



ALZHEIMER'S
AND
DEMENTIA
ARKANSAS
STATE PLAN

2021-2025

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The Alzheimer's and Dementia State Plan Process

Introduction

In 2009, the state legislature initiated Act 92 creating the “Task Force on the Effect of Alzheimer’s Disease” to bring together caregivers, public health officials, patient advocates, and community leaders to tackle a range of Alzheimer’s issues. The task force completed its work and published one of the country’s first state plans of its kind in 2011. This effort aligned with the national strategy to establish a National Plan to Address Alzheimer’s Dementia.

In the fall of 2018, an independent working group was formed to review the existing Alzheimer’s State Plan and begin the process of updating the plan to reflect the current needs of individuals living with Alzheimer’s and other forms of dementia and their caregivers.

Collaborating Partners

The State Plan process brought together a diverse group of stakeholders including industry providers, advocacy organizations, and state agency officials to identify specific and actionable recommendations.

Stakeholder Groups

AARP

Alzheimer’s Association - Arkansas Chapter

Alzheimer’s Arkansas

Arkansas HealthCare Association

Arkansas Hospital Association

Broyles Foundation

Homecare Association of Arkansas

Hospice and Palliative Care Association of Arkansas

The University of Arkansas for Medical Sciences Centers on Aging

State Agencies and Commissions

Arkansas Department of Human Services

Arkansas Health Department

Arkansas Minority Health Commission

Process Summary

Following a series of individual meetings between stakeholders and state agency officials in September of 2018, the decision was made to convene a working group to begin the process of updating the Alzheimer's State Plan which had not been updated since its initial publication in 2011. The working group proceeded with this work independent of a legislative directive. The working group held its first meeting on November 1, 2018.

The working group met at least bi-monthly between the months of November 2018 and August of 2020. Working group members were selected based on the impact and scope of their work as it relates to individuals and families impacted by Alzheimer's Disease and other dementias. The working group began the process with an in-depth review of the previous state plan and assessing the recommendations presented by the previous task force. The working group compared state-specific data collected using the Behavioral Risk Factor Surveillance System (BRFSS) and the Alzheimer's Disease Facts and Figures report provided by the Alzheimer's Association to build a broader picture of the needs in Arkansas. After examining this data, researching approaches that have proven successful in other states, and comparing the state of dementia care in Arkansas the following priorities areas were identified:

Access and Quality of Care

Family Caregiver Support

Public Awareness

Training and Workforce

The working group dedicated each meeting to one of the aforementioned priority areas. Prior to each meeting, the group received state and region-specific data relevant to the topic being covered. The working groups were also given the opportunity to engage with state agency officials, The Arkansas Department of Health, The Department of Human Services, caregivers, and issue experts. After reviewing the data, the working group began recommending steps that can be taken to address some of the gaps in care and services that were identified during the meeting time.

After the publication of the recommendations, the working group is actively working to implement the plan including discussion of each priority area and dissemination of a public health survey.

Implementation and Annual Review

The previous state plan included key components that established the “Alzheimer’s Advisory Council.” Arkansas state statute §20-8-601 established the council with a sunset clause that expired in 2014. The legislative intent was to establish a council that would be charged with developing the Alzheimer’s and Dementia State Plan, supporting its implementation and providing an annual report to the Arkansas General Assembly on the status of Alzheimer’s in Arkansas and opportunities to address it. In the development of the 2021-2025 Alzheimer’s and Dementia State Plan, the working group proposed recommendations intended to be made within the existing systems of care and services in Arkansas. The recommendations offered in this plan are attainable but are only the first steps to addressing this public health crisis. Systematic change requires time so urgent action is needed now.

To ensure the ongoing implementation of the Plan and to continually assess current and future needs toward addressing Alzheimer’s in Arkansas, the working group endorses creating a state Alzheimer’s Disease Advisory Council as its first recommendation. The purpose of the Council would be to monitor and report progress and to describe barriers to the implementation of the state plan. Reports would be provided to the Governor and Legislature on the continuum of services available, data trends, and policy recommendations.

The Alzheimer’s and Dementia State Plan was the result of the collaboration of several stakeholders representing a diverse field of expertise on this issue. Going forward, a unified and collaborative effort is needed from all providers, non-profit organizations, state agencies, and lawmakers to ensure we are serving the needs of Arkansans impacted by Alzheimer’s and other dementias.

The Face of Alzheimer's and Dementia

Definition

Alzheimer's disease is the most common cause of dementia in older adults. It is a progressive brain disorder that slowly destroys memory and thinking skills. It is not a normal part of aging. [1] Alzheimer's disease is the most common form of dementia. Dementia is not a specific disease. It's an overall term that describes a group of symptoms. Dementia is a general term for loss of memory and other mental abilities severe enough to interfere with daily life. It is caused by physical changes in the brain.

There are various types of dementia; however, Alzheimer's Disease is the most common type of dementia, accounting for approximately 60 to 80 percent of all dementias [2]. Vascular dementia - characterized by damage to the blood vessels in the brain - is the second most common cause[3].

Most Common Forms of Dementia

It is not uncommon for the terms "dementia" and "Alzheimer's" to be used interchangeably. Individuals might experience or display the symptoms of dementia and not be diagnosed with Alzheimer's Disease. For the purposes of this report, the working group chose not to single out Alzheimer's and instead be inclusive of all forms of dementia, unless otherwise specified.

Alzheimer's Disease

Alzheimer's disease is a degenerative disease, meaning that it becomes worse with time. Alzheimer's disease is thought to begin 20 years or more before symptoms arise, with changes in the brain that are unnoticeable to the person affected. Only after years of brain changes do individuals experience noticeable symptoms such as memory loss and language problems.

Symptoms occur because nerve cells (neurons) in parts of the brain involved in thinking, learning, and memory (cognitive function) have been damaged or destroyed. As the disease progresses, neurons in other parts of the brain are damaged or destroyed. Eventually, nerve cells in parts of the brain that enable a person to carry out basic bodily functions, such as walking and swallowing, are affected. Individuals become bed-bound and require around-the-clock care. Alzheimer's disease is ultimately fatal.

The symptoms of Alzheimer's and other dementias worsen over time, although the rate at which the disease progresses varies.

In the early stage of Alzheimer's dementia, a person may function independently, still drive, work, and be part of social activities. Despite this, the person may feel as if he or she is having memory lapses, such as forgetting familiar words or the location of everyday objects.

The moderate stage of Alzheimer's dementia is for some the longest stage and can last for many years. During the moderate stage, people may have greater difficulty performing tasks such as paying bills, but they may still remember significant details about their life. As this stage evolves, people may have more trouble communicating and experience mood or behavior changes. They may also have trouble with activities of daily living such as managing medications, dressing, and bathing.

In the final or severe stage of this disease, as more neurons involved in cognitive and physical functioning are damaged or destroyed, people lose the ability to respond to their environment, have a conversation, and, eventually, control movement. They may become bed-bound and require around-the-clock care. On average, a person with Alzheimer's lives four to eight years after diagnosis but can live as long as 20 years, depending on other factors [4]. (See pg. 8 for more information)

Cerebrovascular Disease

Cerebrovascular disease refers to the process by which blood vessels in the brain are damaged and/or brain tissue is injured from not receiving enough blood, oxygen, or nutrients. People with dementia whose brains show evidence of cerebrovascular disease are said to have vascular dementia. About 5% to 10% of individuals with dementia show evidence of vascular dementia alone [5-6]. However, it is more common as a mixed pathology, with most people living with dementia showing the brain changes of cerebrovascular disease and Alzheimer's disease. Vascular dementia is characterized by impaired judgment or impaired ability to make decisions, plan or organize, but memory may also be affected, especially when the brain changes of other causes of dementia are present. In addition to changes in cognitive function, people with vascular dementia commonly have difficulty with motor function, especially slow gait and poor balance. Vascular dementia occurs most commonly from blood vessel blockage or damage leading to areas of dead tissue or bleeding in the brain. The location, number and size of the brain injuries determine whether dementia will result and how the individual's thinking and physical functioning will be affected.

Lewy Bodies

Lewy bodies are abnormal aggregations (or clumps) of the protein alpha-synuclein in neurons. When they develop in a part of the brain called the cortex, dementia (called dementia with Lewy bodies or DLB) can result. People with DLB have some of the symptoms common in Alzheimer's but are more likely to have initial or early symptoms of sleep disturbances, well-formed visual hallucinations, and visuospatial impairment. These symptoms may occur in the absence of significant memory impairment but memory loss often occurs, especially when the brain changes of other causes of dementia are present. About 5% of individuals with dementia show evidence of DLB alone, but most people with DLB also have Alzheimer's disease pathology

Frontotemporal lobar degeneration (FTLD)

FTLD includes dementias such as behavioral-variant FTLD, primary progressive aphasia, Pick's disease, corticobasal degeneration, and progressive supranuclear palsy. Typical early symptoms include marked changes in personality and behavior and/or difficulty with producing or comprehending language. Unlike Alzheimer's, memory is typically spared in the early stages of the disease. Nerve cells in the front (frontal lobe) and side regions (temporal lobes) of the brain are especially affected, and these regions become markedly shrunken. In addition, the upper layers of the cortex typically become soft and spongy and have abnormal protein inclusions (usually tau protein or the transactive response DNA-binding protein, TDP-43). The symptoms of FTLD may occur in those age 65 years and older, similar to Alzheimer's, but most people with FTLD develop symptoms at a younger age. About 60 percent of people with FTLD are aged 45 to 60 [7]. Scientists think that FTLD is the most common cause of dementia in people younger than 60 [8]. In a systematic review, FTLD accounted for about 3% of dementia cases in studies that included people 65 and older and about 10% of dementia cases in studies restricted to those younger than 65 [9].

Parkinson's Disease (PD)

With Dementia Problems with movement (slowness, rigidity, tremor, and changes in gait) are common symptoms of PD. Cognitive symptoms develop either just before movement symptoms or later in the disease. In PD, alpha-synuclein aggregates appear in an area deep in the brain called the substantia nigra. The aggregates are thought to cause degeneration of the nerve cells that produce dopamine [10]. As PD progresses, it often results in dementia secondary to the accumulation of alpha-synuclein in the cortex (similar to dementia with Lewy bodies).

Hippocampal Sclerosis (HS)

HS is the hardening of tissue in the hippocampus of the brain. The hippocampus plays a key role in forming memories. The most pronounced symptom of HS is memory loss, and individuals may be misdiagnosed as having Alzheimer's disease. HS brain changes are often accompanied by accumulations of a misfolded form of a protein called TDP-43. HS is a common cause of dementia in the "oldest-old," individuals age 85 or older.

Diagnosis

There is no single test for dementia due to Alzheimer's disease. Instead, physicians (often with the help of specialists such as neurologists, neuropsychologists, geriatricians, and geriatric psychiatrists) use a variety of approaches and tools to help make a diagnosis.

Such as:

- Obtaining a medical and family history from the individual, including psychiatric history and history of cognitive and behavioral changes.
- Asking a family member to provide input about changes in thinking skills and behavior.
- Conducting problem-solving, memory, and other cognitive tests, as well as physical and neurologic examinations.
- Having the individual undergo blood tests and brain imaging to rule out other potential causes of dementia symptoms, such as a tumor or certain vitamin deficiencies.
- In some circumstances, using PET imaging of the brain to find out if the individual has high levels of beta-amyloid, a hallmark of Alzheimer's; normal levels would suggest Alzheimer's is not the cause of cognitive impairment [11].
- In some circumstances, using lumbar puncture to determine the levels of beta-amyloid and certain types of tau in CSF; normal levels would suggest Alzheimer's is not the cause of cognitive impairment [12].

There is currently no cure for Alzheimer's and no proven way to stop the progression of the disease. However, there are both pharmacological and non-pharmacological treatments to help with symptoms associated with the disease. There are also services available to support family members and caregivers of persons living with dementia. For the benefits to be realized, living persons with dementia and their caregivers must be aware of these services and how to access them.

Risk Factors

Scientists do not currently know exactly what causes a person to develop Alzheimer's disease or how to prevent it. However, research suggests that certain risk factors increase an individual's risk of developing the disease. Demographic groups such as older Black / African Americans and Hispanics are more likely to develop dementia compared to their white counterparts. Overall, the greatest known risk factor for developing ADRD is age; however, other factors may also increase one's risk of developing dementia. Some of these risk factors such as family history, or genetics are unable to be changed. However, other risk factors such as obesity, specific cardiovascular diseases (hypertension, prehypertension, high cholesterol), diabetes, and diet may be risk factors that are modifiable or able to be changed.

Though research is still evolving, evidence suggests that people can reduce their risk of future cognitive decline by making key lifestyle changes including regular physical exercise, eating a heart-healthy diet, maintaining strong social connections, and keeping mentally active.

Finally, there appears to be a strong link between the future risk of Alzheimer's and serious head trauma, especially when the injury involves loss of consciousness. Therefore, reducing the risk of a head injury may also be a strategy to reduce the risk of future forms of dementia.

Alzheimer's is not a normal part of aging. The greatest known risk factor is increasing age, and the majority of people with Alzheimer's are 65 and older. But Alzheimer's is not just a disease of old age. Approximately 200,000 Americans under the age of 65 have younger-onset Alzheimer's disease (also known as early-onset Alzheimer's).

Symptoms of Alzheimer's Dementia

Alzheimer's is a brain disease that causes a slow decline in memory, thinking, and reasoning skills. The most common early symptom of Alzheimer's is difficulty remembering newly learned information because Alzheimer's changes typically begin in the part of the brain that affects learning. As Alzheimer's advances through the brain, it leads to increasingly severe symptoms, including disorientation, mood and behavior changes; deepening confusion about events, time and place; unfounded suspicions about family, friends and professional caregivers; more serious memory loss and behavior changes; and difficulty speaking, swallowing and walking. People with memory loss or other possible signs of Alzheimer's may find it hard to recognize they have a problem. Signs of dementia may be more obvious to family members or friends. There are ten warning signs that individuals often experience that are associated with Alzheimer's or another form of dementia.

TEN WARNING SIGNS OF ALZHEIMER'S

1 **Memory loss that disrupts daily life:** One of the most common signs of Alzheimer's is memory loss, especially forgetting recently learned information.

3 **Difficulty completing familiar tasks at home, at work or at leisure:** People with Alzheimer's often find it hard to complete daily tasks.

5 **Trouble understanding visual images and spatial relationships:** For some people, having vision problems is a sign of Alzheimer's..

7 **Misplacing things and losing the ability to retrace steps:** Putting things in unusual places, and being unable to go back over their steps to find them again.

9 **Withdrawal from work or social activities:** People with Alzheimer's may start to remove themselves from hobbies, social activities, work projects or sports.

2 **Challenges in planning or solving problems:** Some people experience changes in their ability to develop and follow a plan or work with numbers.

4 **Confusion with time or place:** People with Alzheimer's can lose track of dates, seasons and the passage of time.

6 **New problems with words in speaking or writing:** People with Alzheimer's may have trouble following or joining a conversation.

8 **Decreased or poor judgment:** People with Alzheimer's may experience changes in judgment or decision-making..

10 **Changes in mood and personality:** The mood and personalities of people with Alzheimer's can change.

PREVALENCE OF ALZHEIMER'S IN ARKANSAS

Prevalence

In 2020, more than 5 million Americans aged 65 and older were living with Alzheimer's dementia. This number is expected to grow to as many as 14 million Americans by 2050. These individuals are being cared for by more than 16 million informal caregivers. These caregivers provide approximately 18.5 billion hours of care each year, valued at nearly \$234 billion nationally.

In Arkansas, an estimated 58,000 Arkansans aged 65 and older are living with Alzheimer's in 2020. This number is expected to climb to 67,000 by 2025. An estimated 178,000 caregivers provided 203 million hours of unpaid care valued at \$2.6 billion dollars in 2019. (SEE CHART BELOW)



ARKANSAS

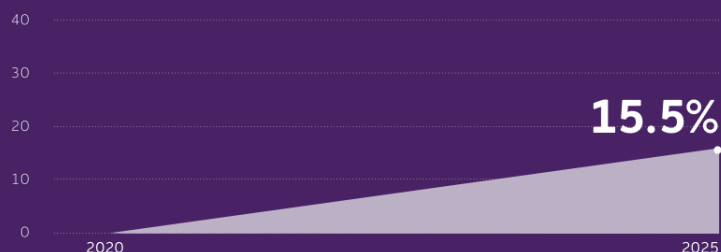
ALZHEIMER'S STATISTICS

65+ NUMBER OF PEOPLE AGED 65 AND OLDER WITH ALZHEIMER'S BY AGE*

Year	65-74	75-84	85+	TOTAL
2020	10,000	26,000	23,000	58,000
2025	11,000	31,000	24,000	67,000

* Totals may not add due to rounding

Estimated percentage change



OF DEATHS FROM ALZHEIMER'S DISEASE (2018)

1,457

8th highest Alzheimer's death rate in America
 238.8% increase in Alzheimer's deaths since 2000
 6th leading cause of death

GERIATRICIANS

of geriatricians in 2019 **51**
 163% increase needed to meet Alzheimer's population needs in 2050

CAREGIVING (2019)

178,000
 Number of Caregivers

203,000,000
 Total Hours of Unpaid Care

\$2,663,000,000
 Total Value of Unpaid Care

HOSPITALS (2017)

1,564

of emergency department visits per 1,000 people with dementia

22.3%
 increase in emergency department visits since 2007

21.8%
 dementia patient hospital readmission rate

HOSPICE (2017)

3,133

of people in hospice with a primary diagnosis of dementia

18%
 of people in hospice have a primary diagnosis of dementia

MEDICARE
\$22,373 per capita Medicare spending on people with dementia (in 2019 dollars)

MEDICAID

\$396 MILLION
 Medicaid costs of caring for people with Alzheimer's (2020)

14.6%
 change in costs from 2020 to 2025



More than **5 million Americans** are living with Alzheimer's. The cost of caring for those with Alzheimer's and other dementias is estimated to total **\$305 billion** in 2020, increasing to more than **\$1.1 trillion** (in today's dollars) by mid-century. Nearly **one in every three seniors** who dies each year has Alzheimer's or another dementia.

For more information, view the **2020 Alzheimer's Disease Facts and Figures** report at alz.org/facts.

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Costs of Care

Treating people with dementia is very expensive. Currently, Alzheimer's disease is the most expensive disease in America, costing more than cancer and heart disease. The financial costs of Alzheimer's for families and the government are enormous. The direct costs to American society of caring for those with Alzheimer's and other dementias was an estimated \$305 billion in 2020, and this figure does not include the value of uncompensated care that is provided by family caregivers. In Arkansas, Alzheimer's will cost the Arkansas Medicaid program \$396 million in 2020; by 2025, those costs are expected to rise by 14.6%.

Health care costs increase with the presence of dementia. In a population-based study of adults aged 70 to 89, annual health care costs were significantly higher for individuals with dementia than for those with either mild cognitive impairment (MCI) or without cognitive impairment [14].

There are several factors that contribute to the higher costs of care. People with Alzheimer's or other dementias have twice as many hospital stays per year as other older people [15]. Moreover, the use of health care services by people with other serious medical conditions is strongly affected by the presence or absence of dementia. In particular, people with coronary artery disease, diabetes, chronic kidney disease, chronic obstructive pulmonary disease (COPD), stroke or cancer who also have Alzheimer's or other dementias have higher use and costs of health care services than people with these medical conditions but no coexisting dementia.

Persons with Alzheimer's or other dementias are hospitalized more frequently than those with other conditions. There are 538 hospital stays per 1,000 Medicare beneficiaries age 65 and older with Alzheimer's or other dementias compared with 266 hospital stays per 1,000 Medicare beneficiaries age 65 and older without these conditions [16].

Skilled Nursing Facility

Skilled nursing facilities provide direct medical care that is performed or supervised by registered nurses, such as giving intravenous fluids, changing dressings, and administering tube feedings [17]. There are 283 skilled nursing facility stays per 1,000 beneficiaries with Alzheimer's or other dementias per year compared with 73 stays per 1,000 beneficiaries without these conditions – a rate nearly four times as great [18].

Home Health Care

Twenty-five percent of Medicare beneficiaries age 65 and older with Alzheimer's or other dementias have at least one home health visit during the year, compared with 10% of Medicare beneficiaries age 65 and older without Alzheimer's or other dementias [19]. Medicare covers home health services, such as part-time skilled nursing care, home health aide (personal hands-on) care, therapies, and medical social services in the home, but does not include homemaker or personal care services.

Support services are critical for individuals with Alzheimer's Disease and other dementias and their families. As the disease progresses the interventions needed and assistance with activities of daily living (ADLs) increases. Individuals and families access various services across the continuum of the disease. Cost's for these services is dependent on the level of care needed. The costs and the need for these services will continue to increase as more individuals reach retirement age.

Mortality Rates

It is difficult to determine how many deaths are caused by Alzheimer's disease each year because of the way causes of death are recorded. According to data from the Centers for Disease Control and Prevention (CDC), 122,019 Americans died from Alzheimer's disease in 2018, the latest year for which data are available [20]. In Arkansas, Alzheimer's is the sixth-leading cause of death. In 2018, the mortality rate for Alzheimer's disease was 48.3 per 100,000 people compared to 34.8 in 2014 for the state.

The CDC considers a person to have died from Alzheimer's if the death certificate lists Alzheimer's as the underlying cause of death, defined as "the disease or injury which initiated the train of events leading directly to death [21]."

In the United States, Alzheimer's disease is counted as a cause of death that can be ranked against other leading causes of death such as cancer and heart disease, but deaths due to other types of clinically diagnosed dementia are not ranked in this manner. The number of deaths from dementia of any type is much higher than the number of reported Alzheimer's deaths. In 2018, some form of dementia was the officially recorded underlying cause of death for 266,957 individuals (this includes the 122,019 from Alzheimer's disease) [22,23].

Therefore, the number of deaths from all causes of dementia, even as listed on death certificates, is more than twice as high as the number of reported Alzheimer's deaths alone.

Although deaths from other major causes have decreased significantly or remained approximately the same, official records indicate that deaths from Alzheimer's disease have increased significantly. Between 2000 and 2018, the number of deaths from Alzheimer's disease as recorded on death certificates has more than doubled, increasing 146%, while the number of deaths from the number one cause of death (heart disease) decreased 7.8% [24.25], the increase in the number of death certificates listing Alzheimer's as the underlying cause of death probably reflects both a real increase in the actual number of deaths from Alzheimer's due in large part to Alzheimer's becoming a more common cause of death as the population ages, as well as increased reporting of Alzheimer's deaths on death certificates over time by physicians, coroners and others who assign causes of death [26].

PUBLIC AWARENESS AND EDUCATION

To make informed choices, individuals and families impacted by Alzheimer's and other dementias need educational tools to identify the disease, access resources, manage their care, and plan for their futures. Currently, there is no centralized resource within the state of Arkansas where families impacted by Alzheimer's and other dementias can turn for this information. State agencies, nonprofits, and health care providers offer a variety of educational tools and resources, but the resources often remain "siloes" in these institutions.

Public awareness of dementia is a challenge in our state. The public is often unaware of the potentially modifiable risk factors that may contribute to the development of dementia. Lack of awareness and understanding of Alzheimer's and other dementia can create barriers to diagnosis/care and impact families physically, mentally, and financially. Furthermore, lack of awareness and education can increase the stigma surrounding dementia and create a more challenging environment for persons with dementia and their caregivers. Education and outreach can promote risk reduction strategies, increase the likelihood of early diagnosis, and improve quality of life for individuals living with dementia and their caregivers.

Public awareness is necessary to provide family members and caregivers the information and access to support services they need across the continuum of Alzheimer's. Arkansas must raise public awareness to promote the cognitive functioning of adults across the life course and address soaring costs to health care, social, and economic systems. Specifically, public awareness can:

Accelerate Risk Reduction: Several modifiable risk factors for developing Alzheimer's disease and other dementias have been identified. Expert panels have called attention to traumatic brain injury, smoking, diet, physical activity, cardiovascular risk, and other modifiable factors that also correspond with an overall healthy lifestyle and improved quality of life [27].

Advance Early Detection and Diagnosis: The earlier dementia is diagnosed, the sooner care can be provided. A formal diagnosis allows people living with dementia to have access to available symptomatic treatments and interventions, build a care team, participate in support services, and potentially enroll in clinical trials. They and their caregivers can set systems in place to better manage medications, receive counseling, and address the challenges of other chronic conditions. Additional advantages include planning for future financial and legal needs and end-of-life choices [28].

Public health departments play a critical role in educating the general public on chronic conditions such as Alzheimer's and other dementias. With an increase in the prevalence of dementia anticipated in the coming years, the need for this information will become more critical.

Data Collection

Among members of the working group, there was wide agreement on the important role of collecting state-wide data to ensure that the messaging on dementia is consistent with the evolving needs of Arkansans. Increased collaboration between state agencies and the private sector would improve the state's ability to collect Alzheimer's and other dementia data.

The Arkansas Department of Health currently uses the Behavioral Risk Factor Surveillance System (BRFSS) to inform public health initiatives and has included the Cognitive Decline and Caregiver Optional Modules in the past. Continued collection of these modules in future years is needed to ensure a strong evidence base and serve as a potential indicator of progress over time. Data collection is also conducted by several partners utilizing community surveys, forums, and specific needs assessments.

Comprehensive needs assessments are at the core of a state's ability to effectively develop, implement and maintain strategies that improve the health and well-being of people throughout the state. The Arkansas Department of Health has expertise developing and conducting needs assessments and can use that expertise to ensure that cognitive health, cognitive impairment, and caregiving are assessed. Ensuring these findings help guide the implementation and direction of the Arkansas State Alzheimer's and Dementia Plan is essential. These findings can also influence other government plans including the state health improvement plan.

Dementia Services Coordinator

Several states have prioritized their response to dementia by creating the position of an Alzheimer's and Dementia Services Coordinator. A state dementia services coordinator is a position within the state government charged with coordinating the state's response to dementia across state agencies and other stakeholders and partners.

The dementia services coordinator would oversee the state plan process including implementation of the plan recommendations, coordinate working groups, evaluate existing Alzheimer's and dementia-specific programs and services, increase collaboration of key partners, identify gaps in services, and increase awareness of care and support services available to families and individuals. Coordination between the public and private sectors is essential to the effective implementation of the Alzheimer's and Dementia State Plan.

Recommendations

1. Prioritize the state's response to Alzheimer's and other dementia by permanently reauthorizing the Alzheimer's and Dementia Advisory Committee.
2. Create the position of Dementia Services Coordinator within the Arkansas Department of Health.
3. Direct the Health Department to incorporate cognitive health messaging into existing state health priorities.
4. Include and maintain the cognitive decline and caregiver modules in the Behavioral Risk Factor Surveillance System (BRFSS) survey of Arkansas adults at least every other year. Publicly disseminate findings from the BRFSS for use in the development of programs and services.
5. Convene appropriate state agencies and provide written recommendations regarding the integration of cognitive impairment and caregiver support into discharge planning procedures at hospitals and other medical and surgical facilities.
6. Support the Minority Health Commission's outreach efforts to underserved communities with access to educational material relating to cognitive health, caregiver support networks, and statewide resources.

Recommendations cont...

7. Evaluate the implementation of telehealth for assessment, diagnosing, treatment, and education of those living with dementia and caregivers throughout the state.
8. Facilitate Alzheimer's outreach and education to minority communities including information about Medicare annual wellness visits, the warning signs of Alzheimer's, the benefits of early detection and diagnosis, and care planning.
9. Ensure physicians are equipped with the tools they need to have conversations about cognitive decline and feel a level of comfort making referrals

Access to care and support services in every stage of Alzheimer's and dementia is critical for individuals and families. There is much confusion about the prognosis of Alzheimer's disease, and what services may be available to help caregivers and families of those with Alzheimer's and other dementias. Understanding what services are needed at what stage of the disease can add to the confusion in understanding what services are appropriate and available to help caregivers and families along a continuum at the point that services are being sought. It is essential that education about the disease, detection, diagnosis, and treatment are available in tandem with the resources to match the needs. Regardless of where they live, individuals across the state need access to these types of supports and health care, as well as up-to-date information on detection, diagnosis, treatment, and other health services.

Many persons with Alzheimer's and their families are not aware of the specialized diagnosis of the disease through neurological examination and the availability of care and treatment options. This problem is compounded because of the distance to services or a lack of awareness of specialists to consult. Thanks to younger people migrating from rural to urban areas, rural areas of the state are left with limited providers, lower median incomes, and few options for home care. Many rural communities have limited access to hospitals, ambulatory care, primary care physicians, and home and community-based service options. Innovative approaches to rural health care, such as geriatric and home-based telehealth, may provide new opportunities for access to quality care.

Health care utilization is higher for people with Alzheimer's or other dementias, with research showing that older people with these conditions have twice as many hospital stays per year as other older people (538 stays per 1,000 Medicare beneficiaries vs. 266 per 1,000) [29]. Moreover, the use of health care services by people with other serious medical conditions is strongly affected by the presence or absence of dementia. In particular, people with coronary artery disease, diabetes, chronic kidney disease, chronic obstructive pulmonary disease (COPD), stroke or cancer who also have Alzheimer's or other dementias have higher use and costs of health care services than people with these medical conditions but no coexisting dementia.

In addition to having more hospital stays, older people with Alzheimer's or other dementias have more skilled nursing facility stays, and home health care visits per year than other older people.

Care Planning

The need for advanced coordinated care planning for individuals living with dementia can have a significant impact on health care outcomes. Care planning provides individuals diagnosed with cognitive impairment and their caregivers with information about medical and non-medical treatments, clinical trials and support services available in the community – all of which can contribute to a higher quality of life. People who receive proper care planning are shown to have fewer hospitalizations and emergency room visits, better medication management, and higher satisfaction with care. In addition, because dementia can complicate the management of other chronic conditions, care planning is key to coordinating a person's overall care.

Residential Care

As the disease progresses, families may no longer be able to provide in-home care services for their loved ones and higher-level interventions are needed including placement in assisted living facilities or skilled nursing facilities.

Alzheimer's caregivers face tremendous challenges regarding the availability and affordability of Home and Community-Based Services (HCBS), limiting their access to support services. Without these supports, people with dementia and their caregivers are forced to spend down their income in order to qualify for more costly residential care. Arkansas should actively examine ways to expand these services to better meet the needs of those with Alzheimer's so these individuals can remain in their communities for as long as possible. Families depend on these essential services.

Home and Community-Based Services

- Chore Services
- Homemaker Services
- Congregate Meals
- Home Delivered Meals
- Personal Care
- Care Coordination
- Adult Day Care Programs
- In-Home or Facility-Based Respite Care
- Environmental Modifications
- Personal Emergency Response Systems

For individuals that meet specific financial and medical eligibility criteria, some of these services may be accessed through one of Arkansas's 1915(c) waiver programs.

Arkansas operates several Medicaid 1915(c) Waivers waiver programs. For Individuals with Age-Related or Physical Disabilities:

- **ARChoices** is a program that provides HCBS services for individuals with disabilities from ages 21-64 and seniors over the age of 65 **[30]**.
- **Living Choices** is a program that provides individuals with access to assisted living facilities.
- **PACE (Program For All-Inclusive Care For The Elderly)** is a comprehensive health and social services program that provides and coordinates primary, preventive, acute, and long-term care services for individuals 55 years of age or older who need nursing facility care. Services are provided in PACE Centers, in the home, and in inpatient facilities. Individuals eligible for PACE must live in an area served by a PACE program and be able to live in a community setting without jeopardizing their health or safety
- **Independent Choices** is a self-directed option for adults seeking HCBS for age-related or physical disabilities.

Recommendations

1. Increase the number of slots on the HCBS waiver to allow more people with dementia to live in the least restrictive setting possible.
2. Research and support innovative models to finance the delivery of home and community-based services. Support the testing of pilot programs to improve options for people with dementia to remain at home instead of more costly Medicaid-funded long-term care services.
3. Review existing Medicaid Level of Care policies and identify areas to appropriately incorporate cognitive decline in the determination of the need for long-term care.
4. Conduct a statewide needs assessment to determine the capacity, availability, and cost, and qualities of existing dementia care options.
5. Research opportunities to increase the number of providers for dementia care in underserved communities.
6. Evaluate existing HCBS waiver policies to ensure that persons with Alzheimer's and dementia are able to remain in their preferred environment and that the waiver offers comprehensive services to support participants with dementia.
7. Commission an independent, external study to explore how acuity-based models impact the access to quality care of persons with Alzheimer's and dementia and the opportunities for implementation in Arkansas.
8. Monitor and evaluate Medicaid waivers and ensure they are inclusive of all persons with Alzheimer's and dementia.
9. Review existing financial eligibility standards for people with dementia seeking long-term services and supports to expand access to care for people with dementia.

Alzheimer's disease does not just affect the person with the disease, but it has a profound impact on families as well. Eighty-three percent of the help provided to older adults in the United States comes from family members, friends or other unpaid caregivers [31]. Nearly half of all caregivers (48%) who provide help to older adults do so for someone with Alzheimer's or another dementia [32]. More than 16 million Americans provide unpaid care for people with Alzheimer's or other dementias [33]. In Arkansas, more than 178,000 family members and friends provide more than 203 million hours of unpaid care, a contribution to the state valued at almost \$2.7 billion. Caring for a person with Alzheimer's or related dementia is often very difficult. As a result, many unpaid caregivers experience high levels of emotional stress and depression. The stress of caregiving impacts the health, employment, and income and financial security of many caregivers.

According to a report published by AARP and the National Alliance for Caregiving, [34] "the number of [unpaid] caregivers has climbed from 18 percent of adults in 2015 to more than 21 percent in 2020, an increase of 9.5 million adults who provide assistance on everything from grocery shopping to wound care to medication management."

Who are the Caregivers?

While understanding there are those with younger-onset Alzheimer's, the majority of people living with dementia are diagnosed in the sixth or seventh decade of life. For them, primary caregivers are:

- Approximately two-thirds of dementia caregivers are women.
- About 30% of caregivers are age 65 or older.
- Over 60% of caregivers are married, living with a partner or in a long-term relationship.
- Over half of caregivers are providing assistance to a parent or in-law with dementia.
- Approximately 10% of caregivers provide help to a spouse with Alzheimer's disease or another dementia.
- Two-thirds of caregivers are non-Hispanic white
- 10% are African American
- 8% are Hispanic/Latino
- 5% are Asian.

- The remaining 10% represent a variety of other racial/ ethnic groups.
- Approximately 40% of dementia caregivers have a college degree or more education.
- Forty-one percent of caregivers have a household income of \$50,000 or less.
- Among primary caregivers (individuals who indicate having the most responsibility for helping their relatives) of people with dementia, over half take care of their parents.
- Most caregivers (66%) live with a person with dementia in the community.
- Approximately one-quarter of dementia caregivers are “sandwich generation” caregivers — meaning that they care not only for an aging parent but also for a child.

(Compiled using figures from the Alzheimer’s Association 2020 Facts and Figures Report)

Caregiver Burden and Stress

The impact of caring for a person with Alzheimer’s or other dementia poses special challenges. People in the middle to later stages of Alzheimer’s experience losses in judgment, orientation, and the ability to understand and communicate effectively. Family caregivers must often help people with Alzheimer’s manage these issues. The personality and behavior of a person with Alzheimer’s are affected as well, and these changes are often among the most challenging for family caregivers.

Individuals with Alzheimer’s also require increasing levels of supervision and personal care as the disease progresses. As symptoms worsen, the care required by family members can result in increased emotional stress and depression among caregivers; new or exacerbated health problems; and depleted income and finances due in part to disruptions in employment and paying for health care or other services for themselves and people living with dementia.

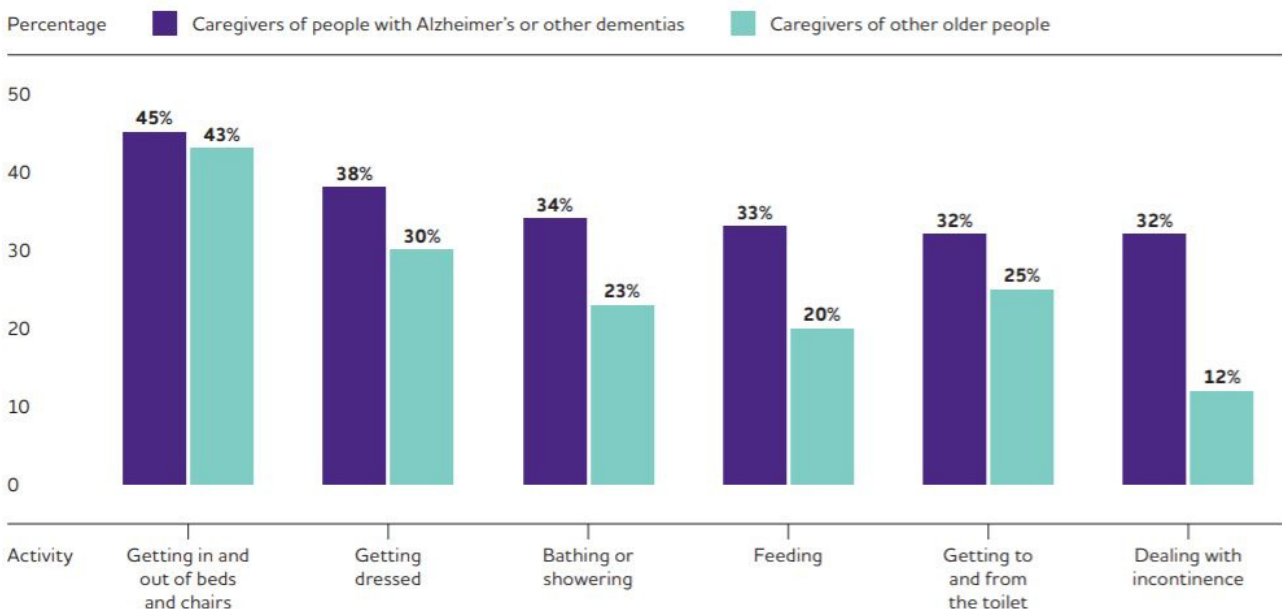
Alzheimer’s and other dementias often complicate an individual’s ability to process what is going on around them and manage the day-to-day Activities of Daily Living (ADLs) both are essential and routine aspects of self-care.



The six essential ADLs include the ability to be able to independently eat, dress, walk or transfer from one position to another, bathe, toilet, and maintain bowel and bladder continence. Although there are many circumstances in which families care for loved ones in a home setting, adding Alzheimer's and other dementias to the mix can increase the intensity of care.

The person diagnosed with Alzheimer's is often confused about what is being asked of them in assisting with their daily care. This creates a unique set of challenges for family caregivers. For some, additional comorbidities such as Parkinson's disease, create neurological and physical challenges that add to required levels of care. There is eventually confusion about their relationships with life-long family members whom they may not recognize someday. All these things come together to create enormous financial and logistical challenges for family members who are caring for their loved ones in a home setting — challenges every day to do the best job they can. The fear, frustration, and heartbreak are palpable and the physical and emotional toll on primary family caregivers is often overwhelming.

Proportion of Caregivers of People with Alzheimer's or Other Dementias Versus Caregivers of Other Older People Who Provide Help with Specific Activities of Daily Living, United States, 2015



(Created from data from the National Alliance for Caregiving and AARP)

The intimacy, shared experiences, and memories that are often part of the relationship between a caregiver and person living with dementia may be threatened due to the memory loss, functional impairment, and psychiatric/behavioral disturbances that can accompany the progression of Alzheimer's. In a national poll, however, 45% of caregivers of people with dementia indicated that providing help to someone with cognitive impairment was very rewarding [35]. Although caregivers report positive feelings about caregiving, such as family togetherness and the satisfaction of helping others, they also frequently report higher levels of stress.

More dementia caregivers were classified as having a high level of burden than caregivers of people without dementia (46% versus 38%) based on the 2015 National Alliance for Caregiving/AARP survey's Burden of Care Index, which combined the number of hours of care and the number of ADL tasks performed by the caregiver into a single numerical score [36]. Compared with caregivers of people without dementia, twice as many caregivers of those with dementia indicate substantial emotional, financial, and physical difficulties [37].

For some, the burden of caregiving can often lead to depression. Caring for people with dementia who have four or more behavioral and psychological symptoms (for example, aggression, self-harm and wandering) represents a "tipping point" for family caregivers, as they are more likely to report clinically meaningful depression and burden (that is, negative emotional reactions to providing care) [38].

For some caregivers, the demands of caregiving may cause declines in their own physical health. As the disease progresses the level of assistance to perform routine tasks can take a physical toll on family caregivers. Evidence suggests that the stress of providing dementia care increases caregivers' susceptibility to disease and health complications [39]. It is not uncommon for caregivers to neglect their own personal health while caring for their loved ones. A 2017 poll reported that 27% of dementia caregivers delayed or did not do things they should to maintain their own health [40].

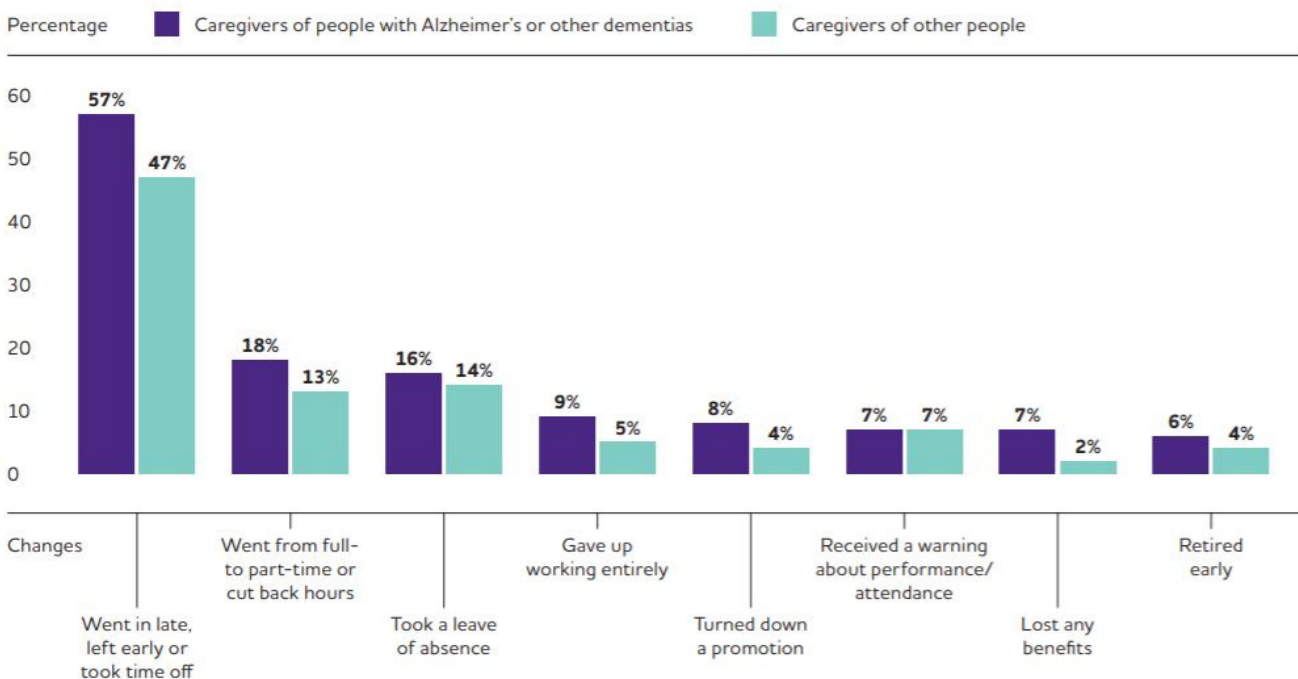
Financial Burden of Caregiving

Many family caregivers balance the obligations of maintaining employment while also providing care for their loved ones. Six in 10 caregivers of people with Alzheimer's or another dementia were employed or had been employed in the prior year while providing care.

These individuals worked an average of 35 hours per week while caregiving. Among people who were employed in the past year while providing care to someone with Alzheimer’s or another dementia,

- 57% reported sometimes needing to go in late or leave early compared with 47% of non-dementia caregivers.
- Eighteen percent of dementia caregivers reduced their work hours due to care responsibilities, compared with 13% of non-dementia caregivers.
- Other work-related changes among dementia and non-dementia caregivers who had been employed in the past year are summarized in the figure below.

Work-Related Changes Among Caregivers of People with Alzheimer’s or Other Dementias Who Had Been Employed at Any Time Since They Began Caregiving



Compiled from data from the National Alliance for Caregiving and AARP

Supporting Family Caregivers

For more than 30 years, strategies to support family caregivers of people with dementia have been developed and evaluated. In general, the goal of interventions is to improve the health and well-being of dementia caregivers by relieving the negative aspects of caregiving. Some also aim to delay nursing home admission of the person with dementia by providing caregivers with skills and resources (emotional, social, psychological and/or technological) to continue helping their relatives or friends at home.

Specific approaches used in various interventions include providing education to caregivers, helping caregivers manage dementia-related symptoms, improving social support for caregivers and providing caregivers with respite from caregiving duties. Investing in interventions will help prevent caregiver burnout and allow individuals and families options to age in their preferred environment.

Type and Focus of Caregiver Interventions

Type	Focus
Case management	Provides assessment, information, planning, referral, care coordination and/or advocacy for family caregivers.
Psychoeducational approaches	Include structured programs that provide information about the disease, resources and services, and about how to expand skills to effectively respond to symptoms of the disease (for example, cognitive impairment, behavioral symptoms and care-related needs). Include lectures, discussions and written materials and are led by professionals with specialized training.
Counseling	Aims to resolve pre-existing personal problems that complicate caregiving to reduce conflicts between caregivers and care recipients and/or improve family functioning.
Psychotherapeutic approaches	Involve the establishment of a therapeutic relationship between the caregiver and a professional therapist (for example, cognitive-behavioral therapy for caregivers to focus on identifying and modifying beliefs related to emotional distress, developing new behaviors to deal with caregiving demands, and fostering activities that can promote caregiver well-being).
Respite	Provides planned, temporary relief for the caregiver through the provision of substitute care; examples include adult day services and in-home or institutional respite care for a certain number of weekly hours.
Support groups	Are less structured than psychoeducational or psychotherapeutic interventions. Support groups provide caregivers the opportunity to share personal feelings and concerns to overcome feelings of isolation.
Multicomponent approaches	Are characterized by intensive support strategies that combine multiple forms of interventions, such as education, support and respite, into a single, long-term service (often provided for 12 months or more).

**Alzheimer's Disease Facts and Figures Report (2020)*

Recommendations

1. Improve access to and use of evidence-informed interventions, services, and supports for people with dementia and their caregivers to enhance their health, wellbeing, and independence.
2. Expand in-home and facility-based respite services for family caregivers of individuals living with dementia.
3. Connect caregivers, family members and individuals with dementia to information about dementia services.
 - a. Work in coordination with state agencies and non-governmental organizations to develop and deliver no-cost training for family caregivers of people with dementia to improve the delivery of care and support better outcomes for family caregivers. Provide special attention to caregivers in underserved and rural communities.
 - b. Regularly survey and assess the needs of family caregivers of people with dementia to ensure the state is providing services in a manner that aligns with caregiver needs.

DEMENTIA TRAINING AND WORKFORCE DEVELOPMENT

The number of Arkansans over the age of 65 living with Alzheimer's dementia is expected to increase by 15.5% over the next five years bringing the state total to an estimated 67,000 [41]. Arkansas needs to continue to invest in equipping the workforce with the education and training needed to address the unique care needs of individuals with dementia. Current training guidelines are reflected below.

Specialty Care Units in Nursing Homes

Arkansas regulation sets forth the requirements for staff training in Alzheimer's Special Care Units in nursing homes. The requirements include 30 hours of training in specific areas including: etiology; philosophy and treatment of dementia; the stages of Alzheimer's disease; behavior management; use of physical restraints; wandering and egress control; medication management; communication skills; prevention of staff burnout; activity programming; ADLs and Individual-Centered Care; and assessments and creation of ISPs. In addition, two (2) hours of in-service training are required every quarter.

Nursing Aide Training in Long-Term Care Facilities

An Arkansas statute requires the Office of Long-Term Care to promulgate regulations regarding the implementation of an aide training program for all long-term care facilities, which must include 15 hours of training specific to Alzheimer's disease and related dementia. The regulations reference the Arkansas LTCF Nursing Assistant Training Curriculum and require 90 hours of training plus one (1) hour of in-service training per month. Facilities are encouraged to also provide in-service training in dementia to nursing home CNAs licensed before July 1, 2006. CNAs must pass a state competency exam.



Adult Day Care Providers

This regulation sets forth the requirements for staff training for adult daycare providers and includes dementia training.

Caregiver Employed by In-Home Services Agency

Arkansas statute and regulation require at least 40 hours of training for caregivers employed by In-Home Service Agencies, including non-specific dementia training.

Disclosure Requirements

There are statutory and regulatory requirements that nursing homes that have specialty care dementia units must make certain disclosures, including unique training requirements, to the Office of Long-Term Care, and to consumers.

Law Enforcement and First Responders

Members of law enforcement and other first responders, frequently interact with individuals who have dementia and are among the first to observe instances of abuse and neglect. First responders interact with people with Alzheimer's while searching for a lost individual, stopping drivers who exhibit unsafe driving, rescuing people with dementia from abuse, and intervening in crisis or disaster situations. Despite the frequency of interactions, most receive little or no formal training to prepare them for the unique physical, behavioral, and communication challenges related to people with dementia.

Adult Protective Services (APS)

Individuals with Alzheimer's and other dementias can also be the victims of elder abuse. But, they may be unaware they are victims and may not know how to — or be able to — report it. People with Alzheimer's may present as uncooperative, disruptive, and combative when they have difficulty communicating and understanding what is happening. Adult Protective Service workers have frequent interactions with persons with dementia with little or no training. Education about dementia and communication tactics can ensure that APS workers are equipped with the training to identify situations of abuse and the safety of both the APS worker and the person with the disease.

Recommendations

1. Require dementia-specific training for physicians, nurses and other health care workers to support early diagnoses and disclosure of dementia, provide effective care planning at all stages of dementia, offer counseling and referral, and engage family caregivers, as appropriate, in care management.
2. Require and implement dementia training initiatives for hospital social workers and discharge planners to better engage people with dementia and their caregivers and to increase their awareness about resources available to individuals patients with Alzheimer's and other forms of dementia.
3. Increase collaboration between the non-profit sector and the medical community to ensure they are aware of the resources available to them and to caregivers.
4. Require and implement dementia training requirements for Adult Protective Service workers and other state and local government employees serving people with dementia (including Area Agency on Aging staff and social services workers).
5. Require dementia-specific training for members of law enforcement as part of the initial curriculum and ongoing training.
6. Increase opportunities and reduce barriers for telehealth to support people with dementia, including in the areas of assessment, diagnosis, treatment, and education of those living with dementia and caregivers throughout the state.
7. Support the expansion of new initial and ongoing dementia training standards for direct care workers to improve their understanding of cognitive impairment and how to effectively support and care for people living with dementia
 - a. Implement and deliver a portable certification for direct care workers in-home health and residential long-term care settings to ensure they understand the principles of providing person-centered care to people with dementia.
 - b. Require that all direct care workers in all long-term care settings (including in the home) receive a minimum of six to eight hours of competency-based dementia training for new direct care workers and returning direct care workers who have not provided care to people with dementia in the last two years.
 - c. Require all direct care workers receive at least four hours of annual, ongoing dementia training.
8. Establish dementia training requirements for other long-term care staff including other health care workers and administrative/auxiliary staff.

1. "Alzheimer's Disease and Related Dementias." *National Institute on Aging*, U.S. Department of Health and Human Services, www.nia.nih.gov/health/alzheimers.
2. Alzheimer's Association (2020) Alzheimer's Disease Facts and Figures: SPECIAL REPORT On the Front Lines: Primary Care Physicians and Alzheimer's Care in America. pg. 6
3. Ibid. 1 (pg.6)
4. Ibid. 1 (pg. 2)
5. Kapasi A, DeCarli C, Schneider JA. Impact of multiple pathologies on the threshold for clinically overt dementia. *Acta Neuropathol* 2017;134(2):171-86.
6. Brenowitz WD, Hubbard RA, Keene CD, Hawes SE, Longstreth WT, Woltjer, et al. Mixed neuropathologies and estimated rates of clinical progression in a large autopsy sample. *Alzheimer's Dement*. 2017;13(6):654-62
7. National Institute on Aging. *What are frontotemporal disorders?* Available at: <https://www.nia.nih.gov/health/what-are-frontotemporal-disorders>. Accessed November 17, 2019.
8. Ibid 1 (pg. 6)
9. Hogan DB, Jette N, Fiest KM, Roberts JI, Pearson D, Smith EE, et al. The prevalence and incidence of frontotemporal dementia: a systematic review. *Can J Neurol Sci* 2016;43(suppl): S96-109.
10. Stojkowska I, Krainc D, Mazzulli JR. Molecular mechanisms of a-synuclein and GBA1 in Parkinson's disease. *Cell Tissue Res* 2018;373(1):51-60
11. Johnson KA, Minoshima S, Bohnen NI, Donohoe KJ, Foster NL, Herscovitch P, et al. Appropriate use criteria for amyloid PET: A report of the Amyloid Imaging Task Force, the Society of Nuclear Medicine and Molecular Imaging, and the Alzheimer's Association. *Alzheimers Dement* 2013;9(1):e1-e16.
12. Shaw LM, Arias J, Blennow K, Galasko D, Molinuevo JL, Salloway S, et al. Appropriate use criteria for lumbar puncture and cerebrospinal fluid testing in the diagnosis of Alzheimer's disease. *Alzheimer's Dement* 2018;14:1505-21
13. Ibid 1 State-specific facts and figures reports are Issued as a supplement to the Associations full report

14. Leibson CL, Hall Lon K, Ransom JE, Roberts RO, Hass SL, Duhig AM, et al. Direct medical costs and source of cost differences across the spectrum of cognitive decline: A population-based study. *Alzheimer's Dement* 2015;11(8):917-32
15. Unpublished tabulations based on data from the National 5% Sample Medicare Fee-for-Service Beneficiaries for 2014. Prepared under contract by Avalere Health, January 2016
16. Ibid 14
17. Medicare. Glossary. Medicare: The Official U.S. Government Site for Medicare. Available at: <https://www.medicare.gov/glossary/a>. Accessed December 4, 2019
18. Ibid 13
19. Ibid 13
20. U.S. Department of Health and Human Services, Centers for Disease Control and Prevention, National Center for Health Statistics. CDC WONDER online database
21. World Health Organization. International Statistical Classification of Diseases and Related Health Problems.
22. Ibid 13
23. Kramarow EA, Tejada-Vera B. Dementia mortality in the United States, 2000-2017. *National Vital Statistics Reports*; vol 68 no 2. Hyattsville, MD: National Center for Health Statistics. 2019. https://www.cdc.gov/nchs/data/nvsr/nvsr68/nvsr68_02-508.pdf
24. Ibid 13
25. Tejada-Vera B. Mortality from Alzheimer's disease in the United States: Data for 2000 and 2010. *National Center for Health Statistics Data Brief*, No. 116. National Center for Health Statistics, Hyattsville, MD; 2013.
26. Taylor C, Greenlund S, McGuire L, Lu H, Croft J. Deaths from Alzheimer's Disease — United States, 1999-2014. *MMWR Morb Mortal Wkly Rep* 2017;66:521-6
27. Alzheimer's Association and Centers for Disease Control and Prevention. Healthy Brain Initiative, State and Local Public Health Partnerships to Address Dementia: The 2018-2023 Road Map. Chicago, IL: Alzheimer's Association; 2018. (pg.6)
28. Ibid. 26 (pg.6)
29. Unpublished tabulations based on data from the Medicare Current Beneficiary Survey for 2011. Prepared under contract by Avalere Health, January 2016.

30. Arkansas Department of Human Services AR Choices in Home Care (June 2018) Available at: https://humanservices.arkansas.gov/images/uploads/daas/PUB-351_ARChoices_In_Homecare_Brochure_rev._06-18.pdf
31. Friedman EM, Shih RA, Langa KM, Hurd MD. U.S. prevalence and predictors of informal caregiving for dementia. *Health Aff* 2015;34(10):1637-41.
32. Spillman B, Wolff J, Freedman VA, Kasper JD. Informal Caregiving for Older Americans: An Analysis of the 2011 National Health and Aging Trends Study. Available at: <https://aspe.hhs.gov/pdf-report/informal-caregiving-older-Americans-analysis-2011-national-health-and-aging-trends-study>. Accessed December 4, 2019.
33. The number of families and other unpaid caregivers of people with Alzheimer's or other dementias: To calculate this number, the Alzheimer's Association started with data from the BRFSS survey. In 2009, the BRFSS survey asked respondents age 18 and over whether they had provided any regular care or assistance during the past month to a family member or friend who had a health problem, long-term illness or disability. To determine the number of families and other unpaid caregivers nationally and by state, we applied the proportion of caregivers nationally and for each state from the 2009 BRFSS (as provided by the CDC, Healthy Aging Program, unpublished data) to the number of people age 18 and older nationally and in each state from the U.S. Census Bureau report for July 2019. Available at: <https://www.census.gov/data/tables/time-series/demo/popest/2010s-state-detail.html>. To calculate the proportion of family and other unpaid caregivers who provide care for a person with Alzheimer's or another dementia, the Alzheimer's Association used data from the results of a national telephone survey also conducted in 2009 for the National Alliance for Caregiving (NAC)/AARP. The NAC/AARP survey asked respondents age 18 and over whether they were providing unpaid care for a relative or friend age 18 or older or had provided such care during the past 12 months. Respondents who answered affirmatively were then asked about the health problems of the person for whom they provided care. In response, 26% of caregivers said that: (1) Alzheimer's or another dementia was the main problem of the person for whom they provided care, or (2) the person had Alzheimer's or other mental confusion in addition to his or her main problem. The 26% figure was applied to the total number of caregivers nationally and in each state, resulting in a total of 16.343 million Alzheimer's and dementia caregivers.

34. AARP; National Alliance for Caregiving (May 2020) Caregiving in the U.S. 2020 - AARP Research Report Available at <https://www.aarp.org/content/dam/aarp/ppi/2020/05/full-report-caregiving-in-the-united-states.doi.10.26419-2Fppi.00103.001.pdf>
35. National Poll on Healthy Aging. Dementia Caregivers: Juggling, Delaying and Looking Forward. Available at: http://www.healthyagingpoll.org/sites/default/files/2017-10/NPHA_Caregivers-Report-PROOF_101817_v2.pdf.
36. National Alliance for Caregiving in partnership with the Alzheimer's Association. Dementia Caregiving in the U.S. Bethesda, MD. Available at: http://www.caregiving.org/wp-content/uploads/2017/02/DementiaCaregivingFINAL_WEB.pdf. Accessed December 4, 2019
37. Kasper JD, Freedman VA, Spillman BC. Disability and Care Needs of Older Americans by Dementia Status: An Analysis of the 2011 National Health and Aging Trends Study. U.S. Department of Health and Human Services; 2014. Available at: <http://aspe.hhs.gov/report/disability-and-care-needs-olderamericans-dementia-status-analysis-2011-national-healthand-aging-trends-study>
38. Arthur PB, Gitlin LN, Kairalla JA, Mann WC. Relationship between the number of behavioral symptoms in dementia and caregiver distress: What is the tipping point? *Int Psychogeriatr* 2018;30(8):1099-107.d
39. Fonareva I, Oken BS. Physiological and functional consequences of caregiving for relatives with dementia. *Int Psychogeriatr* 2014;26(5):725-47
40. National Poll on Healthy Aging. Dementia Caregivers: Juggling, Delaying and Looking Forward. Available at: http://www.healthyagingpoll.org/sites/default/files/2017-10/NPHA_Caregivers-Report-PROOF_101817_v2.pdf

Stricken language would be deleted from and underlined language would be added to present law.

1 State of Arkansas
2 93rd General Assembly
3 Regular Session, 2021

A Bill

HOUSE BILL 1434

4
5 By: Representatives C. Fite, S. Berry, D. Garner, M. Gray, McCullough, Warren
6 By: Senators Hill, B. Ballinger, B. Davis, K. Hammer, G. Leding

7
8 **For An Act To Be Entitled**

9 AN ACT TO CREATE THE ALZHEIMER’S DISEASE AND DEMENTIA
10 ADVISORY COUNCIL; TO PROVIDE FOR THE POWERS AND
11 DUTIES OF THE ALZHEIMER’S DISEASE AND DEMENTIA
12 ADVISORY COUNCIL; TO PROVIDE FOR THE IMPLEMENTATION
13 OF A STATE ALZHEIMER’S PLAN; AND FOR OTHER PURPOSES.

14
15
16 **Subtitle**

17 TO CREATE THE ALZHEIMER’S DISEASE AND
18 DEMENTIA ADVISORY COUNCIL; AND TO PROVIDE
19 FOR THE IMPLEMENTATION OF A STATE
20 ALZHEIMER’S PLAN.

21
22
23 BE IT ENACTED BY THE GENERAL ASSEMBLY OF THE STATE OF ARKANSAS:

24
25 SECTION 1. Arkansas Code Title 20, Chapter 8, is amended to add an
26 additional subchapter to read as follows:

27 Subchapter 11 – Alzheimer’s Disease and Dementia Advisory Council

28
29 20-8-1101. Alzheimer’s Disease and Dementia Advisory Council –
30 Creation – Membership.

31 (a) There is created the Alzheimer’s Disease and Dementia Advisory
32 Council, which shall consist of the following members:

33 (1) A member of the House of Representatives, to be appointed by
34 the Speaker of the House of Representatives, who shall serve as a cochair of
35 the council;

36 (2) A member of the Senate, to be appointed by the President Pro



- 1 Tempore of the Senate, who shall serve as a cochair of the council;
2 (3) One (1) individual who is a family caregiver of an
3 individual living with Alzheimer's disease or another dementia, to be
4 appointed by the Secretary of the Department of Health;
5 (4) The Executive Director of the Arkansas Healthcare
6 Association or his or her designee;
7 (5) The Executive Director of Alzheimer's Arkansas Programs and
8 Services or his or her designee;
9 (6) The Executive Director of the Arkansas Chapter of the
10 Alzheimer's Association or his or her designee;
11 (7) The Arkansas State Director of the Arkansas State Office of
12 AARP, Inc. or his or her designee;
13 (8) The Executive Director of the Arkansas Minority Health
14 Commission or his or her designee;
15 (9) The Executive Director of The Broyles Foundation or his or
16 her designee;
17 (10) The President of the Arkansas Hospital Association or his
18 or her designee;
19 (11) The President of the Arkansas Medical Society or his or her
20 designee;
21 (12) One (1) individual representing the Arkansas Association of
22 Area Agencies on Aging, to be appointed by the Secretary of the Department of
23 Health;
24 (13) One (1) individual who represents home care providers, to
25 be appointed by the Secretary of the Department of Health;
26 (14) One (1) physician who has experience diagnosing and caring
27 for patients with Alzheimer's disease, to be appointed by the Secretary of
28 the Department of Health;
29 (15) One (1) individual representing the University of Arkansas
30 for Medical Sciences Centers on Aging, to be appointed by the Secretary of
31 the Department of Health;
32 (16) One (1) individual who conducts research regarding
33 Alzheimer's disease or other dementias, to be appointed by the Secretary of
34 the Department of Health;
35 (17) One (1) individual from a statewide association
36 representing the interests of nursing professionals, to be appointed by the

1 Secretary of the Department of Health;

2 (18) The Secretary of the Department of Health or his or her
3 designee, who shall be a nonvoting member;

4 (19) The Secretary of the Department of Human Services or his or
5 her designee, who shall be a nonvoting member; and

6 (20) The long-term care ombudsman for the Division of Aging,
7 Adult, and Behavioral Health Services of the Department of Human Services or
8 his or her designee, who shall be a nonvoting member.

9 (b)(1)(A) Each voting member shall serve for a term of two (2) years.

10 (B) If a suitable successor who meets the requirements of
11 this section is not available to be appointed to a position on the council,
12 the current member may be reappointed for an additional term of two (2)
13 years.

14 (2) If a vacancy occurs on the council, the vacancy shall be
15 filled by the same process as the original appointment.

16 (c)(1) The legislative members of the commission shall be paid per
17 diem and mileage as authorized by law for attendance at meetings of interim
18 committees of the General Assembly.

19 (2) Nonlegislative members of the council shall not be
20 compensated but may be reimbursed under § 25-16-901 et seq. for expenses
21 actually incurred in the performance of their duties.

22 (d)(1) The cochaIRS of the council shall call the first meeting of the
23 council within thirty (30) days of the initial appointment of members.

24 (2) Meetings of the council shall be held at least one (1) time
25 every quarter but may occur more often at the call of the cochaIRS.

26 (3) The council shall establish rules and procedures for
27 conducting its business.

28 (4)(A) A majority of the voting members of the council shall
29 constitute a quorum for transacting business of the council.

30 (B) An affirmative vote of a majority of a quorum present
31 shall be required for the passage of a motion or other council action.

32 (5) The Bureau of Legislative Research shall provide staff for
33 the council as necessary to assist the council in the performance of its
34 duties.

35

36 20-8-1102. Duties.

1 The Alzheimer's Disease and Dementia Advisory Council shall:

2 (1) Examine the:

3 (A) Needs of individuals living with Alzheimer's disease
4 or other dementias;

5 (B) Services available in the state for individuals living
6 with Alzheimer's disease or other dementias and their family caregivers; and

7 (C) Ability of healthcare providers and facilities to meet
8 the current and future needs of individuals living with Alzheimer's disease
9 or other dementias;

10 (2) Consider and make findings and recommendations on the
11 following, which shall be known as the "State Alzheimer's Plan":

12 (A) Trends in the state's Alzheimer's disease and other
13 dementias populations and service needs, including without limitation:

14 (i) The state's role in providing or facilitating
15 long-term care, family caregiver support, and assistance to those individuals
16 with early-stage or early-onset Alzheimer's disease or other dementias;

17 (ii) The state's policies regarding individuals with
18 Alzheimer's disease or other dementias;

19 (iii) The fiscal impact of Alzheimer's disease and
20 other dementias on publicly funded healthcare programs; and

21 (iv) The establishment of a surveillance system to
22 better determine the number of individuals diagnosed with Alzheimer's disease
23 or other dementias and to monitor changes to the number of individuals
24 diagnosed with Alzheimer's disease or other dementias;

25 (B) Existing resources, services, and capacity relating to
26 the diagnosis and care of individuals living with Alzheimer's disease or
27 other dementias, including without limitation:

28 (i) The type, cost, and availability of Alzheimer's
29 disease and other dementias care services;

30 (ii) The availability of healthcare workers who can
31 serve people with dementia, including without limitation neurologists,
32 geriatricians, and direct care workers;

33 (iii) Dementia-specific training requirements for
34 public and private employees who interact with people living with Alzheimer's
35 or other dementias, including without limitation long-term care workers, case
36 managers, adult protective services, law enforcement, and first responders;

- 1 (iv) Home-based and community-based services,
2 including without limitation respite care for individuals diagnosed with
3 Alzheimer's disease or other dementias and their families;
- 4 (v) Quality care measures for home-based and
5 community-based services and residential care facilities; and
- 6 (vi) State-supported Alzheimer's and other dementias
7 research conducted at universities located in this state;
- 8 (C) Policies and strategies that address:
- 9 (i) Increasing public awareness of Alzheimer's
10 disease and other dementias;
- 11 (ii) Educating healthcare providers to increase
12 early detection and diagnosis of Alzheimer's disease and other dementias;
- 13 (iii) Improving the health care received by
14 individuals diagnosed with Alzheimer's disease and other dementias;
- 15 (iv) Evaluating the capacity of the healthcare
16 system in meeting the growing number and needs of those individuals with
17 Alzheimer's disease and other dementias;
- 18 (v) Increasing the number of healthcare
19 professionals available to treat the growing aging and Alzheimer's disease
20 and dementia populations;
- 21 (vi) Improving services provided in the home and
22 community to delay and decrease the need for institutionalized care for
23 individuals with Alzheimer's disease or other dementias;
- 24 (vii) Improving long-term care, including without
25 limitation assisted living, for those individuals with Alzheimer's disease or
26 other dementias;
- 27 (viii) Assisting unpaid Alzheimer's disease and
28 other dementias caregivers;
- 29 (ix) Increasing and improving research on
30 Alzheimer's disease and other dementias;
- 31 (x) Promoting activities to maintain and improve
32 brain health;
- 33 (xi) Improving the collection of data and
34 information related to Alzheimer's disease and other dementias and their
35 public health burdens;
- 36 (xii) Improving public safety for and addressing the

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1 safety-related needs of those individuals with Alzheimer's disease or other
2 dementias;

3 (xiii) Addressing legal protections for and legal
4 issues faced by individuals with Alzheimer's disease or other dementias; and

5 (xiv) Improving the ways in which the state
6 government evaluates and adopts policies to assist individuals diagnosed with
7 Alzheimer's disease or other dementias and their families.

8
9 20-8-1103. Reports.

10 (a) By October 1, 2022, and by October 1 of each subsequent year, the
11 Alzheimer's Disease and Dementia Advisory Council shall submit to the
12 Governor, the Speaker of the House of Representatives, and the President Pro
13 Tempore of the Senate an annual report on the status of implementation of the
14 State Alzheimer's Plan recommendations under § 20-8-1102, any barriers to
15 implementation, and any proposed legislation.

16 (b) Every four (4) years, the council shall issue an updated plan
17 addressing the items in § 20-8-1102 and any other issues the council deems
18 necessary and relevant toward addressing Alzheimer's disease and other
19 dementias.

20
21 20-8-1104. Implementation reports.

22 (a) By October 1 of each even-numbered year, the state agencies
23 identified in the State Alzheimer's Plan shall submit a report to the
24 Governor, the Speaker of the House of Representatives, and the President Pro
25 Tempore of the Senate that includes without limitation:

26 (1) The steps the state agency has taken to implement the
27 recommendations in the plan; and

28 (2) If applicable, the state agency's reasons for failing to
29 implement all or any part of the plan.

30 (b) The Alzheimer's Disease and Dementia Advisory Council shall
31 include the council's analysis of the status of state agencies'
32 implementation of the plan in the report required under § 20-8-1103.

33
34 SECTION 2. DO NOT CODIFY. Initial appointments to Alzheimer's Disease
35 and Dementia Advisory Council.

36 Members of the Alzheimer's Disease and Dementia Advisory Council shall

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1 be appointed within ninety (90) days of the effective date of this act.

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