Considerations Regarding the Needs of Long-Term Care Residents for Intimate Relationships and Sexual Activity Spring 2009

Presented By:
Carol Scott, State Long-Term Care Ombudsman
Don Reynolds, Fellow, Center for Practical Bioethics
Cheryl Parsons, RN, LNHA, Consultant

Course Objectives
- Provide practical guidance for long-term care facilities regarding residents’ needs for intimate relationships and sexual activity.
- Establish a framework for managing the tension between the competing values of respecting the residents’ personhood and providing protective oversight for them in context of their intimate relationships and sexual activity.

The Video: What to do about Charlotte?

Assumptions
- Long-term care residents are social. The need for intimate connectedness is a universal human characteristic or trait that extends throughout one’s lifespan.
- Long-term care residents are sexual. Sexuality is a universal human characteristic that extends throughout one’s lifespan.
- Human relationships are informed by the personal values that individuals bring to them. Intimate relationships between long-term care residents may involve competing values.
- Fully articulated policies regarding the intimate relationships of residents address the advent, continuation, and conclusion of those relationships.
- Surveyors respect fully articulated written policies that support the intimate relationships of residents.
- Provided that facilities have fully articulated written policies that support the intimate relationships of residents, surveyors respect the right of residents to accept the risks of an intimate relationship.
- Facilities educate, train, and inform residents, families, staff, and surveyors regarding their processes for accommodating intimate relationships of residents.
Working Definitions

**Intimacy:** An expression of the natural desire of human persons for connection; a state of reciprocated physical closeness to, and emotional honesty with, another. Physical closeness to another includes physical touch as demonstrated by nongenital, nonsexual touching, hugging, and caressing. Intimacy is not a synonym for sex; however, sexual activity frequently occurs within an intimate relationship.

**Protective Oversight:** An awareness twenty-four hours a day of the location of a resident; the ability to intervene on behalf of the resident; supervision of nutrition, medication, or actual provision of care; and responsibility for the welfare of the resident, except when the resident is on voluntary leave.

**Sexual Abuse:** Subjecting another person to sexual contact by use of forcible compulsion. Sexual abuse includes, but is not limited to, sexual harassment, sexual coercion, and sexual assault.

**Sexual Contact:** Includes sexual intercourse, oral sex, masturbation, and sexual touch.

**Sexual Activity:** Includes sexual contact and other activities intended to cause sexual arousal (e.g. viewing sexually explicit photographs and videos, reading sexually explicit text, and phone sex.)

**Volition:** A resident’s clear, unequivocal, unforced willing participation in an intimate relationship or sexual activity. Freedom from coercion is a trait of volition. In this document “Consenting resident” means a resident whose participation in an intimate relationship or sexual activity is volitional.

Principles of Ethics

**Principle of respecting residents as persons.**

We should support efforts to maintain and improve the resident’s quality of life. Support their right to make choices including establishing and maintaining intimate, sometimes sexual, relationships with other people to enrich their lives.

**The principle of doing good and avoiding harm.**

We should act for the benefit of residents and refrain from acting in ways that harm residents. Some things can both benefit and harm a resident, or benefit one resident but harm another. Think: What are the consequences of actions to avoid unintended harm to all residents?
The principles of privacy.

Privacy refers to the right which people have to control access to their interior lives. The principal of privacy permeates the physical, emotional, spiritual, intellectual, and social aspects of everyday life. The principle of privacy allows people to enter into an infinite variety of human relationships – from the most intimate to the most impersonal. Interfering with a resident’s volitional, intimate relationships violates the resident’s privacy. For this reason, absent a compelling need to protect a resident, staff of a licensed long-term care facility should not interfere with the intimate relationships of its residents.

The principles of confidentiality.

We commonly think of privacy in terms of withholding information; however, providing information may also be an exercise of privacy. Confidentiality refers to the obligation that recipients of such information have not to re-disclose private information unnecessarily. When a resident of a licensed long-term care facility re-discloses private information to a member of the facility’s staff, the staff member ought to refrain from disclosing the information to anyone who does not need the information.

The Resident Assessment Instrument Process requires staff to re-disclose otherwise confidential information concerning the intimate relationships and sexual activities of residents.

Conceptual Framework

Licensed long-term care facilities owe two primary obligations to their residents:

Show respect – Facilities show respect for residents by supporting their efforts to fulfill the traits of their personhood.

Provide protection – The obligation of facilities to provide protection is operationalized as “protective oversight”.

Since they are obliged to both show respect and provide protection, facilities ought to adopt policies of conditional support for their residents’ intimate relationships.

Policies of conditional support ought to have two aspects:

1. Provide anticipatory support by:
   A. Informing and training staff regarding the policy
   B. Communicating the policy to residents, families and surrogates.
2. Provide situational support by using the Resident Assessment Instrument Process to:
   A. Develop specific actions in support of particular intimate relationships or sexual activity. (Not every activity deserves support.)
   B. Develop specific responses to problematic activity.

**Procedural Concepts**

1. How to determine willingness
2. The possibility of imbalance within intimate relationships
3. The effect of Congregate setting
4. The Federal Privacy Rule (HIPAA)
5. Reliance on the RAI
6. Relating family members to the intimate relationships and sexual activity of the residents
7. Relating public guardians to the intimate relationships and sexual activity of the residents
8. The role of the facility staff with respect to intimate relationships and sexual activity of residents

**Methodology for developing situational supports**

Federally certified, licensed facilities should use the federally mandated Resident Assessment Instrument Process.
Licensed, but not federally certified facilities should use the Resident Assessment Instrument Process or a substantially similar problem identification resolution process.

< than 4 hugs a day= Depression
4 hugs a day= Survival
8 hugs a day= Maintenance
12 hugs a day= Thriving
Anyone besides me missing out in this category?
What about our resident’s?
The Need for Sexual Activity

Normal Older Adults

Dr. Paul Kettl “Inappropriate Sexual Behavior in Long-Term Care”

Sexual Intercourse

Males 60-69

Dr. Paul Kettl “Inappropriate Sexual Behavior in Long-Term Care”

Quality of Care and Quality of Life

- Meeting the needs of our resident’s including all their needs.
  - Including the ones that we as care givers may not be comfortable with.
  - We often avoid assessing this need because we are not comfortable in talking about it with the resident.
  - We may fear they won’t be comfortable with the subject.
Potential for needs going unmet

- The result is the need can go unmet!
- The potential for negative psychosocial impact is real.
- The impact to quality of life is real.

Recognizing Rights

- Recognize long term care homes are a “normal environment, the “home” of the persons who live there. (Easier said than done.)
- Recognize sexuality is a part of older adults and a part of their life in the long term care setting. (Grandma and Grandpa are still having sex? More information then I need!)
- Recognition and appreciation of individuality of the residents and their diversity in sexual orientation and gender identity.
- Recognition of right of privacy.
  Judith Wahl B.A., LL.B. Advocacy Centre for the Elderly, Toronto, Ontario

Feeling the IMPACT on Quality of Life

![Diagram showing physical, social, and psychological needs]

Psychosocial Well-Being

- What are psychosocial needs?
- As we go through the lists pick at least one from each list that would top your list.
- Consider, as we go if these needs are compromised by the way we currently do things in LTC.
Basic

- Survival
- Safety
- Security
- Emotional Security
- Financial Security
- Sense of being protected
- Sense of being taken care of
- Stability/continuity of environment
- To live in a clean and healthy environment

To be well dressed
To be well groomed
To have one’s personal needs met
Mental stimulation
To nurture

Physical

- Mobility
- Being outdoors
- Freedom of movement
- Freedom from pain
- Right to die/to live

Rational

- Intellectual Stimulation
- To read or to be read to
- Opportunity for competitiveness
- Political involvement
- Patriotism
- Commitment
- Future orientation

Psychological

- Self-esteem
- Dignity
- Sense of self-worth
- Acceptance
- Recognition
- Independence
- Privacy
- Sense of well-being
- Approval
- Self-respect
- Self-satisfaction
- Sense of being useful

- Respect of others
- Honesty
- Integrity
- Self-determination
- Individualization
- Motivation
- Happiness
- Contentment
- A sense of being important
- A sense of being valued
Sensory
- Hearing
- Seeing
- Sense of smell/taste
- Being touched/Opportunity to touch
- Being hugged
- Being massaged

Relational
- One-to-one relationships
- Friendships
- Meaningful relationships
- Intimacy
- Loving and being loved
- Sexual freedom
- Sexual fulfillment

Religious
- Spirituality
- Religious freedom
- Religious involvement
- Sacrament of communion
- Other sacraments
- Communion with God
- Connection with the Universe

Emotional
- Opportunity for venting feelings
- Opportunity for grieving
- Opportunity to deal with own dying
- Opportunity to work through crises
- Caring for others
- Sense of wholeness
- Escape from painful reality

Social
- Contact with others
- Contact with reality
- Contact within own real of reality
- Communication with others
- Socialization
- Social interaction
- Family contact

Creative
- Opportunity for musical/artistic expression
- Creativity
- Self-expression

Freedom/Control
- Freedom of choice
- Freedom of speech
- Freedom of action
- Freedom to make decisions
- Empowerment

- Freedom from discrimination
- To defend one’s basic/civil rights
- To live as independently as possible
- To have control over one’s environment
Quality of Life

- Opportunity to participate in care
- Sense of achievement
- Continue life’s pursuits
- Maintain routine
- Engage in meaningful activity
- Find strength within
- To take risks
- Sense of excitement
- Living life to its fullest
- Self actualization; maximizing human potential

What were some of the ones on your lists?

How would you feel if no one addressed these needs of yours or even asked you about them?

Home is the Fundamental Principle

The long term care home is primarily the home of its residents and is to be operated so that it is a place where they may live with dignity and in security, safety and comfort and have their physical and psychosocial needs met.

The rules of the game are changing; psychosocial holds equal importance to meeting physical needs.

How can our facilities feel like home if we fail to meet the psychosocial needs of the person?

Framework for the Concept

The Center for Practical Bioethics identified two primary obligations for the long-term care facility when considering the Need of Long-Term Care Residents for Intimate Relationships and Sexual Activity. The two obligations were:

1. Respect for the residents personhood
2. Protective oversight

When considering the response to an intimate relationship involving sexual activity by the resident the staff should ask of themselves:

- Can we respond that we showed respect for the resident and provided the necessary protection for the resident?
Managing the Risk

Can we show through documentation that we have explained the risk to the resident? Have we examined methods to reduce the risk? (i.e. use of condoms) Have we examined methods to monitor the risk? (i.e. observing for S/S of STD and testing appropriately)

Inappropriate is determined by two questions:

1. *Are others rights being violated?*
2. *Is someone in danger?*

Very Fine Line

**Appropriate**
- Happy
- Well Adjusted
- Healthy Relationships
- Family and Staff comfortable

**Inappropriate**
- Angry
- Sad
- Hurt
- Withdrawn
- Family and staff uncomfortable
- Unhealthy Relationships

Developing Facility Policy

- Polices should address regarding relationships:
  - Advent (start)
  - Continuation
  - Conclusion
- Polices should support intimate relationships and sexual activities of *consenting* residents and residents who have dementia and don’t have the *ability* to give or deny consent.
- Residents have the right to take risks. Sexual activity and intimate relationships may contain risks. The facility has the obligation to meet this right through education and appropriate management of the risk, not through denial of the right to take the risk.
The facility has an obligation and is responsible for educating and informing residents, families and staff regarding their processes for accommodating residents’ needs for intimate relationships and sexual activity.

Directing Support

Policies should direct two types of support:

1. Anticipatory Support: Facilities need to
   a. Routinely inform their staffs regarding this policy. Special care should be taken to inform staff members regarding the policy’s privacy implications.
   b. Provide training that prepares staff members to perform their roles with respect to the policy.
   c. Develop and implement plans for communicating the policy to residents, families and surrogates.

2. Situational Support: By using the RAI Process, facilities can:
   a. Identify specific actions that staff may take in support of a particular intimate relationship or sexual activity. Some sexual activities are so problematic that they ought not to be supported.
   b. Identify and develop specific responses to problematic sexual activity.
   c. Provide the array of situational supports required to respond to the infinitely various intimate relationships and sexual activities of their residents.

One size fits all is an inherently insufficient response.

Relationships are essentially unique.

Determining Willingness

Volition (i.e., the capability of making a conscious choice or demonstrating a preference). This is the measure we should use in determining willingness.

The Center for Practical Bioethics states; “The standards of informed consent and assent that measure willingness to participate in healthcare are not the standards for willingness to participate in an intimate relationship or sexual activity.”
Discussion:

- Resident #1 is married to her roommate and has been for 52 years. They both are cognitively intact and make their own decisions. They want to have intercourse and she asks you for some kind of lubricate to help with dryness.

- Resident #2 is married to her roommate and has been for 52 years. She has dementia but seems to enjoy their intimate relationship. He asks you for some kind of lubricant to help her with dryness.

- Resident #3 is married to her roommate and has been for 52 years. They both have dementia. Staff respond to her screaming and crying, curled in her bed with him over the top of her.

- Resident #4 and #5 are not married but both are their own responsible parties. They strike up an intimate relationship and want to progress to a sexual relationship but one of their children is very unhappy!

Assessing Ability to Give Consent
Three basic questions help to evaluate a resident’s ability to participate in intimate relationships:

1. Is the resident aware of the relationship?
   a. Aware of who is initiating the sexual contact?
   b. Believe the other person is a spouse or do they know the other person’s identity and intent?
   c. Can they state the level of sexual intimacy they are comfortable with?
2. **What is the residents’ ability to avoid exploitation?**
   a. Is the behavior appropriate with formerly held beliefs and values?
   b. Does the resident have the ability to say no to uninvited sexual contact?

3. **What is the resident’s awareness of potential risk?**
   a. Do they realize the relationship may be time limited and how will they react if it ends?
   b. Is there potential for STD and does the resident understand what that means and the potential consequences?

   **Assess**
   - Does one pull away from the other?
   - Do they seem happy with their relationship?
   - Is there any abusive acts taking place that you can see or feel?
   - Who is the responsible party and what are their feelings on the subject?
   - Is the relationship hurting anyone else?
   - Does there appear to be grief or fear from any participant?

### The Possibility of Imbalance

- **Relationship does not involve sexual contact:**
  - Is the relationship volitional for both parties?
  - Does the party who demonstrates non-volition have the cognitive, emotional and/or physical ability to stop the relationship?
  - When the answer is no to one or both questions the facility needs to provide situational support that protects the lesser situated resident.

- **Relationship does involve sexual contact:**
  - **Assess:**
    - Is the relationship volitional for both parties?
    - Does the party who demonstrates non-volition have the cognitive, emotional and/or physical ability to stop the relationship?
    - Does the RAI process for the relationship yield an evidence-based finding that there may be volition on the part of the lesser situated resident?
    - Is there benefit to continuing an intimate relationship with situational support to prevent the occurrence of sexual contact? (i.e. they both enjoy holding hands and hugging but when it comes to sexual contact)
The Congregate Setting

Nursing homes are regulated to be home-like settings while at the same time showing respect and protecting all residents.
A more accurate understanding might be that facilities are home-like *congregate* residences.
- Residents should have a stake in deciding how the facility responds to the intimate relationships and sexual activities of other residents.

HIPAA
Applies only to medical information.
Intimate relationships and sexual activities that occur in a home-like residential setting are not protected health information. (not covered by HIPAA)
At the same time all residents have the right to privacy and confidentiality of personal information that they do not desire be made public and the facility has the obligation to remind its staff of that right.

RAI Process
The MDS assessment does not currently address sexual activity or intimate relationships.
However, the regulations do not limit the facilities requirement to assess a need, just because it is not included in the MDS assessment.
The RAI process is an established method of assessing a problem, evaluating methodology to address it, and including it in the resident’s care plan.
Using it as a process basis will help the facility to remain resident-centered in their approach to all needs including intimate relationships and sexual activity.

5 Steps to RAI Process

1. **Assessment:** Making informed resident-centered, values-based determinations:
   a. That a resident has questions about the facilities’ policies pertaining to intimate relationships or sexual activity.
   b. That residents have established an intimate relationship
   c. That a resident is otherwise expressing his or her sexuality.

2. **Decision Making:** Deciding:
   a. How to show respect for an intimate relationship between residents by providing supports for the relationship, or to provide protections from the relationship to one or both of the participants
   b. How to show respect for some sexual activities by providing supports, or to provide protections to residents from unwanted sexual activity.
3. Care Planning- Deciding:
   a. How to support (or discourage) an intimate relationship between two residents or
   b. How to support (or discourage) residents from otherwise expressing their sexuality.

4. Implementation: Supporting (or discouraging):
   a. an intimate relationship between two residents.
   b. other sexual activities of residents

Evaluation:
   On an ongoing basis, critically reviewing and modifying as necessary the
   assessment, decision making, care planning, and implementation steps undertaken
   to identify and resolve issues related to the needs and desires of residents for
   intimate relationships and sexual activity.

Why the RAI Process Works

The RAI process works for several reasons:
   a. Residents respond to individualized care plans.
   b. The process requires serious interdisciplinary communication and coordination
      among staff at all levels
   c. Residents and their families are essential participants in the process.
   d. The process encourages clear documentation.

Relating to Family Members

Communication and Education are key.

Involving families in the pre-admission process including issues of intimate relationships
and sexual activity.

Include families in the RAI Process for developing situational responses to the intimate
relationships and sexual activities.

To the extent that the information about their relative-resident’s intimate relationships or
sexual activity is not private, it may be provided.

Educate the family to the facility policy. They do not typically have a management role in
these matters, unless it is afforded to them.

Relating to Public Guardians

In the event that the facility must address a ward’s intimate relationships and sexual
activities provide the guardian a copy of the policy and involve them in the situational
management of the relationship.
The Role of Facility Staff

Inform staff of their responsibilities for:
- Assessing
- Reporting
- Supporting (or not supporting) intimate relationships and sexual activities.

Train them so as to prepare them to respond thoughtfully and compassionately to these emotionally charged complex situations.

Protect them from sexual activities by residents that constitute a hostile work place.

“Social Work Today”

“Change in culture and philosophy of long-term care has the ultimate goal of making the end-of-life process more appealing, and the new attention to residents’ rights to sexual expression is part of the overall change in philosophy. The facility is now viewed as the resident’s home. The term home implies a place of choice, a place of pleasure, where appropriate sexual expression can occur. Warmth, closeness and touching with another resident can alleviate the profound loneliness that affects many long-term care residents.”
Robin Dessel, LMSW assistant director of Social Service at the Hebrew Home Riverdale, NY

“As people age, they do not lose their need for intimacy, and in fact, because of losses due to nursing home placement, declining health, and lifestyle changes, the need for intimacy may even be greater.”
Catherine C. Bradley, MSW, LCSW, ACSW, a long-term care social work consultant for nine years.

From Carol, Don and Cheryl: we hope this training has been helpful.