# Developing Approaches for Intimate Expression Among Persons Living with Dementia in Care

Alzheimer Society Provincial Conference October 21, 2019

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This presentation will focus on the development of responses for intimate expression among persons living with dementia care communities

# Nova Scotia Health Ethics Network (NSHEN)

## Fireside Chat Series

# Ethical Issues Related to Intimate Relationships in Long Term Care

# SEXUALITY

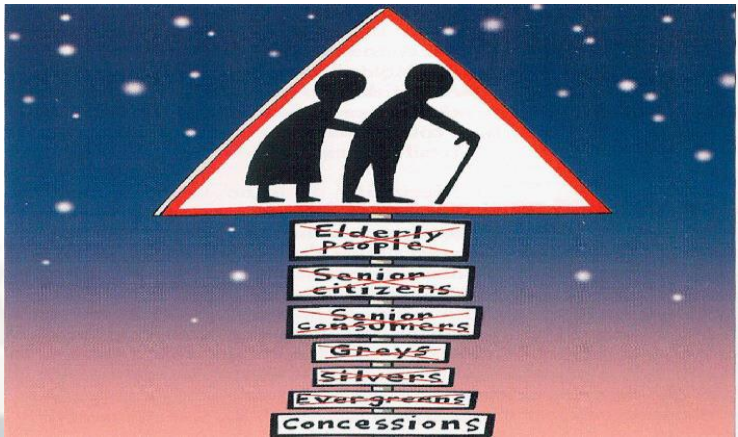
Sexuality is not what we do, but who we are.
We are all sexual beings from birth to death.

# Myths Surrounding Adults Living in our Care Community

There are major myths that need to be dispelled.

older adults are not sexually desirable

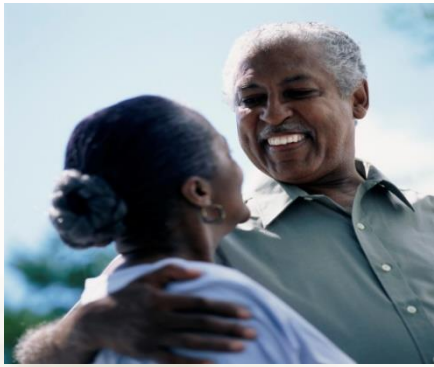
sexually desirous, or sexually capable in later years.



We can alleviate the impact of these myths by:

- educating older adults about their sexuality and helping them develop ways to cope with negative societal attitudes.

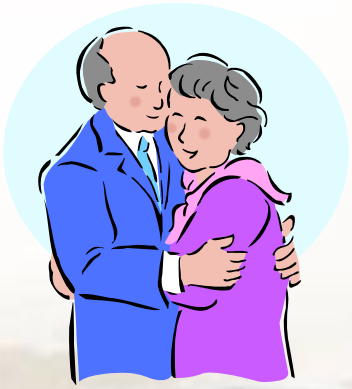
- educating staff to change negative attitudes concerning intimate expression.

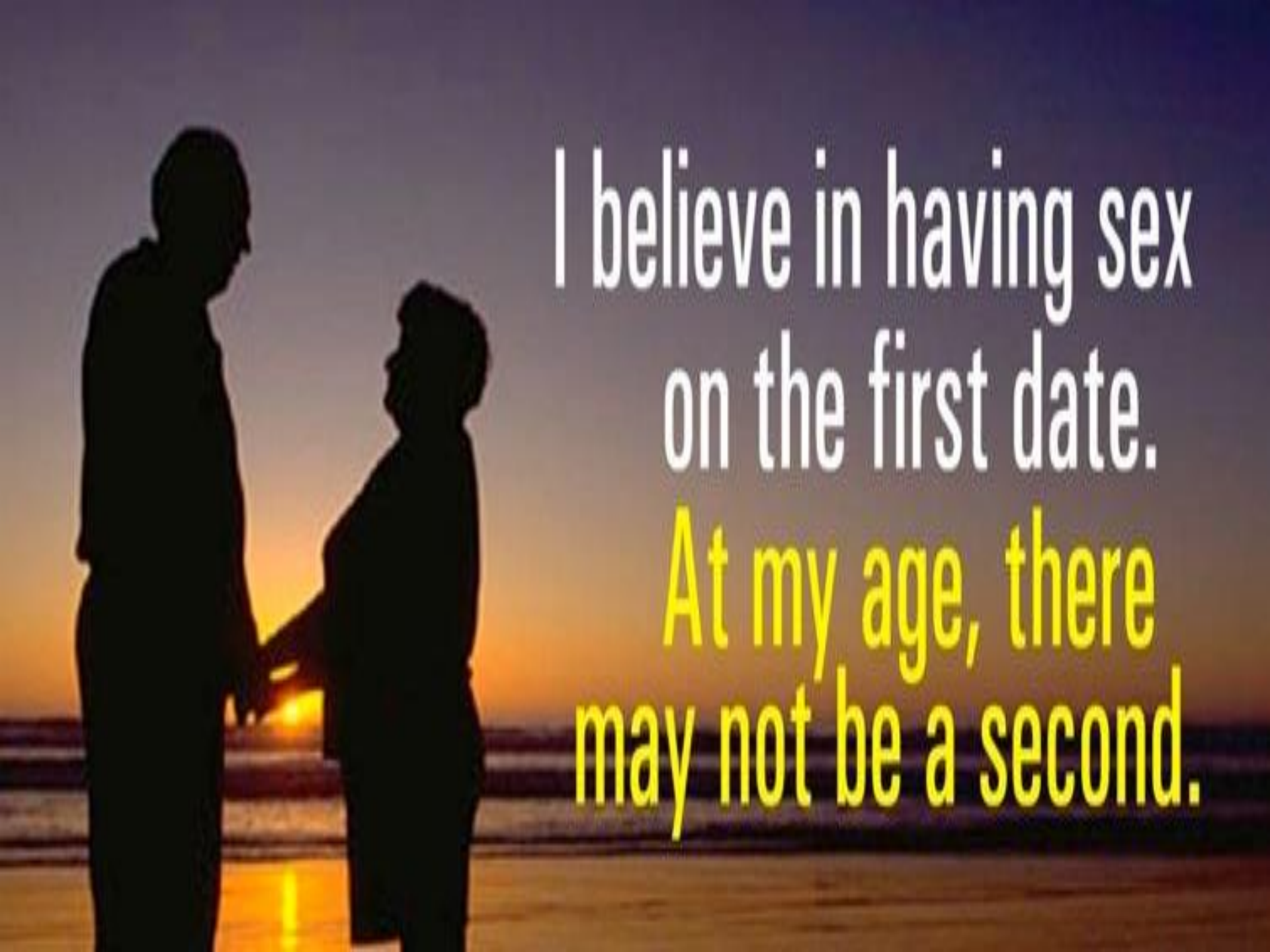


Staff and family members need to reflect upon about their own feelings and attitudes toward intimacy and later-life relationships. Also, if staff take the time to learn about a person's patterns of intimate expression over a lifetime this may provide insight into current behavior.

# Meeting Needs for Intimacy

The needs for companionship and intimacy of people living with dementia and their partners should be met, wherever possible, and treated with respect and dignity.




I believe in having sex
on the first date.
At my age, there
may not be a second.

## Residents/clients/patients in our care may be seeking intimate expression:

- What are we doing within our acute, LTC and home care organizations to support their intimacy needs?
- What, if anything, are the impediments within our organizations to enabling our patients, residents and clients to have their intimacy needs satisfied?

# Situations Involving Intimate Expression by Persons Living with Dementia Which Require Response From Care Staff

## Seeking Companionship with a New Partner

As dementia progresses, persons living with the illness may no longer recognize or remember their partner. They may seek closeness and physical intimacy with a new partner. If the person with dementia chooses a new partner, it is important that both participants consent to the new relationship.

Due to the sensitivity around this issue, care staff must be careful not to intervene in such a way that could prevent a resident from fulfilling their intimacy needs. Care staff must also find ways to support families' adjustment to the new relationship. Their former partner will need support and understanding as a result of this new relationship.

Others living with dementia may experience a decrease in their interest in intimate expression.

## Care Partners Seeking Companionship Outside of an Existing Relationship

Care partners may also have needs for intimacy that are not being met by the person with dementia and may seek to meet these intimacy needs outside the relationship with that person. If so, they will need support and understanding of staff to work through their feelings and to find ways of meeting their needs that make them comfortable and are acceptable to them.

# Disinhibition

The disease process may cause individuals to lose their inhibitions and behave in ways that others might consider inappropriate. This is because the usual mechanism to keep activities in check may no longer be operating. This can be confusing and distressing for the person with dementia, who may not understand why their behavior is inappropriate.

# Misinterpretation of Behavior as Sexual

Sometimes individuals with dementia will behave in ways that may be misinterpreted as sexual when they are not. For example, a care resident may remove their clothing in public to indicate that they have to go to the bathroom or they may find the temperature too hot, but some may view this action as sexually inappropriate.

# CHALLENGES RELATED TO INTIMATE EXPRESSION BY PERSONS LIVING WITH DEMENTIA IN OUR CARE

# Challenges Surrounding Intimate Expression in Acute and LTC

Limited privacy and access to personal space

Concerns around the consent of the cognitive-impaired resident

Conflicts with the personal values of staff, and/or families

Changes in the brain caused by dementia may increase the need for intimacy. This may create issues for residents in care, their staff and family/friend care-providers. If intimate behavior is expressed in inappropriate places or directed toward non-consenting individuals, intervention would be required

# Meeting Needs for Intimacy

Changes dementia causes in a person's interest in intimacy may conflict with the partner's needs. Partners may feel guilty or not know how to respond. Also, as partners take on more of a caregiving role, intimacy may become less appealing.

# LIVING ARRANGEMENTS

Living arrangements which do not allow privacy, such as some long term care and acute care facilities, create an impediment to intimate expression

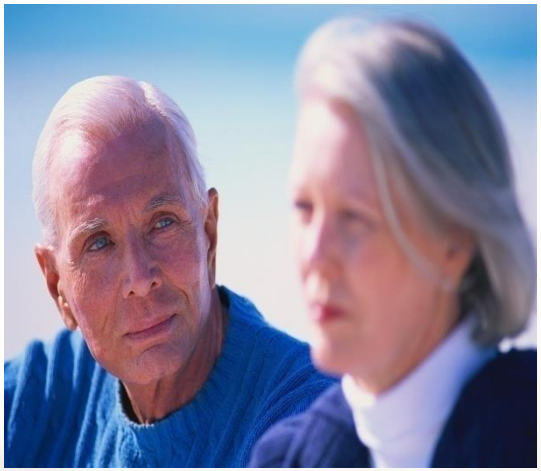
Staff in care communities need to find ways to provide privacy or to help partners deal with changes in their relationships. This can include:

Finding enjoyable activities a partner can share with the person living with dementia during visits

Providing private accommodation for couples wishing to have space for intimacy.

# ATTITUDINAL ISSUES

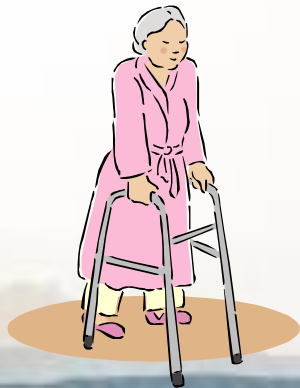
Reaction to attitudes of others (including adult children and other family members) can impact upon an older adults' openness to intimate expression



# Caregiver Attitudes

Staff sometimes discourage intimate expression among their residents/ patients/clients.

As caregivers we need to remind ourselves not to get caught up in societal stereotypes and myths surrounding intimacy and aging. Otherwise, we risk impeding the intimacy needs of our residents/clients.

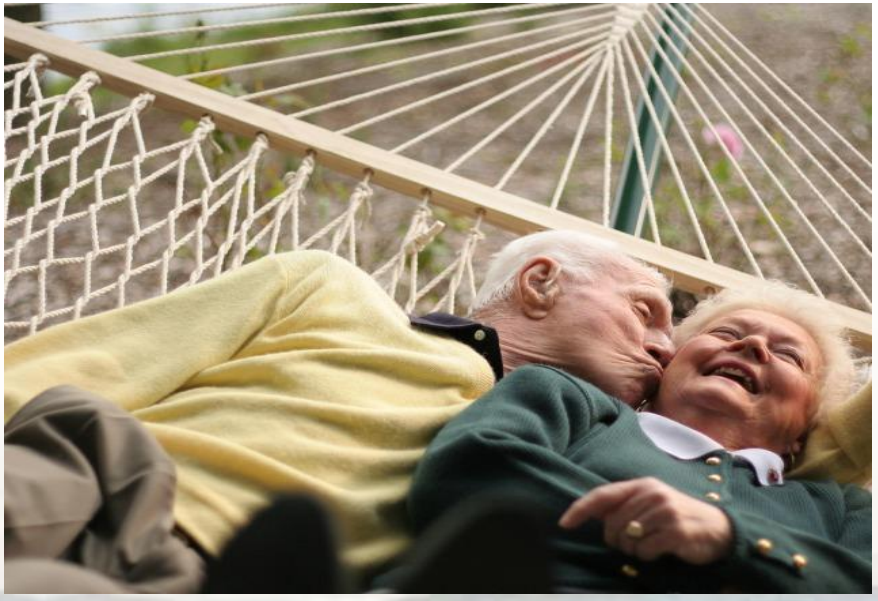


With education we hope, when needed, for a change in attitude towards intimacy on the part of staff.  Minimally, we require a change in response on the part of our staff.

# Factors to Consider When Establishing Guidelines for Intimate Expression in LTC

A significant number of the residents in LTC are living with some degree of cognitive impairment.  This may impact their ability to express informed consent to intimate activity.

Legislation does not expressly provide for substitute decision-making with respect to sexual consent capability



Guidelines for Intimate Expression should not permit “advance consent” to intimate expression by those with diminished capacity.

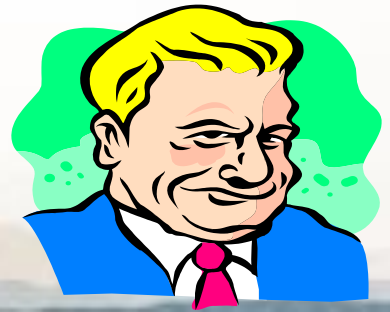
# Clients Who DO NOT Have Sexual Consent Capability

- Capacity for sexual consent involves a continuum of intimacy activities, from nonsexual touching to sexual intercourse.
- When individuals may not have the capacity to consent to sexual intimacy, the inter-professional team may need to intervene to temporarily allow for planning time, provide education and ensure that foreseeable risks of harm have been reduced to a reasonable level.

- Diminished cognition alone does not necessarily imply diminished capacity for sexual consent.
- Higher degrees of intimacy and risk may require a higher threshold of capacity for sexual consent.
- Client vulnerability and potential sources of coercion should be identified when assessing capacity for sexual consent.
- Sexual consent capacity may decrease over time, thus requiring serial assessments as to whether consent capacity is deemed present in a cognitively impaired client.

- Most often consent to intimate expression is not expressed consent but implied where it can reasonably be inferred that a person would have consented.

  For example,
- Can the resident/client object to other things they do not want by either words or behaviors?
- • Do they fully understand the situation and consent to a sexual advance?
- • Does the person have the ability to recognize who the other person is?
- Can they say no or express their wishes nonverbally?

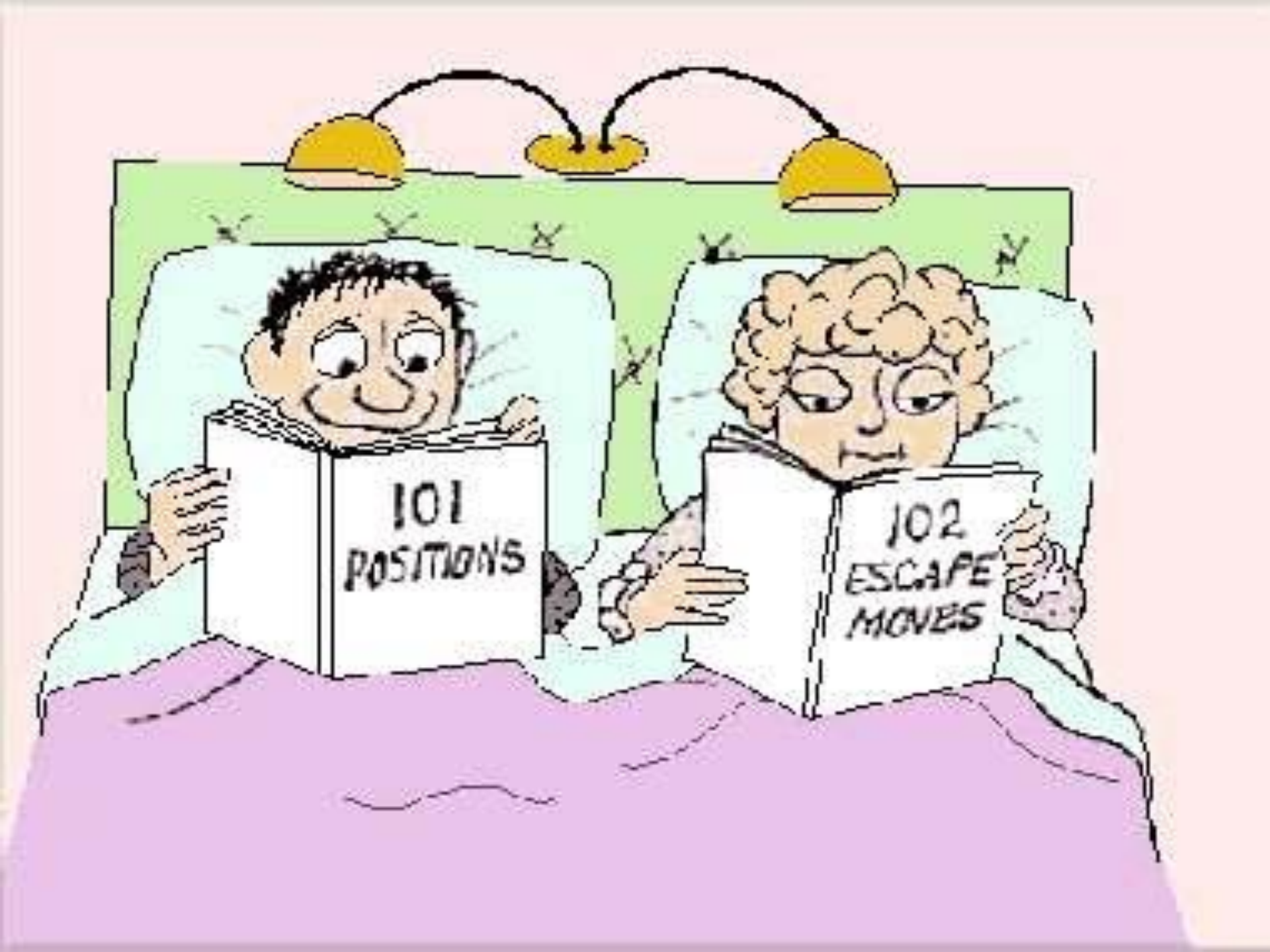


# Other Factors To Include

- There should be **no** intimate expression between residents and staff of the care community.
- All staff members are responsible to maintain professional codes of ethics and to act within professional boundaries and standards of practice. While staff may perform set up and/or clean up for sexual activity, **no employee or volunteer will participate in or be present during sexual activity involving a client**.

# Cognitively Intact Residents/Clients

Guidelines for Intimacy and Sexual Expression should support the appropriate expression of intimacy among resident/clients with capacity for informed, expressed consent. These residents/clients have the right to seek out intimate expression.


101
POSITIONS
102
ESCAPE
MOVES

## Clients WHO HAVE Sexual Consent Capability

- Individuals who have sexual consent capability have the right to engage in sexual activity with no intervention by others, including the health care team. These individuals:
- Have basic sexual **knowledge**, such as the difference between male and female anatomy and function and knowledge of the nature of sexual activity.
- **Understand the possible consequences**, including risks of the sexual activity to themselves and their partners

- Have the **ability to understand** appropriate and inappropriate locations and times for sexual activity.
- Possess the ability to express a **personal choice** and to resist coercion.
- Possess the ability to **recognize distress or refusal** in a partner and stop the activity.

- **If a client is capable of sexual consent, the team responds to requests for education and physical and psychological support to assist decision-making.**

Within our organization, SDM's must always be informed of intimate expression between cognitively-impaired residents incapable of informed consent

If an intimate relationship appears to be enriching to the residents, it should be presented to SDM/ NOK as enhancing the quality of life of the participants.

# “Inappropriate” Sexual Behavior

- Let’s talk about sex!
- Let’s talk about our parents sex lives???

# “Inappropriate” Sexual Behavior

- Focus on behaviors that are
  - Unwanted
  - ‘inappropriate’
  - Challenging
- To?
  - Family
  - Other residents
  - Clinical staff/administrators

# “Inappropriate” Sexual Behavior

- The range of ‘normal’ gets defined by the culture of the environment
- Emotional reactions by staff are often very strong

# Ethics of ISB

- Guidelines for assessing appropriateness of relationship
  - Awareness of relationship
    - Who is initiating
    - Do they think the other person is their spouse
  - Can they state what level of relationship they are comfortable with
  - Are they able to avoid exploitation
    - Is the behavior consistent with formerly held values/beliefs
    - Can they say no
    - Awareness of risks

# “Inappropriate” Sexual Behavior

- No one recognized definition
- Encompasses a range of behaviors
  - Verbal requests for sex
  - Unwanted touching
  - Masturbation
- Ambiguous behaviors
  - Appearing naked or incompletely dressed

# “Inappropriate” Sexual Behavior

- Ozkan et al (2008) ISB grouped into 3 common types:
  - Sex talk
    - The most common
  - Sexual acts
  - Implied sexual acts
    - pornography

# “Inappropriate” Sexual Behavior

- Schwartz, Myran & Sokolowski (2007)
  - Types of sexual behavior:
    - Level 1: intimacy, courtship behaviors; consensual kissing, hugging, fondling, cuddling
    - Level 2: verbal sex talk: nonaggressive flirting or use of suggestive language
    - Level 3: Physical sexual behavior directed towards *self* or *co residents* who are in agreement; or masturbating or exposing oneself during personal care.

# “Inappropriate” Sexual Behavior

- Schwartz, Myran & Sokolowski (2007)
  - Level 4: Unwanted overt sexual behaviors directed towards others

# “Inappropriate” Sexual Behavior

- Sexually aggressive behavior
  - Non consensual
  - Overt physical behavior involving touching another resident in a way that is unwelcome and upsetting
  - Rare
  - Crisis

# Scope of ISB

- Not common (2.6-15%)
  - Greater in LTC
- BPSD
  - Behaviors that are unsafe, disruptive and interfere with care (Ozkan et al 2008)
- Sex ratio is unclear
- No differences based on type of dementia

# Assessment of ISB

- Comprehensive exam including sexual history
- Is this a new behavior?
  - Related to underlying cognitive changes or exacerbation of life-long characteristics
  - Related to underlying psychiatric dx or use of dopamine agents
  - UTI

# Assessment of ISB

- Potential underlying causes:
  - Unmet needs (toileting, uti)
  - Uncomfortable clothing (tight, restrictive)
  - Misinterpretation (organic brain changes lead to misinterpretation of cues)
- Consider context:
  - What is ‘appropriate’ with one’s partner (or willing other) is not ‘appropriate’ with someone else

# Assessment of ISB

- What is the target symptom?
  - Specifically identify what the behavior/symptom is and treatment goal
- Who, What, When?
  - Does behavior occur with all staff?
  - One staff?
  - Only women Only men?
  - During a particular activity (ie bathing, toileting)

# Management of ISB

- Approach
  - Define target behaviors
  - Rule out delirium
  - Review cognitive and sensory factors
  - Review environmental factors
  - *Educate and support caregivers*
  - IF this FAILS
    - Consider nonpharmacological approaches
    - Consider medication**

# Non Pharmacological Strategies

- Comprehensive review of Psychological approaches to the management of Neuropsychiatric symptoms of dementia (Livingston et al 2005):
  - No one strategy was proven effective for any one type of behavior
  - Only behavior management therapies, specific types of caregiver/residential care staff education (and possibly cognitive stimulation) have lasting effect

# Non Pharmacological Strategies

- Lack of evidence should not be interpreted as a lack of efficacy

# Non Pharmacological Strategies

- Modification of social cues
- Environmental manipulation
  - Rear closing clothing
  - Objects to handle
- Supportive therapy (aimed at caregivers)
- Behavior modification
- Change attitudes of staff/family

# Non Pharmacological Strategies

- Avoid becoming angry of embarrassing the individual
- Seek a ‘reason’ or explanation for behavior
- Gently, but firmly remind the individual that the behavior is unwanted
- Try increasing the level of appropriate affection (hugging, dancing, hand-holding)

# Non Pharmacological Strategies

- Try distraction
- Remove to a private place
- Consider practical solutions
    - Rear access clothing
    - Tactile objects
    - ‘Pink Panther’

# Cases

- Mrs. Lonely
  - 84yr old widow with 3 grown children (out of province)
  - Always ‘proper’
    - Moderately-severe-severe mixed dementia with persistent and rapid decline
    - Moved from ‘assisted living’ to LTC, dementia care

# Cases

- Mr. Heart
  - 80+ yr old married man with 2 children living locally
    - Moderately severe-severe AD

# Cases

- Case of Mr & Mrs Lonely Heart
  - Seen holding hands, sitting together, seeking each other out
  - Found lying on his bed together in an embrace, fully clothed

# Cases

- Is this sexually appropriate behavior??

# Cases

- Mr I. S. B.
  - 70yr old never married man
  - Favorite uncle of his nephews
  - Various careers involved in public service
  - Moderate dementia, vascular with prominent disinhibition
    - Frequent requests for sexual interaction with staff, verbally graphic, ‘grabbing’ at breasts and crotch of female staff
    - Touching a co resident who is felt to be vulnerable
    - 1:1 caregiver for safety of co residents

# Cases

- Is this inappropriate behavior?

# ISB Messages

- Uncommon but problematic
- Key is for staff to appreciate that sexual behavior is behavior (BPSD)
- Assessment:
  - Is it sexually inappropriate?
  - Underlying causes?
  - Target behaviors
  - Non pharm approaches
  - *consider meds

# Freedom of Sexual Expression Video Excerpt