Intimacy Unforgotten:
Navigating Dementia and
Sexual Well-being

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I would like to acknowledge my lens when discussing intimacy and sexuality.

I believe in healthy sexuality for all - no matter your sexual orientation or whether you are married, partnered, divorced, single, or widowed.

This presentation will use male/female and heterosexual identifiers but can absolutely be applied to all sexual orientations and all partnered or non partnered individuals.

My request for you throughout this presentation is to open your mind, remove the lenses we have consciously and unconsciously made for ourselves, let go of the traditional female-male sex roles, and embrace your vulnerabilities, desires, and take on the challenge and journey of Intimacy Unforgotten.



What are normal body changes?

Female:

Sexual response is different, not worse.

Menopause: Estrogen production slows then stops, Testosterone levels decrease

The vagina can shorten and narrow

Decreased blood flow and clitoral engorgement

The vaginal walls can become thinner and do not stretch very well.

During arousal, slower lubrication and swelling

During orgasm, strength of vaginal contractions decrease due to decreased strength of the pelvic floor muscles

What are normal body changes?

Male:

Sexual response is different, not worse.

Testosterone levels decline

An erection is not as firm or as large as it once was (\blood flow and smooth muscle relax)

Increased tactile stimulation is needed for sexual arousal

Takes longer to get an erection

Need for direct stimulation of the penis to maintain an erection

May take longer to ejaculate, ejaculation less forceful, decreased ejaculate volume

Erections go down faster after ejaculation

What can impact sexual function and sexual response?

Physical conditions

- Chronic pain
- Fatigue
- Arthritis or mobility issues
- Diabetes
- Heart disease
- Memory loss/dementia
- Depression/anxiety
- Skin problems (LS, psoriasis)
- Sleep disorders

- COPD
- Obesity
- Stroke
- PTSD
- Substance use disorders
- Incontinence
- Pelvic Organ Prolapse
- Prostate disorders
- Cancer



Medications

Antidepressants

Antianxiety meds

Antihistamines

Cardiovascular meds*

Antipsychotics

Chemotherapeutic agents

Corticosteroids

Opioids

Mood stabilizers



Surgeries

- Hysterectomy
- Prostatectomy



Cancer

- Emotional impacts
- Physical impacts
- Medications
- Surgical interventions



Lack of communication about sexuality-related impacts*

Sexual health... and what that actually means



What is Intimacy?

Warm

Loving

Affectionate

Sensual

Pleasure-oriented

Predictable

feelings which reinforce attachment and safety



Not a performance test
There is no 'normal'
Individualized



What is Sexuality?

the way we <u>experience</u> and <u>express</u> ourselves

Feelings

Desires

Actions

Identity

Attraction

Values & beliefs

Taboo & Stigma

US Culture has traditionally denied sexuality and passion for older people.... but it is getting better

Sex is for the young

Older people have shut down on sexuality 'living in the past'

Intense feelings are inappropriate for older people

An expiration date exists

Are older people 'allowed' to be naked?

Religion

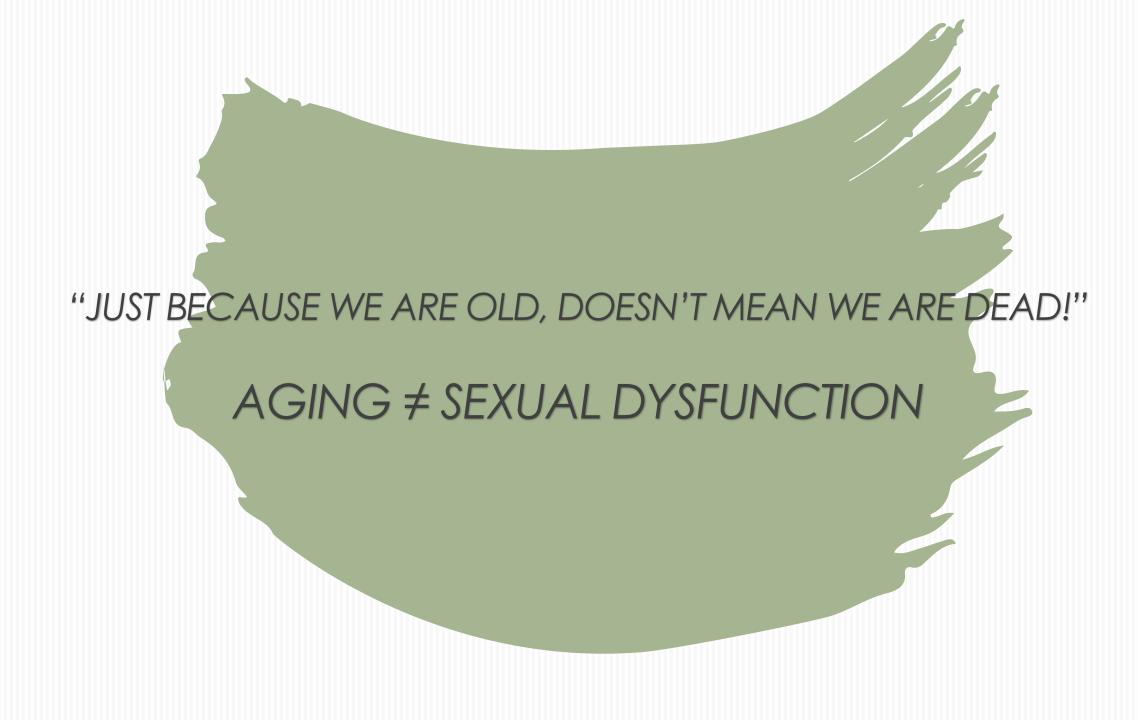
Social media

Movies, TV shows



Stigma in Long Term Care facilities

- Restrictive policies
- Limited to no privacy
- Little or no activities that focus on romance
- Few facilities have a policy of sexual rights among clients



Sexual Dysfunction and Aging

Genitourinary Syndrome of Menopause

AKA vaginal dryness

Due to the loss of estradiol

Affects 27-84% of postmenopausal women

Symptoms: vaginal dryness, painful sex, burning, tearing, recurrent UTIs, shortening of the vagina, narrowing of the vaginal opening

PROGRESSIVE without treatment

Treatment: topical vaginal estradiol (safe for nearly all), vaginal moisturizers/lubricants

Erectile Dysfunction

Multiple causes: brain, hormones, emotions, nerves, muscles, and blood vessels

Affects approx. 20% men

ED is often the first indication of a potential heart issue.

80% of men presenting with erection problems are overweight or obese

Treatment: PDE5 inhibitors, testosterone replacement, counseling

Dementia & its impact on Sexual Health

Know the Road Ahead



Consent

Consent

- Capacity and competence
 - central to all discussion of sexuality

- It is assumed diagnosis = inability to consent
- Persons with dementia may retain capacity until moderate stages of the dementia journey.
 - Capacity on some occasions and incapacity on other occasions
 - Will change over time

Consent

When assessing capacity, does the person with dementia have the following?

- Information
- Comprehension
- Reasoning
- Communication

- Do they understand the nature of the sexual activity?
- Express interest or desire in the act?
- Indicate a clear, affirmative, and ongoing agreement to participate?

Consent for persons NOT affected by dementia is just as important!

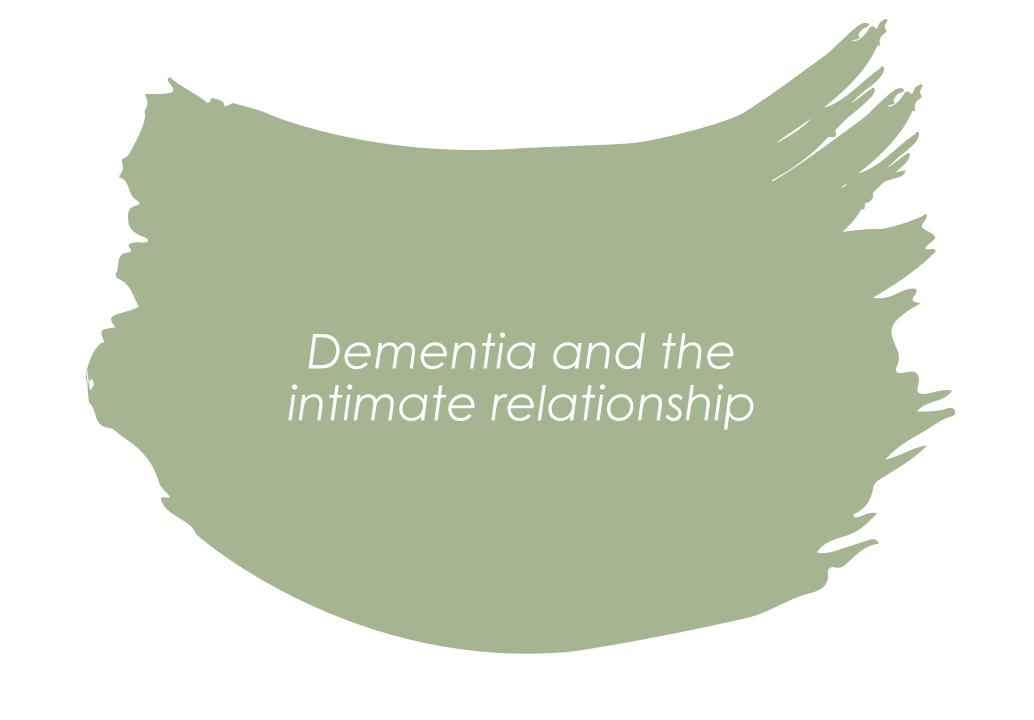
Dementia and Formation of a New Relationship

- Aware about the relationship
 - Is the loved one aware of the person who is initiating sexual contact?
 - Does the loved one believe the person initiating sexual contact is a spouse, or are they cognizant of the other person's identity and intent?
 - Can the loved one state the level of sexual intimacy that they would be comfortable with?
- Ability to avoid exploitation
 - Is the behavior consistent with the loved ones formerly held beliefs/values?
 - Does the loved one have the capacity to communicate refusal of any uninvited sexual contact?

- Awareness of potential risk
 - Does the loved one realize that this relationship may be time-limited (that the placement in the care unit may be temporary)?
 - Is the loved one able to describe how they will react if or when the relationship ends?

Long term care facilities

- Research is scarce
- Admission leads to a general decline of quality of life in both
- The attitude and perspective of formal caregivers makes a difference
- Barriers:
 - Sleeping in two single beds at the residential care facility (RCF)
 - Absence of privacy within the RCF
 - Staff disrespect
 - 'does not feel like home'
 - Can the spouse/partner sleep over?
 - Uncomfortable with showing PDA with unknown people/visitors around
 - Stigma surrounding aging/dementia and sexuality; lack of education
 - Felt like once in the RCF 'nothing could be done' regarding sexual dysfunction
 - · Communication with caregivers is necessary, but difficult
 - Consent isn't always objective



Common behavioral changes

Decline in sexual interest

Increase in sexual interest

Sexual disinhibition and inappropriate sexual behaviors

1.8%-25.9% sexual disinhibition

Emotional withdrawal and changing of relationship dynamics

Younger-onset dementia

Onset prior to age 65

Average time from symptoms to diagnosis – 4.4 years

1.3 years in Late-Onset Dementia

- Decline in the perceived quality of the relationship
- Shifting roles and responsibilities
- Loneliness and social isolation
- Decline in intimacy as care needs increase
- Decline in sexual activity

For the person living with Dementia

Early stage

- Increase in quality of intimacy despite a decline is sexual intimacy
- Desire and value of intimacy and connection remain but struggle with communication or forget shared experiences
- Mood changes
- Impending sense of mortality, grief, anger
- Loss of selfhood
- Loss of employment, financial constraints
- Change in social activities
 - Feelings of 'socially demoted'
 - Loss of interest in socialization
 - Loneliness and social isolation

For the person living with Dementia

Middle to Late Stages

- Confusion may lead to misidentification
- Frustration, anger
- Mood changes
- Requests for forms of sexual behavior or intimacy that are outside the norm
- Disease progression and resulting memory loss creates conflict when one forgets prior differences and believes they have a good relationship
- Emotions not previously expressed (or felt) come to the surface
- Withdrawal from intimacy all together

For the partner

- Relationship role changes
- Missing their loved one
- 'Losing' the partner they used to know
- Grief
- Difficulty with lack of sexual activity
- Fear of taking advantage of their partner/spouse

For the partner

- Conflicting feelings of when to go and admit to a residential care facility
- Loss of sense of self
- Guilt and self-criticism for own needs
- Managing inappropriate behavior
- Companionship and affection were most important
- Increased compassion, feeling closer

Overall affects to the relationship

- Progression of the disease affects the relationship by creating asymmetry, impacting
 - Communication
 - Intimacy
 - Sexuality
 - Sense of closeness
 - Quality of intimacy and sexuality
- Feeling of rejection, guilt, or longing for lost intimacy can impact emotional wellbeing for both.
- Good can be found amongst the bad!
- It is OK to feel a vast number of feelings throughout the Dementia journey.



How to keep the good times going...

Stay in good health
Keep social relationships! **
Affectionate communication
Humor
Redefine intimacy
Adjust expectations
Modify physical affection
Create routine
Use memory triggers
Redirect attention



and going...

Direct communication about desires and acts

Openness, novelty, and variety

Plan play and exploration

New positions

Different foreplay

Set the mood

Consent

Attend routine Men/Women's Health visits!

including exams

Use lubricants

Add a vibrator or toy

Get help (me!)

Don't yuck someone's yum





The role of the support person and caregivers

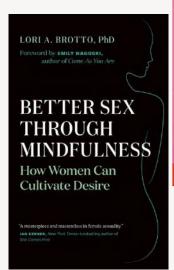
Balancing support with personal boundaries

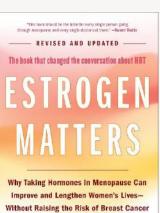
Addressing concerns of family members and healthcare providers

Strategies for fostering emotional connection and non-sexual intimacy

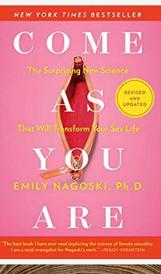
Encouraging open communication and seeking professional guidance

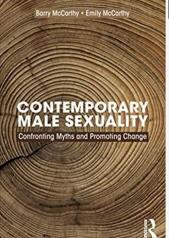
Resources

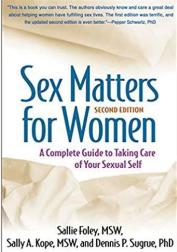


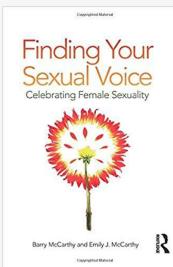


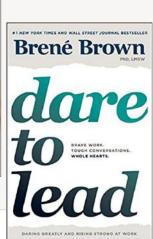
Avrum Bluming, MD, and Carol Tavris, PhD

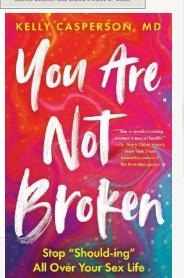


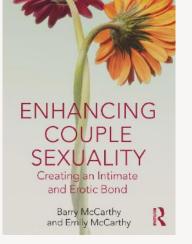


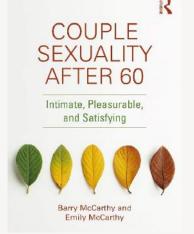


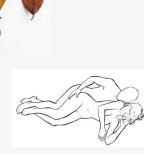




























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Thank you!

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