

Intimacy and Dementia

Intimacy and sexual activity have the reputation of being difficult and taboo topics to discuss, yet they are essential to our needs and wants as humans. They remain important throughout the lifespan, even as we age. Older adults are often stereotyped as being asexual, which leads to embarrassment or shame in discussing sexual activity with health care professionals. It has been found that sexual activity and intimacy are associated with positive outcomes for romantic relationships, physical and mental health, and overall quality of life (Srinivasan et al., 2019). In a study of older adults in the United States, it was found that 53% of respondents aged 65 to 74 years and 26% of respondents aged 75 to 85 years had engaged in sexual activity with a partner in the previous 12 months (Srinivasan et al., 2019). Sexuality and intimacy can be further complicated for older adults if one's partner is diagnosed with dementia. Suddenly, the roles in the relationship shift, and one person is the caregiver and one is the patient. A diagnosis of dementia often changes intimacy and sexual activity in these relationships but the need for intimacy doesn't go away. Below are ideas for maintaining or bringing intimacy into these relationships and resources that can provide support during all the change.

Forms of Intimacy

If you're reading this, and your partner has dementia, I want to take a moment and acknowledge that what you are going through is hard. Your partner has changed and your relationship has changed. One of these changes surrounds intimacy and sexuality. This could be resulting in two

different experiences: one is a decrease in physical sexuality, replaced by intimacy and closeness on a different level; the second is a decrease in sexuality and intimacy, resulting in negative feelings or resentment (Roelofs et al., 2019). Each relationship is unique, so it's possible to fluctuate between these two feelings as the disease progresses. Intimacy also looks different for each couple. The intimacy that existed, or didn't exist, in the relationship before may need to shift to a new form of intimacy. A number of qualitative studies have been published looking at how couples facing dementia have maintained intimacy in their relationships.

Finding things you have in common and doing those together

Commonalities and shared experiences may have been common at the beginning of the relationship, but you may have forgotten to enjoy things together over the years. If your partner has the capacity, this can include playing games, going for walks, enjoying a movie or television show together, going for a drive, gardening, or any activity you both enjoy. Many couples believed that doing things together was important for keeping the love alive in their relationships (Shavit et al., 2019).

Shifting away from sex, but still enjoying touch

Sexual activity and consent can be complicated when one partner has dementia. Some couples found that a dementia diagnosis allowed them to slow down and take the time for small, comforting gestures of love (Shivat et al., 2019). These can include expressions, touches, and looks that express a different, new intimacy (Shivat et al., 2019). Cuddling, holding hands, kisses, hugs, and stroking each other's hair are all examples of intimate gestures.

One study looked at how couples have shifted bathing and grooming from caregiver tasks to opportunities for intimacy and sensual touch. Flirting and words of affirmation from the caregiver to the care recipient, washing their partner's chest and perineal area during bathing, and taking the time for affection during grooming and dressing all fostered intimacy between the couple (Trudeau et al., 2015).

Lying together

This can be particularly helpful for couples who no longer live or sleep together. Couples expressed missing the closeness of sharing a bed with their partner and wanted the privacy to do so when one partner was living in a residential care facility (Roelofs et al., 2019). Being able to do this, even if for a few minutes, can provide great comfort to a couple.

Friendship

It is possible that changes in your partner and changes in your relationship have made it too difficult for you to have physical intimacy with your partner. In this case, some partners found it helpful to reframe their relationship as a friendship. This allowed them to still enjoy being with their partner but without the expectations of sex or intimacy of a romantic relationship (Roelofs et al., 2019).

Who Can Help

If you find yourself to be struggling with the changes in intimacy and sexual activity, you deserve to talk to someone about those feelings.

Occupational therapists help people complete their activities of daily living (ADLs). One of those ADLs is sexual activity. If you are looking for ways to physically or emotionally connect with your partner, occupational therapists can help you develop the tools to do so.

Social workers can also provide emotional support and connect you with resources in the community. If you feel overwhelmed by the responsibilities of being a caregiver, they can assist you with finding professional caregivers for your partner. If your partner is in a residential care facility, discuss with the nursing staff opportunities for you and your partner to be intimate.

Resources

Support Groups

<https://www.alz.org/help-support/caregiving/caregiver-health/relationship-changes>

The Alzheimer's Association website has many resources. It outlines the changes to relationships after an Alzheimer's or dementia diagnosis. It also provides a search feature for support groups in your area, as shown below.

In-person support groups

We offer support groups for caregivers, individuals living with Alzheimer's and others dealing with the disease. All support groups are facilitated by trained individuals.

Due to the COVID-19 pandemic, all support groups will be hosted via phone or video conference instead of in-person. Meeting schedules will be assessed on a month-to-month basis. Please locate your local program in the Community Resource Finder or contact our 24/7 Helpline (800.272.3900) for details.

The screenshot shows a search filter interface with the following elements:

- A horizontal line with the text "Apply Filters" centered above it.
- A text input field labeled "Keyword" with a placeholder text "Keyword".
- A dropdown menu showing "48103" and "Radius" with a downward arrow.
- A green button labeled "Apply Filters".
- A green button labeled "Reset Filters".

The National Institute of Aging

<https://www.nia.nih.gov/health/changes-intimacy-and-sexuality-alzheimers-disease>

This website provides further information on the changes that come with intimacy and sexual activity when your partner has dementia. It also outlines hotlines to call for extra resources and support, as shown below.

For More Information About Changes in Intimacy and Sexuality in Alzheimer's

NIA Alzheimer's and related Dementias Education and Referral (ADEAR) Center

1-800-438-4380 (toll-free)

adear@nia.nih.gov 

www.nia.nih.gov/alzheimers

The National Institute on Aging's ADEAR Center offers information and free print publications about Alzheimer's disease and related dementias for families, caregivers, and health professionals. ADEAR Center staff answer telephone, email, and written requests and make referrals to local and national resources.

Family Caregiver Alliance

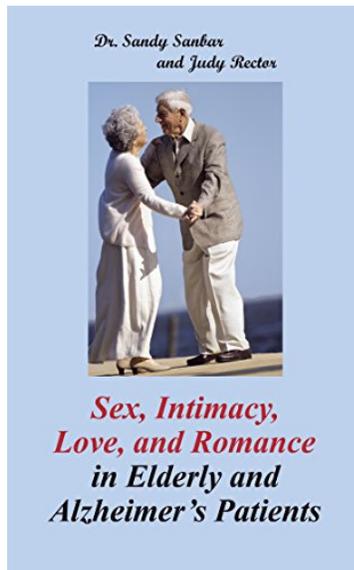
1-800-445-8106 (toll-free)

info@caregiver.org 

www.caregiver.org 

Books

Sex, Intimacy, Love, and Romance in Elderly and Alzheimer's Patients
By Dr. Sandy Sanbar & Judy Rector



<https://www.amazon.com/Intimacy-Romance-Elderly-AlzheimerS-Patients-ebook/dp/B07965WSJ1>

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Roelofs, T. S. M., Luijkx, K. G., & Embregts, P. J. C. M. (2019). Love, intimacy and sexuality in residential dementia care: A spousal perspective. *Dementia*, 18(3), 936-950. DOI: 10.1177/1471301217697467

Shavit, O., Ben-Ze'ev, A., & Doron, I. (2019). Love between couples living with Alzheimer's disease: Narratives of spouse care-givers. *Ageing & Society*, 39, 488-517. Doi: 10.1017/S0144686X1700109X

Srinivasan, S., Glover, J., Tampi, R. R., Tampi, D. J., & Sewell, D. D. (2019). Sexuality and the older adult. *Current Psychiatry Reports*, 21(97), 1-9.
<https://doi.org/10.1007/s11920-019-1090-4>

Trudeau, S. A., Gately, M. E., & Mahoney, E. K. (2015). Expressions of love: Translating bathing into an opportunity for intimacy for couples confronting dementia. *American Occupational Therapy Association*, 38(4), 1-4.

Resources:

<https://www.alz.org/help-support/caregiving/caregiver-health/relationship-changes>

<https://www.nia.nih.gov/health/changes-intimacy-and-sexuality-alzheimers-disease>

<https://www.amazon.com/Intimacy-Romance-Elderly-AlzheimerS-Patients-ebook/dp/B07965WSJ1>