Sexuality, Dementia, and Catholic Long-Term Health Care

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Abstract. Sexual activity between spouses in long-term care settings has received increasing attention recently. This article considers the special case of sexual activity between spouses in long-term care when one spouse has dementia. The complex and interrelated issues of aging, sexuality, and dementia are reviewed, first through examination of a recent court case. Then, issues of sexuality and aging, assessment of capacity and competency in dementia, and institutional responses to these situations are considered in light of Catholic bioethical tradition. The argument is made that Catholic long-term health care facilities ought to proactively address these issues, and some concrete suggestions are offered to address clinical care and risk management in these settings. National Catholic Bioethics Quarterly 15.3 (Autumn 2015): 493–513.

What is old age? At times it has been referred to the autumn of life—so Cicero calls it—following the analogy suggested by the seasons and the successive phases of nature. We need but look at the changes taking place in the landscape over the course of the year, on the mountains and in the plains, in the meadows, valleys and forests, in the trees and plants. There is a close resemblance between our human bio-rhythms and the natural cycles of which we are a part.

—Pope St. John Paul II, Letter to the Elderly

In his beautiful 1999 meditation on the “autumn of life,” Pope St. John Paul II considers both the wisdom and the vicissitudes of old age. Speaking to those who have “made a long journey,” he refers to old age as a time of revisiting one’s past...
with the maturity and wisdom gained over a lifetime. Aging has positive aspects, but in the context of modern societies is often underappreciated or devalued because of an instrumental attitude toward older persons that equates productivity with value.

Most, if not all, health care providers working with the elderly would agree with John Paul II’s assertion that the best place for an aging individual to live is at home or in situations in which individuals feel “at home” and can still contribute to family life. At the same time, situations arise in which an elderly person or couple can no longer manage independent living for physical, cognitive, or psychological reasons, and require institutional level care of some sort. In either case, it is vital that an elderly person continue to feel a sense of belonging and participation with others, including spouses, children, and friends. Our respect for the elderly as persons possessing inherent dignity is captured in the biblical command to “honor your father and mother” (Exod. 20:12; Deut. 5:16). This, John Paul II suggests, entails a threefold responsibility: “Welcoming them, helping them and making good use of their qualities . . . to ensure that elderly people can grow old with dignity, without having to fear that they will end up no longer counting for anything. There must be a growing conviction that a fully human civilization shows respect and love for the elderly, so that despite their diminishing strength they feel a vital part of society.”

Nursing homes, then, should never be places to which the elderly are admitted and then forgotten, but rather institutions in which individuals can feel valued and respected and can maintain contact with loved ones in a meaningful way. Admission of a spouse to a long-term care facility, for example, does not mean the end of a marriage, but a new phase with new challenges in maintaining a deep, loving relationship that in many cases has already existed for decades. A special issue that arises in such settings is the ongoing nature of a couple’s sexual relationship, something that is often ignored, undervalued, or assumed to be absent, but that remains integral to a couple’s relationship as they age.

The issue of sexual activity between spouses in long-term care settings has received increasing attention in recent years for a number of reasons. Not least

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1 John Paul II, *Letter to the Elderly* (October 1, 1999), nn. 3, 10.
2 Ibid., n. 9. Pope St. John Paul II writes, “And what of today? If we stop to consider the current situation, we see that among some peoples old age is esteemed and valued, while among others this is much less the case, due to a mentality which gives priority to immediate human usefulness and productivity. Such an attitude frequently leads to contempt for the later years of life, while older people themselves are led to wonder whether their lives are still worthwhile.”
3 Ibid., n. 13.
4 Ibid., n. 12.
among these are straightforward demographic factors: the steadily increasing number of people in this country over the age of sixty-five, longer life expectancy, and the arrival of the baby boomer generation, which began turning sixty-five in 2011, and for whom discussion of sexuality was much more open in their young adulthood of the 1960s and 1970s. In the United States, the percentage of the population over sixty-five is, according to US Census Bureau projections, expected to increase from 13 percent in the year 2010, to more than 20 percent of the population by the year 2050, a much larger proportion of elderly individuals than ever before.6

Despite a long history of myths to the contrary, sexuality remains an integral dimension of the lives of the elderly, one that long-term care staff must become increasingly comfortable addressing. Elio Cardinal Sgreccia has written that our sexuality is a “structural conformation of the person,” a dimension of our personhood deserving both acknowledgment and respect.7 This will be important for many aging individuals who develop dementia, as it raises unique clinical and ethical concerns in the long-term care setting related to issues such as autonomy and independence, privacy, capacity for decision making, death and dying, and the issue of disinhibition that occurs in some types of dementia, all of which can impact the expression of sexuality.

In this article I would like to suggest that, given that human sexuality is a lifelong dimension of persons, and that dementia impacts our sexuality in varied ways, Catholic long-term care institutions ought to be proactive in addressing sexual relationships between older married couples when one or both spouses live in residential settings. I will approach this first through a case study that touches on many of these issues, then discuss the issues raised, and conclude with some suggestions about how this topic can be addressed within a Catholic long-term health care context.

Case Study: Sex and Dementia

Clinical Case History

Donna Lou and Henry Rayhons of Iowa married in their early seventies, a second marriage for both.8 Both were widowed, and both had adult children from


6 The Baby Boomer generation is defined as those born between 1946 and 1964, a cohort of seventy-six million people, far larger than the number of babies born in the previous twenty years. For an overview of the aging process in its many aspects, see Judith A. Sugar et al., Introduction to Aging: A Positive, Interdisciplinary Approach (New York: Springer, 2014), 11.


8 The individuals in this case are known because the court case was widely reported in the media; see, for example, Pam Belluck, “Sex, Dementia and a Husband on Trial at Age 78,” New York Times, April 13, 2015, http://www.nytimes.com/; Brian Gnley, “Questions about Sex and Dementia Go to a Jury for the First Time,” Bloomberg Weekly, April 20, 2015; Sarah Kaplan, “In an Iowa Courtroom, an Astonishing Case of Sex and Alzheimer’s,” Washington Post, April 7, 2015; and Ina Jaffa, “Can a Person with Dementia Consent to Sex?,” All Things Considered, National Public Radio, April 22, 2015, http://www.npr.org/.
their previous marriages. Henry was a corn and soybean farmer who had also served nine terms in the Iowa state legislature. He met Donna singing in a church choir, and the two married in 2007. By all accounts the couple were deeply in love and their marriage was a happy one.

In 2013, Donna began to show signs of dementia. She had episodes of not being able to recall her daughters’ names and had several experiences at restaurants that raised red flags for her family. In one instance, she was unable to remember how to eat a hamburger. In another, she went to the restaurant bathroom and attempted to wash her hands in the toilet instead of the sink.9 Matters came to a head in March 2014 when one of her daughters was called to pick up her mother, who, arriving at the Iowa State Capitol (where Henry was working), was found to be inappropriately dressed, wearing lingerie and unzipped pants beneath her coat. Health care consultation was sought, and Donna was diagnosed with dementia; later that month she was admitted to the Concord Care Center in Garner, Iowa.10

Henry visited Donna daily, often twice a day, sometimes praying the rosary at her bedside, and he regularly took her to church on Sundays. During some of the nursing home visits, Henry was reported to have engaged in sexual relations with his wife (a fact he acknowledged).

In May 2014, a care plan was established for Donna, recommending limitations on trips outside the facility. Court records indicated that the staff social worker was asked by Donna’s daughter Suzan whether her mother had the capacity to consent to sexual relations. The social worker consulted with the facility’s physician, who responded that Donna did not have the capacity to consent. Donna was moved from a single to a double room, and staff spoke to Henry about his spouse’s lack of capacity

9 It is a now well-established clinical fact (e.g., through beta-amyloid neuroimaging) that individuals with Alzheimer’s disease have the disease biologically for at least a decade before there are any observable signs of memory impairment. See Etty P. Cortes Ramirez and Jean-Paul G. Vonsattel, “The Neuropathology of Neurodegenerative Diseases,” in Dementia: Comprehensive Principles and Practice, ed. Bradford Dickerson and Alirezza Atri (Oxford: Oxford University Press, 2014), 145–159. This book is an excellent single-volume overview of the many aspects of dementing illnesses, with contributions from leading experts in dementia research.

10 Both dementia and Alzheimer’s disease are mentioned in media reports. For clarification, “dementia” refers to any progressive decline in a person’s cognition or functioning not explainable by the minor changes that occur during the normal aging process. It is a descriptive term, and once present, it is critical to determine what illness or injury is causing dementia; the most common form of neurodegenerative dementing illness in the elderly is Alzheimer’s disease. Other common causes of dementia in the elderly include vascular dementia (brought on by small strokes or widespread vascular disease), and a combination of both. In addition, there are numerous conditions referred to as “reversible dementias” in which an individual experiences cognitive or functional decline from a medical condition that once successfully treated can bring about a return to normal cognitive function. Among the elderly in nursing home settings, a common cause of this type of condition is a urinary tract infection, which can cause rapid onset confusion, cognitive decline, and hallucinations. Once successfully treated with antibiotics, a person’s functioning can return to or near baseline.
to consent to sexual activity. He declined to follow this advice. On May 23, 2014, Donna’s roommate complained to staff about noises coming from behind the closed curtain in Donna’s portion of the room, and according to court documents, a security camera in the facility recorded Henry dropping his wife’s underwear into a hallway laundry bag after leaving the room.

At this point, Donna’s daughter Suzan applied for guardianship over her mother. The guardianship was granted, and Suzan had her mother relocated to a different facility at some distance from Henry’s residence, making it more difficult for him to visit her. Donna died in August 2014. A few days after her funeral, one of Donna’s daughters filed sexual abuse charges against Henry. He was arrested, charged, and went to trial.11

The Court Case

Henry Rayhons was charged with third-degree felony sexual abuse. Court documents stated that the “defendant on or about May 23rd, 2014, in Hancock County, did commit sexual abuse upon D. R. by performing a sex act on D. R., a person suffering from a mental defect or incapacity which precludes giving consent, and with whom he was not cohabitating as husband and wife at the time.”12 This was eight days after staff told him that she was not able to consent to sex. The court document also stated,

On 5/15/14, during a care plan meeting with Concord staff and D. R.’s family, the Defendant was informed that D. R. did not have the cognitive ability to give consent to any sexual activity. On 5/23/14, a roommate of D. R. reported to Concord staff, that earlier in the evening, while she was in a shared room with D. R., the Defendant had entered the room and pulled the curtains closed. The roommate then heard noises indicating to her that the Defendant was having sex with D. R. The Garner Police Department was then contacted by Concord staff. Surveillance video showed that the Defendant entered D. R.’s room at approximately 7:43 p.m. and left her room at approximately 8:13 p.m. On his way out, the Defendant also discarded undergarments belonging to D. R., into a laundry bag located in the hallway. During an interview with a DCI Agent on June 12th, 2014, the Defendant admitted to having sexual contact with D. R. on May 23, 2014 and to having a copy of the documentation regarding D. R.’s inability to give consent due to her lack of cognitive ability.13

Several medical professionals and nursing home staff who had been involved in Donna’s care were called to testify at Henry’s trial. Michelle Dornbier, Concord Care’s social worker, testified that Donna was always happy to see Henry when he came to visit and that the Center had a policy that allowed for consensual sex at the facility. The Center did not, however, have any written policies in place at the time that addressed sexual activity in the context of dementia. The social worker testified

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11 The details of these events were reported in Belluck, “Sex, Dementia and a Husband on Trial.”
13 Ibid.
that after Donna’s daughter contacted the facility, she consulted with the Center’s attending physician, who reported Donna did not have the capacity to consent to sexual activity. She informed Mr. Rayhons of the physician’s opinion. Also, testimony was offered by Dr. John Boedecker, Donna’s family physician, who testified that he had done mental status testing with Donna, and noted she was unable to recall three words (0/3 delayed recall) that she was asked to remember as part of a mental status examination.14

In April 2015, a jury acquitted Henry of the felony sexual abuse charges. Had he been found guilty, he could have faced a sentence of up to ten years in prison.15

Issues Raised by the Case Study

Unfortunately, many aspects of Henry and Donna’s case were problematic. I would like to consider, from the perspectives of clinical care and risk management, four issues raised by this case study, and the possibility that different actions on the part of health care staff might have led to different outcomes, as well as a less stressful process for all concerned. These include (1) sexuality and aging, (2) sexuality and dementia, (3) the assessment of capacity and competency, and (4) institutional responses to sexuality in the context of dementia. At the conclusion of each section I will offer, as a clinical neuropsychologist working with the elderly for over two decades in long-term care, inpatient geropsychiatry, and outpatient settings, some thoughts on how these issues might be addressed differently to improve clinical care and reduce risk.

Sexuality Later in Life

Aging and dementia per se are not themselves barriers to sexual desire and sexual activity and, barring medical issues that can directly interfere with sexual expression, individuals continue to engage in sexual relations into their nineties.16 When medical issues interfere with the expression of genital sexuality, older couples

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14 This is a standard part of an office mental status examination. The paradigm is for the examiner to say three words to the patient, who repeats them (e.g., hat, daisy, and chair). This is done several times to verify that the words have been learned. Several minutes later, the examiner asks the patient to recall the three words. If the patient is unable to recall all three independently, cues are given. First, a category cue is given (e.g., “an article of clothing” for the first word “hat”). If this does not prompt recall, the examiner gives the patient a multiple choice cue (e.g., “Was the word jacket, hat or shoes?”). The media accounts do not specify whether such cuing was done, only that Donna could not recall the three words, nor do they relate what else may have been done as part of a mental status exam, or whether any commonly used standardized instruments, such as the Mini-Mental Status Examination, the St. Louis University Mental Status Examination, or the Montreal Cognitive Assessment, were administered.

15 Belluck, “Sex, Dementia and a Husband on Trial.” See also Kaplan, “In an Iowa Courtroom.”

16 See Bauer, “I Always Look under the Bed.” See also Elizabeth A. DiNapoli et al., “Staff Knowledge and Perceptions of Sexuality and Dementia of Older Adults in Nursing Homes,” Journal of Aging and Health 25.7 (October 2013): 1087–1105; and Carien Hartmans
continue to value touch and other aspects of physical intimacy in their relationships, including handholding, embraces, etc.

As noted above, sexuality is with us as long as we live, and in recent decades, cultural prohibitions on discussion about sex have loosened considerably. Recognition has grown that couples engage in sexual activity through the whole course of their marriage. Many married couples wish to see this aspect of their relationship continue even after one of them has entered a nursing home. Research into the aging process demonstrates that stereotypes about aging and sexuality are both unfounded and detrimental to these individuals.17

The Church has long meditated on the nature and purposes of marriage. The Second Vatican Council eloquently expressed the Catholic vision of marriage:

The intimate partnership of married life and love has been established by the Creator and qualified by His laws, and is rooted in the conjugal covenant of irrevocable personal consent. Hence by that human act whereby spouses mutually bestow and accept each other a relationship arises which by divine will and in the eyes of society too is a lasting one. For the good of the spouses and their offspring as well as of society, the existence of the sacred bond no longer depends on human decisions alone. For, God Himself is the author of matrimony, endowed as it is with various benefits and purposes . . . Thus a man and a woman, who by their compact of conjugal love “are no longer two, but one flesh” (Matt. 19:ff), render mutual help and service to each other through an intimate union of their persons and of their actions. Through this union they experience the meaning of their oneness and attain to it with growing perfection day by day. As a mutual gift of two persons, this intimate union and the good of the children impose total fidelity on the spouses and argue for an unbreakable oneness between them.18

In addition, popes before and since the Second Vatican Council have written at length on human sexuality and marriage. John Paul II, for example, offered an extended meditation on love and marriage in different documents before and during his papacy.19 Given the Church’s consistent support for the integrity of marriage, admission to

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18 Paul VI, Gaudium et spes (December 7, 1965), n. 48.
19 See Karol Wojtyła, Love and Responsibility, trans. H. T. Willetts (San Francisco: Ignatius Press, 1981), where he considers how the personalistic norm he articulates is lived out: “If a person can never in any circumstance be a mere object of enjoyment of another person, but can only be the object (or rather the co-subject) of love, the union of man and woman needs a suitable framework, one which permits the full development of the sexual relationship while ensuring the durability of their union. Such a union is, of course, called a marriage” (211). Several essays touching on love and marriage are also contained in Karol Wojtyła, Person and Community: Selected Essays, trans. Theresa Sandok (New York: Peter Lang, 1993); John Paul II, Familiaris consortio (November 22, 1981); and John Paul II, Man and Woman He Created Them: A Theology of the Body, trans. and ed. Michael Waldstein
a nursing home should not be seen as an insurmountable obstacle to the maintenance and continued development of any aspect of a marital relationship.

Sexual relationships in the context of marriage are integral across the life span, which includes old age. Thus, in Donna’s case the following might have been helpful in avoiding later conflict:

- **Education for long-term care staff** in a systematic and ongoing fashion about sexuality in the context of aging in general, including such topics as sexuality as an integral aspect of the whole life span and the whole person, common sexual problems encountered in the aging process, medical issues that can interfere with sexuality such as hypertension and diabetes, psychological factors that can affect sexuality, medical interventions to help improve sexual functioning, and staff education specifically focused on sexuality in long-term care settings.

- **Education in undergraduate and graduate health care programs** incorporating instruction, as a regular part of the curriculum, on aging, sexuality, and dementia that would give future professionals opportunities to consider their own attitudes toward sexuality, and to be knowledgeable about sexuality and aging issues they will encounter in their clinical work.

- **Educational materials** provided by the long-term health care institution to residents and families about sexuality and aging as part of the process of admission to a long-term care facility to help normalize conversation about these issues. Such materials could include fact sheets about aging and sexuality, and institutional policies related to sexual relationships.

- **Conversation** by appropriately trained staff (e.g., social workers, nurses, physicians, nursing assistants, facility administrators, and physical, occupational, and speech therapists) with new residents and family members about sexuality early in the admission process to give them the opportunity to express their own thoughts and feelings in these matters.

The combination of activities such as these can serve to normalize conversations about sexuality, and can let residents know that it is both possible and acceptable for them to give voice to their concerns, which can help circumvent difficulties later on in a resident’s stay.

**Sexuality and Dementia**

“Dementia” is a general term that refers to decline in some aspect of an individual’s cognition or daily functioning. Once it has been established that an individual has dementia, the next vital step is to determine the cause. Some forms of dementia are reversible, some are not.20 Various types of dementia can impact the expression of individual sexuality.


20 Examples of reversible conditions, which can cause profound and sometimes rapid-onset changes in an individual’s cognition and behavior, include metabolic conditions, drugs,
In a 2013 qualitative study in Canada, Michael Bauer et al. interviewed nursing home residents (both normally aging individuals and those with dementia) about their perceptions of needs and barriers to the expression of sexuality in long-term care settings. They found both groups of patients felt that they were viewed by staff as asexual beings, and that sexuality was an aspect of quality of life largely ignored by long-term care staff. Residents noted that sexuality continued to matter to them through their advancing years, and the longing for intimacy remained present in individuals with dementia. Residents also expressed the sense that long-term care facilities were not environments conducive to the development of relationships, physical intimacy, and the expression of sexuality due to the lack of privacy. They felt that staff had little understanding of sexuality in old age and were largely unaware of such feelings in those they cared for. The authors also noted that many long-term residential staff are not comfortable dealing with old-age sexuality partly due to lack of training in this area.21

Dementia can cause significant changes in expression of sexuality. In a study of individuals with dementia and mild cognitive impairment22 affecting intimacy and sexuality, Helen Davies et al. found five difficulties in relationships when one spouse has dementia:

- Diminished communication between spouses.
- Alterations in marital cohesion, the degree to which partners engage with each other as equals.
- Decrease in expressions of affection.
- Perceived caregiver burden, including the physical and psychological burden of caregiving for an individual with dementia.
- Ambiguity about the future of the relationship, including how the relationship would change when one member was admitted to a long-term care facility.23

21 Bauer, “I Always Look under the Bed.”

22 Mild cognitive impairment (MCI) is a clinical term for the slight but noticeable decline in memory, thinking, and decision-making skills that goes beyond what is typical of normal aging but is not serious enough to meet diagnostic criteria for dementia. (MCI is referred to in the current Diagnostic and Statistical Manual of Mental Disorders as mild neurocognitive disorder; see American Psychiatric Association, Diagnostic and Statistical Manual of Mental Disorders, 5th ed. [Washington, DC: APA, 2013], xxx–xxxii, 591, and elsewhere.) A growing body of evidence shows that individuals with MCI in whom the most noticeable impairment is in memory are at higher risk for developing Alzheimer’s disease, and that subjective complaints of memory problems, even from individuals who score normally on cognitive screenings, should be taken seriously, as they may be an early warning sign of an oncoming dementia.

The authors concluded that early intervention and education could assist couples, when one individual has mild cognitive impairment or dementia, to promote modifying activities, behaviors, and their own expectations about the relationship in the service of maintaining long-term relationship satisfaction.24

There is a last important issue that arises in cases of dementia but that should be seen as a separate case: that of behavioral disinhibition and sexualized inappropriate behaviors in dementia (SIBDs). These behaviors fall outside the domain of appropriate intimacy between couples and are cases requiring immediate clinical-behavioral intervention as problematic manifestations of dementing illness that can cause great distress for patients, family, staff, and other residents.

The incidence of behavioral and psychiatric symptoms of dementia in general approaches 100 percent over the course of illness, and up to 25 percent of individuals with dementia exhibit some form sexualized inappropriate behavior. Some types of dementia are more likely to result in behavioral disinhibition, including inappropriate sexual behaviors, specifically, dementias that preferentially attack the brain’s frontal lobes and networks, which frequently results in frontal and dysexecutive symptoms that can include verbal and behavioral disinhibition. Frontotemporal dementia is a common factor in behaviors that transgress accepted norms, causing disinhibition as well as impairments in insight, judgment, and self-regulation.

SIBDs can include sexualized intrusions into the personal space of others, including inappropriate touching, sexually charged comments, requests for sexual contact, kissing, and masturbation in public areas. These can be among the most challenging and upsetting behaviors for staff, family, and other residents of long-term care facilities. Comprehensive behavioral, medical, and (when appropriate) pharmacological intervention can be successful in managing these behaviors, quickly reducing stress for everyone.25

In addition to these clinical issues, from a risk management perspective another important reason for quick and sustained intervention is that unchecked sexually inappropriate behavior can result in both criminal charges and involvement of state protective agencies. Since many health care providers are mandated reporters of elder abuse, failing to intervene can result in adverse decisions against individual professionals as well as negative publicity for facilities where problems occur.

In Donna’s case, the following might be helpful:
• Specific and periodic staff education at the facility specifically focused on dementia and sexuality (including education as part of their professional undergraduate and graduate training).26

24 Ibid.
25 James M. Ellison and Cynthia T. Greywolf, “Management of Depression, Apathy, and Sexualized Inappropriate Behaviors in Dementia,” in Dickerson and Atri, Dementia, 588–599. My focus in this article is not on these problematic behaviors but on normal intimacy between couples when one has dementia.
26 SIBDs require immediate intervention by staff and deserve special consideration on their own in terms of their frequency, content, and current intervention strategies.
• Ongoing staff education about behavioral, medical, and environmental interventions for SIBDs.
• Periodic review of mandated reporting laws.
• The presence, in every long-term care facility, of appropriately trained staff who are able to work with families when problematic issues arise.
• Medical staff well versed in addressing underlying medical causes of dementia-related sexual difficulties in the elderly.

Capacity and Competency Assessment

In the above-noted media articles concerning the Rayhons, mention was made of assessment of capacity for decision making, in this case Donna’s ability to consent to sexual relations. The sole mention of evaluation in these accounts was Donna’s inability to recall three words she had learned a few minutes earlier. While this is a standard part of an office mental status exam, it is only one component of it and not sufficient in itself for making a determination of an individual’s decision-making capacity in any area.

Capacity and competency assessment is a complex clinical and legal issue requiring, first of all, careful and comprehensive clinical assessment, since what is at stake is an individual’s personal autonomy and freedom.27 Clinicians are frequently given a referral simply to “assess competency.” Such a written order is problematic because capacity and competency is not a unified construct; rather, it refers to a number of different cognitive and behavioral abilities dependent on the general integrity of brain function, personal and interpersonal functioning, and cognitive abilities, including language skills, memory, executive skills (such as reasoning, self-awareness, ability to understand and weigh consequences of a decision, etc.), and visuospatial abilities (e.g., in cases of capacity to drive, where impairment in this area correlates with increased crash risk). The essential clinical question to ask in such situations is “capacity for what?”—that is, for what specific activity or ability?

Capacities may be impaired even early in dementia. These impairments may be noticed, for example, in the ability to drive and to handle firearms and power tools. They may also be noticed in the ability to fulfill occupational and social roles, like voting or serving on a jury, and in the ability to make complex decisions, as in estate planning, executing a will, and preparing a health care proxy document. Finally, early impairment may also affect a person’s ability to recognize and resist undue influence and to consent to sexual relations.28 Given the variety and complexity of these activities, there is no simple or brief standardized assessment of an individual’s capacity.

27 “Capacity” is the clinical term regarding an individual’s ability to make decisions for themselves and is assessed by a clinician, typically a neurologist, psychiatrist, or neuropsychologist. “Competency” is a legal term regarding an individual’s ability to manage their affairs and is determined by a judge, for example, in a guardianship hearing.

28 Haythum O. Tayeb, Evan D. Murray, and Bruce H. Price, “Neuropsychiatric Symptoms of Dementia,” in Dickerson and Atri, Dementia, 508–527. A difficult case arises when an individual with dementia, or who may be suspected of having dementia, unexpectedly announces that they want to make alterations to their will, health and financial documents, or
Decision making is a highly complex and integrative task that involves the coordinated functioning of many brain regions and the appreciation of various types of information in context. Regions of the brain that have been implicated in complex decision making include the orbitofrontal cortex, anterior cingulate cortex, dorsolateral prefrontal cortex, temporal lobes, and the brain’s white matter connections between both cortical and subcortical structures.

These matters are further complicated by the existence in the clinical and legal literature of different levels of capacity. Daniel Marson and Katrina Hebert delineated five standards of increasing complexity in the area of medical decision-making capacity, each threshold higher than the one before it:

- **Standard 1**: Capacity to “evidence” a treatment choice, that is, the simple presence (or absence) of a treatment decision, which can be as simple as a yes or no. The quality of the decision does not come into play here.

- **Standard 2**: Capacity to make a “reasonable” treatment choice, when one or more alternatives are considered “unreasonable.” Marson and Hebert suggest that this is not a particularly useful standard for judging a person’s capacity since determining what might constitute a “reasonable” choice can be quite subjective and variable.

- **Standard 3**: Capacity to “appreciate” both emotionally and cognitively the personal consequences of an individual’s treatment choice. The standard requires that a person be aware of the consequences of any treatment choice to be made in both emotional and cognitive terms, including the possible future consequences of a decision.

- **Standard 4**: Capacity to reason about treatment choices or make treatment choices based on “rational” reasons. This is a still higher standard in which an individual must be able to demonstrate logical thinking including demonstrating the ability of comparing risks and benefits of a proposed treatment course.

- **Standard 5**: Capacity to make treatment choices based on “understanding” a treatment situation and any available alternatives. This is the highest standard for assessing capacity to make a treatment choice, which requires relatively intact functioning for a broad range of cognitive skills including attention and concentration, functional expressive and receptive language skills, semantic and episodic memory, and a range of executive skills including comprehension, estate planning. In such cases clinicians need to be alert to the possibility of undue influence of an impaired person, and of potential cases of affinity abuse (attempts by a family member to take advantage of an impaired individual). When beginning or updating estate planning, it is a good idea for seniors to do this with attorneys experienced and trained in elder law, who are sensitive to these types of concerns, and who may refer the person for evaluation to determine and document that they have the capacity to make changes to their future planning.

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reasoning (e.g. the ability to weigh risks and benefits of a proposed course of treatment), judgment, abstract thinking, foresight, planning, and problem solving.

The authors note that “these standards can be readily applied to other competencies to consent, such as capacity to consent to research participation and to decisional capacity, in general.” 30

Clinicians may have in mind different levels of capacity when they conduct evaluations, so there may be disagreements between clinicians about whether a person has capacity in a specific area. How might these capacities play out in clinical settings when the concern is attempting to assess whether an individual with dementia can give informed consent to sexual activity?

Standard 1, for example, might mean that a person can make a statement as simple as a “yes” or “no” when presented with the opportunity for sexual activity. This is straightforward but does not consider whether the person understands the content and possible consequences of the response, or whether undue influence may be present. Standard 2 means verbalizing a “reasonable” choice about sexual activity. As above, this can be quite a difficult standard to apply as reasonable choices might be difficult to delineate generally, let alone specifically, and can be affected by unvoiced regional, religious, and cultural assumptions about aging, dementia, and sexuality. Standard 3 requires an individual with dementia to express in some way emotional and cognitive factors that might come into play before, during, and after sexual activity. In terms of sexuality, standard 4 might be understood as an individual’s being able to verbalize how sexuality and sexual activity are beneficial to his or her relationship with a spouse, as well as being able to think through any potential harm that could result. Finally, standard 5 might be shown in a person’s capacity to demonstrate an understanding of human sexuality in general and how it has functioned in an individual’s relational life in the past, as well as how it might be integrated in the present.

A final complication in this matter is that currently there are no standardized instruments for the assessment of capacity to consent to sexual activity.

Which of these standards might be best applied in assessing capacity to understand and consent to sexual relations with one’s spouse in the context of dementia? I would argue that in the early to middle stages of a dementing process, the best is standard 3, the capacity to “appreciate” both emotionally and cognitively the personal consequences of an individual’s treatment choice. My reasons for suggesting this standard are as follows: First, standards 4 and 5 rely on higher level executive and abstract thinking abilities that are frequently impaired to some degree, even in the early stages of a dementing process. To look to these standards as a guide for clinical decision making would require the individual with dementia to meet standards that may already be lost due to neurological degeneration. Second, standard 1 does not

provide sufficient information to be able to generate a well-formulated and comprehensive clinical decision about capacity. The simple verbal expression of a choice (yes or no) does not demonstrate understanding, and this fact should be coupled with the knowledge that individuals with dementia, even in the early stages, can be markedly more vulnerable to undue influence from others. Third, standard 2, as Marson and Hebert note, would be quite difficult to define, operationalize, and implement in the form of specific questions. Finally, standard 3, showing that one appreciates both emotionally and cognitively the consequences of a choice is, in my opinion, the best option for assessing consent in such situations because (1) it allows for variation in an individual’s cognitive capacities of understanding and language over the early to middle stages of a dementing process, (2) it allows room for non-linguistic assessment by the clinician (e.g., the individual’s mood and body language as these matters are discussed), and (3) it recognizes that cognition and emotion are integral to decision making and allows for the expression of both in a manner grounded in the patient’s perspective, language, and culture.

In terms of assessing capacity and competency in cases similar to Donna’s, these are guidelines that might be helpful from a clinical perspective:

- **Comprehensive capacity assessment by a qualified clinician.** By “qualified,” I mean a geriatric health care professional trained in geriatrics and geriatric assessment (e.g., a geriatric neuropsychologist, a geropsychiatrist, a neurologist specializing in geriatrics, or a geriatric internal medicine practitioner). In order to be considered qualified, a clinician should be trained in assessment, including not only the clinical and ethical standards regarding assessment of capacity, but also an awareness of aspects of the legal process related to capacity evaluations. Professional written reports by clinicians are regularly reviewed by attorneys and judges in guardianship hearings, and health care professionals may be called to testify at such hearings. A competent clinician operating in this area should possess adequate knowledge, in a Catholic health care context, of Catholic teaching on the natural purposes of sacramental marriage as a component of the decision-making process. In addition, professional competence to conduct assessment in this area includes knowledge of the cognitive, emotional, and functional assessment of the elderly, and knowledge of the aging process (including normal aging and dementia). Standardized assessment of capacity should include assessment of premorbid level functioning based on demographic factors, education, occupational roles, and best performance in community activities; assessment of the cognitive domains of attention and concentration, language, visual spatial skills, memory, and executive skills; and assessment of emotional functioning.

- **Completion of a health care proxy prior to admission in individuals capable of doing so.** Assessment prior to admission (e.g., in a hospital setting or outpatient office) may be needed to determine whether an individual can execute a durable power of attorney for a health care document.

- **Consideration of petitioning for guardianship when indicated.**

- **Standardized brief assessment of cognition at the time of admission to a long-term care facility.** For example, an instrument frequently used in geriatric
screening is the Montreal Cognitive Assessment (MoCA), a thirty-point cognitive screening in which scores of 26 and above are considered normal. The MoCA is widely considered to be a better assessment instrument for the elderly than some of the previous commonly used measures (e.g., the Mini–Mental Status Examination) at picking up subtle and early cognitive impairment in the elderly.

Staff in numerous disciplines can be trained in the administration and scoring of the assessment, which can be done in about ten minutes and yields information about orientation and attention, language skills, visuospatial skills, and executive skills (abstract thinking, planning, and cognitive flexibility). In addition, the MoCA is available in over twenty languages, which can diminish concerns about language barriers.

**Institutional Response**

*Context*

In Roman Catholic tradition, the sacrament of marriage is a “covenant, by which a man and woman establish between themselves a partnership of the whole of life, is by its nature ordered toward the good of the spouses.” Created in the image of God, spouses become bearers of that image to each other for the whole of their lives, and this sacramental relationship is neither diminished nor ended by the infirmities that often accompany aging. Given the nature of this bond, Catholic health care institutions bear responsibility to encourage and support marriage when one or both spouses are admitted to long-term care. In my discussion of institutional response that follows, I am assuming previous matrimonial consent.

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31 For the record, I do not have any past or present professional or financial relationship with the authors of the MoCA. I, and many other clinicians across the US and Canada, use it on a regular basis in assessment of the elderly for its ability to detect more subtle impairments in cognition that may occur in Mild Cognitive Impairment and early dementia. An impaired score on the MoCA can be a red flag to consider referral for a more in-depth neuropsychological evaluation to determine the presence and nature of cognitive, affective, and behavioral deficits. As a rule, the earlier such impairments are detected, the better the outcome is for both the patient and caregivers, and much of the current research on Alzheimer’s disease focuses on early detection and intervention, with the hope that in the future it will be possible to make a preclinical diagnosis of the disease in order to begin intervention long before clinical symptoms emerge.

32 The MoCA has been extensively researched and was created with a geriatric population in mind. The website contains the test (on a single page), standardized administration instructions in many languages, normative information and guidelines about corrections for educational level, and references on psychometrics and specific populations. The test can be administered at bedside or in an office setting by a clinician who speaks the patient’s native language, and can also be administered through a translator. There is also a version of the test for individuals with vision impairment. The test and administration directions are free and available for clinical use at www.mocatest.org.

33 *Catechism*, n. 1601.
freely given.\textsuperscript{34} While some of the documents I review below were created outside a Catholic context, it is my intention to present them as sources that can stimulate discussion of how such issues can be effectively dealt with in a Roman Catholic health care environment.

Furthermore, based on the available information from media accounts and court documents, the overall institutional response in Donna Rayhon’s case appears problematic at best, not least because it resulted in criminal charges and a court trial, as well as stirring national debate on the issues it raised. In saying this it is not my intention to single out or in any way to criticize the Concord Care Center, or the Iowa law enforcement and justice system where the events took place. My sense, in fact, is that the nursing home, by all accounts, did the very best it could in caring for and protecting Donna by addressing issues of sexuality and dementia as they arose in that context, using the best knowledge and resources they had available at the time, and that the state exercised its role in protecting the vulnerable according to existing laws. Rather, I want to suggest that the events that occurred there, and their consequences, highlight larger institutional and systemic issues—issues that those of us working in Catholic health care can learn from and address proactively to promote more positive outcomes.

Many long-term care facilities have written policies regarding sexual activity of residents, often referred to as a “Sexual Rights Policy.”\textsuperscript{35} In contrast, relatively few institutions have written guidelines that address sexual activity when one or both persons have dementia. Media coverage of Henry and Donna’s case included reference to the Hebrew Home, a long-term care facility in Riverdale, New York, which was one of the first facilities in the United States to codify a way of addressing sexual activity among nursing home residents when there is concern about possible or diagnosed dementia, and to provide some useful, concrete examples for assessment of an individual’s understanding of sexual activity in these cases. It bears reviewing, and there are aspects of it that may serve to inform Catholic long-term care facilities as they begin to address these issues.\textsuperscript{36}

\begin{itemize}
\item \textsuperscript{34} As the Catechism notes, the free expression of consent requires (1) “not being under constraint” and (2) “not impeded by any natural or ecclesiastical law” (n. 1625). Thus, I speak of a sacramental relationship freely embraced by both spouses, and understood as a lifelong commitment.
\item \textsuperscript{35} There is clearly need and room for discussion about what the name and nature of such documents should be in Catholic health care settings, and this should occur sooner rather than later; my purpose here is simply to address the need for such written documents to exist in some form for both clinical and risk management purposes.
\item \textsuperscript{36} In reading the document it is clear that it is presented in a manner to be broadly construed as governing consensual sexual activity in general. As noted above, I am considering these matters from a Catholic perspective in which a source can be examined and from it taken principles consistent with Catholic teaching that might be useful in a long-term care context. There are innumerable precedents for this activity in the tradition. One need only think of Tertullian’s question, “What has Athens to do with Jerusalem?” (a great deal), and St. Thomas Aquinas’s appropriation of much of Aristotelian thought despite its pagan context.
\end{itemize}
The introduction to the “Policies and Procedures Concerning Sexual Expression at the Hebrew Home” provides an overall framework for addressing sexuality in the context of dementia:

The Hebrew Home at Riverdale (“the Home”) recognizes and respects the importance of emotional and physical intimacy in the lives of older adults. Such close human interactions are viewed as a normal and natural aspect of life. Planning for the social needs of older adults, including those with Alzheimer’s disease and dementia, carries with it a responsibility to uphold their personal and sexual choices. This Sexual Rights Policy applies to all older adults receiving services from or residing at the Home (i.e. tenants, clients, participants), hereafter referred to as “residents”.

The Home’s policy and practice is based on the assumption of autonomy, civil and privacy rights of all people, including the protected rights of all older adults residing in Medicaid/Medicare settings.37

Following these general principles, the policy outlines resident rights, and staff and institutional responsibilities. The document specifically addresses cases in which cognition may be impaired:

This policy recognizes and supports the older adult’s right to engage in sexual activity, so long as there is consent among those involved. Consent may be demonstrated by the words and/or affirmative actions of an older adult:

a. with intact decision-making ability; or
b. with intact decision-making ability who is non-verbal; or
c. with Alzheimer’s disease or Dementia

The former [decision making ability] may require, and the latter [Alzheimer’s] does require an assessment conducted by clinical staff, using the Home’s “Assessing Consent to Sexual Activity” guidelines, to confirm that consent was and continues to be given, and to insure the safety of those involved.38

Moving from the general to the practical, the Hebrew Home’s “Assessing Consent to Sexual Activity” is particularly interesting from both a clinical and legal perspective in that it provides both specific guidelines for staff members and examples of specific questions staff might ask a resident in an attempt to gain a sense of whether or not the person understands what sexual activity involves and whether he or she is able to consent in an informed way.

On a practical and clinical level, the Hebrew Home also has developed guidelines for assessing consent to sexual activity among older adults.39 The document recommends first determining whether inappropriate sexual activity has occurred, such as rape, sexual abuse (such as nonconsensual sexual activity between vulnerable residents), or sexual contact as a result of poor impulse control in dementia.

37 The full policy is available online at http://www.riverspringhealth.org/.
38 Ibid.
The guidelines go on to discuss the need to report suspected violations of the law and to follow statutory reporting requirements for abuse, which differ from state to state. Differences include requirements for mandatory reporters and penalties for failures to report. State laws can vary considerably as they are often passed at different points in time as a result of public outcry in response to particularly egregious abuse cases reported in the media. There is often inconsistency. Clinicians must know the specific reporting laws of the state in which they practice.

Once criminal activity and abuse have been ruled out, the document provides guidelines in the form of questions and observations for assessing consent for sexual activity:

1. Ability to express choices/content
   Ask:
   - What are your wishes about this relationship?
   - Does your sexual partner make you happy?
   - Do you enjoy sexual contact?
   Consider:
   - Observations and non-verbal clues when older adult is unable to verbalize choices (facial expressions and body language)
   - Emotion and mood, before and after sexual contact

2. Ability to appreciate sexual activity
   Ask:
   - Do you know what it means to have sex?
   - What does it mean to you/your partner?
   - What would you do if you wanted it to stop?
   - What if your partner wanted it to stop?
   Consider:
   - Nature of the relationship (monogamous)
   - Emotion and mood, before and after sexual contact

3. Personal quality of life choices in the here and now
   Ask:
   - Was and is intimacy important in your life?
   - What are your social and companionship needs?
   - What brings happiness or fulfillment to your day?
   Consider:
   - Past and present relationships (including family)
   - Impact of cognitive impairment (not an automatic reason to deny relationship)
   - Privacy and intimacy rights
   - Responsibility to uphold older adults’ choices
   - Policies for staff education and practice
   - Impact of third party objectives or values on assessment process

40 Ibid.
I suggest this document can be useful in a Catholic context as a basis for discussion and institutional planning on how to approach consent issues in long-term care settings. In light of the Catholic context, the words “husband,” “wife,” or “spouse” may be substituted for “partner” and “sexual partner.” A monogamous marital context would be assumed. Staff clinical observations would remain the same in terms of considering facial expressions, body language, emotions, and verbalizations.

In relation to Donna Rayhon’s case, here are steps Catholic long-term health care settings might consider taking:

- Creation of general written policies around sexuality and dementia if not already completed.
- Creation of specific written policies addressing sexuality and dementia, including consultation with medical and legal professionals to address clinical and risk-management factors.
- Creation and documentation of a consistent and standardized approach to assessment in cases of cognitive impairment and sexuality, as well as development of a regularly revised list of local professionals who are able to conduct such assessments at the facility, as transportation of residents to outpatient offices are often difficult. A written policy should specifically mention the geriatric specialties competent to conduct capacity assessments so that the facility can ensure maintaining standards of care in this area.
- Development by administration of a regular program of staff education around sexuality, offered to all new facility employees and consultants as part of their orientation process. Such programs could include opportunities for staff to reflect on their own views about sexuality in general and sexuality in the aged, how sexuality is understood and expressed in different cultures, guidance on ways to engage in conversations with residents about sexuality and concerns they may have in this area, and training in behavioral intervention for cases of sexualized inappropriate behaviors in dementia (SIBDs).
- Early in the admission process, education of the patient and family around institutional policies related to sexual expression, and the provision of ongoing opportunities for discussion thereafter, including special issues that may arise in cases of dementia.
- Inclusion of sexuality-related information as part of a resident’s periodic care planning. This can be included as a standard part of the care plan document, along with identification of who is responsible for assessment and documentation.
- Proactive outreach by long-term care administrators to local health care academic training programs (colleges, universities, schools of nursing, etc.) across disciplines to increase awareness of these issues and encourage the incorporation of information about aging, sexuality, and dementia in training programs.
Suggestion for a Catholic Institutional Response

Any institutional response by a Catholic health care facility begins with establishing that (1) the parties involved are married, and (2) assessment has been conducted to verify that no abuse has taken place. In the Catholic vision persons are created in the image of God and reflect and bear that image, which is the grounding for the dignity of all human persons.41 In addition, we are relational by nature, not by choice: a person is “capable of self-knowledge, of self-possession and of freely giving himself and entering into communion with other persons.”42 In considering the Catholic vision of human dignity, Rev. Nicanor Austriaco, OP, discerns four aspects: First, dignity is intrinsic to persons, “a quality that is inherent, essential, and proper” to persons. Second, because persons have dignity, “human life is sacred. It is worthy of respect.” Third, persons are an end in themselves and can never be treated merely as objects or as the means to an end. Fourth, as all persons possess dignity, all persons are equal.43 These qualities are integral to being persons, and as such, inhere through the course of a person’s life. In the case of aging and dementia, dignity is present, and the person is present regardless of any functional deficits he or she may display. As each elderly person is an integral whole, all dimensions of their personhood deserve attention and care, including attending to those aspects of life, including sexuality, that promote well-being and quality of life as we grow older.44

Respect for this dignity suffuses the history of thought and activity of Catholic health care. This dignity is to be respected across the life span, and in the specific issues raised in this article, includes the integrity, promotion, and protection of the marital relationship when it is disrupted by issues of health and dementia resulting in institutionalization.

In terms of a practical response, the Ethical and Religious Directives for Catholic Health Care Services are a logical place to begin, as they provide guidance at the level of values and principles, as well as concrete direction for Catholic health care institutions. The ERDs state that “Catholic health care ministry is rooted in a commitment to promote and defend human dignity; this is the foundation of its concern to respect the sacredness of every human life from the moment of conception until death. The first right of the human person, the right to life, entails a right to the means for the proper development of life, such as adequate health care.”45 As the dignity of persons is present from conception through natural death, attention should be given to

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41 Catechism, nn. 1699–1700.
42 Ibid., n. 357.
44 This is contrary to all functionalist accounts of personhood that would argue that persons are not present when they do not display what a particular author may define as personal functioning or interaction.
these aspects of aging that will become increasingly common in the decades ahead, as the aging population and its health care needs increase.

In this light, it will be important for episcopal conferences, individual bishops, Catholic health care administrators and professionals, and teaching staff at Catholic institutions of higher learning that have health care training programs to consider appropriate responses to issues of sexuality, dementia, and long-term care that are consistent with Tradition and magisterial teaching. They should also formulate and document institutional policies and procedures to provide appropriate education to staff, residents, and families in a sensitive and comprehensive fashion, in the service of caring for the whole person.

The Letter to the Elderly encourages respect for the dignity of persons, especially those moving toward the end of this life’s journey, as a call for all of us working in elder care to think and act in ways that make their last years as rich and meaningful as possible. As John Paul II wrote, “When the moment of our definitive ‘passage’ comes, grant that we may face it with serenity, without regret for what we shall leave behind. For in meeting you, after having sought you for so long, we shall find once more every authentic good which we have known here on earth, in the company of all who have gone before us marked with the sign of faith and hope.”

46 This should include not only health care programs, but also all Catholic disciplines that touch on the nature and dignity of the human person, including academic programs in philosophy and theology, Catholic bioethics, political science, and education around public policy that touches on the many aspects of care for the elderly in terms of local, state, and federal programs for the elderly, Medicare and Medicaid, legislation, jurisprudence, the executive branch, etc.

47 John Paul II, Letter to the Elderly, n. 18.