

# The Task Force on the Effect of Alzheimer's Disease in Arkansas



2011  
Final Report



“The time to act is now, before the opportunity escapes us.”

## **About This Report**

This report was developed by a legislative task force to address the public health crisis created by Alzheimer's disease and other types of dementia. The hope is that Arkansas lawmakers can better understand the future impact of Alzheimer's disease and begin to take action to improve the lives of those affected by the disease.

# ARKANSAS GENERAL ASSEMBLY

Senator Cecile Bledsoe  
Senate Chairman

Representative Butch Wilkins  
House Chairman



## Task Force on the Effect of Alzheimer's Disease in Arkansas

On behalf of the Task Force on the Effect of Alzheimer's Disease, we present to you this comprehensive report on the current and future struggle to contain a disease that affects all Arkansans, young and old. Few of us can say that we have been untouched by Alzheimer's disease or its attendant cognitive impairments; it is a disease affecting as many as one in five elderly Arkansans, and one that will take center stage as the number of individuals aged 60 and over doubles in the coming decade. For every person diagnosed with this terrible disease, the emotional and economic costs are visited also on their children and family who ultimately bear the burden of providing adequate health care and quality of life for their loved one.

The Task Force on the Effect of Alzheimer's Disease, created by Act 92 of 2009, brought together a diverse collection of experts in the public, private, and nonprofit sectors, as well as individuals impacted by this disease, to examine the way Arkansas delivers services to those with Alzheimer's disease. Perhaps most importantly, the Task Force has worked to provide a roadmap for dealing with a potential doubling of Alzheimer's among Arkansas's elderly in the years to come, and a short list of public policy initiatives aimed at reinforcing the care and support already provided. These recommendations do not represent the full range of responses necessary to confront Alzheimer's disease, but they are reasonable first steps toward a more comprehensive response.

We hope that you will read and take to heart the information and call to action within these pages. The challenge is a daunting one, and success will require a broad commitment and cooperation between families, healthcare providers, and public officials. The time to act is now, before the opportunity escapes us.

Representative Butch Wilkins  
Co-Chair

Senator Cecile Bledsoe  
Co-Chair

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*Appointed by Speaker of the House Robbie Wills*

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## Preface

Over 76,000 Arkansans currently suffer from Alzheimer's, a number that will increase to more than 100,000 by 2020. The unavoidable impact of the disease, which is the sixth-leading cause of death in America, promises to be a significant burden on the state and its healthcare industry.

In 2007, proposed model legislation from the Alzheimer's Association was considered by the Council of State Governments (CSG). The bill would establish a Task Force to address the escalating epidemic of Alzheimer's and create a state plan for the inevitable challenges that lie ahead. CSG passed the measure and recommended this model legislation to all 50 states.

In December of 2008, the journey of the Task Force on the Effect of Alzheimer's Disease in Arkansas began. University of Arkansas legend Frank Broyles and Representative Dawn Creekmore of Bauxite rallied legislative leaders to support this measure.

Rep. Creekmore and Sen. Barbara Horn of Foreman led the effort by submitting the bill in the 2009 legislative session. They had a vision of a task force that would identify the state's current resources while creating a readiness plan for the overwhelming growth of Alzheimer's disease. Coach Broyles recognized the importance for "A Game Plan" that would prepare the state for the fight against Alzheimer's over the next two decades. The Alzheimer's Association eagerly worked alongside the authors and strongly supported the bill.

During the following legislative session, the bill received unanimous passage through both the House and Senate and, with Governor Mike Beebe's signature, became Act 92 of 2009. This report is the result of the vision of our state's leadership. It includes recommendations for implementing a strategy to address this public health issue and assist Arkansas to become a dementia-capable state.

Much of the information in this report is provided in facts and figures, which can sometimes create distance between policy and the reality of Alzheimer's. Since its first meeting, the Task Force's motivation was the individuals and families affected by this disease.

This is why the Task Force incorporated the personal accounts of five Arkansans into the following pages. Regardless of their connection to Alzheimer's disease, they all have an important story to share – stories of love, struggles and a desire for a better future for Arkansas. We ask that you read their stories and take action in implementing "A Game Plan."

Sincerely,



Mark Fried, President & CEO

**alzheimer's**  **association®**

Oklahoma and Arkansas Chapter

# 1



## Executive Summary

Many families now need our help, but that number will double in a very short time. We must pull together to fight this terrible disease. It will take us all.

- Rep. Butch Wilkins

## Executive Summary

In the coming decades, the struggle to provide quality care for Arkansans with Alzheimer's disease and related disorders will be played out against a background of shifting demographics, increasing healthcare costs, economic uncertainty, and an understaffed service workforce. Only through reinforcement of the service delivery infrastructure and careful planning will Arkansas be able to meet this challenge.

States with high concentrations of 65 and older populations will be hardest hit as the nation's Baby Boom generation ages, and in Arkansas this group, most at risk for Alzheimer's and related disorders, will likely increase by 75 percent over the next 20 years. In the state of Arkansas alone, there are an estimated 76,496 individuals living with Alzheimer's or other related dementias in the year 2010. Projections indicate the number of people impacted will grow by 31.6 percent by the year 2020, at which point an estimated 100,632 Arkansans would be living with this debilitating disease; and by 2030 a projected 121,937.

A rising tide of Alzheimer's disease brings with it a host of problems that extend far outside the traditional public health realm. Wandering, common among persons with dementia, places additional stress on caregivers and families, and can be life-threatening. The Arkansas law enforcement community joined in 2009 to implement the Arkansas Silver Alert program, providing timely information to the public and news organizations when adults with Alzheimer's or other cognitive impairments are missing. Individuals with lower educational achievement have a higher likelihood of having Alzheimer's, as well as a higher prevalence of physical health problems in general. Families, who bear most of the burden and cost of care for persons with Alzheimer's, have been described as the "hidden victims" of the disease. Indeed, in Arkansas alone there are more than 124,000 family members providing over 142 million hours of unpaid care in 2009.

Act 92 of 2009 created 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. Meeting throughout 2009 and 2010, the Task Force heard testimony from experts and constituents on the front lines of the Alzheimer's battle. Their recommendations, included later in this report, address a spectrum of needs, including grants for patient safety programs; improvement of existing data collection systems to accurately track the occurrence of Alzheimer's and its impact on Medicaid and Medicare; expansion of research programs to promote more effective diagnosis; and increasing access to home and community based long-term care services and supports. Finally, the Task Force recommends the creation of a more comprehensive Advisory Council to further study and coordinate public response by increasing statewide awareness of Alzheimer's disease and related dementia; assessing the need for improved workforce training among caregivers; and examining new models for providing cost-effective care to a growing number of persons with the disease.



# 2



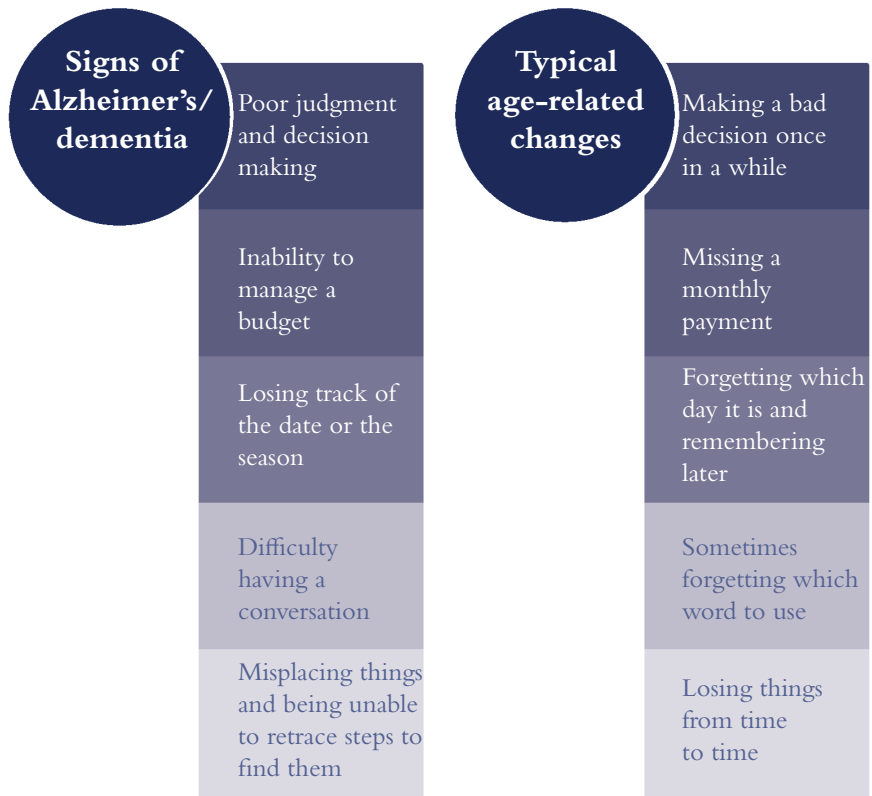
## Overview of Alzheimer's Disease

Alzheimer's disease is the most common cause of dementia and is the 6th leading cause of death in the United States.

# What is Alzheimer's Disease?

Alzheimer's (AHLZ-high-merz) is a disease of the brain that causes problems with memory, thinking and behavior. It is not a normal part of aging. Alzheimer's gets worse over time. The origin of the term Alzheimer's disease dates back to 1906 when Dr. Alois Alzheimer, a German physician, presented a case history before a medical meeting of a 51-year-old woman who suffered from a rare brain disorder. A brain autopsy identified the plaques and tangles that today characterize Alzheimer's disease.<sup>9</sup>

## What's the difference?



Although symptoms can vary widely, the first problem many people notice is forgetfulness severe enough to affect their ability to function at home or work, or to enjoy lifelong hobbies. The disease may cause a person to become confused, lost in familiar places, misplace things or have trouble with language.

Dementia (dih-MEN-shuh) is a general term for the loss of memory and other intellectual abilities serious enough to interfere with daily life. Alzheimer's is the most common form of dementia.<sup>7</sup>

## Types and Causes of Dementia

Alzheimer's disease is the most frequent cause of dementia accounting for 60 to 80 percent of all cases of dementia in Americans aged 71 and older. Other types of dementia include vascular dementia, Parkinson's disease, Lewy body disease, frontotemporal dementia, and normal pressure hydrocephalus.<sup>2</sup>

## Common Types of Dementia and Their Typical Characteristics

### Alzheimer's disease

Most common type of dementia; accounts for an estimated 60–80 percent of cases.

Difficulty remembering names and recent events is often an early clinical symptom; apathy and depression are also often early symptoms. Later symptoms include impaired judgment, disorientation, confusion, behavior changes and difficulty speaking, swallowing and walking.

Hallmark abnormalities are deposits of the protein fragment beta-amyloid (plaques) and twisted strands of the protein tau (tangles).

### Vascular dementia

*(also known as multi-infarct post-stroke dementia or vascular cognitive impairment)*

Considered the second most common type of dementia.

Impairment is caused by decreased blood flow to parts of the brain, often due to a series of small strokes that block arteries.

Symptoms often overlap with those of Alzheimer's, although memory may not be as seriously affected.

### Mixed dementia

Characterized by the hallmark abnormalities of Alzheimer's and another type of dementia — most commonly vascular dementia, but also other types, such as dementia with Lewy bodies.

Recent studies suggest that mixed dementia is more common than previously thought.

### Dementia with Lewy bodies

Pattern of decline may be similar to Alzheimer's, including problems with memory and judgment as well as behavior changes.

Alertness and severity of cognitive symptoms may fluctuate daily.

Visual hallucinations, muscle rigidity and tremors are common.

Hallmarks include Lewy bodies (abnormal deposits of the protein alpha-synuclein) that form inside nerve cells in the brain.

## Common Types of Dementia and Their Typical Characteristics (cont.)

### Creutzfeldt-Jakob disease

Rapidly fatal disorder that impairs memory and coordination and causes behavior changes.

Variant Creutzfeldt-Jakob disease is believed to be caused by consumption of products from cattle affected by mad cow disease.

Caused by the misfolding of prion protein throughout the brain.

### Normal pressure hydrocephalus

Caused by the buildup of fluid in the brain.

Symptoms include difficulty walking, memory loss and inability to control urination.

Can sometimes be corrected with surgical installation of a shunt in the brain to drain excess fluid.

### Parkinson's disease

Many people who have Parkinson's disease (a disorder that usually involves movement problems) also develop dementia in the later stages of the disease.

The hallmark abnormality is Lewy bodies (abnormal deposits of the protein alphasynuclein) that form inside nerve cells in the brain.

### Frontotemporal dementia

Involves damage to brain cells, especially in the front and side regions of the brain.

Typical symptoms include changes in personality and behavior and difficulty with language.

No distinguishing microscopic abnormality is linked to all cases.

Pick's disease, characterized by Pick's bodies, is one type of frontotemporal dementia.

The proportion of cases of dementia attributable to Alzheimer’s disease increases with age. In people aged 90 and older, Alzheimer’s disease accounts for 80 percent of all dementias compared with 47 percent for people aged 71–79.

When Alzheimer’s or other dementia is recognized in a person under age 65, these conditions are referred to as “younger-onset” or even sometimes “early-onset” Alzheimer’s or dementia. A small percentage of Alzheimer’s disease cases, probably less than five percent, are caused by rare genetic variations found in a small number of families worldwide. In these inherited forms of Alzheimer’s the disease tends to develop before age 65, sometimes in individuals as young as 30.<sup>2</sup>

## 10 Warning Signs of Alzheimer’s Disease

- 1 Memory changes that disrupt daily life
- 2 Challenges in planning or solving problems
- 3 Difficulty completing familiar tasks
- 4 Confusion with time or place
- 5 Trouble understanding visual images and spatial relationships
- 6 New problems with words in speaking or writing
- 7 Misplacing things and losing the ability to retrace steps
- 8 Decreased or poor judgment
- 9 Withdrawal from work or social activities
- 10 Changes in mood and personality

## **Risk Factors for Alzheimer's Disease**

While scientists know that Alzheimer's disease involves the failure of nerve cells, why this happens is still not known. However, they have identified certain risk factors that increase the likelihood of developing Alzheimer's.

### **Age**

The greatest known risk factor for Alzheimer's is increasing age. Most individuals with the illness are 65 and older. The likelihood of developing Alzheimer's approximately doubles every five years after age 65. After age 85, the risk reaches nearly 50 percent.

### **Family history and genetics**

Another risk factor is family history. Research has shown that those who have a parent, brother or sister with Alzheimer's are two to three times more likely to develop the disease. The risk increases if more than one family member has the illness.

Scientists have so far identified one gene that increases the risk of Alzheimer's but does not guarantee an individual will develop the disorder. Research has also revealed certain rare genes that virtually guarantee an individual will develop Alzheimer's. The genes that directly cause the disease have been found in only a few hundred extended families worldwide and account for less than five percent of cases. Experts believe the vast majority of cases are caused by a complex combination of genetic and non-genetic influences.

### **Other risk factors**

Age, family history and genetics are all risk factors we can't change. Now, research is beginning to reveal clues about other risk factors that we may be able to influence. There appears to be a strong link between serious head injury and future risk of Alzheimer's.

One promising line of research suggests that strategies for overall healthy aging may help keep the brain healthy and may even offer some protection against Alzheimer's. These measures include eating a healthy diet; staying socially active; avoiding tobacco and excess alcohol; and exercising both body and mind.

Some of the strongest evidence links brain health to heart health. The risk of developing Alzheimer's or vascular dementia appears to be increased by many conditions that damage the heart and blood vessels. These include heart disease; diabetes; stroke and high blood pressure; or high cholesterol.

Studies of donated brain tissue provide additional evidence for the heart-head connection. These studies suggest that plaques and tangles are more likely to cause Alzheimer symptoms if strokes or damage to the brain's blood vessels are also present.<sup>7</sup>

## Treatment of Alzheimer's Disease

No treatment is available to slow or stop the deterioration of brain cells in Alzheimer's disease. The U.S. Food and Drug Administration (FDA) has approved five drugs that temporarily slow the progression of symptoms for about six to twelve months, on average, for about half of the individuals who take them. Researchers have identified treatment strategies that may have the potential to change its course. Approximately 90 experimental therapies aimed at slowing or stopping the progression of Alzheimer's are in clinical testing in human volunteers.<sup>2</sup>

The U.S. Food and Drug Administration has approved five medications (listed below) to treat the symptoms of Alzheimer's disease.

### Approved Medications for Alzheimer's disease

<b>donepezil</b> <ul style="list-style-type: none"><li>• Brand Name Aricept</li><li>• Approved for All Stages</li><li>• FDA Approved 1996</li></ul>	<b>galantamine</b> <ul style="list-style-type: none"><li>• Brand Name Razadyne</li><li>• Approved for Mild to Moderate</li><li>• FDA Approved 2001</li></ul>	<b>memantine</b> <ul style="list-style-type: none"><li>• Brand Name Namenda</li><li>• Approved for Mild to Moderate</li><li>• FDA Approved 2003</li></ul>	<b>rivastigmine</b> <ul style="list-style-type: none"><li>• Brand Name Exelon</li><li>• Approved for Mild to Moderate</li><li>• FDA Approved 2000</li></ul>	<b>tacrine</b> <ul style="list-style-type: none"><li>• Brand Name Cognex</li><li>• Approved for Mild to Moderate</li><li>• FDA Approved 1993</li></ul>
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Created from data from Alzheimer's Association Website, retrieved October 2010

## **Treatment of Alzheimer’s Disease (cont.)**

Researchers are looking for new ways to treat Alzheimer's. Current drugs help mask the symptoms of Alzheimer's, but do not treat the underlying disease. A breakthrough Alzheimer drug would treat the underlying disease and stop or delay the cell damage that eventually leads to the worsening of symptoms. Many experts believe such a breakthrough is possible within the next few years. There are several promising drugs in development and testing, but more volunteers are needed to complete clinical trials of those drugs. Increased federal funding of Alzheimer’s disease research is also needed to ensure that fresh ideas continue to fill the pipeline.<sup>8</sup>

## **Prevention of Alzheimer’s Disease**

A growing body of evidence suggests that the health of the brain — one of the body’s most highly vascular organs — is closely linked to the overall health of the heart and blood vessels. Some data indicate that management of cardiovascular risk factors, such as high cholesterol, Type 2 diabetes, high blood pressure, smoking, obesity and physical inactivity may help avoid or delay cognitive decline. Many of these risk factors are modifiable — that is, they can be changed to decrease the likelihood of developing both cardiovascular disease and the cognitive decline associated with Alzheimer’s and other forms of dementia. More limited data suggest that a low-fat diet rich in fruits and vegetables may support brain health, as may a robust social network and a lifetime of intellectual curiosity and mental stimulation.<sup>2</sup>



I wanted to serve on the Task Force because of my personal experience with this disease. My father was diagnosed with younger-onset Alzheimer's six years ago at age 64. In hindsight it is apparent that his symptoms began some time prior to his diagnosis. A few days after Christmas 2007, at age 67, my father's doctor suggested to my mother that he go to the hospital for a few days in order to regulate his medication. This became an unexpected permanent situation. It soon became apparent that he needed full-time care and we found ourselves looking for the right place for him. For about six months we tried multiple facilities in Camden and Hot Springs. With only the suggestions of his doctors and the staffs at the various hospitals and nursing homes as guidance we were overwhelmed, confused and alone. Finally we found a home for him at a nursing home in Star City that turned out to be a blessing. He has been a resident there now for a little over two years and he is receiving excellent care.

Because of these experiences, I wanted to participate in the work of the Task Force. No family should feel as we did during this difficult time, especially in the state of Arkansas. We, in Arkansas, value our elderly and look after those who need help the most. We are a People who come together in times of need, both legislatively and individually. Arkansas continues to become a state that other states look to for an example on many fronts and I believe we can be a leader in the fight against Alzheimer's also. The devastation this disease causes, leading to early death, takes an unbelievable toll on spouses, families, and other caregivers. While the work of this Task Force will probably not directly help my dad, it is my sincere hope that it will provide much needed help for others who may face the effects of this disease in the future, including myself and my children.

## Cathey McAllister-Griffin

Age 35

*Caregiver for Father  
with Alzheimer's*

**El Dorado, AR**



3



**Arkansas:  
State of the State**

In the state of Arkansas alone, there are currently an estimated 76,496 individuals living with Alzheimer's or related dementias.

# Prevalence of Alzheimer’s disease and Other Dementias

Alzheimer’s is not a normal part of aging. Current research estimates 5.3 million Americans of all ages have Alzheimer’s disease. This figure includes 5.1 million people aged 65 and older and 200,000 individuals under age 65 who have younger-onset Alzheimer’s. The projected number of people aged 65 and older with Alzheimer’s disease varies by region of the country, as well as by state. Not only is there substantial variability by state in the projected numbers of people with Alzheimer’s, but this variability is also reflected between regions of the country. Some of the difference is clearly due to where the 65 and older population resides within the United States. However, between 2000 and 2025, it also is clear that across the country, all states and regions are expected to experience double-digit percentage increases in the numbers of people with Alzheimer’s and related dementias.<sup>10</sup>

## Projected Changes Between 2000 and 2025 in Alzheimer Prevalence by State

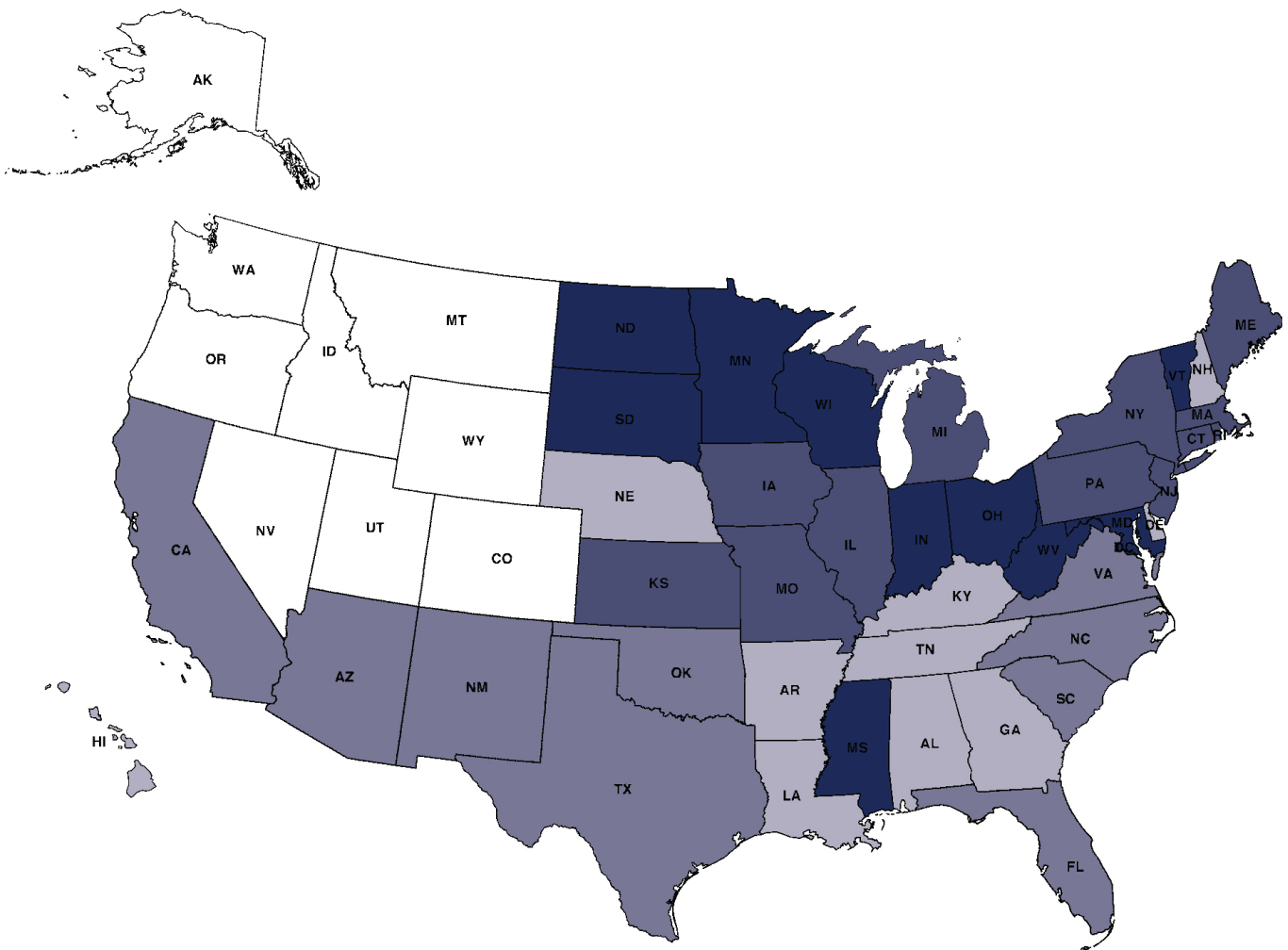
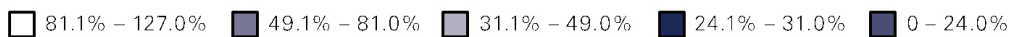
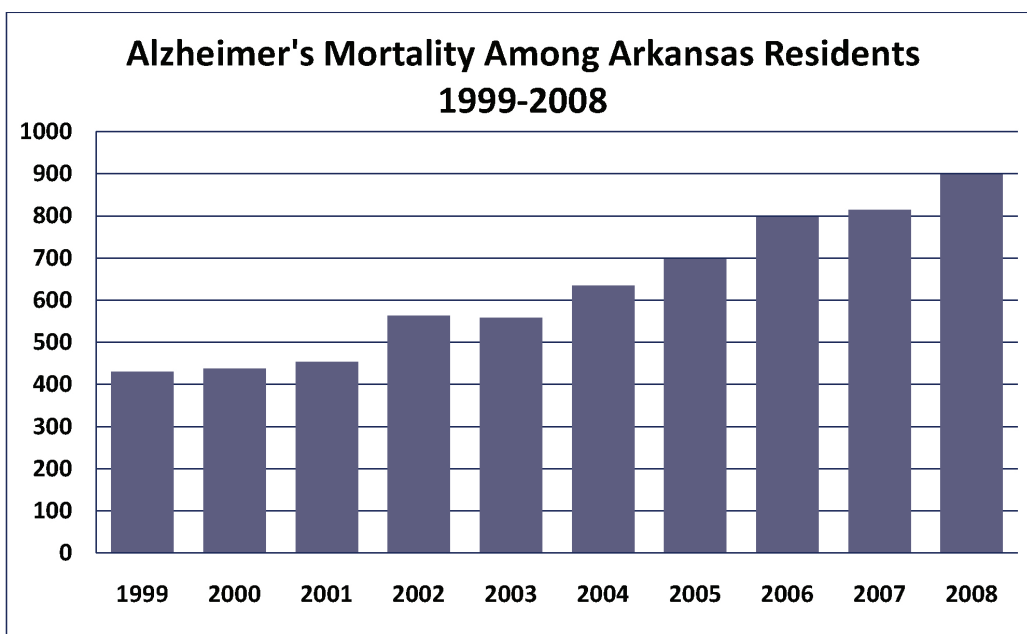


Chart from data from 2010 Alzheimer’s Disease Facts and Figures

Arkansas will experience greater growth in Alzheimer’s disease than many other states based on the proportion of Arkansans over the age of 65. Our state is already ranked tenth nationally in its percentage or share of persons 65 or older. With the impact of Alzheimer’s disease and related dementias reaching across all demographics, the impact of the disease will be dramatic and unavoidable, placing Arkansas in a burdensome position.<sup>6</sup>

Adding to this surge in Arkansas’ aging population is a general increase in lifespan generated by the “longevity revolution,” leading more people to live past age 65. In 2005, the U. S. Census Bureau projected the number of Arkansans over 60 at 521,000, or roughly 19 percent of the total population. By 2030, this population, which is most at risk for Alzheimer’s and related diseases, is expected to increase by 75 percent to more than 900,000.<sup>12</sup>

In the state of Arkansas alone, there are an estimated 76,496 individuals living with Alzheimer’s or other related dementias in the year 2010. Projections indicate the number of people impacted will grow by 31.6 percent by the year 2020, at which point an estimated 100,632 Arkansans would be living with this debilitating disease; and by 2030 a projected 121,937.<sup>5</sup> Arkansas will likely experience greater growth in Alzheimer’s disease than other states given the proportion of the 65 and older population living in these areas. This trend has already begun to present itself as evidenced by Arkansas death certificate data, which shows that the number of deaths due to Alzheimer’s has almost doubled in the past seven years.<sup>17</sup>



Source: Arkansas Death Certificate Data, ICD10 Code G30-G30.9; Primary diagnosis only

## Rural Challenges

Look closer, and the picture becomes increasingly more complicated. Fifty percent of Arkansas's population resides in rural areas. Currently, rural healthcare services are already struggling to maintain an adequate level of care to individuals with Alzheimer's disease. Also, living in a rural area makes the already difficult task of caregiving even more burdensome on families. These difficulties are evidenced by a lack of access or availability of healthcare services and shortages in professionals trained to adequately care for individuals with Alzheimer's disease.<sup>12</sup>

The shortage of health workforce professionals is among the most significant challenges rural communities face, according to "The 2004 Report to the Secretary: Rural Health and Human Service Issues," 74 percent of 1,196 federally designated Mental Health Professional Shortage Areas in 2003 were located in rural counties.

Besides a lack of health professionals in rural areas, there are also fewer community resources, such as adult day care centers where people with Alzheimer's can go during the day for care—and give their caregivers some respite. Many rural communities are limited in fiscal resources and infrastructure to develop their own communitybased programs. The end result of this is that many families are left with very few options and the quality of life for many Arkansans fighting this disease is diminished.

## Wandering Issues

It is common for a person with dementia to wander and become lost; many do repeatedly. In fact, over 70 percent of those with dementia will wander at some point. Wandering can be dangerous – even life threatening – for the person who wanders. The stress can weigh heavily on caregivers and family.<sup>4</sup>

Many people with dementia do not fit the textbook definition of wandering, "to move about without a definite destination or purpose." People with dementia who wander often have a purpose or goal in mind. They may be searching for something that is lost or trying to fulfill a former job responsibility.

## Wandering Issues (cont.)

The Arkansas State Police through a Memorandum of Understanding (MOU) with the Arkansas Sheriffs' Association and Arkansas Association of Chiefs of Police implemented an alert program in 2009 called the Arkansas Silver Alert. This program provides the general public and news organizations a means to receive information on seniors/other adults with Alzheimer's or other cognitive impairments that are missing.

In addition, the Arkansas State Police created a website that allows subscribers to receive email messages when a Silver Alert is issued. The website address is <https://www.ark.org/asp/alerts/mnaa/silver.php>.

Time is of the essence when individuals with Alzheimer's or other cognitive impairments wander or become lost. The Arkansas Silver Alert Program was designed to quickly disseminate vital information to the media and general public to assist in the search and safe recovery of these individuals, and quickly reunite them with their loved ones and/or caregivers.

### **A person may be at risk for wandering if he or she:**

- Returns from a regular walk or drive later than usual
- Tries to fulfill former obligations, such as going to work
- Tries or wants to "go home" even when at home
- Is restless, paces or makes repetitive movements
- Has difficulty locating familiar places like the bathroom or bedroom
- Checks the whereabouts of familiar people
- Acts as if doing a hobby or chore, but nothing gets done

Created from data from *Wandering: Who's at Risk?*, Alzheimer's Association, 2009

## Education

Another concern for Arkansas' population is education and its association with developing Alzheimer's and other dementias. From 2001-2006, 75 percent of Alzheimer's deaths occurred among Arkansans with a 12th grade education or less. Individuals with fewer years of education are associated with a higher likelihood of having Alzheimer's disease. In Arkansas, 82.45 percent of individuals 25 years or older have at least a high school education, while only 19.3 percent have a bachelor's degree or higher compared to 27.5 percent nationally. Attaining fewer years of education is also typically related to other factors, such as lower levels of occupational attainment and higher prevalence of physical health conditions in adulthood, that are also associated with the development of dementia. This again puts Arkansas in a more vulnerable position than other states.<sup>13,14,16</sup>

## Caregivers

Families are the heart and soul of the health and long-term care system for the more than 75,000 people in Arkansas who have Alzheimer's disease. Seven out of ten individuals are taken care of in the home by their loved ones who provide over 75 percent of their care. In Arkansas alone there are 124,841 family members providing around 142,168,622 hours annually of unpaid care.<sup>11</sup>

A report by the Alzheimer's Association and National Alliance for Caregiving found that due to the symptoms that accompany the disease and its long duration (up to 20 years), Alzheimer's caregivers are often more impacted than other caregivers by negative emotional and physical health, employment and financial outcomes. The report notes that, as a result, 74 percent of Alzheimer's caregivers express a need for information and support; specifically the need for more time for themselves, help managing stress, and information on managing challenging behaviors. Dr. Peter Vitaliano, professor of Psychiatry at the University of Washington, has studied these caregivers since 1984 and believes they are the "hidden victims" of the disease.<sup>3</sup>



## Cost of Care

Millions of family members and friends are not only affected by Alzheimer's disease because of the toll it takes on them as caregivers, but also financially. Many people assume that government programs, such as Medicare and others, will pay for the majority of care. However, it is individuals and families that typically pay for many services out of their own pocket.

- The yearly cost of caring for someone with Alzheimer's depends on the stage of the disease.
  - \$18,400 for someone with mild symptoms
  - \$30,100 for moderate symptoms
  - \$36,132 for severe symptoms
- Alzheimer's disease costs businesses \$24.6 billion in health care.
- In the United States 7 out of 10 people with Alzheimer's live at home where 75 percent of costs are absorbed by the family. The remaining 25 percent of care costs cost an average \$19,000 a year.
- It is estimated that Alzheimer's caregivers cost businesses \$36.5 billion. This include the costs of absenteeism and lost productivity in the workplace.
- The average cost of a nursing home in the US is \$42,000 a year. However in some areas those costs can be at least \$70,000.
- Medicare costs for beneficiaries with Alzheimer's disease were \$91 billion in 2005. Medicare costs are expected to increase by 75 percent to \$160 billion in 2010.
- Medicaid expenditures on residential dementia care were \$21 billion in 2005. These cost are estimated to rise by 14 percent to \$24 billion in 2010.<sup>15</sup>



My mother, Jan Baldwin, was diagnosed with Alzheimer's in 2001 at the age of 57, but looking back, she showed signs of the disease as early as 1998. Mom was truly the model Christian citizen; an exemplary mother, wife, and friend to many. Selfless, she always cared about others and was the first to have a pound cake ready for someone in need of a little encouragement!

Mom spent most of her adult life in Magnolia, Arkansas and taught fifth grade Sunday school. She participated in PEO, Junior League, and countless other committees and charitable groups. The community knew that they could count on mom and she never let anyone down. As mom began to decline in health, she was very scared and she couldn't understand why simple tasks like balancing the checkbook and keeping track of time were becoming difficult for her. Interestingly, after foot surgery in 1999, her rapid decline was accelerated. Thanksgiving the same year, she forgot to cook a meal and it bothered her greatly.

Mom loved everyone with so much energy and passion. She was a true love for all. I recently ran into an old acquaintance that told me how much my mom meant to him. Apparently, about 15 years ago, he had some problems with drugs and depression. I had no idea at the time, but he told me how mom would call him and encourage him and tell him that she was praying for him. He told me that her encouragement and prayer meant more to him than anything else he received for treatment.

Mom was healed from Alzheimer's on December 8, 2010 as she walked through the gates of Heaven. Her true spirit lives on and she will always be a great example to many.

Being an Advocate for Alzheimer's Disease is nothing compared to what mom would have done. In a small way, however, it helps give tribute to the first woman that I loved and honor her by sharing her story with others.

## Christian Baldwin

Age 33  
*Son of Mother  
with Alzheimer's*

**Fayetteville, AR**



# 4



## Task Force Recommendations

Above all, our ultimate goal is to prevent, slow or cure Alzheimer's disease. Let's keep our eye on the prize.

- Newt Gingrich

## Tackling a Range of Alzheimer's Issues

The Task Force on the Effect of Alzheimer's Disease in Arkansas makes the following recommendations to Governor Mike Beebe and the Arkansas General Assembly so that we can begin to address the current and future impact of the disease and other types of dementia on Arkansans with a thoughtful, integrated and cost-effective approach that will improve the dementia capabilities of our great state.

### Recommendations

- 1. Create a permanent Advisory Council on Alzheimer's Disease and related disorders consisting of current Task Force appointees plus additional designations to ensure balance and expertise. Responsibilities of the Council would include continued study of the priorities listed in the next section of this report and would report annually to the Governor and General Assembly on the status of services, data and policy recommendations in regards to Alzheimer's disease and related disorders.**
- 2. Mandate the Arkansas Department of Health to utilize the Behavioral Risk Factor Surveillance System (BRFSS) Alzheimer's/cognitive impairment module to capture statewide data that will provide state-specific information to better inform public health and policy audiences in their work.**
- 3. Establish a Patient Safety & Education Grant Program to provide financial assistance and promote public awareness of technologies and programs, such as the Arkansas Silver Alert, designed to protect the safety of individuals with Alzheimer's disease and related disorders from wandering.**
- 4. Work with service providers to create a coordinated and systematic way of collecting Alzheimer's and dementia-related data in Arkansas' Medicaid and Medicare program.**

*(continued on next page)*

## Recommendations (cont.)

5. **Invest in the Pilot Research Program of the Center for Clinical and Translational Research at the University of Arkansas for Medical Sciences (UAMS) to bolster research in Alzheimer’s disease and related disorders and to translate effective diagnosis and treatment of these conditions to Arkansans.**
6. **Commission a study documenting patterns of care and costs of Alzheimer’s disease in Arkansas at the Center for Clinical and Translational Research at the University of Arkansas for Medical Sciences (UAMS). The study will recommend focal areas and key components of a care management program designed to improve care and reduce avoidable costs associated with Alzheimer’s disease within the state.**
7. **Create a student loan forgiveness program for medical and nursing students who specialize in geriatrics and practice in the State of Arkansas.**
8. **Secure permanent funding for The Aging and Disability Resource Center (ADRC) Program to improve access to home and community based long-term care services and supports. Additionally, the ADRC will improve access to home and community based long-term care services and supports by providing a full-time staff person with expertise in Alzheimer’s disease and related dementias.**

## Study Priorities for Advisory Council on Alzheimer’s Disease in the 2011–2013 Biennium

The Task Force on the Effect of Alzheimer’s Disease in Arkansas would like to continue tackling the wide range of Alzheimer’s issues that the group has discussed while developing this state plan. Certain subject matter requires more study than the time frame of the Task Force allowed so recommendation is made that an Advisory Council on Alzheimer’s Disease be created to conduct further analysis that will include but is not limited to the items listed below. The Council will report annually to the Governor and General Assembly on the status of services, data and policy recommendations associated with Alzheimer's disease and related disorders.

1. Work with state and local service providers to develop a statewide public awareness campaign on Alzheimer’s disease and related dementias, increase visibility and awareness of available resources both statewide and locally, and reduce the stigma associated with dementia.
2. Promulgate a common definition of the characteristics of a dementia competent community that can be communicated and adopted by communities statewide.
3. Monitor ongoing implementation of the Silver Alert Program, as well as other technologies and procedures designed to track and assist persons with cognitive impairments.
4. Promote enhancement of training for first responders (law enforcement, fire, EMT, National Guard, NGOs) in identification and assistance of persons with dementia.
5. Assess projected statewide demand for a dementia-competent workforce equipped to support people with dementia and their families. Hold informational hearings on efforts to meet these training needs.
6. Explore potential long-term funding sources for future long term care services for persons with dementia, including enhanced Medicaid prioritization and dedicated state matching funds for Medicaid services for persons with dementia.
7. Research financially viable business models for Adult Day Care and Adult Day Health Care facilities.
8. Research creation of a Medical Advisory Board on Driving (similar to those found in surrounding states to ensure fair treatment of persons with Alzheimer’s disease or other cognitive impairment who need evaluation of their capacity to drive safely.



My level of consciousness about Alzheimer's disease was raised when my mother was diagnosed with dementia. Since then, I have made it my goal to learn all I possibly can about Alzheimer's. We know to engage Mother in exercises for the mind – things as simple as putting together puzzles, word games, reading the newspaper, magazines etc. This is also great fun for her grandchildren and great-grandchildren and a way for them to interact.

I serve as President of the Women's Missionary Society, 12th Episcopal District (comprising the states of Arkansas and Oklahoma) of the African Methodist Episcopal Church, and one of our platforms is Health Education. We were fortunate to have the Alzheimer's Association make a presentation this summer at our Christian Education Congress, held at the University of Arkansas Pine Bluff. The number of people affected by Alzheimer's is phenomenal! Right at the meeting I found that my mother was not the only one with Alzheimer's. Many of the women had family members suffering from Alzheimer's.

My greatest fear is knowing that one day Mother will not know who I am or may forget Dad. My parents have been married for 59 years and enjoy having dinner together every day, even though my Dad is a double amputee and lives in a care facility. He looks forward to Mother's daily visits as much as she looks forward to sharing that time with him.

With three siblings, we have accepted the challenge to take excellent care of our parents. My real debt of gratitude is to my two sisters and brother who bear the brunt of making sure the needs of our parents are met. I live an hour away, so I am unable to be active in the daily care of our parents, but they are always in my thoughts.

As siblings, we depend on our faith in God to keep us grounded and going! There are times we laugh at situations to keep from crying. We reminisce a lot on our lives as children growing up together and the things Mother and Dad would do in rearing us.

It is a joy to have Mother still in our lives, and no matter how debilitating the disease becomes we will always see the glass half-full instead of half-empty.

## Charolett Martin

Age 52  
*Caregiver for Mother  
with Alzheimer's*

**Little Rock, AR**



# 5



## Resource Guide

As a society we need to do a much better job of keeping pace with the stark realities of Alzheimer's, especially the reality of the besieged American woman who is raising our next generation while caring for our last.

– The Shriver Report

## Local Resources

### Alzheimer's Alliance Tri-State

*Their mission is to serve the needs of individuals and families affected by Alzheimer's disease and related disorders through family support, education, advocacy, and encouraging research.*

**1105 College Drive  
Texarkana, TX 75503  
903-223-8021 877-312-8536  
[www.alztexark.org](http://www.alztexark.org)**

### Alzheimer's Arkansas Programs and Services

*Their mission is to provide the information and support needed so that all Arkansans affected by Alzheimer's disease and related dementias are able to live with dignity and comfort until a cure is found.*

**10411 W. Markham, Suite 130  
Little Rock, AR 72205  
501-224-0021 800-689-6090  
[www.alzark.org](http://www.alzark.org)**

### Alzheimer's Association

*Their mission is to eliminate Alzheimer's disease through the advancement of research; to provide and enhance care and support for all affected; and to reduce the risk of dementia through the promotion of brain health.*

### Central Arkansas Regional Office

**1202 S. Main Street, Suite 215  
Little Rock, AR 72202  
501-265-0027 800-272-3900**

### Northwest Arkansas Regional Office

**210 N. Walton Boulevard, Suite 25  
Bentonville, AR 72712  
479-245-2081 800-272-3900**

### Western Arkansas Regional Office

**320 N. Greenwood Avenue  
Fort Smith, AR 72901  
479-783-2022 800-272-3900**

**[www.alz.org/alzokar](http://www.alz.org/alzokar)**

### Adult Protective Services/Adult Abuse Hotline

*They investigate and intervene in reports of abuse, neglect, and exploitation of adults who are physically or mentally impaired and unable to protect themselves from harm.*

**800-782-8049  
[www.aradultprotection.com](http://www.aradultprotection.com)**



### **Arkansas Advocates for Nursing Home Residents**

*They are dedicated to protecting and improving the quality of care and life for Arkansas residents in long term care facilities.*

**P. O. Box 22421  
Little Rock, Arkansas 72221  
501-450-9619  
www.aanhr.org**

### **Arkansas Department of Veterans Affairs**

*They assist individuals in obtaining the benefits earned through serving our country in times of war and peace.*

**2200 Fort Roots Drive  
North Little Rock, AR 72114  
501-370-3820  
www.veterans.arkansas.gov**

### **Arkansas Health Care Association**

*They provide training, education and assistance to care facilities across the state, promoting high-quality care for patients and strict professional standards for staff.*

**1401 W. Capitol, Suite 180  
Little Rock, AR 72201  
501-374-4422  
arhealthcare.com**

### **Arkansas Long-Term Care Ombudsman**

*Their mission is to assure that long term care facility residents have the right to live their lives harmoniously and with dignity, feeling free to voice complaints or concerns without reprisal.*

**501-682-2441  
www.arombudsman.com**

### **Choices in Living Resource Center**

*They are an Aging and Disability Resource Center (ADRC) that provides helpful information about long term services and supports in Arkansas.*

**700 Main Street  
Little Rock, Arkansas 72201  
866-801-3435  
www.daas.ar.gov**

### **Office of Long-Term Care Nursing Home Complaints**

*They conduct investigations of complaints in which abuse or neglect of residents, or misappropriation of resident property, is witnessed, suspected, or alleged in long-term care facilities.*

**1401 W. Capitol, Suite 180  
Little Rock, AR 72201  
501-374-4422 800-582-4887**

## **Area Agencies on Aging**

*Their mission is to assist older individuals in maintaining desired lifestyles through accessible and affordable alternatives.*

### **Area Agency on Aging of Northwest Arkansas**

1510 Rock Springs Road  
Harrison, AR 72601  
870-741-1144 800-432-9721  
[www.aaanwar.org](http://www.aaanwar.org)

### **Area Agency on Aging of Southeast Arkansas**

709 E. 8th Street  
Pine Bluff, AR 71601  
870-543-6300 800-264-3260  
[www.aaasea.org](http://www.aaasea.org)

### **Area Agency on Aging of Southwest Arkansas**

600 Columbia 11 East  
Magnolia, AR 71753  
870-234-7410 800-272-2127  
[www.agewithdignity.com](http://www.agewithdignity.com)

### **Area Aging on Aging of West Central Arkansas**

905 W. Grand Avenue  
Hot Springs, AR 71913  
501-321-2811 800-467-2170  
[www.seniorspecialists.org](http://www.seniorspecialists.org)

### **Area Agency on Aging of Western Arkansas**

524 Garrison Avenue  
Fort Smith, AR 72901  
479-783-4500 800-320-6667  
[www.agingwest.org](http://www.agingwest.org)

### **CareLink (Central Arkansas Area Agency on Aging)**

706 W. 4th Street  
North Little Rock, AR 72119  
501-372-5300 800-482-6359  
[www.care-link.org](http://www.care-link.org)

### **East Arkansas Area Agency on Aging**

2005 E. Highland/Fountain Square  
Jonesboro, AR 72401  
870-972-5980 800-467-3278  
[www.e4aonline.com](http://www.e4aonline.com)

### **White River Area Agency on Aging**

3998 Harrison Street  
Batesville, AR 72501  
870-612-3000 800-382-3205  
[www.wraaa.com](http://www.wraaa.com)

My grandmother was diagnosed with Alzheimer's disease in 2001 and passed away in 2004. Following her diagnosis my family moved from Houston, TX to Fayetteville, AR. I like to believe that my family and I moved to become caregivers, but we ended up better people. The life lessons learned the four years we took care of my grandmother are priceless. I would not be the person that I am today had we not gone through this family crisis; and Alzheimer's is a family crisis. To put it simply, I wouldn't trade one minute of the experience.

My family was incredibly lucky to come out on the other side with a positive attitude. We have made it our life's mission to reach as many caregivers as possible and help them with their journey. In spite of the life lessons gained along the way, those four years were far from easy. In all reality, they were warping, exhausting, and emotional; to say the least.

Some of the most emotionally-trying subject matter that we dealt with was our family relationships. When my family moved back, eventually moving in to grandparents' house, that made 5 of the 6 kids in one area. This may seem like it would make the caregiving process easier, but in many ways it made it worse. A lot of resentment was formed. As my grandmother moved further along in the disease she required 24 hour care, the job fell hard on my mother and my aunt. As a teenager living in the house I did not understand why other members of my family could not step in and help my mom out. I watched my mom slide in to a depression and throw up a wall that no one could get past. In her mind, she was protecting herself. She had a job to do and that was her way of getting through it.

We could not be a "normal" family and do "normal" things. My grandmother either had to go with us, or my mom was not able to attend. My mom was constantly having to choose. There were feelings of guilt for the rest of us for wanting my mom to be with us.

It was also difficult for me to bring friends over to my house. I was afraid that they wouldn't understand why my grandmother repeated the same question over and over, why our house wasn't neat and tidy like theirs, why more often than not, my mom was in her pj's with little time to get ready in the mornings.

I could go on and on with the trials that families face. Each family is unique, but many feelings are the same throughout this state and country. Alzheimer's truly is a family crisis. Without increasing awareness and education, families will continue to go through this journey unprepared.

## Molly Arnold

Age 23

*Cared for Grandmother  
with Alzheimer's*

**Fayetteville, AR**



# 6



## Appendices

I'm confident that we will prevail against Alzheimer's. It's not a matter of "if," it's a matter of "when."

—Maria Shriver

# Appendix A: Act 92 of 2009

Stricken language would be deleted from and underlined language would be added to the law as it existed prior to this session of the General Assembly.

1 State of Arkansas

*As Engrossed: H1/16/09*

2 87th General Assembly

## A Bill

3 Regular Session, 2009

HOUSE BILL 1014

4

5 By: Representatives D. Creekmore, Allen, M. Burris, B. Wilkins, Breedlove, Gaskill, D. Hutchinson,

6 Moore, Powers, Reep, J. Roebuck, Saunders, Stewart, *Adcock, Cole, Dunn, Garner, R. Green, Kerr,*

7 *Lovell, Nickels, Nix, Overbey, Pennartz, Pyle, L. Smith*

8 By: Senators Horn, Broadway, Faris, P. Malone, T. Smith, *Teague*

9

10

11

### For An Act To Be Entitled

12

AN ACT TO ESTABLISH THE TASK FORCE ON THE EFFECT

13

OF ALZHEIMER'S DISEASE IN ARKANSAS; AND FOR OTHER

14

PURPOSES.

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### Subtitle

17

AN ACT TO ESTABLISH THE TASK FORCE ON

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THE EFFECT OF ALZHEIMER'S DISEASE IN

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ARKANSAS.

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

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24 SECTION 1. Findings.

25 The General Assembly finds that:

26 (1) Alzheimer's disease is a progressive and fatal brain disease

27 that destroys brain cells and causes problems with memory, thinking, and

28 behavior;

29 (2) More than five million (5,000,000) Americans now have

30 Alzheimer's disease;

31 (3) Alzheimer's disease is the most common form of dementia and

32 is the sixth leading cause of death in the United States; and

33 (4) No cure exists for Alzheimer's disease, but treatments for

34 symptoms used in conjunction with appropriate services and support can

35 improve the quality of life for those living with the disease.

36

1           SECTION 2. Task Force on the Effect of Alzheimer's Disease in Arkansas  
2 -- Created -- Membership.

3           (a) There is created the Task Force on the Effect of Alzheimer's  
4 Disease in Arkansas to consist of *seventeen (17)* members as follows:

5                   (1) Four (4) members appointed by the Speaker of the House of  
6 Representatives as follows:

7                           (A) One (1) member of the House of Representatives;

8                           (B) One (1) member who has been diagnosed with Alzheimer's  
9 disease;

10                          (C) One (1) member to represent the health care provider  
11 community; and

12                          (D) One (1) member to represent the adult day services  
13 industry;

14                   (2) Four (4) members appointed by the President Pro Tempore of  
15 the Senate as follows:

16                           (A) One (1) member of the Senate;

17                           (B) One (1) member who is a paid caregiver of a person  
18 with Alzheimer's disease;

19                          (C) One (1) member to represent the assisted living  
20 industry; and

21                          (D) One (1) member who is a scientist who specializes in  
22 Alzheimer's research;

23                   (3) Four (4) members appointed by the Governor as follows:

24                           (A) One (1) member who is a family member of a person  
25 living with Alzheimer's disease or other form of dementia;

26                           (B) One (1) member to represent the nursing facility  
27 industry;

28                          (C) One (1) member who is a person active in the state  
29 chapter of the Alzheimer's Association; and

30                          (D) One (1) member who is a person active in the state  
31 chapter of Alzheimer's Arkansas Programs and Services; and

32                   (4) Five (5) members as follows:

33                           (A) The Director of the Department of Health or his or her  
34 designee;

35                           (B) The Director of the Department of Human Services or  
36 his or her designee;

1                   (C) The Director of the Division of Behavioral Health of  
2 the Department of Human Services or his or her designee;

3                   (D) The Director of the Arkansas Center for Health  
4 Improvement or his or her designee; and

5                   (E) The Director of the Department of Workforce Services  
6 or his or her designee.

7           (b) The members of the task force shall be appointed by June 30, 2009.

8           (c)(1) Members of the task force shall serve at the pleasure of their  
9 appointing authorities.

10           (2) A vacancy on the task force shall be filled by the original  
11 appointing authority.

12           (d)(1) The Speaker of the House of Representatives and the President  
13 Pro Tempore of the Senate shall each designate a co-chair from among the  
14 members of the task force.

15           (2) The cochairs shall jointly call the first meeting of the  
16 task force.

17           (e) A majority vote of the members present is required for any action  
18 of the task force.

19           (f) Task force meetings shall be held in Pulaski County, Arkansas, and  
20 at other locations in the state as the task force shall deem necessary.

21           (g) The Bureau of Legislative Research shall provide staff support to  
22 the task force as necessary to assist the task force in the performance of  
23 its duties.

24           (h) Legislative members of the task force shall be reimbursed for  
25 expenses and per diem at the same rate and from the same source as provided  
26 by law for members of the General Assembly attending meetings of the interim  
27 committees.

28  
29           SECTION 3. Duties.

30           (a) The Task Force on the Effect of Alzheimer's Disease in Arkansas  
31 shall:

32                   (1) Assess the current and future impact of Alzheimer's disease  
33 and other types of dementia on the residents of the State of Arkansas;

34                   (2) Examine the existing industries, services, and resources  
35 addressing the needs of persons living with Alzheimer's disease, their  
36 families, and caregivers; and

1           (3) Develop a strategy to mobilize a state response to the  
2 public health crisis created by Alzheimer's disease and other types of  
3 dementia.

4           (b) The task force shall include the following in its assessments and  
5 recommendations:

6           (1) Statewide trends in the number of persons living with  
7 Alzheimer's disease and other forms of dementia and the needs of those  
8 persons;

9           (2) The state's role in providing long-term care, family  
10 caregiver support, and other forms of assistance to persons with early-stage  
11 and younger onset of Alzheimer's disease;

12           (3) State policy regarding persons with Alzheimer's disease and  
13 developmental disabilities;

14           (4) Existing services, resources, and capacity, including  
15 without limitation:

16                   (A) The type, cost, and availability of dementia services;

17                   (B) The dementia-specific training requirements for long-  
18 term care staff;

19                   (C) Quality care measures for residential care facilities;

20                   (D) The capacity of public safety and law enforcement  
21 agencies to respond to persons with Alzheimer's disease;

22                   (E) The availability of home-based and community-based  
23 resources for persons with Alzheimer's disease, including the availability of  
24 respite care for families;

25                   (F) An inventory of long-term care dementia care units;

26                   (G) The adequacy and appropriateness of geriatric-  
27 psychiatric units for persons with behavioral disorders associated with  
28 Alzheimer's and related dementia;

29                   (H) The assisted living residential options for persons  
30 with dementia; and

31                   (I) State support for Alzheimer's research; and

32           (5) Needed state policies or responses, including without  
33 limitation:

34                   (A) Directions for the provision of clear and coordinated  
35 services and supports for persons and families living with Alzheimer's and  
36 related disorders; and



1                   (B) Strategies for addressing identified gaps in services.

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SECTION 4. Reports.

(a) The Task Force on the Effect of Alzheimer’s Disease in Arkansas shall present a draft of assessments and recommendations for meeting the Alzheimer’s disease needs in the State of Arkansas to the House and Senate Interim Committees on Public Health, Welfare, and Labor on or before October 25, 2010.

(b) The task force shall issue a final report of its assessments and recommendations for meeting the Alzheimer’s disease needs in the State of Arkansas to the House and Senate Interim Committees on Public Health, Welfare, and Labor and the Governor on or before January 15, 2011.

SECTION 5. The Task Force on the Effect of Alzheimer’s Disease in Arkansas shall expire on January 15, 2011.

*/s/ D. Creekmore*

## Appendix B: Memorandum of Understanding - Silver Alert



### **MEMORANDUM OF UNDERSTANDING**

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### ***ARKANSAS SILVER ALERT***

The Arkansas State Police through this mutual agreement with the Arkansas Sheriffs' Association and Arkansas Association of Chiefs of Police will host an Internet web site that will provide Arkansas broadcasters and news organizations a means to receive Arkansas Silver Alerts.

The Arkansas State Police will provide to each sheriff's office and police department a uniform questionnaire which will be used to populate an electronic mail template.

Upon declaring a Silver Alert, the template will be electronically returned to the Arkansas State Police, Highway Patrol Division, Troop A Communications Center and re-distributed to all subscribing news organizations and citizens at large.

A Silver Alert may be activated at the request of a local sheriff or police chief based on confirmed law enforcement reports of missing persons who have been adjudicated by a court to be incapable of managing his or her own personal affairs, such as through a guardianship proceeding; or has a documented diagnosis of a mental illness, injury or condition that causes the individual to be incapable of making personal care decisions; or in cases where a caregiver or family member

strongly suspects that the person believed to be missing is afflicted with some form of dementia.

The individual who is eligible to request an alert must be a legal guardian, an immediate family member living in the same household, or a caregiver and has had recent contact with the individual who may become the subject of the alert.

Upon confirmation by the chief law enforcement officer of a sheriff or police department or their designee, the Arkansas State Police Silver Alert questionnaire may be transmitted to the department's Troop A Communications Center along with a photograph of the person identified as the missing person.

The Arkansas State Police will electronically forward the information and photograph to a web based distribution list to include Arkansas broadcast stations and newsrooms who subscribe to the alert notification system. All inquiries from the news media and public at large regarding the missing person will be directed to the originating law enforcement agency.

Any local law enforcement jurisdiction which activates a Silver Alert is responsible for immediately notifying the Arkansas State Police, Highway Patrol Troop A Communication Center upon locating the individual reported as missing at which time the state police will recall the alert.

The Arkansas State Police agrees to provide support personnel and equipment as available to the sheriff or police chief during the course of any search associated with an Arkansas Silver Alert.

The Arkansas Sheriffs' Association agrees to provide to local jurisdictions the applicable training with regard to law enforcement interaction with individuals afflicted with Alzheimer's disease or other cognitive disorders and operating protocols for activation of Silver Alerts.

Any party to this memorandum of understating may withdraw by providing a 60 day notice of intent.

## Appendix C: Acknowledgements

*Special acknowledgement to individuals and groups that gave of their time and talent to this project:*

Molly Arnold

Christian Baldwin

Governor Mike Beebe

Laura Boone

Rosanne Boyd, Chenal Heights Assisted Living

Coach Frank Broyles

Dr. Sheila Cassidy, UAMS Reynolds Institute on Aging

Mark Fried, President & CEO, Oklahoma & Arkansas Chapter of the Alzheimer's Association

Tommy Glanton, Regional Director, Oklahoma & Arkansas Chapter of the Alzheimer's Association

Christine Heider

Harry Johns, President and CEO, Alzheimer's Association

Charolett Martin

Sergeant Tim Phillips and the Baxter County Sheriff's Department

John Ponthie, Summit Health Resources

Patrick Ralston Photography

Kristen Sharp

Dr. Denise Compton Sparks, UAMS Reynolds Institute on Aging

Mike Splaine

Sheri Thomas

## Appendix D: End Notes

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17. *2001-2008 Arkansas Death Certificate Data, ICD10 code G30-G30.9. Analysis by Arkansas Center for Health Improvement - Health Data Initiative, in accordance with the provisions of Arkansas Legislative Act 1035.*



Like a lot of people in Arkansas my introduction to Alzheimer's disease was when it first affected my family. Early in the 1980's my father-in-law was diagnosed at the age of 72. We watched as he lost ground rather quickly until he died at the age of 77.

At the time little was thought about other family members developing Alzheimer's and life pretty much was back to normal. We thought like so many today that this would happen to only old folks.

Fast forward to 1999, my mother-in-law was also diagnosed. Again she was 82 so still I considered it an old folks disease. Two years later my wife at the age of 56 was informed that she also had the disease that had claimed the life of her father and had such a grip on her mother. It was then that I knew how much of a monster we were dealing with.

It has nothing to do with age, this disease can kill at any age. It robbed my family of the love of a mother, wife, grandmother. It puts unbelievable stress on all family members. It is a fatal disease but death comes slowly, robbing the victim and often times the family of everything in life that is normal.

This is a tremendous challenge to Arkansas and the world as we go forward. We must begin now as we can not kick this can down the road. Many families now need our help, but that number will double in a very short time. We must pull together to fight this terrible disease. It will take us all.

## Butch Wilkins

Age 64  
*Caregiver for Wife  
with Alzheimer's*

**Jonesboro, AR**

