Even with profound cognitive impairments, many people with Alzheimer's disease still enjoy a high degree of sociability and a capacity to form intimate relationships. Intimacy may also extend into the realm of sexual behavior.

There is virtually no research published on the nature of sexual intimacy among nursing home residents (Kuhn, 2002). Expressions of sexuality in a nursing home are usually referred to in terms of "inappropriate sexual behavior." Relatively few facilities have the luxury of referring such matters to an ethics committee. This brief article argues for nursing homes to develop a set of guidelines to address these sensitive issues.

Residents with Alzheimer's disease living together on the same floor of a nursing home are essentially compelled to live together for the rest of their lives. Given the fact they are in close proximity at all times, it should not be surprising that some close relationships are formed. Residents who pair off may be content to simply enjoy conversing and participating in activities together. They may also desire to express mutual affection in physical ways, including sex.

If two residents with Alzheimer's disease become sexually intimate, many questions arise that ordinarily do not come into play in "normal" adult relationships. These questions need to be addressed in a proactive manner instead of waiting for an incident to occur that offends residents, staff, or families.

The following case example illustrates some difficult issues:

Mr. B and Mrs. C both had moderately severe Alzheimer's disease and resided on the same unit of a nursing home. Mr. B's spouse died six months before he came to the nursing home. Mrs. C's spouse visited her often, although she often failed to recognize him as her spouse.

Soon after Mr. B and Mrs. C met, they began to spend a lot of time together. Gradually their handholding evolved and became overtly sexual in nature. Attempts by staff members to separate them were unsuccessful. Family members were not informed of the situation because the staff felt their behavior was mutually agreeable, although it seemed inappropriate in public at times.

When Mrs. C's spouse saw his wife and Mr. B fondling each other one day, he angrily confronted the staff who admitted that this had become a pattern. He accused the staff of withholding important information and demanded that Mr. B be transferred to another unit.

The following questions may help you evaluate the situation and determine what to do about it:
• Is this relationship being carried out in ways consistent with each person's past values?
• Do past values fully apply in the present context?
• Do residents with Alzheimer's disease have the same rights to privacy and free association as other residents?
• To what extent should others be allowed to make decisions about these relationships?
• If one or both of the residents are married to others living in the community, is the new relationship acceptable to their spouses, other family members, and staff?
• Are both residents capable of entering into the relationship without coercion?
• Is the facility liable to be penalized if their families perceive coercion?

Given the complexity of such issues, it is no wonder that sexually intimate relationships between residents with Alzheimer's disease are often discouraged by their relatives and staff. Answers to the above questions typically boil down to the matter of each resident's capacity to make an informed decision.

It is often difficult to reach a consensus as to whether a resident is fully competent, partially competent, or fully incompetent. A resident may not be able to remember the name of a particular resident, but may well recognize this person as an intimate partner. A resident with Alzheimer's disease may possess partial competence in a specific situation.

A determination of an "all or nothing" global competence is not likely to be a useful approach. Distinctions about a resident's level of capacity may ultimately determine one's right to engage in an intimate relationship, particularly one of a sexual nature.

It is useful to identify the resident's designated legal representative, but oftentimes neither the resident nor the family had the foresight to complete Durable Powers of Attorney. Therefore, there may be a great deal of confusion about who is to be the resident's surrogate decision-maker and when that person should be involved in substituting judgment on behalf of the resident.

It is vital to work out a formal or informal means of making decisions since the resident presumably will require a surrogate at some point in time. Whether surrogate decision-making extends to the sensitive subject of intimacy is open to controversy.

At present, there is no consensus regarding guiding principles to deal with issues of sexual intimacy between nursing home residents with Alzheimer's disease. Manor Healthcare convened a task force to develop guidelines within its Dementia Special Care Units in facilities throughout the U.S. (Sloan, 1993). The four key principles regarding decision making include:

1. Sexual expression should be permitted if both parties and relevant family members consent, and risks are not judged to exceed benefits.

2. Staff, with family guidance, may decide whether or not to permit a particular behavior.
3. Staff is responsible for determining and documenting consent, for discussing risks, and developing a care plan.

4. It is in everyone's interest, and the staffs' responsibility, to seek a mutually agreeable solution when family members object to consensual behavior between residents.

Taking into account these principles, it is possible to fashion a policy that could be adapted to the particular needs of a residential care facility. Such a policy must address residents' rights, staff responsibilities, and organizational responsibilities as follows:

**Residents Sexual Rights**

1. Residents have the right to seek out and engage in consensual sexual expression.

2. Sexual expression may be between or among residents, or may include visitors.

3. Residents have the right to privacy, including private space for sexual expression.

4. Residents with dementia whose ability to consent to sexual expression is questionable have the right to have a designated representative (e.g.-spouse, adult child, guardian, etc.) involved in decisions involving sexual expression.

**Staff Responsibilities**

1. Staff are responsible for honoring the sexual rights of residents.

2. Staff are responsible for protecting residents from harm or coercion related to sexual expression by others or themselves.

3. Staff are responsible for documenting observations of residents sexual expression and communicating pertinent facts to residents' designated representatives and the Interdisciplinary Care Team.

**Organizational Responsibilities**

1. The organization is responsible for ensuring the right to privacy including private space for sexual expression.

2. The organization is responsible for initial staff orientation and ongoing staff training and sensitivity awareness about residents' sexual rights and staff responsibilities.

3. The organization is responsible for obtaining consultation regarding sexual expression in cases that are deemed complex or controversial.

Facilities or organizations need to develop guidelines regarding intimacy and sexual expression between residents with Alzheimer's disease. Use the attached sample policy and procedures as a guide to developing your own version that meets the unique needs of your residents, families, and staff.

If respecting the personhood of residents with Alzheimer's disease is at the heart of a facility's philosophy, then these sensitive matters can be addressed honestly and openly. In the face of a disease that threatens relationships, nursing home staff must be leaders and advocates in
supporting residents in their desire for closeness and enjoyment with others. How to achieve
that goal requires a proactive and thoughtful approach as well as a set of guidelines for staff to
put into practice.

References

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800-779-8491 for rental/purchase.


Kuhn D. R. (2002). Intimacy, sexuality, and dementia in residential care. Alzheimer's Care Quarterly, 3(2)
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Shindel Martin, L. (Ed.) (2002). Intimacy, Sexuality and Sexual Behavior in Dementia: How to Develop
Practice Guidelines and Policy for Long Term Care Facilities. Hamilton, Ontario. For a copy call (905)
529-1613 or write: info@shalomvillage.on.ca.


Sample Policy and Procedures:

**Sexual Expression in Residents with Dementia or Alzheimer's Disease**

**Policy:**

It is the philosophy and policy of this facility to respect the personhood of residents with Alzheimer's disease. In the face of a disease that threatens relationships, the facility supports each resident's desire for closeness and enjoyment with others.

When residents with dementia or Alzheimer's disease pair up and express their sexuality by engaging in intimate and/or sexual behavior with another resident with dementia or Alzheimer's disease, the facility has an obligation to the residents involved, their designated responsible parties, and the staff.

**Procedures:**

1. The staff shall document observations of residents engaging in intimacy and/or sexual expression and notify the social services staff and Director of Nursing as soon as possible or no later than 24 hours.

2. The social services staff shall notify the designated responsible parties and interdisciplinary team, as soon as possible or no later than 24 hours of initial notification.

3. The social services staff shall educate the designated responsible parties about the disease process and the residents' rights.
   a. Residents with decisional capacity have the right to seek out and engage in consensual intimacy and/or sexual expression.
   b. Residents with decisional capacity have a right to privacy, including private space for sexual expression.
   c. Residents whose ability to consent to sexual expression is questionable, have the right for their designated representative to be involved in decisions about their sexual expression.

4. Care plan meetings with the designated responsible parties and the interdisciplinary team shall be scheduled as soon as possible or no later than 72 hours from initial notification of the social services staff.
   a. The interdisciplinary team and designated responsible parties shall discuss the issues regarding the resident's intimacy and/or sexual expression. The following discussions may help this process:
      i. Determine if this relationship is carried out in ways consistent with each resident's past values.
ii. Determine if past values fully apply in the present context.

iii. Determine if these residents have the same rights to privacy and free association as other residents.

iv. Determine to what extent others should be allowed to make decisions about these relationships.

v. When one or both of the residents involved in a relationship has a spouse living in the community, determine if the new relationship is acceptable to their spouses, other family members, and staff.

vi. Determine if both residents are capable of entering into the relationship without coercion.

b. The interdisciplinary team and designated responsible parties shall reach a consensus and develop a plan of care to address the issues regarding intimacy and/or sexual expression.

5. Based on the plan of care, intimacy and sexual expression shall be permitted if both parties consent, and the risks are not judged to exceed benefits.

a. Staff shall be responsible for determining and documenting consent and discussing risks with the residents involved in the relationship.

b. Staff, with guidance of the designated responsible parties, shall decide whether or not to permit a particular behavior.

6. The facility shall ensure the resident's right to privacy, including providing a private place for intimacy and/or sexual expression, e.g., one of the resident's rooms, vacant resident room, designated private place, etc.

7. The staff shall re-direct residents engaging in intimacy and/or sexual expression in public areas.

a. The staff shall explain to the residents that expressing intimacy and/or engaging in sexual behavior is not acceptable in public areas.

b. The staff shall escort the residents back to one of their rooms, an empty resident room, or other designated private place.

c. Before leaving, the staff shall provide assurance that they are available if the residents need them.

8. The facility shall provide initial staff orientation and ongoing staff training regarding intimacy and/or sexual expression as well as sensitivity awareness about residents’ sexual rights and staff responsibilities.

9. The facility shall obtain consultation regarding intimacy and/or sexual expression in cases that are deemed complex or controversial.