

## DEMENTIA AND DRIVING: ETHICS AND THE LAW

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### ABSTRACT

When caring for older adults with Alzheimer's disease (the most common cause of dementia) there are particular ethical issues that healthcare providers must consider. Driving a car is a complex task, requiring both cognitive and physical skills. While unsafe driving can have risks and health implications for older adults, so can driving retirement. For many adults, driving contributes to their perceptions of independence. Determining when an individual living with Alzheimer's disease should retire from driving is challenging because some drivers are unaware or reluctant to accept their cognitive deficits, especially in the early stages. Moreover, there is no standardized test to determine when a patient with Alzheimer's disease (AD) is unfit to drive. While some state laws have been created to help identify high-risk drivers, healthcare providers are often tasked with formulating this decision. This paper explores the ethical dilemma and current state laws pertaining to driving with a diagnosis of AD. The potential consequences of driving retirement and potential strategies to help those who are challenged are also discussed.

### INTRODUCTION

Driving is the most convenient and preferred method of transportation for older adults in America (Stressel & Dickerson, 2014). Given the trend of older adults living longer and choosing to age in place, more elder drivers are on the road (Dickerson, 2014). According to the Centers for Disease Control and Prevention (CDC), 36 million licensed drivers are older adults, age 65 and older. This number is expected to increase to 40 million by the year 2020 (CDC, 2015). Across all age groups, adults 70 years of age and older have more fatal car crashes (CDC, 2015; Lotfipour et al., 2013). These accidents are often due to visual, motor, and cognitive changes that often occur with aging (CDC, 2015; Lotfipour et al., 2013).

Alzheimer's disease (AD) is one of the many medical conditions that can impair driving capabilities (Yi et al., 2015). Currently, 5.1 million Americans – adults older than 65 years of age – suffer from AD, and this number will increase to 7.1 million by 2025 (Alzheimer's Association, 2016). Initially, AD presents with attention deficits, short-term memory loss, and spatial orientation deficiencies. Problematic driving behaviors (e.g. becoming disoriented, turning incorrectly, deviating lanes, etc.) can occur as a result (Yi et al., 2015). According to The American Academy of Neurology, 34% of older adults with early AD are considered unsafe drivers (Iverson et al., 2010). Compared to the general driving population, patients with AD are at increased risk for driving casualties (Yi et al., 2015). Further, accident rates and traffic violations are five times higher amongst patients with mild-to-moderate AD (O'Connor et al., 2013). Although not all patients with mild-to-moderate AD are incompetent to drive, it is challenging to assess and predict when a driver will become unsafe.

Driving is an important factor in remaining mobile in the community and maintaining social contacts. For some older drivers, driving is a sense of identity and symbolizes independence (Park et al., 2015). Moreover, older adults are often more afraid of losing their independence than the risk of crashing. According to the American Automobile Association report on *Driving Cessation and Health Outcomes for Older Adults* (2015), the study found that driving cessation led to a 51% reduction in social network size and an accelerated decline in cognitive ability (Chihuri et al., 2015). Studies also reveal that driving cessation has been associated with an increased risk for depression (Haustein & Siren, 2014; Chihuri et al., 2015). Other research suggests that older adults who stop driving are five times more likely to be admitted to a nursing home (Annals of Long-Term Care, 2015; Chihuri et al., 2015). A recent study by O'Connor et al. (2013) discovered mortality risk increased 1.5% after driving cessation. It is clear that

driving retirement has been associated with many serious ramifications and begs the question “when is the best time to intervene?”

In addition to the profound effect on older adults, driving retirement also impacts families and communities. Family members are often the first to recognize unsafe driving practices. According to Musselwhite and Shergold (2013) about 60% of older adults followed the advice of their family members and retire from driving. Although family members may have the ability to intervene (e.g. removing keys, removing the car, making the car impossible to start, filing a state report), conflicts and resistance can arise over this highly emotionally charged decision. Many family members also believe that driving retirement is an inconvenience to the family, as other means of transportation must be provided or arranged for the impaired driver (Musselwhite & Shergold, 2013).

### **ETHICAL DILEMMA**

The desire for autonomy is an intrinsic human need and is a key principle in the *Code of Ethics For Nurses* (Lindberg et al., 2014). “Autonomy is defined as a person’s right to hold views, make choices, and take actions based on their personal beliefs and values” (Daly et al., 2001, p.8). Healthcare providers are obligated to acknowledge and respect patients’ autonomy while balancing the health and safety of both the patient and the public (Daly et al., 2001). There are several situations in which healthcare providers may need to invalidate this basic principle. For example, restricting driving privileges for compromised AD patients who fail to stop driving.

A diagnosis of AD does not prohibit an individual from driving, however, driving retirement is recommended at some point as the disease progresses (O’Connor et al., 2013). In the early stages of AD, many people are still socially active, able to manage daily living and make simple decisions (O’Connor et al., 2013). Nearly half of AD patients continue to drive for at least three years after their initial diagnosis even though patients with early AD may begin to recognize their impaired driving abilities (Carr et al., 2010; O’Connor et al., 2013). While studies suggest that many adults with early AD will modify their driving behaviors (e.g. traveling less distances, driving during the day, avoiding the roads during traffic or inclement weather) there are those who lack insight or are in denial and continue to drive when it is no longer safe (O’Connor et al., 2013). In a qualitative study conducted by Chacko et al. (2015), the researchers found many participants with AD expressed high levels of driving confidence and were unlikely to regulate their driving. Findings from another study of AD drivers revealed 94% of participants with AD rated their driving as safe, while only 46% of those drivers were classified as safe by their driving instructors (Andrew et al., 2015).

Patients with AD are still capable of making some decisions despite their diagnosis. Family members and healthcare providers should reframe from making decisions for the patient when their decision-making capacity is deemed intact. A paramount concern for families coping with an individual with AD is driving safety because the rate and progression of cognitive decline is not predictable (Rose & Lopez, 2012). As aforementioned, disagreements, arguments, and family tension can occur when family members believe the patient’s safety outweighs their desire to drive. Family members often seek the advice of healthcare professionals to help make this decision. Healthcare providers, however, may be reluctant to discuss driving retirement because of lack of knowledge, time, and/or comfort with this emotionally charged topic. Moreover, there is no one test that can determine when a person with AD should no longer drive (Rose & Lopez, 2012). Thus, recommending driving retirement at the appropriate time is challenging for all involved, taking into consideration the driver’s sense of autonomy as well as public and patient safety.

### **ETHICAL DILEMMA SOLUTIONS**

There is no real consensus on how to manage AD patients who are unfit to drive. In recognition of potential safety concerns, state licensing policies were developed. The process of driver’s license renewal is however not standardized. While some states like New Jersey have no age-based license renewal procedures, other states implement different methods to assess driver fitness (See Table 1). Vision is a key aspect of driving, however, safe driving also requires motor function, visual-spatial abilities, and cognition (Tefft, 2014). Many states only require a vision screen prior to license renewal. Research suggests that older drivers should not be tested only on vision (Dugan et al., 2013). On-road testing is

widely considered the “gold standard” for driving evaluation because it assesses the driver in real time (Thomas et al., 2013). Only three states – Illinois, New Hampshire, and North Carolina – require adults over a specified age to complete an on-road driving test (Governors Highway Safety Association, 2016). According to Piersma et al. (2016), on-road driving performance is a valid method of assessing fitness to drive in AD patients. Although standardized road tests yield valuable information, road tests are expensive, time consuming, and only provide a snap shot of the person’s driving ability. This test does not capture possible performance fluctuations or incorporate changing environmental conditions. For this reason, law enforcement officials recommend frequent retesting (Thomas et al., 2013).

Healthcare professionals are required to routinely assess a patient’s fitness to drive (New Jersey Motor Vehicle Commission, 2015). Each state has its own laws regarding reporting unsafe drivers (Dugan et al., 2013). In New Jersey, healthcare professionals are mandated to report patients with health conditions that affect driving to the Motor Vehicle Commission (New Jersey Motor Vehicle Commission, 2015). Only six other states – Pennsylvania, Delaware, Georgia, Nevada, Oregon, and California – have mandatory reporting laws regarding potentially impaired drivers. There are tremendous variations on medical diagnoses that require reporting. To complicate matters, many primary care providers lack formal training on medical reporting laws and driver safety requirements (Dugan et al., 2013). One study discovered that clinicians were only 62% accurate identifying hazardous drivers (Bixby et al., 2015). Inaccurate reporting can result in a revoked driver’s license or license suspension. Medical reporting can also compromise the patient’s perception of confidentiality. Consequently, patients may not disclose pertinent information to their healthcare providers in fear of driving retirement.

States that lack driver license renewal policies or mandatory medical reporting often rely on the healthcare provider to determine if a driver may be unfit to drive. Many types of interventions have been proposed to identify high-risk drivers. Because many patients with AD lack insight into their cognitive deficits, family members are often asked to provide information on a patient’s ability to drive. Family members are given multiple occasions to observe driving behaviors. An observational study conducted by Bixby et al. (2015) found adult children were accurate in predicting the driving abilities of their parents. Another study discovered family members’ rating of unsafe driving reflected the opinion of experienced neurologists (Brown et al., 2005). Recognizing the important contribution of family members, the American Academy of Neurology recommends utilizing family members’ opinions when predicting driving performance (Iverson et al., 2010). While some studies have found that family members are good predictors of driving performance, others suggest family members may withhold or alter accurate information in fear of psychosocial consequences (Bixby et al., 2015).

**Table 1: 2015 Governors Highway Safety Associations’ Mature Driver Laws**

State	Length of Regular Renewal Cycle (Yrs.)	Provisions for Mature Drivers
Alabama	4	No additional requirements
Alaska	5	>69: no mail renewal
Arizona	Until age 65	>65: renewal every 5 yrs., mail renewal requires passage of vision exam within the prior 3 months >70: no mail renewal
Arkansas	4	No additional requirements
California	5	>70: no mail renewal
Colorado	10	>61: renewal every 5 yrs. >66: no electronic renewal, mail renewal requires passage of vision exam within the prior 6 months
Connecticut	Choice of 4 or 6	>65: choice of 2- or 6-year renewal, mail renewal requires demonstration of hardship
Delaware	8	No additional requirements
D.C.	5	>70: vision test, possible reaction test, and physician's letter
Florida	8	>80: renewal every 6 yrs. with vision test (in person or physician's letter if renewing by mail or electronically)

Georgia	Choice of 5 or 10; veterans valid until 65 yrs.	>60: renewal every 5 yrs. >64: vision test
Hawaii	8	>72: renewal every 2 yrs.
Idaho	Choice of 4 or 8 for drivers ages 21-62	>63: renewal every 4 yrs.
Illinois	4	>81-86: renewal every 2 yrs. >87: renewal every year >75: road test
Indiana	6	75-84: renewal every 3 yrs. >85: renewal every 2 yrs. >70: no electronic or mail renewal
Iowa	5	>70: renewal every 2 yrs.
Kansas	6	>65: renewal every 4 yrs.
Kentucky	4	
Louisiana	4	>70: no mail renewal
Maine	6	>65: renewal every 4 yrs. 40-61: vision test at every other renewal >62: vision test at every renewal
Maryland	5	>40: vision test
Massachusetts	5	>75: renewal in person only
Michigan	4	No additional requirements
Minnesota	4	No additional requirements
Mississippi	Choice of 4 or 8	No additional requirements
Missouri	6	>70: renewal every 3 yrs.
Montana	8 (or 4 by mail)	>75: renewal every 4 yrs.
Nebraska	5	>72: no electronic renewal
Nevada	4	>70: mail renewal must include medical report
New Hampshire	5	>75: road test
New Jersey	4	No additional requirements
New Mexico	Choice of 4 or 8	>75: renewal every year
New York	8	No additional requirements
North Carolina	8	>66: renewal every 5 yrs. >60: parallel parking not required on road test
North Dakota	6	>78: renewal every 4 yrs.
Northern Mariana Islands	3	No additional requirements
Ohio	4	No additional requirements
Oklahoma	4	62-64: fee reduced >65: fee waived
Oregon	8	>50: vision test
Pennsylvania	4	No additional requirements
Rhode Island	5	>75: renewal every 2 yrs.
South Carolina	10	>65: renewal and vision test every 5 yrs.
South Dakota	5	No additional requirements
Tennessee	5	>60: fee reduced >65: no expiration
Texas	6	>85: renewal every 2 yrs. >79: no electronic or mail renewal
Utah	5	>65: vision test

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Vermont	4	No additional requirements
Virginia	8	>75: renewal every 5 yrs. in person with vision test (in person or physician report)
Washington	5	No additional requirements
West Virginia	8	No additional requirements
Wisconsin	8	No additional requirements
Wyoming	4	No additional requirements

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Many studies have investigated the role of cognitive testing to predict safe driving behaviors. The Clinical Dementia Rating (CDR) is an objective tool used to assess driving competence (Fisher & Thomson, 2013). This semi-structured tool is designed to assess dementia severity by evaluating memory, orientation, judgment, and problem solving (Fisher & Thomson, 2013). The CDR is a well-validated tool utilized in research and has been incorporated in many driving safety guidelines (Fisher & Thomson, 2013). According to The American Academy of Neurology, AD patients with a CDR score greater than 1 are at increased risk for car accidents and should be advised to refrain from driving (Iverson et al., 2010). Typically, the CDR takes 45 minutes to complete. The evaluation process is impractical to conduct in the office given the constraints of healthcare provider's time. Also, providers need to seek permission and receive training to use this test (Fisher & Thomson, 2013). Because patients with AD may not respond honestly, collateral history is often required, which further raises issues of patient confidentiality and patient autonomy.

Although findings from cognitive tests such as the CDR, Mini Mental Status Exam, Clock Drawing Test, Trail Making Tests (Part A and B) can support a clinician's judgment, numerous studies refute the efficacy of cognitive testing as a suitable predictor of driving ability (Dobbs & Shergill, 2013). Furthermore, the process of analyzing and interpreting these cognitive tests are subject to bias and lack discriminative abilities (Dobbs & Shergill, 2013). A brief screening test designed specifically for patients with AD to help identify impaired drivers is warranted.

Given the onus of healthcare providers to determine if patients are safe to drive, New Jersey should create a law that mandates on-road testing before driver's license renewal. This law would be helpful in both preserving the patient and clinician relationship and identifying unsafe drivers. Although the development of standardized state relicensing policies is clearly justified, it cannot be the sole solution (Kulikov, 2011). Findings from Kulikov's research found older adults were more likely to withdraw and forgo driving rather than complete testing requirements (Kulikov, 2011). Thousands of people can become immobilized when communities lack adequate public transit systems (Stav, 2014). According to Koffman et al. (2010), 25% of seniors live in areas without public transportation. Many communities are also not designed adequately to accommodate pedestrians and bicyclists (Shinkle, 2012). Some argue that the risk of injury and death is much higher for pedestrians with AD (Siren et al., 2015). Although increasing public transit services can be a viable option for many older adults, this alternative can be unsafe for patients who have cognitive deficits or become easily disoriented (Kulikov, 2011). State policyholders need to invest in transportation methods that are tailored for patients with cognitive deficits. Presently, there are several states like California that provide dementia training for their public transportation workers. Another solution is investing in programs like the Independent Transportation Network of America (ITN). The ITN is a non-profit organization that helps provide transportation to older adults. This community-based transportation service is less expensive than the cost of taxis (ITN, 2016). Riders are escorted to their destination and no money is exchanged while in the vehicle. Organizations like ITN can provide patients with AD a safe and reliable method of transportation.

### **ROLE OF HEALTHCARE PROVIDERS**

Given the many factors that contribute to safe driving, healthcare providers (HCPs) including nurse practitioners (NPs) can take several proactive steps to offset driving retirement for all older adults and preserve patient's autonomy. First, HCPs can identify and/or treat reversible causes of cognitive and functional decline. Age-related changes in vision, hearing, and motor function can negatively impact

driving skills (Centers for Disease Control and Prevention, 2015). Patients should be encouraged to have annual eye exams to ensure appropriate driving vision. Hearing tests can also help identify any hearing impairments, which can be corrected with the use of hearing devices. The rapid pace walk, motor strength, and range of motion can reveal physical limitations, which can impair driving (Greve et al., 2015). In the event the patient exhibits physical limitations, appropriate referrals to occupational and physical therapy can be made to improve the patient's strength and/or range of motion.

Various history exam findings can be helpful in recognizing potentially impaired drivers. Many medications (e.g. anticonvulsants, antihistamines, antipsychotics, tricyclic antidepressants, bowel/bladder antispasmodics, benzodiazepines, muscle relaxants, and barbiturates) are known to impair driving abilities and should be avoided (Carr et al., 2010). Providers should be aware of potential medication interactions that can cause excessive somnolence or impair decision-making capacity. At any age the use of alcohol or other substances can impair driving abilities, therefore, clinicians should inquire about alcohol consumption and substance use regularly. When there is evidence that a patient may be unsafe to drive, providers should inquire about driving history. Gathering information about recent car accidents, misread traffic signs, and traffic violations can help identify unsafe drivers.

Patients with AD in particular are at an increased risk of car accidents, therefore, early AD identification is essential. Providers must be conscious of potential AD warning signs such as memory loss, difficulty performing familiar tasks, problems with language, disorientation to time and place, poor or decreased judgment, problems with abstract thinking, misplacing things, changes in mood or behavior, personality changes, and loss of initiative (Alzheimer's Association, 2016). Individuals who exhibit several of these systems need a detailed workup for AD and other forms of dementia. If the patient has AD, the healthcare provider can counsel about AD treatments and make appropriate referrals. Although patients with mild-to-moderate AD experience minor benefits from cholinesterase inhibitors, cholinesterase inhibitors have been associated with improved visual attention and executive function (Daiello et al., 2010). This may have some benefit for those who want to preserve their driving privileges in the early stages.

Healthcare providers including NPs can also provide anticipatory guidance about changes that occur with AD. Providing patients and families an opportunity to discuss future driving limitations and/or retirement can help patients and family members adjust and plan for this transition. Nurse practitioners can provide emotional support and help develop strategies to promote patient autonomy while ensuring the patient's welfare. Providers also can offer extensive car safety information by advising patients to wear seatbelts and avoiding conditions that may interfere with driving capabilities (i.e. driving at night, during heavy traffic, or in poor weather conditions).

It is important that HCPs promote the welfare of the community by advocating for policy revisions, laws, and regulations to help support alternative transportation services. Currently, our society does not have an adequate system to provide transportation to individuals who can no longer drive. As this demographic proliferates, there will be profound implications for many patients and family members. Coordination between healthcare providers and licensing agencies is also warranted to help meet the future transportation needs of AD patients.

Taking the car keys away from a patient can be a life-altering event, especially for those patients who cannot comprehend the extent of their cognitive deficits. Although difficult, at some point driving will need to be restricted. In summary, the literature suggests that there is no single assessment or solution that can easily define fitness to drive. The lack of clear and standardized license renewal protocols, likely related to ethics and aging, warrants further investigation to counter this potential safety issue in older adults with functional and/or cognitive impairments. Clinicians require more education and expertise to assess fitness to drive; as evidence indicates cognitive testing alone is not a valid measure of driver fitness (Dobbs & Shergill, 2013). Lastly, more funding for alternative and safe transportation is essential for patients with AD, and also older adults with other limitations.

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