



Sensuality, Sexuality, Survival

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Current SSS Events

Our SSS Consultants have been continuing the fight against breast cancer and its debilitating effects on female sexuality. With 44 Certified Consultants nationwide, our SSS Consultants are scheduling presentations in an area near you! To book an intimacy after breast cancer presentation for your support organization in your area please contact us at sss@pureromance.com.

Pure Romance's *SSS Program* and *The Patty Brisben Foundation* were proud to sponsor two focus groups held in Cincinnati, Ohio on April 16th and 18th in conjunction with the Center for Intimacy After Cancer Therapy, to provide invaluable advice and personal accounts of cancer survivors, for an upcoming book on intimacy after cancer to be published by the American Cancer Society.

On April 22, Erin Hoschouer presented a lecture "Romance and LAM" at the 2007 Lymphangiomyomatosis (LAM) International Research Conference in Cincinnati, Ohio. Attendees were given information on ways to rediscover and rekindle their intimate life and sexuality following a diagnosis of LAM. Participants were encouraged to think objectively about sexuality and intimacy, and were provided with tools and new ideas, as well as a list of resources.



Featured Article: Living with Metastatic Disease

Metastatic breast disease is breast cancer that has not just come back, but has made its way through the bloodstream and spread to other organs of the body, such as the bones, liver, or brain. Cancer spread may be present at first diagnosis or after recurrence. Many women can live for years with metastatic cancer that's under control. For these women, living with a diagnosis of metastatic breast cancer is like living with a chronic disease. It can go into remission, be active sometimes and not others, or move quickly. It frequently involves trying one treatment after another, ideally with breaks in between treatments when you feel good. The goal of treatment is to help you feel as well as possible and live a longer life.

Our Expert Bio

Jennifer (Jan) Simpson is a registered nurse, who currently works at the Franklin Square Medical Center as the Clinical Coordinator for Breast Services. Jan is currently pursuing a Master of Liberal Arts degree in Ethics from Johns Hopkins University. She graduated with Honors in 1997 with a degree in Psychology, also from Johns Hopkins University. Jan has worked as an operating room nurse since 1986 and was the Clinical Coordinator for the Plastic & Reconstructive Surgery of the Breast Center at Mercy Medical Center from 2001 to 2003. Jan has also published many articles on breast surgery as well as speaking for such organizations as the Susan G. Komen Foundation. Jan is also a Certified Breast Health Specialist.

We are thrilled to have Jan as our featured "expert." Her over 30 years of experience as a nurse and her work as a breast health specialist makes her a wonderful addition to Sensuality, Sexuality, Survival.



No one can tell you how long you will live with metastatic disease. That's because every woman's experience is different. Some women live for more than a decade. Others live for just a few seasons. But new and more effective treatments keep being developed. This means that you may do much better today with metastatic disease than someone who had it only a few years ago.

In this phase of breast cancer, the treatment goal is to extend life as long as possible with the best quality of life possible. This means relieving symptoms and putting cancer into remission with the fewest side effects.

Metastatic breast cancer responds best if:

- The cancer has not spread to any organs, such as the liver, lung, and brain.
- If it has spread throughout the body, no more than three organs or parts of the body are involved (the fewer the better).
- Estrogen and/or progesterone hormone receptors are present in these cancer cells.
- There's no evidence that the tumor has stopped responding (become resistant) to hormonal therapy, Herceptin (chemical name: trastuzumab), or chemotherapy.
- You haven't already had many different kinds of therapy or many rounds of treatment.

But even if you don't have these encouraging signs, many treatments are available to you. Many women can live for years even without these signs!

Getting the Support You Need

Once the extent of cancer is known, you, your family, and your doctors need to sit down together and talk about what treatment will work best for you. Make sure you have a supportive team of doctors.

You also will probably find it helpful if you have support at home and at work while you are having treatment. Breast cancer treatment can make you tired and unable to do some, most, or all of your usual activities. But many people are eager to help:

- Community organizations and religious groups often have volunteers who can help you with childcare, meals, or other daily needs.
- Friends and neighbors can help fill your freezer with precooked meals for those days when your energy is low. Or they can pitch in with food shopping, carpooling, or childcare.
- Co-workers are often willing to do more than their share so you can cut back your responsibilities at work. Consider limiting your work hours, if possible. Arrange to do some work from home.
- You can get support from a "cybersister" on the discussion boards and in the chat rooms here at breastcancer.org 24 hours a day, 7 days a week.
- Another excellent place to get support is www.bcmets.org, a Web site devoted to women with metastatic breast disease.

Your Treatment Priorities

You and your doctor should agree about your care. This is very important. You and your doctor need to work out these issues. Let your doctor know how aggressive or laid back you want to be. Even if your attitude is very different from that of your doctor, he or she should respect your wishes.

For example, what if your doctor recommends aggressive treatment, but you want supportive care only? You need to listen carefully to each other. But if you don't agree, your doctor should honor your decision. And if you choose complementary treatments that your doctor knows nothing about or is uncomfortable with, he or she should tell you that. You may figure out a way to work together. If not, find another physician who will accept your views.

How you make decisions about treatment when you are well may be very different from how you make decisions when you have metastatic breast cancer. A study from England reported that patients with active cancer said they were willing to accept a treatment with severe side effects if it offered just a 1% chance of cure. But those in the study who were disease-free said they would need to have a 50% chance of cure to accept such a treatment.

Also, how you make choices may change over time, depending on your options, family issues, and financial concerns. Women with advanced metastatic breast cancer rarely choose hospice care first if they know there are treatments still available that may reduce the size of the tumor, ease symptoms, and extend their lives. There's always something more to celebrate, a life event to be witnessed—a graduation, a wedding, a birth. Many mothers of young children choose to continue aggressive therapy as long as possible for the chance to spend more time with their children. Each woman makes choices that are right for her and her life.

Tell your doctor clearly and firmly exactly what you have in mind. Talk about the treatment choices together. That way your doctor knows exactly what you want, and you fully understand his or her recommendations.

What you want will also change over time. Your philosophy about treatment and your goals will change depending on how you feel and what else is going on in your life and around you. Know, and feel comfortable, that your wishes are of primary importance.

Article adapted from breastcancer.org "Living With Metastatic Disease"



Featured Product: Pearl Penguin

Product Features:

- This sleek vibe has a smooth shaft and an arched tip to hit the g-spot.
- With multiple speeds, the textured shaft creates a sensation inside the vagina that stimulates the nerve endings at the entrance.
- Great for women who have a curved uterus with an angled g-spot.
- Waterproof.

Benefits: The Pearl Penguin is designed to target an erotically sensitive area, the g-spot. It is located on the front wall of the vagina midway between the pubic bone and the cervix. This area varies in size from a small bean to a half dollar. The shape of the toy and the vibrations will increase stimulation to the g-spot. Initially, a woman may experience a slight feeling of discomfort or need to urinate, but shortly after this feeling begins, the tissue should swell and arousal should occur. The tailored shape of the Pearl Penguin allows the break down of this dense tissue and an accelerated sense of g-spot arousal and can be used in the shower for added pleasure.

Application: N/A

Price: \$14.00

My Story: My Step "Monster"

I was ten years old when Lynn, (my step "Monster") came into my life. She made me do things (like chores) that my dad never would have made me do and she didn't let me get away with anything...EVER!!! She quickly came in and took over the household and took care of us and filled a void in our house that I didn't even realize I'd been yearning for. Discipline and structure were the name of the game and oh how I hated her! We fought like cats and dogs, and I was convinced she hated me too! She never had children of her own and I was so worried that my father and my new stepmom were going to adopt a kid of their own to replace me. Fortunately for me or unfortunately, depending on how I look at it now, I remained an only child. So all of her "child rearing" focus remained on me, and man was she strict! It wasn't until I was 19 and away at school that I realized all of the "stupid" things my friends did to get themselves into trouble didn't interest me because of the way I was raised. I actually called her to let her know that I was behaving myself and to thank her for all of her "tough love".

On my 21st birthday I got the most beautiful letter from her telling me how proud she was of me and what a wonderful woman I had become. Letting me know that all of the fights and frustrations we went through during my adolescence were because she loved me like her own daughter and wanted only the best for me. I had gotten married only a month before that and she had worked very hard to give me the wedding of my dreams (and of hers too I think!) In the letter she complimented me on being the most beautiful bride she had ever seen. Almost immediately after I got married she started bugging me for a grandchild! I told her (jokingly) not to hold her breath. Five years later she got her wish. I had a beautiful daughter of my own. My husband and I were living out in California and I so desperately wanted to move back home so that my daughter would know her grandparents. We did end up moving back home and my daughter and my step mother quickly became inseparable. "Nana" can do no wrong in my daughter's eyes! Having my daughter brought us closer than we've ever been and we actually became friends for the first time in our lives.

When my daughter was about 4 years old my stepmom told me she found a lump on her breast. While this scared me a bit, I fell into the mode of "don't worry until there's something to worry about." Well I wasn't prepared for the biopsy results. Lynn called me one day and said "well my results came back and the tumor is



malignant." It took me about 30 seconds to process that information. I quickly said "ok, what are they going to do about it?" strong and business-like, just like she had raised me to be. After we talked about surgery, chemo and radiation and I assured her it was going to be ok (trying more to convince myself than her) we hung up the phone and it hit me like a ton of bricks. I sat on my bed and sobbed, my first thought was "She's not going to get to see her granddaughter grow up." My second thought was "What is Isabella going to do without her Nana?" And last I thought, "I can't fall apart now, these two need me." So that's what I did, pulled myself together and watched as my step "monster" recovered from surgery and lost her hair, and threw up. My daughter new that her Nana was sick and that the doctors were doing everything they could to make her better. Through all of it I finally realized what this woman truly means to me.

It has been three years now and Lynn has a clean bill of health and is doing great. Isabella still has her Nana and I still have my friend. We joke now about the whole step "monster" thing and we all realize just how precious life and family really is.

Angela Mormando

Hearing a personal account of someone going through a similar experience can be very helpful and reassuring. If you would like to share your personal experience with breast cancer please submit your story to sss@pureromance.com.