

# Metastatic Breast Cancer

## Breast Cancer in the Bones

BY ERIN ROWLEY

One day in 2013, **Kelly Shanahan** sneezed and felt horrible back pain. Even as a surgeon, and as someone who had breast cancer before, Kelly didn't suspect metastatic breast cancer.

But that's what tests showed Kelly, now 56, from South Lake Tahoe, California, had in bones throughout her body. That pain in her back was a bone that had fractured because of a metastatic lesion. And a bone in her leg was about to break.

The diagnosis of metastatic breast cancer to the bones can be a shock, even if you've had breast cancer before. But you are not alone. The bones are the most common place for breast cancer to spread. In fact, most people with metastatic breast cancer have it in the bones. You may have metastases in your bones only or in the bones and other parts of your body. Bone pain, fractures and other effects of breast cancer in the bones, called *skeletal-related events*, or *SREs*, often lead to the diagnosis. But different people experience different amounts of SREs, pain and discomfort.

"Sometimes patients have symptoms from one bone metastasis but not another," says **Victoria Blinder, MD**, an oncologist at Memorial Sloan Kettering Cancer Center, in New York City. "There are lots of factors that can contribute to whether or not someone has symptoms, in part, where the [metastatic] site is, how much a person uses that [part of the body], or if it's complicated by a fracture."

Most *systemic treatments* you get for metastatic breast cancer, like chemotherapy, hormonal therapies and anti-HER2 targeted therapies, are likely to be based on the cancer's subtype (hormone receptor-positive, HER2-positive or triple-negative), not on where the cancer has spread. That's because those treatments travel throughout the body and try to keep the cancer from growing or spreading, no matter where it's located.



Kelly Shanahan

But there are some therapies, both systemic and *local* (specific to where the cancer is located) that can ease bone pain, prevent SREs, strengthen bones and treat metastases.

### Surgery

Surgery, a local therapy, is often used to stop bones from breaking and to ease pain.

Six days after her diagnosis Kelly had surgery to stabilize her leg bone with a metal rod. She has also had a *kyphoplasty*, in which cement is injected into certain bones to ease back pain.

How long it takes you to recover from surgery will depend on many factors. Talk to your healthcare team about what to expect after surgery.

### Radiation

*Radiation therapy* is a local therapy that uses high-energy x-rays over a number of days or weeks to kill cancer cells and lessen pain in people with metastatic breast cancer to the bones.



With you, for you.

“We can’t give someone radiation to the whole body to treat the cancer, but we do want to address and minimize pain as much as possible,” Dr. Blinder says. “Radiation therapy seems to work very well for that.”

In many cases doctors don’t recommend you have more than one series of radiation treatments to the same area, but the pain relief radiation provides is usually long-lasting, Dr. Blinder says. Common side effects of radiation include tiredness, which gets worse as the treatments go on, and skin reactions, such as dryness, itchiness, burning or peeling.

## Bone-Modifying Agents

Your doctor may prescribe a systemic therapy called a *bisphosphonate*, a bone-modifying medicine that can make your bones stronger and reduce bone pain. Bisphosphonates may also stop new bone metastases from forming.

The bisphosphonate most often used in metastatic breast cancer is zoledronic acid (Zometa). It is given by vein. It’s been common to get zoledronic acid once a month, but new research shows it works well when given every 3 months. Getting it less often is easier and may mean fewer side effects. At Memorial Sloan Kettering, where Dr. Blinder works, every 3 months is now the standard of care, but other providers may be slower to adopt this. If your doctor recommends treatment with zoledronic acid every month, consider asking why.

RANK ligand inhibitors like denosumab (Xgeva) are a newer type of bone-modifying agent. Like the bisphosphonates, they can also strengthen bones and lessen pain. Denosumab works as well as zoledronic acid, but can be given by injection just under the skin, so many people find it more convenient. Denosumab is given every 4 weeks.

Potential side effects of bone-modifying agents are low levels of calcium in the blood; and rarely, *osteonecrosis of the jaw*, which involves painful, exposed bone. Ask your doctor whether you should take calcium supplements to prevent low blood calcium. To lower your risk of osteonecrosis of the jaw, have a dental checkup and any needed dental work before you begin taking a bone-modifying agent. If you must have dental work during treatment with bone-modifying agents, talk to your oncologist and your dentist first.

Kelly has been on zoledronic acid and denosumab at different points. She found both medicines tolerable and experienced few side effects. But with her insurance, the medicines were very different in price.

“They’re both acceptable options,” Dr. Blinder says of zoledronic acid and denosumab. “Depending on the situation, if one is going to be a lot cheaper for a patient than the other, cost may be just as important a consideration for the patient as the fact that an infusion is going to be less convenient than the injection.”

Talk to your insurance provider about what out-of-pocket costs you’re responsible for with each treatment. If you need help paying, the company that makes the

medicine may be able to help you through a patient assistance program.

There isn’t a lot of information about how long you should stay on a bone-modifying agent, Dr. Blinder says. Taking it for years may increase the risk of fracture in some bones.

“Knowing where the tipping point is between giving someone [enough] therapy and not putting them at increased risk would be helpful. But I don’t think we know that yet,” she says.

Other, less common, treatments for bone pain include steroids and radioactive chemicals given by vein, such as strontium-89. For more information about these treatments, talk to your healthcare team. Your providers can help you manage symptoms of bone metastases and side effects of cancer treatment.

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## Quality of Life

The Friday after Kelly was diagnosed was the last time she performed surgery. After continuing to see patients in the office for a short time, she went on disability.

“Now I have a full-time, unpaid job as an advocate,” she says.

To limit her risk of pain and fractures, Kelly avoids bending over, and she stopped skiing. She considers herself “very, very lucky” that though she has extensive bone metastases, she doesn’t have the severe bone pain some people have.



### BEYOND THESE PAGES

LBBC’s **Thriving Together: 2017 Conference on Metastatic Breast Cancer** is April 28-30 in Philadelphia. Conference highlights include educational presentations (some of which will be available live on the internet), exhibitors, special activities like yoga, and chances to socialize and network.

For more information, visit [lbcc.org/2017thrivingtogether](http://lbcc.org/2017thrivingtogether)

A circular portrait of Marie Laure Grapperon, a woman with glasses and a purple top, looking directly at the camera.

Marie Laure Grapperon

**Marie Laure Grapperon**, 35, from Oklahoma City, is one of those people for whom bone metastases are disabling. She was diagnosed with stage IV breast cancer in July 2015, after experiencing bad back pain that turned out to be broken bones. She spent 6 months in the hospital and had surgeries to stabilize her bones. She also had radiation to help with serious pain.

Marie uses a walker sometimes. She is no longer able to drive. She had to stop working as a French teacher immediately after her diagnosis.

The cancer has changed how Marie looks, and her body image. She has gained weight and gotten shorter and her posture is stooped. She worries her appearance will cause her 4-year-old daughter, Estelle, to be teased or asked uncomfortable questions by other kids when she starts school.

Her appearance also creates misunderstandings with adults. She is thankful that her bones have gotten stronger since she was first diagnosed. But, she says, “Because I can walk much better than I could a year ago, some people tend to think that [the cancer is being cured], but that’s not the case.”

Marie is part of an internet support group of women with stage IV breast cancer. Since she has a hard time getting around, having an online group works great for her. She recommends others struggling with disability do the same.

“Try to connect with people going through the same thing,” she says. “It definitely helped me.” 🍌

## TELLING MY STORY:

# A Q&A With Jacqueline Breedlove

BY ERIC FITZSIMMONS



In 2014 **Jacqueline Breedlove** was retiring from her job as a social worker. She was getting ready to move from her home of more than 30 years in Oakland, California, to Raleigh, North Carolina, where she lives now. Then she was diagnosed with metastatic breast cancer in her bones and lungs. Jacqueline, 65, had been through breast cancer and treatment twice before, as a single mother with a full-time job. At the time she did not have much interest in learning or speaking about the disease.

With her stage IV diagnosis, Jacqueline has become more active in her own treatment and in connecting with the breast cancer community. She advocates for funding for more research, and she shares her story, and the stories of other people living with metastatic breast cancer. She found resources through Living Beyond Breast Cancer and now volunteers through LBBC’s Hear My Voice program.

Jacqueline spoke with LBBC copy editor and content coordinator **Eric Fitzsimmons** about what it means to share her story and hear from others.

## Eric

Had you always been open about your experiences with breast cancer?

## Jacqueline

I hadn't shared my story at all, with anyone, other than a sister that lives in another city who also was diagnosed. But in terms of friends or co-workers: No, I did not share my story. I did not want to receive pity from others, which is the experience I had seen for other people, as a retired social worker. People want to empathize with you but there is no way they can, because you can't have empathy for something you haven't experienced.

## Eric

Why did that change?

## Jacqueline

I think it had to do with getting a diagnosis of [metastatic breast cancer], which is a lifelong disease. ... This is something I have to live with and it's something that I saw other women living with and some of those women were much younger than I was.

[I was] inspired to learn more about metastatic breast cancer and to be able to share that with others, because throughout my diagnosis it was not something shared with me. I was really lost in terms of even knowing what metastatic breast cancer was or the possibility that [breast cancer] would come back. Because a lot of people think of breast cancer and they think, you get chemotherapy and you're done. It's not coming back. You're cured. That may or may not be the truth depending on what's going on within someone's body. I didn't get that message the first two times.

## Eric

What else changed after the metastatic diagnosis?

## Jacqueline

Before I retired, most of my life was minimal exercise and working long hours and gaining weight and not necessarily eating correctly. Once I got my diagnosis I no longer was working a job. And that's not the situation for everybody, because not everybody is in the situation where they can retire. I needed to do some type of exercise — because I had problems with my lungs when I got my diagnosis — to help expand my lung capacity and to become physically stronger. So I started a regimen of water aerobics, and now I'm a water aerobics instructor. That was a big change for me. It doesn't feel like exercise at all; it feels like therapy for my body now.

## Eric

What do you hope people will take away from your story?

## Jacqueline

That you become educated. Even though it's called metastatic breast cancer, there are so many different types of cancer that fall in that category, like triple-negative and HER2-positive [and hormone receptor-positive]. [It's helpful] being able to [learn about] which cancer applies to your situation, to see the new technologies [and how those subtypes] are being addressed.

[Also that you connect] with other women who may be using the same type of therapy that you're using. [I was] able to connect with women over the internet and provide support for them, as well as [find some] for myself. Even though I don't see these women in person, we know when someone's going through treatment or when someone's going to advocate or [go to] some type of march, or whatever kind of activity they're going to participate in so others know that there needs to be more funding for metastatic breast cancer.

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*“Always try to be happy, because life is too short to be any other way. ... Happiness is in your heart and it's not based on anybody else.”*

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## Eric

Is there anything else you wanted to share?

## Jacqueline

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A group of Hear My Voice volunteers

### BEYOND THESE PAGES

Living Beyond Breast Cancer's **Hear My Voice** program trains people like Jacqueline to work within their communities to raise awareness of metastatic breast cancer, to fundraise and to advocate for change.

For more information about Hear My Voice, visit [lbbc.org/hearmyvoice](http://lbbc.org/hearmyvoice)