Cognitive Disorders, Couples, and Intimacy

“The need for love and intimacy is a fundamental human need, as primal as the need for food, water, and air.” - Dean Ornish

"We remember their love when they can no longer remember.” - Unknown

Douglas Lane, PhD, ABPP

- Board Certified in Clinical and Geriatric Psychology

- Clinical Professor, UW School of Medicine, Dept. of Psychiatry and Behavioral Sciences

- Olympic Psychology Services
Tacoma, WA

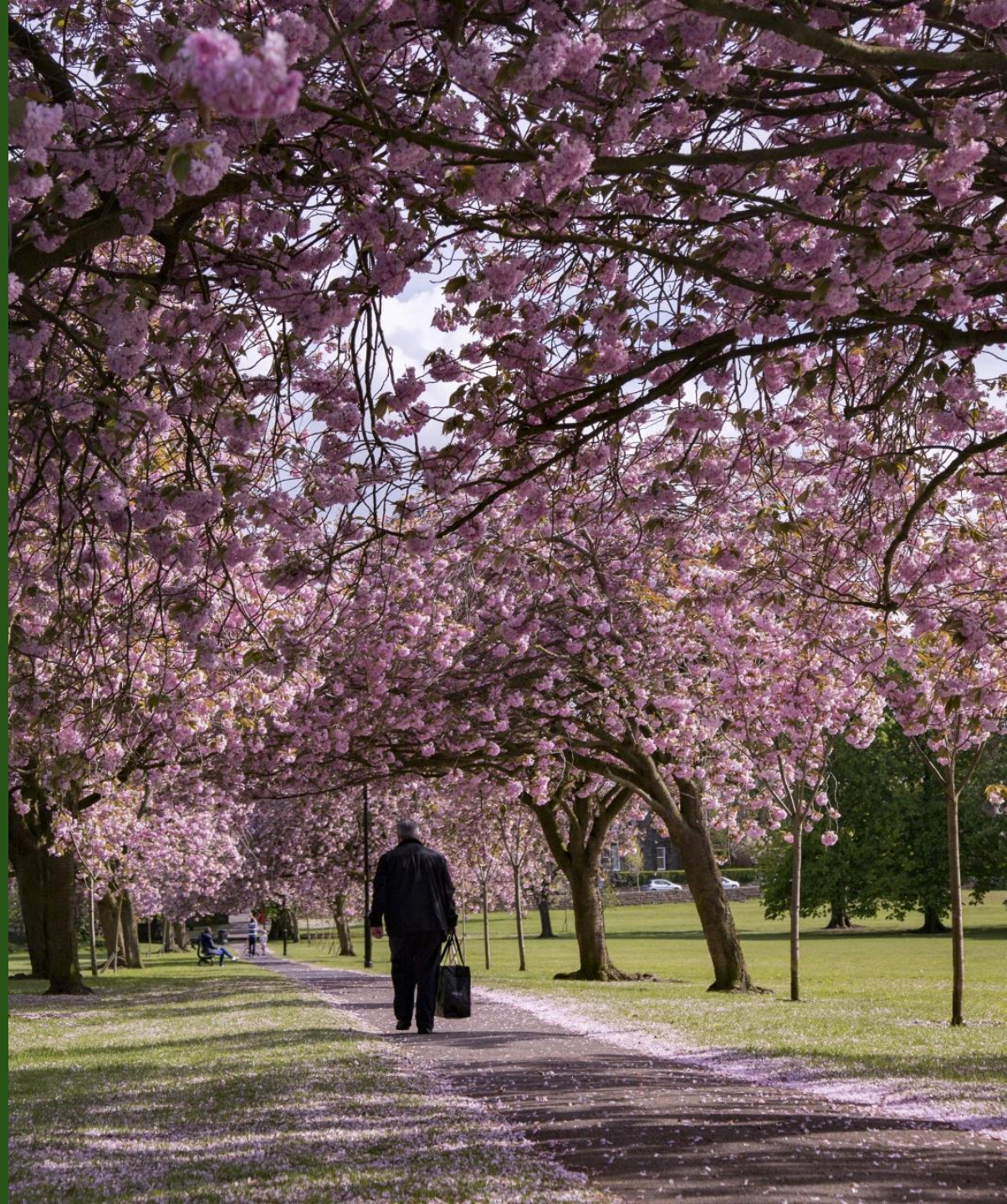
I. DISCLAIMERS

1). The content of this presentation represents the perspectives and opinions of the presenter alone.

2). The information presented, and commentary offered, is intended for general educational purposes only.

3). This seminar should not be interpreted as providing diagnostic or treatment advice. Decisions about clinical care are solely the purview and responsibility of the treating clinician(s).

4). The presenter has no financial relationships to disclose.



DISCLAIMERS:

5). Materials that are included in this course may include interventions and modalities that are beyond the authorized scope of practice for your profession. As a licensed professional, you are responsible for reviewing the scope of practice, including activities that are defined in law as beyond the boundaries of practice in accordance with and in compliance with your profession’s standards.

II. LEARNING OBJECTIVES

1). Discuss the role of healthy intimacy, in its different forms, in the overall well-being of people with cognitive disorders.

2). Identify the role played by ageism in complicating meeting the intimacy needs of people with cognitive disorders.

3). Identify key areas for assessment of the capacity to consent to physical intimacy.

III. DEFINITIONS

Intimacy: A feeling of closeness and connection between two or more individuals.

- Emotional (safe and supported in sharing emotional life)
- Physical (sexual and non-sexual)
- Intellectual (sharing ideas, px solving, planning, sharing burdens, etc.)
- Spiritual/Existential (sharing inner hopes, values, purpose, faith)
- Experiential (time together doing things, play)

- verywellhealth.com (accessed 9/17/24)

IV. GUIDING PRINCIPLES: Complexity

"Geriatrics is both the art and the science of managing complexity."

"Occam's razor is not sharp enough to shave an older person."

Resilience and Coping

"Getting old is like climbing a mountain; you get a little out of breath, but the view is much better!"

- Ingrid Bergman

Diversity

“The greatest mistake in the treatment of diseases is that there are physicians for the body and physicians for the soul, although the two cannot be separated.”

- Plato

“Patients’ backgrounds and experiences often influence how patients understand their own health, their relationship with healthcare providers, and their treatment. ”

- online Advent Health University (accessed 9/30/20)

V. AGEISM & ANTI-AGEISM

- *"Discrimination against older people because of negative and inaccurate stereotypes—and it's so ingrained in our culture that we often don't even notice."* -and-

  "One of the last socially acceptable prejudices."

  - Kristen Weir, "*American Psychologist*" (2023)

- A violation of medical ethics: "Non-Maleficence"
- Clinical harm can be done by stereotypes about aging and older people:
  - Medical; MH; EOL choices, existential
  -"Stereotype Threat"

“Dementia-ism”

“…the dominant view of dementia is grounded in a ‘tragedy discourse,’ which emphasizes the loss of both ability and identity and this view directly harms people living with dementia above and beyond the effects of the pathology of any disease. “

-Reed, Carson, & Gibb, AMA Jn Ethics, 2017

Intimacy: In Their Own Words

“I’m looking at your face to know if it’s ok.”

Our relationship matters.

“It is possible and probable that my mind has slipped over the edge but I have not completely lost all communication with most of reality.”

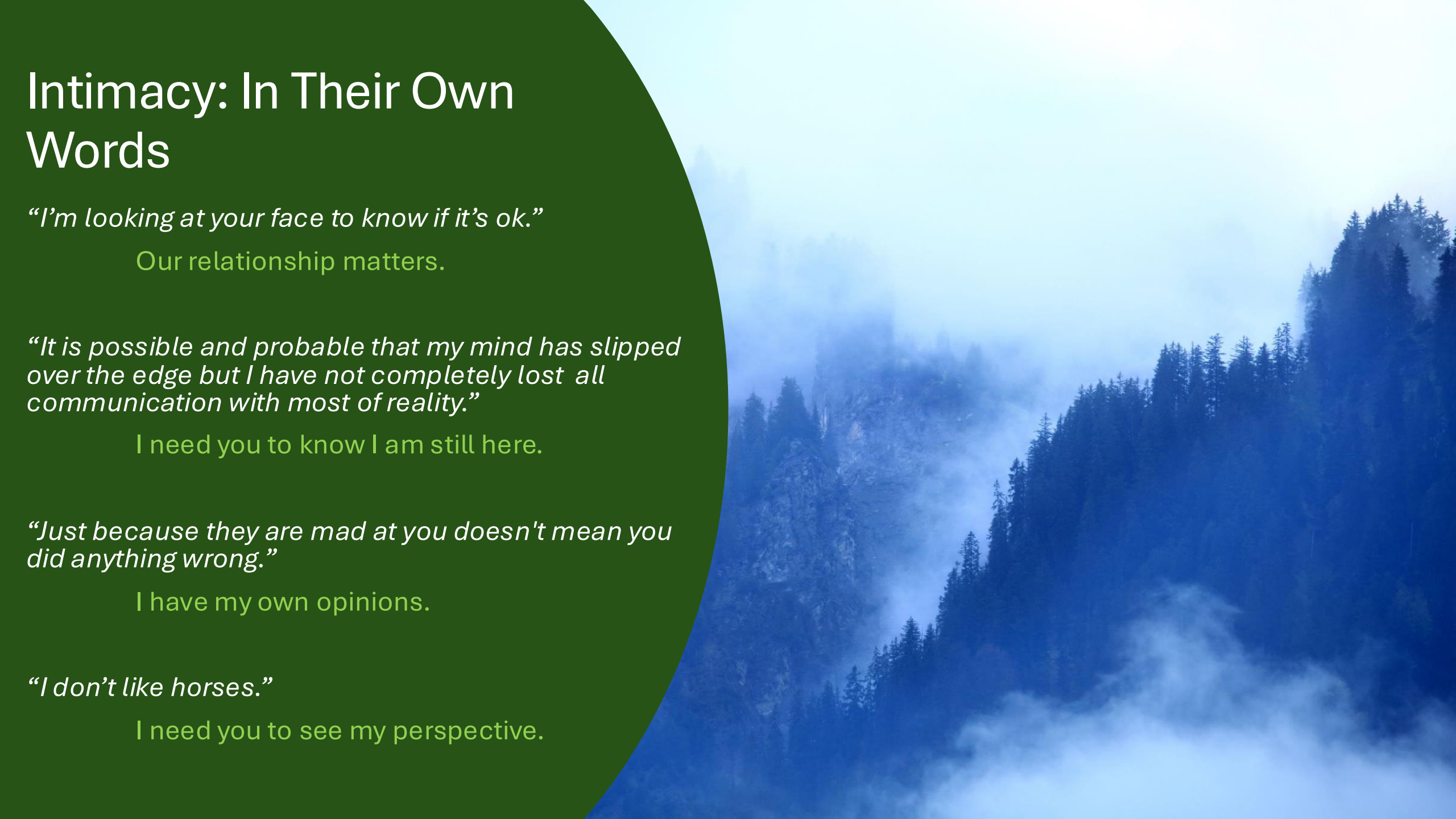
I need you to know I am still here.

“Just because they are mad at you doesn't mean you did anything wrong.”

I have my own opinions.

“I don’t like horses.”

I need you to see my perspective.



Prevalence of Ageism

"Experiences of Everyday Ageism and the Health of Older US Adults", JAMA Open Network, Jun 2022

- Survey of 2035 adults ages 50 to 80 years (1047 women, 988 men, 192 Black, 178 Hispanic, 1546 White, mean age 63 years).
- Assessed ageism along three dimensions:

    a). exposure to *ageist messages* in the form of environmental and social cues reflecting ageist prejudices and stereotypes.

    b). frequency of *ageism in interpersonal interactions*, specifically being targeted by discrimination rooted in others' assumptions and stereotypes about older adults.

    c). endorsement of *internalized ageism*.

Prevalence of Ageism

- Results: 93.4% of those surveyed reported regularly experiencing one or more forms of ageism every day.

- Internalized ageism was reported by 1664 adults (81.2%), ageist messages by1394 adults (65.2%), and interpersonal ageism by 941 adults (44.9%).

Reflective Practice

Who's the oldest person you know well?

- *How old is this person?*
- *What does this person look like?*
- *How does this person communicate?*
- *How is this person's health?*
- *How does this person respond to aging?*
- *How does this person spend her/his time?*

These experiences can influence our perspective on aging (including our own) -> how we conduct clinical care with older people -> specific clinical outcomes.

VI. COUPLES AND COGNITIVE DISORDERS: COPING AND CHANGING

- We must always consider these issues in the context of the individual couple and their unique human differences (e.g. heterosexual, same sex, ethnicity, married, not married, parenting/children, etc., etc.).
- Also, always consider how the couple functioned pre-morbidly (traits, hx of IPV, roles, etc).
- Especially in the early stages, despite day-to-day challenges, both partners may work hard to maintain a sense of couple-hood. "Facing it together like everything else".
- A sense of togetherness can help couples face life's adversities, such as dementia.
- Emotional intimacy may even deepen in the early stages of dementia.
- The healthy partner may assume more and more of the responsibility for maintaining this intimacy as the illness advances and reciprocity falls away.
- As the illness progresses, dynamics can emerge that challenge their traditional definitions of couplehood and these can undermine the different types of intimacy unevenly.
    - Role changes and associated identity changes.
    - Learning to live in the day, accept knowing that we can't always know, and that we are impotent in ways.
    - Moving from "Us" to a "Familiar Stranger" and grieving this.
    - Learning to maximize flexibility and creativity in adapting so that intimacy can be maintained in some form.

“Through Thick and Thin: The Meaning of Dementia for the Intimacy of Ageing Couples” (2022)

“The interconnection of physical and emotional intimacy meant doing everyday household chores together, doing fun things as a couple, and being in close physical contact in other ways, too, such as napping together, cuddling, and holding hands, all of which show how tightly intertwined emotional and physical intimacy is in the couples’ daily lives."

“All the spouses had noticed [impact of behavior change], and the wives, in particular, described situations where their husband with dementia could even behave in a disruptive or aggressive manner. We found that sometimes a person with dementia recognises the changes in their own behaviour, such as having become short-tempered. “

“Through Thick and Thin: The Meaning of Dementia for the Intimacy of Ageing Couples” (2022)

“According to the participants, continuous physical closeness is burdensome, and spousal carers wished to have some distance from the situation and occasionally be on their own. Some spousal carers felt so strongly about this situation that they described it as being ‘like imprisonment’ or ‘having a ball and chain ´. . . . In most marriages, spouses have some time for private activities or their own interests, but dementia may change this. “

“Through Thick and Thin: The Meaning of Dementia for the Intimacy of Ageing Couples” (2022)

“ As dementia progresses, the role of the spouse becomes that of a carer who takes care of a patient or, in some cases, similar to that of a parent looking after a child. . . . The physical and emotional intimacy of a spousal relationship changes into a different kind of intimacy or closeness that includes caring for the bodily and emotional needs of someone who is vulnerable and in need of help. ”

Some Barriers to Healthy Intimacy for Older People

- Ageist myths and stereotypes suggest that older adults are asexual, or that people with dementia don't experience these needs anymore.

- Homophobia, racism, transphobia, sexism, ableism, and other biases can intersect with ageism.

- Decisions to support/prohibit appropriate intimacy may be influenced by family and/or nursing home staff attitudes/fears.

- In a survey of facility staff and administrators, discussion about sexual consent often reflected gendered social norms - men are predators ("dirty old man") and women need protection ("sweet little thing").

  - A reliance on reporting, disregarding private space, and steering residents away from each other, was noted.

  - The result was an environment of surveillance that discouraged sexual and non-sexual intimacy.

Position Statement: Society for Post-Acute and Long-Term Medicine

"Capacity for Sexual Consent in Dementia in Long-Term Care" (2016)

- In the US, all persons who have reached the age of consent (varying by state from 16-18 y/o) have the right to consensual sexual activity.
- People are presumed to have the capacity to consent, unless there is specific evidence otherwise.
- All people have the right not to be the target of unconsented-to sexual behavior.
- People living in residential care have a right to appropriate accommodation for consensual sexual relationships.

VII. CAPACITY TO CONSENT TO PHYSICAL INTIMACY

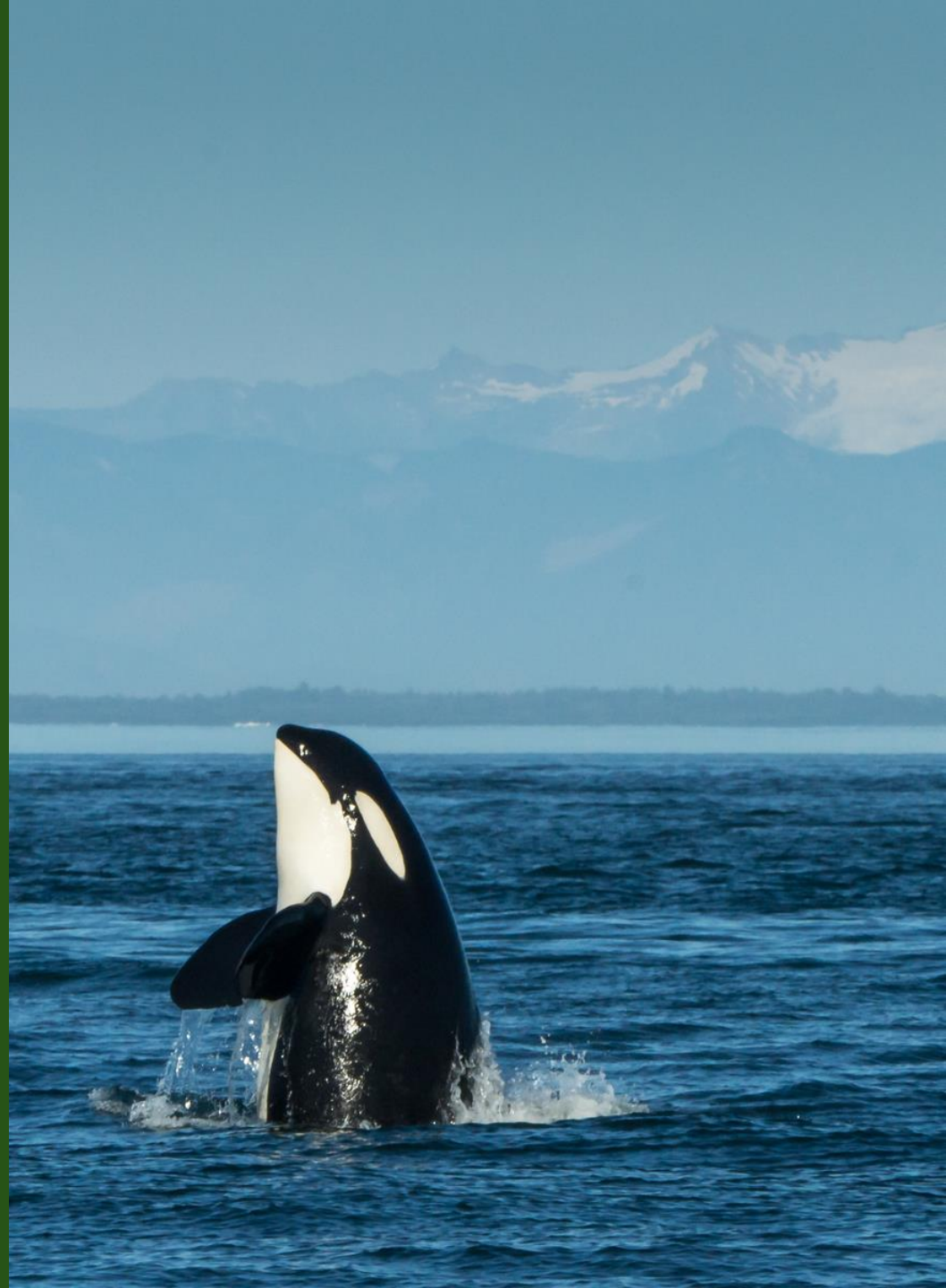
General Elements:

1). An awareness of the relevant issues.

2). The ability to rationally consider available options and the risks/benefits associated.

3). The ability to evidence a reasoned choice that is consistent with well being and values, in the person-environment setting, with sociocultural factors being incorporated.

4). The ability to express a preference or choice.



A Unique Domain of Capacity

- The nature of sexual relationships and interactions is often fluid and may not develop in a logical or planned way.
- The decision is often made in the moment. There may not be an extended time to weigh options or consult others.
- Substitute decision-makers or guardians are rarely, if ever, appointed to an older adult specifically to make sexual decisions.
- It is one of the least-developed capacity domains in terms of assessment and diagnostic strategies.

Key Points of Inquiry in Assessment

1). Does the person know the nature of the sexual or other activity in which they are engaging, including legality?

2). Does the person know the risks of sexually transmitted diseases and other potential consequences?

3). Does the person know how to tell if their partner desires the activity? And to differentiate that from their own feelings?

4). Does the person know appropriate times and places for particular intimate activities, and with whom they are engaging in the activity?

Key Points of Inquiry in Assessment

5). Does the individual have the capacity for the reasoning process inherent to consent, including an understanding of having a choice that is consistent with the individual's values and preferences?

6). Is the choice being made in a manner that is free from undue influence or coercion, i.e., is it a voluntary choice? Can the person protect themself from emotional coercion?

7). Is the person aware of who is initiating intimate contact?

8). Can the person state what level of physical intimacy would be comfortable?

9). Does the person have the capacity to say "no" to uninvited intimate contact? Or, withdraw consent? i.e. to say "stop", push away, etc.

Supporting Healthy Intimacy

- Diminished cognition alone does not necessarily imply diminished capacity for consenting to physical intimacy.
- Capacity for consent to intimacy in cognitive disorders should be viewed along a continuum of intimacy activities, from nonsexual touching to sexual intercourse.
- Higher degrees of intimacy and risk require a higher threshold of capacity.
- Capacity should be evaluated in the context in which the decision occurs.
- Capacity may fluctuate depending on the situation in which the decision is made or on the individuals involved.

VIII. COMMENTS AND QUESTIONS

"This is Us" by Mark Knopfler and Emmylou Harris (2006)

This is us down at the Mardi Gras
This is us In your Daddy's Car
You and the missing link
Yeah, I'd had a little too much to drink
Too long in the sun
Having too much fun
You and me and our memories
This is us

Rocking at the barbecue
Yeah, when we said I do
Hand jiving on the Ballroom floor
You in that wedding coat you wore
And you in that amazing dress
I was stoned on love I guess
You and me we were meant to be
This is us

This is us on our Honeymoon
In our hotel room
Sitting by the wishing well
Checking out of the love motel
Making plans for the sunshine state
Waiting at the terminal gate
You and me making history
This is us

And our baby boy
With our pride and joy
You at the Sunday Game
Standing next to "what's his name?"
On our Anniversary
With the family
You and me and our memories
This is us

IX. ADDITIONAL REFERENCES

- Barmon, C. et al. (2017). Understanding sexual freedom and autonomy in assisted living: Discourse of residents' rights according to administrators and staff. Journal of Gerontology: Social Sciences, 72(3):457–467.
- Boni-Saenz, A. (2016). Discussing and assessing capacity for sexual consent. Psychiatric Times, 33(7).
- Eskola, P. et al. (2022). Through thick and thin: The meaning of dementia for the intimacy of ageing couples. Healthcare (Basel), 10(12): 2559. doi: 10.3390/healthcare10122559.
- Lyden M. (2007). Assessment of sexual consent capacity. Sex Disabil, 25: 3-20.
- Syme, D. et al. (2016). Sexual consent capacity with older adults. Arch Clin Neuropsych, 31: 495–505.

WITH MY GRATITUDE