

What Cancer Patients Want Their Oncologists To Know About Sex During And After Cancer Treatments

I asked the members of several Facebook cancer support groups this question:

“I want to tell radiation oncologists what you want them to know about sex during and after cancer treatments—especially radiation. What would you like them to discuss with you? What do you wish they had told you? What resources do you need? And, if you have found resources (such as Facebook groups or any others) which would you recommend?”

These are some of their answers.

The core factor to consider is that you don't need to have pelvic radiation for your intimacy to be impacted. Fatigue, stress, pain, anxiety—it all impacts sexuality. Clinicians think sexual impacts are cancer-type-related, but it's treatment based, not gender or cancer-based. ~Tess Devèze



The oncologists deal with tons of cancer patients and we are all go through so many similar symptoms. **Why don't they just sit us down at the very beginning and say “Here's what you may experience, and here are some proven treatments/products that have worked for others. Let me go ahead and set you up with a good GYN doctor who is knowledgeable about cancer patients.”**



It is infuriating that this isn't automatically part of women's cancer care. **My radiation center had an entire wall full of pamphlets for men's sexual health after prostate and testicular cancer. The women's pamphlets? There were 2—one for mental health services, and one for head coverings.**



Mine told me I would have to see a specialist for each of my side effects and symptoms—a sex therapist, a dermatologist, a gastroenterologist, therapist/psychologist/psychiatrist and nutritionist etc. even though I had none of the problems I'm having now before my cancer treatment.



Thank you for educating the medical professionals.
I didn't have radiation but have found even as a fellow sexologist that **the conversation about sex is often ignored.** (DMX to flat 10 months ago and struggling with Tamoxifen.)



Sex educators and therapists would help but those **are usually hard to find, and** if found **do not accept insurance. The cost is astronomical.**



Resources: Facebook is my friend. There's a Facebook group for women with breast cancer, a group for LGBTQ people with breast cancer, and a FB group for breast cancer survivors taking aromatase inhibitors. There's also a FB group for sex after breast cancer.



What all the doctors should learn, because none of them seem to know: Join all of these Facebook groups, and LEARN what the problems are. And learn what so many women are saying: **the aromatase inhibitors are wonderful and keep us alive, but atrophy vaginas, kill libido, cause osteoporosis, suicide-inducing joint and bone pain and many other problems.**

As a result, only 60% of patients really take the AI's for the full 5-10 years, and many others take smaller doses. The docs are pleased that something works but if women are miserable that's not good for anyone. Why isn't there research to see if a smaller dose works??? Women are doing it anyway, going rogue in desperation.

I'm told that the big research is to find more ways to control metastatic cancer, which is great. But if side effects of AI's were ameliorated, more women would be compliant and fewer women would progress.

The no-estrogen regimen dries up the body. So vaginas atrophy and libido plummets. There is lots of advice and help for penis-in-vagina folks, next to nothing for the rest of us. There's lots of products for vaginas. Nothing for clitorises, or for people who don't deal with penises. *[The author is a Lesbian woman.]*



The effects of pelvic radiation on the vaginal vault!!! I was not warned about the use of a vaginal dilator at every treatment until got there, handed a lubed "dilator", and asked "Do you want to insert it or me?" Then they tape it in! In a room with 3-4 techs! **Mortified!** And now I'm left with **painful intercourse from a constantly atrophying vaginal vault** that get shallower and shallower. The radiation oncologist said the atrophy can continue for up to 5 years. If I don't have intercourse at least every 2 days, my vault is shallower. 3 months of radiation ended 1.5 years ago. I had rectal resection 2 months ago, so we went 2 weeks

without sex, per surgeon's orders. That 2 weeks made a wall completely close off my vault 1/2inch in. I don't know how I can have pap smears because you can't get to my cervix. To top it off, the radiation was an epic fail. Within 1 month of finishing "intense" radiation, the cancer spread into lymph nodes and the tumor went from microscopic to a tumor protruding from my bottom! BTW, I also have hormone+ breast cancer, so medically-induced menopause and hormone blockers are also wreaking havoc on my lady bits.



I have many questions I wish my radiation and cancer doctor had told me what would happen with radiation. I had uterine cancer in 2014. They did a hysterectomy. stage 1b. In 2019 it came back. They went into debulk it and did a temporary colostomy. I had chemo, immunotherapy (Keytruda) and then chemo and radiation. I had very little problem until the radiation. I was told that the radiation might cause temporary incontinence. **They gave me a dilator and said use it. It hurt so much but I used it. My vagina has very bad stenosis. constant urinary tract infections. some of my vaginal nerves were killed. Never knew that would happen.** I can have oral sex and masturbation, but no regular sex. It isn't the same. I wish I had know this would happen. My vagina is shorter also. The tumor is still the same size. It was shrunk by Keytruda 1.7cm. still. I was told they could put me under and manually break up the scar tissue inside the vagina. Is this possible.? **Why do doctors act like if you are a woman and a certain age you don't need to have a sex life? That was one of the great pleasures of my life.**



Er+ breast cancer here. **Talk openly about nerve damage/disruption and that zingers can disrupt sensation for years to come.** 4 years out from radiation and it still feels like I've been punched in the ribs, and I get electrical shocks from my nipple down my arm. **Tell them to be open about reconstruction and radiation and when the best and safest time to reconstruct is, and what the effect of radiation is on reconstructed tissues.** More emphasis on mobility of arms and shoulders etc.



They need to educate their patients on how to breathe during left breast radiation to move the heart to center so it doesn't get hit with radiation. They need to be Uber cautious about reradiating the same breast due to a second cancer. They need to talk about radiation scatter. **They need to be point blank honest about radiation as it affects the body.**



My radiation oncologist was awesome. He definitely had the whole person in mind while treating me and urged me to get back into mental health therapy. I do feel that radiation oncologists see you for such a short amount of time in comparison to your medical oncologist. At least for my journey. I was diagnosed with stage 3 triple negative bc while

pregnant. So I did some chemo during pregnancy, more after, then DMX with expanders and lymph node dissection. Immunotherapy and 33 radiation treatments. Everyone is different, but **I think for those who have radiation after other treatments, we are still in the thick of those side effects while going through radiation.** The vaginal dryness from chemo, the new body image and fresh scars (and limited mobility) from surgery, which was only 7 weeks prior to radiation. And I had a newborn and two other littles at home while figuring out how to get back to work. Honestly, I was so deep in survival mode that sex was far from my mind and not fun when I did it once in a while for my husband's sake. **Radiation oncologists talk about the fatigue, which is so real, but they probably don't think about it in the context of being too tired for sex, too. Or not having the energy to fully participate and enjoy the experience.**



The medical community doesn't tell you what cancer is going to do to your sex life. I don't even know what sex is anymore. I don't care if I ever have sex again. I didn't have rads or chemo but had a DMX. I'm 54. **Cancer wreaks havoc on your entire being.** There's no resources for anything like this. **I feel broken and incomplete.** My husband is like a dog waiting for you to throw it's toy so it's not him it's me. **And no, the answer is not, have a glass of wine, take a hot bath, go for a walk - none of those things help.** And the answer is not just give him the blow job or have sex even if you don't want to, you'll get aroused as you get going - nope that's not it either.



A lot of straight women who go through searingly painful sex and hope their male partners will not lose hope and leave them. Maybe some education, by oncologist offices, that **sex shouldn't happen if it's that painful.**



This may be a controversial suggestion, **but edibles have been a lifesaver.** It's helped me with multiple issues, appetite, anxiety and also desire. After figuring out the right dosage, **it's helped me feel like my old me again.**



There is also a budding new field of integrative/naturopathic oncology. These docs can advise about substances that reduce recurrence and/or ameliorate side effects from chemo, radiation and pills. **Why don't more regular oncologists refer patients to integrative oncology? Why aren't naturopaths covered by Medicare?** The Facebook group participants recommend loratadine and tart cherry to help with joint pain. It works, but my oncologist never heard of that.



(From a lesbian woman...) I live in Vermont. So all my providers were supportive of my partner coming to medical appointments with me, being there for surgery, etc. They even noted in my medical records when I mentioned we got married, and congratulated me. But **I've heard from other lesbians in other states that they are not as well affirmed as I was. Also transmen have said they felt doubly invisible.**



There is also nothing about living as a lesbian couple, with cancer or cancer treatments, that I've found. Do we all just work through this as best we can?



<https://barbaracarrellas.com/sexuality-cancer-resources/>

