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Moving Beyond Cancer To Wellness

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LET'S TALK ABOUT IT: INTIMACY & CANCER

Let's Talk About It:

There are so many other things to talk about, it is easy to push this topic off to another time.

Here's your opportunity!

Let's talk about...

- how cancer can affect intimacy and sexuality
- some tips for making it better
- and some fun, safe, easy resources to use!

Why is this happening?

Does this happen to everybody?

Who can I talk to?

What can I try?

What else might I consider?

Why is this happening?

- **Intimacy**, relationships, body image...
 - *All of those things take work!*
- Roles and relationships change with *any* stress
 - Good stress and bad stress – it's all *stress*
 - *Who am I now?*
- Cancer and cancer treatments are hard!
 - Treatment itself is rough – *on everyone*
 - Not all changes can be seen on the surface
 - The diagnosis doesn't have to be big to affect us in a big way (*and it doesn't have to be our body, either*)
 - It's not over when it's over
 - *The gift that keeps on giving...*

Does this happen to everybody?

- Well... *yes*. Yes, it pretty much does...
- Cancer survivors report negative effect on sexual function including:
 - Discomfort and decreased pleasure, even with hormone replacement.
 - Relationship and partner issues.
- Sexual problems after cancer treatment are related to reports of:
 - Poor quality of life, depression and anxiety.
 - Decreased self-esteem and body image.
- Sexual concerns after cancer treatment are more likely to become *worse* over time when not addressed.
 - This is *different* than most other treatment late effects.

This happens so often, there is an oncology guideline addressing it! (*So, it's OK to ask for help!*)

American Society of Clinical Oncology Guidelines

- It is recommended that there be a discussion with the patient, initiated by a member of the health-care team, regarding sexual health and dysfunction resulting from cancer or its treatment.
- Psychosocial and/or psychosexual counseling should be offered to all patients with cancer, aiming to improve sexual response, body image, intimacy and relationship issues, and overall sexual functioning and satisfaction.

<http://ascopubs.org/doi/full/10.1200/JCO.2017.75.8995>

If something is wrong, we may have feelings of embarrassment and sometimes shame about being broken, or we believe the problem can't be fixed.

Sage Bolte, PhD, LCSW, OSW-C, 2013

There are so many losses, so much grief that we can't do more than adjust to...
intimacy is something we can actually improve.



Who can I talk to?

- *Yourself, your partner(s), your friends – more on that in a minute...*
- **Your healthcare team –**
 - Oncology team – *who do you feel might be good with this topic?*
 - Primary care – that may have more ease?
 - It's hard to 'complain' to the oncology team
 - Follow-up oncology visits don't have much wiggle room
 - Gynecology, Urology, Physical Therapy, body workers
 - Counselor, chaplain, palliative care
 - *Any others I'm missing?*

What can I try?

- Talk
- Touch
- Products to consider
 - Moisturizers
 - Lubricants
 - Dilators, vibrators, and dildos (*oh, my!*)
 - Many others, too...
- Physical wellbeing
- Connection opportunities

Let's Talk About...

Communication

- Self-talk
 - Talking to ourselves like we'd talk to others
 - Positive sticky notes
- Speaking honestly
 - I like, miss, hope for...
 - I'm afraid of...
 - What helps me is...
- Sex talks
 - Sane & sober
 - On 'neutral ground'
 - Writing may be easier than talking
- Seeking outside help

Touch

- Self-touch
 - Getting 'in touch' with body sensations
 - Baths, showers, skin care, pedicures, massage...
 - Sitting with your body
 - What felt good before?
 - What do I like now?
 - *Sensate Focus*
- Partner Touch
 - Clear limits
 - Clear expectations
 - Clear communication
- *Let each time be its own time*

Let's Talk About...

- Products to consider
- Where to purchase items and learn more

What to Know About Lubes?

- **Water Based Lubricants**
 - Doesn't stain
 - Washes easily
 - Can be used with any toys or condoms
- **Oil Based Lubricants**
 - More slippery
 - Not used with condoms



- **Silicone Lubricants**
 - Super slippery
 - Not to be used with silicone toys
- Vaginal **Moisturizers**
 - Can be used as lubricant and maintenance

What is Added to Lubes?



- Considerations
 - Osmolality 😊
 - Hyaluronic Acid ??
 - “net negative” over time
 - Lidocaine +/-
 - Can help if pain toward surface
 - Oils & Additives +/-
 - Essential
 - Coconut, olive, etc.
 - Marijuana
 - Fragrance, flavors 😞
 - Warming, enhancing 😞

Stores and Web-Based Information

- **SheBop:** She Bop is a women-owned sex toy boutique in Portland, Oregon specializing in body safe products and education. 503-473-8018
<http://www.sheboptheshop.com/>
- **Shine:** A unique cancer specialties store with many books and products mentioned in this talk as well as compression garments and more. 206-606-7560 www.sccashine.org
- **Babeland:** Seattle based erotic toys and books. 206-328-2929
www.babeland.com
- American Cancer Society
www.cancer.org
- CANCERcare
<https://www.cancercare.org>
- Livestrong www.livestrong.org
- Oncofertility Consortium:
<https://oncofertility.msu.edu/>
- Stupid Cancer: All things AYA
<https://stupidcancer.org>
- The National LGBT Cancer Network
www.cancer-network.org
- Many oncology institutions have intimacy and sexuality resources and links on their web sites



What else can I try?

- Things I can do myself
 - Without anything extra
 - Mindfulness, relaxation, gratitude
 - Stretching, yoga, walking
 - With regular household items
 - Light weightlifting, resistance exercise
 - Sticky notes, notebook/pen & paper
 - With easy to find equipment
 - Light weightlifting, resistance exercise



What else can I try?

- Things I can do with others
 - With my partner(s)
 - Walking, getting out and doing things together
 - Stretching, cooking, doing routine activities together
 - In my community
 - Swimming, exercise class, yoga class
 - Support groups
 - support systems - *church, organizations, crafts, book club*
 - Volunteering
 - With professional help
 - Physical Therapy, pelvic floor physical therapy
 - Body work (massage, acupuncture, etc.)
 - Counseling

What else might I consider

Safety first...

- Chemotherapy, immunotherapy, radiation, and surgery create risks for patients and partners:
 - Low blood counts
 - *Infection risk (white count <1000, ANC <500)*
 - *Bleeding risk (platelets <20,000, some risk <50,000)*
 - Integrity of the mouth, gut, vagina, rectum, or skin
 - Virus reactivation and/or infection susceptibility
 - Pain or irritation that persists means stop and seek help
 - Fertility risks – use of birth control during active treatment is strongly recommended
- *Exercise needs to be started mindfully*
 - You may want to take a class or have a physical therapy referral
- If any products or activities feel unhealthy for you, stop them
 - Seek help, if needed



Thank you! I'd love to answer your questions!

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Let's Talk About It: Intimacy & Cancer
Resources and Things to Consider
Leslie Heron, RN, ARNP

Intimacy and sexuality are impacted for most individuals and couples with health conditions. I hope this list is only the 'tip of the iceberg' for resources you consider.

Free Booklets: The American Cancer Society offers several resources on sexuality, intimacy, fertility, body image, and more. (www.cancer.org)

Books: See robust (!) book list on the last page.

Communication: Journals, sticky notes, cards let you write your feelings, a love note, or a wish list. Card decks and games (try: www.bestproductsreviews.com/intimacy-card-game) can be a way to "draw a card" and start a conversation. Apps on communication can be helpful, too (consider: www.Gottman.com).

Body image, reconnecting with your body (or your partners' body): Walking; yoga; swimming; movement to music; taking an exercise class; physical therapy; pelvic floor physical therapy; weightlifting; massage; positive self-talk; and more.

Touch does not have to be sexual or with a partner to be meaningful: Massage oil, body lotions, bath brushes, Reflexology charts/socks, massage tools and vibrators can help give permission for touch. You might start with touching yourself, so you know what works for you (called "*sensate focus*"). Journaling and counseling are other ways to 'get in touch' with yourself and with a partner.

Libido - How to get back to that loving feeling? Talking about it, think about it, talk about it some more... also romantic books and movies, happy memory sharing, and doing fun activities away from the bedroom can spark desire.

Mood: Candles, relaxation, music, put together a travel kit for a romantic getaway (or night at home). Set clear expectations and start slowly to avoid fear, shame, or conflict.

Fear of pain, being demanding, reconnection, not knowing how to talk about intimacy (with partners or medical providers), of being embarrassed, of what is normal, of dating, of telling a partner about your cancer history or body changes – all of those things are normal. Try: Books, talking (friends, providers, partner), counseling (individual, couple, clergy), journaling. Keeping it to yourself is rarely the answer to this concern.

Incontinence – general and/or with orgasm: Kegel exercises; pelvic floor physical therapy; core strengthening exercises such as physical therapy, yoga, Pilates, dance. Surgery may be an option for some causes for loss of bowel or bladder control.

Spasm/pain – Breathing, going slow, lubes, acupuncture, pelvic rehab/PT, surgery. Numbing is not usually the correct answer, but spot-treating with lidocaine-containing lube may be helpful in some cases. Counseling can help, too.

Vaginal dryness and/or pelvic tissue atrophy (loss of stretch) –

- Vaginal moisturizers – apply by hand, on dilator/vibrator, or Lube Tubes
- Internal and external symptoms helped by moisturizing *consistently*
- **Dilators & vibrators** – Inspire is the dilator set I demo; Lelo is the higher end and Fun Factory is the less expensive brand of vibrators I show. There are many, *many* brands and types to choose from! (See ‘Stores’ below.)
- Hypersensitivity: lidocaine, numbing lotions, cannabis creams – use very cautiously, just in specific spots that are problematic.
- Hormone therapy - can help with *consistent* use, may be used with moisturizers. These can’t be used by everyone or with some cancer types, needs an Rx.
- Procedures – laser treatment to stimulate the production of collagen – these can be quite expensive. Mixed reports on effectiveness, not many studies have included cancer survivors specifically.
- Addyi (flibanserin) is a non-hormonal, multifunctional serotonin agonist antagonist (MSAA). Not for most women with health conditions or those on medications due to the many potential side effects.

Erection Concerns

- Can be temporary, intermittent, partial or total
- If any erections happen, then (Rx) medications like Viagra, Cialis, etc. may help improve quality and duration of erections. Pills or injections are available.
- Penile implants are a safe and effective surgical option.
- Using other body parts (mouth, fingers) or toys (dildos, vibrators) can also be satisfying to you and your partner.
- Orgasm is possible without an erection, experiment for what works for you.

Lubrication Products

- Water based: OK for anyone, anytime. Babelube, Sliquid (standard or ‘Sassy’) are the ones I usually demo because they are reliable and not hard to find. Many other brands available and are fine to use. Avoid the ones with alcohol or preservatives – look at ingredient list before you buy.
- Moisturizers: Sliquid ‘Satin’ and Ah! Yes are reliable products. Other brands also available, again, look at ingredients before you buy.
- Oil based: Not for use with condoms or dental dams. Oils are more likely to have allergic reactions – ask/know what oils are used in the product.
- Silicone: Not for use with silicone toys/tools. Very slippery, which can be a pro or con for different people.
- Additives: Flavors, warming, cannabis, etc. – use with caution, and not as the ‘first’ product you try. Hyaluronic acid is not a long-term solution, expensive.

Hormones

- Hormone levels may be altered due to breast, ovarian, prostate, brain and other treatments affecting hormones, such as radiation or transplant.
- Hormone levels can be tested and treated, but often they are not the sole reason or answer to sexual concerns.
- Estrogen: Some forms may be contraindicated with ER+ breast and/or pelvic cancers. Estrogen may be in different forms, pill, vaginal (cream or gel), topical patch, and may be “compounded” (made into a special cream mixture) by a compounding pharmacy.
- Testosterone: Not “the answer” for libido/drive. May be contraindicated for some cancers. Available as injection, pill, topical patch, topical cream, or compounded cream.

Counseling

- Psychology Today Find a Counselor:
<https://www.psychologytoday.com/us/therapists>
- American Association of Sexuality Educators, Counselors & Therapists:
<https://www.aasect.org/referral-directory>

Stores to safely and reliably purchase items mentioned in class or this list:

- Shine – SCCA - 206-606-7560:
<https://www.seattlecca.org/shine>
- She Bop – Portland, OR - 503-473-8018:
<https://www.sheboptheshop.com/>
- Babeland – 1-888-289-8423:
<https://www.babeland.com/>

Talk with your healthcare provider – Let them know this is happening, and that you think it is important enough to talk about. They may know how to get you help or may have other ideas to add to this list. You can talk to your oncologist, primary care provider, gynecologist, urologist, nurse, physical therapist, counselor, social worker, your partner, or a friend. Some people find support in their religious community or through a cancer support group.

This general resource list was created as a place for you to begin your own research. Not everything listed here is appropriate for every person, please talk to your healthcare team if you have questions.

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Intimacy & Cancer Book Suggestions

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- Al Achkar, Morhaf. Roads to Meaning and Resilience with Cancer.
- Albaugh, Jeffrey. Reclaiming Sex & Intimacy After Prostate Cancer: A Guide for Men and Their Partners.
- Blakeway, Jill. Sex Again: Recharging your Libido
- Brown, Richard and Garbarg, Patricia. The Healing Power of the Breath: Simple Techniques to Reduce Stress and Anxiety, Enhance Concentration, and Balance Your Emotions.
- Corwin, Glenda. Sexual Intimacy for Women: A Guide for Same-Sex Couples.
- Guntapalli, Saketh and Karinch, Maryann. Sex and Cancer: Intimacy, Romance and Love After Diagnosis and Treatment.
- Gottman, John and Schwartz-Gottman, Julie. The Love Prescription: 7 Days to More Intimacy, Connection, and Joy, and others www.gottman.com
- Haines, Staci. Healing Sex: A Mind-Body Approach to Healing Sexual Trauma.
- Holtby, Lisa. Healing Yoga for People Living with Cancer.
- Johnson, Sue. Hold Me Tight: Seven Conversations for a Lifetime of Love.
- Katz, Anne. Man Cancer Sex; Woman Cancer Sex; This Should Not Be Happening: Young Adults with Cancer; Breaking the Silence on Cancer and Sexuality: A Handbook for Healthcare Providers, and others www.drannekatz.com/books
- Kollak, Ingrid and Utz-Billing, Isabell. Yoga and Breast Cancer: A Journey to Health and Healing.
- Krasnow, Iris. Sex After: Women Share How Intimacy Changes as Life Change
- Kydd, Sally & Rowett, Dana. Intimacy After Cancer: A Woman's Guide
- Laken, Keith & Virginia. Hope for Couples Facing Loss of Sexual Intimacy
- Maisano, Gina. Intimacy After Breast Cancer: A Practical Guide to Dealing with Your Body, Relationships & Sex.
- Munoz, Alicia. A Year of Us: One Question a Day to Spark Fun & Meaningful Conversations.
- Nagoski, Emily. Come As You Are: The Surprising New Science That Will Transform Your Sex Life; The Come As You Are Workbook; and Come Together: The Science (and Art!) of Creating Lasting Sexual Connections.
- Notte, JoEllen. The Monster under the bed: Sex, Depression and the Conversations We Aren't Having.
- Pennebaker, James and Evans, John. Expressive Writing: Words that Heal.
- Rosenthal, Kairol. Everything Changes: The Insider's Guide to Cancer in Your 20's and 30's.
- Schwartz, Anna. Cancer Fitness: Exercise Programs for Patients and Survivors.
- Shapiro, Dan. And In Health: A Guide for Couples Facing Cancer Together.
- Silk, Danny. Keep Your Love On: Connection, Communication, and Boundaries