INTIMACY, SEXUALITY, SEXUALITY BEHAVIORS, AND ALZHEIMERS DISEASE

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Intimacy, sexuality, and sexual behaviors remain some of the most sensitive and controversial health care issues that arise in long term care facilities. As people with dementia experience changes in cognition and judgment, the expression of their sexuality may result in behaviors that are challenging to manage. Health care professionals working in residential care often perceive people living with dementia as asexual beings. There is a pervasive belief that sex is for the cognitively intact. Consequently, it is often difficult for caregivers, who have strong beliefs, to accept that residents and those they identity as potential partners have any right to seek out and engage in sexual expression, and to be given privacy to carry on intimate relationships, unless there are specific care plans that are developed and implemented that indicate alterations in this right.

While some health care professionals may agree that residents with Alzheimers disease have a right to sexual expression, individual cultural values, personal beliefs, and inadequate training results in obstacles to consistent practice. Some team members may feel that sexual expression between residents with dementia is upsetting to their personal values and beliefs. Other members of the team may support and encourage relationships between residents or between an intact spouse and a cognitively changing partner. Unfortunately, these differing viewpoints make it difficult for team members to discuss assessment, management, and treatment strategies and come to a consensus on how to respond. It makes it even more challenging to determine who and how we could or should include the people directly involved, the residents, their spouse(s), their family members, support staff (such as housekeepers, food service, reception, maintenance, clergy) in discussions and care planning.

It is essential that all agencies providing care to people living with cognitive change and dementia develop a policy that ensures consistency and fairness in management, care, and support strategies. In an actual clinical situation, the values of residents, family, and staff may be in conflict. Without a guiding policy, staff and family may decide on a management response that disregards the preferences of the residents involved.
Such a policy will ensure that residents who are unable to object will be protected from unwanted sexual advances that can result in civil and criminal investigations and charges.


How can I decide what is sexually appropriate for the person with cognitive losses?

It is often difficult to know what is in the best interest of the individual who cannot clearly communicate his or her needs. This may be further complicated when our own needs are intimately intertwined. We all need warmth and tenderness; these needs may be particularly heightened in the person with dementia. A caregiver may ask if it is rape if an individual with dementia is compliant but doesn’t understand. If the individual enjoys or initiates intimate behavior and it is mutually satisfying to both parties, sex may be a familiar way of comforting and reassuring the person whose sense of self is eroded by dementia. The most confused individual with dementia is still a sexual being. Attending to these needs is an important part of caring for the person with dementia.

What are my sexual obligations as a spouse?

Changes brought about by dementia can gradually chip away at the feelings necessary for a satisfying intimate relationship. Feelings of love, grief, anger, and helplessness can change how the caregiver feels and relates to the affected spouse. Previous feelings of love may diminish when the person is no longer able to attend to the feelings and needs of the caregiving spouse or when the person’s behavior becomes demanding or aggressive. Your obligations for your loved one must be balanced with your obligations to yourself. When continuing the sexual relationships is no longer satisfying, you have the right to end it and find new ways of relating to your spouse.

How much should I consider my own needs?

You are not disloyal to your spouse when you consider your own needs. Dementia creates special needs for the affected person and seriously compromises his or her ability to fulfill the obligations as a marriage partner. This does not negate the rights of the caregiving spouse who now must adapt to the changing relationship and who must find acceptable ways of meeting his or her needs. Most often, the dilemma for the caregiver is deciding what is acceptable.
Is it fair to be concerned about my needs when he or she is so sick? To continue the task of caregiver, you must find sources of renewal for yourself. This means taking care of yourself as a whole person—physically, emotionally, and spiritually.

**My spouse is no longer physically attractive. How do I handle guilt over such a superficial consideration?**

Sexual attraction depends on many things, including the physical attributes of one’s partner. When the person with Alzheimer's begins to be lax in hygiene, the caregiver may react with strong emotions which preclude sexual feelings for them. The caregiver should not feel guilty about the lack of sexual attraction for a partner who may have changed greatly in personality or behavior.

**How do I deal with hyper-sexuality and accusations of unfaithfulness?**

Sexuality is an integral part of our personality. The need for affection and to feel sexually attractive may be expressed on a physical and emotional level. Some couples have been able to adjust to the losses created by Alzheimer's by creating new levels of intimacy, including a relationship of celibacy which is mutually satisfying to both partners. This is a very personal, complex process including many factors not within the couple’s control, such as personality changes created by dementia. Couples who have been able to maintain a physical relationship report that this adds significantly to a sense of well-being for both the person with dementia and the caregiver. Other caregivers, however, grieve for the companionship and emotional fulfillment which is no longer possible with a person whose condition precludes rational and emotional involvement. As a caregiver, your needs for affection and sexual intimacy do not end because your spouse can no longer respond to your needs. Each caregiver must decide how to meet intimacy needs, whether choosing celibacy or becoming involved in other things or with other people who provide nurturance and fulfillment.

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