

Metastatic Breast Cancer

When Side Effects Are Too Much

BY JOSH FERNANDEZ

The goal of treatment for metastatic breast cancer is to shrink or weaken the cancer while also helping you maintain your quality of life, your sense of well-being and ability to do your favorite activities. This means helping you manage symptoms and side effects you may experience.

After she was diagnosed with hormone receptor- and HER2-positive stage IV breast cancer in the winter of 2012, **Sherri Fillipo**, 54, of Corning, New York, received chemotherapy followed by a combination of trastuzumab (Herceptin) and pertuzumab (Perjeta). She had such bad stomach problems that she stopped taking pertuzumab.

“The side effects were just too much,” Sherri says. “Living in the bathroom is not a good quality of life.”

Since metastatic breast cancer is a life-long condition, there may be times when, like Sherri, you’ll want to weigh the benefits of a treatment with its risks—especially if its side effects disrupt your daily life.

Communicating About Side Effects

Medical oncologist **Tessa Cigler, MD**, of the Weill Cornell Breast Center in New York, says maintaining clear communication is important to help you and your doctors weigh your treatment options as well as effectively address severe treatment side effects.

“Providers must clearly explain the potential side effects of each treatment, and check in regularly with patients,” Dr. Cigler says. “It’s just as important for patients to be honest with their doctors about the level of discomfort they experience.”

Sherri was very open with her providers, especially when it came to the stomach problems and diarrhea she experienced. Her doctor suggested she take a break from treatment to recover and then resume pertuzumab.



Sherri Fillipo



Paula Vincent

But Sherri said no because the discomfort from the side effects was unbearable. Her doctor understood, and since tests at the time showed she had no evidence of disease, she stopped taking pertuzumab. Sherri’s doctor switched her to ado-trastuzumab emtansine (Kadcyla) after December 2014, when the cancer returned.

“When something doesn’t feel right, it’s important to be able to be frank and upfront with your doctors,” Sherri says.

If you feel a doctor isn’t hearing you or helping you address side effect concerns, consider seeking a second opinion or switching providers.

“For most providers, the days of being offended by patients seeking a second opinion are gone,” says **David Mintzer, MD**, of the Abramson Cancer Center at Pennsylvania Hospital in Philadelphia.

Paula Vincent, 57, of Los Angeles, switched providers when hers challenged her for asking questions about her treatment plan. Paula says her current care team is very understanding and supportive. If she and her doctors disagree about treatment and managing side effects, she declines their suggestions and asks for more options that help her live the life she wants.

“There are times when I defer to my care team’s expertise, but I also want to be in control,” Paula says.



Phyllis Mutzman

Treatment Effectiveness vs. Side Effects

When making medical decisions for metastatic breast cancer, it's important to weigh the pros and cons of an effective treatment that may also cause side effects that negatively affect your quality of life. If you decide to continue treatment in spite of harsh side effects, that's OK—as long as you feel comfortable with your decision.

The side effects Paula experiences often disrupt her daily routine and social life.

Paula receives hormonal therapy and chemotherapy. While she has bone pain, hot flashes and skin changes, those side effects are nothing compared to the neutropenia, a very low count of white blood cells, which weakens her immune system. A weak immune system makes it easier for a person to get sick or develop infections.

Because of the neutropenia, Paula limits contact with family and friends, and is mindful of touching objects handled by others, like door knobs. She has been hospitalized twice because of neutropenia-related infections.

Although the side effects change her quality of life at times, Paula continues treatment because it's shrinking the cancer.

To mentally deal with tough side effects, Paula focuses on the reasons she continues aggressive treatment for metastatic breast cancer—her friends and family.

“For me, my number one goal always has been and always will be prolonging my life,” she says.

Making a Decision

Some, like Paula, prioritize how well a treatment works, while others may place more importance on maintaining as high a quality of life as possible.

If it's important for you to maintain daily activities like walking your dog or spending time with friends and family—while experiencing as little discomfort as possible—make sure you communicate your priorities to your doctors.

Dr. Mintzer says advances in breast cancer care have offered people with metastatic disease more options if a treatment stops working or if the side effects are too much. He adds that you could also consider taking a treatment break—stopping the treatment temporarily—or talking with your doctor about lowering the dose.

When Sherri started taking ado-trastuzumab emtansine, the stomach problems stopped but then she experienced severe fatigue and joint pain.

At her request, Sherri's doctor lowered the therapy dose to try to help lessen the side effects. But after three cycles of the new dose she still had negative side effects. She stopped treatment after talking with her oncologist.

For Sherri, it's more important to be able to be active with her family than stay on a medicine that prevents her from living her life.

Phyllis Mutzman, 57, of Lewisville, Texas, says she places equal emphasis on treatment success and side effects. She stresses the importance of discovering strategies and speaking with providers to help cope with symptoms and side effects.

Phyllis has severe fatigue but decided to continue treatment with her chemotherapy because it's been effective at treating the cancer.

“Sometimes I forget I'm sick, do everything on my to-do list and then I get so tired that I feel wiped out,” Phyllis says. “But being very tired beats the alternative.”

Dr. Mintzer says another option you may want to consider is seeking support from a palliative care team, which many cancer programs now have. These practitioners work to improve your quality of life from the point of diagnosis forward, not just at the end of life. A palliative care team may include doctors, nurses, psychologists, social workers, nutritionists, physical therapists, and others, all dedicated to helping you and your family deal with the physical, emotional, financial and spiritual difficulties caused by cancer and its treatments.

A NOTE ON HOSPICE CARE

Palliative care is also offered through hospice, special care for people who are near end of life. Some people may have had many kinds of treatment already, and may consider stopping treatment completely if side effects become unbearable and no other medicine is available.

Dr. Mintzer recommends talking about end-of-life care early on so that your provider, friends and family know what you want. This may include developing a living will and appointing a healthcare power of attorney, someone who can make decisions for you in the event that you are unable to make decisions yourself. It may also include the type of care you want at the end of life; for example, whether you want to be cared for at home or in a hospital or assisted living facility.

“It's an extremely difficult discussion to have for patients, their families and the physicians, but there is often tremendous benefit in talking about end-of-life wishes early,” Dr. Mintzer says.

Considering Your Lifestyle

After ballerina **Maggie Kudirka**, 24, of Ellicott City, Maryland, learned she had stage IV breast cancer in her bones, she worried treatment and side effects would prevent her from dancing and attending ballet class.

Her nurse practitioner sat down with her and reviewed her course of treatment—chemotherapy followed by trastuzumab, pertuzumab and denosumab (Xgeva)—as well as their related side effects. They discussed strategies to maintain her bone health and energy.

“Just the thought of bone fractures is devastating to a dancer,” Maggie says. “It was reassuring that my providers understood how important saving my bones was to me.”

Maggie’s situation highlights the importance of considering the activities in your life that are important to you. Doing so may help when you make decisions and consider the impact some treatments will have on your day-to-day life.

Dr. Mintzer says that the magnitude and impact of any given side effect varies for different people in treatment for metastatic breast cancer.

“For example, a patient who plays violin may be more impacted by mild nerve damage from treatments causing loss of sensation than a patient who doesn’t play such an instrument,” Dr. Mintzer says. “You just have to talk with your providers and let them know what’s important to you.”

Paula’s children all live on the East Coast, so visiting them means taking time off treatment to travel. Even though her providers were concerned about her stopping radiation therapy for a few weeks, she was able to negotiate taking the time off.

“It was important for me to be able to see my kids and laugh with them,” Paula says. “That, for me, was the treatment I needed.” 🍷



Maggie Kudirka

MAKING AN IMPACT:

A Q&A with Ishiuan Hargrove

BY JOSH FERNANDEZ



Ishiuan Hargrove

After she was diagnosed with stage III breast cancer, **Ishiuan Hargrove**, 42, of Lakeland, Florida, developed a passion for cancer advocacy and outreach.

She worked as a medical physicist, a healthcare professional who researches, plans and tests radiation therapy treatment and technology to diagnose cancer. Ishiuan decided to use her experience to inspire others to support organizations and events that help people affected by the disease.

She’s participated in Susan G. Komen Race for the Cure events; raised over \$85,000 for Young Survival Coalition’s Tour de Pink (her team name was “I Ride 4 Her”); and attended the Reach to Recovery International Breast Conference several times.

In 2013, Ishiuan learned the breast cancer spread to her lung. By 2014, she had developed brain metastases.

Her experience with stage IV breast cancer has inspired her to focus on helping people living with metastatic disease.

Ishiuhan attended the 2014 San Antonio Breast Cancer Symposium as an Alamo Breast Cancer Foundation scholarship advocate, where she learned about the latest research. This spring, she completed training for LBBC's **Hear My Voice: Metastatic Breast Cancer Outreach Program**, which took place at the **Ninth Annual Conference for Women Living With Metastatic Breast Cancer** in Philadelphia.

She recently started her own consulting company, Hargrove Consulting Physics. "The way I look at it, I refuse to let my stage IV diagnosis stop me from doing what I love," Ishiuhan says.

Ishiuhan sat down with LBBC's digital media specialist **Josh Fernandez** to talk about her experience in the program, her interest in sharing her story with others, and more.

Josh

Talking about your experience is important for advocacy and outreach. Why do you share your story?

Ishiuhan

It paints a picture for others, especially those who are not metastatic, about what it is like to live with this disease. But I also think there are a lot of personal benefits to sharing your story with others. I initially got started by writing in a blog for family, friends and myself. I started it to leave a footprint of my experience to share with others, especially my kids.

You end up creating your own support community by sharing your story. As someone with metastatic breast cancer, I've found that some people may be afraid to begin new friendships with you because they fear getting attached to you and then losing you. After attending the 2014 Annual Conference for Women Living With Metastatic Breast Cancer, I met seven women with whom I formed an online group, "Mets Warriors," where we write to each other via email. Two women from that group have since passed away. It's hard, and we know that may be a reality, yet still we embrace our friendship. It helps to make you feel less alone.

Josh

You are active with a number of breast cancer organizations like LBBC and Young Survival Coalition. What other breast cancer organizations or groups have you participated in or served?

Ishiuhan

While on medical leave after treatment in 2007, I traveled to Taiwan—my birthplace—and eventually got involved with the Taiwan Breast Cancer Alliance. I became an advocate and consultant for them, helping them translate resources from English to Chinese and using my medical background

to help produce educational films about breast cancer. I was appointed as an international counselor by TBCA in 2009.

In April, I learned that I was selected as one of the reviewers to sit on the Department of Defense Research Grant Review Board this summer. With this opportunity I can help determine where to direct government grants to fund research that could have an impact on the breast cancer community.

Josh

Why did you participate in LBBC's Hear My Voice program?

Ishiuhan

I learned about the program through your e-newsletter, and thought it would be an opportunity to learn about doing more patient advocacy. I attended last year's conference and learned helpful information and made friends. I thought I'd take my conference experience this year to the next level, and attend the Hear My Voice training to learn how to take more action.

Josh

What did you like most about the program?

Ishiuhan

What I liked most about the training was walking into the room and being instantly inspired by the 31 other women who were passionate and energized to do advocacy and outreach for others in our community. It's impressive to be able to get together and hear *each other's* voices.

Josh

What advice do you have for someone with metastatic breast cancer who wants to get involved in outreach opportunities?

Ishiuhan

I think everyone needs to first start by having a supportive group for themselves. Having that support helps you cope with this diagnosis, which then helps get you in the mindset of doing the best outreach and volunteer work you can do. You also have to be willing to be social and you have to be a good listener. Then you volunteer in person or speak at an event, talk with others and share your story. 🍌