

# Ethical Considerations in Dementia Diagnosis and Care

## AAN Position Statement

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## Abstract

Alzheimer disease and other dementias present unique practical challenges for patients, their families, clinicians, and health systems. These challenges reflect not only the growing public health effect of dementia in an aging global population, but also more specific ethical complexities including early loss of patients' capacity to make decisions regarding their own care, the stigma often associated with a dementia diagnosis, the difficulty of balancing concern for patients' welfare with respect for patients' remaining independence, and the effect on the physical, emotional, and financial well-being of family caregivers. Caring for patients with dementia requires respecting patient autonomy while acknowledging progressively diminishing decisional capacity and continuing to provide care in accordance with other core ethical principles (beneficence, justice, and nonmaleficence). Whereas these ethical principles remain unchanged, neurologists must reconsider how to apply them given changes across multiple domains including our understanding of disease, clinical and legal tools for addressing manifestations of illness, our expanding awareness of the crucial role of family caregivers in providing care and maintaining patient quality of life, and societal conceptions of dementia and individuals' personal expectations for aging. This revision to the American Academy of Neurology's 1996 position statement summarizes ethical considerations that often arise in caring for patients with dementia; although it addresses how such considerations influence patient management, it is not a clinical practice guideline.

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## Glossary

AD = Alzheimer disease; DSM-5 = Diagnostic and Statistical Manual of Mental Disorders, 5th edition; POLST = Physician Orders for Life-Sustaining Treatment.

Dementia and dementia care have undergone important changes since the Ethics, Law, and Humanities Committee, a joint committee of the American Academy of Neurology, American Neurological Association, and Child Neurology Society, addressed ethical issues in dementia a quarter-century ago.<sup>1</sup> Scientific understanding has advanced considerably, with greater recognition of non-Alzheimer dementias and mixed dementia; new evidence for a long prodromal or asymptomatic phase of neurodegenerative causes of dementia; related advances in genetics, neuroimaging, and biomarker testing; and several large-scale clinical trials of agents intended as disease-modifying therapies for Alzheimer disease (AD). Clinical practice has changed with approval of broader but still unsatisfactory treatment options such as cholinesterase inhibitors and memantine, greater awareness of pharmacologic risks of sedatives and neuroleptics, diminished use of tube feeding and physical restraints in care settings, and expanded use of hospice and palliative care. In the legal and ethical domain, conceptions of decisional capacity and models of capacity assessment have been refined; use of advance care planning has expanded; greater attention is now paid to the role and needs of family caregivers; and abuse (physical, financial, and otherwise) of vulnerable older adults has been increasingly recognized. Perhaps most significant are broader societal changes: whereas widespread stigma<sup>2</sup> remains a barrier to patient care and advocacy, patients and families (alongside clinicians and other stakeholders) have engaged in broad action to promote awareness, advocate for research, and build more dementia-friendly communities.

This changing scientific, clinical, legal/ethical, and social landscape presents challenges for neurologists and other clinicians, in seeking to provide care consistent with applicable law and standing ethical and clinical consensus. Although not every ethical problem can be anticipated, this position statement presents an overview of ethical dilemmas that commonly arise in caring for patients with dementia; references are also provided to more extensive analysis of selected topics. This position statement first considers the diagnosis of dementia; genetic and biomarker testing are considered here as they are increasingly used to make or confirm a diagnosis of dementia or identify individuals at risk. Next, problems in decision-making are addressed, including the central topics of capacity assessment and advance care planning, which should be anticipated and addressed early in the course of illness. The following section concerns symptom and behavioral management, which pose problems that vary with dementia stage. Finally, the relationship between dementia care and society is considered, particularly in the context of American society and health care. This document focuses on ethical issues that

arise in clinical care; ethical issues in research, including with patients who have cognitive impairments, are addressed elsewhere.<sup>3</sup>

## Complexities in Communicating the Diagnosis

In communicating the diagnosis, clinicians may find that patients and family members often have different understandings of terms such as “dementia” and “Alzheimer disease.” Because the term dementia has lay connotations of insanity and mental deficiency, some experts have argued for abolishing the term as hurtful and derogatory.<sup>4</sup> The most recent edition of the DSM-5 generally omits references to dementia in favor of a more general term, “major neurocognitive disorder.”<sup>5</sup> Although we retain the term dementia, it should be used with sensitivity and awareness of potential negative connotations. Furthermore, when communicating with patients and families, neurologists should acknowledge widespread misconceptions and clarify what they mean by the term dementia, acknowledging also that its use by other clinicians may be different.

## Not All Dementia Is the Same

While AD is the most common form of dementia, patients and families may benefit from knowing that AD is only one among many different causes of dementia, that dementia is not exclusively a disease of advanced age, and that symptoms can differ significantly across individual patients. For instance, although dementia may be commonly understood to primarily involve memory impairment, mood and behavioral changes often have more of an effect on patients and families than declines in memory or cognitive function. Thus, expectations based on observing other patients or on cognitive test scores may not predict the most consequential features of the patient’s clinical course.

Because dementia is often considered to be exclusively a disease of aging, middle-aged and younger patients with conditions such as early-onset AD, frontotemporal dementia, and Huntington disease face unique problems, as do their families. As earlier onset forms of dementia often present with socioemotional and behavioral disturbances before typical cognitive complaints, diagnosis of sporadic disease is often delayed and patients’ behaviors may be misinterpreted as manifestations of a psychiatric rather than a neurologic disorder. Such patients are often midcareer rather than retired and may have children at home, increasing safety concerns and burdens for other family members. Community resources

such as adult day programs, nursing facilities, and caregiver support groups are also often designed principally for the needs of older patients. Clinicians should anticipate devoting greater time to caregiver education and to identifying resources for such patients; referral to specialty centers is often also useful (see also Genetic and Biomarker Testing).

### Truth-Telling and Disclosure

Prior to communicating a diagnosis, it is important to ascertain how much information patients wish to receive and how they prefer to receive information. Some patients defer to family members or other trusted people who can receive information on their behalf (see also Socioeconomic, Ethnic, and Cultural Factors). In the past, clinicians have sometimes invoked therapeutic privilege to justify withholding information (such as a diagnosis of dementia) deemed too devastating or otherwise harmful to the patient, and clinicians now may receive requests from family members to withhold a diagnosis from the patient due to related concerns. However, unless patients who have capacity specifically make a request that such information be given to others rather than directly to them, such nondisclosure violates patient autonomy, undermines trust, reinforces stigma, and may deprive patients and families of important opportunities to plan for future needs.<sup>6</sup> For patients without decisional capacity, the diagnosis should be disclosed to a legally recognized surrogate decision-maker (see Decision-Making in Dementia) and in most cases also to the patient; in some cases disclosure to the patient may require planning with the surrogate.

It is important to consider the setting and manner of disclosure to minimize the risk of emotional harm to the patient; for instance, involving another clinician with a longstanding relationship with the patient, or facilitating the presence of family members or other loved ones to provide support and assist in recalling details that patients with memory disorders are prone to forget. Involvement of trusted family and friends can also prevent misunderstanding of patients' symptoms and behavior, mitigate social isolation, and facilitate advance care planning. Frameworks established for communicating serious diagnostic or prognostic information, such as the SPIKES protocol (setting, perception, invitation, knowledge, emotion, and strategy and summary),<sup>7</sup> identify important aspects of such encounters. In most cases, family members' fears about potential emotional harm can be assuaged by thoughtful and compassionate disclosure using these strategies.

### Genetic and Biomarker Testing

Degenerative dementias may infrequently result from monogenic, mendelian mutations, but more commonly arise from an interplay among genetic, environmental, and lifestyle factors. A rapidly evolving menu of tests is now available that in symptomatic individuals may be used to confirm the existence and cause of dementia, or in asymptomatic/presymptomatic persons may suggest future risk for cognitive decline. Ethical considerations in testing hinge on whether the testing will be performed in a clinical or research context, whether the patient

is symptomatic or at increased risk of developing dementia, potential implications for other family members, and whether the testing will be diagnostic or solely imply heightened risk.

Genetic testing may be diagnostic in symptomatic individuals with dominantly inherited dementias (such as Huntington disease) and with familial forms of AD, frontotemporal dementia, and prion disease. It can also predict illness in presymptomatic carriers of pathogenic genetic variants. Other gene polymorphisms such as *APOE* are not diagnostic but modify individuals' risk for developing dementia. CSF and PET biomarkers of amyloid and tau aggregation are now also being used to diagnose symptomatic patients with atypical presentations of dementia. In research settings, such biomarkers may provide evidence of pathologic involvement in asymptomatic individuals,<sup>8</sup> raising ethical questions about potential uses in predicting clinical AD among healthy people.

Clinical research regarding genetic and biomarker testing is rapidly transforming our understanding of AD and other dementias. However, translation of these tools into clinical practice is ethically fraught. Early and accurate detection offers potential benefits including diagnostic closure, family planning, and opportunities for advance care planning. Potential harms, particularly when testing asymptomatic individuals, may include adverse psychological responses, confusion provoked by genetic variants of unknown significance and variable penetrance, and vulnerability to discrimination.<sup>9,10</sup> Accordingly, informed consent, which may be challenging in this context (see Decision-Making in Dementia), is requisite for genetic or biomarker testing in degenerative dementias.

Genetic testing should be offered to symptomatic patients who have phenotypes associated with autosomal dominant inheritance (e.g., early-onset AD, frontotemporal dementia, Huntington disease, and prion diseases) and supportive family histories. Similarly, biomarker testing and disclosure may be clinically useful for some symptomatic patients with atypical presentations or other reasons for diagnostic uncertainty (regardless of family history). In asymptomatic, at-risk adult relatives of patients with autosomal dominant dementias such as Huntington disease, predictive testing may be offered with requisite counseling about the absence of disease-modifying treatments and the potential life consequences of both positive and negative test results.<sup>9,10</sup> Currently, for asymptomatic individuals, genetic susceptibility testing and biomarker testing are recommended solely in a research setting.<sup>11-13</sup> This is largely due to potential harms (as previously noted) and the absence of interventions capable of favorably altering the natural history of the disease.

Any patient undergoing genetic testing should receive genetic counseling before and after receiving results; in addition, patients should be informed of relevant legal protections offered through the Genetic Information Nondiscrimination Act (GINA) and other legislation.<sup>14</sup> (Of note, individuals with positive biomarkers are not protected by current regulations

from employment or insurance discrimination.<sup>15</sup>) Formally trained genetic counselors are unavailable in many practice settings. In such cases, the ordering neurologist should either develop competency in personally providing such counseling or arrange access to genetic counseling through telemedicine if available.<sup>16</sup> Genetic testing should be performed at an accredited laboratory after appropriate pretest counseling and informed consent.<sup>17</sup> Neurologists must be prepared to discuss findings with patients who have already received results without pretest counseling (e.g., direct-to-consumer genetic testing) and to assure that patients receive posttest genetic counseling if needed.

## Decision-Making in Dementia

### Appropriate Involvement of the Patient at Different Stages

Given the progressive cognitive decline typically observed in dementia, most patients will eventually become unable to make medical, legal, and financial decisions independently. For patients in early stages who retain decision-making capacity, timely anticipatory planning is crucial to preserve autonomy over future decisions and reduce future strains on caregivers. Patients with mild cognitive impairment and in mild stages of dementia should be encouraged to discuss their overall goals with their families and clinicians and to execute advance health care directives and other documents to guide decision-making in the event of incapacity. In moderate stages of dementia, many patients who lack formal decisional capacity may still be able to participate meaningfully in decision-making; for instance, by conferring with surrogate decision-makers about values that should guide care decisions.

### Capacity Assessment

Many ethical questions in dementia care stem from questions regarding whether (or to what extent) patients retain decisional capacity. Thus, all clinicians caring for patients with dementia should be conversant with principles for assessing capacity. Rarely, psychiatric consultation (e.g., for patients with prior histories of mental illness) or formal forensic assessments (e.g., in borderline cases with significant intrafamilial disputes over the disposition of a patient's assets) may be warranted. Notably, determinations of capacity are always made relative to a particular decision: thus, patients may be judged capable of making some clinical decisions, and incapable of making others. Capacity is not determined simply by diagnosis or scores on cognitive testing. Instead, capacity assessment relies upon a clinician's judgment (often informed by diagnoses, cognitive scores, and other clinical data) regarding the patient's functional ability to provide valid informed consent to medical care and to make valid legal and financial decisions.

One widely accepted model posits 4 component abilities necessary for capacity to make a given decision: understanding, appreciation, reasoning, and choice.<sup>18</sup> Understanding here represents a grasp of basic facts such as the nature of one's condition, the proposed intervention, the alternatives, and their

risks and benefits and may be assessed by asking patients to rephrase provided information in their own words. Appreciation represents recognition of how this information applies to one's own case (related to insight) and may be assessed by asking patients to give a plausible explanation for why a proposed course of action will or will not benefit them. Reasoning includes the ability to compare options and consistently infer their consequences and may be assessed by asking patients how an available option would affect their daily lives. Choice is a matter of expressing a decision, which should be reasonably stable in the absence of new information. The application of such specific legal standards may improve the interrater reliability of capacity assessments.<sup>19</sup>

### Advance Care Planning

It is crucial to encourage advance care planning while patients still have capacity. This facilitates completion of appropriate documents (see the table) conferring legal authority to decision-making surrogates, which preserves a measure of patient autonomy and often spares caregivers a lengthy court process. It is particularly important that the patient choose a surrogate he or she believes is intellectually and emotionally capable of making decisions aligned with the patient's own values (even if these values conflict with the surrogate's values; see Making Decisions for Patients Without Capacity) and communicating with clinicians on their behalf.

Whereas completing an advance health care directive is an important component of advance care planning, this document should not be viewed as the goal or endpoint of planning. When making advance directives, patients are often unable to anticipate the specific circumstances in which they will require care, and appointed surrogates may not know what patients would want in health crises.<sup>20</sup> Consequently, advance care planning should be viewed as a process of engaging with patients and their chosen surrogates to explore patients' values and prepare surrogates for their role in medical decision-making.<sup>21</sup> Patients should know that failure to plan often results in aggressive care by default, which may not conform to their wishes, and may also require families to later undergo burdensome legal proceedings for appropriate authority. In addition, many important decisions involve complex legal and financial issues beyond most clinicians' expertise. Many patients could benefit from early conversations with an attorney specializing in elder or disability law to discuss these elements of their care plans, as patients may lose the capacity to address them relatively early in course of illness.

### Making Decisions for Patients Without Capacity

Decision-makers for patients without capacity for a given decision should give first priority to known preferences expressed by the patient when he or she had capacity (i.e., in an advance directive or clear oral statement). If no explicit statement of the patient's wishes exists, surrogates should apply "substituted judgment," attempting to determine what the patient would have wanted, based on knowledge of the

**Table** Advance Planning Documents for Medical, Legal, and Financial Surrogate Decision-Making (Terminology, Legal Requirements, and Specific Powers Vary Among States)

	Medical decisions	Legal/financial decisions
<b>Authority from the patient (created when patient had capacity)</b>	<p>Advance health care directive: 2 broad types, although many directives include both:</p> <ul style="list-style-type: none"> <li>Durable power of attorney for health care: names a health care agent (in some states called a proxy or representative) to make decisions if the patient no longer can; usually the most important document for patients to have</li> <li>Instruction directive (sometimes called a “living will”): traditionally used to list treatments (like cardiopulmonary resuscitation or mechanical ventilation) that the patient would or would not want in end-of-life situations; in dementia, more usefully applied to document the patient’s overall values and to consider behavioral management and placement decisions that can arise in middle stages of illness<sup>59</sup> (see Symptom and Behavioral Management)</li> </ul>	<p>Many patients would benefit from legal advice to discuss various forms of financial surrogacy, including:</p> <ul style="list-style-type: none"> <li>Durable power of attorney for finances. Names an agent to manage the patient’s money and property.</li> <li>Living trust. A legal tool naming a trustee to manage decisions about money or property during the patient’s lifetime as well as in death.</li> <li>Social Security Representative Payee or Veterans’ Administration Fiduciary. Individuals named to manage Social Security or veterans’ benefits on behalf of patient.</li> </ul>
<b>Authority from the state (may require a court process, often but not always avoidable with advance planning)</b>	<p>Default surrogates—if an incapacitated patient has not designated a health care agent, many but not all states have statutes automatically appointing a surrogate from an ordered list of relatives; state laws vary considerably, and may limit the scope of a default surrogate’s legal authority (e.g., over end-of-life decisions or clinical research)<sup>60</sup></p> <p>Guardianship (in some states called conservatorship or conservatorship of the person)—if a patient lacks capacity and does not have an appropriate surrogate, a judge will appoint someone to make decisions for them; family members or friends may petition to be named the patient’s guardian; other options include professional (paid) and public guardians</p>	<p>No default financial surrogates—generally, families do not have authority to make financial or other legal decisions for the patient; a spouse has very limited authority unless also named as an agent, trustee, or conservator</p> <p>Conservatorship (in some states called guardianship/conservatorship of the estate)—if a patient does not have an agent or trustee and lacks capacity, a judge will appoint someone to make decisions for him or her; family members or friends may petition to be named the patient’s conservator; other options include professional (paid) and public conservators</p>

patient’s general values and beliefs when capacity was present. Finally, if there is insufficient information for substituted judgment, physicians and surrogates should attempt to determine what is in the best interest of patients. Such judgments can be difficult and subjective; in particular, healthy people usually underrate the quality of life of patients with chronic disabilities as judged by those patients.<sup>22</sup> Even when patients lack capacity, it is often still helpful to invite them to participate in broader conversations about the values guiding decisions about their care.

Surrogate decision-makers should be aware that their role is to try to decide as the patient would under the circumstances; in many cases this approach can mitigate subsequent guilt or regret, as the surrogate need not bear full responsibility for decisions that reflect the patient’s wishes rather than their own personal wishes. As the illness progresses, clinicians and surrogates should consider medical decisions for patients in the context of the overall goals of care. These goals should be informed by the patient’s stated wishes and values, as well as by considering how patients’ aims would change in response to clinical developments and assessing what available interventions are likely to achieve. For many patients, it will be appropriate to write do-not-resuscitate or do-not-hospitalize orders if either resuscitation or hospitalization is deemed inconsistent with patient goals. Many states have passed laws for Physician Orders for Life-Sustaining Treatment (POLST; acronyms and terminology vary across states), which, unlike traditional

resuscitation and intervention orders, apply across institutions and also to emergency responders in home and public settings. Although useful for many patients, POLST documents are powerful tools that require cautious application; in particular, they do not substitute for advance directives and are typically appropriate only in advanced stages of illness.<sup>23</sup> If implemented, POLST forms should be reviewed regularly to ensure that they are appropriate to the patient’s current clinical status and the patient’s current wishes (or an appropriate surrogate’s understanding of their wishes).

## Symptom and Behavioral Management

### Early Stages: Balancing Independence and Risk

Many ethical conflicts encountered in mild cognitive impairment and mild dementia concern the extent of patient involvement in instrumental activities of daily living, such as driving, cooking, political participation, and managing finances, especially as patients may lack sufficient insight to monitor their performance. These activities are central to many patients’ identities, but may expose them to personal risks, and in some cases could also endanger patients’ families or the public. Conversely, restricting patient activity can also expose them to risks. For example, while patient financial mismanagement can result in catastrophic monetary losses, delegation of broad financial powers to poorly prepared or unscrupulous family members can expose patients to financial exploitation.<sup>24</sup> Another risk of restricting activities is exacerbating social isolation, which can contribute to depression and

worsening cognitive decline.<sup>25</sup> Clinicians and family members should remain cognizant that no approach can eliminate risks and remain alert to ways of monitoring patients' activities to mitigate risks while preserving patients' independence and dignity where possible.

Driving in patients with dementia poses several ethical challenges. While a diagnosis of dementia does not automatically mean a patient cannot drive, patients should anticipate becoming unable to drive safely as their condition progresses, at which point many will lack sufficient insight to make this determination on their own. The American Academy of Neurology has issued a practice parameter that may help to identify patients at increased risk of unsafe driving.<sup>26</sup> Even when guided by the best evidence and intentions, conversations with patients about restrictions on driving are often contentious; involvement of family members and friends can be helpful to facilitate such conversations.

### Moderate Stages: Agitation and Disruptive Behaviors

About half of patients with dementia exhibit agitated behaviors such as wandering, accusations, nighttime awakening, and violence.<sup>27</sup> These behaviors contribute to caregiver burnout, interfere with personal care, and can endanger patients as well as others in the care setting; such problems are often key factors in the breakdown of home care leading to institutionalization.<sup>28</sup> Decisions about nursing home or memory care placement can be especially challenging, often intersecting with cultural expectations about filial obligations to aging parents, intrafamilial conflicts regarding the disposition of assets, caregivers' own employment and living circumstances, and what are sometimes inflexible beliefs and commitments ("I promised Dad I'd never put him in a home"). Clinicians can often help caregivers maintain patients at home with advice on person-centered communication, behavioral management, and environmental modification,<sup>29</sup> as well as appropriate referral to resources such as advocacy organizations, support groups, caregiver respite, legal aid, adult day programs, and in-home services (see also The Caregiver Role). However, for many families, clinicians should encourage candid reassessments of whether in-home care remains feasible when disrupted sleep and physical or emotional strain interfere with caregivers' self-care, work, and other obligations.

In domestic and institutional care settings, disruptive and combative behaviors can harm the patient and threaten the safety of other residents or staff. The use of mechanical restraints (including bed rails) is now broadly rejected in both practice and policy<sup>30,31</sup> as they can paradoxically increase physical risks to patients via increased agitation, improper application, forced immobility, and masking reversible causes of delirium. In rare cases with no realistic alternative for preserving the safety of the patient and others, the least restrictive possible restraint should be applied following an informed consent discussion (usually, with the patient's

representative) including disclosure of risks and alternatives; their necessity and utility should then be continually reassessed. Pharmacologic restraints, as with benzodiazepines or neuroleptics, also require careful consideration given associated risks of exacerbated delirium, extrapyramidal symptoms, and excess mortality<sup>32</sup>; the Food and Drug Administration has issued a black box warning for atypical antipsychotics. In many cases these medications worsen patients' behavioral symptoms and increase the risk of complications due to polypharmacy, so nonpharmacologic strategies<sup>29</sup> should be exhaustively explored first. If nonpharmacologic approaches are unsuccessful, clinicians should weigh the risks of pharmacologic treatment against other ethically important considerations such as the safety of patients and those living with them, patient quality of life (e.g., if compromised by hallucinations or agitation), and wishes of patients and families to maintain the patient at home for as long as feasible. As with physical restraints, if pharmacologic management is judged necessary, these medications should only be prescribed following an informed consent discussion detailing the associated risks. Depending on state law, health care agents and conservators may need special court authorization to consent to use of such restraints.

### Advanced Stages

While nearly all surrogate decision-makers for patients with advanced dementia believe that comfort should be the primary goal of care,<sup>33</sup> many patients undergo burdensome interventions and hospitalizations inconsistent with these goals. For example, tube feeding is associated with medical complications, takes away the pleasure of eating (for which hand feeding is preferred), and has not been shown to improve survival, quality of life, nutrition, or wound healing.<sup>34</sup> Ethical challenges arise when surrogate decision-makers nonetheless request tube feeding. While respect for autonomy (extended to the surrogate as the patient's representative) does not compel clinicians to provide interventions without medical justification, feeding and nutrition have great symbolic significance for many families. Such requests should be treated as occasions for deeper conversations about the surrogate's perception of the medical benefits of artificial nutrition and their understanding of the patient's overall prognosis.

Patients with advanced dementia may also experience underrecognition and undertreatment of pain due to communication difficulties. Validated pain measures based on caregiver assessment can be useful in these circumstances.<sup>35</sup>

One in 6 patients with advanced dementia die in hospitals, and many others undergo burdensome transitions between hospitals and institutional settings.<sup>36</sup> In part because of the high morbidity of inpatient delirium and nosocomial infection, most conditions including pneumonia are best managed in outpatient settings. Hospitalization often occurs by "default" in perceived crises due to insufficient advance planning and preparation of patients' family members and can in many cases be prevented by anticipatory discussion and the use of do-not-hospitalize

orders in nursing homes when transfers are unlikely to extend survival or improve quality of life.

## Hospice and the Problem of Prognostication

Many patients with advanced dementia would benefit from hospice enrollment, which is associated with reduced hospitalization, greater symptom control for pain and dyspnea, and increased family satisfaction with care.<sup>37</sup> While hospice utilization in dementia is increasing, over 20% of those dying in hospice with dementia only use hospice for 3 days or fewer prior to death.<sup>38</sup> A major policy barrier to earlier hospice utilization for dementia in the United States is that Medicare eligibility requires an estimated survival of less than 6 months based on the Functional Assessment Staging scale, but these guidelines are little better than chance at predicting mortality in dementia.<sup>39</sup> The development of better predictive measures and of eligibility requirements more appropriate to advanced dementia would enable patients and families to utilize hospice services earlier in the course of illness.

## Addressing Requests for Physician-Hastened Death

Physician-hastened death (often referred to as physician aid-in-dying or physician-assisted suicide) has been legalized in several US states, and neurologists have increasingly fielded inquiries from patients and families regarding this practice.<sup>40</sup> US state laws legalizing physician-hastened death (modeled after the Oregon Death with Dignity Act) generally do not apply to patients with dementia, as they require (1) an estimated survival of 6 months or less and (2) that the patient requesting a lethal medication have decisional capacity and be capable of self-administration. (Such requests also must be contemporaneous and cannot be made by advance directive.) Still, neurologists have a responsibility to respond empathetically to such inquiries, which can provide opportunities to elicit deeper concerns from patients and their families (including patients' fears of being a "burden") or to address unmet palliative, psychosocial, and advance care planning needs. Treatable causes of physical and psychological suffering should be addressed; mental health, palliative care, or hospice referral should be made if appropriate; and planning documents such as advance health care directives, do-not-hospitalize orders, and POLST orders should be reviewed and updated.

## Contextual Issues

### Financial Effects

Some of the fear and stigma associated with dementia may be attributable to the financial strains it can place on patients' families. In dementia, the overwhelming majority of costs are attributable to in-home care, nursing home care, and lost caregiver wages for unpaid care, all of which are generally directed at patient impairments in activities of daily living and thus are not covered by medical insurance but instead are predominantly borne by patients' families.<sup>41</sup> Most American families are ill-prepared for these expenses; planning is also

hampered by a widespread misconception that Medicare will cover patients' long-term care expenses.<sup>42</sup> Newer models of providing and financing long-term care are needed to address the needs of patients and their families.

## The Caregiver Role

Family members and other unpaid caregivers are crucial clinical partners in dementia care; for patients with memory deficits, their input is often crucial to obtaining an adequate clinical history, and clinical plans usually depend on them for successful implementation. As discussed above, caregiver strain and burnout are key mediators of institutionalization, so realistic plans to care for the patient at home should anticipate and minimize them; caregiver strain and burnout are also risk factors for patient abuse (discussed below). Some research has suggested that emotional and physical burdens associated with caregiving result in negative health outcomes for the caregiver, although more recent population-based studies indicate more positive emotional and physiologic effects of caregiving.<sup>43</sup> Health effects and positive experiences of caregiving are strongly influenced by social support as well as cultural and relational factors<sup>44</sup>; the financial, emotional, and physical costs of caregiving are disproportionately borne by women.<sup>45</sup> Many caregivers may be unaware of existing programs to provide respite care, financial support, and other services and can often benefit from targeted referrals from social work.<sup>46</sup> These programs can be key tools for maintaining patients in home and community (rather than institutional) settings, and more resources are needed to provide economic and social services support to caregivers.

Progressive communication and memory deficits often complicate a patient's ability to provide a clinical history; thus, during many office visits a caregiver will act as the spokesperson. While the caregiver's perspective is critical, patients have their own perspective that should be elicited and acknowledged; there is often a temptation to omit this as time-consuming. Following core ethical principles of beneficence (concern for the patient's well-being) and respect for patient autonomy (even when diminished), clinicians should be mindful to express both in words and by actions that their primary duty is fidelity to the patient, even when the caregiver is relied upon to speak on the patient's behalf.

## Abuse of the Patient With Dementia

Patients with dementia and other cognitive impairments are at increased risk for abuse, which can take various forms including physical and psychological abuse, sexual assault, financial exploitation, and neglect.<sup>47</sup> Perpetrators of abuse may include family members, friends, and providers of health care or long-term care services; in nursing homes, there is growing recognition of the problem of resident-to-resident aggression.<sup>48</sup> Clinicians should be alert to identify and document potential manifestations of abuse, such as supportive examination findings, direct observations of abusive actions, isolation of the patient from previously trusted family or friends, failure to pay for care needs, and malnutrition.<sup>49</sup> In many cases it is necessary to devise strategies for interviewing the patient separately from

a suspected abuser. There is a common misconception that reporting to Adult Protective Services requires convincing evidence; instead, in almost all US states, physicians and other mandated reporters are obligated to report any reasonable suspicion of abuse. Typically, reports will result in a home visit by a worker from Adult Protective Services to investigate these concerns, which patients with capacity may refuse. Every state also has mechanisms for reporting the suspicion of abuse in nursing homes and other long-term care facilities.<sup>49</sup>

### Socioeconomic, Racial/Ethnic, and Cultural Factors

Black and Latinx older adults are at increased risk for dementia compared with White and Asian American older adults; this increased risk appears not to reflect genetic differences but instead the influence of social determinants of health such as reduced access to primary care and early life adversity.<sup>50</sup> Diagnosis of dementia in Black and Latinx patients is also often delayed due to lack of access to specialist care, differing family and patient expectations around cognitive change and caregiving, and clinicians' reliance upon culturally specific screening and testing materials that do not generalize to the patient's population.<sup>51,52</sup> Another factor in delayed diagnosis may be mistrust towards the medical establishment among minority communities, informed both by awareness of historical abuses (including but not limited to the Tuskegee Syphilis Study) as well as by patients' personal experiences of biased, discriminatory, or culturally insensitive treatment by clinicians.<sup>53</sup>

When evaluating patients who are not fluent in English, clinicians should strive whenever possible to use professional interpreters rather than rely on family members as translators. Many family members would have difficulty in objectively translating a patient's or another family member's report of the patient's cognitive decline or in communicating challenging information back to the patient about the diagnosis. Clinicians should be aware that patients and families whose ethnic or cultural background differs from their own may have different perceptions of illness and priorities for care than they do, while not assuming that all members of a given group or family have identical communication and treatment preferences.<sup>54</sup>

### Multidisciplinary Care and Systems of Care

Providing high-quality dementia care is often challenging due to the fragmentation of our health care system and incentives that often favor technical and invasive interventions over personal attention. Patients are often cared for by multiple specialists in a variety of hospitals and nursing facilities, often with incompatible electronic records systems. This fragmentation, added to the inherent challenges of care management in dementia, likely contributes to potentially preventable and burdensome acute hospitalizations.<sup>55</sup> Policy efforts have emphasized the need for more integrated models of care delivery, in order to anticipate and address the varied psychosocial as well as physiologic effects of dementia on patients and families.<sup>56,57</sup> As one related development, Medicare has introduced Chronic Care Management billing codes to

incentivize care coordination activities beyond face-to-face office visits, such as medication reconciliation, communications with specialists, coordination with home- and community-based service providers, and care planning. However, it remains unclear whether many practices will be able to take advantage of these payments.<sup>58</sup> Further research and policy innovations are needed to foster a practice environment in which neurologists can best provide care that is respectful of patient autonomy, advances patients' welfare, and minimizes harms, and in which the benefits of care are distributed justly among all patients.

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<b>Zachary Simmons, MD</b>	Pennsylvania State University, Hershey	Design and concept, drafted manuscript
<b>Richard J. Bonnie, LLB</b>	University of Virginia, Charlottesville	Revised for intellectual content
<b>James A. Russell, DO</b>	Lahey Medical Center, Burlington, MA	Design and concept, revised for intellectual content



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