Guide to Metastatic Breast Cancer

36 WAYS TO FEEL YOUR BEST

✔ Partner with your healthcare team
✔ Be inspired by others who have stage IV breast cancer
✔ Get answers from a top breast cancer oncologist

“Four years later, I’m here, I’m hopeful... and I’m happy!”

Advocating for herself—and helping others do that, too—gives Christine Hodgdon peace of mind.

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Welcome the joyful moments ahead!

Today’s powerful treatments are cutting metastatic breast cancer down to size, giving you lots to look forward to.

Last week, Anita, 66, was in the audience as her 9-year-old granddaughter, Sydney, sang a solo at the grammar school’s talent show. “It was ‘On My Own,’ from Les Mis!” says Anita. “It’s such a grown-up song, but she loves it, and she sang it so beautifully.” And when Sydney won second prize, Anita rose to her feet, clapping alongside her daughter Jeanne, Sydney’s mom.

It was a proud moment for Anita, a retired project manager from Tulsa, OK. Yet about two years earlier, she wasn’t sure she’d be there to witness the milestones in Sydney’s life. “I started feeling short of breath and kept coming down with one respiratory infection after another. After four months of feeling lousy, I told my doctor, “ recalls Anita. “It didn’t occur to me that it could be related to the breast cancer I’d beaten a few years earlier. I thought that was all behind me.”

But then came the news she hadn’t expected: “My doctor told me that the breast cancer had returned and had metastasized to my lungs—I had stage IV breast cancer. It was devastating. Especially when the first treatments I tried weren’t working.”

Just as she was losing hope, Anita’s doctor told her she was eligible for a new type of treatment—a CDK 4/6 inhibitor—designed to take aim at her type of cancer.

“I jumped at the chance!” says Anita, whose latest scan showed that her tumors had shrunk considerably. “Plus, the treatment is supposed to prevent the cancer from spreading, so I’m still taking it, and you know what? I feel pretty good!”

To find your path to hope, learn as much as you can about your cancer, talk with your healthcare team, explore your treatment options and enlist the support of the people who mean the world to you.

In the pages of this guide, you’ll find the information, inspiration and empowerment that can accompany you on your journey. Read it. Then use it to spark a conversation with your doctor in order to come up with a treatment strategy that makes sense for you.
A closer look at metastatic breast cancer
Metastatic breast cancer, or stage IV breast cancer, occurs when cancer cells break away from the original tumor in the breast and nearby lymph nodes, and travel through blood or lymph vessels to organs or tissues in other parts of the body, such as to the bones, lungs, liver, brain or distant lymph nodes. Generally, women who are diagnosed with stage IV disease have finished treatment for earlier stage breast cancer—in some cases, years earlier—only to learn that their cancer is now present in another part of their body. About 5% of women with breast cancer have metastatic disease when they are first diagnosed with breast cancer, according to the American Society of Clinical Oncology.

Know the signs
Not everyone experiences signs that breast cancer has spread. For those who do, general symptoms include fatigue, loss of appetite or weight loss. Additional symptoms depend on the extent to which cancer has spread and where.

How it is diagnosed
To determine if you have metastatic breast cancer, your doctor may order the following tests:
- **Blood tests:** can check for tumors outside the breast, such as in the liver.
- **Imaging tests:** can check for cancer spread to the bones, chest, lungs, liver and abdomen. X-rays, CT scans, PET scans and MRIs are commonly performed.
- **Biopsy:** can check the hormone status of the cancer and identify the subtype of breast cancer (e.g., hormone receptor-positive, human epidermal growth factor receptor-positive, triple negative). In a biopsy, a small sample of tissue is removed from the place where cancer has spread and is examined under a microscope.

Learn more about your cancer
Identifying mutations in your cancer's genes can further help your doctor determine how the cancer will behave and identify tailored treatment options. Test types include:
- **Genomic testing,** which looks at the genes within the cancer cell to reveal what is causing the cancer to grow.
- **Genetic testing,** which looks at the genes you have inherited from your parents and may be recommended if you have a personal history of breast cancer below a certain age, are Ashkenazi Jewish and/or have a family history of breast, ovarian or other cancers.

With all the information that can now be gathered about your cancer, treatments are more effective than ever at halting or slowing cancer growth and prolonging life. While metastatic breast cancer cannot be cured, it can be treated—including therapies that can ease challenging symptoms such as bone pain—so you can achieve the best possible quality of life. See p. 8 to learn about the various treatment options and how they can help you.
Meet your healthcare team

These healthcare professionals will be alongside you during your cancer journey.

- **Medical oncologist**: specializes in treating cancer with medicine
- **Radiation oncologist**: specializes in treating cancer with radiation
- **Surgical oncologist**: specializes in treating cancer with surgery
- **Palliative care doctor**: specializes in preserving quality of life through pain management and symptom relief
- **Pathologist**: makes diagnoses and may submit cancer tissue for molecular studies
- **Radiologist**: performs MRI studies and nuclear medicine studies
- **Plastic surgeon**: assists with reconstruction after surgery, such as a mastectomy
- **Oncology nurse**: provides inpatient care, support and education during cancer treatment
- **Infusion nurse**: administers medications, such as chemotherapy, through infusions
- **Nurse practitioner (NP), physician assistant (PA), advanced practice provider (APP)**: administers routine care and may prescribe medication
- **Nurse navigator**: provides support, helps you understand therapies and suggests resources to help you get the care you need
- **Psychiatrist/psychologist**: provides counseling; psychiatrists can also prescribe medication
- **Social worker**: helps you manage psychological and social issues, as well as financial concerns

### Location of breast cancer metastasis

<table>
<thead>
<tr>
<th>Location of breast cancer metastasis</th>
<th>Signs or symptoms</th>
</tr>
</thead>
<tbody>
<tr>
<td>Breast or chest wall</td>
<td>Pain, nipple discharge, lump in the breast or underarm</td>
</tr>
<tr>
<td>Skin</td>
<td>Rash or skin nodules, especially on the chest wall</td>
</tr>
<tr>
<td>Bones</td>
<td>Bone pain (particularly in the skull, spine, ribs or hips); fractures</td>
</tr>
<tr>
<td>Liver</td>
<td>Abdominal swelling or pain; yellow, itchy skin; nausea; swollen hands and feet caused by fluid retention</td>
</tr>
<tr>
<td>Lungs</td>
<td>Shortness of breath, chronic cough, bloody cough, pain in the chest wall</td>
</tr>
<tr>
<td>Brain or spinal cord</td>
<td>Severe headache, confusion, memory loss, vision changes, trouble speaking or moving, seizures</td>
</tr>
<tr>
<td>Lymph nodes</td>
<td>Lumps or thickened areas of skin over lymph nodes</td>
</tr>
</tbody>
</table>
When determining your treatment plan, your oncologist will consider several factors, including your age and general health, your symptoms, the characteristics of the cancer cells (such as your hormone receptor status and HER2 status), where the cancer has spread and any breast cancer treatments you have already had.

**SYSTEMIC THERAPIES**
The main treatment options for metastatic breast cancers are systemic therapies, which kill cancer cells throughout the body.

One or more of these therapies may be used simultaneously. They include:

- **Hormone therapy**, which prevents cancer cells from getting the estrogen they need to grow and spread. Hormone therapy may be used if your cancer is estrogen- or progesterone-receptor positive. Hormone therapies include:
  - **Tamoxifen**, which blocks estrogen from cancer cells
  - **Fulvestrant**, which blocks and damages estrogen receptors
  - **Aromatase inhibitors (AIs)**, which stop estrogen production

- **Chemotherapy**, which enters the bloodstream and fights cancer cells throughout the body. Chemotherapy may be used if hormone therapy is not appropriate or if it’s been used and no longer controls the cancer.

- **Targeted therapy**, which uses medication to target specific pathways or mutations in tumor cells. While more focused than chemotherapy, these drugs are also present in many normal tissues. Targeted therapies include:
  - **Trastuzumab**, which treats HER2-positive breast cancers by attaching to the HER2 protein on cancer cells, preventing them from growing

With your doctor’s help, you can zero in on the strategy that feels right.
CDK 4/6 inhibitors: extending lives!

These breakthrough drugs, approved by the FDA in 2017, slow the growth of metastatic breast cancer—and are helping women around the world live longer. Here’s what you should know:

How do CDK 4/6 inhibitors work? CDK 4/6 inhibitors bind to cyclin-dependent kinase (CDK) proteins in cells, especially CDK 4 and 6, ultimately blocking cancer cells’ ability to reproduce. This prevents the cancer from growing and spreading out of control.

How are CDK 4/6 inhibitors given? CDK 4/6 inhibitors are oral medications that are usually given in combination with hormone therapy (e.g., either an aromatase inhibitor or fulvestrant). However, in some cases a CDK 4/6 inhibitor may be used alone.

Who is a candidate for CDK 4/6 inhibitors? You might be a candidate if you have hormone receptor-positive, human epidermal growth factor receptor 2-negative (HR+, HER2-) metastatic breast cancer. Keep in mind: Your status may have changed since your original cancer diagnosis. Ask your doctor if a biopsy should be performed to determine your current status. The result may allow you to benefit from treatment with a CDK 4/6 inhibitor.

• **CDK 4/6 inhibitors**, which treat hormone receptor-positive, HER2-negative breast cancers by blocking a protein that enables cancer cells to spread (see sidebar for more information)
• **PARP inhibitors**, medications used in women with BRCA gene mutations. They block an enzyme involved in DNA repair, so damaged cancer cells cannot repair themselves

**LOCAL THERAPIES**

Local therapies may be used to shrink tumors, slow cancer growth, ease symptoms and prolong life. They include:

- **Radiation therapy**, in which high-energy X-rays are used to shrink tumors and destroy cancer cells that may have spread. Radiation therapy is also used to relieve pressure from tumors pressing on nerves.
- **Surgery**, which may be performed on the breast (via a lumpectomy, when part of the breast is removed, or mastectomy, when all breast tissue is removed) or to remove other cancer sites. Surgery may also be used to remove a tumor that is compressing the spinal cord, to stabilize a bone that faces impending fracture or to repair a fracture.

**WHEN STAGE IV DISEASE PROGRESSES**

If stage IV breast cancer progresses during treatment or recurs after treatment, a different medication or combination of medications may better treat your cancer. In addition, you may be eligible for a clinical trial—discuss the possibility with your oncologist. In any case, remember this: Your care team has a greater arsenal of cancer-fighting treatments than ever before, so chances are good you’ll soon get back to the business of enjoying your life and loved ones! ☁
“This is the happiest I’ve ever been!”

When treatment for metastatic breast cancer gave Christine Hodgdon a second chance, she decided it was time to give back!

—BY KATHLEEN ENGEL

“When I’m here. My treatments have bought me some time, hopefully a lot of time!” says Christine Hodgdon, whose scans have shown “no evidence of disease” since Labor Day 2015. Determined to make that “second chance” meaningful, “I decided that every day I’m on this earth, I need to be happy—and do the things that make me happy.”

One thing that makes Christine very happy is helping other women facing metastatic breast cancer understand their treatment options and locate clinical trials. After Christine counseled a frightened woman with brain metastases, the woman couldn’t thank her enough: “You’re a lifeline for me,” she told Christine, who has a background in science. For Christine, the moment confirmed that she was on the right path and encouraged her to create a clinical trial database on her site, TheStormRiders.org. She also began collaborating with medical researchers at BreastCancerTrials.org. Her mission? To provide comfort.

“It was surreal”

Back in November 2014, Christine, then 34, discovered two breast lumps while showering. Her gynecologist referred her to a surgeon, who assured her everything was fine; after all, she was young and had no family history of breast cancer, so he sent her home. But a few months later, when the lumps had grown, he removed them, and a biopsy confirmed that Christine had invasive ductal carcinoma—breast cancer—as well as suspicious nodules in her neck and lung. It turned out that the nodule in her neck was an easily treatable form of thyroid cancer, but the lung lesion was another matter. A biopsy revealed that it was de novo metastatic breast cancer—a term that describes breast cancer that has already spread elsewhere in the body at the time of the initial diagnosis.

It knocked her flat, but then...

“I took charge!”

Christine remembered the lesson she learned when her father passed away quickly from a rare cancer in 2009: Get a second opinion! “I, in fact, got six,” she says. As a result, she transferred her care to a different doctor and hospital. And she not only researched the drugs and trials that could help her subtype of metastatic breast cancer but all subtypes. “Cancer can change subtypes, so I wanted to be prepared. That’s when I realized that what I was doing could help others—especially people living in rural communities desperate to know about trials.”

And despite rigorous treatment (chemotherapy, surgery and radiation followed by monthly infusions of targeted therapy and daily hormone therapy), Christine seized every opportunity to attend breast cancer conferences, establish an online presence and introduce herself to patients, physicians and...
"I decided that every day I’m on this earth, I need to be happy—and do the things that make me happy," says Christine.
Metastatic breast cancer is relentless and doesn’t take a day off.

Verzenio, the first and only treatment of its kind that can be taken every day*.

*150 mg orally twice a day, as directed by your doctor.

Women live longer without their cancer getting worse
In a clinical trial, Verzenio + an aromatase inhibitor (AI) delayed disease progression for over 2 years (a median of 28.2 months) vs 14.8 months with an AI alone†

More than half of women saw their tumors shrink
In a clinical trial, 55.4% of women on Verzenio + an AI saw their tumors shrink vs 40.2% on an AI alone†

†Clinical trials are ongoing to determine if there is an overall survival benefit.
SAFETY SUMMARY

Important Facts About Verzenio® (ver-ZEN-ee-oh). It is also known as abemaciclib.

PURPOSE
Verzenio is a prescription medicine used to treat a type of breast cancer. It is a medicine you can take if:
- You have a type of breast cancer called HR+/HER2- (hormone receptor positive/human epidermal growth factor receptor 2 negative) and the cancer has spread to other parts of the body (metastasized)
- Verzenio is given along with an aromatase inhibitor as initial endocrine-based therapy for the treatment of postmenopausal women, along with fulvestrant in women whose disease has progressed after hormonal therapy, or by itself in adults whose disease has progressed after hormone therapy and prior chemotherapy

It is not known if Verzenio is safe and effective in children.

WARNINGS
Verzenio may cause serious side effects, including:
Diarrhea is common with Verzenio, may be severe and may cause dehydration or infection. The most common time to develop diarrhea is during the first month of Verzenio treatment. Your doctor may stop your treatment, lower your dose, or tell you to wait to begin your treatment cycle if you have diarrhea.
- At the first sign of loose stools, tell your doctor. You may be advised to start taking an antidiarrheal medicine (such as lopramide) and drink more fluids

Low white blood cell counts (neutropenia) are common with Verzenio and may cause serious infections that can lead to death. Your doctor should check your white blood cell counts before and during treatment. Tell your doctor right away if you have fever or chills.

Verzenio can cause liver problems. Tell your doctor right away if you have any of the following signs or symptoms of liver problems:
- Feeling very tired
- Pain on the upper right side of your stomach area (abdomen)

Verzenio may cause blood clots in your veins or lungs. These may be serious and have led to death. Tell your doctor if you have the following signs and symptoms of a blood clot:
- Pain or swelling in your arms or legs
- Shortness of breath

Verzenio can harm your unborn baby. Use effective birth control during treatment and for at least 3 weeks after the last dose of Verzenio and do not breastfeed during treatment with Verzenio and for at least 3 weeks after your last dose. Verzenio may affect the ability of males to father a child.

COMMON SIDE EFFECTS
The most common side effects of Verzenio include:
- Nausea
- Infections
- Low red blood cell counts (anemia)
- Decreased appetite
- Headache
- Hair thinning or hair loss (alopecia)
- Abdominal pain
- Tiredness
- Low white blood cell counts (leukopenia)
- Vomiting
- Low platelet counts (thrombocytopenia)

These are not all of the possible side effects of Verzenio.

POSSIBLE SERIOUS SIDE EFFECTS
Verzenio may cause serious side effects. For example, diarrhea, low white blood cell counts, liver problems, and blood clots can become serious (see Warnings).

Tell your doctor if you have any side effects. You can report side effects at 1-800-FDA-1088 or www.fda.gov/medwatch.

BEFORE USING
Before you use Verzenio, tell your doctor:
- If you have fever, chills, or other signs of infection
- If you have liver or kidney problems
- About all the medicines you take, including prescription and over-the-counter medicines, vitamins, and herbal supplements. Especially tell your doctor if you take a medication that contains ketoconazole. Avoid grapefruit products while taking Verzenio. Grapefruit may increase the amount of Verzenio in your blood

HOW TO TAKE
Use Verzenio exactly as your doctor tells you.
- Take your doses of Verzenio at the same time every day
- If you vomit or miss a dose take your next dose at your regular time. Do not take 2 doses of Verzenio at the same time to make up for the missed dose
- If you take too much Verzenio, call your doctor or go to the nearest hospital emergency room right away

LEARN MORE
For more information, call 1-800-545-5979 or go to verzenio.com. This summary provides basic information about Verzenio and is not comprehensive. Read the information that comes with your prescription each time your prescription is filled. This information does not take the place of talking with your doctor. Be sure to talk to your doctor or other healthcare provider about Verzenio and how to take it. Your doctor is the best person to help you decide if Verzenio is right for you.

C-AL-US-0404

Learn more at verzenio.com

Verzenio® abemaciclib 50|100|150|200 mg tablets twice a day

Verzenio® is a registered trademark owned or licensed by Eli Lilly and Company, its subsidiaries or affiliates.
Christine offers the strategies that have helped her manage her disease and make the most of every day.

Stay healthy and active—despite metastatic breast cancer

1. Surround yourself with positive people. After her father’s death in 2009, Christine was moved to cut out “toxic people” from her life—and that has remained a priority. “I feel strongly about this: I surround myself with people who have good energy—who don’t suck my energy or make me feel bad.”

2. Get a second opinion. “A good oncologist wants another doctor to corroborate their treatment plan,” says Christine. “A second opinion doesn’t have to mean an office visit—it can be a phone call.” Above all, adds Christine, “you should feel comfortable with the treatment plan and comfortable with the doctor.”

3. Be your own advocate. “Remember that this is your life and you’re in charge of it. People see the white coat and think the doctor’s in charge, but they’re not. Every time I go to the doctor, I have questions. I see them as working for me.”

4. Embrace palliative care. When Johns Hopkins Breast Center director Lillie Shockney (one of this guide’s two medical reviewers) urged Christine to meet with a palliative care team, Christine didn’t see the point. “I remember thinking, I’m stable and doing so well.” But Lillie convinced her it was the perfect time to get things in place, “so that if things do go awry, you don’t have to think about it.” Christine is glad she did. “I got tips for the allergic symptoms I deal with due to my medication, and help with hot flashes and night sweats from hormone therapy. I tell people, your oncologist is focused on the cancer, the palliative care team is focused on the person. They help you deal with the side effects of treatment and improve your quality of life so you can live to the fullest!”

“I listened to my body”

Christine also left her job as a conservation biologist and devoted herself to self-care: She replaced her arduous exercise routine (she’d been training for a triathlon at the time of her diagnosis) for a less rigorous home workout plus yoga. She got hooked on meditation: “It slows my brain down. It helps me cope with anxiety and deal with fear of the unknown.” And she went on a retreat for women with metastatic breast cancer through the Johns Hopkins Breast Center. She also signed up for regular massages with a therapist certified in oncology massage, saw a physical therapist who specializes in lymphedema and started an antidepressant for the hot flashes caused by hormone treatment.

While help, in many forms, is out there, coping with a stage IV diagnosis takes bravery, she says. “Sometimes I’ll think, let me just get through the next five minutes. And then I just breathe.”

Researchers. “At this moment, advocacy work makes me happy,” she says. “If I can help one person be a little less afraid of their future, that boosts my quality of life!”

“I listened to my body”

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true inspiration
Take your quality of life to the next level

Christine didn’t hesitate to seek help for symptoms that were sapping her: “It’s important during treatment to have a good quality of life,” says Christine, who sought relief for hot flashes and insomnia. Take a moment to reflect on ways your days could be better. Fill out this worksheet and review with your care team. They can help you find ways to feel your best.

**Check the response that applies to you:**

<table>
<thead>
<tr>
<th>The following symptoms are a problem...</th>
<th>Rarely</th>
<th>Occasionally</th>
<th>Often</th>
<th>Almost all the time</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pain</td>
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<td>Fatigue</td>
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<td>Nausea</td>
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<tr>
<td>Disturbed sleep</td>
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<td>Distress</td>
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<td>Shortness of breath</td>
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<td>Poor memory</td>
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<tr>
<td>Decreased appetite</td>
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<tr>
<td>Drowsiness and fatigue</td>
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<tr>
<td>Sadness</td>
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<tr>
<td>Vomiting</td>
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<tr>
<td>Numbness</td>
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</tbody>
</table>

**Check the response that applies to you:**

<table>
<thead>
<tr>
<th>Coping with my cancer and its treatment is...</th>
<th>Rarely</th>
<th>Occasionally</th>
<th>Often</th>
<th>Almost all the time</th>
</tr>
</thead>
<tbody>
<tr>
<td>Causing me to limit my general activity</td>
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<tr>
<td>Taking a toll on my mood</td>
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<tr>
<td>Making it hard for me to work</td>
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<tr>
<td>Putting a strain on my relationships</td>
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<tr>
<td>Making it difficult to walk</td>
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<tr>
<td>Sapping my ability to enjoy life</td>
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</table>

**Fill in the blank:**

1. Right now, ___________ is a big problem and disrupting almost every day.

2. It is very important to me to be able to ___________ despite having cancer and undergoing treatment.

3. I wish I could snap my fingers and ___________ would go away.

4. I wish I could snap my fingers and be able to ___________ again.

5. On a scale from 1 (low) to 10 (high), my sense of hope is ___________

**Ask:** Could I benefit from palliative care? If so, can you refer me to a palliative care practitioner?
Q: I’m a single mom and an elementary school teacher, and I’ve just been diagnosed with stage IV breast cancer. Am I going to be able to work? Are there precautions I can take to protect myself?

A: I hope so. We need our teachers! Generally speaking, being able to maintain a normal and healthy lifestyle is a goal for all patients with stage IV breast cancer. At times, the extent of disease and/or side effects of therapy might require time off or a reduced schedule, but many women with stage IV disease are feeling fine and receiving therapies that are very well tolerated—including antiestrogens, chemotherapy drugs given orally or chemo that’s intermittently infused.

Teachers do have a special responsibility to be there for their class, so it is worth discussing with your oncologist how you can expect to feel during the semester or year ahead given the extent of your disease and the planned treatments. You may be a bit more tired, and juggling work and motherhood is a challenge at times even without breast cancer.

In terms of precautions, good handwashing is important, as is getting a flu shot. Most illness in school-age children is viral, and handling of viral infections is generally not a problem for a woman with breast cancer on treatment. An exception might be chickenpox, only if you have not yourself had this in your own childhood, and that is a very uncommon situation.

Q: I was diagnosed with de novo stage IV breast cancer with liver metastases. My oncologist said that mastectomy wasn’t an option and that getting rid of the cancer in the liver was a bigger concern. But a woman in my support group who is also stage IV did receive a bilateral mastectomy. (I’m 63 and she’s 42.) Is age a factor in deciding whether surgery is part of the treatment plan for stage IV breast cancer?

A: I agree with your oncologist as a general principle. Once a cancer has spread from the organ of origin (in this case the breast) to other sites, systemic therapy rather than local therapy is the higher priority. This generally requires medical management, not surgery. If the medical management is successful in controlling the liver metastases, it should also help with the tumor in the breast, as well as other sites that may be involved elsewhere in the body. Age is not a factor in this decision.

Your question is a good one and comes up frequently. As a result, several studies on this issue have been performed, and they have shown no overall benefit to mastectomy at the time of diagnosis for women with stage IV disease. That being said, there are always specific situations where surgery could be helpful, but one would need to consider that carefully case by case. Certainly, for now, start with systemic therapy—antiestrogens, chemotherapy and biologic agents as are indicated by your tumor characteristics. The need for any subsequent surgery can be evaluated as you go along. Most often, it is neither needed nor performed.
GENE TESTING FOR MY DAUGHTER?

Q I was most recently diagnosed with stage IV breast cancer. My daughter, who is 28, wonders if she should go for genetic testing to see if she has an increased risk for breast cancer.

A The best approach to genetic testing is to start by testing the patient who has the cancer. If you do not have a harmful hereditary mutation such as BRCA1 or BRCA2, there is no need to test your daughter; she can’t inherit a mutation from you that you don’t have! That is, if there is no mutation, there is nothing to pass on to your children. Ninety percent of breast cancer is not attributable to a known inherited mutation. A negative genetic test for you would strongly suggest that your cancer falls into this larger category.

That said, testing for your daughter may be wise if there is a history of breast cancer on her father’s side—but that has nothing to do with your recent breast cancer diagnosis.

At times, we also test a woman who has a family history of breast cancer but no personal cancer history because we are unable to test the actual family member who has had a cancer. So, if you meet the current guidelines for testing, get tested and the results will determine whether your children, siblings and other relatives should also be tested. If a specific mutation is identified in your testing, it is also much easier to test other relatives because you are looking for that specific mutation in general instead of screening many genes in detail.

SCARED ABOUT MY FUTURE

Q When I look on the internet, I read about a poor prognosis for my metastatic breast cancer. I’m frightened! Is a better outcome possible?

A The prognosis for patients with metastatic breast cancer is highly variable, and statistical “averages” do not predict outcomes for individuals. Response to treatment is probably the most reliable predictor of the clinical course of disease. New treatment approaches are continually emerging, and many of these have significantly improved outcomes, such as HER2 targeting with trastuzumab and the combination of CDK4/6 inhibitors with antiestrogens. These two breakthrough therapies are examples, and there are many new therapies in the pipeline at present. While not all new treatment strategies will be equally successful, there will almost certainly be continuing progress based on the extent of the ongoing research and development. So, the goal for a patient with metastatic disease today is to achieve the best possible response from the current available treatments and keep an eye on the evolving options for next steps when needed.

HELP FOR DEPRESSION

Q I’m writing about my wife, who’s in treatment for stage IV breast cancer. She’s very moody, often irritable, and seems unable to enjoy anything. But she insists that she’s fine. How can I help her?

A Given the circumstances, it is not unusual that she is feeling discouraged, and perhaps depressed. Talk to her about getting some professional help and recommendations, and you can offer to go with her if she would like. A “situational” depression is often very treatable with therapy and/or medication. There are many existing formats for support beyond medication, ranging from individual therapy to patient groups. Many institutions also offer support—individual or group—for spouses.

OUR EXPERT: Steven E. Come, MD, Associate Professor, Medicine, Harvard Medical School, member of the Breast Medical Oncology Program at Beth Israel Deaconess Medical Center, Boston, MA.
“We’re living full and active lives!”

Thanks to today’s advanced treatment options for metastatic breast cancer, Kelly, Keyla and Nadine are moving forward with faith and optimism! Read on to learn if their strategies can help you, too. —BY AMY CAPETTA

Practice gratitude. “Even though it is really discouraging to get a diagnosis like metastatic breast cancer, being grateful for what I have has been an important part of my life,” says Kelly. “It’s been this way for me from the start—and it really isn’t very hard to find things you’re thankful for.” Kelly is grateful for the four men in her life (her husband, Greg, and their three sons), their extended family (which includes parents, siblings, nieces and nephews), friends, neighbors, and her faith in God.

Find the silver linings. Initially, Kelly’s treatment plan involved getting infusions every three weeks. “As a busy stay-at-home mom of three boys, I looked at it as the time I had to myself,” she says. In fact, she even discovered the upside to having a PET scan. “I had to lie still for one hour in a dark room and stay as relaxed as possible. And I thought, ‘Okay, I like this—I’ll take a nap!’” But the ultimate silver lining? The results of her most recent scan showed that “the cancer is so minimal, it’s almost undetectable!” Kelly now receives infusions every four weeks.

Go to the “science.” “Don’t just pay attention to the blogs and the anecdotes,” says Kelly. As an example, Kelly relied on nutrition advice from a 30-page university study on the connections between breast cancer and food. “The summary said to cut back or eliminate meat, dairy, sugar and alcohol, while adding flax seeds, blueberries, cruciferous veggies (such as broccoli, cauliflower and kale), and green tea, so that’s what I did.” [Note: Discuss any research with your healthcare provider before putting it into practice.]
"Educate yourself"

Keyla Nunny Reece
(pictured here with husband Scott)
Hope Mills, NC
Diagnosed June 2017

**Live by the 3 L’s.** Once the initial shock (and anger) diminished after diagnosis, Keyla came up with a personal mantra: *Love, Live, Life.* “I will ‘love’ my family and friends more than I ever did before being diagnosed,” she explains. “I will ‘live’ every day to the fullest. And I will be thankful and feel blessed for each day that God gives me the opportunity to live my ‘life’ with my family and friends.”

**Learn about palliative care.** This public speaker and patient advocate wants others to understand that palliative care is not the same as hospice. “Palliative care helps ensure that the individual living with any disease—whether it is terminal or not—has an excellent quality of life,” she says. “Palliative care specialists focus on controlling the individual’s pain, not treating the condition.” This service has provided her with anxiety medication for the extra-difficult days, she adds.

**Do your homework.** “Research, research, research!” says Keyla, who believes the key to feeling more in control of your situation is to study the specific type of metastatic breast cancer you have. “Having this knowledge, along with understanding the medical terminology, has allowed me to fully comprehend my diagnosis and treatment plan when speaking with my team of doctors.”

**Schedule “me time.”** Keyla believes that focusing on self-care is vital for overall well-being. “It helps to reset my mind and body so that I can face what lies ahead in the upcoming days and weeks,” she says. Her favorite activity: a pedicure. “When I feel the weight of the world on my shoulders, there is something so relaxing and stress relieving when I put on my earphones and place my feet into that tub of hot water. For the next hour, I allow my mind to forget everything I had to deal with that day.”

PHOTO BY EVAN PIKE
“Stay positive”

Nadine Parsons, Toronto, Canada
Diagnosed January 2018

Establish a positive mindset. Nadine recalls the insightful words that came from one of her physicians. “The doctor said, ‘You could be on a flight to Palm Springs, worried about the plane crash, or you could think about your destination and be enjoying the ride’—and that’s how I’ve chosen to be in my new life,” she says. And her optimistic attitude isn’t just wishful thinking. “It’s been proven that people who have a positive mindset live longer.”

Embrace all kinds of treatments. Both conventional and holistic therapies are part of Nadine’s protocol. Along with taking a chemotherapy medication, she practices meditation (“I meditate each morning,” she says. “I breathe in the word ‘health,’ and breathe out the words ‘negativity’ and ‘disease.’”). And she goes for regular acupuncture sessions, which she says have helped with bone pain. “My naturopath is a huge part of my healthcare team,” she says. “And I take supplements that help work with my Western meds. Everything has been approved by my oncologist, which is key.”

Ditch the junk food. While there is no “magic bullet” diet known to prevent breast cancer or keep it from recurring, Nadine, like many women, has made an effort to “clean up” her diet since her diagnosis. “I’m almost entirely organic with produce,” she says. Beef is off the menu, while organic chicken, fish, eggs and turkey bacon are on. She has also slashed her intake of sugar, limits dairy and eats only fruits that are in-season. “Yet I eat three squares of 78% dark chocolate per day— I’m still living my life!”

Keep moving. Nadine exercises five days a week. On a typical day, she either walks briskly for 30 minutes, practices yoga or Pilates, or does light weight training. And she keeps forging ahead. As a director of a wholesale jewelry company and an on-air style expert, Nadine continues to work full-time from her home office. “I had to stop traveling to America for business meetings in 2018 due to my medical schedule, but I’ll be traveling again in 2019!”

Resist the urge to Google. “Without any sort of education or guidance, a stage IV diagnosis can be overwhelming—and terrifying,” says Nadine. While her instinct was to head to the internet, she quickly learned it wasn’t a good idea. “Dr. Google is not my friend, since it says I’m dying in less than 26 months,” she says. “However, I eventually realized this prognosis was based on statistics from research conducted in 2012-2013, which would have been done about five years before the study was published. The truth is, it’s not accurate information for 2018 and beyond.”
WE ALL KNOW SOMEONE DEALING WITH CANCER. HELP US CHANGE THAT.

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Vanessa, Cancer Survivor

Attacking from every angle.
Keep your immunity high!

Wherever you are in your treatment plan, amping up your immune system can help you feel your best—and may help you respond better to treatment, too!
EAT FOR ENERGY
Taking in the right amount of calories and nutrients helps you weather your treatment regimen and boosts your stamina. Trouble is, some therapies can take away your appetite and cause nausea and vomiting.

What you can do
• Talk to a nutritionist. Many hospitals and cancer treatment centers have nutritionists on staff; some even specialize in oncology nutrition. These professionals help you come up with an eating plan and give you tips for overcoming nausea.
• Eat small meals, frequently. Small meals and snacks may be easier to stomach than large meals, and can help you get the nutrition you need to fire up your energy. Keep snacks like nuts, cheese and crackers, pretzels and dips, and yogurts on hand—and eat whenever you’re hungry, even if it’s a time you normally don’t eat.
• Make food more appealing. If your meals seem to lack flavor, try using marinades, sauces, onions, sharp cheeses and even syrups on your food.

KEEP STRESS AT BAY
Research shows that stress hormones promote tumor growth in people who have cancer—and that people with a negative outlook about their cancer have a faster disease progression and a poorer response to therapy.

What you can do
• Cut anxiety down. Worrying about the future and waiting to see if treatments are effective can be stressful. When you feel yourself becoming tense, replace negative thoughts with something pleasant—such as a call, a meal or a visit from a loved one.
• Focus on the solution. Taking steps to figure out a solution diminishes the problem. Ask yourself, What is the smallest first step I can take to solve it? Then, do it! Are you worried about medical bills? Make an appointment with your nurse navigator to get help.
• Find ways to relax. Christine Hodgdon (read her story on p. 10) meditates, does yoga or goes out for a jog. Anxiety about scans? These activities keep Christine too busy to stress over tests!

FEND OFF DEPRESSION
Depression can make it more difficult to follow your treatment plan and also make you less likely to follow through on healthy behaviors such as eating well or exercising. Plus, certain therapies may cause depression or worsen existing depression.

What you can do
• Open up to your healthcare team. They can assess whether you need to be treated for depression and/or if your treatment plan should be adjusted or even switched to a different plan.
• Get a handle on your treatment plan. You may feel overwhelmed by all it takes to fight metastatic breast cancer. Work with someone on your care team who can help you get through each step, one at a time. It can help just knowing there’s someone in your corner!
• Share your feelings. Consider expressing your emotions in a journal, with a trusted friend or, if you’re okay with going public, in a blog, as well as with a licensed therapist. The important thing is that you put words to your emotions and face them.

feel your best
Questions
to ask at
today’s exam

Getting the answers can help you stay on top of your treatment.

1. What are the results of my tests and scans?

2. What is the subtype of my metastatic breast cancer? How does that affect my treatment options?

3. Could my subtype change, and if so how will we know?

4. What treatment do you recommend at this time, and why?

5. How soon do I need to make a decision about treatment?

6. How will we know if my treatment is working?

7. What are the possible side effects of my treatment? Are there ways to avoid or limit them?

8. Will I be able to work during treatment?

9. What symptoms or side effects should I report to you?

10. What additional tests will I require, and how often will I need to have them performed?

11. What can I do on my own to avoid complications and feel my best?

12. Is there a clinical trial that could help me?