

**The Final Report of the
Task Force on the Effect of
Alzheimer's Disease
in Oklahoma**

Presented to
Governor Brad Henry and the
Oklahoma State Legislature

September 1, 2009



Oklahoma State Legislature

2300 N. Lincoln Boulevard
Oklahoma City, OK 73105

September 1, 2009

Dear Fellow Oklahoma Citizens and Leaders:

In 2008, we began the work of assessing the impact of Alzheimer's disease in Oklahoma and developing a strategy to respond to this growing public health crisis. Why should we care? First and most importantly, it is our responsibility and our duty to care for those who are unable to care for themselves. On a practical level, it is our responsibility as stewards of the taxpayers' dollars to address the increasing costs associated with Alzheimer's disease on the state budget.

By 2010, 74,000 Oklahomans will have Alzheimer's disease and this number is expected to increase to 96,000 by 2025, reflecting a 30 percent increase. The costs of care for these families can be enormous and many must turn to the state Medicaid program for assistance. Fifty-one percent of nursing home residents with Alzheimer's disease and other dementias rely on Medicaid to help pay for their care. An additional 18 percent of those with Alzheimer's disease that live in the community rely on Medicaid to supplement their cost of care. In short, Alzheimer's disease is the public health threat of the 21st Century.

The average Medicaid payment for a person with Alzheimer's disease over age 65 is more than nine times higher than that for a person without Alzheimer's disease in the same age group, and this is expected to grow enormously in the coming years. As a result, the treatment of Alzheimer's disease in Oklahoma is costing our state millions of dollars in Medicaid expenditures each year.

As the number of people in need of care for Alzheimer's disease increases, the state is left with financing the rising costs of care. Much like the pending Social Security and Medicare crises at the federal level, long term care and Medicaid is the coming crisis for the state of Oklahoma. State policymakers must influence options in our long term care system to mitigate the rapidly escalating costs. In doing so, we must also enact policies that preserve the quality of life for those suffering from this disease.

We urge all Oklahomans to review the recommendations proposed by the Task Force on the Effect of Alzheimer's Disease in Oklahoma and to join us in addressing the difficult issues surrounding the disease. We are counting on you to help us make a difference.

Sincerely,

A handwritten signature in black ink, appearing to read "Tom Ivester".

Senator Tom Ivester
Co-Chair, Task Force on the Effect of
Alzheimer's disease in Oklahoma

A handwritten signature in black ink, appearing to read "David Dank".

Representative David Dank
Co-Chair, Task Force on the Effect of
Alzheimer's Disease in Oklahoma

Table of Contents

Introduction to the Task Force	
Letter from the Co-Chairs	3
About the Task Force and Membership	5
Preface	8
Executive Summary	9
Overview of Alzheimer’s Disease	
What is Alzheimer’s Disease	13
Types and Causes of Dementia	13
Symptoms of Alzheimer’s Disease	14
Risk Factors for Alzheimer’s Disease	15
Prevention and Treatment	15
Prevalence of Alzheimer’s Disease and other Dementias	16
Oklahoma: A Current and Future Look	
Costs of Care	20
Family Caregivers	18
Professional Caregivers	21
Economic Value of Unpaid Caregiving	22
Future Outlook	23
Task Force Assessment and Recommendations	
Caregivers and Case Management	26
Education and Training	27
Service Enhancement and Delivery	30
State Government	33
Issues for Further Study	34
Appendices	
Appendix A: Senate Bill 2186	37
Appendix B: Subcommittee Membership	41
Appendix C: Acknowledgements	42
Appendix D: References	43

The Task Force

The Task Force on the Effect of Alzheimer’s Disease in Oklahoma was established with the passage of Senate Bill 2186 (attached as Appendix A). Signed by Governor Brad Henry on May 2, 2008, the legislation called for the task force to examine the overall impact that Alzheimer’s disease and related dementias is having on both the citizens of the state of Oklahoma and state government.

Senate Bill 2186 determined that the task force should “assess the current and future impact of Alzheimer’s disease and related disorders on the residents of the state; examine the existing industries, services, and resources addressing the needs of persons with Alzheimer’s disease or related disorders, their families and their caregivers; and develop a strategy to mobilize a state response to this public health crisis.”

The legislation also determined the entities and individuals that would make up the membership of the task force. Membership was to be made up of nine representatives of private sector industries, non-profit organizations, individuals with Alzheimer’s disease, caregivers; two legislators; and five state agency directors or designees. Members were appointed to serve a 21-month term beginning September 1, 2008 through June 1, 2010.

“Persons with dementia are among the most vulnerable segments of our society. Human decency requires that, as a state, we serve them well and do all within our means to secure for them the best quality of life possible, despite the limitations of dementia” (Michigan Dementia Coalition, 2003).

The formal work of the task force began on December 10, 2008 at which time the task force reviewed the group’s mission and goals, established operational protocols, and formed four subcommittees – Education and Training, Caregiver Assistance and Case Management, Long-term Care and Funding, and Services and Data Collection. Over the course of one year, the task force held monthly meetings and countless subcommittee meetings refining and finalizing the language of the recommendations contained in this final report.

The **mission** of this Task Force on the Effect of Alzheimer’s Disease in Oklahoma is to **improve the lives of Oklahomans affected by Alzheimer’s disease.**

It is the goal of the Task Force: to **educate Oklahomans** about Alzheimer’s disease; to **ensure quality care** based on best practices; to **promote standards of care** for healthcare professionals and caregivers; to **identify and promote support services** available to all affected; and to **create a formal system for recording statistics** pertaining to the number of Oklahomans impacted.

Task Force Members

Senator Tom Ivester
Senate District
Oklahoma State Senate
Co-Chair

Floyd Autin
Administrator
Health Centers at Montereau
House Appointee

Dr. Ron Grant
Younger-onset Alzheimer's Disease
House Appointee

Lisa Pever
Administrator of Assisted Living
Epworth Villa
Senate Appointee

Mark Fried
Executive Vice President
Alzheimer's Association
Oklahoma and Arkansas Chapter
Governor Appointee

Mary Brinkley
Executive Director
Oklahoma Association of Homes and
Services for the Aging
Governor Appointee

Mich Magness
Coordinator of Aging and Long-term Care
Oklahoma Department of Mental Health
and Substance Abuse Services
*Department of Mental Health and
Substance Abuse Designee*

Representative David Dank
House District
Oklahoma House of Representatives
Co-Chair

Bill Major
Executive Director
LIFE Senior Services
House Appointee

Vicki Escajeda
Therapist/Case Manager
Deaconess Senior Diagnostic Center
Senate Appointee

Dr. Chandini Sharma
Assistant Professor and Director Geriatrics
Clerkship, Department of Internal Medicine
OU-Tulsa School of Community Medicine
Senate Appointee

Rev. Linda Brinkworth
Pastor of Care Ministry
St. Luke's United Methodist Church
Governor Appointee

Amy Carte, RN
Manager
Heart Disease and Stroke Prevention
Program, Department of Health
State Department of Health Designee

Melanie Johnston
Psychiatric/MR Analyst
Oklahoma Health Care Authority
Health Care Authority Designee

David Slimp
Program Manager
Oklahoma Employment Security Commission
Employment Security Commission Designee

Lance Robertson
Division Director, Aging Services Division
Oklahoma Department of Human Services
Department of Human Services Designee

Jennifer Case
Policy and Planning Program Supervisor
Aging Services Division
Oklahoma Department of Human Services
Department of Human Services Staff Liaison

Preface

The Task Force on the Effect of Alzheimer’s disease in Oklahoma was charged with the challenging task of mapping out a plan of action in Oklahoma for the individuals and caregivers of Alzheimer’s disease and other dementias. With the ever-increasing frequency of diagnosis and the spectrum of ages affected, the task was not one that was easily approached or resolved.

I wanted to serve on the task force to try to bring my unique perspective to the table. Diagnosed with younger-onset Alzheimer’s at age fifty-five, I represent a somewhat new face of this disease. I am not yet a “senior”; however, my memory is being robbed of recent events and abilities that I have for so long taken for granted. Eventually, this disease will completely take my past and finally my future. The devastation this process causes, leading to early death, takes an unbelievable toll on spouses, families, and other caregivers. Very little of what is accomplished by this task force will directly help me, but I can be a voice for others with this disease and for those that will be affected by it.

After months of diligent work, the task force has set forth a plan of action for the state of Oklahoma. The members represent a very wide range of skills, expertise, and professions. Each member took their appointment to this task force very seriously and as a result, a roadmap has been developed to help the state of Oklahoma address this crisis.

It has been an honor to be a part of this effort and I implore those that have the power and authority to act upon these recommendations to “Please do so now!” You have the ability to dramatically change the course and quality of life for Oklahomans that will have to face the horrors of any form of dementia.

Most Sincerely,

A handwritten signature in black ink, appearing to read "Ron Grant". The signature is fluid and cursive, with a large initial "R" and "G".

Ron Grant
Task Force Member

Executive Summary

On April 29, 2008, Governor Brad Henry signed into law Senate Bill 2186 establishing the Task Force on the Effect of Alzheimer's disease in Oklahoma to "assess the current and future impact of Alzheimer's disease; examine the existing industries, services and resources addressing the needs of persons living with Alzheimer's disease, their families and caregivers; and to develop a strategy to mobilize a state response to this public health crisis."

The task force studied the current infrastructure in the state and reviewed services available to those with Alzheimer's disease and their caregivers. Based on these findings, the task force brought forth recommendations to fill gaps in services and address the needs of the growing number of those diagnosed with the disease and the unique challenges it presents.

According to the Alzheimer's Association's *2009 Facts and Figures* report, more than 5 million people are currently living with Alzheimer's disease in the United States. In Oklahoma, there were an estimated 62,000 people living with Alzheimer's disease as of the year 2000 and this number is estimated to grow to 74,000 Oklahomans by 2010, an increase of 19 percent.¹ There is currently no cure for Alzheimer's disease.

With life expectancy in the United States increasing and "baby-boomers" reaching retirement age, the prevalence of Alzheimer's disease and other dementias will increase exponentially beyond age 65. The number of people affected by Alzheimer's disease, the most prevalent form of dementia, is growing at a faster rate than the progress being made in discovering the means to cope with this emerging epidemic. According to the Centers for Disease Control and Prevention, Alzheimer's deaths have grown 47 percent since 2000, while most other terminal diseases have seen a decrease in percentage of deaths.

The approaching crisis in the national health care system stems not only from the growing number of older people at risk for dementia, but also the rising cost of labor intensive care. Neither the general public nor its policy makers appreciates the magnitude of the pending public health disaster. Alzheimer's disease currently costs the United State government nearly \$148 billion a year. The average annual cost of care per person is estimated to be between \$40,000 to \$60,000, with nearly 500,000 new patients every year.²

The statistics indicate that by the year 2050, the United States will have more than 16 million individuals, up from five million today, affected by Alzheimer's disease and requiring medical care and institutionalization.³ The patterns of growth in the aging population are going to profoundly affect how care is provided for people with Alzheimer's disease.

These patterns will reach their full impact as the "baby-boom" generation ages into late life 20 to 30 years from now. These trends, which foretell the devastating toll of dementia, have already begun to shape the future strategic plans of many public and private organizations.

Almost 10 million Americans provide unpaid care for a person with Alzheimer's disease or related dementias. In 2008 alone, caregivers provided 8.5 billion hours of unpaid care, a

contribution valued at \$94 billion. In Oklahoma, it is estimated that there are currently 113,475 caregivers providing 97,951,999 hours of unpaid care to a loved one with Alzheimer's disease. The market value of unpaid care in Oklahoma alone is \$1,087,267,190.⁴

One study of family and other unpaid caregivers of people with Alzheimer's and related dementias found that 57 percent were employed full-time or part-time. Of those employed caregivers, two-thirds said they had to go in late, leave early or take time off because of caregiving. Eight percent had to quit work entirely.⁵

While there are a number of services available to those with Alzheimer's disease and related dementias in Oklahoma, there are still significant steps to be taken to provide adequate and dignified care. It is estimated that 70 percent of people with Alzheimer's disease live at home, where care is generally paid for out-of-pocket by their families, presenting a unique set of challenges to this population.⁶ While there are existing resources in the state, often caregivers are overwhelmed and unable to identify or search for these services and many programs face gaps in service, often due to funding issues.

It is worth noting that remarkable progress has been made in the last 30 years in understanding Alzheimer's disease. Today the field has access to a rich array of talents, tools, ideas, knowledge, and experiences from diverse disciplines, providing unique opportunities for quantum leaps in uncovering cause(s), treatments, and new models of care. New discoveries and leads have begun to provide some measure of hope for interventions that could delay the onset of disabling symptoms and enable individuals to continue functioning independently for longer periods of time.

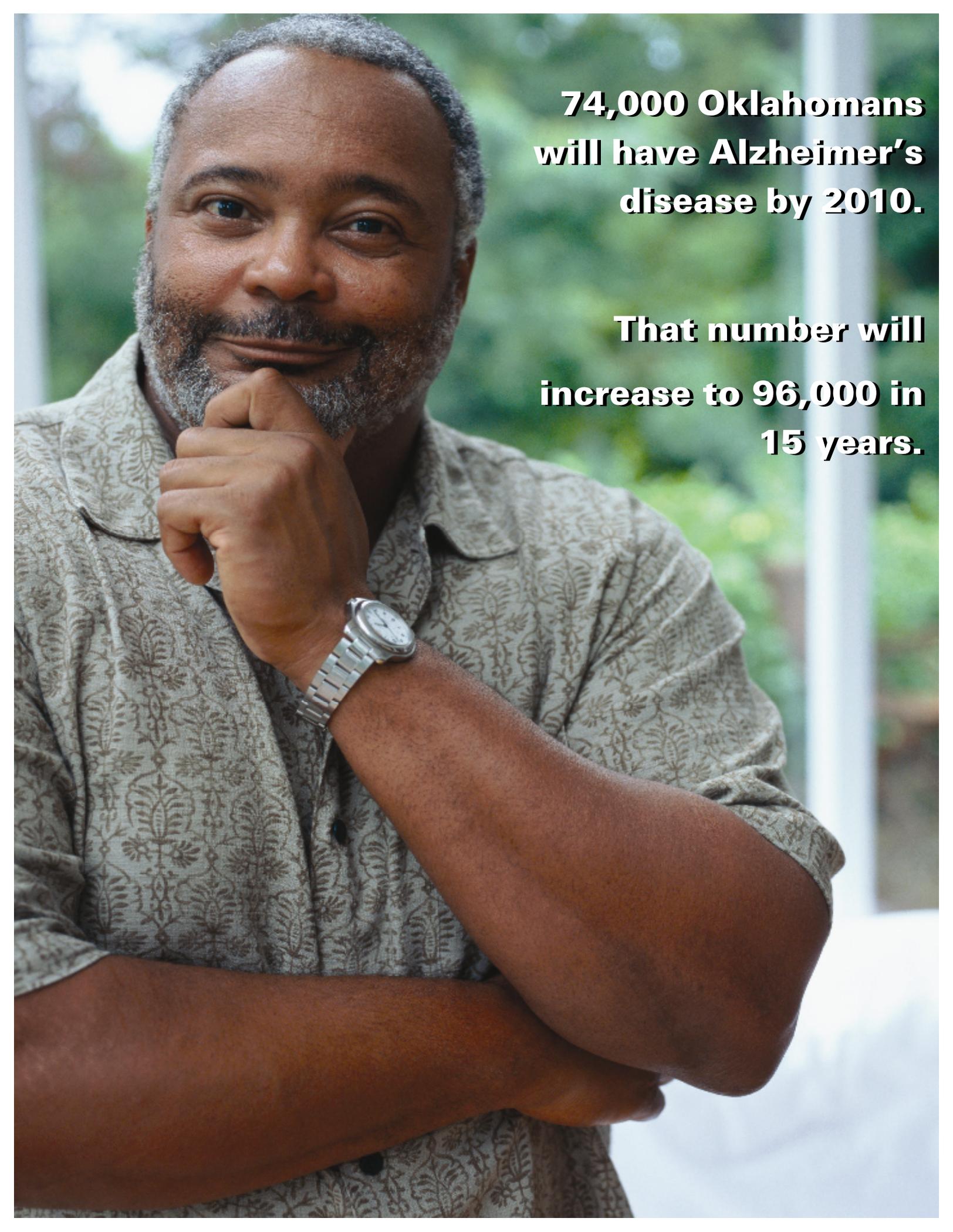
It is with this in mind, that the Task Force on the Effect of Alzheimer's disease in Oklahoma has generated twenty-three recommendations addressing three main areas: promoting and improving standards of care; identifying and promoting support services; and, creating a formal system for recording statistics. The complete list of recommendations include the following:

- **Establish and fund a statewide information and referral system for those with Alzheimer's disease, their caregivers and their families to connect with local case management, support services and information.**
- **Medical and direct care staff at any nursing home, assisted living facility, adult day center, skilled nursing facility, home health agency or hospice agency that is licensed by the state or receiving state funding should be required by law to complete four hours of in-service training per year in Alzheimer's and dementia related care.**
- **Create culturally competent public service announcements to raise the level of public education about brain health and the warning signs of Alzheimer's and dementia, some of which should specifically target populations with disproportionately higher rates of these diseases.**

- **Revise Disclosure Form 613 with the Oklahoma Department of Health to include specific information that qualifies the facility as a specialized care facility. Facilities should not be allowed to advertise an Alzheimer’s unit until the disclosure form has been approved designating their unit as such. The form must specify minimum standards a facility must maintain to be designated as an Alzheimer’s care unit.**
- **Require that the diagnosis of Alzheimer’s disease and related dementias be made an essential competency in state medical schools by 2012, while also providing incentives to physicians to complete dementia-specific modules in the re-licensing process (every 3 years).**
- **Create a student loan forgiveness program for medical school students who specialize in geriatrics and practice in the state of Oklahoma.**
- **Dedicate a funding source for all future long-term care services.**
- **Increase the daily reimbursement rate for funding for Adult Day Center services, as well as increase the number of locations across the state.**
- **Provide enhanced funding to compensate facilities that expend dollars for staff education related to Alzheimer’s care.**
- **Implement an automatic reminder on Electronic Medical Records requiring physicians’ offices to provide referral of diagnosed patients to the Alzheimer’s Association upon diagnosis of Alzheimer’s disease or related dementias.**

In addition, due to the complex nature of these issues, the Task Force recommends that the Governor appoint a Cabinet-level Secretary of Aging and the Legislature form a single committee in both the Senate and House of Representatives to handle all aging-specific legislation.

Full details on the rationale and parties responsible for implementation of these recommendations are available on page 26.



**74,000 Oklahomans
will have Alzheimer's
disease by 2010.**

**That number will
increase to 96,000 in
15 years.**

Overview of Alzheimer's Disease

What is Alzheimer's disease?

In Alzheimer's disease, as well as in other types of dementia, nerve cells deteriorate and die. A healthy adult brain has about 100 billion nerve cells, or neurons, with long branching extensions connected at 100 trillion points. At these connections, called synapses, information flows in tiny chemical pulses released by one neuron and taken up by the receiving cell. Different strengths and patterns of signals move constantly through the brain's circuits, creating the cellular basis of memories, thoughts and skills. In Alzheimer's disease, information transfer at the synapses begins to fail, the number of synapses declines and eventually cells die. Brains with advanced Alzheimer's show dramatic shrinkage from cell loss and widespread debris from dead and dying neurons.⁷

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. Vascular dementia accounts for 17 percent of cases of dementia, and other diseases and conditions, including Parkinson's disease, Lewy body disease, frontotemporal dementia and normal pressure hydrocephalus, account for the remaining 13 percent.

Type of Dementia	Characteristics
Alzheimer's disease	<p>Most common type of dementia; accounts for 60 to 80 percent of cases.</p> <p>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 trouble speaking, swallowing and walking.</p> <p>Hallmark abnormalities are deposits of the protein fragment beta-amyloid (plaques) and twisted strands of the protein tau (tangles).</p>
Vascular dementia (also known as multi-infarct or post-stroke dementia or vascular cognitive impairment)	<p>Considered the second most common type of dementia.</p> <p>Impairment is caused by decreased blood flow to parts of the brain, often due to a series of small strokes that block arteries.</p> <p>Symptoms often overlap with those of Alzheimer's, although memory may not be as seriously affected.</p>
Mixed dementia	<p>Characterized by the presence of 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.</p>

Type of Dementia	Characteristics
Dementia with Lewy bodies	<p>Pattern of decline may be similar to Alzheimer's, including problems with memory and judgment and behavior changes.</p> <p>Alertness and severity of cognitive symptoms may fluctuate daily.</p> <p>Visual hallucinations, muscle rigidity and tremors are common.</p> <p>Hallmarks include Lewy bodies (abnormal deposits of the protein alpha-synuclein) that form inside nerve cells in the brain.</p>
Parkinson's disease	<p>Many people who have Parkinson's disease develop dementia in the later stages of the disease.</p> <p>The hallmark abnormality is Lewy bodies (abnormal deposits of the protein alpha-synuclein) that form inside nerve cells in the brain.</p>
Frontotemporal dementia	<p>Involves damage to brain cells, especially in the front and side regions of the brain.</p> <p>Typical symptoms include changes in personality and behavior and difficulty with language.</p> <p>No distinguishing microscopic abnormality is linked to all cases.</p> <p>Pick's disease, characterized by Pick's bodies, is one type of frontotemporal dementia.</p>
Creutzfeldt-Jakob disease	<p>Rapidly fatal disorder that impairs memory and coordination and causes behavior changes.</p> <p>Variant Creutzfeldt-Jakob disease is believed to be caused by consumption of products from cattle affected by mad cow disease.</p> <p>Caused by the misfolding of prion protein throughout the brain.</p>
Normal pressure hydrocephalus	<p>Caused by the buildup of fluid in the brain.</p> <p>Symptoms include difficulty walking, memory loss and inability to control urine.</p> <p>Can sometimes be corrected with surgical installation of a shunt in the brain to drain excess fluid.</p>

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 71–79.⁸

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 5 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 30.⁹

Symptoms of Alzheimer's disease

Alzheimer's disease can affect different people in different ways, but the most common symptom pattern begins with gradually worsening difficulty in remembering new information. This is because disruption of brain cells usually begins in regions involved in forming new

memories. As damage spreads, individuals also experience confusion, disorganized thinking, impaired judgment, trouble expressing themselves and disorientation to time, space and location, which may lead to unsafe wandering and socially inappropriate behavior. In advanced Alzheimer's disease, people need help with bathing, dressing, using the bathroom, eating and other daily activities. Those in the final stages of the disease lose their ability to communicate, fail to recognize loved ones and become bed-bound and reliant on constant care. Alzheimer's disease is ultimately fatal.¹⁰

Risk Factors for Alzheimer's disease

Although the cause or causes of Alzheimer's disease are not yet known, most experts agree that Alzheimer's, like other common chronic conditions, probably develops as a result of multiple factors rather than a single cause. While Alzheimer's is definitely not a normal aspect of the aging process, the greatest risk factor for Alzheimer's disease is advancing age. Most Americans with Alzheimer's disease are aged 65 or older, although individuals younger than age 65 can also develop the disease. A genetic factor in late-onset Alzheimer's disease (Alzheimer's disease developing at age 65 or older) is apolipoprotein E-e4 (APOE-e4). APOE-e4 is one of three common forms of the APOE gene, which provides the blueprint for a protein that carries cholesterol in the bloodstream. Everyone inherits one form of the APOE gene from each of his or her parents. Those who inherit one APOE-e4 gene have increased risk of developing Alzheimer's disease. Those who inherit two APOE-e4 genes have an even higher risk. However, inheriting one or two copies of the gene does not guarantee that the individual will develop Alzheimer's.¹¹

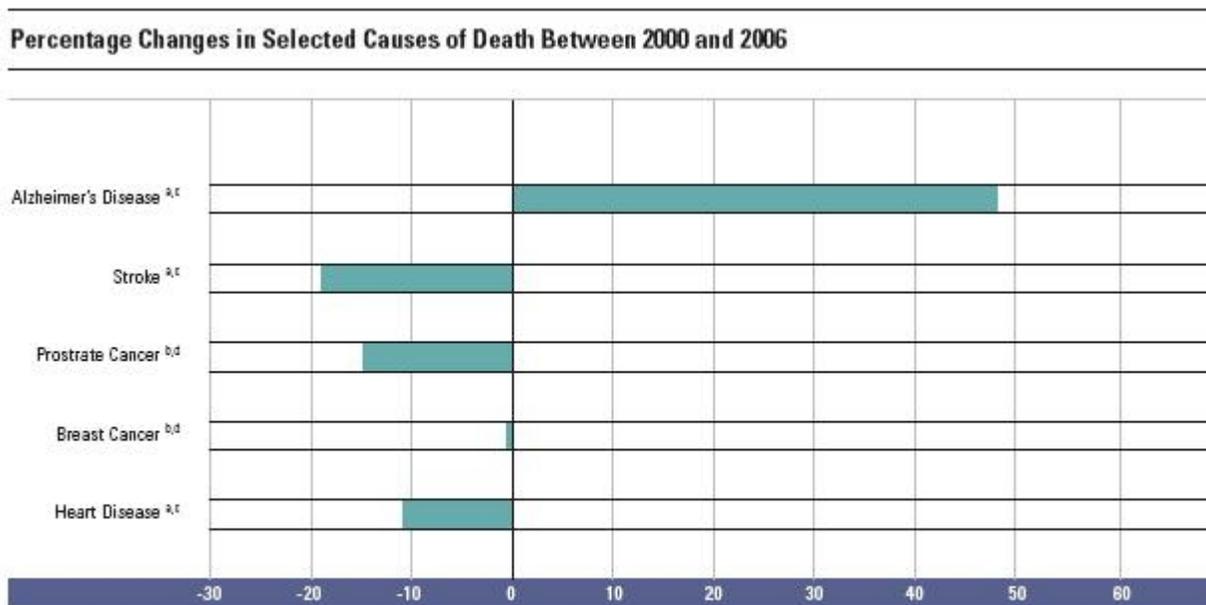
Prevention and Treatment of Alzheimer's Disease

No treatment is available to slow or stop the deterioration of brain cells in Alzheimer's disease. The U.S. Food and Drug Administration has approved five drugs that temporarily slow the progression of symptoms for about six to 12 months, on average, for about half of the individuals who take them. Based on deepening insight into the underlying biology of Alzheimer's and emerging conceptual frameworks for understanding the disease, researchers have identified treatment strategies that may have the potential to change its course. A number of experimental therapies are in clinical testing in human volunteers. Despite the current lack of disease-modifying therapies, studies have consistently shown that active medical management of Alzheimer's and other dementias can significantly improve quality of life through all stages of the disease for diagnosed individuals and their caregivers. Active management includes appropriate use of available treatment options, effective integration of coexisting conditions into the treatment plan, and use of supportive services such as counseling, activity and support groups and adult day center programs. Scientists consider the emerging field of prevention among the most exciting recent developments in the dementia research arena.¹²

Prevalence of Alzheimer’s disease and Other Dementias

Currently, an estimated 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.¹³

With life expectancy in the United States increasing and “baby-boomers” reaching retirement age, the prevalence of dementia will increase exponentially beyond age 65. The number of people affected by Alzheimer’s disease, the most prevalent form of dementia, is growing at a faster rate than the progress being made in discovering the means to cope with this emerging epidemic. According to the Centers for Disease Control and Prevention, Alzheimer’s deaths have grown 47 percent since 2000, while most other terminal diseases have seen a decrease in percentage of deaths.



a National Center for Health Statistics. *Deaths: Final Data for 2000*.¹⁸

b American Cancer Society. *Cancer Facts and Figures 2000*.²¹

c Heron et al.²³

d American Cancer Society. *Cancer Facts and Figures 2006*.²¹

Women are more likely than men to have Alzheimer’s disease and other dementias. Based on estimates from the Aging, Demographics, and Memory Study (ADAMS), 14 percent of all people aged 71 and older have dementia. Women aged 71 and older had higher rates than men: 16 percent for women and 11 percent for men. The 2008 estimate is that 2.4 million women and 1 million men aged 71 and older have dementia.¹⁴

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.¹⁵

Although Alzheimer's disease is not a normal part of aging, the risk of developing the illness rises with age. Current research from the National Institute on Aging indicates that the prevalence of Alzheimer's disease doubles every five years beyond age 65, and nearly half of those over 85 have symptoms of the disease. As our population ages, the disease impacts a greater percentage of Americans. Currently, a person's chance of having Alzheimer's disease at age 65 is 1 in 8 increasing at age 85 to 1 in 2.

Every 70 seconds, someone in America develops Alzheimer's disease. By mid-century, someone will develop Alzheimer's disease every 33 seconds.



**113,000 family caregivers
give over \$1 billion of
unpaid care annually in
Oklahoma.**

Oklahoma: A Current and Future Look

	Population aged 60+	Population aged 65+	Population aged 85+
Total in thousands	626.0	464.4	54.3
National ranking	17 th	18 th	27 th
Percent of total population	17.8	13.2	1.5
National average	16.6	12.4	1.7

Senior Population Data for Oklahoma¹⁶

Oklahoma is predominantly a rural state with two major metropolitan areas, often creating unequal access to prevention and healthcare services. Oklahoma consistently ranks among the least healthy states with a high prevalence of negative health determinants such as smoking, obesity, poverty, and below average public health funding and per capita spending on chronic disease prevention.¹⁷ Currently, Oklahoma ranks 43rd overall for select health status indicators, according to the *America's Health Rankings –2008 Edition*, a joint effort of the United Health Foundation and the American Public Health Association. Oklahoma ranks poorly in cardiovascular disease (49th), and associated risk factors such as prevalence of smoking (48th), adult obesity (43rd), access to primary care physicians (49th), and 18 percent of the population is under- or uninsured (42nd).

Stroke, considered to be just one risk factor for the development of Alzheimer's disease, is currently the 4th leading cause of death and the number one cause of disability in the state.¹⁸ Alzheimer's disease is the 7th leading cause of death in the nation as well as in the state.¹⁹ Oklahoma ranked third highest of the states with the least overall health score improvement from 1990 to 2008.²⁰ According to the CDC's 2007 Behavioral Risk Factor Surveillance System (BRFSS) data, Oklahoma ranks 49th in the nation in stroke deaths, 43rd in cancer deaths, second highest for high cholesterol; fourth highest for current smoking; fifth highest for no health coverage; sixth highest for per capita consumption of moist smokeless tobacco; eighth highest

for high blood pressure, diabetes, and obesity; and the ninth highest for no leisure-time physical activity.

In addition, there are multiple cultural barriers to addressing the disparities of the burden of chronic disease and related risk factors in Oklahoma. Native American populations represent 39 different recognized tribes and a total of over 50 cultural and social systems located in the state.²¹ Also, Oklahoma's rural populations have social and cultural characteristics unique to each region, and Oklahoma's emerging Hispanic population will require the health system to meet new and distinct challenges from their culture and needs.

Costs of Care

In 2004, total per-person payments from all sources for health and long-term care were three times higher for Medicare beneficiaries aged 65 and older with Alzheimer's and other dementias than for other Medicare beneficiaries in the same age group.²² In addition, in 2004, average Medicaid payments per person for Medicare beneficiaries aged 65 and older with Alzheimer's and other dementias were more than nine times higher than average Medicaid payments for other Medicare beneficiaries in the same age group.²³

Average Per Person Payments by Source for Healthcare and Long-term Care Services, Medicare Beneficiaries Aged 65 and Older, with and without Alzheimer's Disease and Other Dementias, 2004

Average Per Person Payments	Beneficiaries with no Alzheimer's or Other Dementia	Beneficiaries with Alzheimer's or Other Dementia
Total payments*	\$10,603	\$33,007
Medicare	5,272	15,145
Medicaid	718	6,605
Private insurance	1,466	1,847
Other sources	211	519
HMO	704	410
Out-of-pocket	1,916	2,464
Uncompensated care	201	261

* Payments by source do not equal total payments exactly due to the effect of population weighting.
Created from data from Bynum, *Medicare Current Beneficiary Survey*.²³

Although the state of Oklahoma has not historically compiled statistical information specifically regarding the cost of caring for a person with Alzheimer's disease or other dementias, the Oklahoma Department of Human Services has determined long-term care costs for the state.

- **Average Cost Per Day in a Nursing Home: \$165**
- **Average Assisted Living Monthly Cost: \$2,254**
- **Average Daily Cost for Adult Day Services: \$53**
- **Average Hourly Cost for Home Health Care: \$18**
- **Average Hourly Cost for Personal/Home Care: \$16.50**

According to the Alzheimer's Association's *2009 Facts and Figures Report*, of the 37,504 nursing home residents in Oklahoma, 31 percent have some form of mild cognitive impairment while an additional 41 percent have severe cognitive impairment.

Family caregivers

While caregiving has its satisfactions, for many, the burden of care is substantial. In every case, Alzheimer's disease results in a progressive decline in one's ability to care for oneself, ultimately leaving the individual dependent on others for help with basic activities of living. As a result, caring for a person with Alzheimer's is often very difficult and poses physical, emotional, and economic challenges. This is particularly true because, contrary to common belief, most care is delivered at home by families. Compared to other family caregivers, those who care for people with severe memory problems are more likely to experience financial hardship, report health difficulties, experience emotional stress (depression or anxiety), and suffer from sleep disturbances.

Currently, there are approximately 113,475 caregivers in Oklahoma providing over 97 million hours of care annually.²⁴ The Health and Human Services Report to Congress in 2003 indicates that unpaid family caregivers will likely continue to be the largest source of long-term care services in the U.S. and are estimated to reach 37 million caregivers by 2050, an increase of 85 percent from 2000. According to the National Alliance for Caregiving and AARP; *Caregiving in the US*, nearly half of all caregivers provide fewer than eight hours of care per week, while nearly one in five provide more than 40 hours of care per week.

- ◇ The majority of family caregivers (79 percent) are providing care for someone over the age of 50.
- ◇ Nearly 60 percent of those caring for an adult over the age of 50 are working; the majority are working full-time.
- ◇ Nearly 40 percent of caregivers are men.
- ◇ The average age for a caregiver of a person over the age of 50 is 47.
- ◇ Most caregivers provide care for a parent or grandparent.
- ◇ Approximately 15 percent of caregivers were providing care to someone who lives an hour or more away.²⁵

The amount of time spent caring increases substantially as cognitive impairment worsens. Among people 70 years and older, those with no dementia receive an average of 4.6 hours per week of care, while those with mild dementia receive 13.1 hours of care weekly. For persons with severe dementia, hours of informal care received rises to 46.1 hours per week. Similarly, nearly one-quarter (23 percent) of caregivers of someone 50+ with some type of dementia

provide over 40 hours of care per week compared to 16 percent of those helping someone aged 50 and over without dementia.²⁶

Caregiving in the United States also revealed over 44 million Americans, or an estimated 21 percent of all U.S. households provide care for an adult family member. The majority of family caregivers (79 percent) are caring for someone over the age of 50.

While researchers have long known that caregiving can have deleterious mental health effects for caregivers, research shows that caregiving can have serious physical health consequences as well. Studies have found that caregivers may have increased blood pressure and insulin levels,²⁷ may have impaired immune systems,²⁸ and may be at increased risk for cardiovascular disease²⁹ among other adverse health outcomes. A study of elderly spousal caregivers (aged 66-96) found that caregivers who experience caregiving-related stress have a 63 percent higher mortality rate than non-caregivers of the same age³⁰. Many caregivers are themselves in poor health. Studies show that approximately one-third of caregivers provide intensive care although they are themselves in “fair to poor” physical health.³¹

Psychological health appears to be the aspect of the family caregiver’s life that is most affected by providing care. Studies consistently report higher levels of depressive symptoms and mental health problems among caregivers than among their non-caregiving peers.³² Depression appears to be the most common psychological disorder, with 20-50 percent of caregivers reporting depressive disorders or symptoms.³³ The higher levels of depression are mostly attributed to people caring for individuals with dementia. Studies show that 30-40 percent of dementia caregivers suffer from depression and emotional stress.³⁴

Caregiver interventions benefit both the caregiver and care recipient. Use of caregiver support services has been shown to have clinically significant outcomes in improving caregiver depression, anxiety, and anger.³⁵ Specific caregiver interventions which appear to be most beneficial include those that work with the caregiver and care recipient, those that emphasize behavioral skills training, and those that are both multi-component and tailored to the caregivers’ specific needs.³⁶

People with moderate dementia have been able to defer institutionalization by nearly a year when their family members receive caregiver support services, including counseling, information, and ongoing support.³⁷

Economic Value of Unpaid Caregiving

The Economic Issues of Caregivers, New Caregiver Research symposium of the American Association of Geriatric Psychiatry estimates that if the services provided by informal caregivers had to be replaced with paid services, it would cost an estimated \$257 billion nationally in year 2000 dollars. According to *The Metlife Study of Employer Costs for Working Caregivers*, Metlife Mature Market Group, the cost of informal caregiving in terms of lost productivity to U.S. businesses is \$11 to \$29 billion annually.

When Alzheimer's disease or other dementias were factored in to caregiving, the value of unpaid care in the United States was \$94 billion in 2008.³⁸ In Oklahoma alone, the cost of unpaid care is estimated to be an economic value of \$1,087,267,190.³⁹

Professional Caregivers

While the burden of care falls primarily on families, the rapid growth in the prevalence of Alzheimer's will also impact Oklahoma's healthcare costs, causing them to rise significantly. In particular, Alzheimer's disease and other dementias are a major contributor to Medicare costs.

Older Americans represent approximately 12 percent of the population. However, they comprise 26 percent of physician office visits, approximately a third of all hospital stays, a third of all prescriptions, nearly 40 percent of all medical emergency responses and 90 percent of nursing home residents, according to the National Academy of Sciences.

In its Executive Summary, the National Academy of Sciences states that an estimated 35 million additional formally trained healthcare providers will be needed by 2030 - more than a one-third increase in the current ratio of providers to the total population - just to maintain current levels of staffing. The Executive Summary also documents that the vast majority of healthcare workers who provide the bulk of services to the elderly do not have training in geriatrics. As of 2007, the number of physicians certified in geriatric medicine totaled 7,128 nationwide and those certified in geriatric psychiatry equaled 1,596. By 2030, the need for geriatricians in this country is estimated to be approximately 36,000.

Future Outlook

People with Alzheimer's disease and other dementias are high users of healthcare and long-term care services⁴⁰ and providing care to someone with dementia is an increasingly normative life experience. The Centers for Disease Control and Prevention (CDC) recently released a report that addressed the reality of Alzheimer's in America. While deaths from the top three leading causes of death - heart disease, cancer and stroke - continue to decline, the report shows that deaths from Alzheimer's disease are on the rise.

By 2010, there will be 74,000 Oklahomans living with the disease, and this number is projected to grow to almost 100,000 in 15 years.⁴¹ This dramatic increase will affect all race and ethnic groups as well as all regions of the state.

The CDC figures reveal that Alzheimer's deaths increased by 46 percent from 2000 to 2006, and this upward trend will not change without a scientific breakthrough.

Starting in January 2010, nearly 500,000 new cases of Alzheimer's disease will develop each year in America, and by 2050, 1 million new cases will develop per year. The nation's health and long-term care systems will be incapable of sustaining sufficient support for a baby-boomer population in which one in eight people will develop Alzheimer's or another dementia. With a

changing demographic landscape, it will become increasingly important for scientists to find effective treatments.⁴²

With the inevitable challenges brought about by Alzheimer’s disease, it makes sense to increase funding for Alzheimer’s research. Currently, research funding is nowhere near the level of other diseases that have experienced significant outcomes and, thus, provided a successful precedent of how to attack a disease that affects so many.

Oklahoma Alzheimer’s disease Projections

Year	Projected Number (in 1,000s) with Alzheimer’s by Age Group				percentage Change in Alzheimer’s (Compared to 2000)
	65-74	74-84	85+	total	
2000	3.8	31.0	27.0	62.0	
2010	3.7	34.0	37.0	74.0	19
2020	5.0	37.0	42.0	85.0	37
2025	5.8	45.0	45.0	96.0	55

Alzheimer’s Disease Facts and Figures, 2009

**Alzheimer's patients
over 65 cost Medicaid 9
times more than those
who don't have
dementia.**



Task Force Assessment and Recommendations

The Task Force on the Effect of Alzheimer’s Disease in Oklahoma categorized the findings of their assessment and the recommendations that resulted into four categories - Caregiver Assistance and Case Management, Education and Training, Service Enhancement and Delivery, and State Government. Accompanying each individual recommendation, the task force has provided an explanation of the need and who would most likely be responsible for implementation.

Caregivers and Case Management

Rick Birkel of the Rosalyn Carter Institute said, “Because caregivers are viewed as expendable resources in systems of care, they are overlooked, ill-prepared and poorly supported. Investing community resources in educating and training caregivers, providing them with a wide range of support including respite, and celebrating their achievements and lives results in a higher quality of care, healthier, more effective caregivers, and a better quality of life for the entire community.”

Caring for a person with Alzheimer’s disease is often an effort of many people. Caregiving is often done in the home, but is also done sometimes from long distances. According to the *2009 Alzheimer’s Disease Facts and Figures* report, caregivers of people with Alzheimer’s disease provide more hours of help than caregivers of other older people and because Alzheimer’s and other dementias usually progress slowly, most caregivers spend many years in the caregiving role. As a result, many caregivers experience high levels of stress and negative effects on their health, employment, income and financial security. In fact, many times the stresses of caregiving can cause the caregiver to become ill and die prior to the person with Alzheimer’s disease.

Case management plays an important role in the caregiving process. Access to case management services allows the person with the disease, as well as their caregiver, important information and tools to make use of services and support. It is suspected that increased access to case managers would greatly reduce caregiver burnout and stress. However, case management can be costly and often the caregiver is unaware that case management services exists or where to find them.

Therefore, the task force recommends the following to fill gaps in services available to caregivers and strengthen Oklahoma’s case management network:

Recommendation: Establish and fund a statewide information and referral system for those with Alzheimer’s disease, their caregivers and their families to connect with local case management, support services and information.

Rationale: A statewide network to provide information, referrals and case management support will provide tangible help for thousands of urban and rural Oklahoma families facing the challenges of Alzheimer's disease. Increased access to information and support allows a family to care for their loved one with Alzheimer's in a way that is cost effective for the family and the state, while preserving the individual's quality of life. The demands for help outstretch current services and the escalating epidemic places greater strains on those services every year. In order for the state to attack this issue with an economically sound approach, funding a statewide support system must be an immediate priority.

Parties Responsible: Oklahoma State Legislature, Oklahoma Department of Human Services - Aging Services Division

Recommendation: Increase the daily reimbursement rate for funding for Adult Day Center services, as well as increase the number of locations across the state.

Rationale: Adult Day Centers are currently unable to sustain quality services for individuals with dementia based on the current reimbursement rate of \$45 per day of service. The cost of providing the services throughout the state range anywhere from \$50 to \$60 per day. To sustain this service an increase in reimbursement rates is essential. In addition, any community with a population of 25,000, or fewer with a significant percentage of seniors, would be better served by an Adult Day Center.

Parties Responsible: Oklahoma Department of Human Services, Oklahoma State Legislature, Oklahoma Association of Homes and Services for the Aging

Education and Training

Education and training encompasses a broad spectrum, including both professional and public needs. Professional caregivers, as well as medical and allied health professionals, often have no specific training in the unique challenges of Alzheimer's disease and other dementias. In fact, this lack of knowledge about Alzheimer's disease often leads to an incomplete diagnosis with little follow-up care for those who are diagnosed. Health care professionals are mostly unaware of services and support in the community to assist someone who has been diagnosed with the disease.

In addition, there is little education about Alzheimer's disease that is readily available to the public. The general public has many misconceptions about Alzheimer's disease and the effects it has on a person.

Therefore, the task force recommends the following to provide better education and training to healthcare professionals, law enforcement, family caregivers, and the general public:

Recommendation: Medical and direct care staff at any nursing home, assisted living facility, adult day center, skilled nursing facility, home health agency or hospice agency that is licensed by the state or receiving state funding should be required by law to complete four hours of in-service training per year in Alzheimer’s and dementia related care.

Rationale: Improve the quality of care by establishing levels of annual dementia-specific training for entities that must receive state licensure or wish to receive state funding. Currently, there is very little training for those staff involved in direct care of persons with any form of dementia.

Parties Responsible: State licensing agencies, Oklahoma Department of Health

Recommendation: Provide enhanced funding to compensate facilities that expend dollars for staff education related to Alzheimer’s care.

Rationale: Facilities that have Alzheimer’s residents must address the staff education needed to adequately care for this sometimes challenging population. Oklahoma’s current reimbursement system recognizes the licensed nursing facilities that expend more dollars for direct care staff and staff education. However, this means there must be an annual appropriation to adjust the rates for these expenditures. All state funded adult care entities that provide staff education should receive compensation.

Parties Responsible: Oklahoma State Legislature, Oklahoma Health Care Authority

Recommendation: Create culturally competent public service announcements to raise the level of public education about brain health and the warning signs of Alzheimer’s and dementia, some of which should specifically target populations with disproportionately higher rates of these diseases.

Rationale: To face the inevitable epidemic, it is a must to increase public understanding of Alzheimer’s disease. This can help with early detection and diagnosis, which typically delays the progression of the disease and the impending medical costs.

Parties Responsible: Oklahoma Department of Health, Alzheimer’s Association

Recommendation: Require that the diagnosis of Alzheimer’s disease and related dementias be made an essential competency in state medical schools by 2012, while also providing incentives to physicians to complete dementia-specific modules in the re-licensing process (every 3 years).

Rationale: Currently, there is a shortage of physicians who have received proper training in the accurate diagnose of Alzheimer’s disease and other related dementias. Inaccurate or missed diagnoses are commonplace. To face the inevitable epidemic, a dramatic increase of trained physicians is crucial to a successful readiness plan.

Parties Responsible: University medical schools, Oklahoma State Medical Board

Recommendation: Develop employee education and support outreach for public and private sector businesses to promote brain health while addressing the needs of employees who are caregivers to persons with Alzheimer’s disease through the use of on-site support groups, case management and other initiatives.

Rationale: Family related work absence due to personal or family illness can be minimized by an educated public. Addressing brain health in the work force can minimize absence due to preventable illness. Presently research suggests that “What is good for the heart is good for the brain,” implying that diet and exercise encouraged by employers can address future potential for absence due to declining brain health. In addition to brain health, connecting those in the workforce with available support services in the community will help employees manage caregivers stress, thus strengthening their performance.

Parties Responsible: Alzheimer’s Association, Oklahoma Department of Health, Oklahoma Department of Mental Health

Recommendation: Codify mandatory dementia-specific training for all First Responders to prepare for Silver Alert.

Rationale: The Oklahoma Department of Health recently reported over 300 instances of adults who wandered away in one year from Oklahoma nursing homes – not including assisted living centers, adult day centers, independent living or private homes. In order for law enforcement to properly assist and approach a vulnerable adult, training regarding the challenges of Alzheimer’s disease is required.

Parties Responsible: Oklahoma State Legislature, Oklahoma Department of Public Safety

Recommendation: Create a student loan forgiveness program for medical school students who specialize in geriatrics and practice in the state of Oklahoma.

Rationale: With the explosion of the aging population across the U.S., an anticipated 36,000 geriatricians will be needed by 2030. However, the absolute number of geriatricians in the U.S. has actually decreased from 9,256 in 1998 to 6,435 in 2005. Oklahoma desperately needs to reverse this trend and readily adopt mechanisms to recruit more geriatricians and geriatric specialists. An educational incentive will help to address this matter.

Parties Responsible: Oklahoma State Legislature

Recommendation: Implement an automatic reminder on Electronic Medical Records requiring physicians' offices to provide referral of diagnosed patients to the Alzheimer's Association upon diagnosis of Alzheimer's disease or related dementias.

Rationale: Most often, those with Alzheimer's disease receive a diagnosis or medication without knowing about available community support or education about the disease or any information about the challenges of the disease.

Parties Responsible: Oklahoma Medical Association, Oklahoma Department of Health, Oklahoma Pharmacists Association

Service Enhancement and Delivery

Services are delivered to an individual with Alzheimer's or other dementias by many entities. They range from government agencies to non-profit organizations to private facilities, just to name a few. Because service delivery is so fragmented, there is often a lack of coordination. In addition, there are often gaps in the quality of service provided, most often due to a lack of funding.

Therefore, the task force recommends the following in order to improve and enhance the services being delivered to individuals with Alzheimer's and their caregivers across the state:

Recommendation: Revise Disclosure Form 613 with the Oklahoma Department of Health to include specific information that qualifies the facility as a specialized care facility. Facilities should not be allowed to advertise an Alzheimer’s unit until the disclosure form has been approved designating their unit as such. The form must specify minimum standards a facility must maintain to be designated as an Alzheimer’s care unit.

Rationale: The form should specify minimum standards beyond being a locked unit that a facility must achieve to be designated as an Alzheimer’s Care Unit. Minimum standards should address staffing levels, staff education, and the physical environment, including outdoor areas to serve this population. Presently, Disclosure Form 613 has no minimum standards assigned to this special designation.

Parties Responsible: Oklahoma Department of Health, Oklahoma Health Care Authority

Recommendation: Include Alzheimer’s specific questioning in the State Health Department’s Behavioral Risk Factor Surveillance System.

Rationale: The Behavioral Risk Factor Surveillance System (BRFSS) was established in 1984 by the Centers for Disease Control and Prevention (CDC); currently data are collected monthly in all 50 states. More than 350,000 adults are interviewed each year, making the BRFSS the largest telephone health survey in the world. States use BRFSS data to identify emerging health problems, establish and track health objectives, and develop and evaluate public health policies and programs. Many states also use BRFSS data to support health-related legislative efforts. There is currently no BRFSS module that directly addresses Alzheimer’s disease included in Oklahoma’s BRFSS survey.

Parties Responsible: Oklahoma Department of Health

Recommendation: Dedicate a funding source for all future long-term care services.

Rationale: Oklahoma presently expends over \$750 million dollars annually on long term care services, primarily through nursing home care and home and community based services. However, with such strong demographic shifts, (by 2020, the population of those living in Oklahoma over the age of 60 will double) the number of citizens requiring long term care services will grow exponentially. It would be prudent for Oklahoma to identify a dedicated funding source to meet this need.

Parties Responsible: Oklahoma State Legislature

Recommendation: Establish insurance coverage for those diagnosed with Alzheimer’s disease within the 2-year waiting period for Medicare once they are on Social Security Disability.

Rationale: Loss of income due to a diagnosis of Alzheimer’s disease or another dementia prior to the age of 65 limits a family’s ability to receive government-sponsored medical insurance for a mandatory two-year period. The implementation of coverage would support those under 65 who are waiting approval for the Medicare program.

Parties Responsible: Oklahoma Insurance Department, Oklahoma Health Care Authority, Oklahoma State Legislature

Recommendation: Include memory screening in annual checkups for patients aged 70 and older.

Rationale: Currently, memory screening is not a part of annual wellness exams. By including memory screening, it will aid in early detection and treatment of the onset of Alzheimer’s, which can slow the progression of the symptoms and save money for families and the state.

Parties Responsible: Oklahoma Medical Association

Recommendation: Enhance training and accountability for agencies with state contracts providing case management services under the Medicaid Advantage Program.

Rationale: The state of Oklahoma will see a rise in the number of those persons with dementia receiving Advantage services as the population continues to age. Therefore, it is critical that case managers receive adequate training regarding the challenges of Alzheimer’s disease and other dementias. By doing so, gaps in services will be eliminated, allowing the person to stay at home instead of being placed in a nursing facility, ultimately saving the state money.

Parties Responsible: Oklahoma Department of Human Services – Aging Services Division, Oklahoma Health Care Authority

Recommendation: Recommend that pharmacists include written referral to the Alzheimer’s Association upon distribution of memory-care medications.

Rationale: By including printed material along with the medications, pharmacists can play a key role in the referral to support services for individuals with dementia and their families.

Parties Responsible: Oklahoma Pharmacists Association

State Government

In order for the needs of persons with Alzheimer's disease, their caregivers, and the healthcare professionals that deliver care to be fully understood by policy makers, it is important that the legislative and regulatory changes proposed be streamlined and more efficient. It is vital that any policy or regulatory changes not be duplicated and that regulations be overseen by a single government entity.

Therefore, the task force recommends the following changes be made in the structure of the Oklahoma state government:

Recommendation: Specify that all aging-related legislation go through a single committee in both the Oklahoma House of Representatives and Senate.

Rationale: Policy changes that impact the senior population are currently considered by many of the state legislature's committees, often causing duplication and gaps in services. Consistency could be achieved by all potential legislation being scrutinized by a single committee.

Parties Responsible: Oklahoma State Legislature

Recommendation: Establish a Cabinet-level Secretary of Aging.

Rationale: Every state agency is being affected by Oklahoma's aging population. Older Oklahomans are impacting and being affected by our Departments of Transportation, Commerce, Human Services, Mental Health, Corrections, Education, and Agriculture to name only a few. An Oklahoma Governor's Cabinet Secretary of Aging could coordinate efforts at each state agency to incorporate the best gerontological science into planning and policy development.

Parties Responsible: Governor, Oklahoma state agencies

Issues for Further Study

Throughout the course of the Task Force's work, it became apparent there are some recommendations that need further study by the Legislature or other entities of state government.

The task force recommends the state conduct a further study of the following:

Recommendation: Study the effectiveness of a GPS tracking system for those individuals with Alzheimer's disease who are likely to wander, as well as the costs and possible financial incentives for implementation.

Rationale: Seventy percent of persons living with Alzheimer's disease are living in their homes. Additionally, sixty percent of those with Alzheimer's disease will wander. In Oklahoma, there is an increased emphasis for persons to age in place. This may increase the risk, however, that persons with Alzheimer's disease might wander as they are often under little supervision. A monitoring system could help reliably locate and retrieve vulnerable persons with dementia who have left the safety of their homes. Currently, several states in other parts of the country are reviewing the implementation of such a system and the state of Oklahoma should coordinate their efforts with those states. Additionally, the state should review the fiscal requirements of such a system, exploring private funding, as well as tax credits for families who subscribe.

Parties Responsible: Oklahoma Department of Public Safety, Oklahoma State Legislature

Recommendation: Evaluate the ability for the state to provide a financial incentive, such as but not limited to a tax credit, for those caregivers who give up their income to care for someone with Alzheimer's disease or other dementias.

Rationale: As Alzheimer's disease progresses, the need for personal care increases. The annual cost of care for a person with Alzheimer's disease is three times more than the cost for a person who does not have Alzheimer's or dementia. The financial burden on the family has far-reaching impact. Caregivers often sacrifice their income to keep their loved one at home.

Parties Responsible: Oklahoma State Legislature, Oklahoma Tax Commission

Recommendation: Explore changes in the Certificate of Need and the licensing process, as well as funding needs, in order to create facilities that provide specialized care for residents with dementia-related psychiatric and difficult behaviors.

Rationale: Currently there are few licensed long-term care facilities with the ability to provide the specialized care these persons require. Due to this fact, these individuals are in and out of inpatient psychiatric facilities with an average cost per day of \$1,000 and an average length of stay of 7-10 days. For one stay in a psychiatric facility, the state of Oklahoma is spending between \$7,000 - \$10,000 per person. Reviewing the Certificate of Need process and allowing the creation of a specialized facility would offset long-term costs for the state.

Parties Responsible: Oklahoma State Department of Health, Oklahoma Health Care Authority

Recommendation: Explore an economic incentive for physicians who accept Alzheimer's and related dementia patients, as well as provide follow-up care.

Rationale: The demand for an adequate supply of physicians who will accurately diagnose and treat an individual throughout the disease process continues to escalate beyond what is available. Increasingly fewer physicians are accepting Medicare, which is the primary funder of Alzheimer's care. There must be a focus on growing the number of physicians who will serve this population.

Parties Responsible: Oklahoma State Legislature, Oklahoma Medical Association



The current financial burden of dementia care in Oklahoma is \$37,000 per person per year.

Appendix A: Senate Bill 2186

ENROLLED SENATE
BILL NO. 2186

By: Ivester and Sparks of the Senate

and

Wesselhoft, Johnson (Dennis), McDaniel (Randy),
Rousselot and McAffrey of the House

An Act relating to Alzheimer's disease; creating the Task Force on the Effect of Alzheimer's Disease in Oklahoma; providing expiration date; stating purpose; providing for appointments; specifying date by which appointments are made; providing for vacancies; providing for designation of cochairs; specifying quorum; providing for meetings and staffing; providing for travel reimbursement; requiring examination of certain information; requiring report; providing for noncodification; providing an effective date; and declaring an emergency.

BE IT ENACTED BY THE PEOPLE OF THE STATE OF OKLAHOMA:

SECTION 1. NEW LAW A new section of law not to be codified in the Oklahoma Statutes reads as follows:

A. There is hereby created to continue until June 1, 2010, the Task Force on the Effect of Alzheimer's Disease in Oklahoma. The purpose of the Task Force shall be to:

1. Assess the current and future impact of Alzheimer's disease and other types of dementia on the residents of the State of Oklahoma;
2. Examine the existing industries, services and resources addressing the needs of persons living with Alzheimer's disease, their families and caregivers; and
3. Develop a strategy to mobilize a state response to this public health crisis.

B. The Task Force shall consist of sixteen (16) members, to be appointed as follows:

1. Four shall be appointed by the Speaker of the Oklahoma House of Representatives as follows:

- a. one shall be a person who has been diagnosed with Alzheimer's disease,
- b. one shall be a representative of the health care provider community,
- c. one shall be a representative of the adult day services industry, and
- d. one shall be a member of the Oklahoma House of Representatives;

2. Four shall be appointed by the President and Co-President Pro Tempore of the State Senate as follows:

- a. one shall be a caregiver of a person with Alzheimer's disease,
- b. one shall be a representative of the assisted living industry,
- c. one shall be a scientist who specializes in Alzheimer's research, and
- d. one shall be a member of the State Senate;

3. Three shall be appointed by the Governor as follows:

- a. one shall be a family member of a person living with Alzheimer's disease or other form of dementia,
- b. one shall be a representative of the nursing facility industry, and
- c. one shall be a person active in the state chapter of the Alzheimer's Association; and

4. Five shall be public sector representatives as follows:

- a. the Commissioner of the State Department of Health, or designee,
- b. the Director of the Department of Human Services, or designee,

c. the Commissioner of the Department of Mental Health and Substance Abuse Services, or designee,

d. the Chief Executive Officer of the Oklahoma Health Care Authority, or designee, and

e. the Executive Director of the Oklahoma Employment Security Commission, or designee.

C. Appointments to the Task Force shall be made by September 1, 2008. Task Force members shall serve at the pleasure of their appointing authorities. A vacancy on the Task Force shall be filled by the original appointing authority.

D. The Speaker of the Oklahoma House of Representatives and the President and Co-President Pro Tempore of the State Senate shall each designate a cochair from among the members of the Task Force. A majority of the members of the Task Force shall constitute a quorum to do business. The Department of Human Services shall provide staff support to the Task Force as necessary to assist the Task Force in the performance of its duties.

E. Members of the Task Force shall receive no compensation for their service, but shall receive travel reimbursement as follows:

1. Legislative members of the Task Force shall be reimbursed in accordance with the provisions of Section 456 of Title 74 of the Oklahoma Statutes; and

2. Nonlegislative members of the Task Force shall be reimbursed by their appointing authorities pursuant to the State Travel Reimbursement Act.

F. The Task Force shall include an examination of the following in its assessment and recommendations:

1. State trends in the number of persons living with Alzheimer's disease and other forms of dementia and the needs of those persons;

2. The state's role in providing long-term care, family caregiver support, and other forms of assistance to persons with early-stage and early onset of Alzheimer's;

3. State policy regarding persons with Alzheimer's disease and developmental disabilities;

4. Existing services, resources, and capacity, including but not limited to the:

- a. type, cost and availability of dementia services,
- b. dementia-specific training requirements for long-term care staff,
- c. quality care measures for residential care facilities,
- d. capacity of public safety and law enforcement to respond to persons with Alzheimer's disease,
- e. availability of home- and community-based resources for persons with Alzheimer's disease, including the availability of respite care for families,
- f. inventory of long-term care dementia care units,
- g. adequacy and appropriateness of geriatric-psychiatric units for persons with behavior disorders associated with Alzheimer's and related dementia,
- h. assisted living residential options for persons with dementia, and
- i. state support of Alzheimer's research; and

5. Needed state policies or responses, including but not limited to directions for the provision of clear and coordinated services and supports for persons and families living with Alzheimer's and related disorders and strategies to address identified gaps in services.

G. The Task Force shall issue a report of its recommendations to the Legislature and the Governor no later than September 1, 2009.

SECTION 2. This act shall become effective August 1, 2008.

SECTION 3. It being immediately necessary for the preservation of the public peace, health and safety, an emergency is hereby declared to exist, by reason whereof this act shall take effect and be in full force from and after its passage and approval.

Passed the Senate the 28th day of April, 2008.

Passed the House of Representatives the 15th day of April, 2008.

Approved by the Governor of the State of Oklahoma on the 2nd day of May, 2008, at 2:05 o'clock p.m.

Appendix B: Subcommittee Members

Education and Training:

Dr. Chandini Sharma

Mark Fried

Ron Grant

Long-term Care and Funding:

Mary Brinkley

Melanie Johnston

Lance Robertson

Floyd Autin

Services and Data Collection:

Lisa Pever

Mich Magness

Amy Carte

David Slimp

Caregiver Assistance and Case Management:

Bill Major

Vicki Escajeda

Linda Brinkworth

Appendix C: Acknowledgements

The Task Force on the Effect of Alzheimer’s disease in Oklahoma would like to thank the following individuals and organizations for their assistance in providing knowledge and expertise on this important topic:

Dr. David Reuben, Professor of Medicine, UCLA

Dr. Rosanne Leipzig, Professor of Medicine, Mt. Sinai Medical School

Keili Hicks, Alzheimer’s Association, Oklahoma/Arkansas Chapter

Esther Houser, Oklahoma State Long-term Care Ombudsman

Saint Simeons Episcopal Home

Paula Avery, Alzheimer’s Association, Oklahoma/Arkansas Chapter

Ruth Drew, Alzheimer’s Association, Oklahoma/Arkansas Chapter

Jennifer Mullens, Oklahoma State Senate

Jennifer Case, Oklahoma Department of Human Services

Appendix D: Endnotes

-
- ¹ 2009 Alzheimer’s Disease Facts and Figures Report, Alzheimer’s Association, Pg 23.
- ² Virginia Commission on Alzheimer’s Disease and Related Disorders – Strategic Plan, Pg. 1.
- ³ 2009 Alzheimer’s Disease Facts and Figures Report, Alzheimer’s Association, Pg. 19.
- ⁴ 2009 Alzheimer’s Disease Facts and Figures Report, Alzheimer’s Association, Pg 43.
- ⁵ The MetLife Caregiving Cost Study: Productivity Losses to U.S. Businesses; MetLife Mature Market Institute National Alliance for Caregiving, July 2006.
- ⁶ Texas Council on Alzheimer’s disease and related disorders, 2006 Bi-Annual Report.
- ⁷ 2009 Alzheimer’s Disease Facts and Figures Report, Alzheimer’s Association, Pg 7.
- ⁸ 2009 Alzheimer’s Disease Facts and Figures Report, Alzheimer’s Association, Pg. 18.
- ⁹ 2009 Alzheimer’s Disease Facts and Figures Report, Alzheimer’s Association, Pg 7.
- ¹⁰ 2009 Alzheimer’s Disease Facts and Figures Report, Alzheimer’s Association, Pg 7.
- ¹¹ 2009 Alzheimer’s Disease Facts and Figures Report, Alzheimer’s Association, Pg 7.
- ¹² 2009 Alzheimer’s Disease Facts and Figures Report, Alzheimer’s Association, Pg 8.
- ¹³ 2009 Alzheimer’s Disease Facts and Figures Report, Alzheimer’s Association, Pg 10.
- ¹⁴ 2009 Alzheimer’s Disease Facts and Figures Report, Alzheimer’s Association, Pg 10.
- ¹⁵ 2009 Alzheimer’s Disease Facts and Figures Report, Alzheimer’s Association, Pg 14.
- ¹⁶ State Program Information: State Profiles; Family Caregiving Alliance, www.caregiver.org, 2007.
- ¹⁷ United Health Foundation, 2008 State Rankings.
- ¹⁸ Oklahoma State Department of Health, Center for Health Statistics.
- ¹⁹ Centers for Disease Control and Prevention, 2007.
- ²⁰ United Health Foundation, 2008 State Rankings.
- ²¹ Oklahoma State Department of Health Vital Statistics.
- ²² 2009 Alzheimer’s Disease Facts and Figures Report, Alzheimer’s Association, Pg 47.

-
- ²³ 2009 Alzheimer's Disease Facts and Figures Report, Alzheimer's Association, Pg 47.
- ²⁴ 2009 Alzheimer's Disease Facts and Figures Report, Alzheimer's Association, Pg 43.
- ²⁵ The MetLife Caregiving Cost Study: Productivity Losses to U.S. Businesses; MetLife Mature Market Institute National Alliance for Caregiving, July 2006, Pg 5.
- ²⁶ National Family Caregiver Alliance, www.caregiver.org.
- ²⁷ National Estimates of the Quantity and Cost of Informal Caregiving for the Elderly with Dementia, Journal of General Internal Medicine: Alzheimer's Association and National Alliance for Caregiving, Families Care: Alzheimer's Caregiving in the United States.
- ²⁸ Reverberation of Family Illness; A Longitudinal Assessment of Informal Caregiver and Mental Health Status in the Nurses' Health Study, American Journal of Public Health.
- ²⁹ Chronic Stress and Age-Related Increases in the Pro-inflammatory Cytokine IL-T, National Academy of Sciences 2003.
- ³⁰ Caregiving and Risk of Coronary Heart Disease in U.S. Women: A Prospective Study, American Journal of Preventive Medicine.
- ³¹ Caregiving as a Risk Factor for Mortality: the Caregiver Health Effect Study, JAMA.
- ³² When the Caregiver Needs Care: The Plight of Vulnerable Caregivers, American Journal of Public Health.
- ³³ Psychiatric and Physical Morbidity Effects of Dementia Caregiving: Prevalence, Correlates, and Causes, The Gerontologist..
- ³⁴ Caring for Relatives with Alzheimer's Disease: The Mental Health Risks for Spouses, Adult Children, and other Family Caregivers, Behavior, Health and Aging.
- ³⁵ Patient and Caregiver Characteristics Associated with Depression in Caregivers of Patients with Dementia, Journal of General Internal Medicine.
- ³⁶ Dementia Caregiver Intervention Research: In Search of Clinical Significance, The Gerontologist..
- ³⁷ Meta-Analysis of Psychosocial Interventions for Caregivers of People with Dementia, Journal of the American Geriatric Society.
- ³⁸ 2009 Alzheimer's Disease Facts and Figures Report, Alzheimer's Association, Pg 34.
- ³⁹ 2009 Alzheimer's Disease Facts and Figures Report, Alzheimer's Association, Pg 43.
- ⁴⁰ Care-giving: National Statistics/Information.
- ⁴¹ 2009 Alzheimer's Disease Facts and Figures Report, Alzheimer's Association, Pg. 23.
- ⁴² Alzheimer's Foundation of America, 2005.