

Sex & Alzheimer's Disease: Deciding in Advance

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INTRODUCTION

When former Iowa legislator, seventy-eight-year-old Iowan Henry Rayhons was accused of sexual assault against his wife, it was headline news. In April, 2015 Mr. Rayhons was acquitted.¹ His wife, Donna, had been an Alzheimer's disease (AD) patient living in a local care facility. Mrs. Rayhons is now deceased. The details of the case suggest that the nursing home did not adequately communicate its opinion to Mr. Rayhons that his wife had become incapable of consenting to sex. This detail, combined with general social discomfort in addressing sexuality in dementia patients, complex family dynamics, and poor prosecutorial judgment, seem to have led to the charges against Mr. Rayhons. Most of the discussion of the Rayhons case has focused on declining decisional capacity during the course of AD and its implications for consenting to sex. In the nursing home setting, capacity to consent becomes a public question, subject to staff opinion and medical evaluation.

ANALYSIS

Traditionally, sexual assault was legally impossible within marriage. It was not until the 1970s that a right of spousal refusal to sex was generally recognized in law, reflecting gains in women's equality. Mr. Rayhons was prosecuted under a 1989 Iowa state law that includes inability to consent in defining marital rape.² In contrast to the 1970s, the legal construction of sexual consent for unmarried adults is now a fraught issue, especially for college students. California has recently moved to require its public universities and colleges to implement an "affirmative consent standard" so that agreeing to sexual activity is "conscious, and voluntary," as well as "ongoing throughout a sexual activity."³

Neither the legal conception of sexual consent in marriage nor the explicit "affirmative consent" model is helpful in structuring sexual relations between AD patients and the spouses or partners they have committed to prior to the onset of their disease. Rather, understanding desire for physical closeness and sex as expressions of enduring appetites distinct from rational capacity to consent is more appropriate. As Daniel Reingold, an elder care expert, was quoted in the *New York Times*, "Touch is one of the last pleasures we lose. . . . So much of aging and so much of being in a long-term care facility is about loss, loss of independence, loss of friends, loss of ability to use your body. Why would we want to diminish that?"⁴ This desire for physical intimacy, including sex, continues even as cognitive ability declines, and it ought to be respected.

We can expect the management of sex and AD to be a continuing subject of debate and policy struggles. In 2013 the AD population in the US was estimated to exceed 13 million, with a potential increase to 13.8 million Americans by 2050.⁵

For couples concerned with preserving their privacy and autonomy in this arena, one possible tool is an

expanded use of the advance healthcare directive. Advance directives are generally crafted to specify preferences for medical treatment when we cannot speak for ourselves or to name someone to speak for us—or both. In response to increased anxieties over living with late-stage AD, some advance directives now include highly specific language on when and how to withhold food and water by mouth so that death is not prolonged by unwanted feeding and hydration.

While sexual contact is not a medical treatment, it may be an important contributor to the both the physical and emotional welfare of the AD person who is beyond cogent verbal expression of desire. Advance directives could simply include language specifying that one's spouse or designated partner retained authority to decide whether sexual expression between the partners was wanted and appropriate. It would be sensible also to establish some very advanced degree of incapacity beyond which even a designated spouse could not chose to engage sexually with their AD partner.

Authorizing one's partner to decide on physical contact does leave room for exploitation. In ethical matters, good choices are often about designating which agent should be empowered to decide correctly, but also to make an honest mistake on our behalf. For the moment, many physicians and institutions will construe a lack of robust ability to consent with incapacity to desire and benefit from sexual contact. This is a failure that potential patients may wish to be spared. In established partnerships decisions about sexual relations ought to be left to the partners, absent some compelling reason to the contrary. Leaving the decisions to partners does create some risk even a well-intentioned person may misread her AD loved one. But unless signs of coercion or abuse are clear, then the consequences of misreadings are less burdensome than the excess conservatism of healthcare professionals and institutions.

CONCLUSION

People diagnosed or concerned about AD should be able to set out in writing in advance that they and their spouse or established partner retain a zone of privacy with regard to sexuality. Limiting the decision on sexuality to a written directive is one plausible protection for the AD spouse against an exploitative partner. Sensitive care for people with AD includes extending their enjoyment of daily pleasures as long as possible, including the satisfaction of physical intimacy. Since the medical and caregiving communities' ability to cope effectively with sexual consent practices in the context of dementia is still developing, patients and their partners can benefit from taking control of their privacy and welfare by advance directive.

¹ Tony Leys and Grant Rodgers, "Rayhons: 'Truth finally came out' with not guilty verdict," The Des Moines Register online, April 22, 2015, <http://www.desmoinesregister.com/story/news/crime-and-courts/2015/04/22/henry-rayhons-acquitted-sexual-abuse/26105699/>

² Dana Dovey, "Iowa Rep Henry Rayhons Arrested for Marital Rape After Alleged Sexual Contact with Alzheimer's-Stricken Wife," Medical Daily, August 19, 2014, <http://www.medicaldaily.com/iowa-rep-henry-rayhons-arrested-marital-rape-after-alleged-sexual-contact-alzheimers-298730>.

³ California Sen. Bill No. 967 (2013–2014 Reg. Sess.), "Student Safety: Sexual Assault." https://leginfo.legislature.ca.gov/faces/billNavClient.xhtml?bill_id=201320140SB967.

⁴ Pam Belluck, "Sex, Dementia and a Husband on Trial at Age 78," The New York Times online, April 13, 2015, http://www.nytimes.com/2015/04/14/health/sex-dementia-and-a-husband-henry-rayhons-on-trial-at-age-78.html?_r=0.

⁵ Liesi Hebert et al., "Alzheimer Disease in the United States (2010–2050) Estimated Using the 2010 Census." *Neurology* 80, no. 19 (2013): 1778-1783. Doi: 10.1212/WNL.0b013e31828726f5.