Intimacy Unforgotten:
Navigating Dementia and
Sexual Well-being

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I have no disclosures

Learning Objectives

- 1. Participants will be able to identify physiologic changes that may affect sexual function and health.
- 2. Participants will be able to identify how dementia can affect sexual health within the couple unit.
- 3. Participants will be able to identify two activities for sexual connection.









Who am I

Women's Health NP with SIU OB/Gyn for 10 years

University of Michigan - Sexuality Counseling and Education Tracts March 2018 – March 2019

AASECT Certified Sexuality Counselor – September 2020 ISSWSH Fellow – March 2022

Offer a Sexual Pain & Vulvar Clinic and Sexuality Counseling Clinic at the Pelvic Wellness Center



What are normal body changes?

Sexual response is different, not worse.

Female:

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 (\perp blood flow and smooth muscle relax)

Increased tactile stimulation is needed for sexual arousal

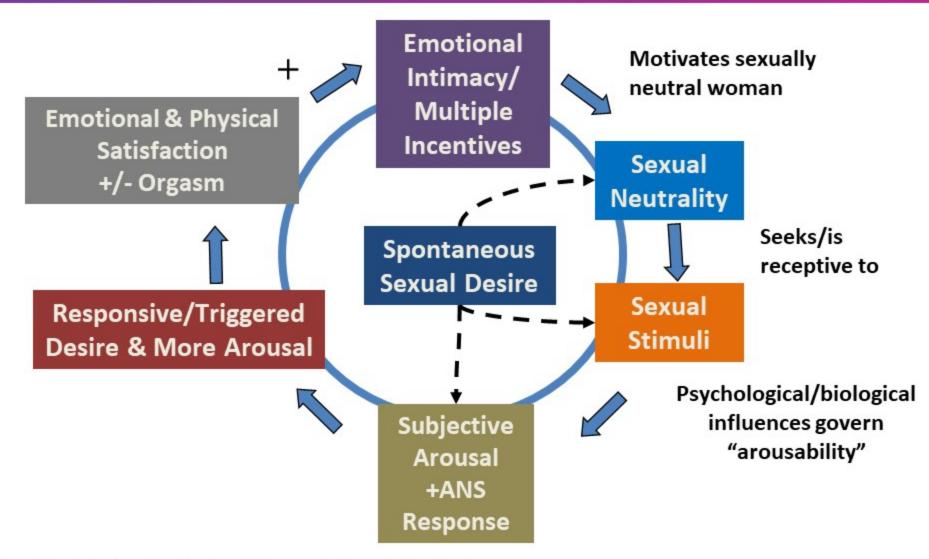
Takes longer to get an erection

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

Circular Sexual Response Cycle





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What is Intimacy?

Warm

Loving

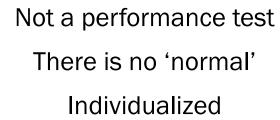
Affectionate

Sensual

Pleasure-oriented

Predictable

feelings which reinforce attachment and safety





What is Sexuality?

the way we experience and express ourselves

Feelings

Desires

Actions

Identity

Attraction

Values & beliefs

NATIONAL POLL ON HEALTHY AGING 2018

SEX AND RELATIONSHIPS AMONG ADULTS AGE 65-80

76% of older adults agreed that sex is an important part of a romantic relationship at any age

Men were more likely to agree (84%) than women (69%).

"Sex is important to my overall quality of life" 54% agreed with this statement

65% older adults described being interested in sex 40% older adults are currently sexually active

73% older adults indicate they are satisfied with their sex life

Who is sexually active?





How does your patient {<u>and their partner</u>} define SEX??

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



Lack of communication about sexuality-related impacts*

Cancer

- Emotional impacts
- Physical impacts
- Medications
- Surgical interventions



Lack of communication about sexuality-related impacts*

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

Barriers to Addressing Sexual Health in Dementia Care

- Personal distress and stigma
- Ethical and legal concerns
- Family and caregiver concerns
- Long-term care policies

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 they are '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

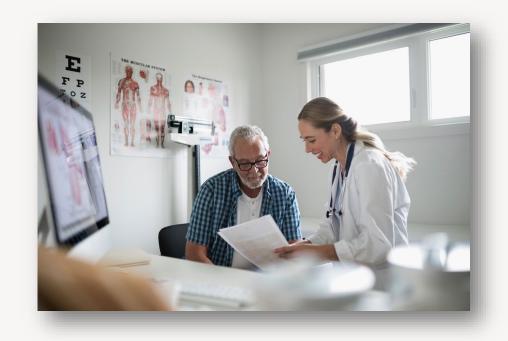
- Restrictive policies
- Little or no activities that focus on romance
- Few facilities have a policy of sexual rights among clients

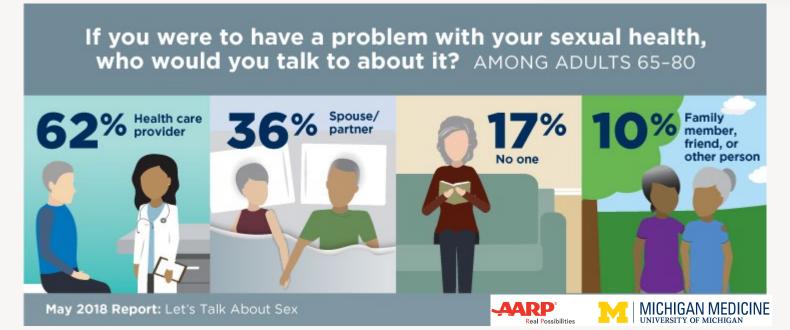
Discussions with patients

1 in 6 (17%) patients reported speaking with their healthcare provider about sexual health in the past 2 years

60% initiated the conversation

88% felt comfortable discussing their sexual health





Discussions with patients.... Why isn't it done?

Factors that can affect both the patient and Provider while discussing ones' sexual health

Why are Providers reluctant to discuss sex?

- Lack of training/comfort in medical school
- Lack of knowledge of structured tools to assess sexual history
- Relates their own sexuality with patients
- Lack of time
- Fear of offending the patient
- Judgmental and making assumptions that the patient does not engage in sexual activity

Why are patients reluctant to discuss sex?

- Believes their sexual concerns is due to illness/age
- Worried that they will be judged
- Feels shameful to discuss sex
- Disturbed body image
- Misplaced or misinformed set of sex-related beliefs and/or thoughts
- No knowledge that treatment is possible

Barriers to Addressing Sexual Health in Dementia Care

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Barriers to Addressing Sexual Health in Dementia Care

Ethical and legal concerns

- There is no gold standard for healthcare decision-making capacity assessment
 - Argument for allowing a gradual model or a black/white model
 - Recommendation for a need for clear legal frameworks and guidelines in order to improve healthcare decision-making capacity assessments
- Clinical judgement remains the closest to a gold standard of capacity assessment.
- Options: ACC-T, The Vignette Method by Schman and The Vignette Method by Vellinga, CCTI, Mac-CAT-T, HCAI, MMSE, MoCA, neuropsychological testing

Catherine Pennington, Katie Davey, Ruud ter Meulen, Elizabeth Coulthard, Patrick Gavin Kehoe, Tools for testing decision-making capacity in dementia, Age and Ageing, Volume 47, Issue 6, November 2018, Pages 778–784, https://doi.org/10.1093/ageing/afy096

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?

Managing inappropriate sexual behavior in clinical and long-term care settings

- Identify triggers: pain, loneliness, medication, or cognitive changes may contribute to sexual disinhibition
- Intervention strategies:
 - Redirecting attention to alternative activities.
 - Setting clear respectful boundaries.
 - Using adaptive clothing for patient who undressed inappropriately.
 - Medication review to assess con shooting factors
- Educating staff and caregivers

Barriers to Addressing Sexual Health in Dementia Care

- Personal distress and stigma
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Supporting and addressing concerns of the support person and caregivers

- Inappropriate behaviors
 - consider the etiology:
 - Worsening disease
 - Memory loss forget societal norms
 - Unmet emotional or physical needs
 - Medication side effect
- Misidentification
 - Damage to the temporal lobes affect facial recognition and relationship recall
- Sexual aggression
 - Forceful or aggressive when seeking intimacy
 - Expressing anger with rejection

- > Redirect attention
- ➤ Maintain clear boundaries
- ➤ Modify environment
- > Evaluate medications
- Engage in non-sexual physical contact (hand massage or comforting touch may fulfill the need for closeness
- ➤ Educate family
- ➤ Memory triggers
- ➤ Assess partner /caregiver safety

Supporting the support person and caregivers

Education and permission giving:

- Attitude and perspective of intimacy
- Balancing support with personal boundaries
- Strategies for fostering emotional connection and non-sexual intimacy

Encouraging open communication and seeking professional guidance

Barriers to Addressing Sexual Health in Dementia Care

- Personal distress and stigma
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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 for patients:
 - 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

Sexual and gender minorities with Dementia & longterm services and supports

Adults aged 50+ in the USA whose gender identity and/or sexual orientation is something other than cisgender and/or heterosexual

Projected 5 million people by 2060 who identify as SGM

Older SGM adults rely on long-term services and supports more due to lack of familial support

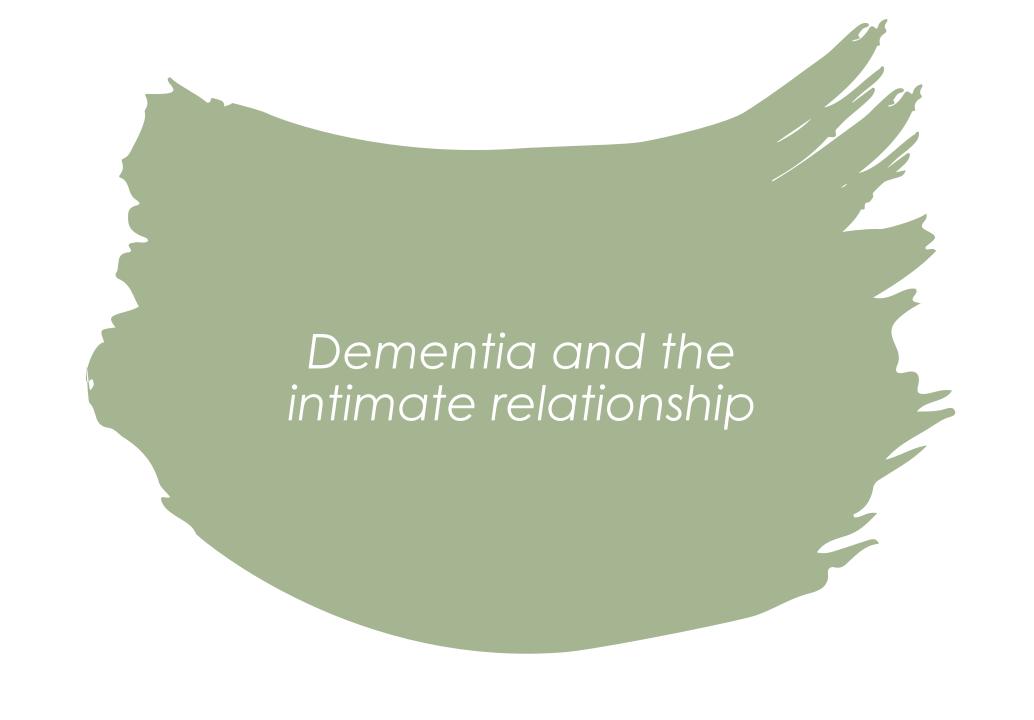
Older SGM adults experience a greater number of health disparities

Estimated 240,000-400,00 SGM adults have cognitive impairments

They are experiencing discrimination in nursing homes and assisted-living facilities

Sexual and gender minorities with Dementia & longterm services and supports

- The lived experience of discrimination can become compounded with the addition of a diagnosis of Dementia.
- Fear of loss of identity
- Three themes within the literature
 - 1. Resident Experiences of Discrimination
 - 2. Need for Staff Training with Attention to Residents with Dementia
 - 3. The Role of Policy



Know the Road Ahead



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 let 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

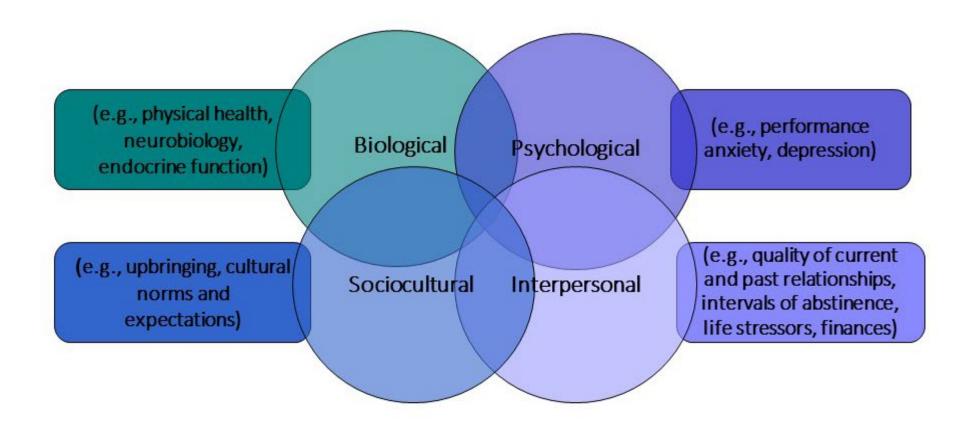
- Progression of the disease affects the relationship by creating asymmetry, impacting
 - Communication
 - Intimacy
 - Sexuality
 - Sense of closeness
 - Quality of intimacy and sexuality
- Feeling of rejection, guilt, or longing for lost intimacy can impact emotional well-being for both.
- Good can be found amongst the bad!
 - Maintain empathy through the journey not silver lining
- Give the permission and normalize the vast number of feelings throughout the Dementia journey.



"JUST BECAUSE WE ARE OLD, DOESN'T MEAN WE ARE DEAD!"

AGING ≠ SEXUAL DYSFUNCTION

Biopsychosocial Approach to Care Model





Multifactorial & Multidisciplinary

Biological

Psychological

Sociocultural

Pathophysiology

Critical life events

Relationships

Interdependent

Intersectionality

Primary Care

Urogynecology

Gynecology/Vulvar Specialist

Gastroenterology

Integrative Medicine

Urology

Pain Specialists

Mental health specialists

Sex Therapy/Counseling

Pelvic Floor Physical Therapy

Neurology

Oncology



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

Use lubricants

Add a vibrator or toy

Get help (me!)

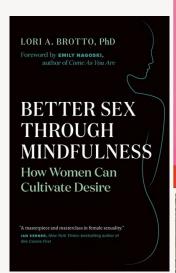
Don't yuck someone's yum

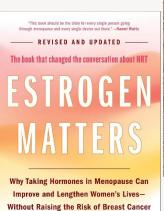
See it as a challenge – 'beating the odds'



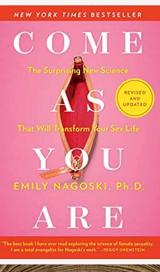


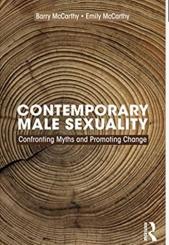
Resources

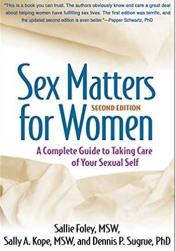


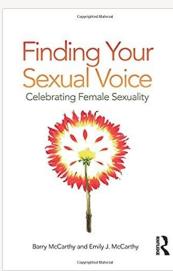


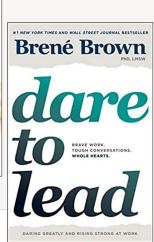
Avrum Bluming, MD, and Carol Tavris, PhD

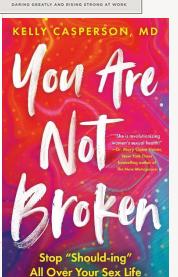


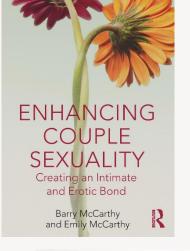


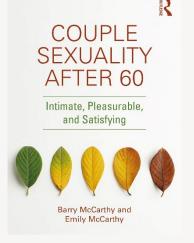






















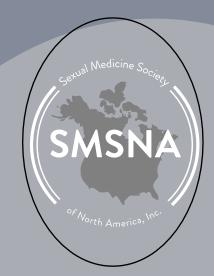








Helpful Organizations



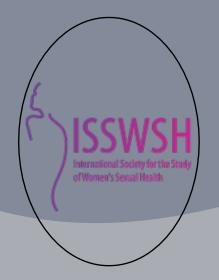
SMSNA

Sexual Medicine Society of North America



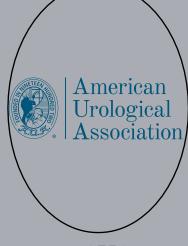
AASECT

American Association of Sexuality Educators, Counselors, and Therapists



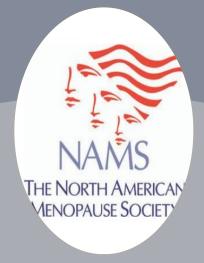
ISSW SH

International Society
for the Study of
Women's Sexual
Health



AUA

American Urologic Association



NAMS

The North American Menopause Society

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