The Case
During the course of her routine afternoon rounds, a nursing assistant entered the semiprivate room of an 84-year-old male resident with moderately severe dementia. The patient himself was nonambulatory and required assistance with all basic activities of daily living. He was on a scheduled toileting program every 2 hours and wore an incontinence garment.

The nursing assistant knocked on the resident’s door, announced herself, and, hearing no answer, turned the door-knob and entered. To her surprise and embarrassment, she happened upon a scene in which the male resident was lying in bed while another resident, a 72-year-old wheelchair-bound woman from another floor of the facility, was performing oral sex on him.

The nursing assistant, having never encountered a situation like this before, left the room in some distress and immediately contacted her supervising nurse. The nurse entered the room and interrupted the proceedings, to the apparent chagrin of the couple (who had not previously been observed socializing together). Subsequently, the director of nursing, the facility administrator, the attending physician, the medical director, the wife of the male resident, and the adult children of the female resident were all notified of the apparent change in each resident’s condition.

When contacted by facility nursing staff, the medical director asked about the residents’ decision-making capacity and whether there was any evidence of coercion. The director of nursing asked what the residents and their families thought. The administrator expressed concern about the gentleman’s hygiene, while the female resident’s attending physician, apparently concerned about patient safety, asked, “Was her wheelchair locked?”

The family members contacted the medical director, the wife of the male resident, the attending physician, the administrator, the medical director, the attending physician, the social work director, the patient advocate, the quality assurance manager, and the medical director of another facility. The care plans of both residents and their families were reviewed. The right to privacy as well as the right to freedom of movement within the facility was respected by the values of their parent organization. These may include explicit policies regarding sexual expression and its propriety or lack thereof, which a resident may not share.

Patients with dementia may forget that they are married. They may mistakenly believe that another facility resident is a spouse. They may lack the cognitive ability to make complex decisions and yet have a strong sexual desire and a diminished ability to control sexual impulses. Sexual behaviors are basic, fairly primitive, and overlearned during a lifetime, while the social rules regarding sex, just like the rules regarding urinating in a bathroom instead of one’s pants, may be long forgotten in patients with cognitive impairment.

Decision-Making Capacity
The standard for decision-making capacity varies as a function of the complexity of the decision to be made and the risks associated with the choices. More complex decisions, such as that to undergo a complex chemotherapy regimen, require much greater cognitive ability than the decision to accept a dose of pain medicine. The cognitive threshold for decision-making capacity regarding sex is considered to be fairly low. Moreover, while the psychosocial consequences of sexual activity may be quite complex, the decision to engage in sex may be driven more by emotion and biology than by intellect, even among individuals with normal cognitive function. In addition, physical desire and physical ability may persist despite cognitive incapacity.

In decades past, issues of sexuality in young adults with impaired decision-making capacity due to developmental disabilities or those considered “mentally unfit” because of epilepsy or another neurologic condition were approached very paternalistically. Many of these people were subjected to involuntary sterilization to prevent pregnancy. In more recent years in Western culture, autonomy has taken precedence over competing moral and ethical concerns.

Respect for Autonomy
Virtually everyone who lives in a nursing facility (even briefly) is there because they have lost some physical or cognitive capacity. In this circumstance, laws, regulations, and policies are generally guided by the ethical aspiration that people with impairments should have as much power and control over their lives as possible. The Americans with Disabilities Act, the UN Convention on the Rights of Persons with Disabilities, and numerous state and local policies and regulations support these goals.

The Case
The following morning, the male resident was found to be unresponsive and inert in bed. He was on a scheduled toileting program every 2 hours and wore an incontinence garment.

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Continued on next page
Dementia Onset Steers Nursing Home Admissions

Patients in whom dementia symptoms appear before age 65 are cared for at home longer than are people whose symptoms develop later in life, according to results from Needs in Young Dementia (NeedYD) Study in the Netherlands.

Christian Bakker of the Florence Mariahoeve Centre for Specialized Care in Early Onset Dementia in The Netherlands and his colleagues used baseline data on 215 people with early onset dementia and 119 people with symptoms starting after 65. The researchers interviewed each person’s primary caregiver about the year of onset and the nature of first symptoms.

The team also assessed neuropsychiatric symptoms and dementia severity. The time from onset of symptoms to institutionalization was more than twice as long for people with early onset dementia (9 years vs. 4 years). Apathy and caregiver competence were significant predictors, but neuropsychiatric symptoms were not.

These results emphasize the importance of timely diagnosis to begin appropriate care and additional support programs for caregivers, especially those caring for people with neuropsychiatric symptoms, the researchers said. They reported their findings in the April JAMDA.

—Jeffrey S. Eisenberg

Caring for the Ages Welcomes New Advisers

Caring for the Ages welcomes William Simonson, PharmD, Dr. Dennis L. Stone, CMD, and Dr. Jeffrey Nichols, as members of its Editorial Advisory Board. Dr. Simonson has specialized in senior medication issues for more than 35 years. He has more than 150 publications and is the author of two books.

He has a faculty appointment as senior research professor (pharmacy practice) at Oregon State University. He has served four terms on the United States Pharmacopeia Advisory Panel on Geriatrics.

Dr. Stone was the first medical director of On Lok Senior Services, the forerunner of today’s PACE programs. He is currently the chief medical officer of Signature HealthCARE and of Integritas HealthCARE, a Louisville, Ky.-based nonphysician staff providing transitional medical and psychiatric services in nursing, home, and outpatient venues.

He has been an advisor to the AMA’s Relative Value Update Committee and CPT Committee for 15 years and is a past president of AMDA.

Dr. Nichols is medical director, Our Lady of Consolation and Good Samaritan Nursing Homes, Suffolk County, N.Y., senior vice president for clinical effectiveness of the Catholic Health Care System of Long Island. He joined the Editorial Advisory Board in 2012, after last year’s AMDA annual meeting.

We thank our outgoing board members Dr. Jon Berg, CMD, Frederick L. Wendt, RPh, and Dr. Bonnie Wirfs, CMD, for their service.