

**Caring for People with Dementia:
Focus on Intimacy and Sexuality**



MODULE 1

This Alzheimer's Association program and materials are supported by funds awarded from the Wisconsin Department of Health Services, Quality Assurance and Improvement Committee. Any opinions, findings, conclusions, or recommendations expressed in this training are those of the authors and do not necessarily reflect the views of the Department of Health Services.

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This is an Overview of 6 Modules

**With video clips, exercises, and case
examples; consider this state of the
art material for staff training.**

Six Classes

1. Introduction to Dementia and Dementia Care
2. Creative Responses to Challenging Behaviors
3. Intimacy & Sexuality in Older Adults with Dementia
4. Intimacy & Sexuality between Residents
5. Non-Consensual Intimacy & Sexuality
6. Supporting and Protecting Residents in Intimate or Sexual Situations

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Learning Objectives

- Know the basic medical facts about dementia and Alzheimer's disease.
- Understand principles of Person Centered Care.
- Understand the importance of relationships in caring for people with dementia.

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Time for a Dementia Quiz

True



False



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Video:
What is Alzheimer's?

www.AboutAlz.org

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What is Person Centered Care?

- A positive approach to the care of people with dementia that promotes their dignity and their remaining abilities.
- People with dementia can enjoy a good quality of life but they depend on us to make this happen.
- It involves knowing and meeting each person's unique needs.

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Four Principles: V.I.P.S.

- V** People with dementia need to feel Valued.
- I** People with dementia need to be treated as Individuals.
- P** People with dementia need others to see the world from their Perspective.
- S** People with dementia need a positive Social environment.

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Creative Responses to Challenging Behaviors

MODULE 2

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Learning Objectives

- Understand how impaired brain functions lead to distress among people with dementia.
- Explain triggers for challenging behaviors.
- Discuss creative responses to prevent or minimize these behaviors, including the “soft approach.”

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A + B + C = Dementia

Dementia: gradual loss of key brain functions.

- A. Activities of Daily Living** – loss of ability to independently bathe, dress, toilet, and eat.
- B. Behavior** – loss of control over emotions and inhibitions (e.g., - irritability, agitation, impulsive, resistant to care, sexual acts).
- C. Cognition** – loss of memory, problem solving, language, and orientation to time and place.

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Group Exercise:

Personal and Private Space

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Imagine!

- A stranger rings your doorbell at home and tells you it's time to assist you with your shower. How would you feel and what would you do?

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What Are Challenging Behaviors?

- Actions meant to communicate distress.
- Responses to an unmet need – e.g., personal safety.
- There is meaning behind behaviors; it's up to us to figure out the root cause or causes.

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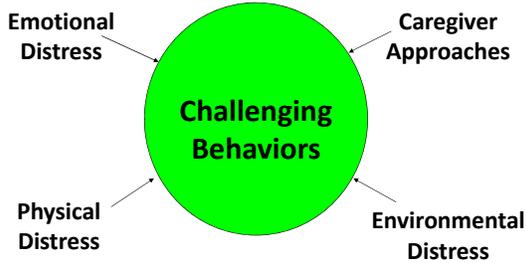
Why Do These Behaviors Occur?

- Verbal agitation
- Physical agitation
- Sexual talk or touching
- Delusions (false, fixed beliefs)
- Hallucinations



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Potential Triggers



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Physical Triggers

- Acute or chronic illness
- Fatigue or sleep deprivation
- Medication side effects
- Pain



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Physical Triggers, *con't*

- Sensory deficits – seeing and hearing problems
- Dehydration, thirst or hunger
- Incontinence or impaction

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Video Clip

Josephine and her CNAs

Excerpt from
*Everyone Wins:
Quality Care without Restraints*

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Use the “Soft Approach”

- Rapport
- Reassure
- Reconsider
- Redirect
- Review



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Rapport

- Make eye contact, smile, and position yourself at the same level.
- Use the person's preferred name and introduce yourself every time.
- Use gentle touch and a positive tone of voice.
- Invite participation, go slowly



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Refrain and Reconsider

- Do not reason or argue.
- Stop what you are doing.
- Apologize sincerely.
- Ask yourself: Is this worth doing now?

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Redirect

- Use personal facts to change the subject or ask the person to help you do something.
- Do something pleasant.
- Be creative and fun.



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Intimacy and Sexuality in Older Adults with Dementia



MODULE 3

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Learning Objectives

- Explore our personal attitudes about expressions of intimacy and sexuality by our residents.
- Understand how dementia may affect their expressions of intimacy and sexuality.
- Discuss how to respond creatively to certain sexual behaviors of residents.

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Our Attitudes about Intimacy, Sexuality and Dementia

- We may be unaware of our personal attitudes.
- Our attitudes shape our behavior toward residents.
- Our attitudes may support or conflict with the rights of our residents to express themselves.

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Old People and Sex?



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Rights of Nursing Home Residents

- All residents have federally protected rights and three concern intimacy and sexuality:
 1. The facility guarantees the resident's right to a dignified existence and self-determination.
 2. The facility guarantees the resident's right to private and unrestricted communication by mail, telephone, or visitation with the resident's physician, attorney, or any other person inside and outside the facility.
 3. The facility guarantees the resident's right to be free from mental, verbal, sexual and physical abuse.....

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Sexual Diversity

- A small minority of men and women are attracted to the same sex.
- Many older gay men and lesbian women have suffered from prejudice and discrimination.
- Discrimination based on sexual orientation is prohibited.



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Protecting Residents' Rights

- It is a shared responsibility among all staff.
- They don't live in our workplace; we work in their home.
- Surveyors – Wisconsin Dept. of Health Services
- Ombudsmen – Wisconsin Board on Aging and Long Term Care: (800) 815-0015

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Impact of Dementia on Intimacy and Sexuality

- Relationship changes.
- Loss of interest.
- Loss of capacity.
- Increased interest.



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Video Clip

Everett and Betty

Excerpt from
More Than a Thousand Tomorrows

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Impact of Dementia on Intimacy and Sexuality

- Confusion about people, time, and place.
- Increased need for personal security.
- Loss of inhibitions, poor judgment.



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Residents and Us

- They spend most of their time with us.
- We help them and we are nice to them.
- Sometimes they confuse our friendly relationship with romantic interest.

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Sexual Behaviors Directed to Staff

- Flirting and suggestive talk.
- Aggressive acts such as kissing, fondling, and groping.
- Don't take it personally!



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Responding to Sexual Behaviors

- Set limits.
- Be respectful in word and action.
- What words and actions have worked for you?

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Responding to Sexual Behaviors

- Report to supervisor.
- Document facts, not feelings.
- Apply lessons learned and share with co-workers.

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Masturbation

- Normal behavior done in a private place.
- Inappropriate behavior in a public place.
- Our role: preserve dignity and protect from harm.



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Intimacy and Sexuality Between Residents



MODULE 4

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Learning Objectives

- Discuss types of intimate and sexual behaviors that residents may express toward each other.
- Understand the need to assess the ability of residents with dementia to take part in these behaviors.
- Discuss steps to take to protect the rights of residents with dementia to engage in or refrain from intimate or sexual behaviors.

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Relationships in Long Term Care

- This is the final home of most residents.
- Companionship should be expected and promoted.
- Special friendships between residents should not be surprising.

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Special Relationships

- Not common - need to be respected.
- Residents are mainly interested in companionship.
- Most residents were once married. They may still enjoy someone's company.
- If still married, dementia often causes them to forget their spouse.

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Levels of Behavior

- **Level 1:** Consensual intimacy without overt sex such as kissing, hugging, handholding, and cuddling.
- **Level 2:** Consensual sex acts such as fondling, disrobing, oral and genital sex.
- **Level 3:** Non-consensual intimacy and sex acts.

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Video Clip

**Level 1: Consensual Intimacy
without Sex**

Woody and Kathy

Excerpt from
HBO's *Alzheimer's Project:*
The Memory Loss Tapes

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If you saw Woody and Kathy going into his room and close the door, what would you say or do?

- A. I would knock on the door & ask what they were doing.
- B. I would knock on the door & then separate them.
- C. I would ignore them but report to my supervisor.
- D. I would contact my supervisor for help to stop them.

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Woody and Kathy

- Does it concern you that they think they belong together?
- Does this appear to be a case of an extramarital affair or infidelity?
- How do you think Woody's wife reacts to them?

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Consent and Decision-Making

- Refers to one's mental ability to make a good decision and to act in one's own self-interest.
- People with dementia may not be able to safely do complex things such as drive a car, manage money, or live alone.
- People with dementia may be able to make simple choices for themselves.

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Abilities Needed for Consent

1. The ability to voluntarily participate (free of coercion or exploitation)
2. The ability to say "no."
3. The ability to be safe from harm (e.g. STDs).

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Low and High Risks

- Decisions involving low risks require low levels of understanding and voluntariness (e.g. choosing clothing, food, or friends or engaging in non-sexual intimate acts).
- Decisions involving high risk require high levels of understanding and voluntariness (e.g. driving a car, managing money, executing a will, engaging in overt sex acts).

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Who Determines Consent?

- Consent to participate in intimate or sexual acts depends upon each person's remaining abilities.
- The interdisciplinary team is often able to make this determination.
- If consent is questionable, the resident's primary care physician or a mental health professional may be asked to make a determination.

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Consent by Woody and Kathy

- Does each person appear to have the capacity to decide about engaging in this intimate behavior?
- Does their relationship appear consensual?
- Should they be able enjoy their relationship as they choose or should there be restrictions?

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Supporting Residents

- If a resident is capable of consent, he or she has a right to participate in an intimate or sexual relationship with another consenting person.
- Likewise, someone incapable of consent has a right to be free from coercion or abuse.
- Families deserve to know what's happening.

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The Role of the Family

- Past relationships, current concerns.
- Whose best interests?

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Protect the Family from Worry

- If you observe two residents engaging in intimate or sexual behaviors, tell your supervisor immediately.
- If you suspect coercion or abuse, stop it.

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Protect the Family from Worry, *con't*

- Our designated staff will report to family and our care team will assess.
- Education and counseling may be needed.

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Non-Consensual Intimacy and Sexuality



MODULE 5

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Learning Objectives

1. Review levels of intimate and sexual behaviors expressed by or toward our residents.
2. Review abilities needed to consent to participate in these behaviors
3. Discuss steps to take to protect residents who are unwilling or unable to participate in intimate or sexual behaviors.

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Levels of Behavior

- **Level 1:** Consensual intimacy without overt sex such as kissing, hugging, handholding, and cuddling.
- **Level 2:** Consensual sex acts such as fondling, disrobing, oral and genital sex.
- **Level 3:** Non-consensual intimate and sexual acts.

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Abilities Needed for Consent

1. The ability to voluntarily participate, free of coercion or exploitation.
2. The ability to say "no."
3. The ability to be safe from harm (e.g. STDs).

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Sexual Consent

- Wisconsin law (940.225): any sexual contact without consent is a crime.
- "Consent means words or overt actions by a person who is competent to give informed consent indicating a freely given agreement to have sexual intercourse or sexual contact."

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Level 3 Behavior Non-consensual intimate and sexual acts

- A resident may be unwilling or unable to consent.
- It is our duty to protect a resident from coercion or harm and report this offensive behavior immediately.

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Level 3: Non-consensual intimate and sexual acts

- The offending person may be another resident, a spouse or some other visitor.
- Any incident involving actual or potential harm needs to be reported to your supervisor.
- The team will address the issue of consent.

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Non-Consensual Sex is Assault/Abuse

Wisconsin law (940.225) indicates that sexual assault is:

- sexual contact for which there is no consent,
- or with a person who is unable to give consent,
- and/or when a service provider engages in sexual contact with a client.

It is our duty to intervene. This is a form of abuse.

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Our Policy and Procedures

- Everyone here has a shared responsibility to protect our residents from harm.
- We have a policy regarding all forms of abuse.
- An actual or potential incident should be reported for investigation and action.

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State Agencies

- State agencies may be called in.
- Surveyors – Wisconsin Dept. of Health Services
- Ombudsmen – Wisconsin Board on Aging and Long Term Care

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Supporting and Protecting Residents in Intimate or Sexual Situations

MODULE 6

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Learning Objectives

1. Review intimate and sexual behaviors involving residents with dementia.
2. Discuss how to support and protect residents.
3. Discuss ways to support spouses and partners living in the community.

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Behaviors Directed to Self or Others

- Masturbation
- Intimate behaviors
- Sexual behaviors
- Hypersexuality – a rare symptom of dementia

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Level 1 Behavior

- Consensual intimacy without sexual activity, e.g. holding hands, kissing, hugging, and cuddling.
- Low level of mental capacity required for consent.
- Family must be informed and educated.

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Case Example



Former Supreme Court Justice Sandra Day O'Connor and her husband, John



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Level 2 Behavior

- Consensual sexual acts, e.g. fondling of breasts or genitals, intercourse, oral or anal sex.
- High level of mental capacity required for consent.
- Family must be informed

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Video Clip

Two widowed people, she had Alzheimer's and he did not. Their daughters reflect on their romance.

Excerpt from
Freedom of Sexual Expression

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Level 3 Behavior

- Non-consensual intimate or sexual acts.
- Some residents are unable or unwilling to consent.
- They deserve our protection.
- We must follow our abuse policy.

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Spouses and Partners

- Let's help spouses and partners enjoy meaningful visits with their loved ones.
- Our residents can be visited in private unless there is reason to restrict or supervise visits, e.g. - potential or actual abuse.
- Some spouses and partners may form relationships with others living in the community.

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Video Clip

Everett and Betty:
Six Years Later

Excerpt from
More Than A Thousand Tomorrows

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