

# Joint Conference on Ethical/Legal Issues in the Progression of Dementia

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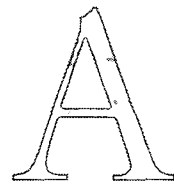
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BOOKSHELF

# *Joint Conference on Legal/Ethical Issues In the Progression Of Dementia*

**By Carrie McAdams**



As our elderly population grows, becomes more diverse, and lives longer, dementia is expected to become more prevalent and complex to treat. A recent symposium issue of the Georgia Law Review provided eleven articles from a multidisciplinary meeting last fall that addressed the span of legal and ethical issues that surround dementia. The articles are written from various perspectives, with some focusing on policy development to improve the rights of individuals suffering from dementia, and others providing guidance on existing policies. The compilation of articles is an excellent resource for practitioners who would like to gain a better understanding of the legal and ethical issues that complicate

the representation of individuals with dementia.

The first article of the symposium is "Dementia and Alzheimer's Disease: An Overview" by Dr. Peter V. Rabins, a Professor of Psychiatry and Behavioral Sciences at Johns Hopkins Medical Institution. This article clearly details the symptoms of Alzheimer's disease, and is an excellent tool for practitioners who are trying to get a better understanding of some of the behaviors that they can expect as the disease progresses. The author acknowledges that the progression of Alzheimer's disease varies; however, he tries to break the illness into three distinct periods on the basis of what he categorizes as "cognitive" symptoms such as memory impairment, personality changes, language impairments, and feeding difficulty. He also discusses "non-cognitive" symptoms such as violence, hallucinations,

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and suspiciousness. Rabins illustrates how the symptoms of Alzheimer's disease can affect ethical and legal issues, and outlines five major areas of treatment, with suggestions on how to control symptoms and prevent caregiver stress over the course of the disease.

The article "Ethics, Ethnicity, and Dementia: A 'Culture-Fair' Approach to Bioethical Advocacy in Dementing Illness," by Ramón Valle, Director of the Alzheimer's Cross-Cultural Research and Development Effort based in San Diego, examines how the changing demographics in the United States have impacted bioethical decisionmaking, particularly for individuals with dementia. Valle describes how minority populations within the United States such as Mexican-Americans, African-Americans, and Asian-Americans, are identified with different preferences about healthcare information disclosure. As a result, the author concludes that imposing the "autonomy" bioethical decision-making model on every ethnic group is inappropriate.

Valle examines how decision-making for an individual with dementia is complicated by ethnic and cultural differences, and recommends that practitioners build cultural competency by investigating three distinct areas of an ethnic group's culture: the methods of communication; customs, rituals and interactions; and the values and normal expectations of the ethnic group and the individuals that comprise the ethnic group. The understanding of cultural factors in the context of making bioethical decisions can be further frustrated by other factors such as literacy, socio-

economic status, and varying power differentials. Valle advocates that this framework "acculturation continuum assessment strategy" be used to accomplish the intimidating task of assisting ethnically diverse individuals with dementia. This approach provides practitioners with guidance on how to reach a culture-fair understanding of the individuals in which the practitioner is assisting.

As Alzheimer's disease progresses, it becomes more difficult for individuals to carry out ordinary everyday tasks, such as driving or cooking. These activities can create immense concern because the individuals do not realize that they lack the ability to carry out these skills. Furthermore, caregivers face challenges when trying to reason with the individuals to refrain from such activities that are dangerous to themselves and others. "Freedom Fading: On Dementia, Best Interests, and Public Safety," deals with the issue of restricting the liberty of individuals with dementia to protect members of society from harm. Author Bruce Jennings, who is a Senior Research Scholar at The Hastings Center in Garrison, New York and lecturer for Yale School of Public Health, presents three models that attempt to solve this problem. The focus of each model varies: The first model concerns public safety; the second model concerns individuals' best interests through a paternalistic type of control; the third model concerns the care provided to individuals through the dynamic progression of dementia. The author also analyzes how the models shift responsibilities and duties among the community, state, and private caregivers.

As Jennings scrutinizes each model, he explains its limitations. He concludes that none of the models alone provides an adequate solution to the dilemma. He suggests that a synthesis of these models—or possibly a new perspective—is needed to balance the conflict between restricting the liberty of an individual with dementia and protecting the public.

Edward P. Richards, Professor of Law and Director of the Center for Public Health Law for the University of Missouri Kansas City School of Law, analyzes tort liability for individuals with Alzheimer's disease who injure their caregivers or members of society. His article, "Public Policy Implications of Liability Regimes for Injuries Caused by Persons with Alzheimer's Disease," examines how the law has developed in relation to the mentally ill (who traditionally are liable for their torts) and traces the current trends. Richards proposes approaches other than tort liability to respond to negligence by people with mental illness.

He also questions what, if any, liability should be placed on the caregivers for preventing injuries to the public. The courts have placed different duties on professional caregivers than on informal caregivers who comprise the overwhelming majority of care providers and have little or no training and very limited resources. Richards advises that if tort law mandated a duty for informal caregivers to provide nonnegligent care, a disincentive would be created for families to care for individuals with Alzheimer's disease. He recommends more research to determine what risks individuals with

dementia really pose to others so that interventions can be established that will successfully prevent negligent behavior.

In "Decisionmaking at the End Of Life: Patients with Alzheimer's or Other Dementia," Leslie Pickering Francis, Professor of Philosophy at the University of Utah, reviews the complex issues that riddle the process of making healthcare decisions for patients suffering from Alzheimer's disease and how to prioritize available options when decisions are made. The author discusses the implications of dementia for the individual's ability to make his or her own decisions and how symptoms of dementia such as cognitive deficits, depression and difficulties in communication, can hinder the individual's capacity for decisionmaking.

Francis explores advance directives, specifically the standards to create and revoke an advance directive, the thresholds that must be met before the directive becomes an effective option, and the limitations of advance directives, particularly for patients with dementia. Francis challenges the use of advance directives as empirical evidence suggests that individuals tend to change their minds.

Clearly, when individuals with dementia change their minds, it is difficult to weigh their current expressed wishes against those that were expressed previously when the patients were competent. Some commentators believe that the decisions made by a patient who is now demented should take precedence over the wishes expressed when the patient was competent because immense personal changes take place in individuals with Alzheimer's dis-

ease. Francis argues against the idea of a new self emerging and having decisionmaking authority, and examines the "best interest" standard which many reason supports the new self as the decision maker.

A presumption exists that advance directives provide the answer to legal or ethical questions concerning the health care of an incapacitated patient. Nancy Neveloff Dubler, the Director of the Division of Bioethics at Montefiore Medical Center, raises doubts about this in her thought-provoking article, "Creating and Supporting the Proxy-Decider: The Lawyer-Proxy Relationship." The article highlights several shortcomings of living wills for practitioners to consider when drafting advance directives for clients. For instance, the language commonly used in living wills is meant to be clear and concrete, but Dubler argues that the language may not accurately reflect a patient's real wants and may leave no room for physicians to try an intervention for a short course. The article provides several hypothetical situations that clearly support this point.

On the other hand, Dubler strongly discourages lawyers from creating individually crafted living wills that give detailed individual preferences because unfamiliar language or ambiguity can cause physicians to make risk-averse decisions that may not reflect a patient's wishes. She also discusses how the incentive for shorter hospitalizations in combination with living wills may result in decisions that reflect the pressures of healthcare financing rather than the best medical and ethical course for the patient. She proposes that a proxy is the pref-

erable solution when a patient is incapacitated. Dubler's rationale is that the proxy is more flexible and the language restrictions that exist with the living will are avoided.

Thomas Finucane, Associate Professor of Medicine for the Division of Geriatric Medicine and Bioethics Institute at Johns Hopkins University School of Medicine, authored, "Thinking About Life-Sustaining Treatment Late in the Life of a Demented Person," which examines the conflicts that arise when an elderly person, incapable of making decisions, develops a critical life-threatening illness. Many lawyers follow the Standard Paradigm in this situation to find the balance between overtreatment and undertreatment of the terminally ill person. The Standard Paradigm emphasizes patient autonomy by first asking patients what they want. If a patient is not capable of communicating his or her wishes, the lawyer will look to advance directives. If this is not available, a legitimate substitute decision maker can provide information about a patient's wishes. In the event that none of these options are available, the last step of the Paradigm is to preserve life. Finucane analyzes the Standard Paradigm and identifies for practitioners several pitfalls in this process, such as restrictions on advance directives and the inability to trust the decisions of non-designated substitute decision makers, such as family members.

Finucane suggests the implementation of a more compassionate approach. He recommends that physicians play a greater role in the decisionmaking process because they have insight into the outcomes of decisions,

unlike many other advocates. Finucane's discussion of two very common treatment decisions, tube feeding and CPR in nursing homes, offers practitioners, families and patients a perspective that defies the philosophy of exhausting all means for patient care. He is opposed to both of these options and provides evidence that there is little benefit to be gained from these measures.

Better medications, symptom control, and the complete prevention of Alzheimer's disease are goals of dementia research. However, to achieve these goals, scientists must study individuals with dementia. This raises many ethical concerns because individuals with Alzheimer's disease are very vulnerable as a result of their inability to protect themselves. Rebecca Dresser, Professor of Law and Ethics in Medicine at Washington University in St. Louis, describes the history of dementia research and addresses the ethical dilemmas that stem from such research in her article, "Dementia Research: Ethics and Policy for the Twenty-First Century." The central focus of the article is on the decisional capacity of the research participants. Dresser examines the issue in conjunction with recommendations made by several advisory committees.

The author explores what options exist if an individual lacks the ability to consent to research, and what safeguards should be instituted to protect these individuals. For instance, the article includes an evaluation of when it is appropriate that a healthcare proxy make decisions about whether a decisionally incapable individual can participate in research that will yield no direct benefit to the participant. Over-

all, Dresser stresses the importance of devising policies that are tailored to individuals—rather than relying on broad classifications—because the dementia population is extremely diverse.

Dementia research has so far been slow to produce medical interventions, but genetic research has made extraordinary progress in gene discovery and the development of genetic tests. As a result, a gap exists between the identification of genetic risk and the amelioration of the risk. This has raised many ethical, legal and social concerns. Mark A. Rothstein, Director of the Institute for Bioethics, Health Policy and Law for the University of Louisville School of Medicine, addresses these concerns within the context of regulating insurance providers in his article, "Predictive Genetic Testing for Alzheimer's Disease In Long-Term Care Insurance." Rothstein focuses particularly on using genetic testing to underwrite long-term care insurance, which is currently regulated in only two states. He suggests that long-term care insurers may be lured into using genetic information to underwrite policies because of increasing life expectancy, the growth in long-term care insurance, and the costs associated with caring on a long-term basis for individuals with Alzheimer's disease.

Rothstein gives an overview of the genetics of Alzheimer's disease and what progress has been made thus far in discovering the genes associated with the disease. He discusses whether state and federal laws currently prohibit discrimination for insurance coverage on the basis of genetic testing and what the policy considerations are for using genetic

information to underwrite long-term care insurance policies. Rothstein acknowledges that very little serious debate has occurred concerning this topic because the issue of genetic discrimination in health and life insurance has overshadowed long-term care insurance. He advocates that long-term care insurance should mirror health insurance in that the use of genetic information would be unlawful to underwrite policies.

The article, "Lawyer's Ethical Dilemmas: A 'Normal' Relationship When Representing Demented Clients and Their Families," co-authored by Robert B. Fleming, Partner at Fleming & Curti, PLC in Tucson, Arizona, and Rebecca C. Morgan, Professor at Stetson University College of Law, captures the issues that practitioners face when representing clients with dementia and provides excellent guidance on how to avoid conflicts that may surface through this representation. Initially, the article discusses the Model Rules of Professional Conduct, which requires that lawyers maintain a normal client-attorney relationship, yet fails to provide direction on how to accomplish this when a client has dementia. The authors list the components of a normal client-attorney relationship in juxtaposition to the symptoms that are associated with dementia to illustrate the challenges involved with meeting this standard.

The article then examines the practical problems that arise for the different roles such as advocate, advisor, and guardian ad litem, which a lawyer may be required to fill while representing a client with dementia. The issue of confidentiality is discussed for

several situations, such as when an attorney may represent a married couple in estate planning if one spouse suffers from dementia. The authors debate whether to use waivers of confidentiality and provide guidelines for how to determine whether that is an appropriate measure. The article concludes with instructions on how to facilitate a normal relationship with clients impaired by dementia, prevent conflicts of interest, and represent multiple individual clients.

Erica F. Wood's article, "Dispute Resolution and Dementia: Seeking Solutions," is an excellent source for practitioners, care-

givers, and family to gain insight into the kinds of disputes that are likely to arise with individuals suffering from dementia and what methods of resolution are available. Wood, Associate Staff Director of the American Bar Association Commission on Legal Problems of the Elderly, depicts several types of disputes that are most common for an elderly individual with dementia and provides hypothetical situations to illustrate how these conflicts would evolve in both early and late stages of dementia.

The article discusses how differences in personality, situation, and legal context can influence

conflict resolution. An overview of the various processes used to resolve disputes is featured, with a focus on mediation. Wood's assessment of the positive and negative aspects of mediation offers practitioners a valuable source to use when determining whether to initiate the process. The article then narrows its focus to evaluate the use of mediation in disputes involving individuals with dementia by looking at various pilot mediation programs. For individuals who lack full capacity to participate in mediation, the article suggests to accommodate and facilitate their involvement.