

CANCER AND SEXUAL HEALTH POCKET GUIDE

FAST FACTS

- 87 percent of cancer survivors say that they experienced sexual side effects and that these issues were not addressed by their oncologist. Female patients were especially unlikely to be asked about sexual disfunction following chemotherapy, radiation, and/or surgery.^{1,2}
- More than 6 in 10 women report effects on sexuality and sexual response following cancer treatment.³
- More than 7 in 10 men who have prostate cancer surgery report problems getting an erection.

SEX AND CANCER

Your sex life doesn't have to end when you are diagnosed with cancer. What's likely, though, is that it will change, just as it changes with other life events. Cancer has physical, mental, and emotional effects on your sex life. It's important to emotionally prepare for the changes that may occur and eventually adjust to the change that you have experienced because of cancer treatment.

How cancer affects sexuality

The cancer itself may affect your sexuality physically and emotionally, but often it is the treatment that has the largest impact on sexual function. Erectile dysfunction (ED) is often an immediate post-operative side effect of surgery for prostate cancer that may last 18 to 24 months post-surgery, but it may also happen before cancer treatment. For women, surgery that removes the uterus or ovaries or chemotherapy and other medications, like aromatase inhibitors for breast cancer, that cause menopause affect sexual health. Loss of breast tissue, nipples, and feeling in the breast area following a mastectomy can also impact sexuality. Radiation to the pelvis, surgical scars, gaining or losing weight, and even losing or growing hair all affect how your body feels and how you feel about it.

On an even deeper level, Jennifer Bires, MSW, LCSW, OSW-C, executive director of the Life with Cancer and Patient Experience department at Inova Schar Cancer Institute, says fatigue has a major effect on sexuality when you live with cancer. "Fatigue can be crushing at times," she says. "People with cancer are more likely to be depressed or anxious, which also lowers libido." If you are taking antidepressants as part of your treatment, you should know that these also can cause changes in desire, arousal, and orgasm.

The emotional impact of cancer can include "changes in your relationship, changes in roles for you and your partner, or changes in your interest and capacity to date or form new relationships," Bires says. "Whether on the emotional side or in physical activity, there is likely to be a pause in sexual activity and a change in how you feel about your body and your sexuality."

The oncologist's view of your sex life

"The impression I get from my provider is that I should be lucky to be alive," says Steve, who is struggling with the physical effects of cancer treatment—but wants to stay connected with his wife. Steve says his oncologist's view of sex seems to be, "Why would you care about that right now?"

Derrick faced a similar attitude from his surgeon. "His attitude was, yes, you will probably have ED, but in your sixties, how much does

that matter?" In fact, maintaining a healthy sex life with his partner was very important to Derrick and not something he was willing to give up. He sought treatment advice from two more surgeons before choosing one who understood the need to treat him as a whole person with cancer, not just a cancer patient.

Feeling empowered to search for solutions for changes in sexual health is an important first step in advocating for yourself. This means keeping what matters to you front and center in conversations with your care team.

Health-care providers who can help

Your cancer care team can include health-care providers to help with sex, relationships, and sexual rehabilitation, including:

- A gynecologist (specialist in women's sexual and reproductive health).
- A urologist (specialist in the urinary system, for men and women).
- A pelvic floor physical therapist (specialist in assessment and rehabilitation of your body's strength and function).
- An endocrinologist (hormone system specialist).
- A counselor, marriage and family therapist, or sex therapist (emotional and behavioral specialists).

Because energy and appearance are important to sexuality, you may also consider the following team members:

- Personal trainer or exercise class instructor (including free and low-cost online instruction)
- Meditation or wellness coach (including free and low-cost online instruction)
- Massage therapist (consider group sessions or partner training for reduced fees)

The [Maple Tree Cancer Alliance](#) has exercise and nutrition programs specifically designed for people with cancer who are going through treatment.

For appearance, [Fighting Pretty](#) and [Look Good, Feel Better](#) (for women) and [Look Good, Feel Better](#) (for men) have helpful resources.

Ask your health-care provider about sex

"What's important to you should be important to your health-care provider," says Bires. "Shared decision-making is important, especially when treatment will affect your quality of life as much as sexual side effects can."

If your provider makes a gendered assumption about you—for example, that you are interested in fertility preservation but in reality don't plan on having children—speak up! It's important that they have all the information possible so that they can tailor your treatment options for your unique needs.

You may want to ask your health-care provider some of the questions below:

- Will this cancer affect my interest in sex, my desire for sex, or ability to have children in the future, if I want them?
- How will treatment affect the way I look? Will these changes be permanent?
- Of the treatment options for this cancer, which would impact my sexual health the least?
- How can I cope with side effects such as early menopause?

- My relationships [spouse / dating life / desire to get married / desire to have children] are very important to me. What's the best way to maintain those connections and plan for the future?

For more examples of questions for providers, see this [article on WomanLab](#).

For men, [Penn Medicine's Onco](#) has a guide to sexual health with information on how particular chemotherapy agents can affect sexual partners and a list of questions to consider when speaking to your provider.

Sex will change, and that's OK

It's easy to accept the media ideal of sex as something we constantly desire and are constantly ready for. However, expectations meet reality in many life stages. Consider the following situations:

- The teen, longing for connection and experience, who doesn't have or may never have had a partner.
- The young adult, single and starting out in the working world.
- The parent with a newborn who has little time, desire, or energy for sex.
- The military service member who is far from their spouse or partner.
- The divorced adult who is getting back into dating.
- The adult who has a passionate relationship with their partner.
- The senior citizen who is unexpectedly widowed.

If sex isn't possible for the short or long-term, what are other ways of exploring intimacy with a partner?

- Hand-holding, resting your head on your partner's shoulder, or hugging—the healing power of touch is a powerful tool in intimate relationships.
- Non-sexual massage—reiki or therapeutic touch are other ways to harness the healing power of touch.
- Regular check-ins with a partner—taking time to tell your partner why you love them.
- Date nights—making time to be together and have conversations that don't involve kids, work, or household duties.
- Attend a relationship workshop or see a counselor. Couples therapy isn't just for relationships that are in trouble. Talking through some of the issues that come up as you navigate cancer will help you to develop the tools you need to have meaningful conversations with the people you love. Whether you struggle with asking for help or you need space, being able to have an honest conversation can strengthen your relationship.

Accepting change and loss

Cancer creates an undeniable experience of the inevitability of change, and all change involves some loss. "A lot of sexual health work involves grieving," Bires explains. "With cancer, your sex life

may not go back to where it was before. You need to grieve for sex as you used to define it and grieve your expectations for what sex will be like.”

Acknowledging that things have changed and grieving that loss is necessary before you “put your sex life back together,” says Bires. She is clear, however, that a new sex life is very possible. “It will look different, but it could be very satisfying,” she says. “Having cancer and dealing with changes means you have to work with your own body, talk to your partner, and become more aware of what’s important to you sexually.”

Single, with cancer

Should you date? Are you healthy enough, and do you even want to? What do you have to offer a partner—and when do you tell them about the cancer?

Marcus solved the problem by responding to one of the dating-profile questions—things you can’t live without—with “Velcade,” the name of his chemotherapy drug. He figured that potential partners who responded to his dark humor might be good matches. “I also got a lot of hate mail,” he says. “People who couldn’t believe I’d be so callous or that I was even dating when I’m living with cancer.”

Dating and relationship decisions

- Do I want to date now?
- When do I share that I have (or have had) cancer? How much information is too much? Do I need to share this right away? There is more to me than cancer.
- How will I respond if someone says something insensitive about my cancer diagnosis and/or treatment?
- What is my goal for dating?

Resources

In one study, more than half of the patients who were asked about sexuality during cancer asked for “practical tips.” This section has tools, resources, and tips to help you understand and nurture your sexuality during cancer and treatment.

- [Well-known sex therapist Sallie Foley’s resource page](#), including free downloads on:
 - Dilator therapy. If you have radiation treatment to the pelvis, you will likely need dilator therapy to keep your vagina healthy and supple.
 - Lubricants. Which type is best for you? Why you almost always need it, and which ones are organic.
 - Stretching, strengthening, and moisturizing your vagina. Important for everyone, but especially for women in menopause, single or not having regular sex with a partner, or recovering from treatment that affects the pelvic area.

- [Scientific Network on Female Sexual Health and Cancer](#)
 - A collated list for female cancer survivors covering various aspects of sexual health.
- [American Association of Sexuality Educators, Counselors, and Therapists](#)
 - Choose “Find a Professional” to search for a professional in your home state.
- [Herman & Wallace Pelvic Rehabilitation Institute’s low-cost download “Orthopedic Considerations for Sexual Activity”](#) (Low cost download)
 - Shows sexual positions appropriate for when you are tired, had surgery, or have other physical needs.
- [The Prostate Recovery MAP by Craig Allingham](#)
 - Low-cost book on recovering sexual function and ability to control urine after prostate cancer treatment.
- [Unite for HER](#)
 - Enriches the health and well-being of those diagnosed with breast and ovarian cancers by funding and delivering integrative therapies.

Tips from an oncology social worker

Jennifer Bires has these tips to help you appreciate, rest, and rehabilitate your sexuality:

- Take the time for full recovery. Chemotherapy, surgery, and radiation all take a toll on the body. Keep your expectations for sexual activity modest and reasonable.
- Try “sensate focus” exercises, where you touch your partner without the goals of specifically being sexual or having an orgasm. Massage or extended sex play can count as “sex,” too!
- Plan to be sexual when you know you have energy and feel your best. Don’t hesitate to take pain medication, enjoy a warm bath, and experiment with new positions to see what works best.
- If culturally appropriate, don’t be afraid to explore your own body. It is hard to tell other people what feels good if you don’t know yourself.
- If you have a longtime partner, remember that you have started many new chapters as a couple, and cancer or survivorship is just one more.
- Creativity and laughter can be key. There are endless ways to be sexual and intimate. Changing your mindset to one of exploration rather than one of loss can be helpful in regaining sexual satisfaction.

Bires also has a word of advice for caregivers. “You may want to be sexual and miss your partner’s touch. But you may also be afraid to injure them or tire them out. Don’t ignore your needs—ask them! If you’re caring for them a great deal, they may be happy to do something for you, even a simple massage or kissing.”

Sample script for talking with your partner about sex

Talking about sex can be scary, but communication is key. It is often helpful to have this conversation in a neutral space without distraction—not when someone is trying to initiate a sexual experience. When you are ready to talk about sex with your partner(s), it can be helpful to use a model similar to the one below.

- **Fact:** We haven't had sex since your cancer diagnosis.
- **Belief:** I think you might feel you're not attractive to me right now.
- **Feeling:** But I feel sad, and miss being with you sexually.
- **Need:** I need to feel close to you physically. Would you be OK talking about some ways to do that again?

Using a model like this allows your partner(s) to understand why you may be thinking or feeling the way you do without blaming, and it can help them open up about their point of view without becoming defensive.

More Pocket Guides and Tools

- [The Pocket Guide to Nutrition and Cancer](#)
- [The Pocket Guide to Movement and Cancer](#)
- [Fertility: An Integrative Approach to Your Reproductive Health](#)
- [Your Healing Journey: A Patient Guide to Integrative Breast Cancer Care](#)
- [Your Healing Journey: A Patient Guide to Optimal Healing Environments](#)
- [How Healing Works: Get Well and Stay Well Using Your Hidden Power to Heal \[book\] by Dr. Wayne Jonas](#)
- [The Caregiver's Companion: Caring for Your Mind, Body and Spirit](#)

Website

- <https://savemyfertility.org/>

Notes and questions

References

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