



JAMES L WEST
CENTER *for* DEMENTIA CARE

Sexuality and Dementia

*James L. West Center for Dementia Care
Dementia & Caregiver Education*

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Hollie Glover, MA, LPC, NCC

- ▶ Hollie Glover, is a Licensed Professional Counselor, who currently works for the James L. West Center for Dementia Care in Fort Worth. She is the Director of Education and Family Support Services. She facilitates the center's family support groups and is involved in many of the numerous education services provided by the center.
- ▶ Hollie is a Dementia Care Specialist and Certified Grief Counseling Specialist. She has over twenty-eight years of experience in education and working with people of all ages. She has degrees from Southwestern Oklahoma State University, Sam Houston State University, and Dallas Baptist University. She also attended Southwestern Theological Seminary to obtain hours in theology.
- ▶ Hollie has been recognized as a national and statewide speaker on topics such as Dementia, Hospice, and Professional and Caregiver Stress. One of the highlights of her career includes getting to meet and speak before First Lady Rosalynn Carter and Senator Elizabeth Dole. She has also written a therapy to be used with patients at the end of life, that focuses on the individual needs of the person and their family.
- ▶ Her passion is educating the public and helping families who have a loved one diagnosed with dementia.
- ▶ Hollie is married and has one daughter who is following in her footsteps. Joanna graduated from the University of Texas at Arlington in August of 2020 with her Master's degree in Social Work, specializing in hospice care.



Educational Objectives

Upon completion of this program the participant will be able to:

- ▶ Describe inappropriate sexual behaviors.
- ▶ Discuss misconceptions about sexuality that increase caregiver stress.
- ▶ List ways to respond to sexual behaviors.
- ▶ Identify Texas resident rights for sexuality and intimacy.
- ▶ List ways to remain intimate.



Coping with Changes in Your Intimate Relationship

- ▶ The Family Caregiver Alliance found that the subject of intimacy rarely comes up in conversations professionals who deal with patients and caregivers of those with dementia. The idea of sexuality in the elderly or sick seems to be a taboo topic.
- ▶ We are all sexual beings, and it is normal to have needs and feelings. It is OKAY. The diagnosis of dementia does not imply the cessation of sexuality.
- ▶ Your loved one may no longer be interested in sexual intimacy or be able to perform. What you do together sexually will change as the disease progresses.
- ▶ It's common for both people to feel guilt, anger, rejection and/or shame about changing sexual feelings or inhibition.
- ▶ Try not to take the changes in sexual desire personally. It's normal to feel lonely and rejected. Talk to someone you trust about these feelings.



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- ▶ Being sexual in a relationship is part of how we show connectedness and closeness. It can be very comforting and a time to be reassured. It is usually a place where couples are comfortable, even if nothing else is going right. It is something we've done for a long time that is pleasurable and makes us feel good.
- ▶ Dementia forever changes the ways in which spouses relate to each other – it changes the behaviors and expectations in relationships that often have been nurtured for many years.
- ▶ Caring for a loved one with dementia can be very stressful. You must accommodate the disease since they cannot.
- ▶ The loss of the sexual relationship is a major part of the grief caregivers feel.
- ▶ Focus on all the pleasurable aspects of your relationship.

Coping with Changes

Sexuality and Dementia

- ▶ With increasing losses, the self-esteem of someone with dementia suffers badly. They may be afraid, worried, depressed, angry, and/or suffering from low self-esteem.
- ▶ You, the caregiver, may pull away emotionally and physically. You may be upset about the demands of caregiving. You may also be frustrated by their constant forgetfulness, repeated questions, and other bothersome behaviors.
- ▶ In the early stages of the disease, intimacy may be affected by the changes in the level of emotional connection and sexual desire. These changes are normal, but difficult to deal with.
- ▶ Many caregivers relate that after taking on the role of caregiver the role of intimate partner tends to fade away.
- ▶ Your role changes from partner to caregiver. This will change your sexual relationship with your partner. If you have fewer sexual feelings toward your partner, **do not feel guilty. It is okay to have conflicting feelings.**



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Facts

- ▶ Sexuality is a continuing human need common to all people.
- ▶ As we age, we have little change in our interest in sex and intimacy
- ▶ A person with dementia may not be able to express their sexual needs or may express them in socially inappropriate ways
- ▶ It is okay for you and your loved one to be sexually close in any way **that you are both comfortable.**



Facts: National Social Life, Health and Aging Project

- ▶ 46% of men and 18% of women in early stages of dementia and mild cognitive impairment report being sexually active
- ▶ 77% reported sexual dysfunction: (55% erectile dysfunction in men, 60% decreased desire in women)
- ▶ 10% reported feeling sexually threatened
- ▶ 17% reported feeling obligated to engage in sexual activity



Consent

- ▶ Physical arousal alone is not consent.
- ▶ Sometimes the person with dementia may be unaware of your needs, and it is you who doesn't consent.
- ▶ Nobody should be forced into any sexual or intimate activity that they are not comfortable with.
- ▶ As their partner, you should feel confident that you can recognize non-verbal consent before you start any sexual activity.
- ▶ You should NEVER initiate sexual activity without clear consent. You must stop at any sign of reluctance.
- ▶ alzheimers.org



Capacity

- ▶ Specific to time, person, and place
 - ▶ The absence of coercion
 - ▶ The absence of delusion
 - ▶ Understanding of the sexual activity
 - ▶ Expressing interests or desire in the act
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- ▶ When in doubt: guidelines recommend that the partner be guided by the nature of the relationship and the sexual preferences of the person prior to the onset of dementia. New paraphilias may be indicative of impaired capacity.
 - ▶ If the person is inactive all sexual activity should stop.



Misconceptions that Increase Caregiver Stress

Elderly have little or no interest in sex

Women are unable to have orgasms after menopause

The idea of sexuality in the aged is shameful and perverse

Frail old people will get hurt having sex

Caregivers needs or distress are signs of selfishness or incompetence

All caregiver energy and effort must go to patient

More Misconceptions that Increase Caregiver Stress

A caregiver should be able to assume all required tasks and responsibilities

It's not okay to have sex with someone with dementia

The person with dementia is a stranger

The person with dementia seems to forget that the partner is there OR how to make love

The spirit is willing....

Health related factors such as: Diabetes, hypertension, depression, hormone imbalance, and prostate problems can affect sexual desire

Heart disease, osteoporosis, arthritis, incontinence and emphysema can affect ability and enjoyment

Side effect of medication

Fear of heart attack or stroke during intimacy

Sex may not be as gratifying or as frequent and it may be awkward.

Most Common Changes in Sexuality in Dementia

- ▶ A decrease in or loss of interest in sexual activity
- ▶ Awkwardly conducted or sequenced sexual activity
- ▶ Requests for forms of sexual behaviors or intimacy that are outside the usual repertoire of the relationship
- ▶ Participation in sexual activity in the absence of or decreased physiological arousal
- ▶ Lack of consideration for the responses and satisfaction of the partner
- ▶ Making FALSE sexual allegation



Inappropriate Sexual Behaviors

Touching,
hugging or
kissing strangers
85%

Undressing or
being naked in
public 50%

Using sexual
laden language
7%

Suggestive
behavior or
language 7%

Aggressive or
repeated sexual
overtures 40%

Exposing
oneself during
personal care
tasks 25%

Masturbating in
public 16%

Responding to Unacceptable Behaviors

- ▶ Do not scold, shame, or ridicule
- ▶ Observe what triggered behavior
- ▶ Ignore annoying behaviors
- ▶ Praise and encourage acceptable behaviors
- ▶ You may choose to sleep apart from your loved one
- ▶ Use delaying tactics and redirection (food, music, animals, children)
- ▶ Medications may have to be used temporarily.
- ▶ Stop unsupervised visits with children or vulnerable adults.



Responding to Unacceptable Behaviors

- ▶ Use touch in everyday routines
- ▶ Use distraction and redirection (food, music, animals, children)
- ▶ Validation therapy
- ▶ Do not overreact or express shock
- ▶ Avoid becoming angry or augmentative **DO NOT** try to reason or be rational
- ▶ Be sensitive and reassuring
- ▶ Redirect to a private area if the behavior isn't appropriate for a public setting



Pharmacological Management

- ▶ Antidepressants: Brings down level of cognitive arousal
- ▶ Antipsychotics: Reduces “acting out” behaviors
- ▶ Anticonvulsants: Reduces “acting out” behaviors
- ▶ “Memory Meds”: helps with some sexual behaviors
- ▶ Hormones: reduces testosterone levels



Management Tips

- ▶ Environmental modification: Watch for signs of under-stimulation and uncomfortable clothing, as well as temperature control of the room. Contact with the person whom the aggressiveness is being directed at should be limited. The person should leave the room, if it is the primary caregiver, until the behavior ceases.
- ▶ Behavioral management: Many times what is being sought is physical touch. Offer stuffed animals to hold and cuddle. Adaptive clothing may be needed for a time that buttons or zips up the back. (www.buckandbuck.com) Gently, but firmly redirect and distract or guide them away from the source of stimulation.



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Is it really sexual?

- ▶ Time of day-they may be thinking they are getting ready for bed
- ▶ Clothing may be too tight, twisted, itchy, or uncomfortable
- ▶ They may be hot
- ▶ They may need to go to the bathroom
- ▶ Fondling genitals
- ▶ Getting in bed with another resident
- ▶ Misinterpreting cues from others. This is very confusing, distressing and frustrating for them, especially if they thought it was their partner and it isn't.
- ▶ ADL time
- ▶ Expressing a need for affection

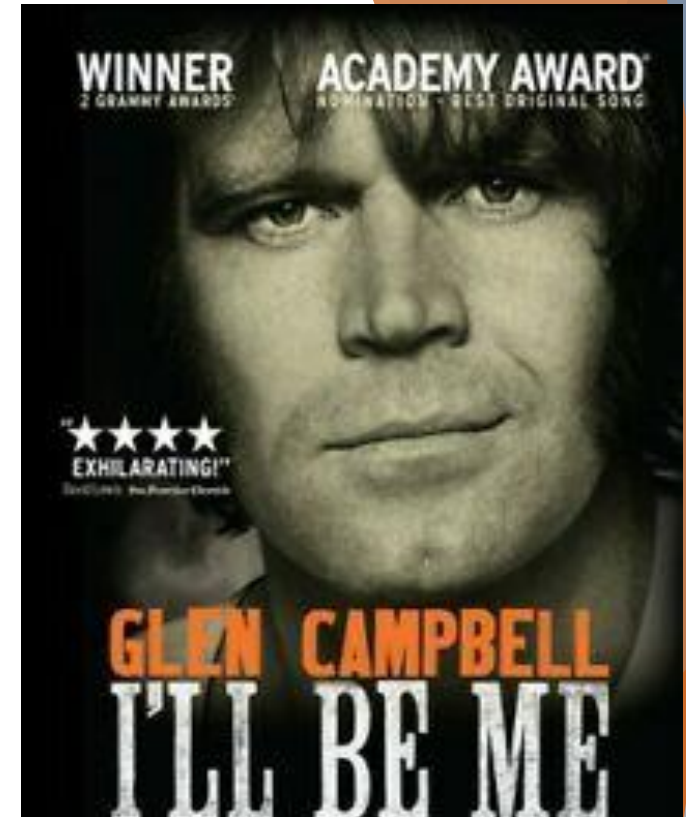


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Hypersexuality

- ▶ Hypersexuality-sometimes people with dementia are overly interested in sex. They may masturbate or try to seduce others. They are symptoms of the disease and many times do NOT mean they want to have sex.
- ▶ Try to give them more attention and reassurance. Try to use other types of affection to meet their emotional needs.
- ▶ Explore non-sexual touch.
- ▶ Share intimate moments that do not require touching, but invoke strong feelings of belonging together such as, reminiscing, sharing a meal, going on a date, watching a movie, etc.
- ▶ Sometimes medication must be used, temporarily, to control their behaviors.



Deserving of Respect

Person loses their awareness of needs, rights and wishes of others

Person no longer understands consequences of their actions on themselves or impact of actions on others

Loses social skills that may have made his company desirable

Unable to return in any meaningful way the same measure of affection and attention

Moss and Schweibel Study: 5 Components of intimacy

1. Commitment: the desire to remain together permanently
2. Affect intimacy: the emotional depth and closeness shared by a couple
3. Cognitive intimacy: the shared thinking, information, values, and goals within the relationship
4. Physical intimacy: the shared physical attractiveness, encounters, and sexuality within the relationship
5. Mutuality: the mutual interaction and exchange of energy for the maintenance of the relationship (give and take)



Ways to Remain Intimate

- ▶ Putting lotion on loved one
- ▶ Combing and brushing hair
- ▶ Dancing
- ▶ Range of motion exercises
- ▶ Cutting and polishing nails
- ▶ Helping feed loved one
- ▶ Bathing or showering together
- ▶ Massage or Reflexology
- ▶ Hug/Snuggle/Cuddle
- ▶ Hold hands
- ▶ Tell them that you love them
- ▶ Assure them that they are safe
- ▶ Kissing
- ▶ Touching
- ▶ Sitting side by side
- ▶ Intercourse



He/She no longer recognizes me as his spouse

- ▶ “Till death do us part”
- ▶ Address psychological well-being of healthy spouse. You may wish to talk to a professional who specializes in dementia care.
- ▶ Share with other spouses in same situation
- ▶ Try not to feel guilty if you no longer wish to have sex with your partner. Find new ways to connect
- ▶ Look for books and websites on the subject. (alzconnected.org)
- ▶ Attend support groups for spouses of those with dementia.
- ▶ Talk to your PCP, social worker, counselor, or clergy. You need someone who will listen that is safe and will hear you, even if they don't have any answers. This is grief.



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Dementia and Forming New Relationships after Placement: What Must be Considered

- ▶ They are usually seeking reassurance and comfort
- ▶ Are they aware of the person who is initiating the relationship?
- ▶ Do they believe it is a spouse or are they aware of the person's identity?
- ▶ Can they state what they would be comfortable doing with the other person?
- ▶ Are the behaviors consistent with former values?
- ▶ Do they have the ability to communicate refusal?



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Other issues:

- ▶ Social limbo - single spouse
- ▶ Caregivers often wonder if they are taking advantage of their spouse by initiating sex.
- ▶ Caregivers may feel guilty and selfish if they masturbate or pursue an intimate relationship outside of the marriage.
- ▶ Answer only to yourself and your spouse - seek companionship, happiness or relief from loneliness. Do what feels best for you.
- ▶ Caregivers admit to using sex to calm down their spouses when they are agitated, but sex without emotion or passion can leave one feeling degraded and used.



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Texas Health and Human Services System: Resident's Rights-Sexuality and Intimacy

Residents are entitled to express themselves sexually as long as the expression:

- ▶ Is not a public display
- ▶ Is consensual (must have the mental capacity to make the decision and be on the same cognitive level) between residents
- ▶ Does not harm the resident or others

Staff members responsibilities:

- ▶ Develop policies and procedures taking into consideration the resident's rights
- ▶ Protect the residents from harm
- ▶ Document observations of sexual expression
- ▶ Report information regarding the resident's sexual expression to family members are required
- ▶ Provide the resident with privacy



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Other Resources

- ▶ *Sexuality and Dementia: Compassionate and Practical Strategies for Dealing with Unexpected or Inappropriate Behaviors* by Douglas Wornell MD Amazon
- ▶ *G.A.S. & Dementia: Exploring Issues of Grief, Aggression, Sexuality and Dementia* by Joanne Berrigan Amazon
- ▶ *Dementia and Sexuality: A Rose that Never Wilts* by Elaine White Amazon
- ▶ *Dementia, Sex, and Wellbeing* by Danuta Lipinska and Caroline Baker Amazon
- ▶ *Away From Her* Rating:PG-13 Amazon
- ▶ *Glen Campbell I'll Be Me* Rating PG Amazon
- ▶ Alzheimer's Society www.alzheimers.org
- ▶ Alzheimer's Association www.alz.org
- ▶ Family Caregiver Alliance www.caregiver.org
- ▶ Journal of Psychosexual Health



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James L. West is a faith inspired, not-for-profit organization serving persons impacted by dementia. As a trusted expert, we provide personalized, innovative care and support for families, as well as specialized education for caregivers, healthcare professionals and the community at large.

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