

Metastatic Breast Cancer

Sex, Intimacy and Metastatic Breast Cancer

BY ERIN ROWLEY

Shiana Gregory, from Chicago, was diagnosed with metastatic breast cancer in 2013, at age 25. After she began chemotherapy, her desire for sex dropped, and sex became painful. Though she's been on many different treatments since then, that hasn't changed.

At least 80 percent of women with breast cancer experience some sexual changes, including in their desire for sex and ability to have sex comfortably, says **Sage Bolte, PhD, LCSW, OSW-C, CST**, a licensed clinical social worker and certified sex therapist.

Sex and intimacy are related, but they aren't the same thing. Sexual activity is physical closeness that often includes sex, as you and your partner define it, or intercourse. Intimacy involves emotional closeness. These two ideas often go hand in hand. But it's possible to have sexual pleasure without intimacy. It's also possible to have intimacy without sex, and exploring that idea can be vital for someone with metastatic breast cancer who wants to stay close and connected to a partner, but has side effects that make sex, penetration or sexual play less wanted, or painful.

Many breast cancer treatments can affect your desire for and comfort with sexual activity. Chemotherapy and hormonal therapy often cause menopausal symptoms such as vaginal dryness, which can make sex painful; joint pain; hot flashes; and lower sex drive, or libido. Other common side effects of these and other breast cancer treatments that can affect your sex life are

- anxiety and depression
- changes to your body, like hair loss or breast removal, that can lead to body image issues



Shiana Gregory and her boyfriend, Chris

- diarrhea, constipation or other bowel movement changes
- insomnia and fatigue
- neuropathy, numbness, pain, burning, tingling or loss of feeling in your hands or feet

Younger women like Shiana tend to express more distress about sexual changes, Dr. Bolte says. Most haven't had menopausal symptoms before, and have less experience working with a partner to find creative ways to work around sexual challenges or improve their sex lives. They're also less likely to have friends who have dealt with menopausal symptoms or cancer, and who could make their situation feel more normal or provide support and guidance.

But older women struggle with these changes, too. **Mary Mathis**, 70, from Grants Pass, Oregon, thought she was done with menopause because of her age. Then, in 2014, she was diagnosed with metastatic breast cancer.

Mary guesses she's switched cancer treatments about 10 times. She describes her changing treatment side effects as "going through menopause again and again and again."



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Each new treatment affects her desire for and comfort with sex differently, so she and her husband “have to make it up as we go,” she says. And for the first time in almost 40 years of marriage, they had to learn how to be intimate without focusing on sexual activity.

Women face many of the same sexual issues whether they are in treatment for early-stage or metastatic breast cancer. The big difference with metastatic disease, Dr. Bolte says, is treatment doesn’t end, so the side effects do not necessarily go away on their own without findings ways to manage them.

If you had sexual side effects after an early-stage diagnosis, knowing treatment was temporary may have helped you cope with them. Women with metastatic breast cancer have to adjust to long-term changes in how they feel, physically and emotionally, about the role of sex in their lives.

In her practice, Dr. Bolte focuses on understanding what parts of life are important to each person she treats. That may or may not include intercourse. Some people find great pleasure by focusing on intimacy with touching, kissing or massage. Desires can also change as time goes on.

Dating

Shiana was single when she was diagnosed and afraid her diagnosis would scare potential partners away. And her lack of sexual desire left her insecure about dating.

“I wasn’t sure if people would understand, if they would want to put up with it, if it was too much of a burden on this person to deal with a person with stage IV breast cancer,” she says.

Dr. Bolte helps single clients of all ages figure out what to say to a new love interest about their health, and when to say it. You may have more options than you think. For example, if your treatment doesn’t have visible side effects like hair loss, you may choose to tell someone about the cancer later. If you can, keep your health status to yourself until you’re sure you want to get to know your date better, she says. Be careful if you’ve shared about cancer on social media. When you do tell your date, be prepared for questions that may be awkward.

“They may ask ignorant questions,” Dr. Bolte says, “but they may ask important questions, so being able to answer those questions could put them at ease.” You can prepare for potentially awkward questions by practicing answers to them with a friend.

People with cancer use the same dating sites everyone else uses. There are also specialized sites for people with serious illnesses. Some people want to date a person who has also had cancer. Some don’t. Decide what’s right for you.

After her diagnosis, Shiana reconnected with a high school boyfriend. They’ve now been dating for about 2 years. He’s also dealt with health problems and is understanding about sexual issues related to her treatment. They make it a point to be intimate with each other in nonsexual ways, like cuddling, but they rarely have sex, and Shiana feels guilty about that. It was hard for her to explain she felt pain because of vaginal dryness and she rarely desired sex.

“It made me feel bad as a girlfriend because at times I wasn’t able to fill that void in the relationship as much as I would like to,” she says.



Mary Mathis

Partners

Guilt isn’t exclusive to the person with cancer. Partners also may feel guilty, selfish or insensitive for wanting sex while their loved one is sick. Some fear sex could hurt their partner.

Partners need to know that their needs are important, just like they were before their loved one’s cancer diagnosis, Dr. Bolte says. But they may have to accept their sexual life may not be the same as before.

Helping your partner understand how treatment affects your sexual experience can help. Try telling your partner about specific side effects and their impact. For example, you could let them know that a lack of vaginal lubrication does not necessarily mean you aren’t feeling pleasure, or that you need more foreplay before sex to build lubrication up.

Dr. Bolte also recommends “giving yourself permission to fumble and take a more curious approach [to sex and sexual play], rather than being frustrated it won’t work as it used to.” Explore each other’s bodies and provide feedback on what does or doesn’t feel good. Let your partner get to know your body after breast cancer, and be open to helping him or her make adjustments. It can be important to remind your partner that your changes in sexual desire are caused by cancer and its treatment, and do not mean that your feelings about or attraction to them has changed. Being willing to laugh and be creative with sexual play can help you redefine your sexual intimacy.

Checking in with each other every few months to ask if anything feels different or needs to change can be helpful. It’s important to create an environment where conversations can happen without judgment, Dr. Bolte says. To do this, pick a place outside of the bedroom to have the conversation where you both feel comfortable, and try using “I” statements to express your feelings. “I” statements are useful because they allow you to say how you feel without your partner feeling criticized or accused. For example, say “I feel like we aren’t as sexually connected as we were before my cancer diagnosis. I want to talk about it because I miss our closeness,” instead of “You make me feel like I’m not sexy anymore.”

Make plans to be intimate with your partner. Talk about ways to connect intimately that feel good, whether that’s sex, laying naked together or holding hands on the couch, rather than assuming intimate moments will happen on their own. If you already had relationship problems before a metastatic diagnosis, talking to a counselor or social worker may help you avoid more challenges, Dr. Bolte says.

Getting Help

If you're struggling with sexual side effects and changes despite trying different strategies to cope with them, it's OK to ask for professional help. Specialists in sexual health, cancer survivorship or sexual medicine can provide more individualized help for sex and intimacy issues caused by cancer. If you start to experience vaginal dryness, sexual pain or other side effects that upset you, tell your doctor, or ask for a referral to a specialist.

Your doctor or specialist may recommend that you stretch, strengthen and moisturize the vagina and the vulva. There are products available to treat vaginal dryness, and using a vaginal moisturizer like Replens can help make intercourse more comfortable. Using water-based or silicone-based lubricants right before and during intercourse can also help.

Dr. Bolte says also practicing kegel exercises, which strengthen the muscles that support the bladder, uterus, and bowels, can help improve pleasure with intercourse, as can dilator therapy. In dilator therapy, you use a series of rod-shaped inserts to gently widen and lengthen the vagina to help strengthen it, and to help make intercourse more comfortable.

Unless your doctor says it's OK, avoid products with estrogen in them. Some believe those products could encourage the cancer to grow. Your providers can share the research with you.

Your cancer care team can help you with menopausal symptoms, depression, fatigue or other problems affecting your sex life. And though it may feel awkward, talking to other people about sexual side effects can improve your quality of life. Many other women with cancer know what you're going through, and may have advice for you.

"I just wish there was a little bit more conversation [about sex]," Mary says. "I'm not asking anybody to solve my problems, but it helps to hear that other people have them and what they're doing about them." 🌟



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Dr. Bolte's presentation on sex and intimacy from LBBC's **Thriving Together: 2016 Conference on Metastatic Breast Cancer** is available

at lbcc.org/metastatic-breast-cancer-sex-intimacy.

ADVOCATING FOR HERSELF AND HER COMMUNITY:

A Q&A With Lana Dunn

BY ERIN ROWLEY



Lana Dunn

Lana Dunn, a 21-year U.S. Army service member, wife and mother of two, was diagnosed with stage III triple-negative breast cancer in 2013, at age 37. Despite aggressive treatment, in 2015 the cancer spread to her lungs and liver, and in 2016 it spread to her spine.

Lana is a member of Living Beyond Breast Cancer's Young Advocate Program, which provides the tools and training to help women diagnosed before age 45 use their personal breast cancer experience to make a difference in their communities, further their understanding of the disease and advocate for others.

Lana answered questions about her breast cancer experience from LBBC's writer and content coordinator, [Erin Rowley](#).

Erin

How did it feel to have been diagnosed with breast cancer at such a young age?

Lana

Because I was away from home at a military training school, I didn't really get a chance to thoroughly think about the diagnosis. Once I returned home, I immediately started treatment. Things were moving so fast, it kept me from dealing with the emotions and feelings that come with a cancer diagnosis. For my first four rounds of chemo, I worked as if things were normal. When I started losing my hair, reality set in and I was overwhelmed with feelings and emotions. All I could think about was, "Am I strong enough to beat cancer?" and, "Will I be alive to see my kids grow up?" and, "Will I be the same person when it's all over?"

As my treatment moved forward, I found it necessary to seek mental health therapy because I could not control my thoughts or feelings. One minute things were great and a minute later, I would break down and cry. It wasn't until I met with a mental health therapist that I came to terms with my diagnosis and realized that I was in a mourning state of mind. I was mourning the loss of who I was and worried about who I would be when the treatment was over.

Erin

How have you approached talking to your children about breast cancer?

Lana

Initially, I did not tell the kids. But as the treatment started to affect my body, I could no longer hide it from them. They were so young when I was diagnosed and I didn't know if they would understand, and they didn't. I purchased a children's book about cancer, and the kids and I read the book. I also left the line of communication open. We started family meetings and decided that any time they had a question, concern or wanted to talk about it more, anyone could call a family meeting.

Erin

In your experience, does the African-American community look at or talk about breast cancer, and metastatic breast cancer in particular, differently than other groups? If so, how?

Lana

In my experience, there is not a lot of talk in the African-American community about breast cancer or metastatic breast cancer. In fact, I didn't even know what metastatic breast cancer was until my diagnosis. I am the first in my family, on both sides, to have breast cancer. I also think that education and awareness is lacking in our community, and because of that, there are a lot of late-stage diagnoses.

Erin

Why is volunteering for organizations like LBBC important to you?

Lana

LBBC is a great organization and a great resource. Volunteering with LBBC gives me another outlet to share my journey and help educate those who are not getting their annual checkups or doing breast self-exams. LBBC provides me with the education and tools to advocate on several different levels. If I had not volunteered for LBBC, I would not have known about all the ways to advocate. Volunteering also gives me the ability reach out to the African-American community, helping educate them and provide resources.

Erin

Do you have any advice for other women dealing with a metastatic breast cancer diagnosis?

Lana

My advice to other women dealing with metastatic breast cancer is

- listen to your body. If it tells you or shows something that is not normal for you, seek medical attention.
- become a well-informed patient. Being knowledgeable about your cancer and your treatment helps you help your medical team. Breast cancer treatment is individualized. What works for one person may not work for you. Being informed also helps you to understand what your medical team is telling you.
- research, research, research. Familiarize yourself with medical terms, clinical trials, etc.
- you are your own best advocate. When you have stage IV breast cancer, you have to find the balance between treatment and quality of life, and only you can make the decision about your quality of life.
- lastly, there is always something worth fighting for. Remember that when things get tough or your emotions and bad thoughts try to consume you. Figure out what is worth fighting for, and if you don't fight for anybody else or any other reason, fight for that very thing. 🍷



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At **Thriving Together: 2017 Metastatic Conference on Breast Cancer**, Lana was a panelist during the session **Learning From Each Other: A Panel Discussion**. Watch a video of that session and others at livestream.com/lbbc/2017metsconference.