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# *Intimacy, Sexuality, and Residents* with Dementia

BY DANIEL KUHN, MSW

*Persons with Alzheimer's disease and related dementias who express themselves in intimate and sexual ways while living in care facilities often pose dilemmas for staff members and families. This article aims to explore such dilemmas and promote the healthy self-expression of intimacy and sexuality by persons with dementia. Awareness of one's biases about the intimacy and sexual needs of older people, particularly those disabled by dementia, is necessary to address these needs in a sensitive and respectful manner.*

*Key words: Alzheimer's disease, assisted living facilities, dementia, intimacy, nursing homes, residential care, sexuality*

"In addition to physical needs such as safety, nutrition and good health, people with Alzheimer's disease have the same psychosocial needs as other individuals. They need stimulation and companionship, they need to feel secure, to feel they are unique and valued individuals, and to feel a sense of self-esteem."—Alzheimer Society of Canada in Guidelines for Care<sup>1</sup>(p.3)

Intimacy and sexuality are basic human needs that are often overlooked in discussions about the well-being of persons with dementia living in nursing homes, assisted living facilities, and other types of residential care settings. This article explores ways to promote healthy expressions of intimacy and sexuality by persons with dementia living in these care settings. Free association with others and privacy, both essential for intimacy and sexuality, are federally protected rights in the United States.<sup>2</sup> However, these rights come into question with

the complex issues arising from Alzheimer's disease (AD) and related dementias. There is a dearth of research on the topic of intimacy and sexuality in residential care facilities, although it is a practical concern for everyone working in facilities. Staff members must be aware of their own values and biases in addressing residents' expressions of intimacy and sexuality. Enabling persons with dementia to maintain their social skills and sense of self in close relationships is essential to enhancing their quality of life. Expressions of intimacy and sexuality must be seen in this person-centered context.

Old age alone does not diminish the desire for human closeness and sexual expression. It is well documented that when older people are not involved in an intimate or sexually active relationship, it is primarily due to lack of

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an available partner.<sup>3-6</sup> Residents with dementia living in the same care facility are essentially compelled to live together for their rest of their lives. Therefore, it should not be surprising that exclusive and intimate relationships are sometimes formed. Given the likelihood of intimate relationships in their near and distant past and their increasing reliance on long-term memory as dementia advances, residents might be expected to pair off. It is simply natural for men and women living in close proximity at all times to form relationships within their “co-ed” home. The possibility of close, same-sex relationships must also be considered.

Residents who become couples may be content to simply enjoy conversing and participating in activities together. Friendship may be all that is needed and sought. In some cases, however, there may also be a desire to express mutual affection in physical ways, including sex. Giving and receiving intimacy does not end with a diagnosis of AD, although personal expressions may change over time. The need for closeness in a relationship may be intensified in light of the fear often instilled by the disease and may increase to compensate for the resulting losses. Buckland explains this particular challenge for caregivers: “The insecurity and loneliness of a dementing illness make the interpersonal relationship the most important aspect of care.”<sup>7(p.33)</sup>

## REVIEW OF LITERATURE

Intimacy can be defined in many ways but here refers to five major relational components proposed by Moss and Schwebel:<sup>8</sup> commitment (feelings of closeness, cohesion, and connection), affective intimacy (a deep sense of caring, compassion, and positive regard), cognitive intimacy (thinking about and an awareness of another), physical intimacy (sharing physical encounters ranging from proximity to sexuality), and mutuality (a process of exchange). The need for human intimacy probably lasts until the end of life, but sexual interest and ability may wane, primarily due to the disabling effects of disease. Several studies report varying degrees of sexual interest and capability among persons with dementia, but the majority of persons appear indifferent about sex, particularly by the late stages.<sup>9-11</sup> A study of community-dwelling men with AD reported that most became impotent concurrent with the onset of their disease.<sup>12</sup> A minority of persons with dementia remain sexually interested and capable well into the disease process.

Little research is published on the nature of sexual intimacy among residents with dementia living in care facili-

ties. The existing literature typically refers to sex in the context of “inappropriate sexual behavior,” and there is not much written about truly positive and meaningful relationships that occasionally arise. Holmes and colleagues<sup>13</sup> surveyed 144 American nursing home staff about the prevalence of sexual activity in a dementia-specific population. Respondents estimated that 16 percent of males and 10 percent of females engage in some form of sexual activity, about the same prevalence as cognitively intact residents. In this survey, sexual activity included a wide range of expressions including masturbation, mutual genital and nongenital touch, and sexual intercourse. The prevalence of genital sex between residents with dementia was estimated at less than 5 percent. Although most staff agreed that sexual expression between residents is healthy, 42 percent felt that genital contact should be discouraged. Interestingly, a similar survey completed by 22 managers of residential care facilities in Scotland yielded similar results.<sup>14</sup>

## POTENTIAL BENEFITS AND RISKS

Intimacy can bring happiness, joy, and meaning into a person’s life and serve as a major factor in creating a home-like atmosphere in a residential care facility. Shared trust, warmth, humor, touch, comfort, and safety are elements of an environment in which residents with dementia can continue to be connected to others. The opportunity for a good quality of life in physical, psychological, and spiritual terms is enhanced under such conditions. Likewise, the risks of mood disorders, behavioral disturbances, and excess disability are decreased if a resident is engaged in positive interpersonal relationships. In Denmark, where the sexual needs of all nursing home residents are taken seriously, one administrator recently observed that a variety of sexual activities seem to have greater calming effects than traditional medical treatments.<sup>15</sup>

If two residents with AD become sexually intimate in an exclusive relationship, many questions arise that ordinarily never come into play in “normal” adult relationships that develop in the “real world.” Few people would question the right of cognitively intact adults to make decisions regarding intimacy and sexuality. However, the split personality of public facilities also serving as individuals’ homes is bound to lead to conflicting ideas about what types of behavior should be permitted among residents. The following questions pose serious dilemmas for residents, staff, and families:

- If one or both of the residents in a relationship is married, is this current relationship acceptable to their spouses, other family members, and staff?
- Even if both residents are unmarried, are they capable of entering into the relationship freely and without coercion?
- Is the facility liable to be penalized if either resident's relatives perceive sexual relations to be coercive?
- Do either or both residents misidentify one another for a spouse?
- Is the relationship consistent with each person's past values?
- Do past values always apply in this context? For example, is it appropriate to characterize a relationship between two residents who are married but whose spouses live in the community as an "extramarital affair"?
- To what extent should others be allowed to make decisions about the relationships of residents?
- Does anyone have a right to impose a code of behavior as long as no laws are broken?
- Who decides and how?

Given the complexity of such questions, it is no wonder that sexually intimate relationships between residents with AD are often discouraged by their families and staff. Many of these questions relate to a resident's capacity or competence to make an informed decision. The person with AD is often perceived as needing protection from his or her own impaired memory and judgment. Consequently, others routinely assume responsibility for their health care and financial decisions. Whether surrogate decision making extends to the personal realm of sexual intimacy is debatable.

Most residents do not have formal legal advocates. Balancing the needs of residents, families, and staff can be extremely difficult in such delicate matters as relationships between two residents. Conflict may arise among staff, family members, and residents about what seems best for the residents. Due to the potential for litigation, a facility's administrator may feel pressured to yield to the wishes of the family regarding the appropriateness of sexually intimate relations. Ideally, the surrogate decision maker would understand the nature of AD and represent a resident's needs and interests. Disagreements among different parties may necessitate guidance by an ethics committee, an ombudsman, or some other experienced mediator.

The proper time to find out who is to be consulted about any decisions regarding the person with dementia

is prior to admission into the care facility. While gathering information about the prospective resident's medical history, needs, and abilities, it is equally important to find out about the person's social history, including intimate relations that may be reflected in the resident's life in the care facility.<sup>16,17</sup> A resident's sexual orientation, sleeping arrangements while at home, and current level of sexual interest and capacity also need to be explored in a forthright yet sensitive fashion. Family members must be reassured that this lifestyle information is needed so that a successful transition to the facility can be made.

Mental capacity and competence are central to decision making but should not be the sole determinants in the life of a resident with dementia. Ethicists speak of the principles of beneficence and autonomy to clarify issues related to capacity and competence. Beneficence generally refers to making choices for the good of another person who lacks the capacity to make informed decisions, while autonomy refers to a personal rule of the self to make choices without interference from others. Protection from one's own vulnerabilities versus freedom to risk making good or bad choices is at stake here. The tension between these two principles is readily apparent in a situation in which two residents with AD become sexually intimate.

It is often difficult to reach a consensus as to whether a resident is fully competent, partially competent, or fully incompetent. Such distinctions may ultimately determine a resident's right to engage in an intimate relationship, particularly one of a sexual nature. Some might argue that anyone with AD impaired enough to require full-time care in a facility should automatically be considered incapable of making decisions. On the other hand, it is well recognized that persons with AD typically retain a task-specific competence, even those with severe cognitive impairment (e.g., MMSE score of less than 10). A resident may perform poorly on a mental status test but his or her preference for a special friend or lover may be quite evident. Thus, determining an "all or nothing" global competence is not likely to be a useful approach.

## POLICIES AND GUIDELINES

At present, there are no consensus statements or principles to address issues of sexual intimacy between residents with AD living in residential care facilities. Thus far, at least three groups have delineated guidelines or policies. Lichtenberg and Strzepek<sup>18</sup> first described guidelines used in their facility to assess residents' competency to participate in sexually intimate relationships. Residents



were asked a series of questions in three basic areas: awareness of the relationship, ability to avoid exploitation, and awareness of potential risks. It can be argued that such questions have limited value in light of the reliance on residents' verbal ability to articulate needs and understand future risks. Two other sets of guidelines may hold more practical value. In the early 1990s, a national chain of American nursing homes convened a task force to develop staff guidelines within its Dementia Special Care Units.<sup>19</sup> Four key principles regarding decision making included:

- Sexual expression should be permitted if both parties and relevant family members consent and the risks are not judged to exceed benefits.
- Staff, with family guidance, may decide whether to permit a behavior.
- Staff members are responsible for determining and documenting consent, for discussing risks, and for developing a care plan.
- It is in everyone's interest and the staff's responsibility to seek a mutually agreeable solution when family members object to consensual behavior between residents.

In addition, the Hebrew Home for the Aged in Riverdale, New York, developed a set of policies and procedures concerning their residents' sexual rights, staff responsibilities, and organizational responsibilities.<sup>13</sup> While generally supportive of the need for consensual sexual intimacy among residents, the document states that the interdisciplinary care team has the final say in decisions. However, the designated representatives of residents are to be involved in the decision-making process.

The above guidelines tackle some of the tough questions involving residents who become sexually intimate, but each set of guidelines has its merits and limits. It is undoubtedly a laborious process for a work group or task force within a care organization to address controversy and achieve a consensus in light of the diverse opinions among residents, families, and staff. It is likely that no simple set of policies or guidelines will please everyone. Nevertheless, to ignore the issue of intimacy and sexuality among residents is to ignore a reality in which staff members play an important role. If residents merely live in the *staff's place of employment*, then such personal matters can be disregarded. Alternatively, if staff members work in the *resident's home*, every consideration will be given to understanding and meeting their needs. A facility's basic philosophy on this central issue can help define whether care facilities are primarily public or pri-

vate places and determine how policies and guidelines are formulated and enacted.

## LEVELS OF INTIMACY AND SEXUALITY

Staff and family responses to observed or reported behaviors will, for the most part, be tied to the particular level or type of intimacy. At minimum, everyone should agree that any coercive or unsafe behaviors are unacceptable, and measures will be taken to protect any resident who is deemed vulnerable on these grounds. In this same vein, the rare and troubling cases of hypersexuality should be addressed immediately for the sake of all concerned.<sup>20,21</sup> Furthermore, for the sake of protecting residents' dignity, public masturbation is unacceptable, and residents wishing to engage in this activity should be quietly directed to the privacy of their own rooms. Any such "problem behaviors" by residents should be seen as driven by some unmet need. Kitwood put forth a challenge to everyone caring for people with AD: "It is necessary to seek to understand the message, and so to engage with the need that is not being met."<sup>22(p.10)</sup> In contrast to cases of coercion, abuse, hypersexuality, and public masturbation, couples involved in consensual affectionate or overt sexual relations present more ambiguous issues.

Companionship and psychological intimacy between two residents may appear benign at first glance. However, close relations between two residents may be objectionable to their spouses or adult children. For example, a husband may be upset to discover that his wife with AD no longer recognizes him and she has paired off with a male resident. It may be more disturbing if this same husband observes his wife hugging, kissing, or having genital contact with another man. Therefore, any expression of intimacy needs to be brought to the attention of the resident's primary family caregiver or legal representative for the sake of discussion. At all times, however, staff must consider the perspective of the residents.

Public or private expressions of sexual intimacy between two residents with AD will inevitably be questioned—by other residents, visitors, or staff members. For the sake of the residents' dignity, public acts need to be discouraged, but whether or not staff should direct them to a private room is seldom made clear. While some couples may be satisfied with kissing or hugging, others may enjoy fondling or cuddling together in bed. Still others may desire genital contact or sexual intercourse. It is likely that the concerns of others will grow as the couple's behavior becomes more sexually explicit. Is it proper to let them do as they please, or do restrictions need to be



imposed? Is the relationship an exclusive one or seemingly indiscriminate? Is one partner taking advantage of another? Both staff and family members are likely to have strong feelings about the nature of such relationships. Families will usually demand an absolute or partial role in any decisions, regardless of their legal right to do so, and often irrespective of the residents' opinions. Staff should anticipate these scenarios and attest to the meaning of close relationships between residents.

## INTERVENTIONS

Any form of intimacy may be perceived as problematic, and, therefore, solutions must be considered at all levels. Archibald<sup>23</sup> designed a framework for action or problem-solving process that is helpful in sorting out a variety of complex situations. It is essentially a stop, look, and listen approach. It begins with describing the event, based solely on observations. To be as objective as possible, the event needs to be described and documented in behavioral terms. After the initial facts have been gathered, then it is fair to ask, "Is this really a problem, and, if so, for whom?" If it is determined that a problem exists for a resident, staff, family member, or the facility, then further assessment is needed to identify the antecedents or "triggers" of the problem. Thereafter, a plan of care needs to be developed, implemented, and monitored for effectiveness. The following scenario involving two nursing home residents with AD will be used to illustrate the steps involved in the framework for action:

Mrs. Chatham had been cared for at home for 6 years by her husband. However, Mr. Chatham's worsening heart disease forced him to relocate his wife to a local nursing home. At the nursing home, Mrs. Chatham met Mr. Burns, a widower who had lived at the nursing home for almost a year. Mr. Chatham visited his wife three times weekly although she could no longer recognize him as her spouse. Meanwhile, Mr. Burns and Mrs. Chatham began to spend much time together. Staff first saw them holding hands but their mutual touching soon became overtly sexual in nature. Attempts by staff to separate them were unsuccessful and drew hostile reactions from both of them. Staff rationalized that their behavior was not harmful although a bit inappropriate at times in public. While visiting one day, Mr. Chatham saw his wife and Mr. Burns caressing each other. Mr. Chatham angrily confronted a key staff member who then admitted that this behavior had become a pattern. Mr. Chatham accused staff of withholding important information from

him and demanded that Mr. Burns be transferred elsewhere.

Mrs. Chatham and Mr. Burns have no sense of impropriety and indeed enjoy each other's close company. In this case, Mr. Chatham and the staff share a problem. Further discussion with Mr. Chatham reveals that he is grief-stricken. He is no longer able to care for his wife at home, she no longer recognizes him, and another man has easily replaced him. He is overwhelmed by sadness and loneliness. Moreover, he feels angry and betrayed that staff members did not tell him about the relationship. At the same time, Mr. Chatham realizes that his wife enjoys the attention from Mr. Burns and is relieved that she has found someone to keep her happy. Key staff members acknowledge their mistake in not disclosing the relationship to Mr. Chatham and promise to keep him informed in the future. They also acknowledge his emotional pain. At the same time, they note that the relationship appears beneficial for both parties. They admit the dilemma posed by Mr. Chatham's demand to separate them. Mr. Chatham immediately accepts the apology from staff. As his ambivalence about the relationship comes to light, he reconsiders his initial reaction. He notes that it would be "unfair" to separate his wife and Mr. Burns. Although upset about the nature of the relationship, he says that his wife's happiness is paramount and his own feelings are secondary. Staff members are deeply touched by his devotion. He accepts a referral to a local social worker to discuss his mixed feelings. Thereafter, he quickly adjusts his outlook on the relationship and gradually discovers a new lifestyle apart from his wife. Regular follow-up at care plan conferences with Mr. Chatham reveal that he is satisfied with what he calls "this unusual arrangement."

A "cookie-cutter" approach is unrealistic in light of the uniqueness of each resident, each relationship, and each family situation. A situation originally described as a problem may turn out not to be problematic, or as the above example shows, the problem may be redefined in the course of the assessment process. A relationship between two residents that has moved beyond friendship into the realm of sexual intimacy is often viewed as a problem by staff and/or families. Advocacy on behalf of residents should be foremost since they often cannot speak for themselves except in behavioral terms. Therefore, a great deal of education and counseling needs to be devoted to staff and families to help them accept the need for residents to be intimate, even sexually intimate at times. Staff members invariably project their own





sense of personal morality in these situations. The religious and cultural mores of staff will be challenged. The complex issues of intimacy and sexuality should be woven into orientation as well as in-service education and training programs. Staff members also deserve opportunities to air their concerns about close relationships among residents.

If a relationship between two residents is allowed to continue without restrictions, then every effort should be made to afford them the privacy they deserve. On the other hand, if it is determined that a relationship may continue under certain conditions (e.g., no explicit sexual acts or no time together behind closed doors), then staff accept responsibility for identifying alternative ways of meeting residents' intimacy needs or engaging residents in other types of activities that might divert their attention.

Distraction and redirection by staff or family members may reduce contact between residents on a short-term basis, but more creative approaches may have to be employed. Hiring paid companions to engage one or both residents for a few weeks may diminish the intensity of the relationship. More frequent physical activities might also be tried, including a structured exercise program. Introducing various forms of music, dance, art, drama, pets, and massage may also enable residents to feel connected to others. Staff expressions of affection for residents such as hugs should also be encouraged.

If a decision is reached to completely separate two residents, then transferring one of them to another unit or facility will be necessary. Relocation is a drastic measure because any sudden change may be traumatic for both residents, particularly for the one who has been moved. Moreover, each person may continue to seek out another relationship with another person elsewhere. The only occasion when relocation may be necessary is when a relationship is deemed not to be consensual.

A less compelling reason for moving a resident relates to a well spouse's difficulty accepting a resident's "new" relationship. In other cases, adult children of residents may feel that a sexually intimate relationship is inconsistent with a parent's past moral or religious values and seek to uphold a resident's prior prohibition against such relationships. Also, in rare cases, a resident with dementia may develop a same-sex relationship, contrary to his or her sexual history, so that the relationship is not acceptable to the well spouse or adult children. In most cases, same-sex relationships are simply close friendships and do not involve sexual activity. Respecting the wishes

of family members must be carefully weighed against a resident's choice of partners.

## NEED FOR STAFF TRAINING

Personal, cultural, and religious attitudes and biases shape how staff members react to any form of sexual expression by residents. Sexual intimacy between residents with AD may be difficult to confront because it would appear to violate two taboos: sex is for the young and for the cognitively intact. Staff members are typically young people, and their parents or grandparents may be about the same age as the residents in their care. If staff members are not comfortable with either their own sexuality or the sexuality of older adults, then it will be even more difficult for them to perceive residents with AD as sexual beings.

Even though sex has become more explicitly portrayed in the media in recent decades, it is still a subject that most individuals consider a private matter that should not be discussed openly. One's attitudes about sexuality are seldom examined or questioned, so that personal biases are likely to be reflected in interactions with others. For example, a staff member may unconsciously think that residents with AD should not be allowed to be intimate under any circumstances in light of preconceived notions about sexuality and aging. In another instance, a staff member who is heterosexual may be appalled by a relationship between two lesbian women. Awareness about the origins and development of one's sexual attitudes and assumptions is essential to understanding the diverse nature of the human race and appreciating the uniqueness of every individual.

The Staff Attitudes about Intimacy & Dementia (SAID) Survey found in Appendix A may be a useful tool to help staff members identify their personal attitudes about aging, intimacy, sexuality, and dementia. Staff members are asked to privately rate their attitudes on a scale from 1 to 4 (Strongly Agree to Strongly Disagree) regarding 20 statements involving persons with dementia living in residential care facilities. The SAID survey, in part or as a whole, can serve as a basis for group discussion and demonstrate the need for improved staff communication to address sensitive issues.

The entire staff of a nursing home should be committed to a process of self-examination and team building through a series of in-service training programs. Training exercises can help break down the "us and them" barrier

that often gets in the way of person-to-person contact between residents and caregivers.<sup>24</sup> Although nurse's aides provide the greatest amount of direct care to residents, they should not be the only group involved in the learning process. Administrators, nurses, social workers, and activity staff are instrumental in setting a positive tone throughout a care facility and need to be an integral part of training. Other staff, such as clerks, housekeepers, and dietary personnel, should be included because they too comprise the overall human environment.

Residents and families are seldom included in training programs, but their participation at some level in this training may broaden the spectrum of perspectives. At the very least, families deserve their own forum for discussing these important issues. Everyone who works, visits, or lives in a care facility is part of the "culture" and participates in some way in the communal life. Therefore, as many people as possible should be encouraged to receive specific education and training on this aspect of life within the care facility.

The leader of a training program need not be a sex therapist or have any formal expertise as long as he or she is comfortable in raising pertinent issues, facilitating group discussion, and enabling others to feel comfortable in addressing the intimacy and sexual needs of residents. The leader must also promote the notion that these needs are not "problem behaviors" but are expressions of a normal human desire to feel connected to others. All information and discussion in an effective training program should be geared to asking salient questions and offering concrete answers. Otherwise, training will be seen as a pointless intellectual exercise. A variety of components constitute a good training program, but identifying the learning needs of participants is the place to begin. Focus groups and individual interviews with different staff in advance of the actual training program may prepare the trainer and participants in developing the right content and methods. The diverse cultural, religious, and educational backgrounds of staff will shape what is to be learned and how it might best be learned.

Keeping in mind the particular learning needs and styles unique to a particular group of staff members, basic elements of education and training should include the following:

- Information about sexuality and aging
- Understanding the subjective experience of AD
- Understanding the perspectives of families

- Understanding different cultural, religious, and legal perspectives
- A working knowledge of the framework for action in addressing specific situations
- Ways to maintain connectedness and support self esteem

A lecture format will have limited value in staff training. Group participation in discussion, playing a game, or role-playing can be both enlightening and fun. Viewing educational videos such as *Intimacy and the Dementia Patient in Long-Term Care*<sup>25</sup> and *A Thousand Tomorrows: Intimacy, Sexuality and Alzheimer's*<sup>26</sup> may serve as icebreakers. The short documentary film, *As Time Goes By* (Canadian Broadcasting Corporation, 1998), is also a good introduction to the general topic of aging and sexuality.<sup>27</sup> An excellent way to get a group involved in discussing sensitive issues without embarrassment is to use the educational game, "Sex and Aging: A Game of Awareness and Interaction."<sup>28</sup> This board game relies on responses to numerous hypothetical scenarios involving older persons that enable staff to explore their personal attitudes in a nonthreatening manner.

Real or hypothetical scenarios for group discussion may also be useful. (See Appendix B for three case examples and discussion questions.) Participation in case discussions among staff will be enhanced if they are assured that right or wrong answers are unlikely to emerge in the course of discussion. Brainstorming any number of good and poor responses may reveal a wide range of opinions about what types of behavior are "right" or "wrong." Having the group analyze every situation from different angles and applying the framework for action in each case scenario will raise questions and enable the group to reach a consensus. Controversy is to be expected, so a leader must be prepared to help staff members respect diverse opinions.

## EVALUATING THE SUCCESS OF POLICY AND PRACTICE

Ballard<sup>29</sup> lists indicators that a care facility has adopted a considerate, respectful approach to the sexuality of its residents. These measures of success can be summarized as follows:

- When the primary goal of care is to enhance the well-being of residents in a holistic approach: social, emotional, spiritual, physical, and sexual needs are respected.



- When staff members feel comfortable and effective in addressing the intimacy and sexuality needs of residents and can employ practical strategies for dealing with specific situations involving residents and their families.
- When the administration of a facility has established guidelines or policies and procedures for resolving dilemmas involving sexually intimate relationships between residents.
- When family members or legal guardians have a clear understanding prior to the admission of residents about the potential for intimate relationships and the facility's guidelines or policies on such matters; staff ensure that an intimacy profile is completed during the admissions process.

## CONCLUSION

Creating a warm, safe place for residents with AD so they can use their remaining abilities as long as possible involves hard work. It means building a compassionate community among staff, residents, and families that recognizes the intimacy of every person as ordinary human attempts to feel connected with one another. Expressions of intimacy may include sexuality in some cases. When

staff members enable residents to engage in close relationships, including sexual activity in appropriate cases, one of the last vestiges of normalcy in their lives is preserved and respected. In the face of a disease that threatens to break up relationships, staff must be dedicated to finding ways of supporting residents in their desire for closeness and enjoyment with others. We must assure people with AD that we will respect their desire to engage in close, one-to-one relationships with other residents. If residents are free to express feelings of closeness, connection, caring, compassion, and positive regard while living in a care facility, their final experience of "home" will be rich and meaningful.

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# The Staff Attitudes about Intimacy & Dementia (SATD) Survey

The following statements are intended to reveal your attitudes about intimacy and sexuality issues which arise among persons with dementia living in residential care facilities. Circle the numbered response that best suits your viewpoint. You do NOT have to share your responses with anyone.

1. Competent and consenting residents who are married are entitled to be sexually intimate with their spouses in a private place within a care facility.  

<i>I Strongly Agree</i>	<i>I Agree Somewhat</i>	<i>I Disagree Somewhat</i>	<i>I Strongly Disagree</i>
1	2	3	4
  
2. Competent and consenting residents who are single are entitled to be sexually intimate with each other in a care facility.  

<i>I Strongly Agree</i>	<i>I Agree Somewhat</i>	<i>I Disagree Somewhat</i>	<i>I Strongly Disagree</i>
1	2	3	4
  
3. Competent and consenting residents who are married, but not to each other, are entitled to be sexually intimate with one another in care facility.  

<i>I Strongly Agree</i>	<i>I Agree Somewhat</i>	<i>I Disagree Somewhat</i>	<i>I Strongly Disagree</i>
1	2	3	4
  
4. A married couple with one spouse living in the community and the other one with dementia residing in a care facility is entitled to be sexually intimate in a private place within the facility.  

<i>I Strongly Agree</i>	<i>I Agree Somewhat</i>	<i>I Disagree Somewhat</i>	<i>I Strongly Disagree</i>
1	2	3	4
  
5. Residents who have dementia are not capable of making sound decisions regarding participation in sexual relationships.  

<i>I Strongly Agree</i>	<i>I Agree Somewhat</i>	<i>I Disagree Somewhat</i>	<i>I Strongly Disagree</i>
1	2	3	4
  
6. A married couple, with one spouse living at home and one with dementia residing in a care facility, is entitled to be sexually intimate even though the one with dementia appears unable to give consent.  

<i>I Strongly Agree</i>	<i>I Agree Somewhat</i>	<i>I Disagree Somewhat</i>	<i>I Strongly Disagree</i>
1	2	3	4
  
7. A spouse living in the community is entitled to become intimately involved with someone else if his or her spouse has dementia and resides in a care facility.  

<i>I Strongly Agree</i>	<i>I Agree Somewhat</i>	<i>I Disagree Somewhat</i>	<i>I Strongly Disagree</i>
1	2	3	4
  
8. Two residents, both of whom have dementia, are entitled to an exclusive and consensual relationship but should not be sexually intimate if one of them is married to another person.  

<i>I Strongly Agree</i>	<i>I Agree Somewhat</i>	<i>I Disagree Somewhat</i>	<i>I Strongly Disagree</i>
1	2	3	4



9. Two residents, one with Alzheimer's disease and the other who is cognitively intact, are entitled to be sexually intimate as long as they are both single and their relationship appears consensual.
- |                         |                         |                            |                            |
|-------------------------|-------------------------|----------------------------|----------------------------|
| <i>I Strongly Agree</i> | <i>I Agree Somewhat</i> | <i>I Disagree Somewhat</i> | <i>I Strongly Disagree</i> |
| 1                       | 2                       | 3                          | 4                          |
10. Two residents, both of whom are single and have dementia, are entitled to be sexually intimate if their relationship appears consensual and their family members do not object.
- |                         |                         |                            |                            |
|-------------------------|-------------------------|----------------------------|----------------------------|
| <i>I Strongly Agree</i> | <i>I Agree Somewhat</i> | <i>I Disagree Somewhat</i> | <i>I Strongly Disagree</i> |
| 1                       | 2                       | 3                          | 4                          |
11. Two residents, both of whom are single and have dementia, are entitled to be sexually intimate if their relationship appears consensual although one confuses the other for a deceased spouse.
- |                         |                         |                            |                            |
|-------------------------|-------------------------|----------------------------|----------------------------|
| <i>I Strongly Agree</i> | <i>I Agree Somewhat</i> | <i>I Disagree Somewhat</i> | <i>I Strongly Disagree</i> |
| 1                       | 2                       | 3                          | 4                          |
12. A resident with dementia is entitled to be sexually intimate with two different residents as long as there is no sign of coercion in these relationships.
- |                         |                         |                            |                            |
|-------------------------|-------------------------|----------------------------|----------------------------|
| <i>I Strongly Agree</i> | <i>I Agree Somewhat</i> | <i>I Disagree Somewhat</i> | <i>I Strongly Disagree</i> |
| 1                       | 2                       | 3                          | 4                          |
13. A resident is entitled to masturbate in private as long as his or her personal safety is ensured.
- |                         |                         |                            |                            |
|-------------------------|-------------------------|----------------------------|----------------------------|
| <i>I Strongly Agree</i> | <i>I Agree Somewhat</i> | <i>I Disagree Somewhat</i> | <i>I Strongly Disagree</i> |
| 1                       | 2                       | 3                          | 4                          |
14. Two residents who are of the same sex are entitled to have a close friendship but sexual activity between them is unacceptable.
- |                         |                         |                            |                            |
|-------------------------|-------------------------|----------------------------|----------------------------|
| <i>I Strongly Agree</i> | <i>I Agree Somewhat</i> | <i>I Disagree Somewhat</i> | <i>I Strongly Disagree</i> |
| 1                       | 2                       | 3                          | 4                          |
15. Two residents who are of the same sex are entitled to be sexually intimate with one another as long as their relationship appears consensual.
- |                         |                         |                            |                            |
|-------------------------|-------------------------|----------------------------|----------------------------|
| <i>I Strongly Agree</i> | <i>I Agree Somewhat</i> | <i>I Disagree Somewhat</i> | <i>I Strongly Disagree</i> |
| 1                       | 2                       | 3                          | 4                          |
16. Staff should provide a private place so as to allow a male and female resident to engage in sexual activity as long as both of them are cognitively intact.
- |                         |                         |                            |                            |
|-------------------------|-------------------------|----------------------------|----------------------------|
| <i>I Strongly Agree</i> | <i>I Agree Somewhat</i> | <i>I Disagree Somewhat</i> | <i>I Strongly Disagree</i> |
| 1                       | 2                       | 3                          | 4                          |
17. Staff should provide a private place so as to allow a male and female resident to engage in sexual activity, even though both of them are mildly impaired due to dementia.
- |                         |                         |                            |                            |
|-------------------------|-------------------------|----------------------------|----------------------------|
| <i>I Strongly Agree</i> | <i>I Agree Somewhat</i> | <i>I Disagree Somewhat</i> | <i>I Strongly Disagree</i> |
| 1                       | 2                       | 3                          | 4                          |
18. If family members object to a relative with dementia having sexual relations with others, it is the duty of the staff to prevent such activity.
- |                         |                         |                            |                            |
|-------------------------|-------------------------|----------------------------|----------------------------|
| <i>I Strongly Agree</i> | <i>I Agree Somewhat</i> | <i>I Disagree Somewhat</i> | <i>I Strongly Disagree</i> |
| 1                       | 2                       | 3                          | 4                          |
19. A resident displaying hypersexual behavior should be transferred out of the facility.
- |                         |                         |                            |                            |
|-------------------------|-------------------------|----------------------------|----------------------------|
| <i>I Strongly Agree</i> | <i>I Agree Somewhat</i> | <i>I Disagree Somewhat</i> | <i>I Strongly Disagree</i> |
| 1                       | 2                       | 3                          | 4                          |
20. No one should interfere in the sexual lives of residents as long as no civil or criminal laws are broken.
- |                         |                         |                            |                            |
|-------------------------|-------------------------|----------------------------|----------------------------|
| <i>I Strongly Agree</i> | <i>I Agree Somewhat</i> | <i>I Disagree Somewhat</i> | <i>I Strongly Disagree</i> |
| 1                       | 2                       | 3                          | 4                          |



## Case Examples

Case #1: Upon entering the nursing home, the widowed Mrs. French met Mr. Green and they became inseparable, even at bedtime on most nights. Mr. Green treated Mrs. French with utmost respect and became very protective of her. Mrs. French clearly enjoyed the attention. Mrs. French's daughter objected to this relationship because Mr. Green often refused to let the staff assist her mother with bathing and her hygiene was becoming poor. The daughter also complained that her mother seemed more confused after the nights spent with Mr. Green. The daughter insisted that they be kept apart at night to enable Mrs. French to receive personal care as well as proper rest.

1. Whose problem is it?
2. Does the daughter have a legitimate demand? Can staff meet this demand?
3. Who from the nursing home staff should be the primary contact with Mr. Green?
4. What are potential plans of action?

Case #2: After 7 years of caring for her husband with Alzheimer's disease at home, Mrs. Dowd placed him in a nursing home just yesterday. Upon returning to visit him today, she found him walking hand-in-hand with a female resident. Mrs. Dowd broke into tears upon seeing them together and cried to a staff person, "It's devastating to know

that someone could easily take my place. Our marriage is over!"

1. Whose problem is it?
2. What would you say to Mrs. Dowd in response to this situation?
3. What, if anything, would you say to the family of the female resident?
4. What are potential plans of action?

Case #3: Mrs. Antoine was admitted to the nursing home a month ago as her husband no longer felt capable of caring for her at home. Mr. Antoine visits her often and generally appears protective of his wife. Yesterday he was seen taking his wife into her room in spite of her apparent resistance to him. Staff strongly believe that Mr. Antoine initiated sexual contact but wonder if Mrs. Antoine could understand what was happening due to her severe dementia.

1. Whose problem is it?
2. Does Mr. Antoine deserve privacy with his wife or is this an abusive situation?
3. What might be motivating Mr. Antoine to continue sexual relations with his wife?
4. Who from the nursing home staff should be the primary contact with Mr. Antoine?
5. What are potential plans of action?