

Sex after a Cancer Diagnosis: What Patients Really Need to Know

September 22, 2021

By Brier Jirka LIMHP, CPC, CST

Conflict of Interest

- ▶ Conflict of Interest:
 - ▶ A conflict of interest occurs when an individual has an opportunity to affect educational content about health care products or services of a commercial interest with which he/she has a financial relationship.
- ▶ There are no relevant financial relationships with any commercial interests pertaining to this activity or slides.

A Little About Me

- ▶ Grew up in Nebraska and attended Millard North High School
- ▶ Undergraduate degree in Psychology from Arizona State University
- ▶ Masters Degree in Counseling and Guidance from University of Missouri- Kansas City
- ▶ Certification in Sex Therapy from the American Association of Sex Educators, Counselors and Therapist (AASECT).
- ▶ Populations treated: Sexual trauma, Sexual issues related to medical diagnosis (Cancer, Stroke, TBI's), post pregnancy sexuality, Menopause transitioning, Lack of desire and arousal, Orgasm complaints, Pelvic Pain/Painful intercourse, sexual confidence and communication.

Norms related to sex differences in Cancer sexuality have concerns

In one study 74% of patients thought important to address after cancer

Out of the individuals that got information

29% were Breast Cancer survivors

79% Prostate Cancer Survivors



Stats

- ▶ One sample of 1956 women diagnosed with breast cancer
 - ▶ 73% reported decrease in the extent to which they felt desirable
 - ▶ 51% attributed changes in their sexual wellbeing to feeling unattractive
 - ▶ 44% to feeling uncomfortable exposing their body
 - ▶ 38% to having loss confidence in themselves.

Ussher JM, Perez J, Gilbert E. Changes to Sexual well-being and Intimacy after breast cancer. *Cancer Nurs* 2012; 35: 456-465

World Health Organization (WHO)

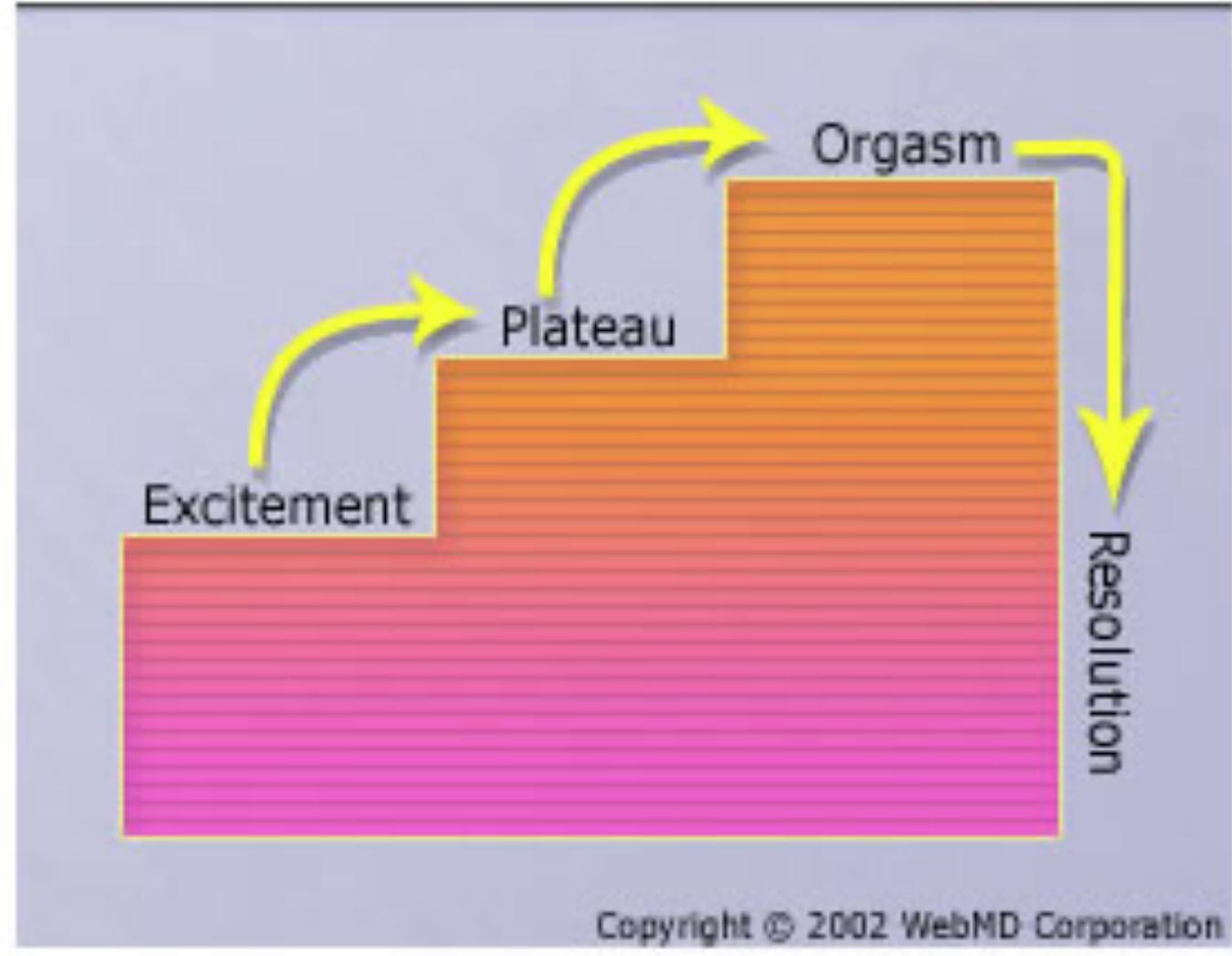
. The WHO defines sexual health as the integration of the physical, emotional, intellectual and social aspects of sexual being in ways that are positively enriching and that enhance personality, communication and love

Sexual Response Cycle

- ▶ Originally developed by Masters and Johnson in the 1950's
- ▶ Has evolved over time through sexual research
- ▶ Men and Women are different in sexual response
- ▶ Four/Five Stages: (Desire), Excitement, Plateau, Orgasm, Resolution

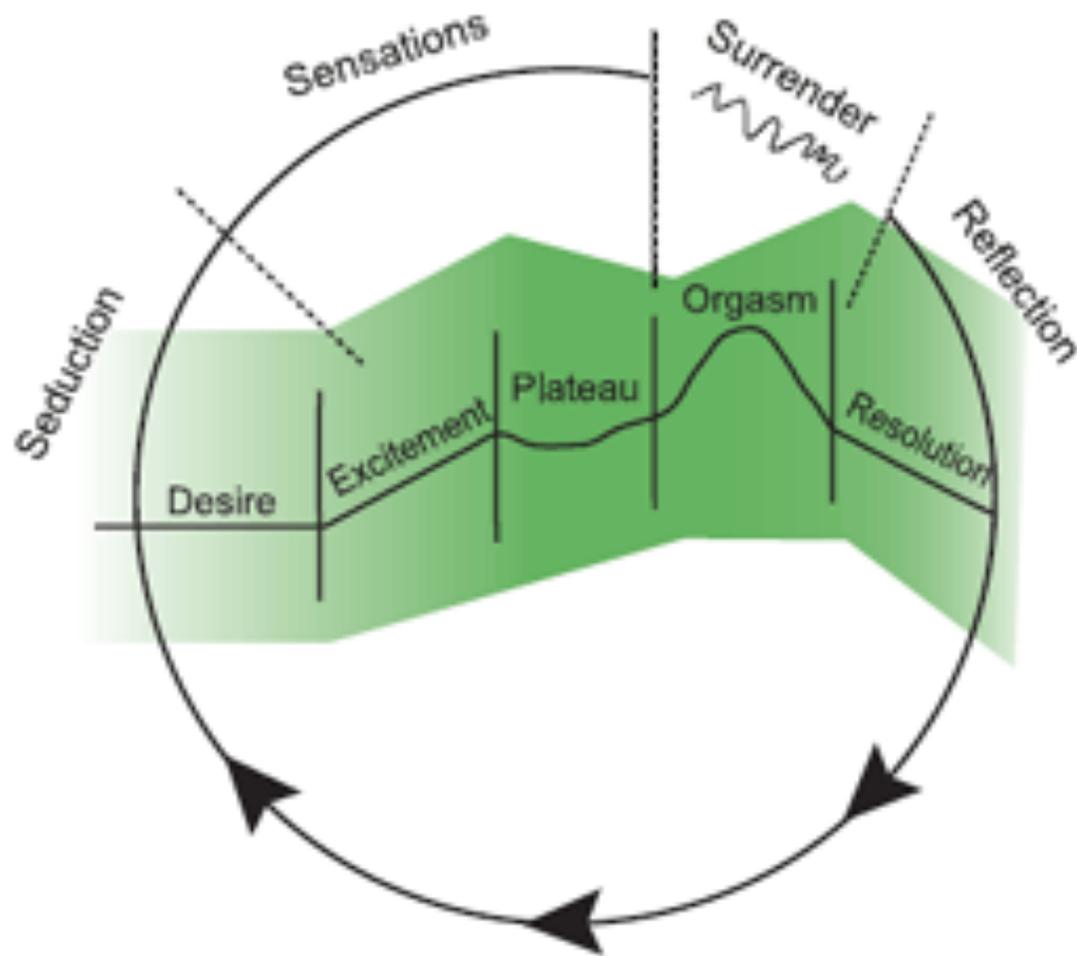
Males

Sexual Response Cycle



Females

FIGURE 2. Circular Model of Female Sexual Response
Developed by Whipple and Brash-McGreer⁵



Whipple and Brash-McGreer's circular model of female sexual response shows how pleasure and satisfaction during one sexual experience can lead to the seduction phase of the next sexual experience.

Sexual Anatomy

Anatomy Drawings/Images to follow

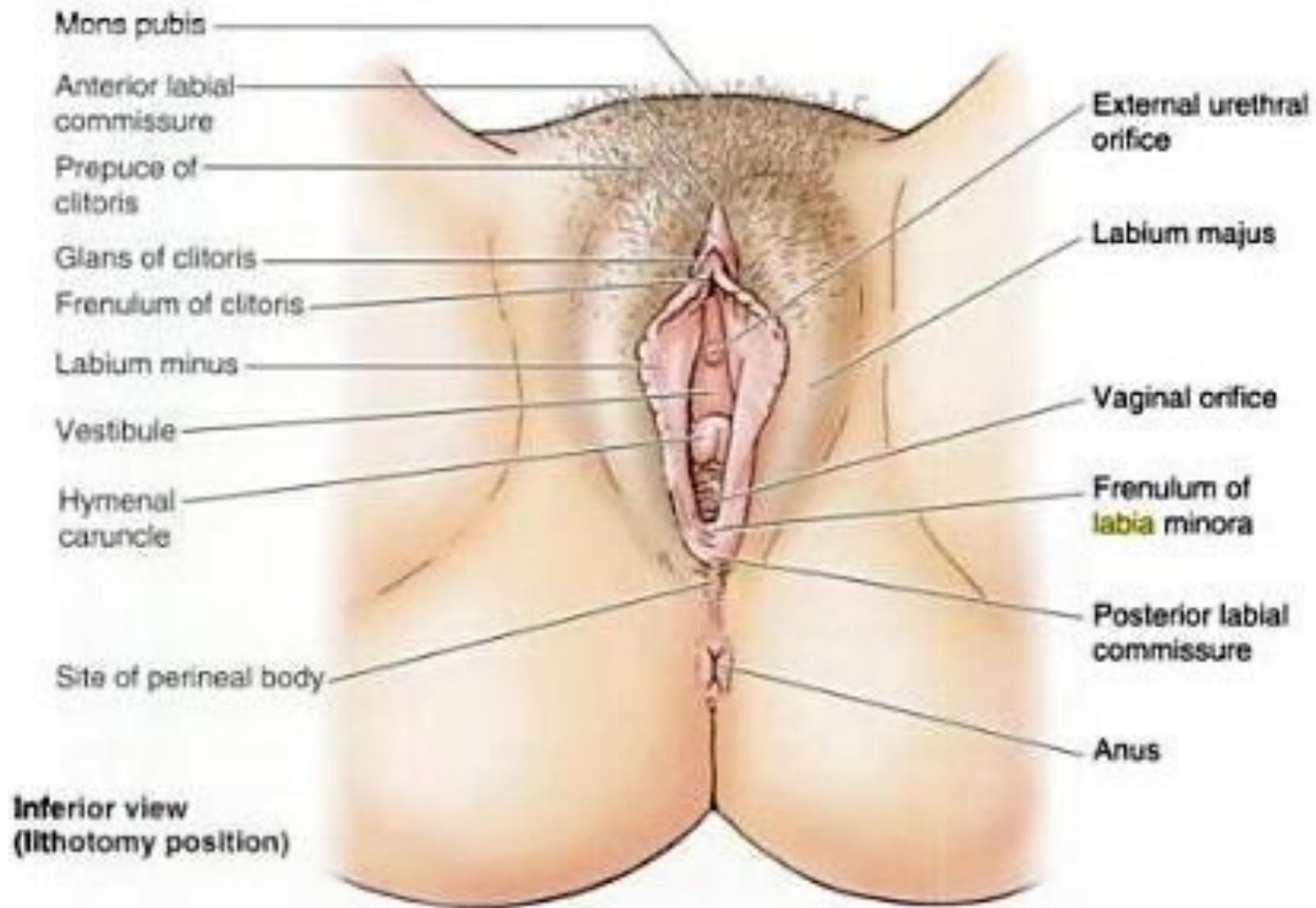
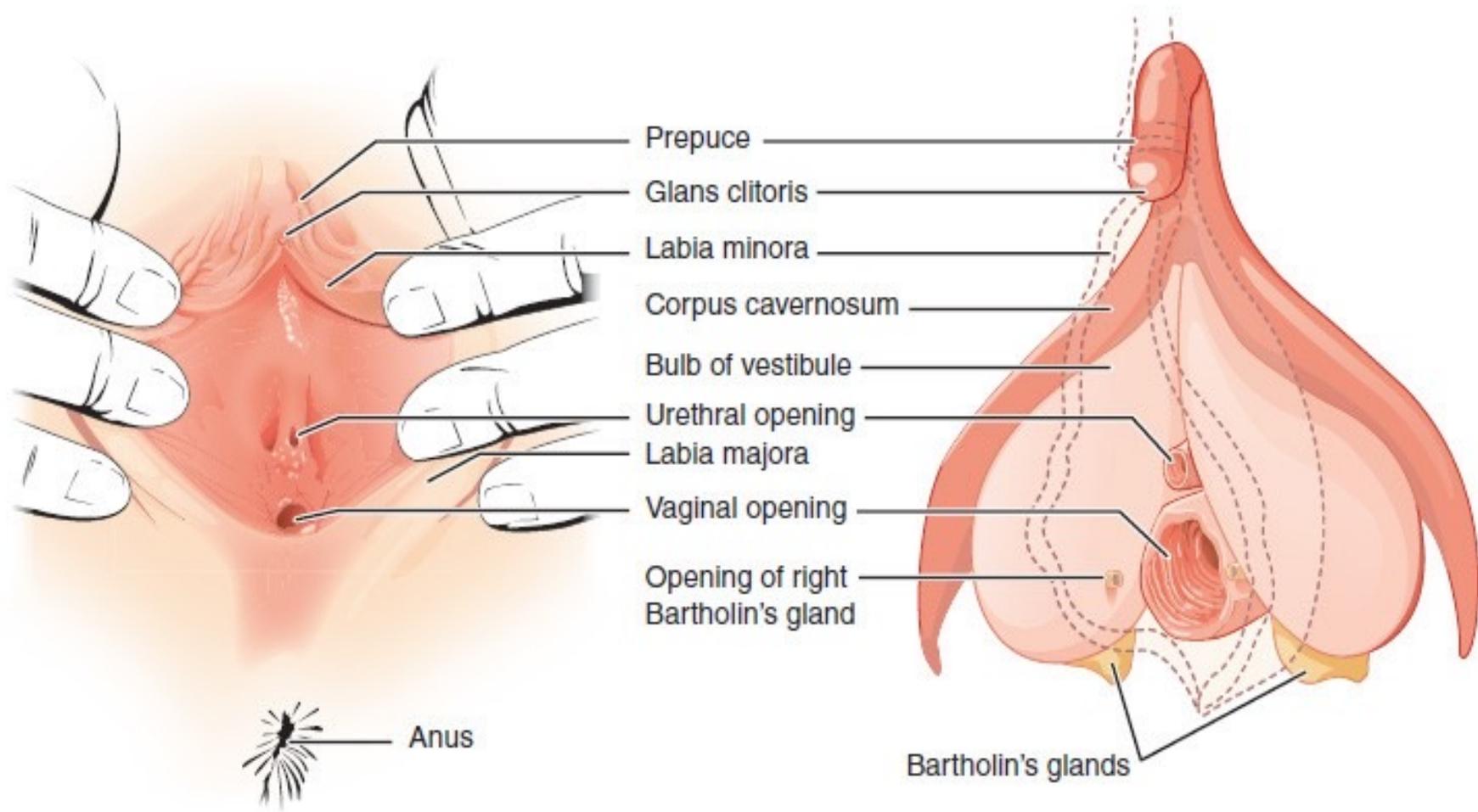
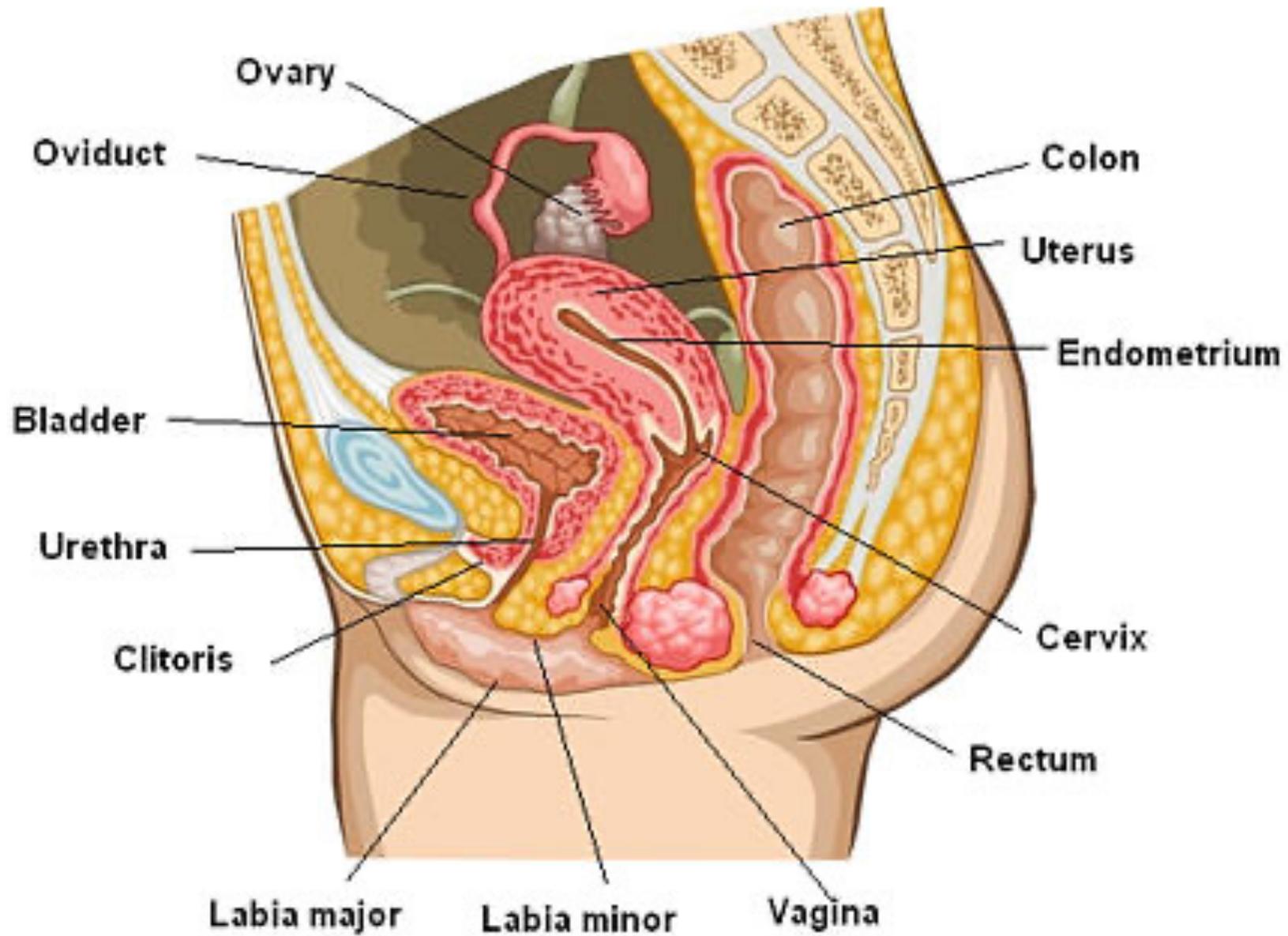


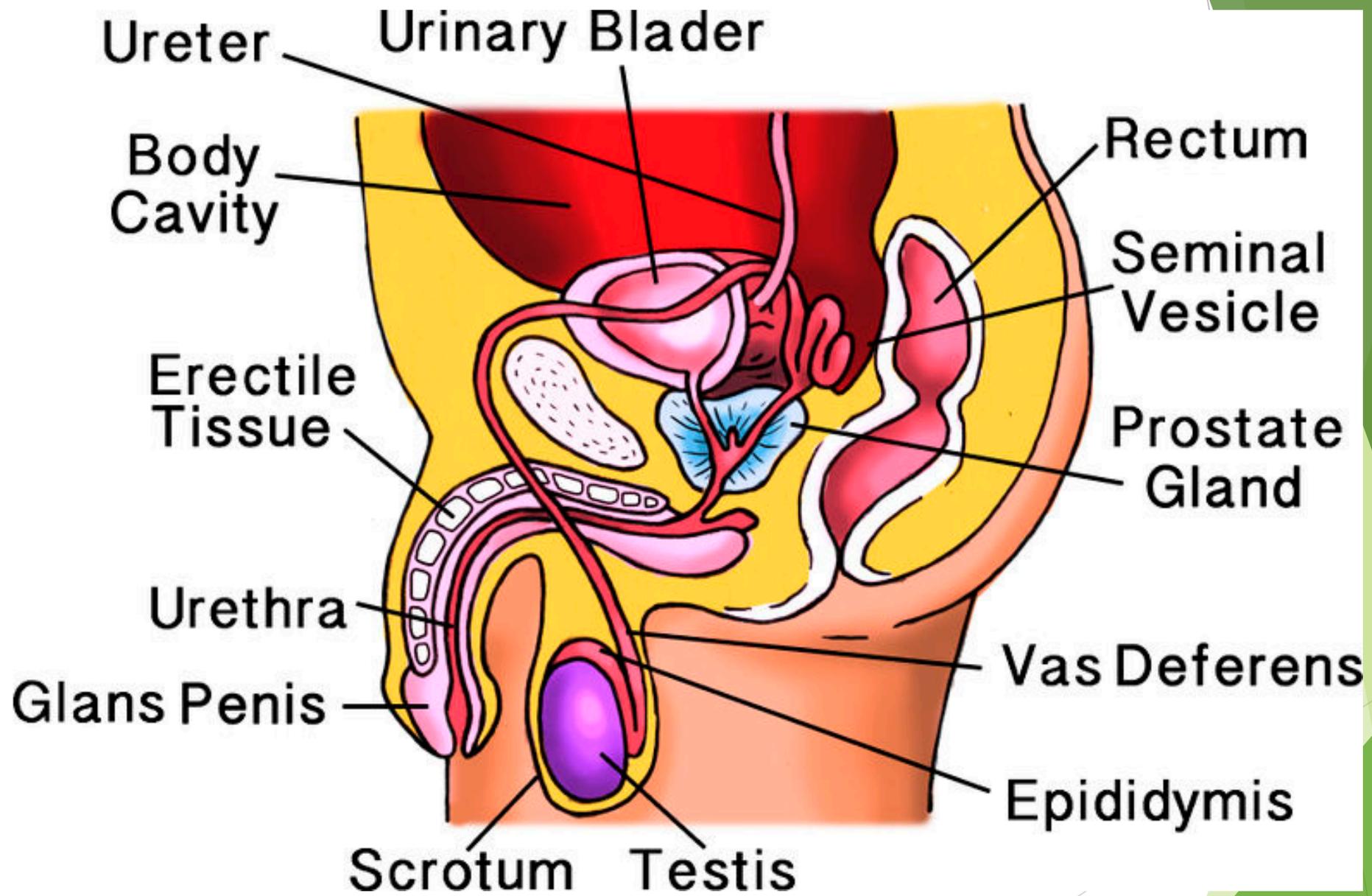
Figure 3.52. Female external genitalia. The labia majora and minora are separated to show the vestibule, into which the external urethral orifice and the vaginal orifice open.



Vulva: External anterior view

Vulva: Internal anteriolateral view





Most important sex organ is.....



Largest Sex Organ.....



Picture taken for the 2016 Pirelli calendar

Women cancer survivors experience these sexual dysfunctions

- ▶ Sexual desire: Body Image, Spousal support, overall self worth change, absence of desire
 - ▶ Arousal: Tissue changes, Lubrication changes, Hormone changes
 - ▶ Orgasm: Relationship trouble, lack of blood flow, can't get out of head
 - ▶ Pain: anatomy changes, nerve changes, bloating from chemo drugs, increase in yeast infections
 - ▶ Fertility issues
- Most patients report comorbid symptoms

Men cancer survivors experience sexual dysfunctions as well

- ▶ Sexual desire: Body Image, Spousal support, overall self worth change
 - ▶ Arousal: Tissue changes, Lubrication changes, Erectile dysfunction
 - ▶ Orgasm: Relationship trouble, Retrograde ejaculation, Premature ejaculation
 - ▶ Pain: anatomy changes, nerve changes
- Most patients report comorbid symptoms

Alternative sexual life styles

BDSM (Bondage, Discipline, Sadism and Masochism)

- Physical harm due to consensual play can happen but is rarely addressed by patients due to fear of judgement
- Mental health concerns due to “minority stress” due to sexual preferences.

Swinging

- Exchanging of sexual partners

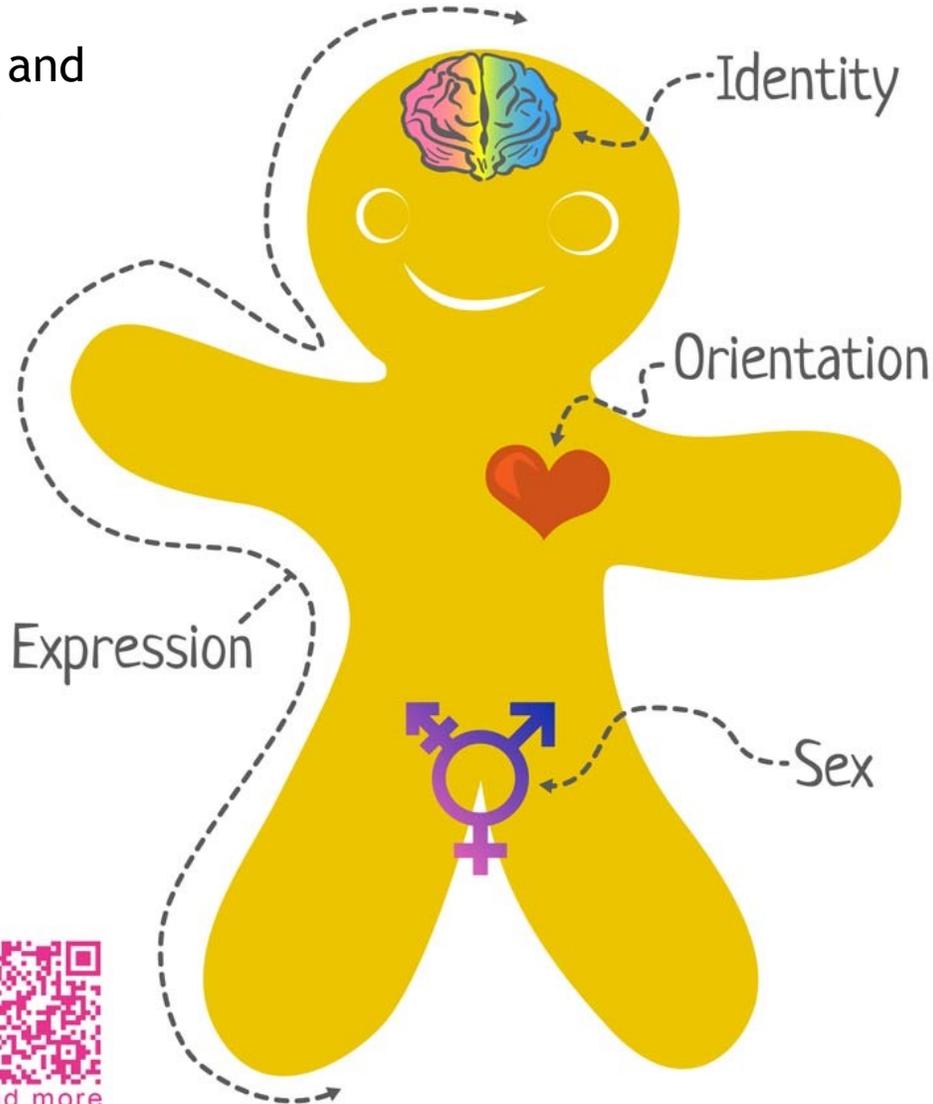
Polyamory/ Open Relationships

- Having more than one partner. Can be sexual or emotional or both in nature.

The Genderbread Person

by www.ItsPronouncedMetrosexual.com

Cisgender and Nonbinary



Gender Identity

Woman Genderqueer Man

Gender identity is how you, in your head, think about yourself. It's the chemistry that composes you (e.g., hormonal levels) and how you interpret what that means.

Gender Expression

Feminine Androgynous Masculine

Gender expression is how you demonstrate your gender (based on traditional gender roles) through the ways you act, dress, behave, and interact.

Biological Sex

Female Intersex Male

Biological sex refers to the objectively measurable organs, hormones, and chromosomes. Female = vagina, ovaries, XX chromosomes; male = penis, testes, XY chromosomes; intersex = a combination of the two.

Sexual Orientation

Heterosexual Bisexual Homosexual

Sexual orientation is who you are physically, spiritually, and emotionally attracted to, based on their sex/gender in relation to your own.

Is it safe to have sex during Treatments such as Chemotherapy

Yes, some studies suggest chemotherapy by-products may be present in semen, they suggest condom use or barrier use up until the third month after treatment

Women Side Effects

Nausea, weight gain, fatigue, lymphedema, premature menopause

Effects Ovarian production of Testosterone → low Libido

Men Side Effects

Erectile issues

Slows testosterone output

Can flare up genital herpes or genital warts if had prior

Infertility

Premature Menopause/Chemical Menopause

- Effects most women but more severe for younger cancer patients, due to dramatic change in hormones
- Vaginal dryness leads to Dyspareunia
- Hot flashes, sleep disturbances and mood changes

Radiation

- ▶ Side effects: loss of hair, fatigue, nausea these then have an effect on self esteem and lower desire
- ▶ Physical changes: Size of Vagina can change, ovaries stop hormone production, size of arteries in penis change
- ▶ Testosterone levels usually return in 6 months- for men
- ▶ Erectile issues can get worse due to takes longer for radiation to effect the body

ASTRO's annual conference October 2012

- ▶ Study found that men receiving Viagra before and after their radiation had improved sexual functioning.
- ▶ Before, 6, 12 and 24 month follow ups. Use of IIEF scale. Medication gave 3 days before and daily for 6 months then on as needed basis.
- ▶ Many men saw significant increase in erectile functioning after radiation treatment.
- ▶ Again surgery see improvement over time radiation see more decline over time

Breast Cancer Surgery

Mastectomy and lumpectomy

- ▶ The most common sexual side effect from these procedures is feeling less attractive
- ▶ Physical changes: loss of nipple and breast sensations
- ▶ Emotional changes: Feeling of being less of a woman, society and culture strong emphasis on breast in the U.S.
- ▶ Lymphedema, from lymph node removal, 30% of patients, can occur immediately after surgery or weeks to years later

Body Image and Self Esteem

- ▶ This is the most reported complaint after cancer treatment.



Antidepressants

Lower Sex Drive

- Wellbutrin is a non serotonin reuptake inhibitor antidepressant (SSRI) that is often used to counteract other antidepressants that effect sex drive



Erectile Medications

► Erectile Dysfunction

- These can often have an effect on erectile issues as well.
- Use of medication to counteract effects



Grief

- ▶ The need to Grief the loss of the previous self and learn to accept the current
- ▶ Stages of Grief: Denial, Bargaining, Anger, Depression and Acceptance
- ▶ “Grief is a lot of questions with no answers”

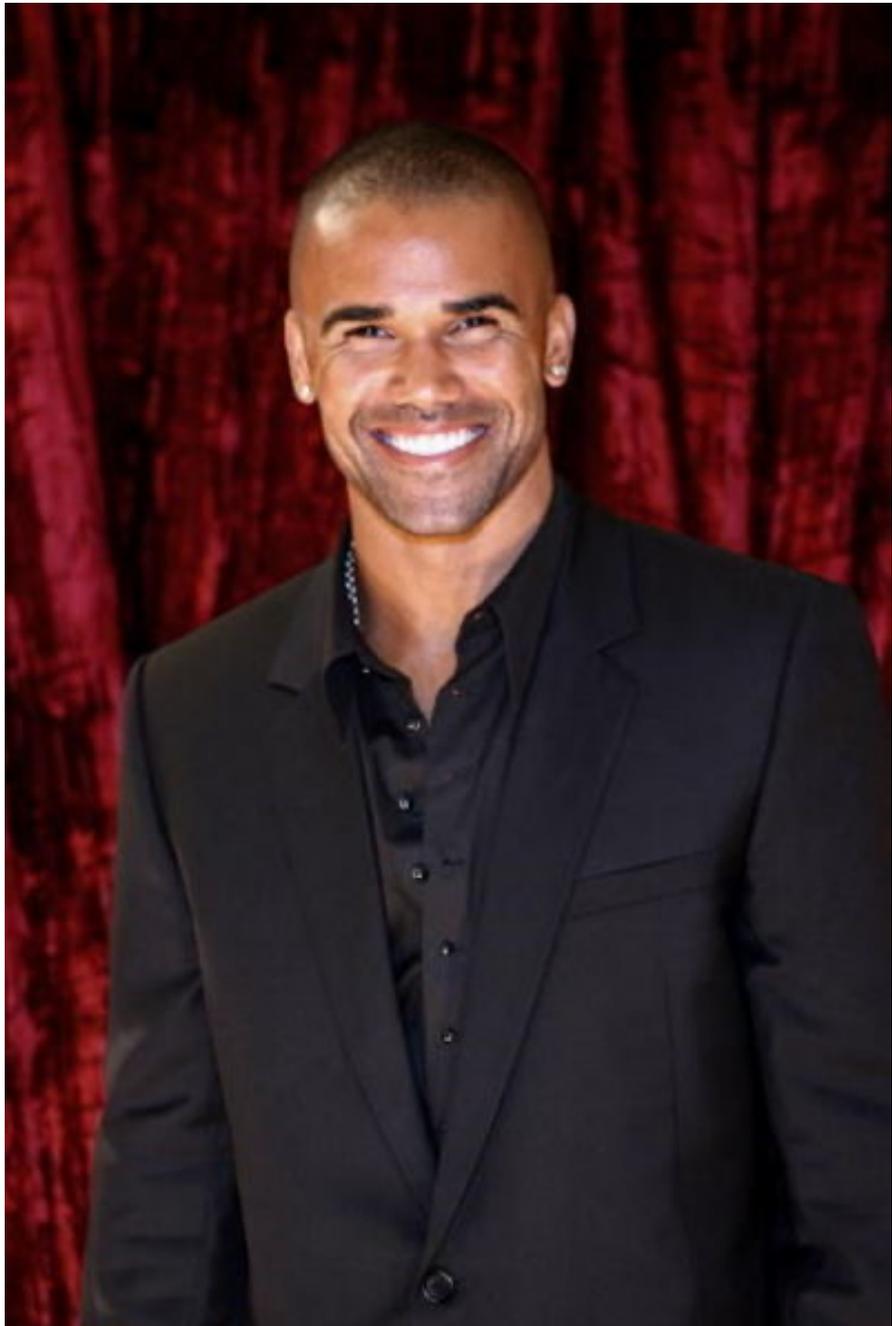
Psychological Changes

- ▶ Feelings of loss and associated depression, anxiety, and grief
- ▶ Feelings of less confident or self-conscious
- ▶ Feelings of being incomplete or a fraud
- ▶ Feelings in sexual confusion: less attractive and/or less sexual
- ▶ Feelings in self identity: “Less feminine or masculine”
“cancer survivor”
- ▶ Negative associations/reminders of the cancer
- ▶ Loss of trust in the body

How does Depression effect sexuality

- ▶ Giving a patient a depression check list can help give them a baseline of their depression symptoms and will allow you to start a conversation about these scores.
- ▶ Depression takes away motivation to be sexual
- ▶ Medications can affect physical response





Vaginismus

- ▶ Involuntary spasmodic contractions of the muscles of the outer third of the vagina
- ▶ Result in extreme pain upon insertion of a penis, or even a finger, into the vagina
- ▶ Caused by a number of different possible physiological, psychological, and situational factors
- ▶ Women can learn to minimize or prevent the contractions with treatment

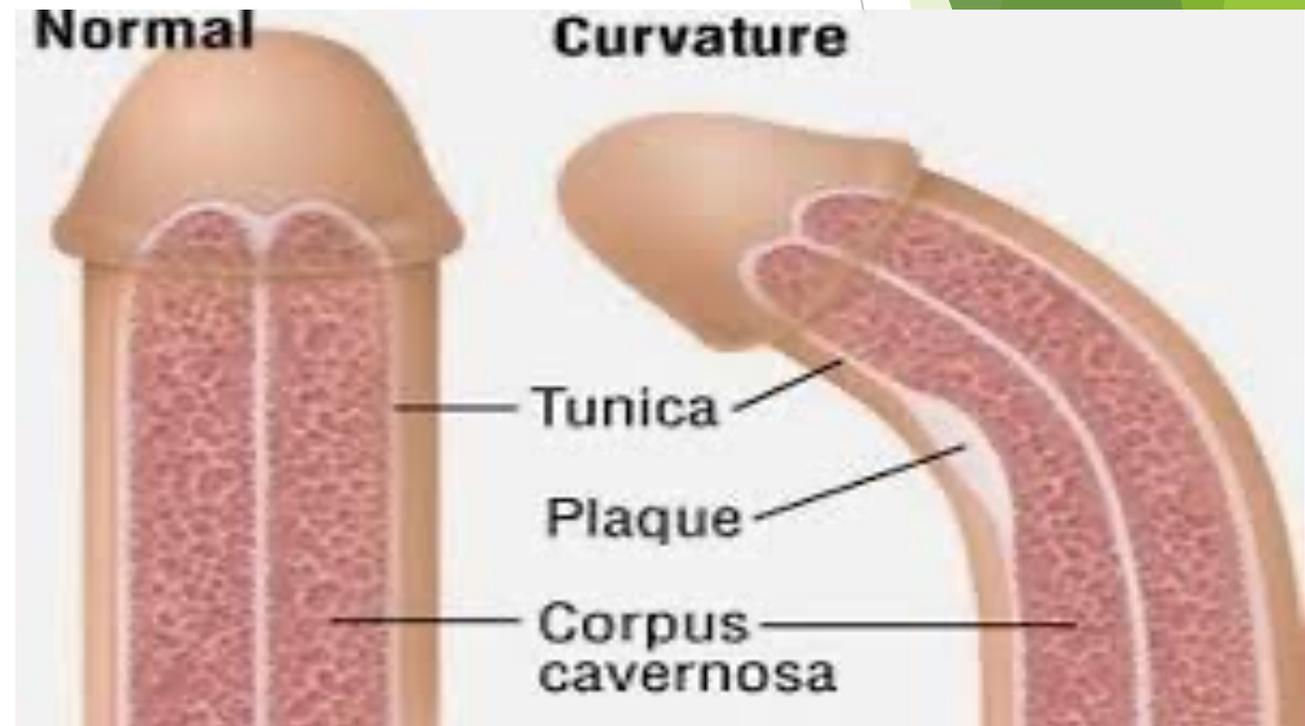
Vaginal Pain

- ▶ Many suffer alone “Silent Suffering”
 - ▶ Most can be effectively controlled
 - ▶ Premarin Vaginal Cream. Cream that contains estrogen that is used on vagina and vulvar tissues.
- Vaginal Dilators
 - Used to stretch vaginal tissues



Erectile Pain

- ▶ Glands and or Urethra may be irritated from cancer treatment
- ▶ Some men may develop a painful curve of the penis during erection called Peyronie's disease



Dyspareunia: Pain or Discomfort during Intercourse

Women

- More common in Women
- Not enough lubrication
 - Not fully aroused, hormones
- Infections
 - Irritates vaginal walls
- Contraceptive irritation
 - Sensitivity to spermicides, latex, or lubes
- Deep pelvic pain
 - UTI's, or previous surgeries

Men

- Not as common
- Problems with foreskin
 - Circumcised or uncircumcised men
- Infection
 - Glans, urethra, prostate, seminal vesicles
- Peyronie's Disease
 - Fibrous tissues and calcium deposits in penis

Pelvic Floor Physical Therapist

- ▶ These are Physical therapist that have special training in pelvic floor work which can help with sexual pain disorders as well as bowel and urinary issues that can affect sexual behaviors.
- ▶ Help clients understand how their physical bodies react to sexual stimuli
- ▶ Pelvic Floor is the muscle that contracts during orgasm.

Penile Shrinkage

- ▶ Many patients are not informed of this
- ▶ For some men up to 6 months on average after surgery men may notice a change in penis size
- ▶ No exact cause is known
- ▶ May be due to nerves that control erection are healing, similar to when on cold water or environment

How to Manage your Colostomy

- ▶ 1. Before sexual activity, empty bag and check the seal
- ▶ 2. Keep sense of Humor
- ▶ 3. Use smaller pouch when sexually active
- ▶ 4. Sexy Lingerie or Pouch covers can be purchased
- ▶ 5. Wear a scarf around your waist
- ▶ 6. Tape your bag in place
- ▶ 7. Avoid gas producing food
- ▶ 8. If Ostomy release is predictable schedule sexual activity around it



What are some of the treatments for sexual dysfunction- How can you help your Patients

- ▶ PLISSIT
- ▶ Lubricants
- ▶ Medications/ Labs
- ▶ Sexual Arousal Devices
- ▶ Blood restoring devices for Erections
- ▶ Sensate Focus
- ▶ Refer to sex therapist: Individual and Couples Therapy- discuss self esteem, changes in couple dynamic since cancer, work on communication

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www.glasbergen.com



**“That pill they advertise all the time on TV.
I’m not sure what it is, but I want it!”**

How to help your patients

PLISSIT Model

- ▶ Permission
- ▶ Limited Information
- ▶ Specific Suggestions
- ▶ Intensive Therapy

Where to Start? Permission

- ▶ Ask permission to discuss the topic
- ▶ Mention that the presenting condition may impact sexual activity
- ▶ Give permission to discuss the topic
- ▶ Listen
- ▶ Be direct, but appropriate with language
- ▶ Consider patient's body language
- ▶ Feel personally comfortable or don't bring it up

Providing Limited Information

- ▶ Sexual Response Cycle
- ▶ Anatomy & Physiology
- ▶ Effects of Illness
- ▶ Effects of Medications
- ▶ Life-Cycle Changes



Providing Limited Information

- ▶ **Ways to improve sexual functioning**
 - ▶ Timing: Early morning, in relations to medications
 - ▶ Empty bladder before sexual activity
 - ▶ Communicating needs and wants to your partner openly with out defense
 - ▶ Take time to set the mood and atmosphere for sexual relations
 - ▶ Being open to changing “Normal” sexual routine
 - ▶ Positional Changes- Herman and Wallace H/O
 - ▶ Counseling (Marital/Relationship/Individual)

Providing Limited Information

- ▶ **General patient information handouts**
 - ▶ Medications affecting sexual ability and desire
 - ▶ Physical body changes that can interfere with sexual ability and desire
 - ▶ Myths about sexuality
 - ▶ Handouts
- ▶ **Referral to sexual medicine clinic or/and sex therapist for more specific help or give more specific information.**
 - ▶ This may be as far as some feel comfortable, in that case we are here to help the best we can

Lubricants

- ▶ Water (glycerin and non glycerin)

- ▶ Silicone



- ▶ Natural oil/coconut oil (not mineral)

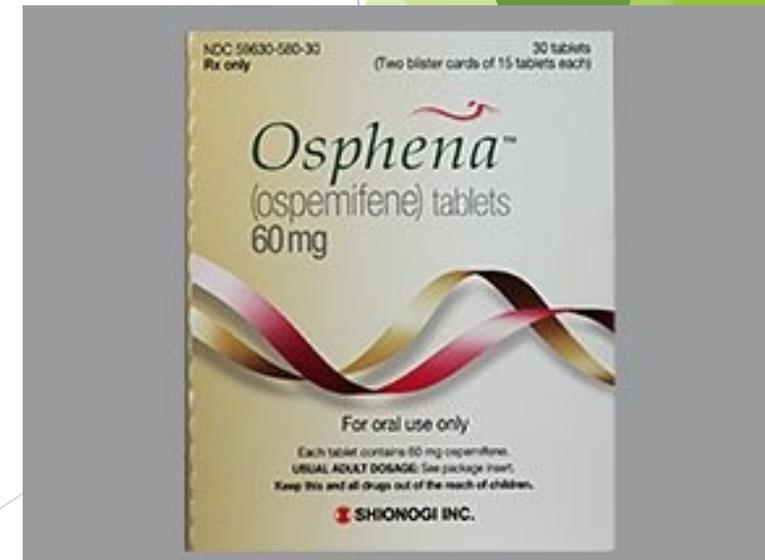


- ▶ Fertility Promotion - Pre-Seed



Osphena 2013 and Intrarosa 2017

- ▶ Both are approved by the FDA to treat post menopausal women with vaginal pain during penetration.
- ▶ They both have hormonal effects and are not recommended for women with breast cancer



Female Low libdo drug- Addyi (Fibanserin)

- ▶ Only prescribed by certain medial professionals/pharmacies that have gone through extensive online certification to be able to prescribe.
- ▶ Addyi, known generically as flibanserin, is the first drug that acts on brain chemicals that affect mood and appetite.
- ▶ Company trials showed women taking the drug generally reported one extra "sexually satisfying event" per month, and scored higher on questionnaires measuring desire.
- ▶ Can not take Alcohol on it due to decrease in blood pressure

Vyleesi - EpiPen - like drug for Low libido, FDA approved June 2019

- ▶ Bremelanotide is used to balance out brain chemicals for women. Increasing excitement and lowering inhibition in premenopausal women
- ▶ Auto-injector like EpiPen self injected into abdomen or thigh at least 45 minutes before sexual activity
- ▶ Company funded study stated 60 percent of 1200 participants diagnosed with HSDD say they “benefited” from the drug



Sexual Arousal Devices(Sex Toys)

- ▶ Many different brands, shapes, colors, textures
- ▶ Have many uses for an individual or a couple.



Vacuum Constriction devices

- Placed around the penis and pumps out air to produce vacuum around the outside of the penis.
- Blood comes into the Spongy areas of the penis
- Stretchy band placed onto the base of the penis

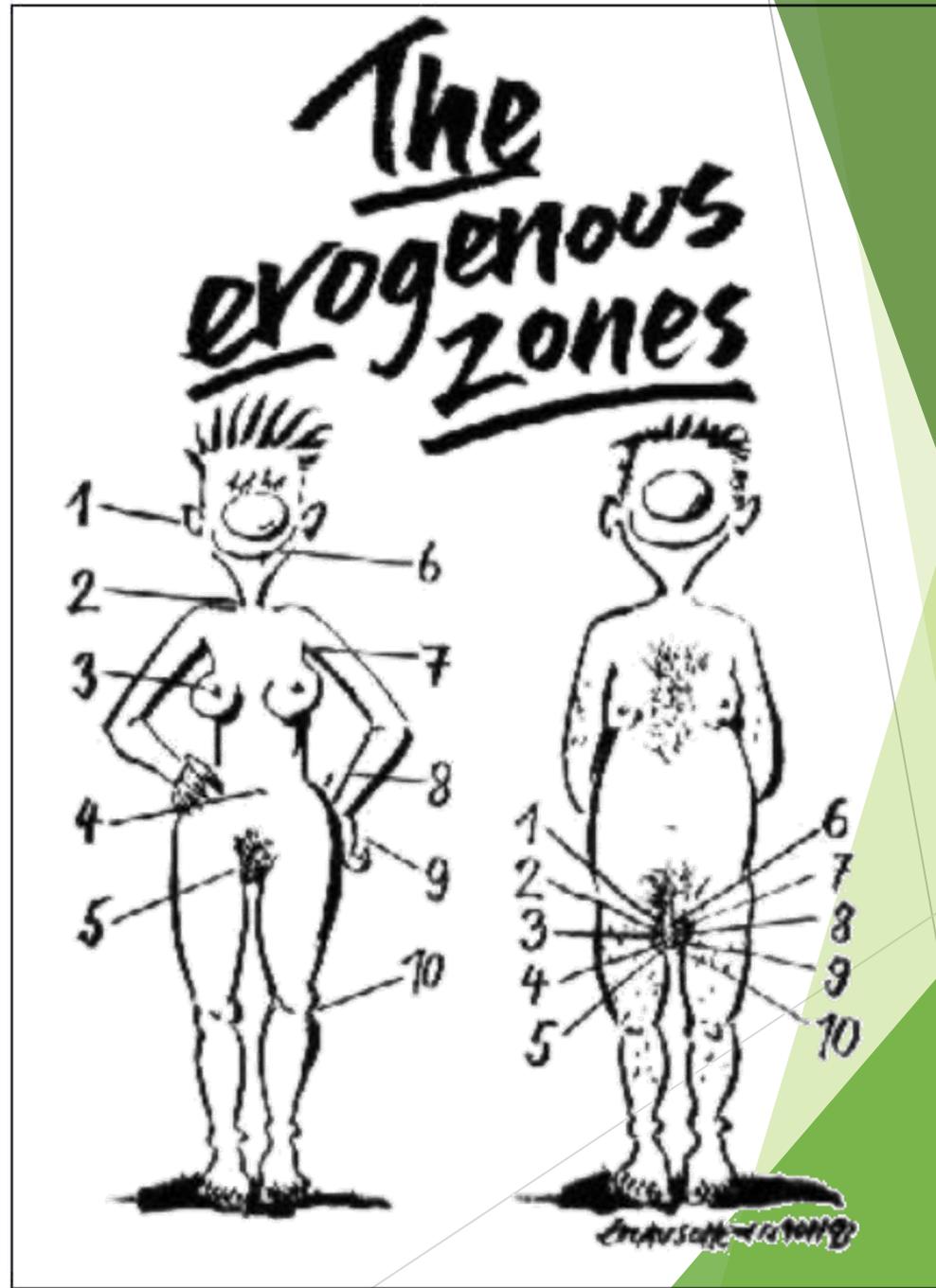


Sensate Focus

Progressive, four stage exercise to gradually help couples explore and reprioritize intimacy

Includes:

- Sensual touching
- Communicating likes/dislikes
- Discovering new sexual desire
- Decreasing performance anxiety
- Overcome body image problems



Ways Sex Therapist help Patients

- ▶ Go over different kinds of sexual touches
- ▶ Restructure sexual expectations
- ▶ Discuss how to dialogue with their partners or how to discuss with new dating partners
- ▶ VENIS

Types of Touch

1. Affectionate Touch

- ▶ Holding hands, kissing, hugging

2. Sensual Touch(clothed or not)

- ▶ Cuddling, massage, showering together

3. Playful Touch

- ▶ In bed, dancing, on the couch

4. Erotic Non-Intercourse Touch

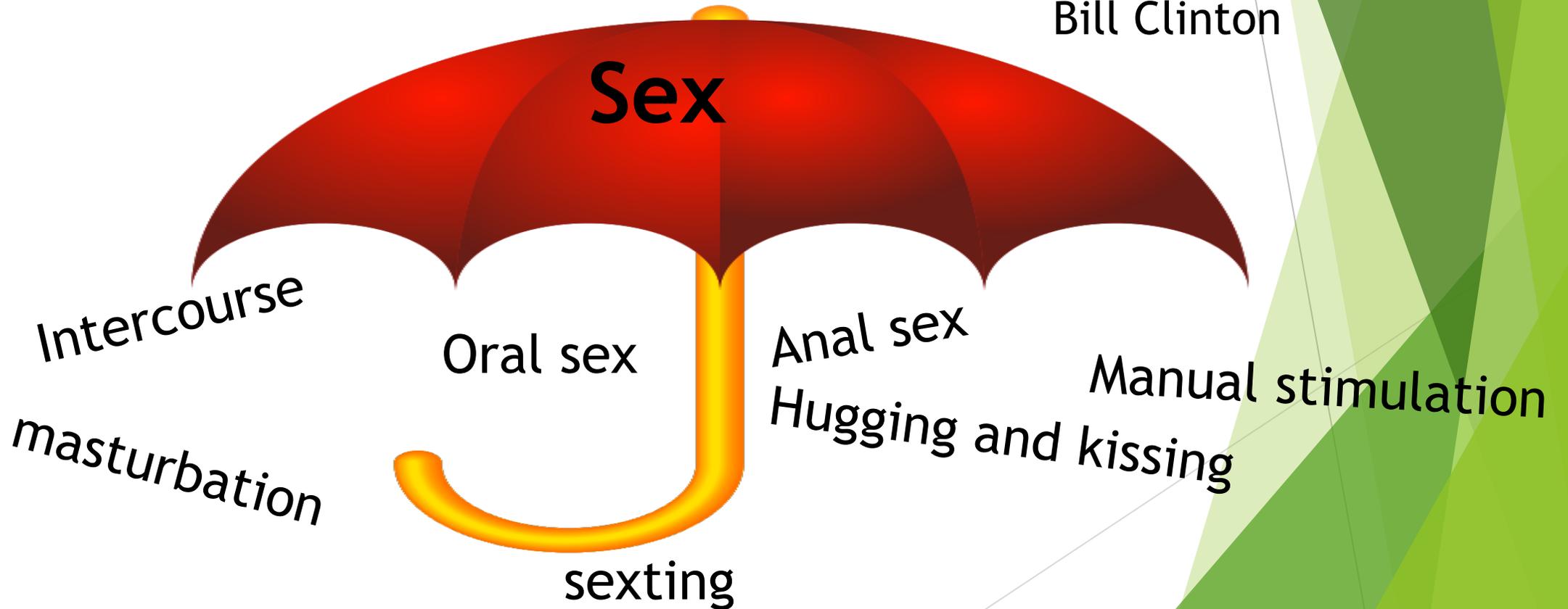
- ▶ Manual, oral, or rubbing

5. Erotic Intercourse Touch

- ▶ Penetration

Sex equals intercourse- Need to Redefine

“I did not have sexual relations with that woman” - President Bill Clinton



Partners

- ▶ Remember they are also in a stage of adjustment
- ▶ Some become overprotective
- ▶ Others need more time to process what is happening
- ▶ 1/3 of patients reported in a study that their partners were “Overprotective and afraid of hurting them”



Single and Sex after Cancer



VENIS

- ▶ Due to painful intercourse or just being too tired for full intercourse this is a way to still connect sexually and intimately
- ▶ Very Erotic Non-Insertive Sex
 - Bathe Together
 - Massage Each Other
 - Eat foods off each other
 - Share your Fantasies
 - Kiss
 - Cuddle
 - Masturbate

Surprising Health Benefits of Sex

- Relieves Stress
- Boosts Immunity
- Lowers Blood Pressure
- Provides Exercise
- Burns Calories
- Improves Cardiovascular Health
- Boost Self Esteem
- Improves Intimacy
- Reduces Pain
- Strengthen Pelvic Floor
- Helps you sleep better



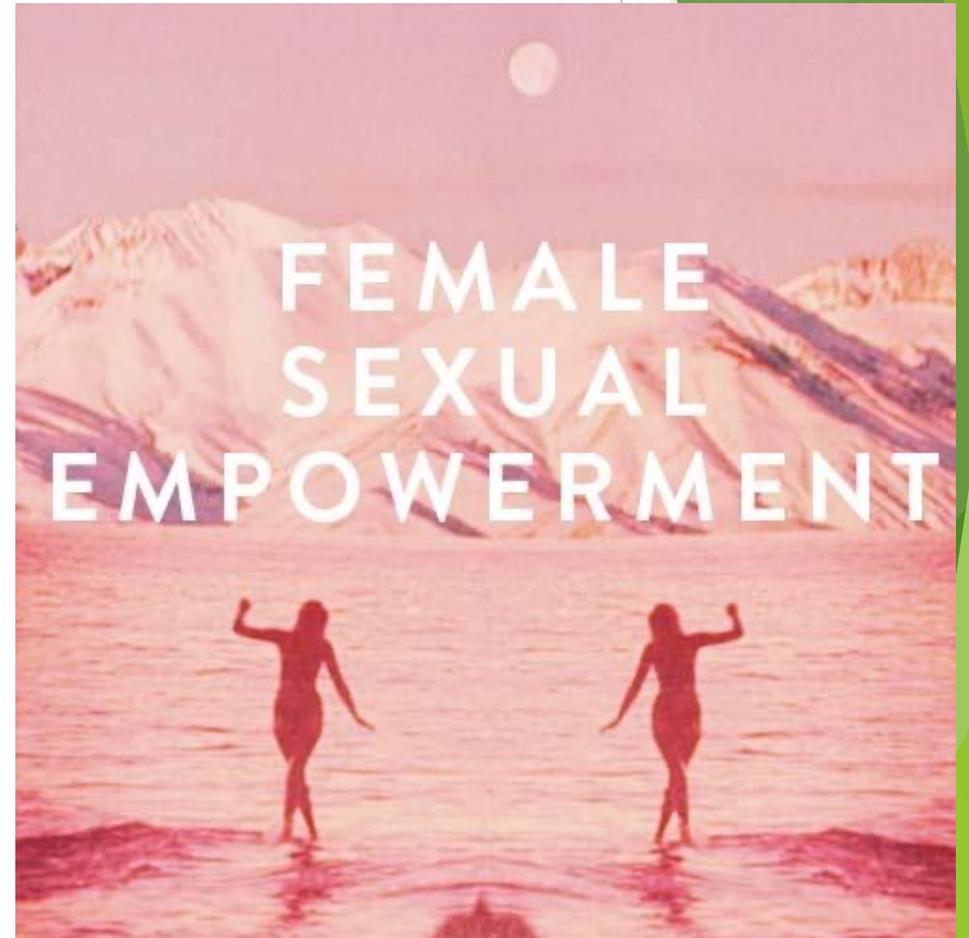
So how come we are
not talking about sex
during treatment?

Why Sex is not being addressed at oncology appointments

- ▶ Embarrassed about topic
- ▶ No time in appointment
- ▶ Do not want to offend patient
- ▶ Patient does not feel important enough to ask questions
- ▶ Patient's feel symptoms will go away on their own
- ▶ Many providers feel another provider will address the issue (social experiment- someone else will (Call 911))
- ▶ Doctor not familiar with the topic
 - ▶ 42.6% of medical schools in the US and Canada train on sexual Dysfunction

How to address some these issues

- ▶ Sex is **healthy** and **Normal** part of life
- ▶ Everyone needs to give themselves permission to address sexual concerns
- ▶ Choose **Quality of life** after cancer



How patients can address some of these issues

- ▶ Write out concerns ahead of time (call, fax, email, or bring in)
- ▶ Can Practice the following questions with a friend or partner
- ▶ Use the format FACT, FEELING, BELIEF and QUESTION formula
 - ▶ “I noticed that I have increased discomfort with intercourse (fact), and I’m upset about it (feeling). I believe it’s because of the treatments I was on (belief). Are there any tests that can be done or professionals I can talk to about how to improve this? (Action)



By Sage Bolte, PhD, LCSW, OSW-C, CST

Collaboration is key

“Alone we can do so little; together we can do so much.” - Helen Keller

- ▶ One of the most important outcomes that we see in our patients is when their whole team is working together
- ▶ Need to address the major parts of the patient: Medical, Physiological, and Psychological
- ▶ This is not always easy due to the complex nature of sexual issues as well as the treatment team is usually across organizations, private practice and many different disciplines



LONE QUIXOTE

“My mission in life is not merely to survive, but to thrive; and to do so with some passion, some compassion, some humor, and some style.”

– Maya Angelou

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