

# **INTIMACY, SEXUALITY AND SEXUAL BEHAVIOUR IN DEMENTIA**

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

## **Intimacy, Sexuality and Sexual Behaviour in Dementia**

### **How to Develop Practice Guidelines and Policy for LTC Facilities**

#### **Acknowledgment**

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## **Intimacy, Sexuality and Sexual Behaviour in Dementia**

### **How to Develop Practice Guidelines and Policy for LTC Facilities**

#### **Introduction**

A group of professionals 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 behaviour 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.

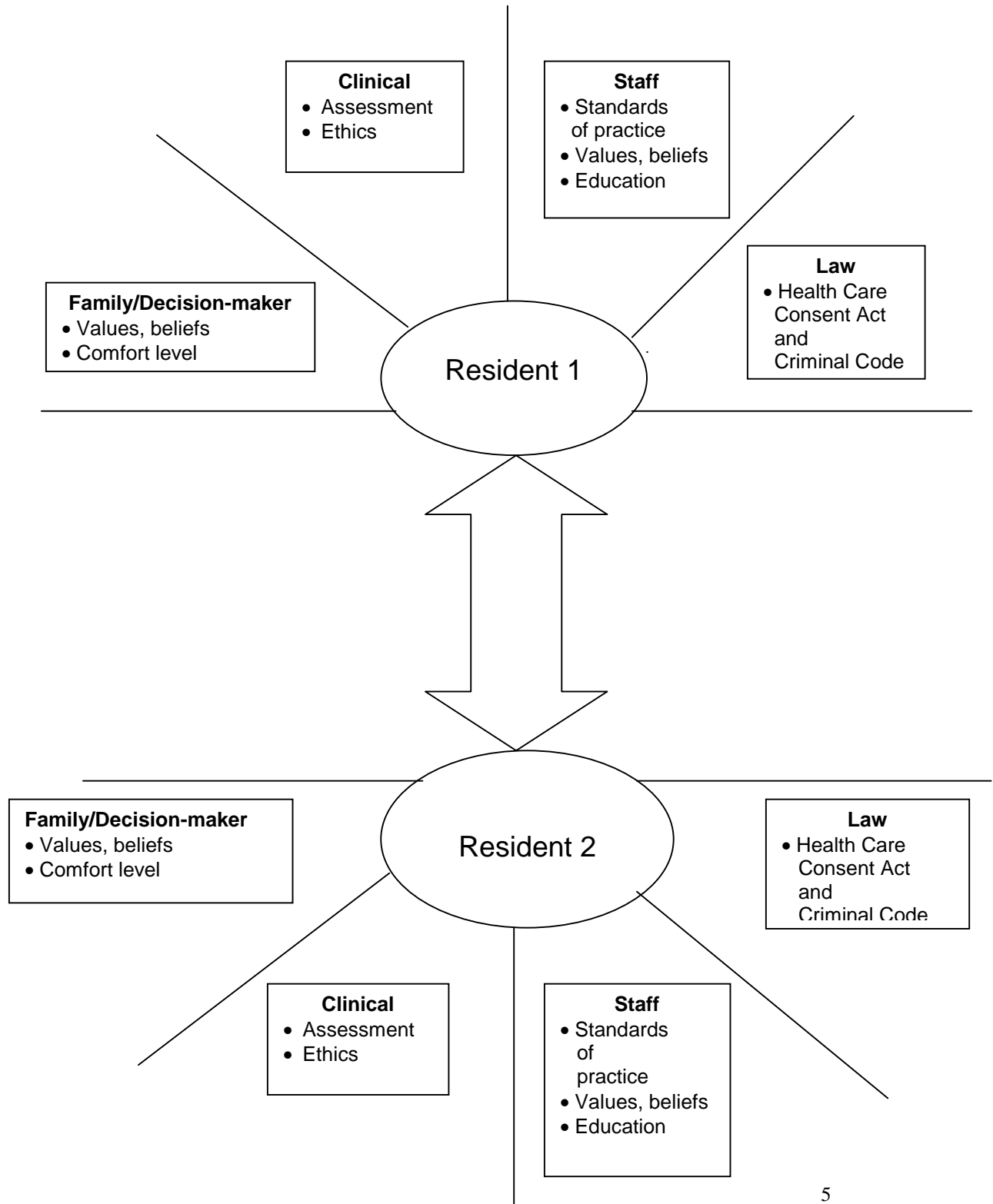
## Why is sexual expression in dementia so difficult?

Intimacy, sexuality and sexual behaviours 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 judgement, 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 front-line 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 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 behaviours 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 behaviour and relationships takes place within the context of the law, family belief systems and practice standards (See Figure 1).

**Figure 1**  
**Issues related to sexuality in long term care**



In addition, the topic evokes an awkward emotional response in many health care providers; 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.

### **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 behaviour 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 behaviours 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  
 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 and 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 behaviour, acceptable behaviour and pathological behaviour 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 behaviour
  - sexual behaviours to be interpreted as normal
  - sexual behaviours requiring assessment
  - sexual behaviours of concern/risk (Sloane, 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.

In addition, the facility needs to develop working definitions of consent related to sexual behaviour 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 a 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 behaviour consistent with formerly 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 (1997) has developed a preliminary decision-tree that may help the organization:

**Decision Tree 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

**Patient's ability to avoid exploitation**

**Yes**

Continue evaluation

**No**

Patient unable to consent

**Patient's awareness of the relationship**

**Yes**

Continue evaluation

**No**

Patient unable to consent

**Patient's awareness of risk**

**Yes**

Consider patient competent to participate in an intimate relationship

**No**

Provide frequent reminders of risk but permit relationship

Lichtenberg (1997)

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, be able to avoid exploitation, 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 behavioural interventions as a first-line treatment response in the absence of high-risk behaviour. 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 behaviour, 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 behaviours, including informing families.

- Documentation procedures, appropriate terminology to be used with objective observations recorded, not personal values statements. The documentation system should support notations that explicate the frequency, intensity, duration and level of risk associated with observed sexual behaviours.
- Team discussion/meeting expectations to review the parameters of sexual behaviours 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 police 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 Resident's 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 behaviour 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 situations. For additional suggestions for educational 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 behaviour 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 that is practical and useful. The team should review the literature periodically, revising the policy to reflect the current understanding of sexual behaviour in dementia every two years.

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November 25, 26, 28, 30, 2001  
December 3, 5, 2001  
March 14, 19, 2002

## Appendix A

### Reference List

#### Key articles and book chapters

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### **General reading**

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### **Videotape Resources**

"A Thousand Tomorrows". Produced by Daniel Kuhn. Distributed by Terra Nova Films. Contact number: 773-881-8491; [www.terranova.org](http://www.terranova.org)

“The Heart has No Wrinkles”. Produced by Health Media, New South Wales, Australia. Distributed by: Kinetic Inc. Contact number: 416-963-5979

“Freedom of Sexual Expression: Dementia and Resident Rights in Long-Term Care Facilities”. Produced by National Alzheimer Center of The Hebrew Home for the Aged At Riverdale. Distributed by Terra Nova Films. Contact number: 773-881-8491 or [www@terravnova.org](http://www@terravnova.org)

## Appendix B

### Agency Contacts for Practice Guidelines/Policy

Reviewing examples of policies from other organizations may assist a facility to develop practice guidelines. It is recommended that facilities undertaking the development of practice guidelines use the policy of other organizations only as samples. The working group who developed this Guide do not advocate the use of any one policy over the others included in the list below. Staff members in a facility are more likely to adopt practices recommended in a policy if they have been involved in the development of practice guidelines within their own organization.

Lori Schindel Martin  
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Phone: 905-529-1613, ext. 228

[lori@shalomvillage.on.ca](mailto:lori@shalomvillage.on.ca)

Contact for information on sexual behaviour practice guidelines, sample policy and questions about articles in the bibliography

Dr. Maggie Gibson  
Psychologist, Veterans Care Program  
Parkwood Hospital, St. Joseph's Health Care London  
801 Commissioners Road East  
London, Ontario N6C 5J1

Phone: 519-685-4292, ext. 42708

Fax: 519-685-4031

Email: [maggie.gibson@sjhc.london.on.ca](mailto:maggie.gibson@sjhc.london.on.ca)

Contact for information on practice change and models of care delivery for behavior associated with dementia and literature on sexual behaviour

Beth Treen, R.S.W.

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Phone: 905-627-3541, ext. 2241

Email: [btreen@sjv.on.ca](mailto:btreen@sjv.on.ca)

Contact for information on a decision-making flowsheet for sexual behaviour

Brad Hall, RN

Administrator

Macassa Lodge

701 Upper Sherman

Hamilton, Ontario

L8M 3M7

Phone: 905-546-2800

Email: [bhall@city.hamilton.on.ca](mailto:bhall@city.hamilton.on.ca)

Contact for information on intimacy and sexuality guidelines, including a decision-making tree for management of sexuality, guidelines number NM-04-01-02 (in nursing manual)

Linda Jackson, MSW, RSW

Director of Social Work

Baycrest Centre for Geriatric Care

Phone: 416-785-2500, ext. 2434

Email: [LJackson@baycrest.org](mailto:LJackson@baycrest.org)

Contact for information on abuse policies that also discuss sexual behavior, policy numbers, VI-130, VI-132, VI-133

Tricia Stiles

Clinical Specialist

Homewood Health Centre

Guelph, Ontario

Phone: 519-824-1010

Contact for information on sexual behaviour policy

Cindy Martin  
Recreation Therapist  
Providence Centre  
Scarborough, Ontario  
Phone: 416-285-3666  
Contact for information on sexuality guidelines for staff, policy  
number: VII-40

Meg Reich  
Program Manager  
Windsor Essex Geriatric Assessment Program (GAP)  
Windsor Regional Hospital  
1453 Prince Road  
Windsor, Ontario  
N9C 3Z4  
Contact for workbook "Intimacy and sexuality in long term care  
facilities" April 1999, developed by Windsor Geriatric  
Assessment/Consultation Program, contains a sample policy, and  
decision-trees for clinical issues related to sexual expression

## Appendix C Sexuality and Intimacy Worksheet

1. Description of the observed behaviors from team (including family): \_\_\_\_\_  
\_\_\_\_\_
  
2. Assessment of competency (See Lichtenberg, 1997 for example of assessment, page 9 of this document):  
\_\_\_\_\_  
\_\_\_\_\_
  
3. Beliefs and values:
  - resident:  
\_\_\_\_\_
  - family:  
\_\_\_\_\_
  - staff (personal and professional):  
\_\_\_\_\_
  
4. Any differences within team regarding beliefs and values? Are they resolvable? Can the team come to a compromise? If the resident cannot participate in decision-making about the relationship, then what does the family say about it continuing?:  
\_\_\_\_\_  
\_\_\_\_\_
  
5. Given the differences and/or compromises made, what are the circumstances and conditions (parameters) under which the relationship or behavior will continue?:  
\_\_\_\_\_  
\_\_\_\_\_
  
6. List specific interventions identified for the situation:  
\_\_\_\_\_  
\_\_\_\_\_

## Appendix D

### Sexuality Focus Group and Education Session Facilitator's Guide

#### Getting Ready

- Begin by viewing the videotapes before screening them for others, and note your own reactions to it.
- Videos are best used in small group settings. Learning is encouraged by comparing one's own experiences, beliefs and values to those of others.
- Ensure that the location for the focus group or program is reserved and that it has adequate space, facilities and accessibility for the number of people attending.
- Notify participants of the date, time and location of the session.
- Arrange to have the necessary equipment and supplies available for the viewing and learning activities to follow. This may include:
  - TV/VCR
  - Paper and pencils
  - Handouts
  - Overhead projector
  - Flip charts and marker pens
  - Tables
  - Refreshments
- In planning a learning activity for people who work in the same setting, choose one resident whom everyone knows. After describing and discussing behaviours frequently observed, use the worksheet in Appendix C to identify the circumstances and conditions under which the behaviour or relationship will continue and possible interventions. It is important that all participants are supported despite any differences in knowledge or values that may become obvious.
- Plan questions and activities to follow viewing that are geared to the objectives you have set for your particular audience. For example:
  - What are your immediate gut reactions to this videotape/case study/presentation?
  - How will this information help us with our day-to-day practice?
  - How could this videotape help us with our real life case, Mrs. X?
- You will need to be prepared for questions and discussion about some "difficult issues" which may be generated by this sensitive topic. If you anticipate

some responses that will make you uncomfortable, plan how you will respond. Front-line workers will be concerned about the specific responses they should use when they observe sexual behaviours and the ethics of protecting residents who are vulnerable to exploitation by others. Administrators, managers and family members will also be concerned with protecting residents' rights. Facilitators can turn any comments to the group for their reaction or can offer their own perspective (or both).

### **Sample 60 Minute Session Plan**

00 – 10	Welcome, Introductions Purpose and plan for session
10 – 20	Sexuality quiz handout (Appendix E) and brief discussion on results Use this to discuss beliefs, values, biases of those present Ask the group to discuss how they see these applying to residents with dementia
20 – 50	Show videotape “The Heart Has No Wrinkles” or “Freedom of Sexual Expression: Dementia and Resident Rights in Long-Term Care Facilities” (see Appendix A) Take a few minutes after the viewing to ask people how they felt about the video Use this as springboard to help staff identify how they could change their practice in response to sexual behaviour in dementia Record ideas you get from the video and practice changes identified during discussion about sexuality on flip chart
50 – 60	Discuss how identified interventions could be incorporated into practice guidelines and circulate in form of newsletter or minutes for staff not able to attend

### **Other activity ideas**

- Divide participants into small groups, ask them to record their values and beliefs about sexual expression in dementia and report back to larger group.
- Take Sexuality and Intimacy Worksheet (Appendix C) and discuss a specific case that all participants are familiar with.
- Use the discussion guide attached to the videotape to help staff identify issues related to sexual expression in the nursing home. Both “Heart has No Wrinkles” and “Freedom of Sexual Expression” has excellent discussion guides in the video package.



## Appendix E Sexuality and Older Adults: Facts and Myths

***Please read and mark yes if you agree with the statement, mark no if you disagree.***

**Yes   No**

1.      Very few older adults engage in sexual activity
2.      Sexuality is only expressed through intercourse
4.      There are positive links between sexuality and health
5.      Sexual dysfunction is an inevitable result of the aging process
6.      Older adults express themselves sexually by remaining physically attractive
7.      It is sinful for older adults to have sex
8.      Institutionalized elders don't have sexual needs
9.      The elderly are sexually undesirable
10.     The need for intimacy and affection is lifelong and helps us define our identify
11.     Sexual needs of the aged are the same as those of younger people but with variation in intensity and response
12.     Older adults have sexual desires and needs
13.     Sex is only for the young