



## Relationships, Intimacy, and Sexual Function

### Changes in Your Sex Life

You've experienced so many transitions over the course of your illness and treatment, and these changes can be difficult to talk about. A particularly challenging topic to broach for many of us is sex and how cancer has affected it. Lots of people (and even many providers) don't acknowledge that a person's sexuality is just as important as any other system in the body. If cancer has had an impact on your body, then it's had an impact on your sex life, too. Symptoms range from the physiological to the psycho-emotional and interpersonal.

Whether you're partnered or single, you deserve to have a meaningful and satisfying sex life, and the good news is that there are solutions to many sexual issues that arise for cancer survivors.

If you do have a partner, we recommend that at least for now, you put yourself and your sexuality first. It's impossible to give anything to anyone else before you address your needs and preferences and honor all that you've been through. The following topics will focus on you as an individual. Later, we'll offer guidance on how to effectively communicate, connect, and write a new sexual narrative with your significant other.

But before we get started, please note: when we refer to sex, we mean much more than intercourse, we are referring to any activity which gives your body sexual pleasure. "Sex" is NOT synonymous with "intercourse".

#### *Why does sexual intimacy often decrease after your illness?*

The cancer experience slows down your body. It takes longer to do lots of things, and this includes time to feel and express sexual feelings. Additionally, intercourse may be uncomfortable or even painful if you've been thrown into sudden-onset menopause. Many Sharsheret callers may have had little-to-no sex from the time of diagnosis through treatment.

While these statements may be true, please be mindful of the fact that every person is unique, and so is their experience with sex after illness. There are so many variables that can impact sex, so try and avoid the comparison cyclone.

#### *Who can I turn to for help?*

Good question because it can seem like no one's talking about sex and cancer! If sex has been lackluster (or even non-existent), talking with your care provider can be helpful. However, bear in mind that most medical professionals receive very little training in sexual medicine. As a result, they don't routinely ask about a patient's sex life. On the other hand, those who

take a whole body (holistic) approach to treatment may be able to guide both you and your partner, if you have one. You can choose to have these discussions collectively or on your own.

If you don't get anywhere with your current provider, you can seek out a sex therapist or a social worker, or psychologist who is trained in sexual health. Unfortunately, some social workers, psychologists, and psychiatrists are uncomfortable dealing with sexual issues. You'll need someone who is truly comfortable and knowledgeable to assure that you will feel comfortable and safe! Another option is to find a sexual health center or sex therapist that works with a medical practice since so many of your issues will be a combination of the physiological (medical) and the psychological and sociological.

Additionally, a support group may be more helpful than you might realize. People in these groups often share advice that extends to the bedroom, including ways to increase sexual pleasure that are explicit and specific for people who've had cancer.

### ***What causes loss of libido?***

Perhaps the most frustrating change in your sexual life is the loss of libido, or the desire to be sexual. You might have lost your hair, your body has been altered and parts of it may be gone, you might be experiencing menopause, perhaps you've put on weight, you have no energy, you're tired, you might be nauseated, and you hurt in new places. You've also had a dramatic change in hormones! And not to mention you're likely distracted and perhaps even depressed. No wonder you're not feeling sexy.

Your sex life may be altered by vaginal pain resulting from cancer treatment, especially after bone marrow transplantation. Certain chemotherapies can cause short-term ulcers in the body's mucous membranes (mouth, throat, vagina, rectum). Physical changes may result from treatment-induced menopause, tamoxifen therapy, or the end of hormone replacement therapy. Add the psychological and emotional stress, and sexual pleasure may seem like ancient history.

Advice from your doctors or friends who've been down the same road may help, but some impairment of sexual function is generally unavoidable. Over time, however, things do get better. So, let's address some specific cause-and-affect when it comes to illness, treatment, and sexual dysfunction.

### **Depression and Libido**

Depression is a common result of both the diagnosis and the treatment of cancer, and it directly affects your interest in sex. If you're depressed, sex may be the last thing you want. In some cases, an aversion to sex may even develop.

If you're depressed and unable to turn the corner, don't suffer in silence.

Treatment can include:

- Individual and group therapy. Ask your doctor or your Sharsheret social worker or turn to other reputable sources to find providers.
- Antidepressant medications
  - Medications must be carefully administered and monitored by a qualified medical professional (usually a psychiatrist). Some therapies for depression may cause loss of libido, including Prozac (chemical name: fluoxetine) and Zoloft (chemical name: sertraline).
  - Effective dose levels are important and not always appropriately prescribed (which is why working with a specialist is critical).
  - Efficacy for several of these medications can take three weeks or more.
  - If you are taking tamoxifen, talk to your doctor about which antidepressants are safe for you to take. Some medications -- including Paxil (chemical name: paroxetine), Wellbutrin (chemical name: bupropion), Prozac (chemical name: fluoxetine), Cymbalta (chemical name: duloxetine), and Zoloft (chemical name: sertraline)-- interfere with the body's ability to convert tamoxifen into its active form, preventing you from getting the full benefit of tamoxifen.

### Hormones and Libido

You may find a significant decrease in physical sensation, and it may be harder to experience orgasm. "It takes so long to make it happen," said one Sharsheret caller, and we know this is a common complaint. Be open with your doctor, so that they can suggest appropriate medical solutions (again -- if your own provider isn't comfortable with or well-researched in sexual health, seek support from a specialist).

Why does all of this happen? Loss of desire and arousal may be directly related to your lower estrogen, progesterone, or testosterone levels (which occur as a result of cancer treatment). So, what can you do?

- If you're having problems with sex, you might want to try downplaying the importance of orgasm, at least for a while. See if you can focus instead on the experiences of pleasure, emotional connection and other kinds of physical sensation and intimacy. Sometimes, when you take the pressure off and become less goal-oriented, conditions will improve more quickly. Kissing, touching, holding, cuddling -- all of these activities can help you re-engage with your sexuality.
- Explore and play! This might be the time in your life to approach your sex life a bit differently. Expand your sexual repertoire by reading some books on sex. (We've included a bibliography on the last page.)
- Vibrators can be an incredibly helpful addition to your sex life, especially now that it is a bit more difficult to get aroused and have an orgasm. They provide a level of stimulation that is just more regular

and stronger than your partner's hand or mouth. And using one with your partner may take much of the stress off for both of you.

- Erotica can help you get back in touch with your sexuality, and there's simply no end to variations on the theme! Find some books, films, audio programs that turn you on and use them by yourself or with your partner.
- Ask your doctor for a hormone evaluation. Sex drive is extremely dependent on the hormone testosterone which is produced in the ovaries and the adrenal glands. A little-known fact is that your provider may be comfortable with your use of testosterone if medically appropriate. A little goes a long way, and an adjustment may help restore sexual interest. Testosterone is not FDA approved for women and there is little research on how it may affect survivors of breast cancer. For these reasons it's imperative to speak with your doctor to see if a testosterone trial may be right for you.
- There are two new medications that have received FDA approval for sexual desire in the last few years: Addyi and Vylessi. You can discuss them with your provider and see if they think either of them would be effective in your situation. Many people find them extremely helpful.

### Pain:

Pain can destroy your interest in sex faster than anything else.

- Vaginal ulcers that can arise during certain chemotherapies (such as 5-fluorouracil) are a major source of such pain. The ulcers may be particularly severe in people who have had bone marrow transplantation, but they do go away when treatment ends.
- People with genital herpes may have an outbreak brought on by stress and a weakened immune system.
- Steroids and antibiotics can cause yeast infections in the mouth and vagina.
- Pain medications, narcotics in particular, can also reduce libido.
- Menopause, whether naturally occurring or treatment-induced, can cause thinning and shortening of the vaginal walls. Vaginal dryness (lack of natural lubrication) is another menopausal side effect. These conditions can contribute to pain during sex.
- A common by-product of cancer treatment is the tightening of the muscles in the vagina which make insertion of anything painful.

But do not get discouraged. There are very effective approaches that can reduce pain and help heal the vagina.

- While many physicians avoid the use of estrogen systemically with women who have had cancer, more and more physicians are prescribing "local" estrogen. Depending on what type of cancer a person has had, there may be the possibility that they can be prescribed an estrogen product that only reaches and effects the vagina and vulvar area. This can help heal and restore the vaginal mucosa and make it more pliant and elastic.

- There are new lasers (including The MonaLisa Touch) which work non-hormonally to restore the vaginal canal's lining and work to increase the elasticity of the vaginal lining, resulting in more lubrication and pain-free intercourse for many.
- A number of other non-hormonal products are currently on the market, including hyaluronic acid and although not as effective as estrogen, they can be extremely helpful and useful in restoring the health of your vagina. Make sure that you find a provider who is knowledgeable about the options that are available for you.

### *Accepting the nude you*

If your self-image has been hurt by your cancer, you're not alone. Accepting your naked body, even if you never did before, is like striking a truce with yourself. It's important to work toward making peace, little-by-little, with your body. This can take a long time, and it's a process. Make sure to get support from peers, loved ones and even a professional if you're struggling with all of the physical transitions of treatment. Self-compassion, too, can go a long way here, so find it wherever you can. Whether you're single or partnered, body image can play a big role in how you feel sexually.

- If you're going to great lengths to avoid looking at the scars on your chest, your reluctance is understandable. But experts on healing suggest it's important to move forward in a healthful way. Don't rush it, but know it is a good goal for the future.
- Lingerie or nightwear can help prevent initial shock. If you want that protection or camouflage, go for it. Indulge yourself. Plenty of people keep their clothes on in bed.
- You may consider reconstruction or prosthesis, which may allow you to feel more comfortable about yourself. Beneath clothing, a reconstructed breast or a good prosthesis feels very much like the real thing; it has the bounce, the weight, and the resilience of a natural breast. Many small shops offer an excellent variety of prostheses and cleverly adapted prosthesis pockets fitted into underclothing and swimsuits. Ask Sharsheret for some of these resources, your local American Cancer Society for a list of shops, or search online.
- It is also absolutely okay to decide that your breast or prosthesis is not something you want to expose to others right now. Your body, your feelings, your timeline. Period.
- Easing into exposure using "Mirror Therapy". Dr. Leslie Schover suggests this four-step approach:
  - Use a mirror (preferably full-length) in a private area, dressed up in your favorite clothes.
  - Study your image in the mirror for 15 minutes and pick out three things you really like about yourself.
  - After that, try the exercise in lingerie or underwear.

- Finally, take 15 minutes to look at yourself in the nude, and again, identify things about yourself that are pleasing.
- Focus on the positives.
- Some people find it freeing to walk around their room or home totally naked. One Sharsheret caller invited close friends over for dinner and after their meal, she showed off her new reconstructed breasts to “oohs” and “aahs” of approval.
- Being vulnerable with someone else is often the last stage of releasing anxiety about your self-image. One Sharsheret caller who was in a new relationship finally worked up enough courage to let her partner see her naked chest—and he applauded: “You really did something big, letting me see you. But I told you before, it wasn’t going to matter to me.” Ultimately, you’ll hopefully feel comfortable sharing your body with a partner. Considering a lot of sex takes place in near or full darkness, you can ease into things without feeling totally exposed.
- That said, some people (with or without cancer) just don’t enjoy parading around naked. You may need to face what you look like, but you don’t have to share yourself with anyone!

### *Filling your cup as you recover.*

You know the old oxygen mask cliché (place your mask over your nose and mouth *before* you help others)? Well, there’s no more important time than recovery from cancer to put this into practice. You simply can’t be there for anyone else until you build enough reserves, energy, and strength for yourself.

While partners can offer primary support, there are times when you want to just commit to activities and practices that are just for YOU. Here are some suggestions:

- Fantasy can enrich your life. Countless people read, listen to podcasts, and watch tv and movies for escape and distraction (historical fiction and romance novels are enormously popular).
- Join a book club, synagogue, or a group that meets to discuss investments, movies, local politics, or other interests.
- Do more with individual friends, like walking, shopping (“retail therapy”), etc.
- Take a class or watch a online tutorial to learn more about a hobby you’ve always wanted to check out.
- Enjoy planning special occasions such as birthdays, anniversaries, and other celebrations.
- Expand your involvement in community or spiritual activities.
- Get active in the cancer community: camaraderie for a cause close to your heart where you’ll also meet others who have been affected.
- Consider counseling or therapy to address any issues you’re having.

## *You and your partner.*

Successful relationships are about sacrifice and compromise, and there's no such thing as perfection. But as a survivor, you may find that cancer shines a blinding light on the problems in your relationship. What's your tolerance for them now? Can you enjoy your relationship even as you contemplate what's missing? Can you piece the puzzle together in alternate ways? Give serious thought to your needs and how to meet them. And make sure that, when you are able, consider and make space for your partner's concerns. A sensitive partner picks up on your discomfort, needs and preferences and exhibits patience and support while you recover. But the reset button, so to speak, isn't always so easily accessible for either of you.

Cancer is not good for relationships, but good relationships can be made stronger by sharing hardship. Your partner may have doubts, and miss and mourn the "old" you, just as you may be doing. But that doesn't mean they are prepared to trade you in. "My partner stood by while I cried and screamed, and hugged me when I let them get close enough," said one Sharsheret caller. "Our relationship is better now than it ever was before."

Remember, it can be helpful for you both to consult with your doctor at the same time. This way each partner has an opportunity to express and dispel fears and replace myths and false information with facts.

### What do partners of cancer patients care most about?

Despite what you may imagine, studies show that the answer is simply this: their loved one is alive and feeling well. The loss or alteration of your body is almost meaningless in contrast. "I don't care what they take from you as long as I can see your face," is a common sentiment. Most caring partners see their loved ones as having many parts to love and as being more than the sum of those parts.

There will be ups and downs. While you're experiencing feelings of inadequacy, your partner is dealing with worry, anxiety, and maybe even guilt, wondering: "Could I have been responsible? Could I in some way have contributed to the cancer? Will I become radioactive if I touch her, if I touch her? Is her cancer contagious? Will I hurt her if I touch her?" And (perhaps feeling guilty), "When will I be able to worry about myself for a change?" If they don't initiate intimacy, you may assume it's because you're no longer desirable. But consider all the worries they're experiencing as well.

### Communication is key

Talking and listening – these are the foundational building blocks of any intimate relationship. But most people haven't a clue about how to address something as big as cancer. So here are some tips to help get you started:

- *Find some time.* Most couples have limited time together. A cancer diagnosis just adds more to the inter-relational plate. Even when you do find an opportunity to talk, the conversation may go absolutely nowhere because of the various and sundried distractions that use up valuable energy. Schedule some time in a quiet place where you know you won't be interrupted.
- *Start somewhere.* Begin by talking about something comfortable and manageable—your job, the shows you're watching, even the weather. Once you're talking, you can then focus your conversation on your fears, concerns, how the illness has changed you, and the importance of your relationship. It may be hard to identify your concerns, let alone express them. Try to make your requests as carefully and positively as possible: "You've been working so hard, doing so much—and it's made a huge difference. But what I really need right now is to be close to you and tell you what's making me nervous and anxious. I need you to listen, and maybe just hold me."
- *Talk, talk, talk.* Even if your partner is a person of few words, it doesn't mean they aren't listening. You may need to do most of the talking but, hopefully, your partner will truly hear you, and process what you're saying. Stop along the way to get feedback. Use "I" statements ("I feel great when you..." or "I feel badly when you..."). Eye contact and touch can give your words greater meaning and emphasis.
- *Reassure your partner.* Your partner may feel you're burdened enough without listening to their fears and concerns. Make it clear you WANT to hear how they're feeling and that you're both in this together.
- *Bring in a third party.* If you're both having trouble communicating, a couple's counselor will create a safe space for you both in which to express yourselves and can help facilitate positive communication.
- *Write it down.* Sometimes it's easier to write how you're feeling in the form of a letter or even a journal entry than to say it face-to-face.

### What the future may hold.

- If you see yourself as damaged goods, you probably assume your partner feels as you do. One consequence of feeling less than lovable is fear of being abandoned. In some cases, an unsupportive partner could see their partner's altered body as a personal reflection of their own value—and want out. Other partners simply come apart under stress. These relationships were likely already on shaky ground.
- Statistics show that just as many people leave their partners as are left after cancer. This proves that survivors don't want to waste their time in unfulfilling, unhappy partnerships.
- Flawed relationships don't have to come apart, with or without cancer. Divorce rates are not higher among couples in which a person has had cancer. Sometimes the shock of a cancer diagnosis pushes partners in a troubled relationship to consider the source of their problem and seek counseling, which can strengthen the relationship in the long run.



- You may be surprised to be the one who responds unpredictably. One very independent Sharsheret caller told us about feeling overwhelmed, uncertain, and very dependent when her cancer was diagnosed. This new "frailty" devastated her, and her marriage went through a rough spell until she finally was able to process her trauma, return to more stable footing and then find interpersonal harmony again.
- Ideally, you have an understanding and supportive partner who helps you feel better as you build back your confidence, but that may just be unrealistic. They are probably suffering, too, and may be less able to express that suffering than you are. Ginny could not understand her partner's silence. "What's the matter with you? Why don't you talk to me about what's happening? I have CANCER! Say SOMETHING!" Ginny felt as though she was yelling at a stone wall. Many partners try to keep a "stiff upper lip" and might not be as emotionally expressive as you'd like. That's a lot of emotional bone burying, and it can be tough to dig out. But with time, patience, grace, effective communication, and support for each other (and from others), you can find your way back to your body, your partner, and a healthy and satisfying sexual relationship.

Cancer has become so common that most people know someone in their lives who has suffered the disease. There's no way to predict how any one person will respond, but most partners are able to do the heavy lifting required. Talking through your expectations and hopes with the important person in your life will help communication channels stay open and yield the support you need.

#### Recommended Books about Sexual Health:

- Sex Points: Reclaim Your Sex Life with the Revolutionary Multi-Point System, Author: Dr. Bat Sheva Marcus
- Sex Matters for Women: A Complete Guide to Taking Care of Your Sexual Self, Author: Sallie Foley
- Guide to Getting It On, Author: P.N. Joannides
- Come As You Are, Author: Emily Nagoski
- Becoming Orgasmic-A Sexual & Personal Growth Program for Women Author: Heiman & LoPiccolo
- Healing Pelvic Pain, Author: Amy Stein
- The Hormone of Desire: The Truth About Testosterone, Sexuality & Menopause, Author: Susan Rako, MD
- The Erotic Mind, Author: Jack Morin

This piece was created in partnership with **Maze Women's Health**. As the largest women's sexual health practice in the U.S., Maze Women's Health provides treatment for pelvic pain, low libido, orgasm challenges, hormone imbalances and menopausal symptoms. Utilizing a holistic approach that treats both the physical and emotional causes of sexual issues, Maze helps

many survivors offering non-estrogen-based options. They're located in midtown Manhattan and Westchester, NY and offer free phone consultations. For more information and help recapturing intimacy and your sexual identity, as well as navigating through and reestablishing partner relationships please reach out at [MazeWomensHealth.com](http://MazeWomensHealth.com)

For additional resources, you can contact a member of Sharsheret's support team at 866.474.2774 or [www.sharsheret.org](http://www.sharsheret.org).

Remember to always discuss your medical questions or concerns with your health care team.