

Intimacy and Sexuality



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the *Guide to Understanding
Intimacy and Sexuality*.

Thank you

for helping Living Beyond
Breast Cancer improve our
programs and services.



Dear Friend:

Sexual health is one of the most popular topics at Living Beyond Breast Cancer programs. No matter what your age or relationship status, women tell us they want more information about ways to maintain and enhance sexual life during and after treatment for early-stage and metastatic breast cancer.

Our *Guide to Understanding Intimacy and Sexuality* explains how breast cancer can affect your sexual desire and response, and offers ways to restore sexual drive and pleasure.

We give practical tips for talking with your healthcare team and your partner; simple ways to improve sexual health and resume sexual activity; and resources for more help. What you read here should be helpful, no matter what your stage of diagnosis, treatment type or recovery from breast cancer.

We are committed to our mission of connecting you with trusted breast cancer information and a community of support. Please take comfort in knowing we are here for you, every step of the way.

Warmly,

A blue ink handwritten signature, appearing to read 'Jean A. Sachs', written in a cursive style.

Jean A. Sachs, MSS, MLSP
Chief Executive Officer



**LIVING BEYOND
BREAST CANCER®**

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Toll-Free Breast Cancer Helpline

lbbc.org/helpline

(888) 753-5222

All people pictured in this guide
are LBBC volunteers whose lives have been
affected by breast cancer. We thank them
for sharing their experiences.

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How Breast Cancer May Affect Your Sexuality

Your first priority after a breast cancer diagnosis is to find the most effective treatments for you. It is also important to learn about possible side effects. One of those side effects is the change you may feel in your sexual relationships, sexual health and function, and level of sexual satisfaction.

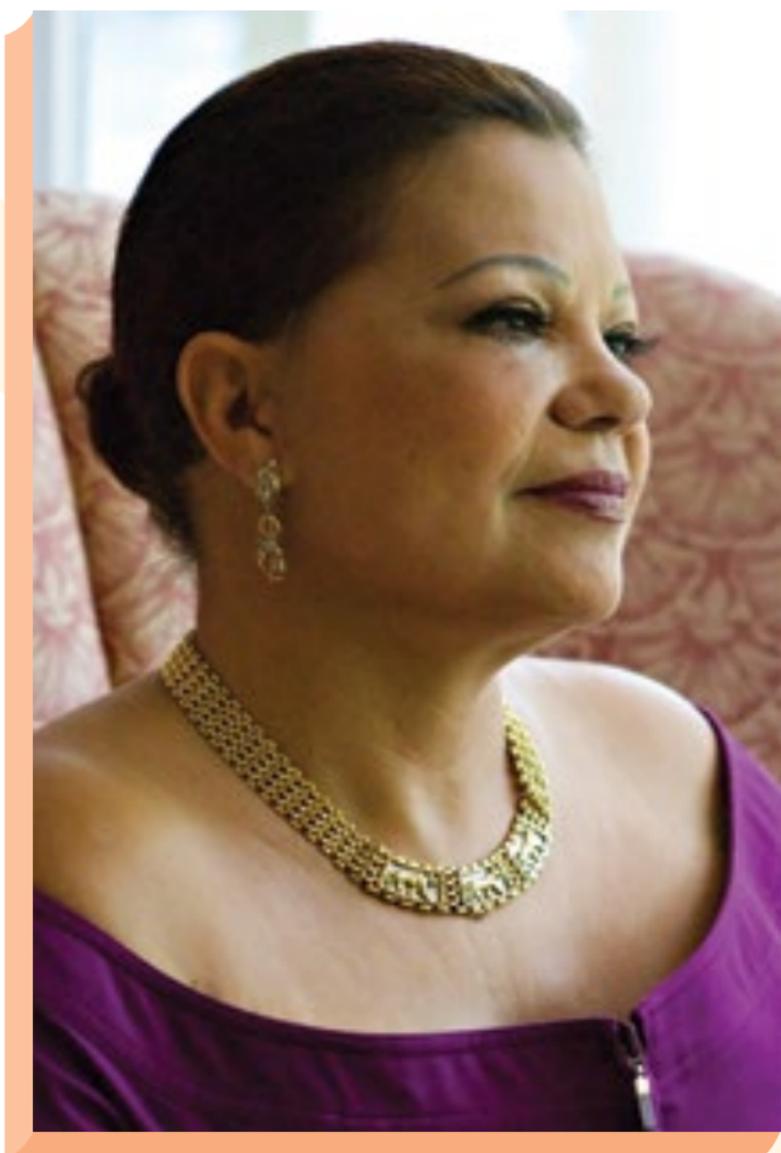
Treatment can affect both intimacy and sexuality. Intimacy is often thought of as the same as sexuality, but it is different. **Intimacy** means an emotional connectedness or closeness with another person. **Sexuality** involves your feelings and beliefs about yourself as a sexual being. Sexuality includes how you feel in your own body, and how you feel being touched and touching, kissing, masturbating, and having intercourse or penetration. You can have intimacy without sex — and sex without intimacy.

For many people, intimacy and sexuality are an important part of everyday life. They can foster our enthusiasm for living and for our self-image, our bodies and our relationships. Even so, your health-care providers may not bring them up.

Many factors can come together to reduce sexual desire, including fatigue, menopausal symptoms, pain during sexual activity and breast cancer treatment itself. Anxiety, fear, depression, weight gain, grief over the loss of your breast or breasts, negative feelings about changes in your body, and worry about treatment or recurrence can impact your ability to express yourself sexually.

Your age, social and cultural background, religious beliefs or past sexual history might affect your comfort in reading about sexuality and sexual pleasure. To make it easier, we divide our guide into sections. Thumb through the material and read the parts most helpful for you. We will provide you with practical tips you can explore on your own and with your healthcare team.

You may also wish to talk to a woman who has had breast cancer. When you are ready, we invite you to contact our **Breast Cancer Helpline** at lbbc.org/helpline or toll-free at **(888) 753-5222** for guidance, information and peer support.



Sexual Side Effects From Diagnosis and Treatment

It is normal to lose interest in sex after diagnosis and during treatment. Breast cancer treatments or the cancer itself can cause fatigue, discomfort, pain and other side effects that impact your sexual desire and activity. These side effects can crop up during treatment, or months or years afterward.

It may help to talk with your doctor or another member of your healthcare team about potential short- and long-term side effects of treatment and any steps you can take to prevent or counter them. If your provider does not bring up sexual side effects, you can kick off the conversation yourself (see page 20).

Keep in mind, no matter what kind of treatment you have, you will still be able to feel pleasure from touching. Something as simple as holding hands, caressing an arm or getting a hug can nurture intimacy and help you remain connected to your partner. Pleasure and sexual satisfaction are possible (see page 16), even if some aspects of your sex life have changed.

Here are common breast cancer treatments and possible side effects that can impact your sexuality. For more details, speak with your care team.

SURGERY

Surgeries can alter your body image. **Mastectomy** and **lumpectomy** may make you feel less attractive or change how your body feels to you and your partner. Other surgeries, like those to remove lymph nodes or to reconstruct the breast, may also affect your sex life. Changes caused by surgery may include:

- **Chest wall pain.** You might feel burning and constricting sensations or sudden, piercing pain.

- **Loss of or change in sensation of the breast or nipples.** This may concern you if you enjoy breast play or have orgasms when your breasts, nipples or **areolae** (the darker skin surrounding the nipples) are touched.
- **Menopause.** If you had your ovaries removed in a surgery called **oophorectomy**, you may experience hot flashes and vaginal dryness.
- **Lymphedema.** A condition in which extra lymph fluid causes swelling in tissues under the skin of the hand, arm, breast or torso, on the same side that breast cancer occurs. **Lymphedema** can cause discomfort and affect your body image.
- **Scar tissue or cording.** Axillary web syndrome, also known as **cording**, is a possible side effect of lymph node removal. Ropelike structures develop under the skin of the inner arm that develop near the site of scarring and may extend down the inner arm to inside the elbow. The cords tend to be painful and tight, making it difficult to lift your arm higher than the shoulder or fully extend the elbow.
- **A decrease in arm mobility and range of motion.** These can be caused by surgery itself, cording or lymphedema.



RADIATION

Radiation therapy directs high-energy x-rays at precise areas to destroy cancer cells. Breast radiation does not decrease sexual arousal or response on its own, but it can cause side effects that may, including:

- **Breast discomfort**, due to tenderness and swelling.
- **Fatigue.**
- **Range of motion problems** because of scarring or lymphedema.
- **Skin changes**, such as redness, more or less sensitivity and thickening of the breast tissue or skin. If you enjoy breast play or have orgasms from touching your breasts, nipples or areolae, skin changes may be of special concern. Also, skin changes can make breast reconstruction more difficult and less natural looking.
- **Your partner mistakenly believes** that your radiated skin may be radioactive (it is not).

CHEMOTHERAPY

Chemotherapy is a **systemic therapy**, which means it travels through the bloodstream to kill fast-growing cells throughout the body. Although very effective at killing cancer cells, chemotherapy also affects healthy cells, including some that help make sex comfortable.

Chemotherapy can have physical and emotional side effects that impact your sexuality. If you lose your hair, you might feel less feminine or desirable. It can be a shock to lose your pubic hair or hair on other parts of your body. If you gain or lose weight, have nerve tingling or weakness, or need chemotherapy ports to stay in place for weeks or months, it can be hard to keep a positive self-image.

Sometimes chemotherapy irritates the tissues lining the **vulva** (the area outside the vagina) and the vagina itself, making it dry and inflamed. Irritation can spark flare-ups of genital herpes or genital warts if you had them in the past. Other side effects from chemotherapy may include:

- **Trouble achieving arousal and lubrication** or reaching orgasm.
- **Lack of energy for sexual activity** because of upset stomach, nausea, vomiting, fatigue or weakness.
- **Low libido** (sexual desire).
- **Pain during penetration**, when the penis, a sex toy or finger is inserted in the vagina. Touching the vulva may cause pain.
- **Menopausal changes**, such as hot flashes and irregular or no menstrual periods. As the lining of the vagina thins, you may have light spotting after penetration.



TARGETED THERAPY

Targeted therapies look for specific features of cancer cells to stop those cells from growing or dividing. Only cancers with those features are expected to respond.

Targeted therapies often have fewer side effects than chemotherapy, but many are given with chemotherapy. If your treatment plan includes a targeted therapy as well as chemotherapy, you could have the same side effects as you would with chemotherapy alone, such as hair loss, nausea, fatigue and loss of sexual desire.

HORMONAL THERAPY

Hormonal therapy, also called endocrine therapy, starves the cancer of the hormones it needs to grow. It is used to treat hormone receptor-positive breast cancers. There are three types of hormonal therapy:

Aromatase Inhibitors (AIs) block the activity of an enzyme called **aromatase**, which the body uses to make estrogen in the ovaries and in other tissues. The three AIs are anastrozole (Arimidex), exemestane (Aromasin) and letrozole (Femara).

Estrogen Blockers prevent estrogen from causing breast cancer cells to grow. The medicines in this family are tamoxifen, raloxifene (Evista) and toremifene (Fareston). Your doctor may call estrogen blockers SERMs, selective estrogen receptor modulators, or SERDs, selective estrogen receptor downregulators.

Estrogen Receptor Antagonists (ERAs) block estrogen's effects on breast cancer cells. The medicine fulvestrant (Faslodex) is an ERA.

Hormonal therapy can cause or worsen menopausal symptoms and impact your sexual health. Side effects include hot flashes, night sweats, insomnia, irritability, weakened sex drive, less lubrication and pain during penetration. It can interrupt your periods and cause dryness and **vaginal atrophy**, thinning of the walls of the vagina.

Tamoxifen may increase mood swings and depression, which can contribute to lack of sexual desire. Bone pain, a side effect of aromatase inhibitors, could also greatly affect your desire for sex.

LEARN MORE

To learn more about these treatments and tips for managing side effects, download our *Guide to Understanding Hormonal Therapy*.

OTHER MEDICINES

Some antidepressants, called **selective serotonin reuptake inhibitors (SSRIs)**, can lessen sexual desire and affect your ability to reach orgasm. SSRIs are also sometimes prescribed to help with hot flashes.

Depression is a common diagnosis during and after a treatment for breast cancer. Recognizing the signs and symptoms of depression, and getting treatment for it, are critical. If you believe antidepressants are causing sexual concerns for you, talk with your doctor about switching to another medicine. Different antidepressants have different sexual impacts, sometimes even in the same person. Always talk with your doctor before stopping or changing any medicine. You might also consider counseling or talk therapy, which can be very effective for mild and moderate depression.

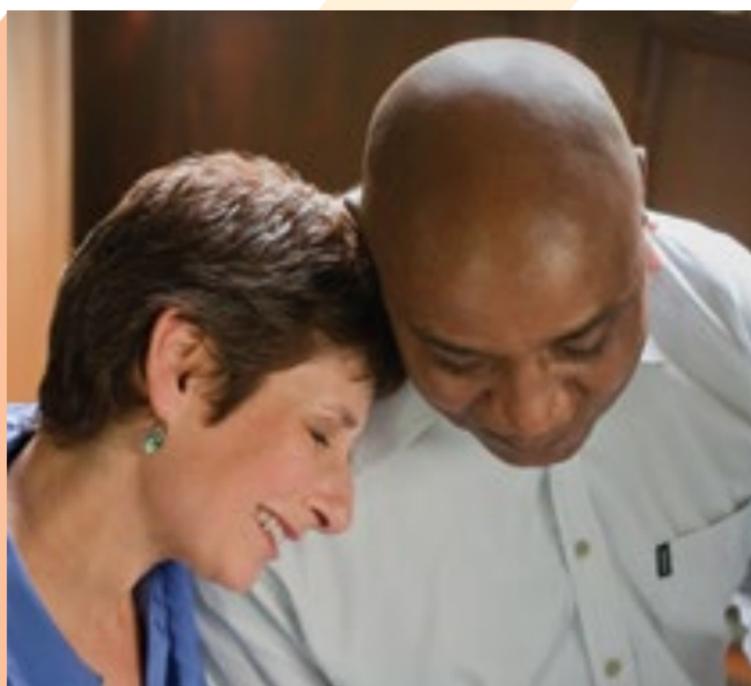
Antidepressants with the lowest rate of sexual side effects are:

- Bupropion (Wellbutrin, Wellbutrin SR, Wellbutrin XL)
- Mirtazapine (Remeron, Remeron SolTab)

Some common SSRIs that may cause sexual side effects are:

- Citalopram (Celexa)
- Escitalopram (Lexapro)
- Fluoxetine (Prozac, Prozac Weekly, Sarafem)
- Paroxetine (Paxil, Paxil CR, Pexeva)
- Sertraline (Zoloft)

Antiemetics, medicines used to control or stop nausea during chemotherapy, have side effects that may interfere with sexual desire. These include drowsiness, diarrhea, constipation, headache and fever. Other medicines used during treatment can affect your sexual interest by making you feel tired or by causing bone pain.



A Note on Fertility and Birth Control

If you were not menopausal before your treatment and you are sexually active, it is important to discuss birth control with your doctor. Even if your periods become irregular or stop for a time because of treatment, it may still be possible for you to become pregnant.

If you want to get pregnant after treatment, talk with your healthcare team as soon as possible. Your team should speak with you about the impact of chemotherapy and other treatments on your fertility. Timing is critical, so try to talk before you start any type of therapy. You may be sent to a **reproductive endocrinologist**, a doctor who can explain ways to preserve or protect your fertility and help you plan for future pregnancies. Ask your doctor how long to wait before you can safely conceive.

Early in pregnancy, chemotherapy and hormonal therapy can harm a fetus and lead to birth defects, so it's important not to become pregnant during treatment.

Hormonal birth control (the pill, patch, shot and implant) is not recommended for women who have had breast cancer, especially if the cancer was hormone receptor-positive. Some non-hormonal birth control methods to consider include:

- **Condoms.** These are thin sheaths that fit snugly over a man's erect penis. Women whose ovaries have been affected by cancer treatment may find lambskin, polyurethane or polyisoprene condoms more comfortable than latex. If you are experiencing vaginal dryness, chafing, or

narrowing, apply lubricants generously to help reduce any discomfort.

● **Diaphragm.** This type of birth control is a shallow silicone cup inserted in the vagina. To be effective, diaphragms must be used with a spermicide cream, gel or jelly.

● **IUD.** The intrauterine device (IUD) is a small, T-shaped frame inserted in the uterus. It prevents sperm from fertilizing an egg. Not all IUDs are the same, so make sure to use one, like the ParaGard IUD, that does not contain hormones.





Breast Cancer Does Not Mean an End to Sexual Life

Women of all ages enjoy sex, so we are all affected by the sexual side effects of treatment. But breast cancer does not mean the end of sexuality in your life.

Try not to limit sex to the act of penetration. Hugging, sensual caresses, massages, cuddling and kissing can satisfy you and your partner both physically and emotionally. It can be fulfilling to touch your genitals or have oral sex. Caressing or stimulating yourself can satisfy you and keep you in touch with your body and sexuality, whether or not you have a partner.

Start slowly. There is no need to rush if you are not ready for sexual activity. Sexual encounters can focus on pleasure or being together, rather than on the genitals, orgasm or penetration. It is important not to feel pressured to be any more or less sexual than you want to be. There is no “right” way to be. Just remember that you deserve pleasure — and only *you* can define what that means for you.

Breast cancer isn't the only thing that affects your sexuality. So can your upbringing and cultural or religious beliefs, past sexual experiences or abuse, the natural effects of aging, poor communication or relationship issues with your partner, financial pressures, and stress.

Talking with your partner and healthcare team can help you find solutions, whether the issue is breast cancer or another concern.

Talking With Your Partner

If you had difficulty discussing your feelings about sex with your partner before your breast cancer diagnosis, it will probably still be difficult now.

Your partner may be unsure how to best show support and affection and may wait for you to say when to resume a sexual relationship. In some cases, your partner may worry about hurting you or causing you pain.

When you feel comfortable, talk about the concerns you have about physical touch and your sexual relationship. Try to be open about any fears of rejection, lack of desire and discomfort. Let your partner know where you do, and don't, want to be touched.

Talk about your concerns — and your partner's concerns — openly and honestly. This can reassure you and help you find solutions to ease you back into a fulfilling sex life. If your partner worries about hurting you, agree on a signal you will use if you feel pain. It is also important to let your partner know when something feels good.

Some tips to help you get started:

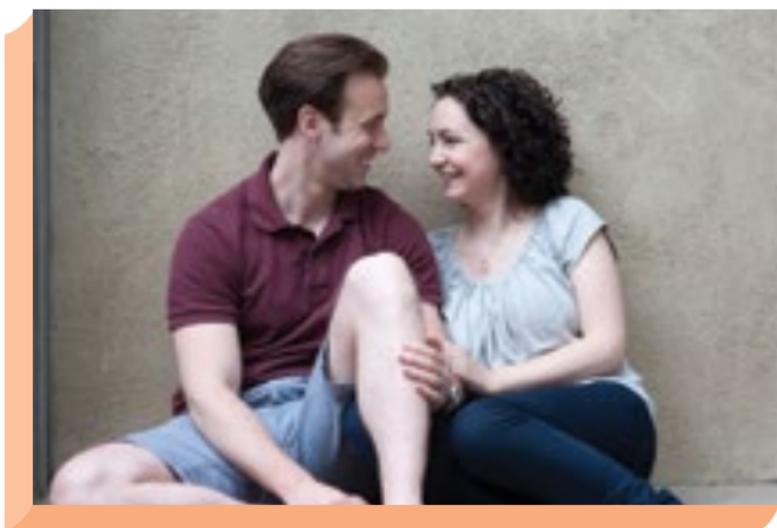
● **Just start talking.** Sometimes talking about things unrelated to cancer, such as friends or common interests, can make it easier to bring the conversation around to your fears, how breast cancer affected you and the importance of your romantic relationship. Or just be direct, and say what's on your mind. Even if your partner isn't a good talker, that doesn't mean he or she isn't listening. Make eye contact and touch your partner as you speak to give your words greater meaning. Choose a quiet time with less chance of interruptions, and keep distractions to a minimum.

● **Reassure your partner.** Don't assume your partner's silence means he or she isn't concerned about what you are going through. Your partner may not want to burden you with his or her own fears about your health, or simply may not know what to say. Making it clear you want to know your partner's concerns sends the message you are in the situation together.

● **Write down your concerns.** Sometimes writing a letter and giving it to your partner is easier than saying the words face to face. A letter gives you the chance to say exactly what you want without feeling embarrassed or uncomfortable. After your partner reads the letter, find a quiet time to talk together.

Keep in mind that while a diagnosis of and treatment for breast cancer may lessen sexual desire, they do not reduce the need or desire for physical closeness. Sometimes just giving and getting a hug or a kiss or holding hands is enough.

Another option is to seek advice from a couples counselor or sex therapist. You could also join a support group. Do either on your own, or together.



Communicating With Your Healthcare Team

If you don't feel comfortable talking about sex with your providers, you are not alone. A study in the journal *Cancer* reported 42 percent of women with breast and gynecologic cancers wanted medical attention for their sexual health needs but only 7 percent asked for advice. In the same study, 62 percent of women with vaginal and cervical cancer said no doctor ever asked them about the sexual side effects of cancer or treatment.

It is important to address quality-of-life issues, including sex. Many providers want to help you. Even if they do not have all the answers, your providers can lead you to other professionals who can help.

Don't be afraid to ask for advice or for a referral. While it is understandable to feel shy or embarrassed, if you don't discuss your sexual concerns, you may never get the help you want.

Many women worry about sexual side effects, so it is very likely others have asked similar questions. Your providers have a wide range of options to help improve your sexual life. Here are some tips to kick off a conversation:

- When you make your appointment, mention you would like a few extra minutes to ask questions.
- Write down questions and symptoms before your appointment. Knowing what you want to ask ahead of time may help you overcome any shyness.
- Be specific. For example, ask, "I have pain during penetration. Will the problem get better? What can I do to get relief?"
- Rehearse what you want to say with your partner or a friend before your appointment. Even saying the words out loud in front of a mirror can help.

When You Want More Help

If you find your doctor, nurse, social worker or other providers are unsure how to help or seem uncomfortable discussing your sexual concerns, ask for a referral to a specialist in sexual health, cancer survivorship medicine or both. These professionals can provide specialized care to women with cancer who are coping with sexual and intimacy issues.

These groups can also help you find a therapist or counselor in your area, as well as provide sex education information:

- American Association of Sexuality Educators, Counselors and Therapists: (202) 449-1099, aasect.org
- American Psychological Association Psychologist Locator: locator.apa.org
- International Society for Sexual Medicine: issm.info
- International Society for the Study of Women's Sexual Health: (952) 683-9025, isswsh.org
- Maze Women's Sexual Health: (914) 328-3700, mazewomenshealth.com

These books are also good resources:

- *100 Questions & Answers About Breast Cancer Sensuality, Sexuality and Intimacy* by Michael L. Krychman, MD, Susan Kellogg-Spadt, PhD, CRNP, and Sandra Finestone, PsyD (Jones & Bartlett Learning, 2010)
- *Woman Cancer Sex* by Anne Katz, PhD, RN (Hygeia Media, 2009)

One Woman's Story

For Kathi, 58, the most troubling side effect of breast cancer treatment was the plunge in her sexual desire.

Diagnosed with stage II hormone receptor-positive cancer, Kathi had a double mastectomy and received chemotherapy with doxorubicin (Adriamycin), cyclophosphamide (Cytoxan) and docetaxel (Taxotere). For several years she took tamoxifen.

After her mother was diagnosed with metastatic ovarian cancer, Kathi chose to have her ovaries removed. She's been on exemestane ever since.

The fear of having cancer, plus all the surgeries, chemotherapy and hormonal treatment, took a toll on her sex life.

"My husband and I were not sexual very often the first year of my treatment because I felt so terrible, and he was very concerned about me," Kathi says. "Then, after a double mastectomy, I felt unattractive and that I had this alien body I wasn't comfortable with. It was impossible for me to imagine that anyone else could be comfortable with it either."

Once Kathi finished active treatment, she and her husband had intercourse a few times but it was painful. Kathi's gynecologist recommended she use a dilator to stretch her vaginal tissue to increase elasticity. It helped. But once Kathi had her ovaries removed, her

estrogen levels dropped even further. Her vaginal dryness increased, and she no longer desired sex. It's a problem she and her husband are still working out.

Without that driving sexual desire, it's easy for physical intimacy to fall down on the list of things to do. We have to constantly remind each other to move it back up the list.”

—KATHI

Always affectionate before Kathi's diagnosis, the couple stays close by holding hands and giving each other gentle massages. And they keep the lines of communication open.

“For a long time I thought I was really disappointing my husband because I wasn't being sexually assertive, but he said that it was OK because at age 65 he's not feeling as high a level of sexual desire either,” Kathi says.

“While I miss the level of sexual intimacy we used to have, it doesn't mean our relationship isn't as good as it ever was. Even if I never had cancer, other life stresses would likely affect my libido. I can't blame everything on cancer. I would probably be dealing with these issues regardless of the cancer, and that's reassuring.”



Improving Your Sexual Health

Sexual activity after diagnosis and treatment has benefits for your body, mind and soul. It can help you stay connected to yourself and to your partner, if you have someone in your life.

As many as 50 to 90 percent of women who have had breast cancer report concerns about sexual health after treatment. Nearly one-third feel lingering problems for years, and even decades.

If you experience any sexual side effects, talk them over with your healthcare providers. There are many safe, effective remedies available now to provide relief and improve your sexual satisfaction. Even more are being studied in clinical trials. Beyond medicine, there are many practical steps you can take (see page 32).

Before using any over-the-counter product, be sure to consult with your doctor, nurse or another member of your care team.

Vaginal Lubricants

One main reason for sexual troubles after chemotherapy or hormonal therapy is low estrogen, which can cause the vagina to become dry.

Vaginal dryness makes for painful penetration, or what doctors call **dyspareunia**. Even rubbing and caressing the area outside the vagina can be painful. Low estrogen can also trigger burning, pain and itching in the vagina and contribute to ongoing urinary tract or yeast infections.

Vaginal lubricants may be used before penetration or for sex play. They come as a liquid or gel and can increase your comfort. Lubricants are usually applied to the vulva and in and around the opening to the vagina. They may also be used on the penis and on sex toys.

Use water- or silicone-based products. Gel lubricants that warm or cool, or have a scent or flavor, may irritate your tissues. Avoid petroleum jelly-based products that can harbor bacteria in your vagina and lead to infection. They can also break down the latex in condoms, increasing the chances for breaks or tears and making condoms less effective as birth control (see page 14). Do not use silicone-based products with silicone sex toys; they will destroy them.

You can purchase most products in your local drug-store, but if you prefer more privacy, you may order them online from many major chain retailers or MiddlesexMD.com. Some over-the-counter products include:

- Astroglide
- Slippery Stuff
- Good Clean Love
- K-Y Sensitive
- SYLK Personal Lubricant
- Wet Original Gel Lubricant

Vaginal Moisturizers and More

Unlike vaginal lubricants, **vaginal moisturizers** are used inside the vagina and not on the vulva. These products are used for daily comfort and not for sexual activity. Generally, you insert an applicator of moisturizer two to five times a week to keep the tissues in your vagina hydrated and elastic.

As with vaginal lubricants, avoid products with fragrance. Look instead for those with vitamin E or hyaluronic acid. You can also get these items in stores or online. Some over-the-counter products to try include:

- Emerita Personal Moisturizer
- Luvena
- Replens

LIDOCAINE

If you have pain or burning during the start of penetration, see your doctor for a pelvic exam. He or she will check for tenderness in the vagina and the vestibule, the opening of the vagina, to identify where you're feeling pain. If the pain is at the vestibule, a medicine called lidocaine can help. You may be familiar with lidocaine as a pain relief cream sold in many drugstores. But for pain at the opening of the vagina, your doctor will prescribe it in liquid form. You will need a prescription to get it from your pharmacy.

You'll completely soak a cotton ball with the liquid lidocaine, and then place the cotton ball on the opening of your vagina for three minutes before you plan to have sex. Doing so can make penetration more comfortable.

Vaginal Estrogens

Vaginal estrogens are in a family of medicines called hormones. They come as creams, rings and tablets inserted into the vagina. Local estrogens restore the vaginal tissues and may increase elasticity and lubrication to allow for easier penetration. Non-hormonal moisturizers and lubricants are often used alongside them.

These medicines are not FDA approved for women who have had breast cancer, but some healthcare

providers may prescribe vaginal estrogens **off-label** to treat vaginal dryness. Many oncologists have strong reservations about vaginal estrogen use in women with a history of breast cancer, especially if you had hormone receptor-positive disease. The body may absorb even small amounts of estrogen, and little research has been done on vaginal estrogens in women with breast cancer to know their impact. While clinical trials continue to study their safety, any off-label use of vaginal estrogens means a frank talk between you and your care team. Weigh the possible risks and benefits, and ask your team's feeling about safety. You may also be able to take part in clinical trials.

Vaginal Dilators and Vibrators

Vaginal dilators are rod-shaped inserts that can be put in the vagina. They gently stretch the vagina to maintain and increase elasticity of the walls. Vaginal dilators slowly increase the length and width of the vagina, making sex less painful. They may also build your confidence in trying penetration by helping you learn to relax the muscles that surround your vagina.

Vaginal dilators are often made of glass, plastic, silicone or rubber. They come in sizes from extra small to extra large. When selecting a dilator, choose one made of hypoallergenic material that comes in a small size your body can easily fit. A healthcare provider with expertise in sexual concerns can give advice on the type of dilator that would work best for you.

Use a water-soluble lubricant on your dilator and insert it carefully into your vagina. Leave it in place for 5 to 10 minutes a day, every day. As small-size dilators become easier to use, gradually use medium- and large-size dilators until you achieve comfort with a dilator that is close to the size of your partner's penis and is easy to move around.

You can buy dilators in sex shops or online at these websites:

- Goodvibes.com
- MiddlesexMD.com
- Pureromance.com
- Vaginismus.com

A **vibrator**, or self-stimulator, is a small device that may be shaped like a dilator or a penis. It vibrates at different speeds to provide a pleasurable feeling, and it can be used for massage or sexual pleasure.

It is common for both men and women to use vibrators during sexual activity. Vibrators can increase sexual pleasure and the ability to reach orgasm that may not be possible through penetration or use of the hand or mouth alone.

The thought of using a sex aid such as a vibrator, either to stimulate yourself or to enhance sexual pleasure with a partner, may embarrass you, but vibrators are good for sexual health. They are thought to increase blood flow to the vagina and vulva.

Vibrators can be purchased in sexual toy shops and online at Goodvibes.com and Pureromance.com.

Energy-Based Devices for Vaginal Rejuvenation

As you've dealt with the effects of cancer treatment, you may have heard about using laser therapy to help with sexual side effects. During an in-office visit, a doctor stimulates the tissues of the vagina using a special type of laser. The goal is to help new blood vessels grow in the skin, which may lessen dryness, itching and burning in the vagina.

Some women report that laser therapy helps them. But whether it's useful for women with breast cancer, especially women taking hormonal therapy, is not clear. There have also been reports of laser therapy causing pain or burns. In 2018, the FDA issued a warning that the agency can't prove the safety and effectiveness of these devices. If you're interested, talk with your doctor for more information, and check with your health insurance company – this type of therapy is not usually covered by insurance.

If You Feel Pain

Even though treatment can impact many parts of your sexual life, you should not bleed or feel pain during penetration. If you do, it's very important to talk with your healthcare provider.

If penetration is painful, your pelvic muscles may tighten as you anticipate pain. This may make penetration impossible. Vaginal dilators and lubricants can help stretch your vagina and improve elasticity, reducing pain and discomfort.

Try out different sexual positions that let you control the movement. If deep penetration hurts, try to make the thrusts less deep. One position to try is for you and your partner to lie on your sides, either with your partner behind you, like spoons, or face to face.

If these tips don't work and your pain persists, ask for advice from members of your care team, including your gynecologist and oncologist. Your gynecologist may recommend you have a pelvic exam to check for pelvic floor muscle spasm or a urinary tract or vaginal infection.

A referral to a sexual pain specialist may also help. A specialist in dyspareunia may recommend muscle relaxants, physical therapy or **desensitization therapy**, learning exercises that relax the entrance to the vagina and decrease pain. If you and your partner avoid sex because of pain, you may also want help to improve communication and restore sexual intimacy. A counselor or sex therapist can help.

These organizations provide information on painful sexual activity and can help you find a physical therapist or specialist in dyspareunia:

- American Association of Sexuality Educators, Counselors and Therapists: (202) 449-1099, aasect.org
- American Physical Therapy Association: (800) 999-2782, apta.org
- Maze Women's Sexual Health: (914) 328-3700, mazewomenshealth.com





Caring for Yourself

Your sexual health and satisfaction are linked to your overall health. Eating well, controlling weight, reducing stress, getting enough sleep and doing regular exercise are all important to maintain a positive body image and increase energy levels during treatment and recovery. Most of these activities can be done on your own, but you may also want to include a friend or a partner. Exercising, cooking or getting massages together can bring fun and closeness to your relationships.

Smoking, drinking too much alcohol and taking recreational drugs not only impact your general health, but also can affect your sexual arousal and response.

The Basics: Getting Started

The side effects from surgery, chemotherapy and radiation therapy can be short- or long-term. But there are many self-care measures you can include in your life to restore your physical, emotional and sexual well-being.

Some tips to try include:

- **Take care of yourself emotionally.** We often put others' needs before our own. Try putting your needs first sometimes by asking for practical help or emotional support. Connect with a friend or family member or attend a support group. Consider counseling or antidepressants if you feel edgy, anxious or depressed.
- **Eat a well-balanced diet.** We know this is never as easy as it sounds! Talking with a nutritionist or dietitian can help you learn to meet your nutrition needs and manage your weight.

- **Stick with a regular exercise program.** Staying active can restore your self-confidence, boost your energy, improve body image and lift your mood. The best exercise for you is the one you'll stick with and enjoy doing. Brisk walking, running, swimming, bicycling, yoga and dance are good options. Inviting along a friend can help you maintain your exercise routine and increase your fun while doing it. Before you start or resume an exercise program, check with your care team.
- **Make time to enjoy yourself.** Doing things that give you pleasure can renew your self-esteem, help reduce stress and improve your mood. Create a list of things that make you feel good, such as having a manicure, relaxing in a bubble bath, working in the garden or getting a massage. Studies show that massage helps with anxiety, fatigue and pain. Look for a licensed massage therapist who has experience with women affected by breast cancer. To find a qualified massage therapist in your area, visit the American Massage Therapy Association at amtamassage.org.
- **Limit or avoid alcohol.** While alcohol can relax you and may enhance sexual pleasure, studies show a link between alcohol and breast cancer recurrence. If you drink, limit your intake.



Maintaining Your Self-Image

Around the world, the female breasts are an important part of sexuality. For many, they are closely linked to what it means to be a woman.

Breasts are sex organs that are essential to some women's self-esteem. Changes to the breasts and changes in body image after breast cancer and its treatment may directly affect how you see yourself sexually, your sexual response and your relationships.

If you have scars, you may fear you have lost your attractiveness. The scar may be a visible reminder of what you have been through. You may feel less sensation in your breast area as a result of your treatment. Some women even report they have more erotic sensitivity at the site of the breast scar.

Weight gain or loss because of chemotherapy could affect your self-image. Even short-term changes, such as losing your hair and eyelashes, can have a major effect on how you feel about yourself. Losing pubic hair from chemotherapy makes some women feel less sexual because they feel they look like "little girls 'down there.'" Others enjoy this change. Your hair, on your head and elsewhere, will likely grow back at the end of treatment, or after switching to another type of treatment.

If you had a mastectomy, you may choose to have your breast rebuilt, use a **prosthesis** (a breast form) or wear nothing at all. Breast reconstruction may restore the shape and size of your lost breast so that it looks very much like your other breast. It cannot restore normal feeling in the breast.

In a rebuilt breast, the feeling of pleasure from touching the breast and nipple may be decreased, or you may not have any sensation at all. Over time, the skin on

the rebuilt breast gets more sensitive, but usually you will not feel the same kind of pleasure as before the mastectomy. Still, breast reconstruction may help restore your sexual enjoyment because it could boost your feelings of wholeness and attractiveness.

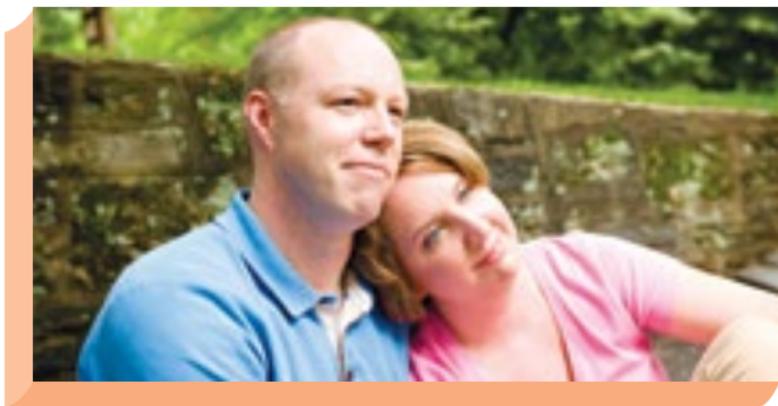
Whether you choose to reconstruct or not, you may need time to get used to your new body. Looking in the mirror may help you feel more comfortable over time. Try to be kind to yourself and accepting of your new body. Seek the advice of a mental health professional with expertise in treating women with cancer, or take part in a breast cancer support group. Over time, these actions may help you adjust, release negative feelings and embrace the future.

To rebuild your self-image:

- **Give yourself time to adjust.** Learning to accept a breast cancer diagnosis may change your life. Give yourself time to adjust to a new way of feeling about yourself or how you look. Your body has gone through difficult treatments.
- **Stay calm and embrace humor.** Laughter has many positive effects and may help you relax during a tense time.
- **Take small steps.** Do little things along the way to your bigger goal of feeling better about yourself. Shower and dress to feel good every day, even when you're not in the mood. Buy bras and shirts in styles you like. Get exercise you enjoy.
- **Buy lingerie.** After breast cancer surgery, it's common to feel self-conscious about being nude during sexual activity. You may choose to wear clothes instead. Camisoles, lingerie or nightgowns might make you feel sexy, open your mind and boost your confidence. Try them on your own and, when you want, with a partner. Or, you might prefer to cover yourself with a T-shirt or flannel PJs — that's OK, too.

If you have trouble finding what you need in your department store, try Amoena, at amoena.com or AnaOno Intimates, at anaono.com.

🗨️ **Talk with your partner.** When it comes to sexuality, breast cancer’s emotional impact is just as or more important than its physical impact. Talking with your partner (see page 18) about what feels good sexually can help you move forward.



Taking Your Hormonal Therapy

All hormonal therapy (see page 11) can cause menopausal symptoms and affect sexual desire. Research shows many women stop taking medicine or don’t take it as prescribed, often because they forget or get fed up with side effects.

If this sounds like you, do not be embarrassed. It’s vital to address your concerns so you can continue your treatment. Not taking hormonal therapy as prescribed may make it less effective, increasing your risk for recurrence. But that doesn’t mean you have to “put up with” menopausal symptoms and their impact on your sexual life.

Although you might feel uncertain about talking with your care team about sexual side effects, give it a chance. Your providers have heard these questions before and can help you find solutions. Check out our tips for getting the conversation started (see page 20).



Resuming and Maintaining a Sexual Life

Whether you are married, partnered or single, a breast cancer diagnosis and its aftermath does not mean an end to a rewarding sexual life. While your life may change, the insight you gain from experiencing breast cancer may enrich your relationships and restore a joyous sense of your body.

If You Have a Partner

Sexual activity is a potent trigger for the release of **endorphins**, natural hormones in the body that lead to feelings of euphoria. Rebuilding a sexual relationship with your partner after treatment may take time as you adapt to a new sexual style.

If some types of sexual activity are painful, you and your partner can discuss other options. Touch parts of your body you may not have explored before. You may be surprised to find they bring about sexual pleasure!

Talk to your partner about what feels good (or doesn't) and about new activities you may want to try. Sharing your feelings and your sexual fantasies will help the two of you find new ways to be intimate.

If you have a hard time becoming aroused during sexual touch, try to rekindle the spark by using sexual aids like vibrators (see page 28). Read erotic stories together or watch erotic movies. Write your fantasies in a journal, and share them with your partner.

If these ideas make you uncomfortable, try making smaller changes, like setting the mood with scented candles or watching a romantic movie before love-making.

There may be ups and downs as you navigate your new sexual territory. But it's important to remember that studies show partners of women affected by breast cancer care most that their loved one is alive and feeling well. It's OK to resume sexual activity slowly and give yourself and your partner time to adjust.

One Woman's Story

Despite having a fulfilling sex life throughout their 8-year marriage, once Lana*, 62, was diagnosed with invasive breast cancer and underwent treatment, her husband no longer wanted to have sex.

The rejection left Lana feeling unloved and hurt. The cancer was confined to her left breast. But because it was aggressive and Lana had several lumps in her right breast, her oncologist recommended a bilateral mastectomy, followed by chemotherapy with docetaxel and cyclophosphamide. She now takes the aromatase inhibitor letrozole to help decrease the risk of recurrence.

Even though Lana had breast reconstruction to match the size of her natural breasts and felt well enough to have sexual relations, her husband wasn't interested.

"I would put on something sexy and tell him that I was still the same person I always was, but he would just look at me and not say anything. I thought he didn't desire me anymore," Lana says.

On the rare occasions the couple had sex, such as Lana's birthday, Valentine's Day and their anniversary, penetration was painful. This discouraged her husband even further.

Finally, a few months ago, Lana's husband broke his silence. He told her he still loves and desires her but he had some concerns. "One thing that bothered my husband was that I wouldn't take off my bra and camisole during sex. I didn't want to go bare breasted because I felt so self-conscious. I thought I'd look better covered up. I guess I wasn't that comfortable with my new look. But the last few times we've had sex, I've taken off my top, so there has been some progress," Lana says.

Another concern was vaginal dryness, a side effect from Lana's chemotherapy. After talking over the problem with her oncologist, Lana tried Estrace vaginal cream at her doctor's recommendation. It's helping.

Communication is key, Lana says, to adjusting to life after cancer and resuming sexual activity.

Both my husband and I were too embarrassed to talk about what was happening, even though we had a wonderful sex life prior to my diagnosis. I suffered in silence too long. But I've learned that you can't be afraid to talk openly about these issues to your husband and to your oncologist and find a solution."

—LANA

* We withheld Lana's real name at her request.

Same-Sex Relationships

Just like heterosexual couples, couples in same-sex relationships cope with the sexual aftermath of treatment based on the emotional strength of the relationship before diagnosis.

Little research has been done on the sexual side effects of breast cancer for lesbian and bisexual women. Some studies suggest that lesbians with breast cancer have a better body image than heterosexual women, may feel less disruption in a sexual relationship, have fewer sexual concerns, and have more understanding and supportive partners.

If you are in a same-sex relationship, it is important to talk with your partner about your feelings. She may have her own worries about your or her own health. If she still has breasts, she might feel sadness or grief on your behalf, or worry that touching you will hurt you. Giving voice to your own and shared concerns can build trust and closeness.

As a lesbian or bisexual woman, you may have other unique concerns, including the difficult decision to come out to your care team. To get support for sexual concerns, it is important to share your orientation. If your providers assume you are heterosexual, they may not be able to give you appropriate care.

LEARN MORE

For more tips for talking with your doctor about your sexuality, read our brochure, *Breast Cancer inFocus: Getting the Care You Need as a Lesbian, Gay or Bisexual Person*.

You may worry about discrimination from healthcare providers. Or, your providers just might not be sure how to help you. Providers you trust should be able to refer you to professionals who can help.

Some women report problems getting information and support about sexuality. It may be hard to find support groups. These groups provide information that may help:

- American Cancer Society Cancer Survivors Network: csn.cancer.org
- GLMA: Health Professionals Advancing LGBTQ Equality: (202) 600-8037, glma.org
- Women's Health Services at Howard Brown Health: (773) 388-1600, howardbrown.org/womens-health
- Whitman-Walker Health: (202) 745-7000, whitman-walker.org
- National LGBT Cancer Network: (212) 675-2633, cancer-network.org



One Woman's Story

After a diagnosis of triple-negative breast cancer in her right breast at age 49, Alice* had genetic testing and was found positive for the *BRCA1* gene mutation. She was given chemotherapy, then a lumpectomy, additional chemotherapy and radiation therapy.

Two years after her surgery, Alice was diagnosed with ductal carcinoma in situ in her left breast and decided to have a bilateral mastectomy. She chose not to have reconstructive surgery.

“First, my right breast tried to kill me. Then, the left breast was trying to do the same thing. I felt I couldn’t afford to be sentimental about this part of my body,” Alice says. “I think that part of my reasoning has to do with being a lesbian. I believe a lot of women who are not heterosexual have an opportunity to think differently about their body image. I felt that my breasts, although they were important to me, were not the most important part of my body to other people.”

Although Alice grieved the loss of her breasts, she now feels happier without them. She is more comfortable in her body. “My breasts were very sensitive, and in some ways it’s very freeing not to have that oversensitive breast tissue,” she says.

Single during her diagnosis and treatment, Alice is now in a fulfilling relationship with a woman she dated in the past.

What's interesting is to be sexually involved with someone I had been involved with before having breast cancer, when I still had breasts. Her observation is that I'm much less guarded now about my body as a whole. I think that's true for me sexually as well."

—ALICE

That level of comfort has renewed Alice's self-confidence in her sexuality. "My partner doesn't care whether I have breasts or not and has said that my not having breasts doesn't make any difference to her," she says.

Even without her breasts, Alice still has sexual fantasies in which her breasts are as responsive as they always were. That has added to her and her partner's sexual experience.

"Fantasy is a helpful way to get away from the literalness of our bodies. Even though my breasts are literally gone, they are still there in my imagination and I — and my partner — can still experience that pleasure. My breasts are still here in our heads," Alice says.

*We withheld Alice's real name at her request.

If You Are Single

Breast cancer does not mean an end to romantic love, no matter what your age.

If you want to start dating, you may want advice on how to meet new partners and when and how to tell a prospective sexual partner about your cancer experience. Bringing up the issue too soon may scare away a potential partner, but waiting too long may make the person angry you withheld important information about yourself.

The conversation should happen when you feel the timing is right or intimacy seems likely. It may help to take new relationships slowly. Make friends before thinking about becoming intimate, and be honest about what your partner can expect. Don't forget other issues you still need to address: sexually transmitted diseases, such as HIV and herpes; safe sex and birth control (see page 14); and fertility concerns.

It may help to talk with a mental health professional or your support group for advice on sharing your history of breast cancer with dating partners. You can also contact **LBBC's Breast Cancer Helpline** at lbcc.org/helpline or toll-free at **(888)-753-5222**. These suggestions may also help ease you back into the dating world:

● **Get the word out.** Finding good partners is tough under any circumstances, and you've got to do what anyone would to meet the right person. According to *Sex in America*, most couples meet through family members, friends, co-workers, classmates or neighbors. Don't be shy about asking for an introduction to single friends. Participate in activities you enjoy, take a course or volunteer for a cause important to you — these are also good ways to meet potential partners. Online dating sites (see below) may also help.

- **Consider the type of person you want to meet.** Ask yourself what kind of person you're looking for and what your priorities are. Is it important you have the same values and interests? Religious beliefs? Are close in age and economic status?
- **Practice what you're going to say.** Tell your story in the mirror or to a trusted family member or friend first. Be honest in letting your potential partner know what to expect, explaining what was done, how you're doing now and how you feel. Remember, other women and men you meet may also have had to cope with cancer or another serious illness.
- **End the relationship.** If the person can't cope with your breast cancer history or just isn't right for you, move on. You deserve better!

In addition to the many popular dating websites, these dating and friendship sites help people with cancer and other health conditions make connections with each other:

- [CancerMatch.com](https://www.cancermatch.com)

Although not dating sites, these websites also help people with cancer connect with each other:

- **American Cancer Society Cancer Survivors Network:** csn.cancer.org
- **LIVESTRONG:** [livestrong.org/we-can-help/preparing-yourself/meeting-others-like-you](https://www.livestrong.org/we-can-help/preparing-yourself/meeting-others-like-you)

One Woman's Story

At just 24, a breast cancer diagnosis was the last thing on Rachel's mind. Because she was diagnosed with stage III hormone receptor-positive cancer in her right breast, Rachel's medical team advised a mastectomy, followed by six rounds of the chemotherapy regimen TAC (Taxotere, Adriamycin and Cytosan), plus radiation.

Because she had just started a new relationship, losing both a breast and her hair made Rachel feel vulnerable and self-conscious about her appearance, especially during sex.

"When it came to boyfriends, I was never self-conscious about anything, but once I lost my breast and my hair, I wanted to avoid unflattering angles when I was being intimate," Rachel says. "I tried as hard as I could to position my head and body so that my boyfriend wasn't staring at my bald head or my chest scars. Men are such visual creatures. This was a new relationship for me, and I didn't want to turn him off."

Although her boyfriend never made her feel uncomfortable about her appearance, he was unable to cope with Rachel's cancer diagnosis and broke up with her midway through her treatments. The experience made her question whether she would ever have a healthy relationship again.

"I didn't think I would be able to find a normal person who would want to deal with a girl going through cancer, and I have to carry this

diagnosis the rest of my life. Having cancer is always going to be a part of who I am. I went through a phase when I went numb and didn't care what I did or what other people did, and that was a low point," Rachel says.

Rachel opted for breast reconstructive surgery. While her new breast doesn't look or feel exactly like the breast she lost, it helped her regain her perception of herself as a sexual being.

After rekindling a relationship with a man she dated in the past, Rachel is now more open to discussing her concerns about being sexually attractive with her partner.

“He’s my best friend and I talk to him about everything,” Rachel says. “He reassures me that even though I’ve lost my long hair and my breast, he still finds me attractive. That has helped me regain my confidence. I’ve learned that feeling and being sexy starts within me. No one else can give me that or take it away. Now I realize that I’m still the person I always was.”

—RACHEL



Resources

We hope this guide helps you feel you can take action to maintain or improve your sexual life and health. By taking small and large steps, you can recapture joy with yourself or with your partner.

Living Beyond Breast Cancer is here for you if you want more resources and peer support about sexual health. When you are ready, please contact our **Breast Cancer Helpline** at lbcc.org/helpline or toll-free at **(888) 753-5222**.

Here are some other helpful resources. The information is current as of March 2019 but may change:

- American Cancer Society: Sexuality for the Woman With Cancer: cancer.org/treatment/treatments-and-side-effects/physical-side-effects/fertility-and-sexual-side-effects/sexuality-for-women-with-cancer.html
- Breastcancer.org/tips/intimacy
- Dr. Laura Berman: drlauraberman.com
- A Woman's Touch: sexualityresources.com

Words to Know

Antiemetics. Medicines used to control or stop nausea during chemotherapy.

Areolae. The rings of skin surrounding the nipples.

Aromatase. An enzyme the body uses to make estrogen.

Aromatase inhibitors (AIs). Hormonal therapy medicines that block the activity of aromatase.

Condoms. A form of birth control that consists of thin sheaths made of latex, lambskin, polyurethane or polyisoprene that fit snugly over a man's erect penis.

Cording. A possible side effect of lymph node removal that involves ropelike structures under the skin of the inner arm developing near the site of scarring. They may extend down the inner arm to inside the elbow. The cords tend to be painful and tight, making it difficult to lift your arm higher than the shoulder or fully extend the elbow. Also called axillary web syndrome.

Desensitization therapy. A sexual pain specialist may recommend this treatment, which involves learning exercises that relax the entrance to the vagina and decrease pain.

Diaphragm. A form of birth control that involves a shallow silicone cup inserted in the vagina. To be effective, diaphragms must be used with a spermicide cream, gel or jelly.

Dyspareunia. Painful penetration. May be caused by vaginal dryness.

Endorphins. Natural hormones in the body that when released lead to feelings of euphoria. Sexual activity is a potent trigger for the release of endorphins.

Estrogen blockers. Hormonal therapy medicines that prevent estrogen from causing breast cancer cells to grow.

Estrogen Receptor Antagonists (ERAs). Hormonal therapy medicines that block estrogen's effects on breast cancer cells.

Hormonal therapy. Used to treat hormone receptor-positive breast cancer. It starves the cancer of the hormones it needs to grow. Also called endocrine therapy.

Intimacy. An emotional connectedness or closeness with another person.

Intrauterine device (IUD). A small, T-shaped frame that is inserted in the uterus. It prevents sperm from fertilizing an egg.

Libido. Sexual desire.

Lumpectomy. Breast-conserving surgery that removes the tumor and a rim of healthy tissue around it, but leaves the rest of the breast.

Lymphedema. A condition in which extra lymph fluid builds up, causing swelling in tissues under the skin of the hand, arm, breast or torso, on the same side that breast cancer occurs.

Mastectomy. Surgery that removes the entire breast.

Off-label. The legal use of a prescription medicine to treat a disease or condition when the medicine has not yet been approved for that use by the U.S. Food and Drug Administration.

Oophorectomy. Surgery to remove the ovaries.

Prosthesis. A breast form that some women wear after a mastectomy.

Radiation therapy. A type of breast cancer treatment that directs high-energy x-rays at precise areas to destroy cancer cells.

Reproductive endocrinologist. A doctor who can explain ways to preserve or protect your fertility and help you plan for future pregnancies.

Selective serotonin reuptake inhibitors (SSRIs). Antidepressants that can depress sexual desire and affect your ability to reach orgasm.

Sexuality. Involves your feelings and beliefs about yourself as a sexual being.

Systemic therapy. Treatments, such as chemotherapy, that travel through the bloodstream to kill fast-growing cells throughout the body.

Targeted therapy. Anticancer medicines that are used when a specific feature or marker is present on or within a cancer cell. Only cancers with that feature or marker are expected to respond to the medicine.

Vaginal atrophy. Thinning of the walls of the vagina.

Vaginal estrogens. Creams, rings and tablets in a family of medicines called hormones. They restore the vaginal tissues and may increase elasticity and lubrication. Talk to your doctor before using.

Vaginal dilators. Rod-shaped inserts that can be put in the vagina. They slowly increase the length and width of the vagina, making sex less painful.

Vaginal lubricants. May be used before penetration or for sex play, as a way to decrease vaginal dryness. They come as a liquid or gel and can increase your comfort. Lubricants are usually applied to the vulva and in and around the opening to the vagina.

Vaginal moisturizers. Used inside the vagina for daily comfort, not specifically for sexual activity.

Vibrator. A small device that may be shaped like a dilator or a penis. It vibrates at different speeds to provide a pleasurable feeling, and it can be used for massage or sexual pleasure.

Vulva. The area outside the vagina.



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