Sensuality, Sexuality, Survival

WWW.PUREROMANCE.COM/SSS OCTOBER 2007

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 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*.

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 view an extensive list of our Certified SSS Consultants, please visit www.pureromance.com/sss. To book an "Intimacy after Cancer" presentation for your support organization in your area, please contact us at sss@pureromance.com.

Pure Romance's SSS Program has been involved in events all over the country, including a hospital presentation at Magee-Women's Hospital of UPMC in Pittsburgh, PA, Relay for Life in Wisconsin, Nevada and Ohio, and Komen walks all over the country! Pure Romance had an SSS team at the Cincinnati Race for the Cure, where we had the largest team two years running. With 105 people registered, Pure Romance and SSS really stood out as a 'Sea of Pink'!

Featured Article:
Effects of Cancer Treatment on Female Sexual Desire and Response

Information provided by: The American Cancer Society

Both men and women often lose interest in sex during cancer treatment, at least for a time. At first, concern for survival is so great that sex is far down on your list of needs. This is quite normal. Few people are interested in sex when they feel their life is being threatened. When people are in treatment, loss of desire may result from worry, depression, nausea, pain, or fatigue.

Cancer treatments that disturb the normal hormone balance can also lessen sexual desire. If there is a conflict in the relationship, one partner or both might lose interest in sex. Any emotion or thought that keeps a woman from feeling excited can interfere with desire for sex. Distracting thoughts can keep her from getting aroused. Her vagina then stays tight and dry, making intercourse somewhat painful.

Many people who have cancer worry that a partner will be turned off by changes in their bodies or by the very word "cancer."

Pain

Pain is the most common problem for women during intercourse. Often, it is related to changes in the vagina's size or moistness. These changes can occur after pelvic surgery, radiation therapy, or treatment that has affected a woman's hormones.

Sometimes the pain sets off a problem called vaginismus. If a woman has vaginismus, the muscles around the opening of the vagina become tense without the woman being aware of it. Her partner cannot enter the vagina. Pushing harder increases the woman's pain because her vaginal muscles are clenched in a spasm. Vaginismus can be treated with counseling and some special relaxation training. These treatments are described in the section, Dealing with Sexual Problems.

Premature Menopause

Another common way that cancer treatment can affect a women's sex life is by causing premature menopause. Symptoms are often more severe than the slow changes that happen during a natural menopause. When a woman’s ovaries are removed as part of a cancer surgery, or when the ovaries are affected by chemotherapy or pelvic radiation therapy, the loss of estrogen can trigger hot flashes and vaginal atrophy (a condition when the vagina becomes tight and dry). Some women can take replacement hormones to help these problems.

Women who have premature menopause sometimes have low androgen levels, decreasing sexual desire and pleasure. A blood test can identify this problem. Often replacement androgen hormones can safely be prescribed. Women with cancer of the breast or uterus usually cannot take estrogen; however; they may benefit instead from some of the suggestions in the section, Dealing with Sexual Problems.

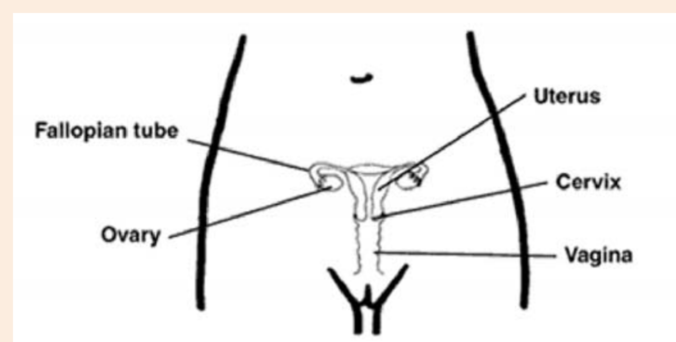
If you are thinking of using hormone replacement, it is wise to talk with your doctor or nurse to learn about the benefits and possible effects of hormonal therapy.

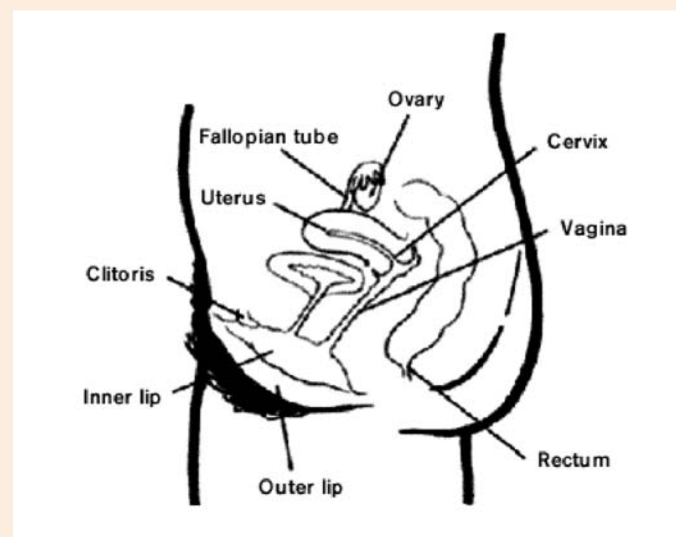
Orgasm

A woman's capacity to reach orgasm usually remains intact unless cancer treatment has damaged the spinal cord, which causes the genital area to be numb, or if cancer surgery has removed sensitive areas like the clitoris or lower vagina. Sometimes pain during intercourse may distract a woman from reaching orgasm. In some cases, a woman might need to try ¬different positions or types of genital ¬touching. She might also need to practice having orgasms.

Organs That May Be Involved in Pelvic Surgery for Cancer

The female genital and reproductive organs include the uterus, (or womb), cervix (the entrance to the womb at the top of the vagina), fallopian tubes, ovaries (the organs that produce eggs and hormones), vagina, vulva, bladder (the storage area for urine), and rectum (the bottom end of the intestines).





Radical Hysterectomy

Radical hysterectomy is an operation used to treat some cancers of the cervix. The surgeon removes the uterus and the ligaments (tissue fibers) that hold it in place in the pelvis. The cervix and an inch or two of the deep vagina around the cervix is also removed. A hysterectomy for uterine or ovarian cancer removes less tissue.

After taking out the cervix, the surgeon stitches the vagina at its top. Some fluid drains from the vagina during healing. The top of the vagina soon seals with scar tissue and becomes a closed

tube. The vagina does not, as some women fear, become an open tunnel into the pelvis.

If a woman is less than 40 years old, the surgeon will often try to leave an ovary or part of one during a hysterectomy. Even one ovary can produce enough hormones to prevent a woman from going through early menopause. Because the uterus is removed, however, a woman will not have menstrual periods and she will not become pregnant.

If a woman is between 40 and 50 at the time of surgery, doctors consider the advantages of removing both ovaries in order to prevent ovarian cancer versus the costs of producing an early menopause. Women should discuss these choices with their doctor before surgery. Many cancer centers have sexual health programs where trained health care professionals (gynecologists and sex therapists) can help women with any concerns. Many offer a consultation before surgery so women can discuss their concerns about how surgery will affect their sexual function.

For women over the age of 50 undergoing this surgery, a surgeon most often removes both ovaries. The operation does not usually change a woman's ability to feel sexual pleasure. Although the vagina is shortened, the area around the clitoris and the lining of the vagina remain as sensitive as before.

Some women feel less feminine after a hysterectomy. They may view themselves as "an empty shell" or not like a "real" woman. Such negative thoughts can keep you from thinking about the sexual function that is still possible. A trained therapist often can help you with such concerns.

When cancer causes pain or bleeding with intercourse, the hysterectomy can help stop those symptoms and can actually improve a woman's sex life. Although the vagina may be shorter, couples usually adjust to this change. Extra time spent on caressing and other forms of foreplay can help ensure that the vagina has lengthened with excitement to accommodate intercourse.

If the vagina seems too shallow, there are ways a woman can give her partner the feeling of more depth. She may spread some lubricating gel on her outer genital lips and the tops of her thighs and press her thighs together during intercourse. She can also cup her hands around the base of her partner’s penis during intercourse.

A radical hysterectomy can affect a woman's ability to pass urine while the nerves in the tissue around the uterus are recovering from surgery. Often a woman cannot fully empty her bladder for a few weeks after surgery. To prevent urinary tract infections, she may be taught to slip a small tube, called a catheter, through the urethra and into the bladder to drain out the remaining urine. This is called self-catheterizing. A few women need to do this several times a day for the rest of their lives. If you are self-catheterizing, make sure your bladder is empty before intercourse to help prevent urinary tract infections or discomfort during sex.

Orgasm After Surgery

Women who have had a radical hysterectomy or cystectomy sometimes ask whether the surgery will affect their ability to have orgasms. Many women who have had the front walls of their vaginas removed as part of a cystectomy say that this has little or no effect on their orgasms. Most were still able to have orgasms during intercourse and said their orgasms felt just the same as before surgery. Typically, it did not take any longer to reach orgasm. In fact, some women reported having multiple orgasms for the first time in their lives.

Treatment for Cancer of the Vulva (Vulvectomy)

Cancer of the vulva is sometimes treated with an operation called a radical vulvectomy. The surgeon removes the whole vulva. This includes the inner and outer lips and the clitoris, and often the lymph nodes that drain lymph fluid from the vulva. The vagina, uterus, and ovaries remain intact. Doctors often try to spare as much of the vulva as they safely can, knowing that it sometimes can be a challenge for a patient to adjust to the effects or radical surgery.

After vulva surgery, women often feel discomfort if they wear tight slacks or jeans since the "padding" around the urethral opening and vaginal entrance is gone. The area around the vagina also looks quite different.

Women often fear their partners may be turned off by the scarring and loss of outer genitals, especially if they enjoy oral stimulation as part of lovemaking. Some women may be able to have reconstructive surgery to rebuild the outer and inner lips of the genitals.

Women who have had a vulvectomy may have problems reaching orgasm. As discussed, the outer genitals, especially the clitoris, are important in a woman’s sexual pleasure. For many women, the vagina is not as sensitive. Women may also notice numbness in their genital area after radical vulvectomy. Feeling may return over the next few months.

When touching the area around the vagina, and especially the urethra, a light caress and the use of a lubricant can help prevent painful irritation. If scar tissue narrows the entrance to the vagina, penetration may be painful. Vaginal dilators can sometimes help stretch the opening. When scarring is severe, the surgeon may use skin grafts to widen the entrance.

When the lymph nodes in the groin have been removed, women often have swelling of their genital areas or legs. This can result in pain and fatigue. It also can be a problem during sex. Couples should discuss these issues to decide what solutions work best for them.

Total Pelvic Exenteration

Total pelvic exenteration is the most extensive pelvic surgery. It is most often used when cancer of the cervix has recurred, or come back, in the pelvis in spite of prior surgery or radiation therapy. The uterus, cervix, ovaries, fallopian tubes, vagina, bladder, urethra, and rectum are removed. Two ostomies are created, one for urine and one for stool. In addition, the vagina is usually rebuilt.

Recovery from total pelvic exenteration takes a long time. Most women don't begin to feel totally healed for up to 6 months after surgery. Some say it takes 1 or 2 years to fully adjust to the changes in your body.

Nevertheless, having a total pelvic exenteration doesn't limit a woman's ability to lead a happy and productive life. With practice and determination, patients who have had this procedure can also have sexual desire, pleasure, and orgasm. Often the outer genitals, including the clitoris, are not removed, which means a woman can feel pleasure when touched in this area.

Rebuilding of the Vagina

Until recently, only one method of vaginal reconstruction (or restoring) was available. This method used skin grafts or pieces of intestine to create a new vagina. Although the intestine provides tissue that is tube-shaped, there can be problems with odor and mucus discharge.

When the vagina is repaired with skin grafts, the woman must use a vaginal stent. This stent is a special form or mold worn inside the vagina to keep it stretched. At first, the stent must be worn at all times. Then it is worn for most of each day for many months after surgery. After about 3 months, regular sexual intercourse or the use of a plastic tube or dilator to stretch out the vagina for a few minutes each day is enough to keep the vagina open. Without dilation, the new vagina may shrink or scar shut.

Skin grafts are not problem-free, but they may be the best way to repair the vagina after a less extensive operation than total pelvic exenteration.

The most widely accepted way to rebuild the entire vagina is to use flaps of muscle and skin from both inner thighs. The blood vessels and nerves for this tissue remain attached to their original site. Therefore, the new vagina is sensitive and stays open without a stent. The surgeon forms the flaps into a closed tube which is lined by the skin surface. It is then sewn into the area where the vagina has been removed. When the new vagina heals, it is similar in size and shape to the original. .

Chemotherapy and Sexual Organs

Many chemotherapy drugs can damage the ovaries, reducing their output of hormones. Sometimes the ovaries recover after chemotherapy, and sometimes they don't. Because it may still be possible to get pregnant, women who do not want to become pregnant should use some type birth control after having chemotherapy.

Women taking chemotherapy often have symptoms of early menopause. These symptoms include hot flashes, vaginal dryness, tightness during intercourse, and irregular or no menstrual periods. As the lining of the vagina thins, light spotting of blood may occur after intercourse. Some chemotherapy drugs irritate all mucous membranes in the body. This includes the lining of the vagina, which often becomes dry and inflamed. Yeast infections are common during chemotherapy, especially in women taking steroids or

antibiotics to prevent bacterial infections. If you have a yeast infection, you may notice itching inside your vagina. You may also have a whitish discharge that often looks somewhat like cottage cheese, and you may feel some burning during intercourse.

Chemotherapy can also cause a flare up of genital herpes or genital wart infections if a woman has had them in the past. If you have a vaginal infection, consult your doctor and have it treated right away, since any infection may pose a greater problem to your weakened immune system.

Yeast infections can often be prevented by not wearing pantyhose, nylon panties, or tight slacks. Wear loose clothing and cotton panties to avoid trapping moisture in the vaginal area. Wipe front to back after emptying your bladder and avoid douching. Your doctor may also prescribe a vaginal cream or suppository to reduce yeast cells or other organisms that grow in the vagina. And since your immune system may be weakened, it is especially important to avoid sexually transmitted diseases. If you are having sex with someone, it is important to practice safe sex, and to use condoms, from start to finish, every time you have oral, anal, or vaginal sex. For more information about safer sex, you can contact the American Social Health Association.

During sexual intimacy, it is important to avoid touching the vagina and the urethra with anything that has been used to stroke near the anus. Lingering germs from the bowel can cause infection if they invade through these areas.

Chemotherapy is often given through an intravenous (IV) tube, which sends it through a vein directly into the bloodstream. However, new ways have been developed that bring drugs directly to a tumor. For cancer of the bladder, for example, a liquid is placed directly into the bladder through a catheter in the urethra. Such a treatment usually only has a minor effect on a woman's sex life. She may notice some pain if she has intercourse too soon after the treatment. This is because the bladder and urethra may still be irritated.

Women with tumors in the pelvis may take chemotherapy by pelvic infusion. The drugs are put into the arteries that feed the tumor and provide an extra strong dose to the genital area. Since this method is fairly new, doctors do not yet know the long-term effects on a woman's sex life. The immediate side effects are similar to those of IV chemotherapy.

Another way of giving chemotherapy is by intraperitoneal infusion. For cancer of the ovaries or colon, the cavity around the intestines is filled with drugs in liquid form. This causes the abdomen to swell temporarily. The drugs and liquid are then drained back out after a short period of time. The procedure can be somewhat uncomfortable and can feel a bit unusual.

It is always helpful to ask your chemotherapy doctor or nurse when you may resume sexual activity and how your specific treatment will affect your sexual function.

Chemotherapy and Sexual Desire

Women who are receiving chemotherapy often experience decreased sexual desire. The physical effects, including upset stomach and weakness, may leave little energy for relationships. Sexual desire most often returns when a woman feels better. If a woman is getting chemotherapy every 2 or 3 weeks, that time period might be only the few days before she is due for her next treatment. After chemotherapy ends, the side effects slowly fade, and sexual desire often returns to its normal levels.

Women on chemotherapy also tend to feel unattractive. Hair loss, weight loss, and sometimes infusion catheters (tubes in the vein for chemo or other drugs) that stay in for weeks or months can interfere with having a positive sexual image of yourself. Ways to begin to handle these problems are discussed in the section, Dealing with Sexual Problems on the American Cancer Society's website.

Hormone Therapy

Hormone therapy, used to treat cancers of the breast and of the lining of the uterus, starves the tumor of the hormone it needs to grow. For example, the drug tamoxifen prevents breast cancer cells from using estrogen, as do progestins, a group of hormones normally made in the ovaries. Other drugs -- exemestane, anastrozole, and letrozole -- block the conversion of testosterone to estrogen.

A few women have their ovaries removed or have their ovaries rendered inactive by radiation, in order to deprive a cancer of the hormones it needs to grow.

Any of these treatments will most likely produce the symptoms of menopause. These include hot flashes, an interruption of the menstrual cycle, and vaginal dryness.

In spite of these problems, a woman should still be able to feel sexual desire and reach orgasm. Sexual intercourse will not cause any harmful increases in estrogen.

When other hormone treatments no longer work, women with breast cancer may also be treated with large doses of androgens. This type of androgen treatment may raise a woman's sexual desire. At the same time, large doses of androgens can also deepen her voice, cause her to develop acne, and cause the growth of facial hair. Her clitoris may also enlarge slightly. Androgens will not, however, change her personality or make her feel more like a man. When androgens are given to control cancer, the benefits outweigh the minor problems. Very low doses of androgens may be helpful to a woman with premature menopause. A small amount of androgens sometimes can boost sexual desire without causing other unwanted side effects.

Local Treatment for Breast Cancer

Sexual problems have been linked to mastectomy and lumpectomy. Losing a breast, or occasionally both breasts if a woman has a second tumor later on, can be quite distressing.

The most common sexual side effect from these procedures is feeling less attractive. In our culture, breasts are often viewed as a basic part of beauty and womanhood. If a breast is removed, a woman may feel insecure about whether her partner will accept her and still find her sexually pleasing.

The breasts and nipples are also sources of sexual pleasure for many women and their partners. Touching the breasts is a common part of foreplay. Some women can reach orgasm just from the stroking of their breasts. For many others, breast stimulation adds to sexual excitement.

Local treatment for breast cancer can interfere with pleasure from breast caressing. After a mastectomy, the whole breast is gone. Some women still enjoy being stroked around the area of the healed scar. Others dislike being touched there and may no longer even enjoy touching of the remaining breast and nipple.

Some women who have had a mastectomy feel self-conscious being the partner on top during sex. The area of the missing breast is more visible in that position. A few women have chronic pain in their chests and shoulders after radical mastectomy. This may be improved by supporting these areas with pillows during intercourse. Also, to prevent discomfort, avoid positions where weight rests on the chest or arm.

If surgery removed only the tumor (segmental mastectomy or "lumpectomy") and was followed by radiation therapy, the breast may be scarred. It also may be different in shape or size. During the radiation period, the skin may become red and

Featured Product: Ex-T-Cee Original

Benefits: Heighteners, such as Ex-T-Cee, are a wonderful way to enhance arousal for many women. Ex-T-Cee should be applied on the genitalia during foreplay. It can both enhance and stimulate arousal; therefore it will increase blood flow, sensitivity, and sensation, allowing the female the possible attainment of an orgasm.

Selling Features:
- This edible heightener is designed specifically for women.
- Ex-T-Cee is formulated with a 'pleasure tingle' mint compound, which acts as a cooling stimulant, causing greater sensation and sensitivity to where it's applied.
- Ex-T-Cee is available in several toe-curling flavors, including Crème de Menthe, Original, Strawberry and White Chocolate Cherry.
- Great for oral favors.
- Recommended heightener for first-time user.

Application: Apply a pea-sized amount to the clitoris to increase sensitivity during the state of escalating arousal.

Shelf Life: 1 year **Price:** $10.50

swollen. The breast also may be a little tender. Breast and nipple feeling, however, should remain normal. Breast reconstruction may restore the shape and size of the breast, but cannot restore normal breast sensation. With time, the skin on the rebuilt breast becomes more sensitive but may not give the same kind of pleasure as before mastectomy. Breast reconstruction often makes women more comfortable with their bodies, however, and helps them feel more attractive.

There is no physical reason why breast surgery or radiation to the breasts decreases a woman's sexual desire. Nor does it change her ability to experience sexual pleasure or lessen her ability to produce vaginal lubrication, to feel and enjoy normal genital sensation, or to reach orgasm. If a woman is past menopause and has been taking estrogen replacement therapy when breast cancer is found, her doctor may advise her to stop taking the hormones. If vaginal dryness or tightness results, water-based lubricants or a vaginal moisturizer can help.

The table below provides a summary of some of the common cancer treatments that can affect sexuality and fertility.

Female Sexual Problems Caused by Cancer Treatment

Treatment	Low Sexual Desire	Less Vaginal Moisture	Reduced Vaginal Size	Painful Intercourse	Trouble Reaching Orgasm	Infertility
Chemotherapy	Sometimes	Often	Sometimes	Often	Rarely	Often
Pelvic radiation therapy	Rarely	Often	Often	Often	Rarely	Often
Radical hysterectomy	Rarely	Often*	Often	Rarely	Rarely	Always
Radical cystectomy	Rarely	Often*	Always	Sometimes	Rarely	Always
Abdominoperineal (A-P) resection	Rarely	Often*	Sometimes	Sometimes	Rarely	Sometimes*
Total pelvic exenteration with vaginal reconstruction	Sometimes	Always	Sometimes	Sometimes	Sometimes	Always
Radical vulvectomy	Rarely	Never	Sometimes	Often	Sometimes	Never
Conization of the cervix	Never	Never	Never	Rarely	Never	Rarely
Oophorectomy *(removal of one tube & ovary)*	Rarely	Never*	Never*	Rarely	Never	Rarely
Oophorectomy *(removal of both tubes & ovaries)*	Rarely	Often*	Sometimes*	Sometimes*	Rarely	Always
Mastectomy or radiation to the breast	Rarely	Never	Never	Never	Rarely	Never
Tamoxifen therapy for breast or uterine cancer	Sometimes	Often	Sometimes	Sometimes	Rarely	Always
Androgen therapy	Never	Never	Never	Never	Never	Uncertain

*Vaginal dryness and size changes should not occur if one ovary is retained or if hormone replacement therapy is given.

Pure Romance's *Sensuality, Sexuality, Survival* program is designed to help women overcome some of these side effects of a cancer diagnosis and treatment. For more information, please visit www.pureromance.com/sss.

For the complete article, please visit:
http://www.cancer.org/docroot/MIT/content/MIT_7_2x_Cancer_Treatments_Effects_On_Female_Sexual_Desire_And_Response.asp?sitearea=MIT

My Story

My name is Cynthia Melton, I am 19 years old. When I was 16 my best friend and biological aunt, Shannon Melton, was diagnosed with breast cancer. She also found out during that same doctors' visit that she was pregnant. The doctor then told her that they had good news for her; they had caught the cancer early enough to treat it with little complication. However, the high dosage of chemotherapy and radiation she would need to survive would mean it would be nearly impossible for her unborn baby to survive.

Shannon didn't hesitate when she replied, "I couldn't be so selfish" and then she asked me to take care of her baby. I didn't know what to say or do. The doctor explained to her that she could have a light enough dose of chemotherapy to keep her alive until the baby was born and asked again if that's what she really wanted to do. To try to convey the type of person Shannon was, she looked as though she couldn't believe her eyes and asked him if people really choose themselves over their child.

At only the age of 16, I missed school to stay by her side for 6 months. Between her sixth and seventh month of pregnancy her heart stopped beating. At this point, I thought mine would too. I promised her I would help with her baby after she was gone, but he hadn't even been born. I was so confused and not ready for this at such a young age. I had so much growing up to do! When Shannon's heart stopped they removed the baby. He was named Matthew Alexander, just as she wished. He was only 4 pounds 12 ounces and 18 inches long. I longed for her to be able to see what she died for and as I prayed for her to see her baby a miracle happened. She opened her eyes again and asked for the baby. Her heart was beating strong! I couldn't do anything but cry and hand her son to her.

Shannon lived for another three wonderful months. I was by her side until she died and then returned to school and work. It was such a struggle to juggle all of my responsibilities, including taking care of a new baby, but I made it work. Matthew inspired me! I took him to daycare every morning, went to school then worked at the hospital for my CNA. During school I continued to get more involved and I joined two clubs, FCCLA (Future Career and Community Leaders of America) and HOSA (Health Occupation Students of America). I had one goal in mind when joining these clubs – to raise awareness for breast cancer.

I began taking Matthew to classes with me to tell his story. I started a campaign collecting can tabs, where each tab I collected allowed me to raised 10 cents toward chemotherapy treatments for someone with breast cancer. I took my story and new campaign to a state regional and national competition, and won both gold and silver for them. I graduated two years ago and have an 8 month old little boy of my own, but I continue to be inspired by Shannon and Matthew. I share their story by continuing to visit classes and raise awareness, while also collecting money for chemotherapy treatments.

~Cyndi Melton – Pure Romance Consultant

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.