

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

Celebrating a Second Chance at Life
Survivorship Symposium

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Jennifer A. Vencill PhD, ABPP, CST
Assistant Professor and Consultant, Division
of General Internal Medicine, Department
of Psychiatry & Psychology, Mayo Clinic

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!

Kelly et al., 2021; Nørskov et al., 2015; Syrjala et al., 2008

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

Transplant does NOT erase your sexuality...

Help is available!

Sexual / Genital Pain

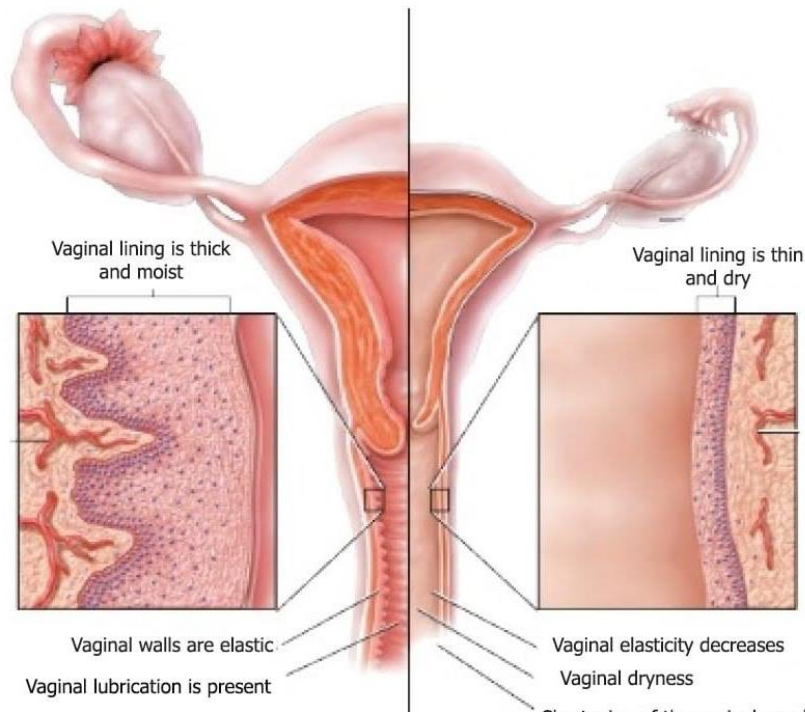
Sexual/Genital Pain & Transplant

- Vulvovaginal tissue health changes
 - Genitourinary syndrome of menopause (GSM)
 - Genital graft vs. host disease (GvHD)
- Pelvic floor muscle tension

Vulvovaginal Changes: Treatment-Induced Menopause

Healthy Vagina

Vaginal Atrophy



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

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

Vulvovaginal Changes: Genital GvHD

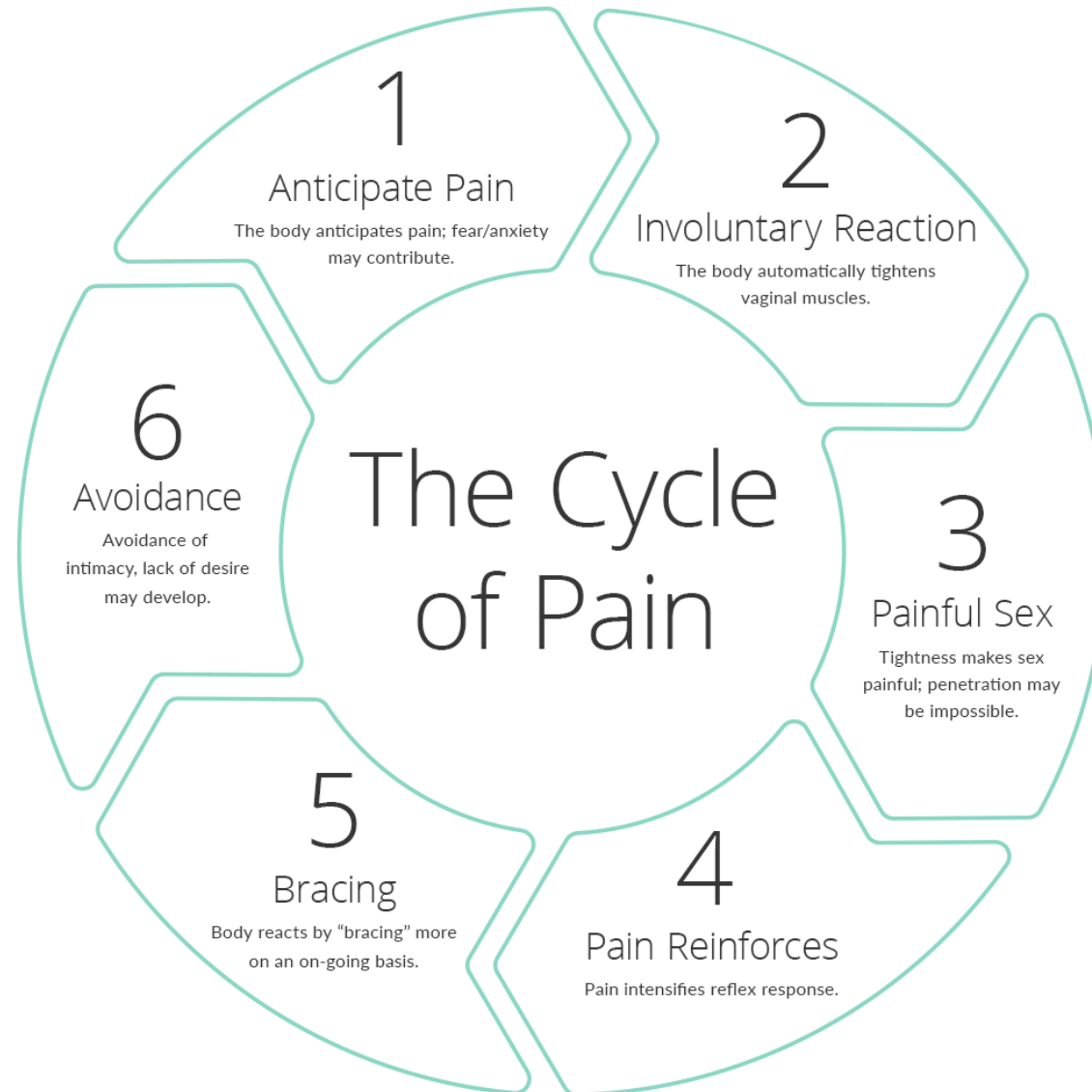
Graft vs host disease (GvHD)

- 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

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

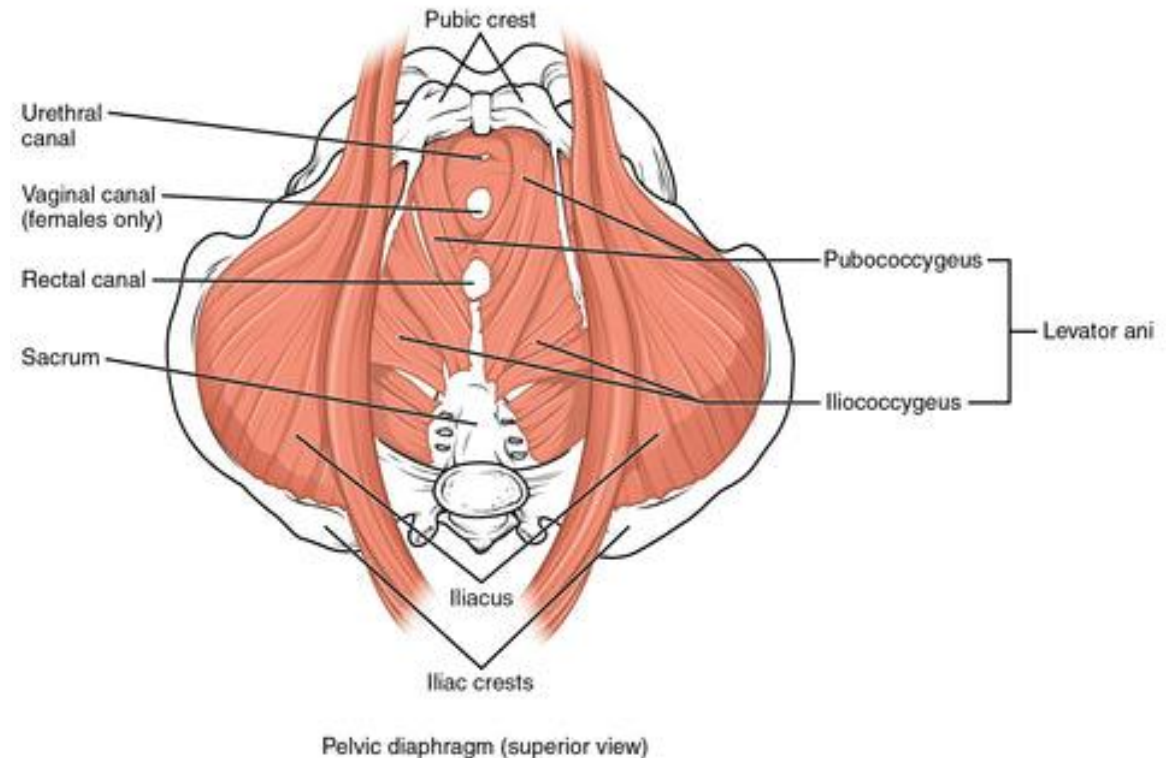
The Sexual Pain Cycle



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!



"1115 Muscles of the Pelvic Floor" by OpenStax is licensed under CC BY 4.0.; Goldstein et al., 2023

2024 SURVIVORSHIP SYMPOSIUM

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)



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

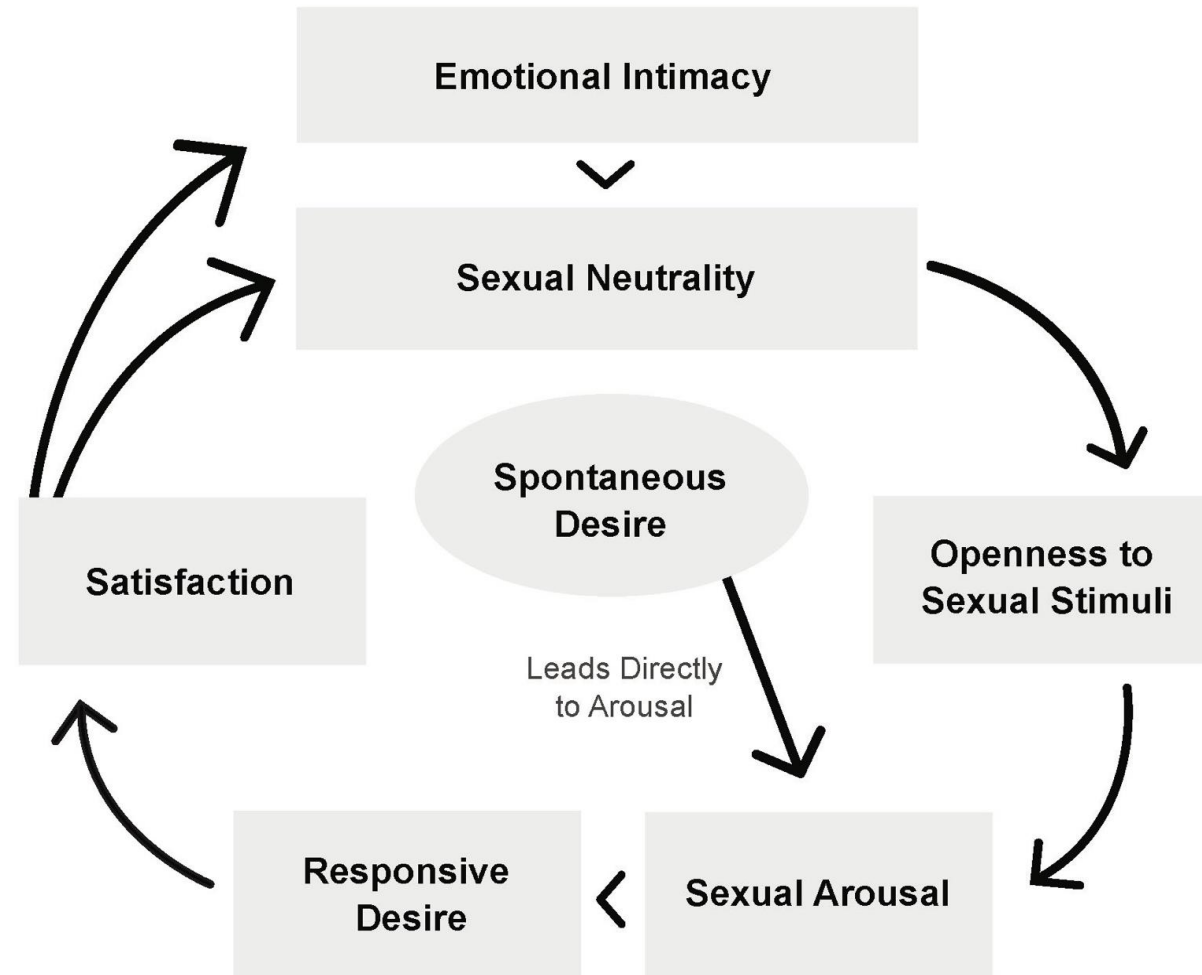


Spontaneous
Sexual Desire



Responsive
Sexual Desire

Basson's Circular Model of Sexual Response



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

Biological Influences to Spontaneous Libido

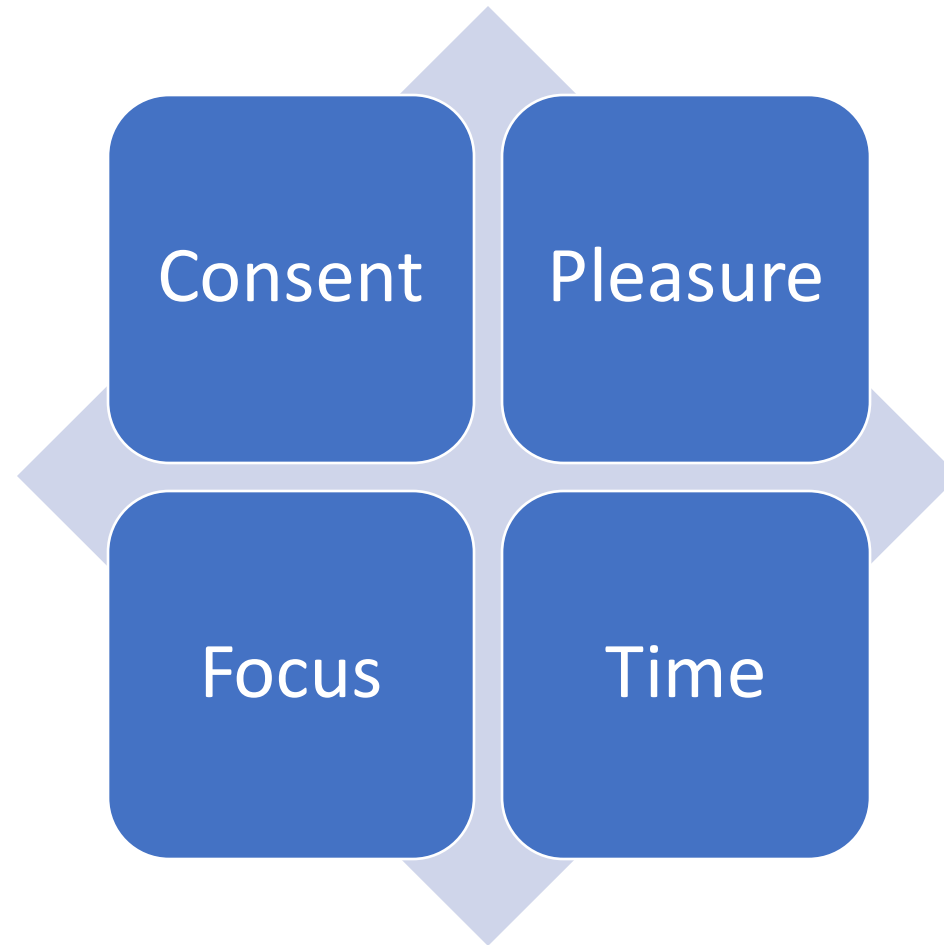


- Reproductive hormones
 - e.g., estrogen, testosterone
- Neurotransmitters in the brain
 - e.g., dopamine
- Both often impacted by cancer treatment!



Responsive Sexual Desire

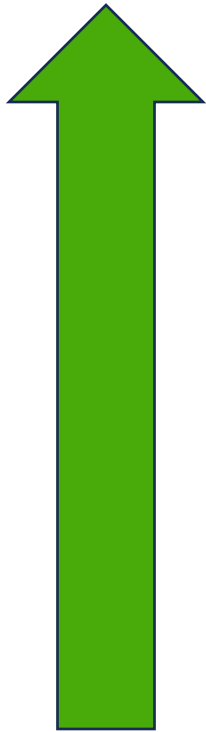
Four Requirements for Responsive Desire



Fogel Mersy & Vencill, 2023

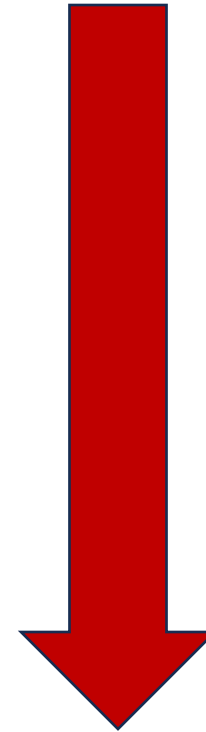
Different Libido Styles?

- 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)

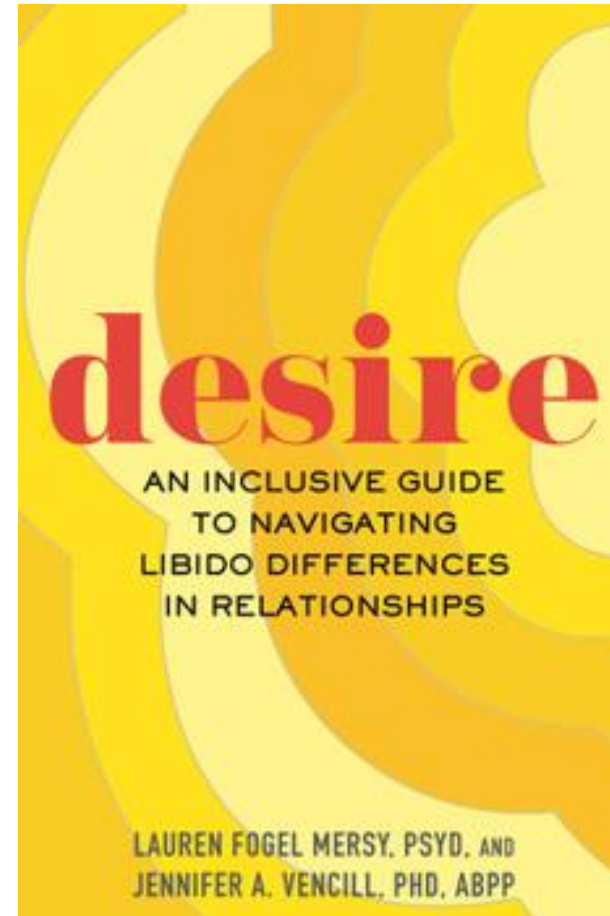
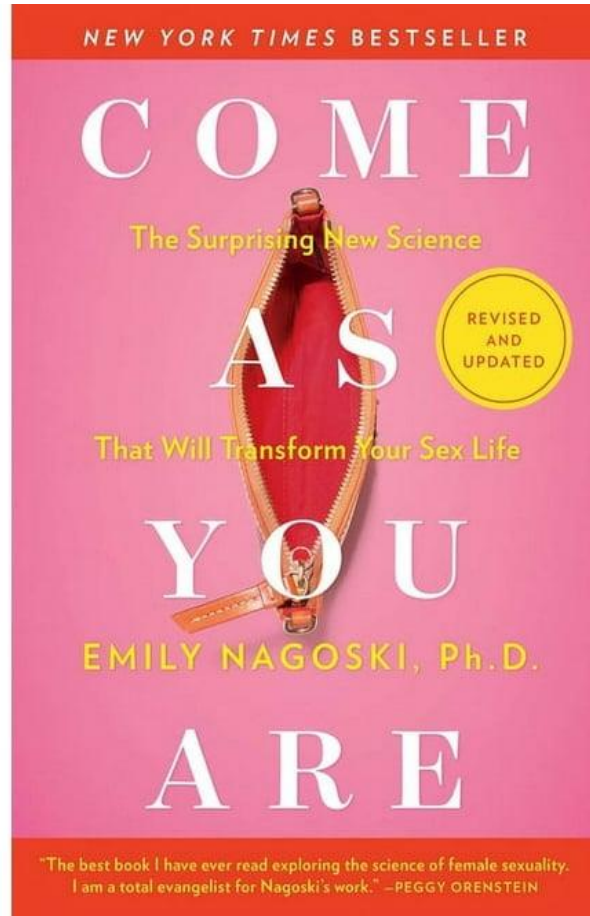
- Pain
- Fatigue
- Body image struggles
- Feeling obligated
- Partner conflict
- Anxiety, depression

Person- and context-dependent

Biopsychosocial

One person's accelerators may be another's brakes!

Important Resources for More Information

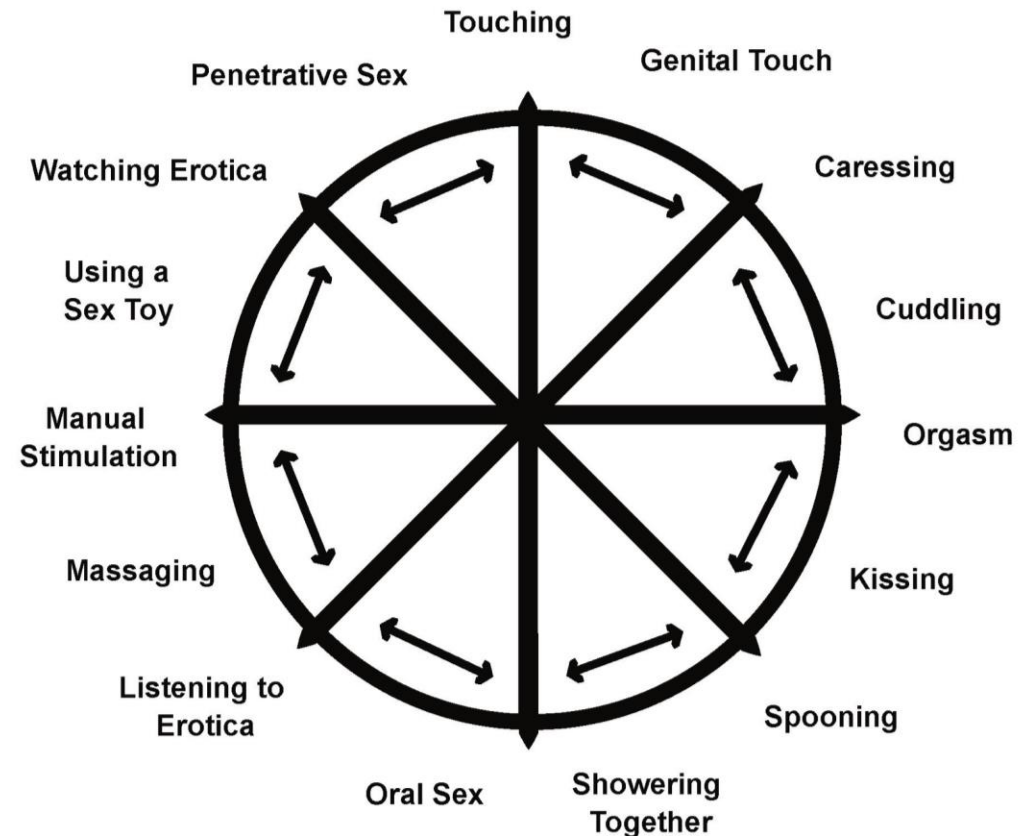
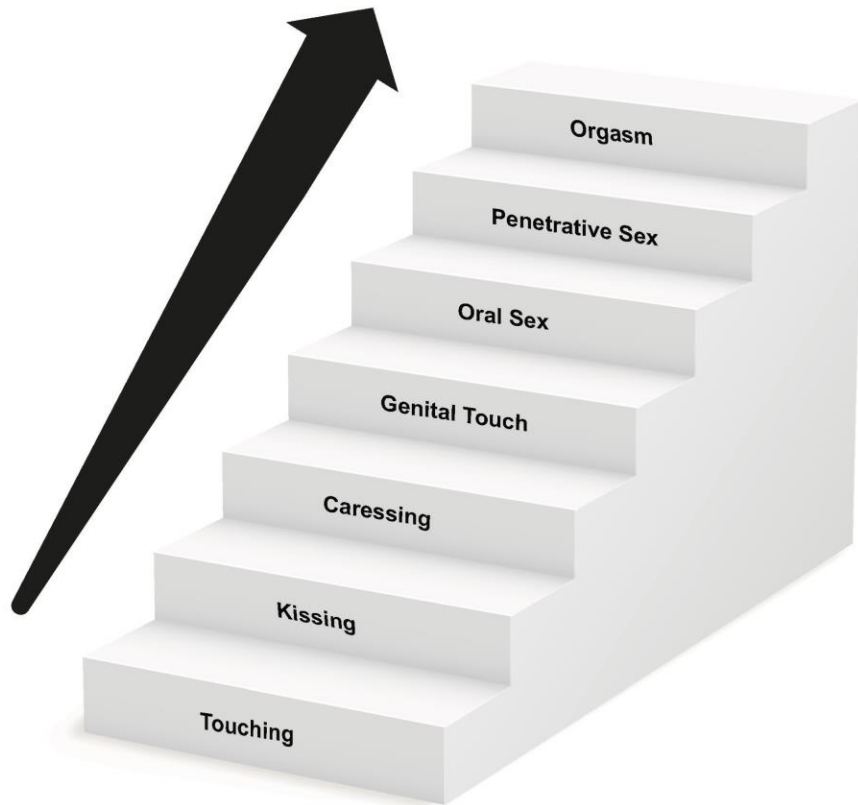


Sexual Desire: Take Home Points

- 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

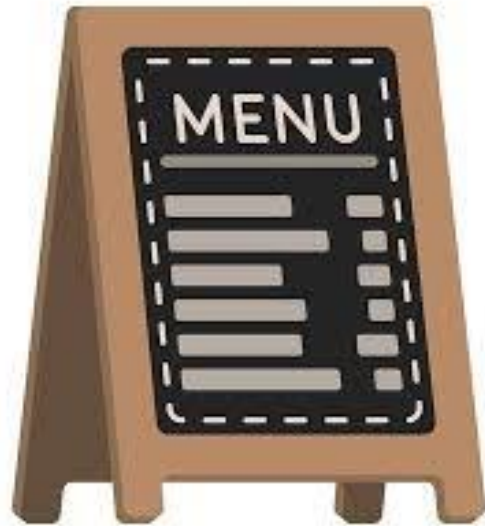
Addressing an Anxiety-Avoidance Cycle

Sexual Scripts: A Tale of Two Models



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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](https://www.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!



@drjennifervencill





Questions?



Jennifer A. Vencill PhD, ABPP, CST

Assistant Professor and Consultant, Division
of General Internal Medicine, Department of
Psychiatry & Psychology, Mayo Clinic

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