

Continuing Education Series #5



Too Much or Too Little Care, Closeness and Love How to Establish Boundaries and Guidelines for Intimacy, Sexuality and Sexual Behavior in Assisted Living and Nursing Home Environments.

How to Develop Practice Guidelines and
Policy for Long Term Care Facilities

**GUIDELINES FOR ASSESSING COMPETENCY
TO PARTICIPATE IN AN INTIMATE RELATIONSHIP**

Mini-Mental State score greater than 14

Yes	Perform assessment interview	No	Patient unable to consent
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Patient's ability to avoid exploitation

Yes	Continue evaluation	No	Patient unable to consent
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Patient's awareness of the relationship

Yes	Continue evaluation	No	Patient unable to consent
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Patient's awareness of risk

Yes	Consider patient competent To participate in an intimate relationship	No	Provide frequent reminders of risk but permit relationship
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Lichtenberg (1977)

INTIMACY, SEXUALITY AND SEXUAL BEHAVIOR IN DEMENTIA
HOW TO DEVELOP PRACTICE GUIDELINES AND POLICY FOR LTC FACILITIES

INTRODUCTION

A group of professional representing long term care in the Hamilton region formed as a result of concerns about practice patterns in response to issues of sexuality and dementia. Members included representatives from various long term care facilities, a Ministry of Health and Long term Care Advisor, a Police Officer and a Psychiatric Social Worker. The purpose of this community wide initiative was to provide a vehicle for discussion and reflection about a clinical issue that was somewhat overwhelming at first glance. The resulting dialogue assisted participants to educate themselves and increase their comfort level so that their respective LTC facilities would be able to develop responsive and effective policies regarding this issue.

The working group reviewed a variety of policies and guidelines from a number of agencies throughout the province of Ontario. The group also reviewed the literature on the identification and management of sexual behavior in the face of dementia. This Guide is a compilation of the knowledge, ideas and experiences acquired by the working group. The Guide will assist long term care facilities to develop a resident-oriented policy that will balance resident rights with the mission and goals of their organizations.

WHY IS SEXUAL EXPRESSION IN DEMENTIA SO DIFFICULT?

Intimacy, sexuality and sexual behaviors remain some of the most sensitive and controversial health care issues that arise in long term care facilities. As older persons with dementing illnesses experience changes in cognition and judgment, the expression of their sexuality may result in behaviors that are challenging to manage in a communal environment. Health care professionals working in long term care facilities often perceive elderly residents with dementia to be asexual beings. There is a pervasive belief in society that “*sex is for the cognitively intact.*” Consequently, it is often difficult for frontline workers to accept that residents and those co-residents they identify to be potential partners have the right to seek out and engage in sexual expression, and be given privacy to carry on intimate relationships (Davies, Zeiss, Shea & Tinklenberg, 1998).

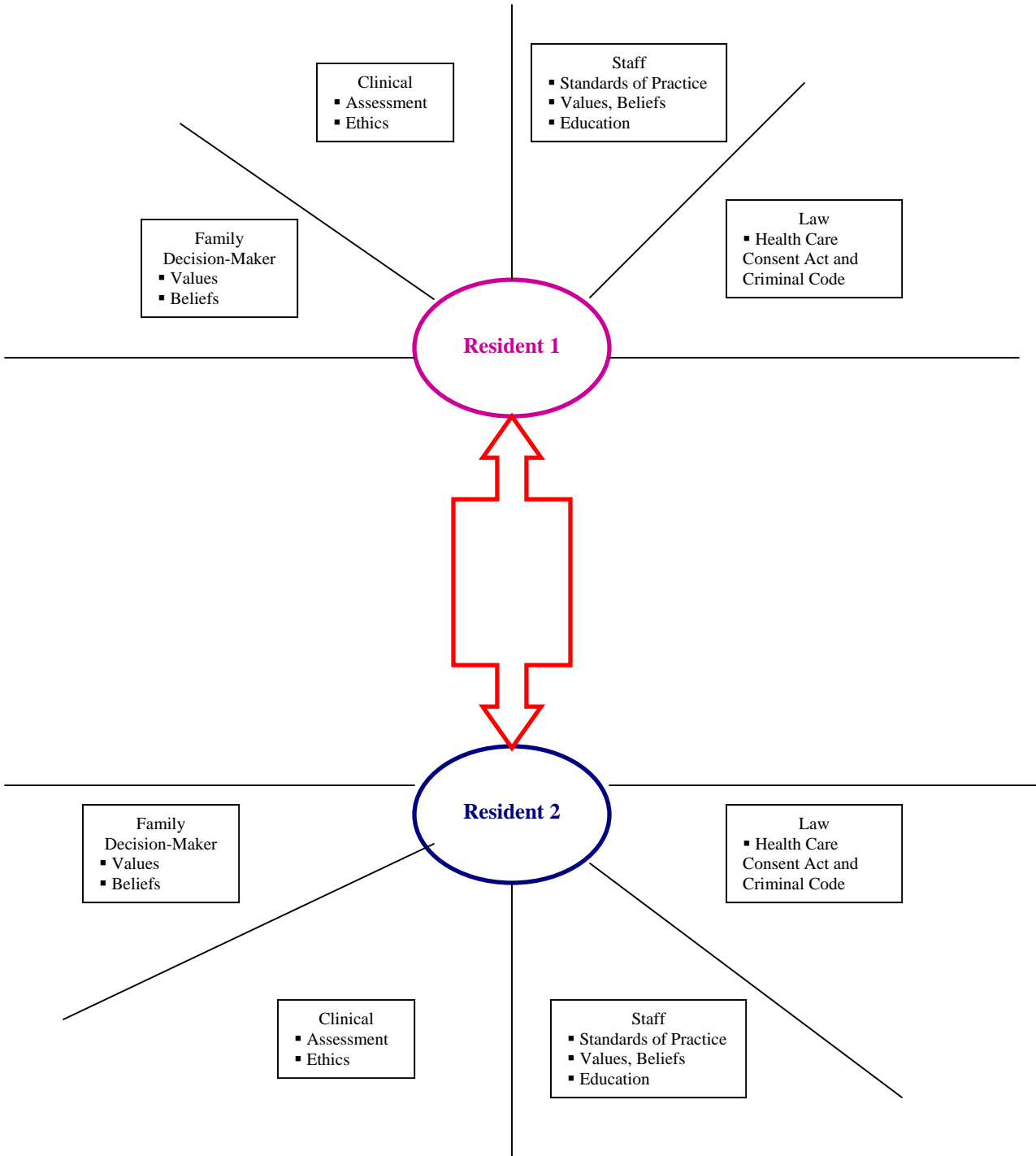
While some health care professionals may agree that residents with Alzheimer’s Disease (AD) have a right to sexual expression, cultural values, personal beliefs and inadequate training result in obstacles to consistent practice. Some team members may feel that sexual expression between elderly residents who are demented is a direct affront to their personal values and beliefs. Other members of the team may support and encourage relationships between elderly residents with dementia (Harris & Wier, 1998). 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.

There are many reasons why intimacy, sexuality and sexual behaviors remain challenging issues for health care teams in long term care. The issues involved are very complex and require careful and detailed assessment. Interpretation of sexual behavior and relationships take place within the context of the law, family belief systems and practice standards (see Figure 1).

In addition, the topic evokes an awkward emotional response in many health care workers; sexual activity of any kind in a communal setting and consensual sex between demented individuals both raise many ethical questions. There is also a lack of research in the current literature to guide practice.

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FIGURE 1
ISSUES RELATED TO SEXUALITY IN LONG TERM CARE



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WHY DOES THE FACILITY NEED A POLICY ON SEXUAL EXPRESSION IN DEMENTIA?

The manner in which intimacy, sexuality and sexual behavior will be interpreted and responded to varies greatly between individual members of any health care team. Personal beliefs, moral codes and cultural attitudes about sexuality may conflict with expected professional beliefs.

It is essential that long term care facilities develop a policy that ensures consistency and fairness in management 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 also ensure that residents who are unable to object will be protected from unwanted sexual advances.

Some facts about sexual behavior and dementia:

- The impact of dementia on sexual behavior is a reduction in sexual drive. In fact, sexual apathy is reported in 23% of cases (Miller et al, 1995).
- An increase in libido is reported in about 14% of those elderly with dementia (Cummings & Victoroff, 1990).
- The incidence of sexually inappropriate behaviors in persons with dementia is reported to be very low, ranging from between 2.6% to 8% within samples of residents diagnosed with Alzheimer’s Disease (Harris & Wier, 1998).

For other facts about sexual expression and dementia, please review the articles located in the bibliography (Appendix A).

HOW TO USE THIS GUIDE.

The guide has been designed as a resource to use as the facility develops its own policy guidelines. It includes:

- Steps outlining policy development.
- Listing of facilities and resources to contact.
- Extensive bibliographic information.
- Worksheet to assist team to discuss clinical cases.

STEPS TO DEVELOP A POLICY

Step 1: Assemble a team.

Assemble a group of key stakeholders that should be involved in developing the policy. Ask for volunteers from the list of key players listed below. Front line workers must be included in the development process. Staff members who are not able to participate need to be kept informed of the process and be asked to provide input to revisions of the draft policy. Key players that may be involved in the process include:

- Health Care Aide/Personal Support Worker
- Nutrition Services
- Housekeeping
- Registered Practical Nurse

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- Registered Nurse
- Social Worker
- Recreational Therapy
- Physiotherapist
- Physician
- Family
- Administrator
- Board Representative
- Pastoral Care/Chaplain Services/Spiritual Care
- Volunteer Coordinator

The facility may wish to include an ethicist in the policy development process if one is available.

Step 2: Learn about the issues.

It is important that all members of the team read some of the pertinent articles listed in the bibliography. This helps participants remove themselves from their own pre-existing beliefs and biases about sexuality and sexual behaviors in demented elderly. The team members should discuss pertinent issues that arise from the literature review. An experienced facilitator may help the group work through this.

Step 3: Consider conducting focus groups.

Initial focus groups should concentrate on values clarification exercises as a discussion of the literature reviewed in Step 2. This should involve as many team members as the facility’s personnel resources allow. The facility’s working group members may act as facilitators for the focus groups. It is important that individual staff members be encouraged to discuss their values, beliefs and personal moral codes and how these may conflict with their stated professional position. Focus groups will also facilitate discussion around issues such as consent and risk assessment. It will assist each unique facility to identify the organizational comfort zone and barometer through which normal behavior, acceptable behavior and pathological behavior will be identified.

Step 4: Review sample policies from other organizations.

Contact other long term care organizations to review their policies (Appendix B.) Facilities within a specific geographical area may be able to work together to develop a regional policy. Individual organizations can use features from each policy to build practice guidelines that will best match their own organization’s philosophy and mission statement.

Step 5: Create working definitions of key concepts in the policy.

Define: sexuality, intimacy and sexual behavior
sexual behaviors to be interpreted as normal
sexual behaviors requiring assessment
sexual behaviors of concern/risk (Sloan, 1993)

The facility may want to include their viewpoint of relationships between residents of the same gender. If a facility has a specific cultural or religious affiliation, the policy needs to reflect those inherent values.

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In addition, the facility needs to develop working definitions of consent to sexual behavior and relationships. Lichtenberg (1997) and Lichtenberg and Strzepek (1990) suggest that the following questions should be asked to identify under what conditions and circumstances a relationship between co-residents should be allowed and/or encouraged to continue.

1. Resident’s awareness of the relationship.
 - a. Is the resident aware of who is initiating sexual contact?
 - b. Does the resident believe that the other person is a spouse and thus acquiesce out of delusional belief, or are they cognizant of the other’s identity and intent?
 - c. Can the resident state what level of sexual intimacy they would be comfortable with?
2. Resident’s ability to avoid exploitation.
 - a. Is the behavior consistent with formally held beliefs/values?
 - b. Does the resident have the capacity to say no to any uninvited sexual contact?
3. Resident’s awareness of potential risks?
 - a. Does the resident realize that this relationship may be time limited (placement on unit is temporary)?
 - b. Can the resident describe how they will react when the relationship ends?

Lichtenberg’s (1997) ideas may prove helpful as to develop the policy. However, it may be necessary to make some adjustments to the decision-tree. For example, a Standardized Mini-Mental State Examination (SMMSE; Molloy, Alemayehu & Roberts, 1991) score of 14 may be too limiting when assessing competency in this context. Many residents with lower SMMSE scores in fact, may have an awareness of the relationship, and give an account of risks of the relationship. Therefore, it may be unreasonable to forbid the relationship on the basis of an SMMSE score alone.

Step 6: Identify interventions.

It is important that the policy include a list of interventions that clearly outline expectations regarding how staff will respond. For example, encouraging non-sexual forms of physical intimacy such as hugging, holding hands and dancing. Initiate environmental and behavioral interventions as a first-line treatment response in the absence of high risk behavior. Persistent hyper-sexuality that presents high risk of physical injury to co-residents would be the clinical indicator for discussing the initiation of antilibidinal hormones. Without this indicator, the introduction of medication as a management response is not prudent practice (Kuhn, Greiner & Arseneau, 1998).

Step 7: Draft a working policy document.

The policy is now ready to be developed. Ensure that the policy defines consent and risk. A specific reference to sexual expression should be in the mission statement. Consider the following distinct issues and where they might fit into the policy, with focus on the specific expectations for staff professional practice:

- Assessment procedure to be followed to determine level of risk associated with any sexual behavior, including the implementation of any assessment tools and taking a sexual history upon admission. An example is the P.I.E.C.E.S. manual for assessment guidelines that many facilities have.
- Reporting procedure of observed sexual behaviors including informing families.

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- Documentation procedures, appropriate terminology to be used with objective observations recorded, not personal value statements. The documentation system should support notations that explicate the frequency, intensity, duration and level of risk associated with observed sexual behaviors.
- Team discussion/meeting expectations to review the parameters of sexual behaviors in each clinical case, and to identify, implement and evaluate interventions. Remember that family/substitute decision makers/power of attorney’s involvement in team meetings and decision-making is crucial to good practice. A sample team discussion worksheet can be found in Appendix C.
- Reference to when policy involvement might be deemed necessary according to the Ministry of health and Long term Care’s reporting requirements for unusual occurrence incidents. For example, extreme circumstances such as serious physical injury requiring hospitalization would warrant police consultation.
- Consider having a decision-tree that helps staff identify management responses to sexual behaviors.
- Educational training for staff (expectations of participation).
- Outline the organization’s commitment and intent for ongoing staff training and orientation, and orientation of new families to the facility’s policy.
- Include case studies as an addendum to the policy that can be used for orientation of new staff.

Step 8: Implement the policy.

Circulate the policy as a draft. Have staff members involved in preliminary focus groups examine the draft policy and give feedback. It would be helpful to involve the Residents’ Council at this point. If family members were not involved in the working group, then it may be prudent to have their input at this point in the development of the policy.

Once the policy is finalized, circulate it to staff and update them about the policy and its implications for their practice. Have staff meetings to introduce the final version of the policy. Consider having a sexual awareness day/week for staff to review policy on an annual basis. Have a guest speaker who can talk about this issue come to the facility as part of an educational initiative attached to this awareness week. Show a videotape to promote discussion about sexual behavior in the nursing home and how the policy helps determine the appropriate management response. Some suggestions are included in the bibliography, Appendix A. The videotapes, available through local Alzheimer Society resource libraries often include discussion guides to help plan educational events. Consider having role-plays with staff during team meetings that would help them learn appropriate responses to sensitive sessions, see Appendix D and E.

Step 9: Evaluate the policy

The policy will most likely be a work in progress. It will be important to set up feedback mechanisms that will help revise the policy. When sexual behavior is observed and reported, a meeting of the clinical team may assist to make the necessary adjustments to help the policy evolve into a working document

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that is practical and useful. The team should review the literature periodically, revising the policy to reflect the current understanding of sexual behavior in dementia every two years.

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APPENDIX A
REFERENCE LIST

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