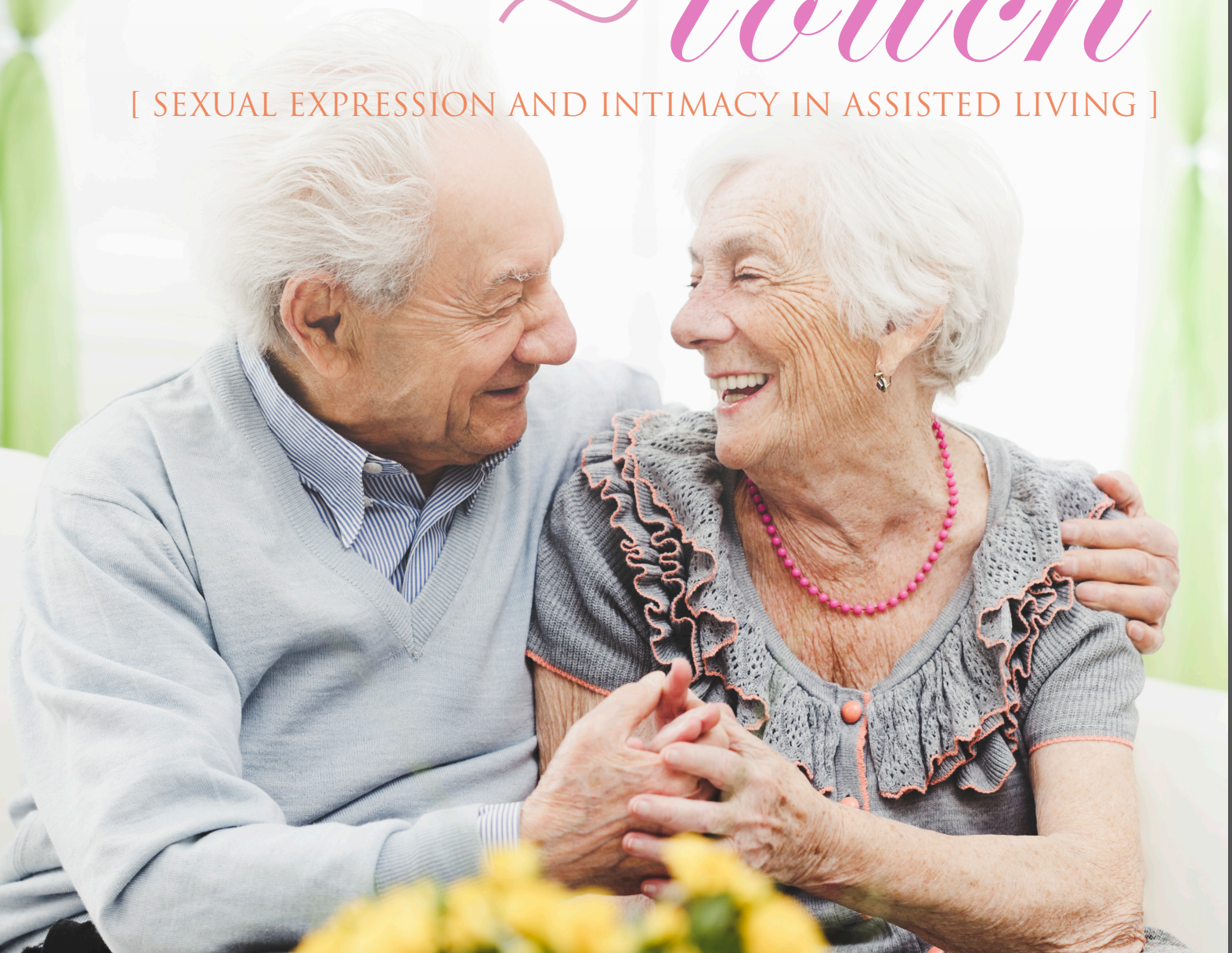
DR. RUTH WESTHEIMER once said, “Our way is not soft grass, it's a mountain path with lots of rocks. But it goes upward, forward, toward the sun.” Best known for her radio and television shows on sex, Dr. Ruth could easily have been referring here to the difficulty in talking about intimacy and sexual expression. But while it may be an uncomfortable topic of discussion, sexual intimacy is also an essential part of human life.

THE POWER OF HUMAN ~touch

[SEXUAL EXPRESSION AND INTIMACY IN ASSISTED LIVING]



We asked four authorities to illuminate the issues surrounding sexual expression in Assisted Living environments and to get the conversation started so that providers, residents, and family members can approach individual situations with respect and understanding.

Melanie Davis, PhD, is a sexuality education consultant in private practice; a graduate and undergraduate adjunct professor; and a Certified Sexuality Educator/Supervisor through the American Association of Sexuality Educators, Counselors and Therapists. She is co-president of the Sexuality and Aging Consortium at Widener University.

Elizabeth Edgerly, PhD, is a clinical psychologist and serves as Chief Program Officer of the Alzheimer's Association, Northern California & Northern Nevada. Dr. Edgerly joined the Alzheimer's Association in 1995 and oversees all chapter programs for persons with dementia, their families, and professionals.

Robin Goldberg-Glen, PhD, MSW, is an associate professor in the Widener University Center for Social Work Education. She has published in journals including the Journal of Gerontological Social Work, Journal of Women and Aging, and the Journal on Aging and Human International Development. She is co-president of the Sexuality and Aging Consortium.

Joel Goldman is a partner at Hanson Bridgett, founding board member of CALA, and nationally known expert on Assisted Living.

Q CAN YOU SPEAK TO SOCIETAL ATTITUDES REGARDING THE SEXUALITY OF OLDER ADULTS AND WHAT ISSUES MAY OCCUR BECAUSE OF THOSE ATTITUDES?

Melanie Davis & Robin Goldberg-Glen: A common perception in the dominant culture is that older adults are not as attractive, sexually desirable, sexually interested, or physically capable of enjoying sexual activity as younger people. We refer to this as age-related sexual privilege, i.e., younger people inherently have more sexual rights than older ones. For example, younger people see peers in romantic and sexual scenarios in literature, movies, TV, and advertising. They can easily find dating partners in person or online. They can show physical affection in public without being considered either cute or disgusting. Their physicians may automatically inquire about their sex lives and assess their risk for sexually transmitted infections. And they can be open about their gender identity and sexual orientation.

The flip side of this is that older adult sexuality is not seen as normative. Older adults are typically absent from marketing and entertainment focused on beauty, romance, intimacy, and sexual activity. When they are shown, with a few exceptions, their sexuality is portrayed as cute or as "dirty" old men and women, when of course, older adults often have deeply rewarding intimate relationships and report high levels of satisfaction with their sexual lives. Despite this, physicians often assume older patients aren't having sex, so they don't include questions during medical exams that would detect risky sexual behavior or lack of pleasure or consent. This is also true of other helping professionals including psychologists, nurses, social workers, and care managers who often fail to include questions about sexual wellbeing and health on their intake forms. The problem is further compounded by the fact that few young professionals and students in these professions want to work with older adults, often due to negative portrayals of this population. Older adults who are lesbian, gay, bisexual, and transgender may feel compelled to hide their sexual identity for fear of caregiver condemnation.

Elizabeth Edgerly: There's not much to see or read in popular media about the sexual expression of seniors because it's uncomfortable for people to picture and to accept the idea of sexuality in older adults in general in their parents, in particular. But we need to talk about it; nobody calls complaining about a resident's lack of sexual expression. Societal and personal attitudes around sexual expression especially come into play when caring for those with cognitive impairment. We tend to use substitute judgment for people with cognitive impairment whose own desires may not be immediately understood. But if the preferences of a person with dementia are not consistent with our own, it may not go well.

Joel Goldman: Society is pretty much in denial that older adults have sex. I have seen this denial manifest in many situations where family members are shocked when told that a resident is engaging in intimate activity. "My mother would never do that willingly!" Similarly, we have seen staff over-react when they discover that residents are engaged in sexual activity.

And somewhat surprisingly, I have seen instances in which law enforcement failed to take appropriate action. For example, I know of two situations in which residents were found by staff with illegal material on their computers. In both cases, the police failed to arrest the resident and simply confiscated his computer. In the second case, the police stated that normally they would have taken the person to jail, but were not doing so because he was older. In another situation, the police simply warned a resident who had solicited sex from 16-year-old waiters. And police declined to arrest a resident who fondled a housekeeper and solicited sex from a caregiver. In each of these situations, a younger person would have been facing jail time, yet the police seemed not to take these situations seriously because of the age of the resident.

Q WHAT POTENTIAL PROBLEMS CAN OCCUR REGARDING THE SEXUALITY OR SEXUAL PRACTICES OF OLDER ADULTS LIVING IN RESIDENTIAL SETTINGS SUCH AS ASSISTED LIVING OR MEMORY CARE COMMUNITIES?

Elizabeth Edgerly: Even taking sexual expression out of it, you still have cultural and personal differences and preferences to contend with in a residential setting. Imagine living with a roommate whose music you hate. The question is essentially how can you live with others in harmony? There are no clear-cut guidelines.

With cognitively impaired residents, notions of consent and capacity around sexuality can be problematic. Family members, staff, and other residents place judgments on what is "right" and "wrong," often based on their own values, religion, and sexual preferences. Even if you feel confident that the person has the capacity to make decisions about sexual expression, there are still challenges. So you say, "Ok, yes, they can enter into a relationship." Then how do you structure that in a residential setting and how will you evaluate it over time?

Melanie Davis & Robin Goldberg-Glen: Residents' sexuality isn't the problem; rather, it's the lack of understanding and knowledge that leads to problems. Older adults and/or their partners may not ask, prior to signing a contract, whether a community's policies will protect their sexual rights. They may not realize that upon entering Assisted Living, they may lose their right to sexual expression in private, with or without a partner. Their spouses or partners may not realize that if they are sexually intimate with a partner with cognitive loss, they may be suspected of sexual abuse. Adult children may interfere with their parents' rights to express their needs for intimacy and sexual contact.

Staff and administrators may unnecessarily and inadvertently create barriers to residents' sexual expression. These may include not providing opportunities for privacy, such as a guest room where a spouse can meet their partner and be intimate, or rooms where married or partnered couples can reside together. This lack of private space relays the message to residents, family members, and staff alike that older adults no longer have sexual needs and desires. At a time in the life cycle when loss is so prevalent, disregarding the need and desire for older adult intimacy can have serious consequences in terms of mental health and loneliness.

Moreover, it's important to consider the conflicting interests of the resident, spouses/partners, adult children, primary caregivers, and administrators—each of these people have attitudes and beliefs about sexuality that they bring to bear on the resident's sexual identity, interests, and behaviors. While one caregiver may request permission before entering a room, another may barge in and "catch" a resident masturbating. This creates unnecessary embarrassment and discomfort for both the aide and the resident. Residents in semi-private rooms may find that there is nowhere in the community to find time alone, other than perhaps a bathroom.

Fear, shame, and an inability to communicate abuse are significant dangers to residents. On the other hand, staff or family members may too quickly presume that abuse has occurred simply because a resident can no longer verbally express consent to sexual activity.

There is always a risk of sexually transmitted infection (STI) among any group of sexually active adults. We've spoken to administrators who assume that if there are no reports of STIs, there aren't any among the residents; however, since testing isn't routine, who would know? Also, even in a hypothetically STI-free setting, all it takes is one new resident or visitor with an STI before the risk becomes real.

Q WHAT OTHER EMOTIONAL, PRIVACY, OR CONSENT ISSUES SHOULD FAMILY MEMBERS AND THOSE PROVIDING CARE TO SENIORS BE AWARE OF?

Joel Goldman: We need to distinguish between residents who are mentally competent and those who are not. If a resident and their sexual partner are competent, an Assisted Living community has no right to interfere with sexual activity. However, communities are responsible for the well-being of residents. If, for example, a staff member is assisting a sexually active resident with showering and notices vaginal bleeding, there is a duty to assist the resident in getting appropriate medical attention.

Where a resident has a dementia diagnosis, the issues become much more complicated. The legal standard of competency to engage in sexual activity is not the same standard as competency to enter into a contract. A resident may be considered incompetent to make health care or financial decisions but still be legally competent to engage in sex. The standard in California, among other states, is whether the person understands the nature and consequences of sexual activity. If they do, they are competent to consent to sex and it would be a violation of personal rights to interfere with sexual activity. If they do not understand the nature and consequences of sexual activity, they are deemed incapable of consenting and it would be the duty of a community to prevent statutory rape from occurring. Unfortunately, this standard was devised for people with developmental disabilities, not for a resident with Alzheimer's. Memory care residents may well be able to understand the nature and consequences of sex but not be able to articulate them.

Thus, depending on the degree of memory impairment of a particular resident, a community may be violating resident rights if they interfere with sexual activity or may violate resident rights if they fail to intervene. As a practical matter, problems typically arise when one or more family members object. There was a recent case in the Midwest where the children of a female nursing home resident objected to the conjugal visits of her husband (who was not their father). The husband was charged with rape, put on trial, and acquitted by the jury. While these sorts of issues are typically raised by family members, I have seen at least one circumstance where staff

members were uncomfortable with residents having sex and contacted the authorities.

Because it may be difficult to ascertain whether someone has the capacity to consent, it may be necessary to bring in an outside professional to undertake an assessment. We had a situation not long ago in which a younger female resident with frontal lobe dementia was having a sexual relationship with the nephew of another dementia resident (whom she met when he was visiting his aunt). The community hired a nurse who had experience dealing with these sorts of issues to interview the female resident. She determined that the resident was competent to engage in sex; she was able to articulate that she knew what sex was, that she had initiated the relationship, that she knew that one could get pregnant from having sex but that she was too old to get pregnant. And her capacity to consent to sex was further confirmed by her closing comment: "There was no spark there. When you've had the best, it's hard to go back."

Elizabeth Edgerly: You can definitely get into difficult emotional areas when one partner is cognitively impaired. It is beneficial for people to touch and hold, and to have physical closeness. The desire for physical intimacy doesn't go away with cognitive impairment. But where's the line between physical touch that's desired and touch that's unwelcome? It's different for each individual.

Any discussion on this can be uncomfortable for intimate partners or family members. And even if a resident currently has the capacity to consent, the reality of progressive dementia is that there will be a point at which they will lose that capacity, when they don't know their partner or are unable to say "no" to unwanted advances.

Melanie Davis & Robin Goldberg-Glen: The primary responsibility should be to what the resident wants and needs. If they are cognitively capable, they should be the arbiters of their sexuality. Some older adults are done with sexual activity but may still want to be well-groomed and attractive to others. Some may want to be intimate with an existing partner, or with a resident they meet. Administrators, staff, and families should respect the wishes of residents, even if they differ from what might be the norm for the community's population or for the administrators, staff, and families—as long as the resident's wishes don't infringe on others in shared public space.

In terms of privacy, a basic kindness is to require staff to knock on a closed door and listen for a "Come in," prior to entering a room. If the room is semi-private, the staff person can still ask permission to enter the private space. A resident could also post a do not disturb sign similar to those used in hotels. These basic courtesies allow residents time to pull themselves together if they've been self-pleasuring, cuddling with a partner, etc.

There are very few contraindications to human contact. People with severe illnesses and disabilities—even those who are close to the end of life—benefit from being able to be close to other people in a non-medical way. For the least physically or cognitively capable, hair brushing, hand massage, and other forms of contact can be very rewarding. Always, the focus should be on how much contact the person would enjoy, rather than how much can be regulated.

Q WHAT CAN ADMINISTRATORS DO TO CREATE A POLICY AND CULTURE OF RESPECT FOR RESIDENTS' SEXUALITY WITH REGARD TO THEIR STAFF, RESIDENTS, AND FAMILY MEMBERS?

Melanie Davis & Robin Goldberg-Glen: We have been impressed by the work of the Hebrew Home in Riverdale (the Bronx) New York's pioneering work. In 1995, they wrote the first sexual expression policy in the country, called "Resident Rights to Intimacy and Sexual Expression." Robin Dessel, the Hebrew Home's director of memory care and a sexual rights educator, is on the Sexuality and Aging Consortium's Advisory Board.

Another of our Advisory Board members, Gayle Appel Doll, is the director of the Center on Aging at Kansas State University. She has researched sexuality in long-term care settings and is the author of *Sexuality & Long-Term Care: Understanding and Supporting the Needs of Older Adults*. Consortium members use that information and their own expertise as they consult with communities on policy development and staff training.

We encourage communities to look at this issue holistically. What's best for the resident? How can the families be assured that their loved ones are not being taken advantage of? How can staff be trained to embody the community's values and policies, even if their personal attitudes may be different? How can administrators come to the understanding that sexual expression is an important part of their residents' lives?

We also encourage communities to take an interdisciplinary approach so that all professionals are on the same page when it comes to policies and respect of our older adult population. Moreover, communities should work with their residents' council and Ombudsman to encourage inclusivity and conversation on the topic.

Joel Goldman: This is really less of a legal question than a sociological question. First, I think that we need to change society's attitudes about older persons and sex. I suspect that this will change as baby boomers come of age, and I think that we may start to see people address issues pertaining to sexuality in their advance directives. In the interim, I recommend that issues of sexuality be included in staff training and that communities with memory care programs provide families with information at the outset of admission. That way, families can be made aware of the issues pertaining to sexuality without being confronted with a difficult personal situation. The Alzheimer's Association had an excellent (and very touching) film that they showed at a CALA conference a few years back. Resources like this could be used to help facilitate discussion.

Elizabeth Edgerly: Address the issue on admission. Having an early discussion with family members is wise. You can open the conversation with something along the lines of, "People develop relationships here. Having new friends is a healthy part of living here. Sometimes these relationships can become romantic. We like to talk about this possibility before people move in. What are your thoughts about that? Do you have any specific concerns about this that we should know about?" You should also have a written policy on intimacy. If you don't have one yet, reach out to colleagues for models.

It's hard that there are no black-and-white guidelines, but it's also good. It's not like we can have regulators weigh in when they know nothing about individual situations. It shouldn't be an attitude of "yes/no," but "how." For instance, I was speaking at a conference and the audience was asked how many would allow pornography. This was a very mixed audience of all types of providers: conservative, liberal, religious, etc. Yet despite this, I was shocked at how many had a policy in place allowing pornography. One person who worked in a faith-based community said, "This goes against my personal and religious beliefs, but because this is the policy of the place I work, I'm ok with it." Remember: it's about fostering an attitude of privacy, dignity, and respect for each individual's sexuality and intimate needs.■