Women’s Sexual Health after Transplant and CAR T-cell Therapy

Celebrating a Second Chance at Life Survivorship Symposium

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Learning Objectives

• Understand the impact of cancer and transplant on sexual function
• Review causes of sexual pain following transplant
• Identify the two types of sexual desire/libido
• Discuss medical, psychological, and relational approaches to optimizing sexual health post-transplant
“It hurts too much to have sex. It feels like I’m being torn.”
“I have absolutely no sexual desire. I don’t care if I ever have sex again. But my partner isn’t happy.”
“The doctor says my vagina has closed up since treatment. I can’t even have sex with my husband.”

“I feel like a horrible wife. I don’t even want him to touch me.”
Sexual difficulties are one of the most common late effects of transplant.
Sexual difficulties tend to persist or worsen over time...

Unless treated!
Common Sexual Concerns After Transplant

- Vulvovaginal dryness
- Sexual / genital pain
- Low sexual desire or interest
- Reduced sexual quality and frequency
- Changes in orgasm
- Poor body image / feeling less attractive

Humphreys et al., 2007; Nørskov et al., 2015; Syrjala et al., 2008
Transplant does NOT erase your sexuality...

Help is available!
Sexual / Genital Pain
Sexual/Genital Pain & Transplant

• Vulvovaginal tissue health changes
• Genitourinary syndrome of menopause (GSM)
• Genital graft vs. host disease (GvHD)
• Pelvic floor muscle tension
Vulvovaginal Changes: Treatment-Induced Menopause

Genitourinary syndrome of menopause (GSM)

- Vulvovaginal dryness is one of the most common problems during and after cancer treatment
  - Up to 90% of patients!
- Lack of estrogen to genital tissues
- **Progressive** thinning, dryness, atrophy, inflammation of genital tissues

Couriel et al., 2006; Crean-Tate et al., 2019; Shanis et al., 2012
Estrogen & Sexual Functioning

- Maintains physiological function of the genitals (including urinary health)
- Critical for:
  - Preserving genital sensation, elasticity, adequate lubrication
  - Reducing risk of sexual pain
  - Improving sexual arousal
- No estrogen = GSM

Crean-Tate et al., 2019; Potter & Panay, 2021
Vulvovaginal Changes: Genital GvHD

Graft vs host disease (GvHD)

- 1.6% - 69% of allogeneic stem cell transplant survivors
- If you have non-genital GvHD, you are likely to have genital GvHD
- 70% vulva only
- Median onset = 8.7 months post-transplant, but can develop years later for some

Couriel et al., 2006; Shanis et al., 2012; Spinelli et al., 2003
Vulvovaginal Changes: Common Symptoms

• May be asymptomatic at first – pelvic exams are important!
• Vulvovaginal dryness
• Sexual or genital pain
• Decreased elasticity of vaginal canal
• Adhesions and scarring
• Vaginal stenosis
The Sexual Pain Cycle

1. Anticipate Pain
   The body anticipates pain; fear/anxiety may contribute.

2. Involuntary Reaction
   The body automatically tightens vaginal muscles.

3. Painful Sex
   Tightness makes sex painful; penetration may be impossible.

4. Pain Reinforces
   Pain intensifies reflex response.

5. Bracing
   Body reacts by "bracing" more on an on-going basis.

6. Avoidance
   Avoidance of intimacy, lack of desire may develop.
The Pelvic Floor Muscles

Pelvic floor tension and pain are very common, often under-recognized

- May affect bowel, bladder, and sexual function
- May cause low back or hip pain
- Pelvic floor physical therapy is the gold standard treatment!
What Do I Do if Sex Hurts?

Step 1:

• **STOP!**
  • Reinforcing a connection between pain and sex makes things worse
  • Leads to avoidance (and harms libido)

Step 2:

• Optimize vulvovaginal tissue health
• Assess pelvic floor muscle health
  • Pelvic floor physical therapy may be needed

Step 3:

• Explore pleasurable, non-penetrative sexual activity
Optimizing Vulvovaginal Tissue Health

Over the counter:
• Lubricants
  • Water-based or silicone
• Vaginal moisturizers
• Vibrators

Prescription:
• Vaginal estrogen
• Topical corticosteroids (for GvHD)

Cox & Panay, 2023; Potter & Panay, 2021; Preston & Richards, 2023; Rullo et al., 2018
Assessing Pelvic Floor Muscle Health

Sexual medicine providers

• International Society for the Study of Women’s Sexual Health
  isswsh.org

Pelvic floor physical therapists

• Herman & Wallace:
  hermanwallace.com/list-of-certified-pelvic-rehabilitation-practitioners

• Academy of Pelvic Health Physical Therapy:
  aptapelvichealth.org/ptlocator
Sexual Pain: Take Home Points

• Three main causes:
  • Treatment-induced menopause (GSM)
  • Genital GvHD
  • Pelvic floor muscle tension

• Step 1: **STOP having painful sex!** Explore pleasurable, nonpainful/penetrative activities as pain is being assessed & treated.

• Step 2: Optimize vulvovaginal tissue health

• Step 3: Assess pelvic floor muscle health. Treat, as needed.
Sexual Desire
(aka Libido/Sexual Interest)
Types of Sexual Desire/Libido

Spontaneous Sexual Desire

Responsive Sexual Desire

"Lightening strikes in Silver Spring, MD" by Kristen Becker is licensed under CC BY-SA 2.0.; "Thinking woman" by Xuan Zheng is licensed under CC BY-SA 2.0.
Basson’s Circular Model of Sexual Response

1. Emotional Intimacy
2. Sexual Neutrality
3. Spontaneous Desire
4. Satisfaction
5. Openness to Sexual Stimuli
6. Responsive Desire
7. Sexual Arousal

Leads Directly to Arousal

Fogel Mersy & Vencill, 2023; Image adapted from Basson, 2000, designed by Jennifer Pearl (Team Computer) & used with permission
Biological Influences to Spontaneous Libido

• Reproductive hormones
  • e.g., estrogen, testosterone
• Neurotransmitters in the brain
  • e.g., dopamine
• Both often impacted by cancer treatment!
Responsive Sexual Desire
Four Requirements for Responsive Desire

- Consent
- Pleasure
- Focus
- Time
Different Libido Styles?

• Sexual initiation likely needs to shift to a more responsive libido framework
  
  • **Not:** “Do you want to have sex?”
  
  • **But:** “Are you willing (to see if desire responds)?”

• 0 - 10 “willingness scale”

• Explore brakes & accelerators
Accelerators (Gas Pedal)
- Partner appearance
- Feeling relaxed
- Being well rested
- Pleasant body/genital sensations
- Feeling safe/loved/special
- New relationship energy

Inhibitors (Brake Pedal)
- Pain
- Fatigue
- Body image struggles
- Feeling obligated
- Partner conflict
- Anxiety, depression

Person- and context-dependent
Biopsychosocial

One person’s accelerators may be another’s brakes!
Important Resources for More Information

- **Come As You Are**
  - By Emily Nagoski, Ph.D.
  - The surprising new science that will transform your sex life.

- **Desire**
  - By Lauren Fogel Mersy, PsyD., and Jennifer A. Vencill, PhD, ABPP
  - An inclusive guide to navigating libido differences in relationships.
Sexual Desire: Take Home Points

• Two different “types” or “styles”
  • Spontaneous
  • Responsive

• Responsive libido often becomes a predominant style with hormone changes, aging, and in long-term relationships

• Optimize responsive sexual desire by:
  • Understanding the 4 requirements and your brakes/accelerators
  • Using the willingness scale
Addressing an Anxiety-Avoidance Cycle
Sexual Scripts: A Tale of Two Models

Fogel Mersy & Vencill, 2023; Images designed by Jennifer Pearl (Team Computer) & used with permission
The Intimacy Date Exercise

- Intentional time to practice the wheel model
- Planning an intimacy date versus scheduling sex
  - Partners can plan a day and time, but **NOT** the specifics of the activity
  - Restaurant analogy
- Focuses on flexibility and helps to disrupt negative anticipation
Intimacy Date Sample Menu

- Back massage
- Laying your head on your partner’s chest
- Spooning
- Showering together
- Mouth kissing
- Kissing other body parts
- Mutual self-stimulation
- Talking about sexual fantasies
- Using a sexual aid/vibrator together
- Playing with your partner’s hair
- Touching yourself while your partner holds you
- Penetrative sex
- Reading or listening to an erotic story
- Foot massage
- Cuddling
- Full body massage
- Rubbing genitals together without penetration
- Oral stimulation
- Manual stimulation
Other Behavioral Approaches

• There are many options for improving one’s sexual relationship!
  • e.g., bridging exercises, sensate focus exercises
  • See the book *Desire: An Inclusive Guide to Navigating Libido Differences in Relationships* for lots more ideas

• Consider seeing a sex therapist for additional support
  • AASECT.org
Avoidance Cycle: Take Home Points

• Get off the Staircase!

• A flexible, open-ended approach to sex helps to address pain, libido, and sexual anxiety concerns
  • Ultimately helping us to reconnect and disrupt avoidance

• Intimacy dates and other behavioral exercises are key

• Consider sex therapy for further support
Overall Take Home Points

• Transplant does not take away your sexuality.

• Painful sex? STOP and talk to your doctor!
  • Optimize vulvovaginal tissue and pelvic floor muscle health
  • Try moisturizers, lubricants, vibrators, non-penetrative sex

• Understand the two types of libido and maximize responsive sexual desire

• Avoidant cycle?
  • Get off the Staircase with intimacy dates and other behavioral exercises

• Consider sex therapy for further support
Thank you!

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Questions?

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