

A State Analysis of the Legal Implications of an Alzheimer's or Other Dementia Diagnosis

OCTOBER 2023

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List of Abbreviations

ABA	American Bar Association
AD	Alzheimer's Disease
CMS	The Centers for Medicare & Medicaid Services
DMV	Department of Motor Vehicles
DTC	Direct to Consumer Testing
FDA	Food and Drug Administration
FINRA	Financial Exploitation of Specified Adults
GINA	Genetic Information Nondiscrimination Act
HIPAA	Health Insurance Portability and Accountability Act
MCI	Mild Cognitive Impairment

The Under-Discussed Issues Facing Those with Dementia

Alzheimer's disease and other dementias are diseases of loss: memory loss, mood or personality changes, and eventually, difficulty with basic daily functions, like walking.¹ Experts estimate that in the U.S., approximately 6.7 million older adults (65 years of age and older) are living with Alzheimer's; this number is expected to grow as the population ages.²

While people often anticipate health and lifestyle challenges, there are some issues that are under-discussed at a state level regarding the dementia community.

After diagnosis, people must navigate a new chapter of their life as they progress through various stages of the disease, starting with mild cognitive impairments (MCI) such as short-term memory loss and mood changes, and gradually moving towards difficulties expressing ideas, getting lost, confusion, and difficulty completing daily tasks.³ This puts decision-making processes in question and can lead to tricky navigation around capacity to address serious questions around finances, estate, and legal management.

Questions to the legal implications of a diagnosis often go unaddressed and unanswered.

Despite the fact that attention to Alzheimer's and dementia has increased significantly in the past decade (as of December 2022, annual federal funding for Alzheimer's research is more than \$3.7 billion), many of those who are diagnosed or are seeking a diagnosis still struggle to understand the legal implications of this diagnosis.⁴

Stories of adults with Alzheimer's and dementia grappling with the court system, for instance, paint a painful picture of how these patients are not properly understood and accommodated as they are diagnosed.⁵

The issue becomes even more complex as individual states have unique legislation and different approaches to issues touching dementia.

Common questions could include:

Will I be able to keep my driver's license?

What legal protections are in place if I become too impaired to actively manage my day-to-day life?

Is genetic testing a course of action for me and/or my family? Will my health data be compromised if I opt for genetic testing?

What happens to my savings and investments? Will I still be able to manage my own money?

What happens if there's a miscommunication with my bank or an encounter with the justice system?

This report seeks to highlight areas where more attention is needed at a state and national level to protect individuals with Alzheimer's and dementia and better understand their rights.

Our Approach

In order to further support those who receive, or are seeking, a dementia diagnosis, this report intends to address the advantages and challenges of having a dementia diagnosis within the legal system and set the foundation to demand further legal action, improve state and national support systems and accountability, and provide clearer resources on the legal implications for those seeking a diagnosis.

Based on research consisting of interviews with legal experts, financial experts, and prominent elder justice organizations, and a review of state laws and recent restructuring efforts, we've identified five areas which offer the most opportunity to support the dementia community at the state and national level:

- Financial management and abuse
- Guardianship
- Justice system
- Genetic testing
- Access to basic services

Financial Management and Abuse

Are people with dementia at risk for financial abuse?

Alzheimer's and dementia are often discussed as a series of losses. But what happens when you lose account of your finances? In one year between 2021 and 2022 in the U.S., there were 7.8 million reported cases of elder financial abuse for those 60 and over.⁶ While there is a shocking dearth of official numbers, with over 10 percent of Americans 65 and older diagnosed with some form of dementia, it's likely a significant number of those with dementia experience financial abuse.⁷ Those without a diagnosis are at an even greater risk of exploitation due to lack of protections, particularly if they are under 65.

Despite the fact that many states strongly advocate for elder rights, there is no consensus on how to approach financial exploitation of older adults. Additionally, most states themselves do not provide significant resources on this matter to support their residents.

Losing financial control to fraud and exploitation can not only be detrimental to one's livelihood but also to one's care: the total lifetime cost of care for someone with dementia has been estimated at \$392,874.⁸ Therefore, in order to consider the best support for the millions of people experiencing dementia, we examine two questions:

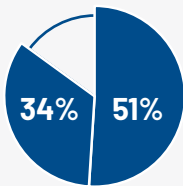
- What mechanisms are in place in states to ensure people with dementia aren't financially abused?
- How can people be better prepared for that potential before they are diagnosed?

What will happen to my money? The status of fraud, abuse, and financial mishaps.

Older adults are a key at-risk population for financial fraud and exploitation. According to an exploratory study by Comparitech reviewing several data sources more than 2022 in the U.S., the cost of elder financial exploitation has grown by over 54 percent, rising from \$177 billion in 2020 to around \$269.5 billion in 2022.⁹ According to data from the Internet Crime Complaint Center (IC3), while the number of cases of financial fraud



About half of senior financial exploitation is perpetrated by strangers (51%), while 34% is committed by family, friends and neighbors.¹²



The top five states with the highest rate of elder fraud:¹³

CASES OF EXPLOITATION
PER 100,000 SENIORS

Delaware: 49,854
Oklahoma: 29,040
Colorado: 18,313
Nevada: 16,332
Minnesota: 16,178



Nearly half (21) of states do not have an adult abuse registry.¹⁸



decreased, financial losses increased dramatically at 84 percent since 2021.¹⁰ A report by Bank of America estimates that “about half of senior financial exploitation is perpetrated by strangers (51%), while 34% is committed by family, friends and neighbors.”¹¹

People with dementia are at an especially high risk of financial fraud and exploitation. While there haven’t been recent studies assessing the number of people with dementia in the U.S. affected by financial exploitation,ⁱ most experts suggest that people with dementia are highly susceptible to this sort of abuse.^{ii,14}

Insufficient mechanisms are in place to support older adults, particularly those with dementia, who may be victims of financial exploitation.

Currently, there are two dominant mechanisms used by states and institutions to decrease financial exploitation: 1) elder abuse registries and 2) banks’ alert and review systems.

State elder financial abuse registries are growing in number but lack power.

In the U.S., 34 states have specific legislation covering senior financial exploitation and abuse. Most recently, Alabama instituted Shirley’s Law in 2022, which created an elder abuse registry which includes the names of those convicted of abuse, neglect, or exploitation (including financial abuse or exploitation), and those with protective orders against them involving older adults.¹⁵ While registries are a positive step towards addressing elder financial abuse, there are several issues, including lack of access by family and friends to these lists and the fact that not all states with registries bar employers from hiring these individuals, even if they are required to check the list.¹⁶ These registries also don’t directly address offenses against those who have dementia, though some point out those committed against those with developmental disabilities.¹⁷

Banks and other financial management institutions are underequipped to support those with dementia and issues with cognitive impairment.

Financial managers are given support and training to support their clients and recognize potential symptoms, but there is uncertainty in legal next steps for clients and their trusted associates.

While banks and financial institutions cannot pursue legal action directly, there are ways they can help flag and support their clients. FINRA rules on the Financial Exploitation of Specified Adults, enacted in 2018, allow banks to put a hold on a wire transfer if it looks suspicious due to suspected

i. A 2011 study in a London care home found that 15 percent of care recipients experienced financial abuse. Alzheimer’s Society. (2011.) Short changed: protecting people with dementia from financial abuse.

ii. One Virginia study did find, though, that older adults who were not experiencing dementia or confusion were 29 percent more likely to experience pure financial exploitation than the victims who were experiencing dementia or confusion. <https://nij.ojp.gov/topics/articles/financial-exploitation-elderly>

money laundering, fraud, or cognitive impairment risk.¹⁹ This rule, FINRA Rule 2165, is the first uniform national standard for placing temporary holds to address suspected financial exploitation.²⁰ According to FINRA, institutions can place a fifteen-day hold on a securities transaction or disbursement of funds and if further investigation is allowed, an additional ten-day hold can be placed.²¹

Did you know that financial advisors are some of the first people to detect dementia? Eric Chess, MD, director of the Financial Security and Cognitive Health Initiative at the University of Denver's Knoebel Institute for Healthy Aging, discovered in his research that impulsive and irrational investment and spending decisions signal the first signs of cognitive impairment.²² Many financial institutions, like Bank of America, have a working group intended to review financial exploitation for older clients (over 60) at high risk. Their financial advisors are given extensive training on identifying potential red flags.²³

Some financial institutions are implementing new strategies to make their clients aware of potential threats. In a recent report from Bank of America, they list several potential scams and fraud risks for their clients, including:

- Identity theft
- Charity scams
- Checks from the government
- FDIC and banking
- COVID-19 funeral assistance
- Medicare fraud
- Genetic testing fraud
- Investment fraud
- Reverse mortgage and home equity fraud.²⁴

State highlights

Amongst the 34 states who have specifically denoted elder financial exploitation, only **Indiana, Georgia, and Oklahoma** have specifically denoted people with dementia at risk for financial exploitation in elder law statutes.²⁵

While almost every state has some resource on adult protective services for general cases of abuse, neglect and fraud, few designate specific resources for financial exploitation. And only one, **Pennsylvania**, details exploitation in the case of dementia.

The following state has resources that discuss financial exploitation in the case of dementia including the different types of financial exploitation and steps to take to avoid being targeted:

Pennsylvania	Department of Aging ²⁶
The following states have resources that specifically discuss elder financial exploitation:	
Arizona	Arizona Elder Abuse Coalition ²⁷
California	CBA ²⁸
Georgia	Office of the Attorney General ²⁹
Maryland	Project SAFE (Stop Adult Financial Exploitation) ³⁰ and PROTECT Week (no collated resources but hosts an annual event on elder financial exploitation) ³¹
Michigan	Department of Attorney General ³²
Missouri	MOSAFE (Missourians Stopping Adult Financial Exploitation) ³³
New Hampshire	Department of Justice ³⁴
New York	Adult Protective Services ³⁵
Ohio	Department of Commerce (only concerns reporting abuse) ³⁶
Tennessee	Department of Financial Institutions ³⁷
Washington	Department of Financial Institutions ³⁸

Recommendations

- Broaden elder financial abuse legislation and registries** to include and specifically recognize offenses against people with dementia. A study to determine the precise number of people living with dementia in the U.S. who are affected by financial abuse would support advocacy efforts around this legislation.
- Incentivize Alzheimer's and dementia education for all financial advisors and bank employees** to support those who have and have not been diagnosed.
- Recommend aging adults meet with a trusted source or financial advisor to draw up a financial roadmap** in the case of future dementia or other disability.

Guardianship

Guardianship in the U.S.

What is guardianship? According to the U.S. Department of Justice, guardianship is defined as “appointment by a court of a person or entity to make personal and/or property decisions for an individual whom the court finds cannot make decisions for themselves,” which is often, but not always, a family member or friend.³⁹ They are considered fiduciaries and are legally entailed to act in the best interest of their clients. Professional guardians and the state are the final option when all other choices are exhausted.⁴⁰ While different states have different definitions of what constitutes the need for a guardian, most agree if someone is mentally, intellectually, or developmentally incapacitated then there may be a petition for guardianship. This can include Alzheimer’s and dementia.

1.3 million U.S. adults are under guardianship, according to the National Council on Disability, and courts oversee at least \$50 billion under adult conservatorships.⁴¹

While many states list dementia as a key reason why people submit for guardianship or conservatorship, the data is limited when it comes to how many people diagnosed with dementia are under a guardian’s or conservator’s care. 83 percent of dementia care is provided by family, friends and unpaid caregivers.⁴² Yet little is understood about who is asking for guardianship, there is no available state data on who is requesting guardianship for people living with Alzheimer’s and other dementia.⁴³

In the past five years, there have been significant efforts for guardianship reform at a national and state level to provide better protections for those under its care and to provide alternative pathways besides guardianship. In what scenarios does guardianship provide valuable support to people with dementia and what laws are in place to ensure these guardianships are beneficial?

Why guardianship should be a priority for dementia advocates

According to the American Bar Association (ABA), “most of the time, guardianship or conservatorship accomplishes what it is intended to do,” which is to protect a person’s rights and engage the individual to maximize their quality of life and care.⁴⁴

However, there are several complications about the process that should render guardianship a measure of last resort:

It provides an opportunity for financial abuse. In a review of six states by the U.S. Government Accountability Office (GAO), they concluded the full extent of abuse is unknown due to lack of data.⁴⁵ The most complete report, from 2010, concluded that in 20 cases, “guardians had stolen or otherwise improperly obtained \$5.4 million from 158 incapacitated victims, many of whom were older adults.”⁴⁶

Those under guardianship might not actually need it. Understanding of the decision-making capacity of an individual is still debated science. Recently proponents for alternative measures to guardianship have advocated to improve the expansion of rights for those who are experiencing mental and intellectual difficulties.⁴⁷

Applying for guardianship is cost-prohibitive. When guardianship is appropriate, the costs involved in securing guardianship can be a problem for those with lesser means. While the court costs can range from approximately \$12 to \$500 for a guardianship petition, the associated legal fees can add up, from a minimum of \$1,200 to an average of \$3,500.⁴⁸

Due to the unique nature of dementia, the line between self-sufficiency and requiring guardianship is hazy at best. Therefore, a lack of legal protections make one with a diagnosis particularly vulnerable.

Where guardianship measures can be improved and the status of current efforts

Data on guardianship is patchy at best. A significant 2020 survey by the National Center for State Courts (NCSC) on adult guardianship monitoring found that the recording of monitoring practices is minimal; despite receiving data from 46 states, the majority of the information came from “a handful of states” including California, Michigan, Oregon, Virginia, and Florida, and items were often missing including date of birth.⁴⁹



“Nearly all data on adult guardianship is held at the local court level with no system available in most states for reporting this information into a statewide database.”⁵²

—American Bar Association

According to 45 percent of judges and court administrators surveyed across the country, there was unavailable and clearly insufficient funding to gather and monitor data on guardianship cases.⁵⁰ Further, according to the ABA, “Nearly all data on adult guardianship is held at the local court level with no system available in most states for reporting this information into a statewide database.”⁵¹ Specific data on dementia cases within guardianship is even rarer.

Legal prioritization efforts are underway. Guardianship is a top priority for ABA. It highlights resources including decision-making tools, statutory information, and has a support network—Working Interdisciplinary Networks of Guardianship Stakeholders (WINGS)—for partnerships in states to drive improvements in guardianship policy.⁵³ In the ABA’s 2021 recommendations to improve adult guardianship legislation, it strongly recommends that state governments and organizations should expand pilot programs including: “Focus pilot programs on diverse populations as defined by differing disability issues and conditions (including, but not limited to, intellectual and developmental, physical, psycho-social, mental health, substance use, traumatic brain injury, communication, dementia, and other cognitive impairments), linguistic and cultural and intersectional identities, and across the life span.”⁵⁴

Greater research is needed on decision-making processes. As the need for guardianship is a tricky line to walk, many organizations including the National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR) and National Institutes of Health have recommended further research into the decision-making processes of people with dementia and their capacity to make informed decisions.⁵⁵

Appointed guardianship in appropriate scenarios protects people with significant cognitive impairment like dementia from abuse and supports the best possible care. However, guardianship needs to be made available in a safe way for individuals who have no representation or for individuals who have been abused by family members.

State highlights

In **New York**, 41 percent of the petitions for guardianship were for dementia.⁵⁶ In **Indiana**, 25.8 percent were for dementia.⁵⁷

While there are several statutory laws related to guardianship and court visitors, only two states have stated specific circumstances for mental illness/cognitive impairment—**Illinois** and **Tennessee**.⁵⁸

Amongst all state WINGS organizations, only **Minnesota** and **North Carolina** offered any additional information on decision-making for people with dementia.⁵⁹ While many states, such as **Pennsylvania**, offer a variety of resources that support people with dementia there is little connection made between dementia in guardianship.⁶⁰

North Carolina is the **only** state to include dementia protections in guardianship discussions. One of Dementia-Capable North Carolina's focus areas is Initiative Rethinking Guardianship that promotes less restrictive alternatives to guardianship, while also promoting a redraft of NC's General Statute 35A to ensure greater rights and protections for adults with dementia under guardianship.⁶¹

In 2018, the **U.S. Senate Special Committee on Aging** issued a report on guardianship of older adults with a goal to strengthen state efforts to "overhaul" guardianship. These efforts included improved oversight of guardianship and guardianship arrangements, less restrictive alternatives, and better data collection.⁶² But despite the significant number of people with dementia affected by guardianship, the disease was not specifically incorporated in this effort.

Recommendations

1. **Incorporate dementia into guardianship legislation.** Despite the use of dementia as a key justification for guardianship, it is rarely mentioned in guardianship reform efforts.
2. **Provide better alternative pathways to guardianship for people with dementia.** Dementia should not immediately qualify someone for guardianship. Understanding alternative measures to help people with dementia retain control of their assets even under the disease would be a necessary protective measure.
3. **Implement mandatory dementia training for potential guardians of older adults.** Ensure that anyone who intends to control key life decisions for those with dementia is fully understanding of their disease state.
4. **Develop dementia guidelines in guardianship task forces.** State WINGS groups and other similar organizations have insufficiently considered dementia in their guidelines for reforming the U.S. guardianship system. There is an opportunity to partner with existing Alzheimer's and dementia organizations to directly integrate specific needs into future discussions.

Justice System

The risks of dementia and the justice system

People living with dementia are at greater risk of negative interactions with law enforcement and the justice system—as are people with mental health conditions more broadly—but slip through the cracks of existing procedures and resources designed to help those with mental illnesses within the justice system.⁶³ Law enforcement personnel only sometimes receive training on dementia, but even when training exists, it is often insufficient. People living with dementia while incarcerated are particularly vulnerable within the prison system and only a few programs exist to serve their needs.

Each step of the process has risks

State Law Enforcement Training

Only seventeen states legally mandate law enforcement training on dementia, and those that do provide training often have a focus limited to wandering behavior.^{64,65,66} Interactions with police may escalate quickly when people with Alzheimer's or dementia are unable to understand or follow police instructions, and their distress may be interpreted as resistance or aggression.⁶⁷ Instances in various states of people with Alzheimer's disease or other dementias suffering grievous injury or death in interactions with police have spurred calls for increased training for law enforcement and other first responders.^{68,69} Law enforcement is a particular focus for Alzheimer's and dementia advocates because people living with the disease are more likely to come into contact with police and other first responders than other aspects of the justice system. Providing training ensures that law enforcement officers are equipped with the skills they need to serve their communities.

Assessment for Competency to Stand Trial

When someone with dementia is charged with a crime, it is necessary to determine their competency to stand trial. State laws vary, but generally competency is determined by the defendant's ability to understand the criminal proceedings and provide informed consent to participate in their criminal defense strategy.⁷⁰ One study found 30-50% of older adults with Alzheimer's disease charged with a crime were found incompetent to stand trial.⁷¹ Other forms of dementia, such as frontotemporal dementia, may



By 2030, more than 1/3 of the prison population will be 55 or older.



Between 17-52% of older people currently incarcerated will have dementia by 2030.



inhibit the ability to control one's behavior without impairing comprehension of the wrongfulness of the act, and thus these individuals are technically competent to stand trial in many states despite the disease's direct link to their actions.^{72,73} If an individual is found incompetent to stand trial, standard procedure dictates commitment to a mental health facility for treatment intended to restore competency—but in the case of dementia, restoration of competency is currently impossible given the progressive, irreversible nature of the disease.⁷⁴ Some laws specifically exclude dementia as a qualifying treatment for commitment, and leave few options for appropriate treatment facilities, especially when the crime in question is violent in nature.⁷⁵ Tests assessing competency also do not necessarily account for the fluctuations in mental status that may be associated with Alzheimer's disease and other dementias, as they only assess the state at the point of testing rather than a cumulative picture.⁷⁶ Further, not all evaluators have experience with dementia: in one case, court-appointed psychologists determined a defendant was faking dementia symptoms, but lacked experience with dementia. The defendant was ultimately found incompetent to proceed to sentencing due to dementia when the judge required the assessment of a more qualified expert.⁷⁷



Incarcerated people have a higher risk of developing dementia.



The Aging Prison Population

Estimates suggest that **by 2030, more than 1/3 of the prison population will be 55 or older.**⁷⁸ As prison populations age, so too will the proportion of those living with dementia while incarcerated—one 2020 estimate suggests by 2030, **between 70,000 and 211,000 of the 400,000 older people currently incarcerated will have dementia.**⁷⁹ Incarcerated people have a higher risk of developing dementia, and dementia poses unique challenges during incarceration: those living with dementia in prison may have trouble understanding and following directions, putting them in conflict with corrections officers or other inmates and potentially leading to infractions with secure confinement which worsens their condition.⁸⁰ Incarcerated people with dementia are also vulnerable to being targeted by other inmates for harassment, violence, or other mistreatment.⁸¹

State highlights

These states currently or will soon require training for law enforcement personnel:

Alabama

Alabama includes people living with Alzheimer's disease and other dementias in its laws pertaining to missing and endangered persons, and requires law enforcement personnel to complete first responder training for missing persons with Alzheimer's disease or other forms of dementia "if the training is available through the department, the Alabama Peace Officers' Standards and Training Commission, or the free training and certification program offered by the Alzheimer's Association."⁸²

Arkansas

Arkansas passed Act 202 (formerly HB 1396) in March of 2023, requiring two hours of additional training for enrollees of police academies specifically on Alzheimer's diseases and other dementias, which will include best practices for communicating with people with Alzheimer's disease or other dementias and be administered by a medical or mental health professional. This law will go into effect in January of 2024.⁸³

Colorado

Colorado law requires all police officers to receive training on interacting with people with disabilities, specifically including "a person with dementia diseases and related disabilities." A 2021 law established a commission to assess additional training requirements beyond the two hours already required for police officers in interacting with people with disabilities.⁸⁴ However, the commission ultimately provided resources without requiring their specific implementation, and police officers are required only to have training generally on disabilities on a rotating 5-year schedule.⁸⁵

Florida

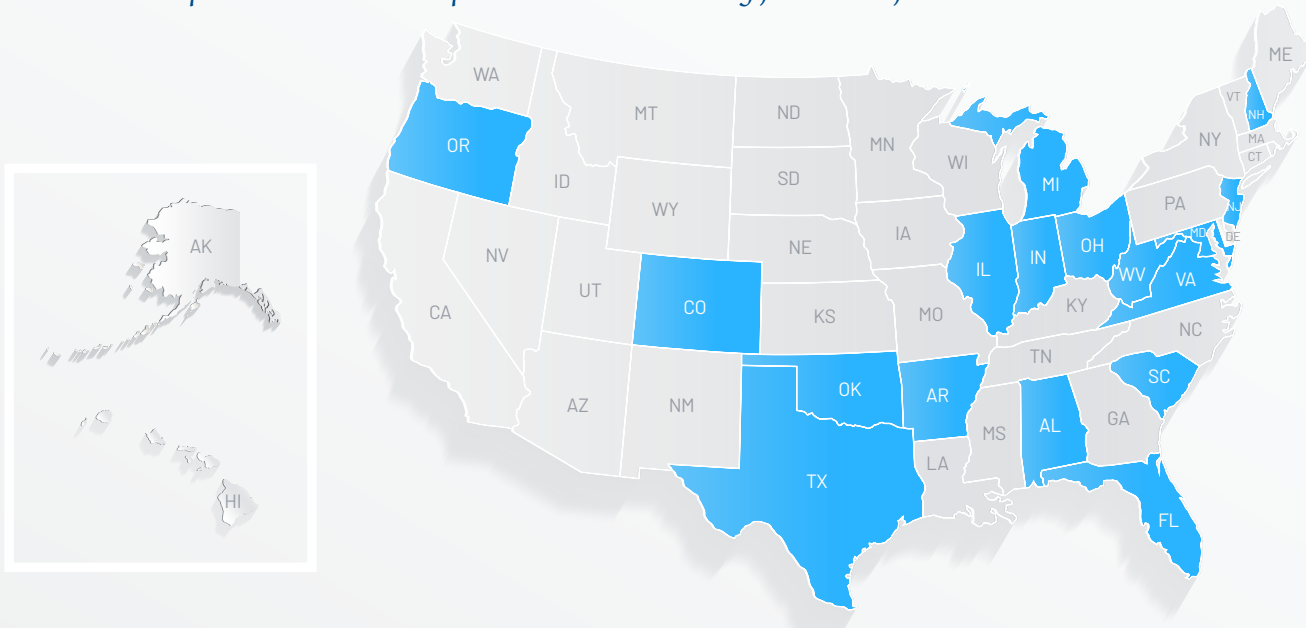
Florida requires law enforcement officers to complete training on identifying and investigating elder abuse and neglect as part of basic training or continuing education. The training must include the identification of and appropriate responses for people with dementia.⁸⁶

Illinois

The state of Illinois requires training for law enforcement personnel in the "Silver Search Awareness Program" and toolkit, which is an alert system for missing people with Alzheimer's disease, other dementias, or dementia-like cognitive impairment.⁸⁷

Indiana

In 2013, Indiana passed an update to existing state law, which requires six hours of training on interacting with people with mental illness and specific developmental or intellectual disabilities, to include Alzheimer's and dementia among the conditions on which law enforcement trainees and personnel will receive training.⁸⁸

States that Require or Will Soon Require Dementia Training for Law Enforcement Personnel**Maryland**

Maryland has enacted a “Silver Alert Program,” a program established in 2009 by state police for reporting and finding missing older adults with Alzheimer’s or dementia.⁸⁹ This program requires state police to provide training for local law enforcement on guidelines and procedures to handle instances of a missing person with cognitive impairment including dementia.⁹⁰

Minnesota

Minnesota mandates instruction in Alzheimer’s disease and dementia as part of its six-hour crisis intervention and mental illness crisis training.⁹¹

New Hampshire

New Hampshire requires the director of the police standards and training council to provide education and training on Alzheimer’s Disease and other related dementias for law enforcement personnel, which may include the educational program developed with the state department of health and human services and (unspecified) “additional components as may be appropriate.”⁹²

New Jersey

In 2005, New Jersey enacted a “Safe Return” program and required training for state and local law enforcement on identifying, communicating with, and caring for those who have Alzheimer’s disease or other dementias who have become lost and disoriented.⁹³

Ohio

As of April 2023, Ohio law mandates “dementia-related training” in police officer training (not to exceed two hours for completion of basic training, and not to exceed one hour for continuing professional education), which includes identifying symptoms, effective communication, and addressing behavioral issues including alternatives to restraints, as well as identifying signs of abuse or neglect.⁹⁴

Oklahoma	Oklahoma began requiring a minimum of two hours of education and training “related to recognizing and managing a person experiencing dementia or Alzheimer’s disease” as part of their basic training courses for law enforcement certification. ⁹⁵
Oregon	Oregon’s basic police training manual includes a brief discussion of dementia as part of their mental health training. ⁹⁶ By law, state police and sheriff’s offices are required to adopt written policies related to missing vulnerable adults, including training to interact with individuals with cognitive impairments including dementia. ⁹⁷
South Carolina	South Carolina established its Endangered Person Notification System in 2010, which serves as a statewide system for “rapid dissemination of information regarding a missing person” with dementia or other cognitive impairments as part of its Missing Person Information Center. The amendment establishing the notification system also includes a requirement to “provide education and training to local law enforcement agencies,” though it is not specified what form this education and training may take. ⁹⁸
Texas	Texas recently passed House Resolution 568, which mandates 40 hours of training for law enforcement personnel on interacting with individuals with Alzheimer’s disease and other dementias, including de-escalation, alternatives to physical restraints, and communicating effectively. ⁹⁹ This law will go into effect September 1, 2023.
Virginia	Virginia legally mandates training standards and model policies for law enforcement personnel in “identification of, communication with, and facilitation of the safe return” of those with Alzheimer’s disease and dementia, specifically including techniques for communication, techniques for addressing behavioral symptoms including alternatives to physical restraint, protocols for identifying abuse, and protocols for contacting caregivers when an individual with Alzheimer’s disease or dementia is found wandering or during an emergency or crisis situation. ¹⁰⁰
West Virginia	In 2023, West Virginia passed legislation to require a two-hour training for law enforcement and corrections officers on interacting with people with Alzheimer’s and related dementias, as well as the development of guidelines for law enforcement response to people living with Alzheimer’s or another dementia who are victims or witnesses to a crime, or suspected or convicted of a crime. ¹⁰¹

Other states have “silver alert” or similar programs and may offer training on these programs but do not legally require it, such as **Maine** and **Massachusetts**.^{102,103}

In 2023: California is currently considering legislation to expand existing mandated training in mental health to include Alzheimer’s disease and other dementias.¹⁰⁴ **Mississippi** introduced a bill in its state House that would have mandated training for law enforcement personnel, but the bill died in committee.¹⁰⁵

A number of states have programs specifically for older people with dementia who are incarcerated:

Ohio

A collaboration among the Geriatric Workforce Enhancement Program, Ohio Council for Cognitive Health, Benjamin Rose Institute on Aging and the Ohio Department of Rehabilitation and Correction developed a pilot program, “Dementia Friends for Incarcerated Settings,” which was deployed in all 27 prisons to address staff knowledge of working with incarcerated people living with dementia.¹⁰⁶ Ohio also has a specialized unit at the Allen Oakwood Correctional Institution specifically for incarcerated people living with dementia.¹⁰⁷

California

In California, a group of Alzheimer’s Association-trained inmates called “Gold Coats” for their identifying uniforms are assisting fellow inmates who have Alzheimer’s or other dementias. Paid \$50 a month, Gold Coats help with basic needs like dressing and personal hygiene, escort patients to appointments, lead exercise classes or memory-stimulating activities, and provide protection against other inmates who might take advantage of or hurt their charges.^{108,109} The program has been rolled out in 11 California prisons.¹¹⁰

Connecticut

60 West Nursing Home in Connecticut was established because other nursing homes would not take patients from the correctional system and serves primarily “hard-to-place” individuals such as those granted compassionate release or those who have been otherwise released from prison.¹¹¹

New York

The Unit for the Cognitively Impaired in the Fishkill Correctional Facility opened in 2006 with 30 beds and resembles a nursing home with specially trained staff.¹¹²

Massachusetts

The Federal Medical Center in Devens Massachusetts opened a Memory Disorder Unit (MDU) for inmates with a dementia diagnosis. The facility shares a similar “nursing home model” to the Unit for the Cognitively Impaired. The unit is staffed with inmates who are certified nursing assistants (CNAs) who also receive training on dementia.^{113,114} (This program is part of the federal prison system, rather than a state facility.)

Recommendations

1. **Mandate and provide training for law enforcement personnel and corrections officers.** Untrained law enforcement officers may misinterpret behavior as threatening or defiant in stressful situations, and people living with Alzheimer’s disease and other dementias are at risk of physical harm and severe emotional distress in police interactions. These risks are also present in correctional settings.

2. **Develop care facilities to provide adequate living facilities and appropriate care for those incarcerated.** Cognitive impairment is likely to reduce the ability to comply with direction from correctional officers, and incarcerated people with Alzheimer’s or other dementias are at greater risk of harassment or abuse by other inmates. Providing alternative facilities or support systems within existing facilities, including additional training for correctional officers, is necessary for humane incarceration.

3. **Develop and implement legal protections, including appropriate assessment of competency, for those charged with a crime.** Standardize and implement screening for dementia in older people charged with a crime, including forms of dementia beyond Alzheimer’s disease which may not currently be included in assessments.

4. **Ensure existing programs for police de-escalation incorporate the needs of those living with Alzheimer’s and other dementias.** Many states already require law enforcement personnel to complete some training on mental health conditions, and Alzheimer’s disease and other dementias should be included in this training.

Genetic Testing

The complexity of testing for Alzheimer's disease

With the advent of genetic testing unlocking opportunities for detecting various diseases and traits, direct-to-consumer (DTC) companies like 23andMe are increasing in popularity. On April 6th, 2017, the FDA approved the first DTC tests that provide information for 10 disease areas or conditions, including late-onset Alzheimer's disease.¹¹⁵ This provoked more conversation about the role of genetic testing in Alzheimer's diagnosis. The demand for testing will increase dramatically in the coming years as treatments for Alzheimer's progress.¹¹⁶

Yet legislation around this issue has not kept pace with this advancing technology. As testing increases, there must be ways patients can use this knowledge effectively and be reassured that their test results will be safeguarded.

The genetics of Alzheimer's disease and dementia are complex. As technology advances, these companies can offer genetic testing at more affordable rates, prompting doctors, bioethicists, policy makers, and patients to contemplate the potential extent and ramifications of this testing.

The testing process

Genetic testing for diseases is now cheaper and more accessible than ever. While many see this as a new era of access to health information, it raises serious ethical concerns about the use of genetic testing data and privacy laws. This issue is complicated by the fact that the relationship between Alzheimer's and genetics is still a largely gray area.

Alzheimer's disease involves a complex interplay between genetic and environmental factors, with genetics playing a role in influencing the risk of developing the condition. Late-onset Alzheimer's, the most prevalent form, is affected by multiple genetic risk factors. Among these, the APOE gene is a well-established genetic risk factor, with the $\epsilon 4$ variant being particularly associated with increased susceptibility to the disease. Inheriting one or two copies of the $\epsilon 4$ allele elevates the risk, though it does not guarantee the development of Alzheimer's. Instead, it contributes to a higher likelihood of the disease onset. Furthermore, a negative test for this gene does not guarantee Alzheimer's will not develop. Genetics is only one piece of the puzzle, as lifestyle choices, environmental factors, and other genetic

variants all come into play, collectively shaping an individual's overall risk for Alzheimer's.^{117, 118} It is extremely important to recognize the laws surrounding genetic testing as the use of it increases among consumers.

Federal laws on genetic data privacy

U.S. federal law prohibits discrimination based on genetic data. When it comes to genetic data privacy, the first law that comes to mind for most is the Genetic Information Nondiscrimination Act (GINA) of 2008, which "prohibit[s] discrimination on the basis of genetic information with respect to health insurance and employment."¹¹⁹ There is a significant omission here: this law does not include disability, long-term care or life insurance.



Did you know?

The National Human Genome Research Institute has a Genome Stature and Legislation Database to search for state statutes and bill introduce between 2007-2020.¹²²

In addition to GINA, there is the Health Insurance Portability and Accountability Act of 1996 (HIPAA) which protects patients' health information.¹²⁰ While HIPAA rules and regulations do apply to genetic tests run by doctors, it does not apply to DTC kits because they are not considered medical tests.¹²¹ Therefore, there are clear gaps between national laws and the current use of genetic testing, which has expanded since these laws were introduced.

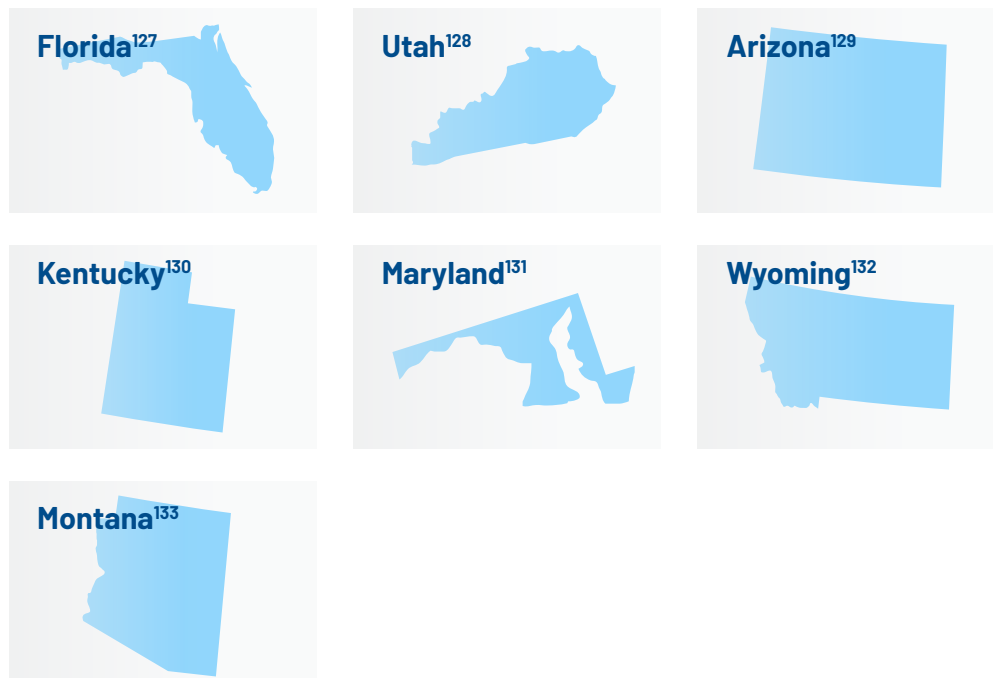
According to the Alzheimer's Association, genetic testing is not recommended unless you have prior counseling with a trusted physician and/or genetic counselor. Genetic counselors are a valuable source of information and can help you understand which tests you may want to conduct, and even more importantly, how to interpret results of these tests.¹²³ The Mayo Clinic has similar recommendations.¹²⁴

State highlights

Most recently, **Virginia** passed a genetic privacy act in 2023 which contains much of the language from previous states' laws.¹²⁵

California was one of the first states to introduce a genetic privacy law. S.B. 41, now the Genetic Information Privacy Act, "puts restrictions on the data collected by direct-to-consumer DNA testing companies...[it] requires customers to give express consent before their genetic data can be used for scientific research or shared with a third party. If customers consent to having their data used for research, companies must provide a simple way for them to opt out at any time."¹²⁶

This set the standard for many of the laws enacted afterwards:



Of note: Some states have sections similar to **South Dakota**, which passed a law prohibiting life insurance and long-term care insurance companies from using genetic test results without the customer's written consent, and from requiring a genetic test before determining coverage.¹³⁴

Recommendations

- 1. Increase research focusing on the genetics of Alzheimer's disease.**
More research into the genetics of Alzheimer's disease is needed to better understand how genetic risk factors and hereditary patterns increase the likelihood of a person developing Alzheimer's disease.
- 2. Provide further education on genetic testing for Alzheimer's disease.**
Testing for any disease, particularly Alzheimer's disease, requires the guidance of a professional such as a genetic counselor. Better educating people on the results and limitations of genetic testing can provide reassurance and clarity.
- 3. Introduce comprehensive testing privacy laws at the state and federal level.** More laws are needed to cover gaps in existing privacy laws. Many of these laws at the federal level are from the early days of gene sequencing, and only some states have additional genetic data privacy laws that go beyond these policies.

Access Issues

Everyday life

According to the U.S. Declaration of Independence, all people are “created equal, that they are endowed by their Creator with certain unalienable Rights, that among these are Life, Liberty and the pursuit of Happiness,” and these rights are guaranteed to U.S. citizens through the Bill of Rights and further constitutional amendments.¹³⁵ Are these rights adequately protected if one has dementia?

Some states have implemented restrictions to certain services and certifications, namely driving, based on their dementia diagnosis. If diagnosed, a person could lose their driver’s license and likewise freedom of movement.

Others may question if they still are guaranteed voting rights, or will they be discriminated based on the perception that they may no longer know who their elected officials even are?

And finally, if they reveal their diagnosis at work, how will this play out with their employers? Will they have any guarantee of their employment and continued job security as long as they can perform their tasks?

Driving

According to the Federal Highway Administration (FHA), nearly one third of drivers are 65 and over.¹³⁶ However, the number of licensed drivers drops significantly starting at age 60 and continue to topple.¹³⁷ While some may stop driving due to slower reflexes, less confidence, or lack of places they want to go, others may be forced off the road.

In two states—**Alaska and California**—there are driving restrictions for people diagnosed with dementia.^{138,139} In these two states, when a person is diagnosed with Alzheimer’s, they may need to complete an evaluation at the Department of Motor Vehicles (DMV) to maintain their driver’s license. This evaluation needs to be repeated after several months. Most states have avenues for reporting unsafe drivers or drivers with a medical condition that may impair their ability to safely operate a vehicle.¹⁴⁰



In 2020, The Centers for Medicare & Medicaid Services (CMS) sent a memo reminding nursing homes that they must help residents exercise their right to vote.¹⁴⁴

Voting

There are clear precedents that protect the rights of those with disabilities to vote, and individuals with dementia are no exception to this. In fact, one study found that persons with very mild to mild Alzheimer's disease were still able to cast votes.¹⁴¹ Numerous federal laws mandate accessibility for voters, both to sign up to vote as well as casting their votes.¹⁴² According to one study, persons with very mild to mild Alzheimer's disease retained the adequate ability to vote based on a scoring of their mental capacity to reason and appreciate voting choices. The American Bar Association (ABA) released guidelines for assisting persons with cognitive impairment (including dementia and Alzheimer's) with voting.¹⁴³

While there are no legal barriers to voting with Alzheimer's and other dementias, it's important to be aware of potential structural barriers that can make it more difficult for someone to vote. While 43 states and Washington D.C. offer an early voting period of more than 7 days,¹⁴⁵ only 35 states and D.C. make no-excuse voting by mail available.¹⁴⁶ Among those, only 8 states have all-mail voting, where everyone is mailed a ballot automatically—for someone with Alzheimer's or dementia, this would likely be the most convenient option to ensure there's no red tape to grapple with to vote.¹⁴⁷

Additionally, only 27 states plus D.C. offer curbside voting for people with disabilities, enabling drive-through voting without waiting in line.¹⁴⁸

Workplace

An AD diagnosis does not mean a person must stop working. For many employees, simple accommodations can be implemented to accommodate employees. The Americans with Disabilities Act does provide some protection to people with Alzheimer's disease and other dementias in the workplace, requiring that companies with 15 or more employees provide "reasonable" accommodation.¹⁴⁹

While legal protection exists, the definition of "reasonable" is wide and sometimes there are no sufficient accommodations to be made. For example, in a case study by the Dementia Action Alliance, an employee with dementia symptoms went on medical leave after having difficulty carrying out his professional responsibilities. The employee then requested a position with reduced work with a salary cut but the company was not able to provide this and instead encouraged him to retire. The employee did so, but it caused an additional sense of identity loss and challenging loss of income for his family.¹⁵⁰

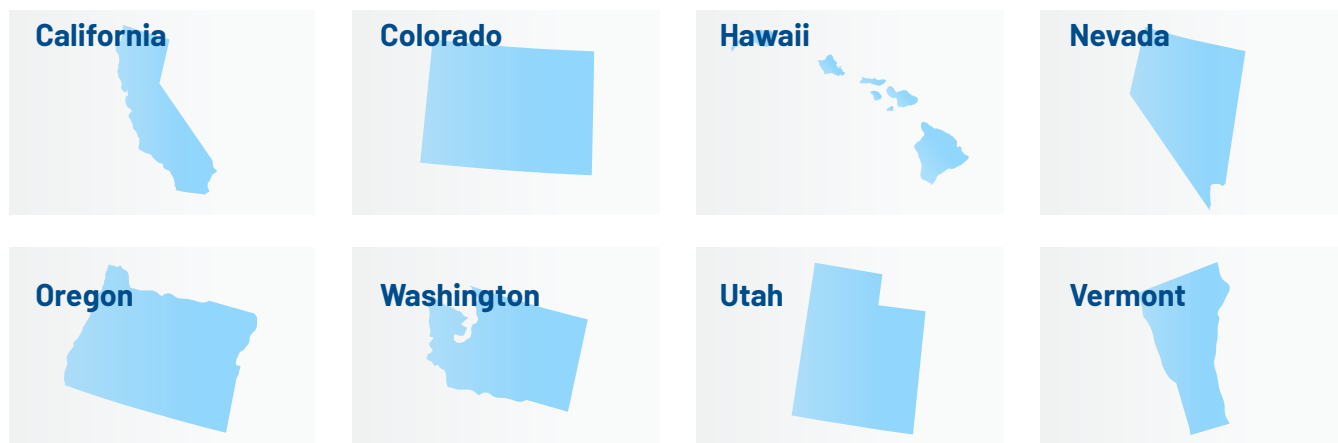
State highlights

Only two states clearly reference dementia in their safe driving laws:ⁱ

In **Alaska**, you may report someone as an unsafe driver due to a medical condition, which would require an evaluation by the DMV. Alzheimer's Disease is listed under possible medical conditions that may affect driving. This report must come from firsthand knowledge and clearly explain why an evaluation is necessary. There is no mandatory reporting law for physicians, though they can report patients to the DMV without informed consent of the patient.¹⁵¹

In **California**, drivers diagnosed with dementia must take a driver knowledge test and attend a reexamination. If they pass, the DMV will schedule another reexamination in 6-12 months. If a driver is deemed severely mentally or physically incapacitated, the DMV may revoke a license.¹⁵²

Only 8 states have all-mail voting, where everyone is mailed a ballot automatically—for someone with Alzheimer's or dementia, this would likely be the most convenient option to ensure there's no red tape to grapple with to vote.¹⁵³



i. State government websites outline the steps to request accommodations to vote with a disability, including what accommodations are available.

Recommendations

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1. **Clarify if evaluation is required to maintain a driver's license after receiving an Alzheimer's disease or other dementia diagnosis.** This will ensure full disclosure on one seeking to maintain their driver's license.

 2. **Include the rights and accommodations that are available for individuals diagnosed with Alzheimer's and other dementias who wish to vote within voting disability resources.** States have an opportunity to fully support all citizens voting regardless of illness by making them well aware of all options available.

 3. **Establish clear legal protections for workers living with Alzheimer's and other dementias.** Companies should have clear policies explaining how Alzheimer's Disease can be accommodated in the workplace. An Alzheimer's Disease diagnosis does not require an employee end their employment. Employees and employers can have a conversation about ways to accommodate needs in the workplace and what further steps need to be taken. Often, simple changes can be implemented to help an employee, such as changing a schedule or incorporating technology.¹⁵⁴ Having an honest conversation together benefits both parties, as employers can retain quality employees and employees can stay at their current job.

 4. **Incentivize businesses to support employees with cognitive decline.** While under law, businesses need to make accommodations, there is a lack of clarity on how to institute that. By creating systems that support businesses to support their workers, organizations can make smoother transitions and ensure that someone doesn't have to leave work earlier than necessary.
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Summary

Alzheimer's and dementia are devastating diseases that put significant stress on those diagnosed, their families, and caregivers. The lack of research, data, and rhetoric around improving legal resources and accountability further complicates an already complicated situation.

The gaps at the state and local level highlighted in this report reveal significant opportunity for greater clarity and development of legal protections for those with Alzheimer's and dementia.

A Greater Need for Understanding

Dementia is the link. While there have been several policy movements and laws instated that address each of these issues, dementia has not been recognized as a key component of any of them. There is a significant opportunity at the state and national level to update dementia plans to include the legal issues of financial abuse, guardianship, justice reform, genetic testing, and access barriers.

The layers of dementia are complex and wide-reaching—state and national legislation should acknowledge this. State legislation uses many words to describe what could be dementia, without acknowledging how these different phrasings could influence someone with the disease. There is a need for education and understanding around these complex policy issues and there should be discussion with medical experts before enacting any legislation involving someone with a cognitive disorder.

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This report made possible by support from GCOA member Eli Lilly & Company

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