# A personal choice

## Sex, consent and nursing home liability in the age of Alzheimer's can put providers in unfamiliar, uncomfortable and untenable situations — if they aren't prepared

**By Kimberly Marselas**

At Asbury Methodist Village in Gaithersburg, MD, incoming residents are asked to sit for a brief interview, take a brief mental status test and share their daily needs.

It's a common process meant to determine a resident's level of independence and suss out which community programs might help them thrive. For those in healthcare settings, such assessments also set a baseline for care plans.

But what none of these commonly used physical or cognitive evaluations can truly do — despite their carefully calculated ability to account for educational and life experiences — is measure one's capacity to make deeply personal decisions.

That shortcoming is of increasing concern for caregivers of dementia patients, given a growing recognition that many elderly residents still value intimate physical relationships (and sometimes choose to start new ones).

The April prosecution of Henry Rayhons, an Iowa man charged with sexually abusing his wife while she was in the late stages of Alzheimer's, raised difficult ethical and legal questions about sex among cognitively impaired long-term care residents.

When does an individual lose the right to consent to sexual relations? If doctors deem intimate contact inappropriate, how do caregivers in nursing homes and other community settings enforce no-contact rules? How can facilities support residents' rights to engage in a basic human activity and still protect themselves?

Most importantly, could taking intimacy out of loving relationships actually cause some residents more harm than good?

Photo: Thinkstock

**Entrance interviews lack when it comes to measuring incoming residents' ability to make deeply personal decisions.**

"This particular story, because it was about memory loss and the ability to choose, it really rang a bell with people," says Gayle Doll, Ph.D., director of the Center on Aging at Kansas State University. "People were thinking, 'How can I tell people what I want when I can't actually tell them?'"

### 'Frequent' sex

It's no secret that sex between spouses and non-married residents happens frequently in assisted living communities and nursing homes, says Howard Degenholtz, Ph.D. and associate professor of health policy and management at the University of Pittsburgh's Center for Bioethics and Health Law.

But many adult children live in denial that intimacy is something aging parents want even as their bodies fail them. Meanwhile, the person-centered care movement has ushered in more private rooms and practices that respect dignity and encourage autonomy, such as sleeping arrangements that reflect couples' preferences.

"We have a big challenge, and I don't think we can easily reconcile it," Degenholtz says.

When the Hebrew Home at Riverdale in New York (of the recently renamed RiverSpring Health) issued the nation's first sexual rights policy for older adults in healthcare settings in 1995, it was "very innovative and controversial then, and still is," says Tina Batra Hershey, assistant professor of health policy and management and assistant director for law and policy at Pitt's Center for Public Health Practice.

A quarter of facilities had similar policies in 2013 and half said they planned to adopt one, according to a survey by AMDA—the Society for Post-Acute and Long-Term Care Medicine.

Doll says some policies help couples find alone time or outline sex education efforts. Other components are designed to regulate disturbing sexual behavior, such as masturbating in common areas or making aggressive, unwanted advances.

"It's probably safe to say that policies are propagating," says attorney Batra Hershey. "But my hunch is that it's incident-driven."

Last September, the Wisconsin Board of Aging and Long-Term

Care issued its own guidelines stating that policies "should uphold the belief that healthy consensual relationships are central to quality of life … address the right of the resident to engage in any consensual relationship even if the relationship creates challenges to religious, doctrinal, family or societal beliefs … and acknowledge (a facility's) responsibility to protect residents who may not be able to consent to sexual relationships."

Wisconsin, like many states, has no statutes that address sexual consent except in criminal cases. That means even the best policies remain murky.

### Not saying no

In the Rayhons case, the wife reportedly scored zero points on a Brief Interview for Mental Status given just days before the alleged abuse took place. A doctor had noted in her file that she could no longer consent to sexual activity.

The husband was ultimately exonerated.

**"You have to decide whether sex is a basic need like food or if it's a skill like balancing a checkbook. That's what it really comes down to."**

Howard Degenholtz, Ph.D.
University of Pittsburgh's Center for Bioethics and Health Law

Batra Hershey says it makes sense for facilities to look for assessments that provide black-and-white answers. Still, she concedes that dementia cases aren't clear-cut.

"Capacity to make decisions, it fluctuates over time and varies by the type of diagnosis," she says. "It can be confounding."

Degenholtz wonders whether a model in which a patient assents to certain activities might be more appropriate in cases of dementia.

"To say that you have to be able to give consent in this way, with this standard, then very few people with cognitive issues severe enough to live in a nursing home will pass," he says. "I have to question whether that's really practical."

It may be easier to understand when Alzheimer patients don't want something, says Degenholtz. Doll agrees, pointing out that patients who no longer speak can clearly express their dislike of being bathed.

Clinical psychologist Elizabeth Edgerly, Ph.D., chief program officer for the Alzheimer's Association, told the *Associated Press* "one of the biggest pieces" of the puzzle is determining if a patient can say no.

Loving, physical connections can be helpful for people with Alzheimer's, experts agree. Without some sort of meaningful touch, says Doll, seniors show the same failure-to-thrive as neglected infants. It's no surprise, then, that seniors would want to maintain intimacy with a spouse, or even turn to a new companion to fulfill physical needs.

"It's like muscle memory," says Doll, author of "Sexuality in Long-Term Care." "You don't forget how to do it or if you want it."

### Happy now?

Erika Baylor, director of social services at Asbury Methodist of Gaithersburg, MD, sees her residents' lives shrinking, their interactions changing.

"Every time you're giving up something, your things, your space, your independence," she says. "We want them to have as much control over their life as we can give them."

That translates into small choices — such as allowing assisted living and skilled nursing residents to decide when they shower and eat — but also more significant

## MANY SEE BRAIN GAMES AS A HEDGE AGAINST COGNITIVE DECLINE

Many seniors fear losing their minds more than losing their lives.

It's a sentiment Cathy Richards hears often as director of lifestyle and wellness for Asbury Methodist of Gaithersburg, MO. She launched a popular brain fitness program two years ago, and the class often attracts independent residents who have no signs of cognitive impairment.

"Their fears really have to do with their ability to self-advocate, to make decisions for themselves," says Richards. "There are some things you can't control with aging, but there are many things you can."

In addition to BrainWaves, the Wellness Center offers a place to talk about deeper fears and issues related to memory loss. A lifestyle questionnaire asks residents whether they have hope for the future and how often they laugh. Many express how critical it is that they preserve their relationships with their spouses, especially if one is declining before the other.

The number of brain games, software programs and physical activities continues to grow as facilities look for ways to help residents stave off dementia or limit its

Photo: thinkstock

impact. Many are designed to use information from a resident's assessments to tailor a unique combination of exercises or apps.

But leaning on a mini-mental state exam alone to evaluate capacity to engage socially can be a mistake, says Charles De Vilmorin, CEO and founder of Linked Senior, a cloud-based dementia and therapy engagement platform.

"People sometimes forget you're trying to assess true well-being, not just the cognitive aspect," he says.

By the end of the year, his company will provide feedback on which MMS is best matched to a particular patient. He's not alone in his quest to improve on cognitive assessments.

Australian Helen Guthrie is working with two American brain fitness advocates to develop a questionnaire that gives memory-challenged seniors a chance to more easily express their wishes and desires.

"A lot of the different instruments really focus on health status and clinical needs," Guthrie says. "They might take one page of life history, but it's a snapshot of who that person was. It doesn't talk about who they are now and what they want now."

Lars Holmquist, chief commercial officer for Simple C, says caregivers using his product are asked for input on what patients need.

Sometimes, the information comes directly from highly functioning patients. Other times, facility staff coordinates with the medical team and family to help understand an individual's values.

"If we can capture some of that information at the outset, then we have a baseline to work with," says Holmquist.

ones. If a resident with failing health wants to stay in an apartment with a spouse, they can opt for adult day services or more help from a care management team.

Staff try to record wishes early on so that those who struggle with cognitive issues later will have already provided actionable information. An ethics team comprising pastoral, medical, social work and family members steps in on tougher cases, says Baylor.

Experts warn that family members can complicate issues around sexual decision-making, placing their own values above those of their loved ones.

In cases where one patient fears another or physical harm has occurred, facility staff are required to intervene, with or without family input.

But one state ombudsman told Doll of a situation where the husband was abusing his wife and the family refused to separate them when informed.

Often, children bristle at the thought of Mom "sleeping" with a fellow resident. Some have asked staff to move a perceived offender to another floor.

If the family pays the bill and an adult child has medical power of attorney, it's likely that a nursing home will cave to that child's wishes, Doll says. But she's heard far more examples of severe decline following a forced split than she has about harm from unwanted sex.

"I think you have to look at the situation and say, 'What's best for Mom now?' Accept that it makes her happy."

Doll says some seniors have considered writing an advance directive that focuses on the right to have sexual relations. But Hershey says there is no legal guarantee that such documents would be honored.

"People have this perception of Mom not being able to function in the community, so how could she make decisions about sex?" says Degenholtz. "But you have to decide whether sex is a basic need like food or if it's a skill like balancing a checkbook. That's what it really comes down to: Where do you see sex on the continuum?" ■

## CONSENT MARKERS

In Wisconsin, case law suggests four guidelines on which to base an assessment to determine a person's ability to consent to sexual contact.

They include:

- The individual must understand the distinctively sexual nature of the conduct
- The individual recognizes her/his body is private and that s/he has the right to refuse to engage in sexual activity
- The individual recognizes the sexual contact may create possible health risks and physical consequences
- The individual needs to understand there may be negative social or societal response to the sexual behavior

*Source: Wisconsin Board of Aging and Long-Term Care's Recommendations for Addressing Resident Relationships*