whether a medical strategy, treatment or device is safe and effective for humans. These studies also may show which strategies work best for certain illnesses or groups of people. Because current treatments are very unlikely to cure advanced breast cancer, patients are encouraged to think about taking part in clinical trials.

Many falsehoods about clinical trials persist because people typically don’t learn about clinical trials until they’re faced with considering them as a treatment option. Read on to discover key information you should know to help you make an informed decision about participating in a clinical trial. Be sure to read Myth vs Fact on page 7, which addresses several misconceptions about clinical trials.

Benefits. All the advances in cancer treatment that are saving lives today have come directly from clinical trial research. As a volunteer, you are carefully monitored. You are guaranteed to receive the current standard of care during the trial. Additionally,

<table>
<thead>
<tr>
<th>Targeted therapy option</th>
<th>Type of breast cancer</th>
<th>Approved/recommended treatment</th>
</tr>
</thead>
<tbody>
<tr>
<td>everolimus (Afinitor)</td>
<td>ER+, PR+, HER2+, metastatic</td>
<td>In combination with exemestane (Aromasin) for postmenopausal women who have already been treated with letrozole or anastrozole</td>
</tr>
<tr>
<td>palbociclib (Ibrance)</td>
<td>ER+, HER2+, metastatic</td>
<td>In combination with letrozole for postmenopausal women as a first hormone-based therapy</td>
</tr>
<tr>
<td>ado-trastuzumab emtansine (Kadcyla T-DM1)</td>
<td>HER2+, metastatic</td>
<td>For women previously treated with trastuzumab and a taxane, separately or in combination</td>
</tr>
<tr>
<td>lapatinib (Tykerb)</td>
<td>HER2+, metastatic</td>
<td>In combination with capecitabine (Xeloda) or trastuzumab (Herceptin), typically after treatment with trastuzumab-based therapy and ado-trastuzumab emtansine</td>
</tr>
<tr>
<td>pertuzumab (Perjeta)</td>
<td>HER2+, metastatic, or as neoadjuvant therapy</td>
<td>In combination with trastuzumab and docetaxel in individuals who have not been treated with anti-HER2 therapy or chemotherapy</td>
</tr>
<tr>
<td>ribociclib (Kisqali)</td>
<td>ER+, PR+, HER2+, metastatic</td>
<td>In combination with an aromatase inhibitor as first-line endocrine-based therapy for post-menopausal women</td>
</tr>
<tr>
<td>trastuzumab (Herceptin)</td>
<td>HER2+, metastatic</td>
<td>In combination with paclitaxel as first-line treatment, with other chemotherapy drugs, or with lapatinib for later lines of therapy, as a single agent in patients who have received one or more chemotherapy regimens</td>
</tr>
</tbody>
</table>
by simply participating, you are making a valuable contribution to cancer research.

■ Types. Patients with advanced breast cancer may consider therapeutic trials and quality-of-life trials. Therapeutic trials determine if new treatment options are better than current treatment options, while quality-of-life trials study ways to improve the quality of life for people with cancer. There are also non-treatment trials that analyze tumor or blood specimens and those that ask for completion of questionnaires and medical information.

■ Timelines. The four phases of therapeutic clinical trials can take several of the 10 to 15 years it takes for a single drug to be developed. You may be part of a single phase or multiple phases of a trial.

■ Costs. Patient care costs include those related to doctor visits, hospital stays and some testing procedures that are part of standard care, which would be incurred if you did not participate in the trial and chose standard treatment. You are responsible for those, and they will be covered by your insurance as outlined in your plan. The Affordable Care Act requires all insurance companies to cover the routine patient costs from in-network providers associated with an approved clinical trial. An approved trial is defined as a trial in any phase that is aimed at preventing, detecting or treating cancer. Research costs, which are directly related to the clinical trial and include drugs and procedures, are typically covered by the trial sponsor. Always explore your plan benefits with your insurance company before volunteering for a clinical trial. The consent form that patients sign to participate in the trial always contains a section on which costs are covered by the trial and which are the responsibility of the patient or the patient’s insurance.

■ Safety Measures. All clinical trials are regulated by the U.S. Food and Drug Administration, with several safeguards in place to protect the safety of all participants. Every participating clinic, hospital, university and cancer center, regardless of location, must follow the same set of rules, known as protocols, that is developed for each study, along with an informed consent form, both of which have to be approved by a special group known as the Institutional Review Board. Protocols ensure consistency in eligibility criteria, tests and procedures performed, medications and doses, and study length. Throughout the clinical trial process, safety checks are done to ensure that the potential health benefits of a drug continue to outweigh the risks. If a safety issue arises, the trial is delayed or stopped.

■ Resources. Your treatment team members can give you more information about clinical trials in your area, but they may not be aware of all the trials available in other locations. Using online tools, such as Metastatic Trial Search (see above), makes it easy to search for trials that apply to you. (See Find A Clinical Trial below and Advocacy & Financial Resources on page 17.)

Introducing Metastatic Trial Search

Metastatic Trial Search is the first-ever clinical trial search designed for people with metastatic breast cancer. Along with providing valuable general information about clinical trials, this easy-to-use tool filters through hundreds of research sites in the United States to find search results tailored to your situation. Here’s how it works:

1. Visit BreastCancerTrials.org and click Get Started under METASTATIC TRIAL SEARCH.
2. Enter your birth year, zip code, gender, breast cancer types and sites with current evidence of disease.
3. Click Show Trials for a list of current trials that may be options for you.

Along with a brief summary of the trial, each listing contains links to learn what’s involved, whom to contact, how to find out if you qualify and if travel is required.

The BreastCancerTrials.org home page also offers the BCT Trial Alert and Match to Trial services. Simply enter your personal data to begin matching to available trials, or click to learn more. You’ll be prompted for what you need throughout the process, such as medical history and pathology reports. Don’t worry about having everything with you to get started — you can save your information and return at any time.
I was pleased with my medical care, but I felt compelled to get a second opinion. Shockingly, tests performed by a new doctor revealed my cancer had progressed and was now Stage IV. Because it had spread deeper into my chest wall, my doctor called it the beginning of metastatic disease, in spite of no bone or organ development. I was treated with more surgery, six cycles of eribulin (Halaven) and radiation therapy.

To add to these struggles, my marriage was failing and my husband was our single source of income. When we separated, I was devastated in more ways than one. My family and friends became my support network.

At one of my appointments, my son asked my oncologist how he could help. We decided to make fleece-tied blankets to keep patients warm during chemotherapy. The first blanket we made comforted a woman and her family in her last hours of life and that showed me how one simple act can make such a difference. We continued and called it “Thoughtful Thursdays,” donating blankets to local cancer centers. It became a great distraction for my kids during my treatments, and it took off as a fundraising effort in our community.

Two years later, I started Kimberly Jewett Consulting, Inc. to provide patient advocacy strategy and oncology marketing consulting to corporations from a patient perspective. A key part of my mission is advocating for more funding for metastatic-focused research. I partner with pharmaceutical companies, visit Capitol Hill as a patient advocate and give motivational speeches. I’m also on the board of Bear Necessities, a non-profit pediatric cancer foundation in Chicago.

I’m now 39 years old and doing well, but I’m facing this lifelong disease and the fear never leaves. Every three months I go for scans and blood work, and the anxiety comes back for me and my kids. But I can see how this experience has shaped them in a positive way. They make choices to live life better through eating right and exercising. My daughter hopes to be an oncologist someday but, for now, she’d like to help other kids whose parents have cancer.

This journey has changed my life in more ways than I could have imagined. I am blessed that I’m able to see my kids grow and be a part of their lives.

My oncologist gave me three pieces of advice that I live by every day. In fact, I close every speech with them and they always give me chills:

1. Have faith. I am a medical doctor, and I can do everything possible medically, but the man above has the final say.
2. Hope. There are lots of drugs in research coming to market every day.
3. Go home and celebrate with a glass of champagne, and live every day to the fullest.

Over Memorial Day weekend in 2008, I told my mother I was having some achiness in my left breast. She was recovering from brain cancer and suggested I give myself a breast exam. I did, and I felt a lump under my left armpit. My OB-GYN wasn’t alarmed, but I persisted. A mammogram led to an ultrasound that uncovered an 8-mm nodule. I had cancer. At 31. It didn’t seem possible.

I immediately turned to the Internet. I found fantastic websites and joined discussion rooms, trying to learn everything I could about breast cancer. That was the beginning of so many things: fear of not being around to raise my two young children, strength in advocating for my own health, and the role faith plays in my journey.

My cancer was slow-growing and fed on estrogen, so I had a double mastectomy (my left breast to remove the tumor, my right breast as a prophylactic measure) with immediate reconstruction and six months of chemotherapy. I was completely exhausted, struggling to do ordinary things like tuck my daughter into bed.

After overhearing her pray to give her mommy the strength to fight cancer, I did the same. I was cancer-free for three years.

In July 2011, I underwent tests to investigate swelling under my left breast but the results were inconclusive. In January 2012, I awoke feeling like someone had kicked me hard in the rib. I was told a PET scan was the only test left and insurance might not pay for it. I insisted, knowing I might have to pay out of pocket. The area in question was clear, but a localized mass was detected deep within my left chest wall. I had surgery to remove the mass and a portion of my chest wall. I also had my implants removed so they couldn’t prevent me from noticing tumors in the future. Now I wear prosthetics.

Kimberly Jewett spent most of her 30s fighting for her life. After being diagnosed with Stage II breast cancer in 2008 at 31 and Stage IV at 35, she has emerged a stronger, independent single mom with a career dedicated to awareness and advocacy.
Treatment for your advanced breast cancer targets cancer cells. However, sometimes it also affects healthy cells, which can cause side effects. There are many ways to manage these side effects.

HORMONE THERAPY
Hormone therapy may cause fatigue, muscle and joint pains, vaginal dryness or discharge, hot flashes and mood swings. Your doctor will work with you to manage these effects. Blood clots are a less common but more serious side effect of tamoxifen. If a blood clot develops, it is usually in a leg, but sometimes a clot breaks off and travels to the lungs. A clot in the lungs is called a pulmonary embolism and can be life-threatening. If pain, redness or swelling develops in your calf or you have shortness of breath or chest pain, call your doctor right away. These could be symptoms of a clot.

STEROID THERAPY
The initial treatment for brain metastasis is usually a corticosteroid, which helps decrease swelling around the brain. Treatment with a corticosteroid may continue for several weeks. Some common side effects of corticosteroid use include weight gain, acid indigestion, muscle weakness, difficulty sleeping, mood swings, elevated blood sugar, acne and swelling of the face.

CHEMOTHERAPY
Chemotherapy targets cells that divide quickly because cancer cells divide quickly. Unfortunately, chemotherapy also affects normal cells that divide quickly, such as hair and nail cells. Because of this, side effects of chemotherapy can include hair loss, nail changes, mouth sores, low blood cell counts and risk of infection. Chemotherapy may also cause nausea, vomiting and changes in appetite. Your doctor may prescribe anti-nausea drugs to help you navigate chemotherapy. Cooling caps may reduce hair loss due to chemotherapy. A cooling cap is a computer-controlled system that circulates cooled liquid to a cap worn on the head during chemotherapy. The cooling cap is covered by a second cap made of neoprene, which provides insulation.

TARGETED THERAPY
This class of drugs has its own unique side effects depending on the therapy (see Table 1). Most side effects of HER2-targeted therapy such as pertuzumab (Perjeta) and trastuzumab (Herceptin) are mild, such as diarrhea. However, some drugs carry a risk of congestive heart failure, which usually goes away after the drug is no longer taken. Palbociclib (Ibrance) can cause low white counts and fatigue, while everolimus (Afinitor) can cause mouth sores, fatigue and lung inflammation. Talk with your doctor before making any treatment decisions.

RADIATION THERAPY
Radiation therapy can help relieve pain from metastasis to the bone. With radiation therapy, high-energy rays or particles are targeted to the area of the metastasis. Pain relief is usually immediate but may not be complete. Side effects that may occur with radiation therapy include fatigue, loss of appetite, skin changes and low blood cell counts. In cases of increased fracture risk, surgery may be required, and radiation therapy is typically done after surgery. Whole-brain radiation therapy can improve or stabilize symptoms of brain metastasis, such as headaches, pain and seizures. It is most often used when there are several sites of metastasis in the brain. Among the potential side effects are memory loss, extreme fatigue, temporary baldness, skin rash and hearing loss. For smaller brain metastases, stereotactic (also known as gamma knife) radiation can be done to one or more focused areas and has fewer side effects than whole-brain radiation.

SURGERY
Surgery for bone metastasis can help relieve pain and prevent fractures. Placing screws, rods, pins, plates or other devices can help stabilize the bone, making fractures less likely. For a bone that is already broken, surgery...
may relieve pain. Side effects include soreness at the incision site and pain.

PERSONAL PERSPECTIVE

Dikla Benzeevi / Advanced Breast Cancer

“Learning to live with metastatic breast cancer becomes a balancing act of working with your oncologist to modify or change medications based on their effectiveness and side-effect severity.”

MEDICAL SUPPORTIVE THERAPIES

Your doctor will likely recommend daily calcium and vitamin D supplements. In addition, your doctor may prescribe a bone-modifying drug (see Table 2, page 9) to help prevent bone problems. These drugs may damage the jawbone, so people taking bone-modifying drugs should take care of their mouth, gums and teeth. They should also avoid invasive dental work.

Be sure to tell your medical team when symptoms persist despite treatment or if you experience any new symptoms. They will work with you to manage your symptoms, provide you with greater control over your daily activities and improve your quality of life.

[DEFINING CANCER-RELATED PAIN]

Cancer-related pain is caused by several different factors. In most cases, it is directly related to the cancer itself and the location of the tumor(s). As a tumor grows, it can press on internal organs, tissues and joints, creating pressure that ultimately leads to pain in that specific area. Pain can also be caused by cancer that has spread to bone. This pain is typically felt in the back, pelvis and hips, as these bones are the most common sites of cancer spread (metastasis). Cancer-related pain may be felt in parts of the body other than where the primary tumor is located, especially in advanced disease.

In addition to cancer-specific pain, diagnostic procedures and treatments, including surgery, chemotherapy and radiation therapy, may cause different types of pain. After surgery, pain is usually felt in the area of the surgery. This pain will gradually lessen as the body heals and recovers. The pain or discomfort caused by chemotherapy and radiation therapy can be mild to severe, but often (although not always) ends when treatment does. Sometimes, a hormone imbalance or treatment-related nerve damage may contribute to chronic pain.

[TYPES OF PAIN] Doctors refer to pain in three categories: nociceptive somatic, nociceptive visceral and neuropathic. These terms seem complicated, but their meaning can be simplified. Nociceptive pain arises when nerve cells (called nociceptors) are stimulated to send pain signals by some kind of ongoing injury, such as pressure by a tumor or the cut of a surgical scalpel. Pain caused by stimulation of nerve cells in soft tissues or muscles is defined as nociceptive somatic; pain caused by stimulation of nerve cells in body organs is defined as nociceptive visceral. Neoplastic pain is caused by damage to nerves, causing these nerves to send pain signals even though there isn’t ongoing injury. Each of these categories of pain has distinct causes. Pain is also defined by its timing:

• Acute pain is pain that occurs suddenly; it is sometimes related to a diagnostic procedure or treatment. This type of pain is time-limited; in other words, the pain usually resolves once the body recovers and heals.

• Chronic pain, also called persistent pain, lasts for at least one month — usually longer — after treatment. This type of pain is usually related to the direct effects of a tumor or cancer treatment but, in a small number of people, pain may be unrelated to either the cancer or the treatment.

• Breakthrough pain includes severe flares of pain that “break through” during treatment with pain medication. Breakthrough pain can range from mild to severe and can last minutes to hours.

[DESCRIPTIONS OF PAIN] Your doctor will ask you to describe your pain. Think about your pain and describe it carefully, as your doctor will be better able to determine the cause of your pain. For example, if pain feels like burning or “shock-like,” it is most likely related to damaged nerves. Your doctor will also ask about the severity of your pain. A scale of 0 to 10 (with 10 being the worst) is the most common way to rate how bad pain is.

Also give your doctor details about your pain: What makes it worse? Does anything make it better? How does it affect your daily life?

[CAUSES OF CANCER-RELATED PAIN] Some of the more common side effects of cancer and cancer treatments that can cause pain include the following:

• Loss of motion may occur after surgery. For example, many people have pain related to loss of motion in the arm after a mastectomy.

• Lymphedema occurs when excess fluid builds up and causes abnormal swelling, typically in an arm or a leg. Swelling ranges from mild to extreme and is most likely to occur after surgery involving removal of lymph nodes from the underarm, groin, pelvis or neck. Typically, the more lymph nodes removed, the greater the risk for lymphedema.

• Peripheral neuropathy is a condition caused by damage to the peripheral nerves, the nerves outside the brain and spinal cord. Some chemotherapy drugs cause peripheral neuropathy, which is experienced as numbness and tingling in the hands and feet, a decreased sensation of hot and cold, muscle weakness, cramping and balance problems.

• Osteoporosis occurs when healthy bone isn’t rebuilt at the same rate as it is being destroyed by cancer cells or certain treatments. As a result, bone becomes weak, brittle and painful. This condition can happen naturally with age but is intensified by cancer.

• Bone metastasis is the spread of cancer into bones. Pain is caused by damage to bone cells as cancer cells invade.

[TALKING ABOUT PAIN] Regardless of the cause or type of cancer-related pain, there are options for managing it so that you can have less pain and a better quality of life. Be sure to talk to your doctor or other member of your cancer treatment team about your pain so that they can discuss options with you.

ADDITIONAL RESOURCES

• Academy of Integrative Pain Management: www.integrativepainmanagement.org

• American Cancer Society: www.cancer.org

• American Society of Clinical Oncology: www.cancer.net

• Brainmetsbc.org: www.brainmetsbc.org

• Cancer Pain Research Consortium: www.cancerpainresearchconsortium.org

• Metastatic Breast Cancer Network: www.mbcn.org

• National Cancer Institute: www.cancer.gov

• Susan G. Komen: www5.komen.org

• Managing Pain Related to Metastatic Breast Cancer

www.brainmetsbc.org

“Dikla Benzeevi”
Live, Love & Laugh Often

For six months I had been feeling lethargic and sick, going to doctors and being checked for things like thyroid issues, hormone issues and diabetes. I finally found a lump in my breast on October 7, 2013, and immediately contacted the women’s hospital close to me. As a woman who had always been in tune with her body, I felt certain the biopsy result would come back as cancer.

Even though I expected the cancer diagnosis, I was shocked to hear I had Stage IV disease. I had no family history of breast cancer, and I had always done breast exams. I have two boys, now ages 26 and 20, and two grandchildren, so I underwent genetic testing. I am not a carrier of the BRCA gene, so at least I know I haven’t passed it to my sons.

My doctor basically told me I had metastatic breast cancer, and it had spread. I had two years to live, and I should go home and make my arrangements. I told her three things:
1. You don’t know me very well.
2. You’re not God.
3. You’re fired.

Despite the way my doctor broke the news, I chose to adopt a positive mindset about my journey. I was referred to another oncologist, and I couldn’t be happier. He has more than 35 years of experience working with people with metastatic breast cancer, some of whom he’s treated for 12 years. I think it’s important to note that in getting a second opinion, I didn’t think I would hear a different outcome, but I was looking for the kind of positivity that I get from him. I think your mindset might just make the difference between living life on your own terms and living in fear from this disease.

My body has responded fairly well to treatment. I started with docetaxel, trastuzumab (Herceptin) and pertuzumab (Perjeta) for five months, and I am now just taking trastuzumab, pertuzumab, goserelin (Zoladex) and anastrozole (Arimidex). I take a daily pill and go in for infusions every three weeks.

I’m coping with the side effects as best I can. A rash will last three to four days about every three to four treatments. My neuropathy is continual, and my hair loss or thinning will be continual.

Gaining weight and losing my long, lustrous hair have been hard. I just purchased my first wig, and I’m going to get it cut by my stylist. It’s a little shorter, and it will be something different!

Emotionally, I’m in a good place although it is a roller coaster. The ups and downs of daily life, especially the financial stress and knowing I will be doing this for the rest of my life, make it difficult. I work full-time as an HR manager. Fortunately, my employer has made accommodations for me to work at home when I need to. Like clockwork, I work from home every third Monday after treatment.

Even so, I have a lot to live for. My grandchildren are the light of my life, and I have a tremendous support system in my family and friends. I’ve learned that I have instilled strength, much love and positivity as well as resilience in my children. They have been a constant source of support for me from the very beginning. I told them all from the start what it is and the possible reality of the outcome. I am very open about it, even with strangers. It keeps me positive.

After my diagnosis, I went online and found some resources for people with metastatic breast cancer, but I had a hard time finding people who were going through what I was. I have found great support groups through Facebook. It was there I became involved with Little Pink Houses of Hope (www.littlepink.org), an organization that donates vacations to families fighting breast cancer. My family and I were able to take a week-long vacation the first year I was diagnosed. We put my cancer on the back burner and just enjoyed being together.

None of us are promised tomorrow, so enjoy the little things as well as the big. And, remember:
Hope - the sun is always on the horizon
Faith - only God knows
Strength - You will find it in the deepest part of your core exactly when it’s needed
With advanced breast cancer, tracking how your disease responds to treatment is an important part of the overall care plan. To monitor your cancer, you will undergo routine testing. If that testing shows that your treatment is not slowing or stopping the growth of your cancer, you and your health care team will begin to consider alternative treatment options.

Several different tests help monitor the response to treatment in addition to your symptoms and physical examination. Often, more than one test is needed to determine how well treatment is working. These tests include imaging studies, tumor marker testing and a blood test that measures a special type of tumor cell in the blood. To have a baseline for comparison with later studies, your doctor will perform one or more of these studies before treatment begins.

You will probably have routine visits with your doctor during treatment. Use these visits to tell your doctor about any new or changing symptoms. Pain relief, easier breathing or increased energy could all be signs that the cancer is responding to treatment. Depending on the sites of metastasis, your doctor may be able to tell if treatment is working by performing a physical exam. For example, if a lymph node is a site of metastasis, your doctor may be able to feel that the node has gotten smaller, which means that the metastasis has shrunk.

Together, a physical examination and the results of ongoing, specific testing can tell you and your doctor how well your treatment is working.

**IMAGING STUDIES**

Many imaging studies can help your doctor monitor the response of advanced breast cancer to treatment. Imaging studies are typically done about eight to 12 weeks after treatment starts. These studies enable your doctor to measure the size of a tumor or metastatic site. A tumor or metastatic lesion that is smaller than it was before treatment is one sign that your cancer is responding to treatment.

Imaging studies that you may have include bone scans, X-rays, computed tomography (CT), magnetic resonance imaging (MRI) and positron emission tomography (PET). Your doctor will choose which imaging study to do on the basis of the location and extent of the metastasis. Imaging studies typically cause few or no side effects.

**TUMOR MARKERS TO HELP MONITOR METASTATIC BREAST CANCER**

<table>
<thead>
<tr>
<th>Tumor marker</th>
<th>Testing sample</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Estrogen receptor/progesterone receptor (ER/PR)</td>
<td>Tissue</td>
<td>Identifies tumors most and least likely to respond to hormone therapy</td>
</tr>
<tr>
<td>HER2 antigen</td>
<td>Tissue</td>
<td>Identifies tumors most and least likely to respond to specific HER2-targeting drugs</td>
</tr>
<tr>
<td>CA 15-3, CA 27.29 and CEA</td>
<td>Blood</td>
<td>Rising levels over time suggest progression of disease</td>
</tr>
<tr>
<td>Circulating tumor cells (CTC)</td>
<td>Blood</td>
<td>Predict survival and assess response to therapy</td>
</tr>
</tbody>
</table>

**Bone scan**

Bone scans are used to determine the extent of bone metastasis. Before the scan, a small amount of a radioactive substance is injected into a vein in your arm. Then, the radioactive substance collects in areas of metastasis in the bone. The bone scan includes a special camera that shows where the radioactive material has collected, which indicates where the cancer is. Most of the radioactive substance will be eliminated from your body within one day, and it should be completely gone within two days. Except for the brief discomfort of the needle for the injection, a bone scan is painless.

**X-ray**

X-rays are used primarily to monitor metastatic lesions in the lungs and bones. X-rays may be useful for detecting lesions elsewhere in the body, but other imaging studies may be needed to confirm the presence of a lesion. X-rays are painless.

**CT**

CT is a specialized X-ray technique that provides cross-sectional images of internal organs. CT can be used to monitor metastatic lesions in the lungs, bones or liver. During the procedure, you will lie on a table that moves slowly through the CT scanner. Sometimes, a contrast material is injected into a vein in your arm before the scan to enhance the quality of the images. CT is painless and typically takes about 30 minutes.
PET scan
A PET scan is a specialized imaging exam in which a small amount of radioactive material (tracer) is injected into a vein. The amount of radioactivity in the tracer is very low. Breast cancer cells absorb more of the tracer than regular cells do. A special camera in the PET scanner finds where the tracer collects, which shows your doctor where metastases are. The camera also takes images of the areas of metastasis. PET scans are usually not routine, but they may be beneficial if the results of other imaging studies are inconclusive. PET scans are often done at the same time as CT scans. Having both scans at the same time is known as PET/CT. You may feel a sting when you receive the tracer, but the PET scan itself is painless. PET scans of the breast often take about an hour and a half.

CAREGIVER PERSPECTIVE  Cate Edwards

Every patient is different. Keeping the line of communication open and being willing to talk about the disease, how the patient is feeling on a day-to-day basis, and what their needs are is vital.

TUMOR MARKERS
In addition to ER, PR and HER2 tests performed on tumor tissue, cancer antigens measured in the blood are other types of tumor markers (see Table 1). Cancer antigens are proteins given off by cancer cells. Measuring the amount of cancer antigens in your blood may provide information about how many cancer cells are in your body and how it is changing over time, making it a useful tool for monitoring response to treatment. The three cancer antigens associated with metastatic breast cancer are cancer antigen (CA) 15-3, CA 27.29 and carcinoembryonic antigen (CEA). These three antigens are found in many women with metastatic breast cancer. The results of cancer antigen tests are not definitive. Low levels of an antigen do not necessarily mean that cancer is responding to treatment, and high levels may be a sign of a condition other than cancer. Because of this, experts agree that tumor markers should not be used alone to monitor the response of cancer to treatment. Instead, tumor markers should be used in combination with imaging studies.

Monitoring CA 15-3, CA 27-29 and CEA is usually done prior to treatment and periodically after treatment starts. Before that, levels can be falsely elevated. Tumor marker testing is done on a small sample of blood drawn from a vein (usually in the arm).

CIRCULATING TUMOR CELLS
Circulating tumor cell (CTC) testing can help determine prognosis and monitor response to treatment when used with imaging studies and other tests. A CTC test may also be referred to as a liquid biopsy (see Figure 1). CTCs are cells that break away from a tumor and enter the bloodstream. The test measures the number of CTCs in the bloodstream. To perform a CTC test, your doctor takes a sample of your blood and then places it in a special device. Studies have shown that the number of CTCs in the blood correlates to progression-free survival and overall survival. Knowing your CTC count can help you and your doctors make a more informed decision about your care.

It may be several weeks or months before imaging studies can detect response to treatment. Tumor marker levels are usually first determined about three to four months after treatment starts. Although the CTC test alone cannot be used to determine response to treatment, CTC counts can give your doctors an early indication of how you are doing and should be used with imaging studies and other clinical markers.

TALK TO YOUR MEDICAL TEAM
No single test provides the complete picture of how your cancer is responding to treatment. Your medical team will work with you to determine the kind of testing that is best for you and how often it should be done. If you experience symptoms before your next scheduled test, alert your medical team right away.

ADDITIONAL RESOURCES
- American Cancer Society: www.cancer.org Exams and Tests for Cancer
- American Society of Clinical Oncology: www.cancer.net Biomarkers to Guide Treatment for Metastatic Breast Cancer
A diagnosis of metastatic disease can be overwhelming. You’ll experience a range of emotions. This is completely normal. Allow yourself to express your emotions freely, no matter what they are. You’re still the same person you were before your diagnosis. Expressing your emotions helps you stay that person.

IMPORTANCE OF A HEALTHY LIFESTYLE
Maintaining your physical health can help boost your mental health. The right amount of sleep, regular exercise and a healthy diet can all improve your mood.

Although it sounds counterintuitive, physical exercise is sometimes the best treatment for fatigue. Studies have shown that people with breast cancer who get regular aerobic exercise, such as walking or biking, feel less tired and have more energy. Think about the physical activity you enjoy most and do it daily, as often as you can tolerate it. You can modify your favorite form of exercise if you experience pain or discomfort.

Side effects such as loss of appetite or nausea can make proper nutrition challenging, but a healthy diet will help you gain strength, which is especially important during treatment cycles. Nutritionists recommend eating a variety of foods, including vegetables, fruit, low-fat milk and dairy products, whole grains and legumes, and healthy snacks, such as yogurt or nuts. Light exercise before mealtime may help increase your appetite.

Finding a way to manage stress will strengthen your coping abilities. Explore various ways to reduce stress to learn what works best for you. Some options include meditation, guided imagery, muscle relaxation and yoga. Yoga may help relieve some of the discomfort associated with metastasis. Ordinary “escapes,” such as reading, watching television and playing games, can also help you relax.

SET PRIORITIES
Now is the time to examine your life and determine your priorities. Everyone has different priorities, so listen to yourself, not others, while you set yours. Some women find comfort in maintaining their current routine and continue working. Others choose to devote more time to hobbies, traveling or spending time with family and friends. Many people with advanced breast cancer have noted the importance of simply “finding joy in life” by having fun in ordinary ways or seeking adventure in new ways. Volunteering in your community may give you perspective as a sense of purpose, and you may find comfort in spirituality. Think about what matters most to you.

POWER OF RELATIONSHIPS
Maintaining strong relationships is crucial to emotional well-being. People who want to support you don’t always know how to show it. If some of the people in your life seem to avoid you, it is just because they don’t know what to say or are nervous they will say the wrong thing. Reach out to family and friends, and tell them about your range of emotions. Offer to get together. You can take the initiative. Admit that you may need assistance, and let your friends and family help you. Keep talking with them about the everyday things you talked about before your diagnosis. This will help them realize you’re still the same you.

Intimate relationships are sources of strength, but they may change in challenging ways after your diagnosis. Cancer and its treatment can affect how you feel about yourself and your body and how you relate intimately to your partner. It’s normal to have doubts and concerns, such as wondering whether your partner finds you attractive. Open communication with your partner is essential to maintaining a strong intimate relationship. You and your partner should share your concerns and fears with each other.

The anxiety of coping with metastatic disease, and side effects such as fatigue and pain, affect how you feel sexually. Many people with cancer lack sexual desire. This is something you can work to change. Managing your side effects can help you feel better overall, which may help you feel more desirable and more interested in sex. Unless your doctor says otherwise, it is safe to have sex during cancer treatment.

Talk with your partner about ways to be intimate other than sexual intercourse. If you are single during your cancer treatment, you may decide to give yourself some time to adjust to your new normal before beginning a sexual relationship. Counseling (individual, couples and/or sex therapy) may also be helpful.

MONITORING FOR SIGNS OF DEPRESSION
For some people, the emotional distress of living with advanced breast cancer can develop into depression. Remember that depression is more complex than feeling sad or hopeless. A diagnosis of depression requires that at least five of the following symptoms occur every day for at least two weeks:

- Persistent sad, anxious or “numb” feelings
- Loss of interest or pleasure in hobbies and activities
- Feelings of hopelessness
- Feelings of guilt, worthlessness or helplessness
- Fatigue and loss of energy
- Difficulty concentrating, remembering and making decisions
- Sleep problems
- Changes in appetite and/or weight
- Thoughts of death or suicide, or suicide attempts
- Restlessness or irritability
- Social withdrawal
- Repeated episodes of crying

People with mild depression may benefit from counseling without medications. Moderate or severe depression is typically managed with a combination of counseling and medication (antidepressants). Many antidepressants are available. Each one has different side effects, which can often be managed by adjusting the dose. Your doctor will work with you to find the antidepressant that works best for you with minimal side effects. Drugs known as selective serotonin reuptake inhibitors (SSRIs) are usually recommended as first-line treatment. Antidepressants often take about four to six weeks to start working.

Talk therapy, or psychotherapy, for depression most often includes cognitive behavioral therapy. In cognitive behavioral therapy, a mental health professional will help you change negative thoughts and behavior. Counseling can help you improve your communication with family members and friends, as well as ease fears about your chronic illness.

SUPPORT GROUPS
No person should have to face advanced breast cancer alone. Talking to others with advanced breast cancer can help you learn more about the disease, treatment options, resources and how to cope. Support groups provide emotional support and help you feel less alone.

Various kinds of support groups are available. Your doctor should be able to provide you with a list of local meetings. Some are held online, offering the advantage of being available all the time. These are good options for people who prefer not talking face-to-face or who do not feel well enough to go.

Advanced breast cancer changes your life, but it doesn’t change who you are. Taking care of your emotions helps you stay yourself.
THE ROLE OF A CAREGIVER

Caring for a loved one with advanced breast cancer presents different challenges from caring for someone with a curable disease. Because advanced breast cancer has become a permanent part of the person's life, your commitment, support, and kindness can make this lifelong burden easier to bear.

- **Attend medical appointments.** Your loved one may experience information overload, making it hard to digest or understand information. Two heads are better than one. Bring a list of questions to appointments, take notes and offer reminders later for follow-up items.
- **Educate yourself.** Learn everything you can about advanced breast cancer. When you attend appointments with your loved one, don’t be afraid to show you’ve done your research by asking questions. Make sure you understand the current status and the treatment plan. The more informed you are, the better advocate you will be.

- **Get on the same page.** When it comes to breast cancer, we often hear the term “survivor”; we hear it less from people with advanced breast cancer. Because they will always live with this disease — be it a short or long time — people with advanced breast cancer tend to feel very strongly about how they identify themselves, opting for alternatives such as “lifters,” “thriver” or “metster.” Talk with your loved one about her or his feelings. The topic could prompt other valuable conversations.
- **Make lists.** Keep a list of questions about side effects, treatments, nutrition, exercise, etc., for the treatment team.

- **Be a thoughtful listener.** Sometimes your loved one will want to talk about cancer. You know that advanced breast cancer is incurable, so don’t dismiss his or her feelings by giving unhelpful advice such as “Don’t worry about it,” or “It’s going to be fine.” Just listening is completely acceptable, and that simple act is often a source of comfort.
- **Suggest support groups.** Realize that as the caregiver, you are not the only outlet for your loved one. Connecting with others who are dealing with the fears, feelings and experiences surrounding advanced breast cancer can be extremely therapeutic.
- **Revisit your role from time to time.** Your loved one’s needs — and your own — will change, so make sure to reset expectations as needed to ensure you are providing the type of care that is expected and most helpful.
- **Take care of yourself.** Caregiving is a mentally and physically exhausting responsibility, and you won’t be any good to your loved one if you aren’t good to yourself. Eat right, exercise and get enough sleep. Don’t ignore your favorite hobby. Lose yourself in a good book or movie. And don’t feel guilty when you enjoy yourself. Everyone deserves a diversion.
- **Know when to ask for help.** Some anxiety and fears about your loved one’s illness and your responsibilities are normal, but if they prevent you from helping him or her or taking care of yourself, it’s time to seek help. Ask treatment team members for resources. They will be glad to help.

HELPING WITH PRACTICAL TASKS

Daily life carries on despite an advanced breast cancer diagnosis. Clothes must be washed, refrigerators must be restocked and carpool obligations must be met. Seemingly simple household chores can take a great deal of your loved one’s time and energy, but you can knock them out in a fraction of the time.

Before offering your help, assess your own strengths. Are you good with children? Better with pets? A social media whiz? Once you’ve determined how you can best assist, be very specific about how and when you’d like to help. Your loved one might be hesitant to accept assistance, and clear-cut offers are much harder to turn down. Finally, keep in mind that advanced breast cancer is a chronic illness. The initial outpouring of support when someone is diagnosed soon fades and, as time goes on, your loved one may be left without much help. Space out the times you lend a hand.

TIPS FOR THE MALE CAREGIVER

- **If you are a man caring for your partner** with advanced breast cancer, you face a unique situation. To provide the best care you can, you may need to step outside of some of the stereotypes that have defined your relationship up to this point:
  - **Open up.** Not a fan of talking about your relationship? Since your partner’s diagnosis, communication is much more than just talking about your relationship. It includes talking about her feelings, your feelings and anything else that is on your minds — cancer-related or not. Knowing you’re not bottling up your feelings will be a stress reliever for her, too. You’re both going through an incredibly difficult time, so don’t be afraid to talk about it. Sometimes communicating just means listening, and that is just as important.
  - **Choose to be positive.** There will be speed bumps that derail you and mountains that seem impassable. While you can’t always avoid those setbacks, you can choose to adopt a positive and realistic attitude. Your genuine optimism may show your loved one a different, stronger side of you.

- **Channel these emotions.** If you are typically the “fixer” in the relationship, an advanced breast cancer diagnosis for your partner will really challenge you. You may feel angry, cheated and scared that this disease has invaded your life and you can’t cure it. You’re not the only one! Instead of letting those emotions get the best of you, channel that energy into controlling things you can. Finish those home repairs that you’ve been putting off, tackle items on the household To Do list or take on some household tasks that she typically handles. Keep up your other relationships/friendships.

- **Take the sexuality out of the diagnosis.** Your partner may be overwhelmed by fear that her body will look and react differently after treatment, but she may fear your reaction to these changes even more. Listen to her concerns. Assure her that her breasts, like her lungs or bones, are simply body parts affected by this disease. If this becomes an area of ongoing concern for either of you, don’t hesitate to ask your treatment team for guidance.
### CAREGIVING

#### TOP 10 WAYS TO HELP

<table>
<thead>
<tr>
<th>WHAT TO DO</th>
<th>WHAT TO SAY</th>
<th>HOW IT HELPS</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>COMMUNICATE</td>
<td>“I’d like to set up an email group or use social media to share your treatment updates with family and friends. Let’s spend a few minutes talking about how you’d like me to share the news and with whom you’d like me to share it.”</td>
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<tr>
<td>2</td>
<td>COOK</td>
<td>“Don’t plan anything for dinner on Wednesday because I’m cooking. What time can I drop off a fabulous home-cooked meal?”</td>
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<td>3</td>
<td>ORGANIZE</td>
<td>“I bet you’re up to your ears in paperwork. ‘Organization’ is my middle name. Can I come by on Saturday to help you make sense of it all?”</td>
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<td>4</td>
<td>DRIVE</td>
<td>“Tuesday is my day off. Can I take you to an appointment or on errands?” When kids are involved: “I’ve reorganized the carpool schedule, and I’m taking your week. Enjoy your week off!”</td>
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<tr>
<td>5</td>
<td>CHILD CARE</td>
<td>“Are you ready for a couple of hours of alone time? I’d like to take the kids to a movie on Saturday afternoon.”</td>
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<td>6</td>
<td>PET CARE</td>
<td>“Has your dog been to the dog park lately? I’d like to take him this weekend.”</td>
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<td>7</td>
<td>CLEAN/DO LAUNDRY</td>
<td>“I’m going to swing by on Saturday morning to throw in some laundry for you. I think I’ll vacuum and do a quick bathroom cleaning while I’m there, so let me know if you’re running low on laundry detergent or cleaning supplies.”</td>
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<td>8</td>
<td>OUTDOOR CHORES</td>
<td>“When I’m doing my yard work this weekend, I thought I’d do yours as well.”</td>
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<td>9</td>
<td>SHOP</td>
<td>“I’m making a grocery run. What can I pick up for you?”</td>
</tr>
<tr>
<td>10</td>
<td>MAKE PLANS</td>
<td>“I miss spending time with you. Can I come over for a little bit this weekend and we can have tea, watch a movie or just chat?”</td>
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The Avon Breast Cancer Crusade is a member of the new Metastatic Breast Cancer Alliance of 30 cancer and advocacy organizations. The Alliance’s mission is to unify the efforts of its members to improve the lives of and outcomes for those living with metastatic breast cancer and their families through the following:

- Increasing awareness and providing education about the disease
- Improving data on how many people are living with metastatic breast cancer
- Advancing policy
- Strategically coordinating research funding, specifically focused on metastasis, that has the potential to extend life, to enhance quality of life and, ultimately, to cure

Finally, the Alliance encourages the community to support their efforts through donations, advocacy, and awareness campaigns.
This patient education guide was produced with support from: