

Interim Report



Missouri Alzheimer's State Plan Task Force

Report to Governor Jeremiah W. (Jay) Nixon and the Missouri General Assembly

February 2012

Printing of the Missouri Alzheimer's State Plan Task Force Interim Report is compliments of Dolan Residential Care, Missouri Department of Health and Senior Services, Missouri Association of Area Agencies on Aging and the Alzheimer's Association St. Louis Chapter.



LIEUTENANT GOVERNOR OF MISSOURI
JEFFERSON CITY
65101

Peter D. Kinder
LIEUTENANT GOVERNOR

State Capitol Room 224
OFFICE PHONE: (573) 751-4727

February 14, 2012

**The Honorable Jeremiah W. Nixon,
Missouri State Capitol, Room 216
Jefferson City, Missouri 65101**

Dear Governor Nixon:

The Missouri Alzheimer's State Plan Task Force was created in 2009 by the Missouri General Assembly to address the current and future impact of Alzheimer's disease and related dementia issues in Missouri. As chairman of the task force, I am pleased to report that we had a very successful year. Attached for your consideration is the 2012 Supplement to the Task Force's State Plan.

The Task Force's State Plan first was submitted to you and the Missouri General Assembly in November 2010. The State Plan assessed the impact of Alzheimer's on Missourians and included recommendations for responding to this serious public health crisis. The 2012 Supplement contains new statistical and legislative data and addresses our five recommendations for effectively combating Alzheimer's disease and related dementia issues in Missouri.

On behalf of the task force, I submit this Supplement to you and the Missouri General Assembly for your review and consideration. The information and recommendations set forth will help improve the lives of Missourians affected by Alzheimer's disease and their caregivers.

It is an honor to serve as the chairman of the Missouri Alzheimer's State Plan Task Force. Please let me know if I or the other task force members may be of any further assistance as you review our recommendations.

Sincerely,

A handwritten signature in cursive script that reads "Peter Kinder".

Lt. Governor Peter Kinder
Chairman, Missouri Alzheimer's State Plan Task Force

Missouri Alzheimer's State Plan Task Force Membership

Lt Governor Peter Kinder
Chairman

Pam Dixon

Lt. Governor's Designee

Margaret Donnelly

Director, Health & Senior Services

Glenda Meachum-Cain, Health & Senior Services
Designee

Keith Schafer

Director, Mental Health

Jan Heckemeyer, Mental Health Designee

Brian Kinkade

Interim Director, Social Services

Theresa Valdes, Social Services Designee

Senator Maria Chappelle-Nadal

House of Representatives Member

Senator Bill Stouffer

Missouri Senate Member

Gwendolyn Richards

Member with early-stage Alzheimer's or related
dementia

VACANT

Maureen Dempsey (resigned Nov. 1, 2010)

Member who is a family caregiver of a person with
Alzheimer's or a related dementia

Dr. John Morris

Member who is a licensed physician with experience in
the diagnosis, treatment, and research of Alzheimer's
disease

Carol Scott

Member from the office of the state ombudsman for
long-term care facility residents

Lisa Baron

Member representing the home care profession

Timothy Dolan

Member representing residential long-term care

Deborah Ellis

Member representing the adult day services profession

John Huff

Member representing the insurance profession

Molly White, Designee

Jean Leonatti

Member representing the area agencies on aging

Joseph Palm

Member with expertise in minority health

Lois Zerrer

Member who is a licensed elder law attorney

Clara Carroll Rodriguez

Member from the leading voluntary health organization
in Alzheimer's care, support, and research

Joan D'Ambrose

Member from the leading voluntary health organization
in Alzheimer's care, support and research

Executive Summary

Alzheimer's disease will not wait. It affects all classes of people across all regions of the country. There are 5.4 million Americans with Alzheimer's – 110,000 here in Missouri. It is the 6th leading cause of death and the only one among the top ten without a way to cure, prevent or slow the progression of the disease.

The Missouri Alzheimer's State Plan Task Force was commissioned by the 95th General Assembly to address the Alzheimer's crisis in Missouri. The 19 member task force developed a plan that focuses on five key goals. These goals were a result of the input gathered from hundreds of participants at community forums across the state regarding Alzheimer's disease:

- Promote access to statewide expert diagnostic services that can lead to early intervention and support.
- Create a Road Map for care and support that provides quality information on services across the continuum from early diagnosis to end of life.
- Provide a wide array of community and home based services that may offer more cost-effective options for the rapidly increasing number of Missourians with Alzheimer's and for their caregivers.
- Ensure a sufficient, dementia conscious, quality workforce at all levels of the care continuum.
- Maintain Missouri's status as a research leader in Alzheimer's disease and related disorders.

The prevalence of Alzheimer's continues to increase and the Missouri economy continues to struggle. In this challenging environment, the Alzheimer's State Plan Task Force has focused on advancing these five goals by building on existing resources, leveraging public / private partnerships, focusing on areas of greatest need, and promoting Missouri as a world leader in Alzheimer's research.

Highlights - 2011 activities

- To advance better access to early detection and community support, the Department of Health and Senior Services is implementing **Project Learn MORE**, a statewide project that builds on partnerships between with the Alzheimer's Association Chapters and Area Agencies on Aging. Funded by the Administration on Aging, Project Learn MORE is designed to establish a unified system of screening, referral, care planning and service for Missouri citizens with Alzheimer's and related dementias.
- To increase detection, diagnostic services, and knowledge about supportive services among health care professionals, the task force identified twenty-five statewide health care conferences as opportunities for education. Six presentations are scheduled for 2012.
- A Road Map Workgroup was established by the task force and charged with identifying existing resources that will provide Missourians with quality information on Alzheimer's services. The **Alzheimer's Navigator** is an online assessment program designed to help caregivers and individuals with dementia evaluate their needs, execute action steps and connect with local programs and services. The program will be launched in the spring of 2012.
- Respite care assistance was identified during community forums as an area of greatest need as well as a cost effective option to help families care for their loved ones at home. **Alzheimer's Service Grants** fund respite care programs across Missouri. Unfortunately, the demand for assistance far outweighs the

available resources. The task force recommends increased state appropriations for Alzheimer's Service Grants in order to better support families caring for their loved ones at home.

- To gain a better understanding of long term care insurance in Missouri, the task force researched and published a white paper, included in this report, on long term care insurance coverage. Although readily available, long term care insurance accounts for less than 2% of the total market for medical insurance products in Missouri.

- The MO HealthNet programs provided medical services to 18,212 participants with Alzheimer's or other dementias at a cost of \$191,641,741 in state fiscal year 2011. The majority of expenditures (82.6%) for Alzheimer services incurred by the necessity of nursing home care. The task force recommends that Missouri seek approval from the Centers for Medicare and Medicaid Services for a 1915c Home and Community Based waiver. This would provide a more cost effective alternative to institutional care that addresses the gap in services for individuals with Alzheimer's and related dementias.

- To ensure a sufficient, dementia conscious, quality workforce, the task force completed an analysis of Missouri's regulations for dementia training and recommends that the Department of Health and Senior Services address current inconsistencies and strengthen regulatory language to ensure compliance with dementia training requirements as outlined in state statute (660.050.RSMO) and new CMS requirements (Section 6121 of the Affordable Care Act).

- Missouri is a world leader in Alzheimer's research. In 2011, approximately \$22 million in federal and foundation grants were awarded to Missouri Alzheimer' researchers. The task force supports the reinstatement of funding to the Alzheimer 's Disease and Related Disorders Project and the passage of SB482, which would increase individual research grants from \$30,000 to \$50,000.

Introduction

We cannot afford to ignore Alzheimer's disease. Each day over 10,000 baby boomers turn 65, the threshold age at which an individual's risk for developing Alzheimer's disease increases.

In 2009, the Missouri legislature recognized this growing epidemic and passed legislation calling for the development of a strategic plan for Missouri to help change the trajectory of this disease.

The Missouri Alzheimer's State Plan Task Force delivered their plan to Governor Nixon and members of the General Assembly in 2009. At the same time both houses of Congress unanimously passed the National Alzheimer's Project Act (NAPA).

In 2010, the Missouri Alzheimer's State Plan Task Force convened community forums in Missouri to gather public input regarding their experience with Alzheimer's. The input from the forums in Missouri became the main foundation of the issues the task force has focused on combating. During 2011, NAPA held more listening sessions in Missouri and across the country to hear from the public about the biggest obstacles faced by individuals with Alzheimer's. The sentiments expressed in 2011 echoed the issues mentioned in 2010:

- Lack of public awareness
- Insufficient research funding
- Difficulties with diagnosis
- Poor dementia care
- Inadequate treatments
- Specific challenges facing diverse communities
- Specific challenges facing those with younger-onset Alzheimer's
- Unprepared caregivers
- Ill-equipped communities
- Mounting costs

The Missouri Alzheimer's State Plan outlines goals and strategies to address these concerns.

- Promote access to statewide expert diagnostic services that can lead to early intervention and support.
- Create a Road Map for care and support that provides quality information on services across the continuum from early diagnosis to end of life.
- Provide a wide array of community and home based services that may offer more cost-effective options for the rapidly increasing number of Missourians with Alzheimer' or related disorders and their caregivers.
- Ensure a sufficient, dementia conscious, quality workforce at all levels of the care continuum.
- Maintain Missouri's status as a research leader in Alzheimer's disease and related disorders.

This supplemental report provides updated information regarding Alzheimer's disease in Missouri and details the progress made by the task force.

Task Force Recommendations: Updates

I. Access to Early Interventions and Support

Goal: Promote access to statewide expert diagnostic services that can lead to early intervention and support.

Methods:

- Increase access statewide to expert diagnostic services that allow for early detection of Alzheimer's disease and related dementia.
- Offer educational opportunities for physicians and health care professionals regarding early detection and diagnostic services and inform them of resources on support for newly diagnosed individuals and their families.
- Pilot statewide dementia assessments through implementation of tools such as the AD-8 tool.
- Promote public awareness campaigns on Alzheimer's disease that encourage early intervention and diagnosis and provide resources for individuals and their loved ones.

This past year the National Alzheimer's Project Act (NAPA) held listening sessions across Missouri. One of the most common issues expressed by Missourians was their frustration with getting an accurate diagnosis in the beginning stages, especially for people with early memory loss. Another concern was the lack of information and support from physicians following the diagnosis.

The task force has identified twenty-five statewide conferences for health care professionals that could be opportunities for presentations on early detection and community support services. Our goal is to present at six conferences in 2012. Dr. John Morris and his staff from the Knight Alzheimer's Disease Research Center at Washington University are developing the presentation's content, which will include information on the new diagnostic guidelines released in 2011. Additionally, Dr. Morris and his staff are identifying potential presentation speakers.

The speakers are intended to be physicians who have participated in the Clinician Partners Program (CPP). The CPP is a three day mini-residency on Alzheimer's diagnosis, treatment and care. It is designed to support the learning needs of clinicians in rural environments, who serve minority elders. The CPP is funded by a grant from the National Institute on Aging and held at the Knight Alzheimer's Research Center.

The task force is considering presenting at the following conferences this year: Missouri State Medical Association, Missouri Frail Elderly Conference, Missouri Institute of Minority Aging, Missouri End of Life Coalition: Policy Summit, Missouri Association of Long Term Care Physicians, and the Show Me Summit on Aging and Health.

Physician education is necessary for addressing the Alzheimer's crisis. However, early detection and connecting with supportive community services can also be provided by organizations and professionals other than an individual's physician. In Missouri, Project Learn MORE (funded by the Administration on Aging) has enabled the Department of Health and Senior Services, in partnership with the Alzheimer's Association Chapters and

Area Agencies on Aging, to implement programs providing early diagnosis and support. These programs target undiagnosed and newly diagnosed individuals in the early stages of dementia, with a focus on low income, rural and minority populations.

Under Project Learn MORE, Missouri's ten Area Agencies on Aging assess clients using the AD-8 dementia-screening tool¹. The AD-8 was developed by Dr. Jim Galvin and colleagues at Washington University and identifies early stages of dementia. New clients receive an AD-8 initial assessment and then have a six-month follow-up screening. The AD-8 tool provides a mechanism to determine if an individual is experiencing any changes in memory, problem-solving abilities, orientation, and daily activities. The AD-8 is a quick, accurate and easy tool to use.

Individuals who score two or higher (indicating memory loss) on the AD-8 are referred to the Alzheimer's Chapter within their region for a care consultation. The care consultation helps connect individuals and their families with supportive community-based services such as enrichment classes, support groups and volunteer opportunities.

Upon completion of the Project Learn MORE grant next fall, Missouri will have established a unified system of screening, referral, care planning and service for its citizens with Alzheimer's and related dementias. Because the AD-8 assessment tool is easy and inexpensive to administer, Project Learn MORE may serve as a successful model for other states to follow.

The biggest challenge to a statewide public awareness campaign on early intervention and diagnosis is a current lack of funding. In 2011, the Department of Health and Senior Services recorded and released an excellent podcast regarding Alzheimer's that is informative and easy to understand. The podcast is available on various websites including the Department of Health and Senior Services, the Lt. Governor's Office and other senior advocacy groups. Although podcasts are limited in reach, they are inexpensive and effective ways to educate Missourians. The task force will continue to pursue non-governmental funding for statewide public awareness campaigns in 2012.

¹ James E. Galvin, MD, MPH, Professor of Neurology and Psychiatry and is the Director of Clinical Operations for the Center of Excellence, Director of the Pearl Barlow Center for Memory Evaluation and Treatment, and Associate Director of the Alzheimer Disease Center. in New York, New York.

II. Road Map for Care and Support

Goal: Create a Road Map for care and support that provides quality information on services across the continuum from early diagnosis to end of life.

Methods:

- Identify existing statewide resource databases and evaluate them for inclusion of dementia related resources.
- Create a Road Map that includes information on community organizations such as the Alzheimer's Association and Area Agencies on Aging Network and provides unbiased information on care planning and in-person consultation.
- Develop a strategy for dissemination of the Road Map to consumers, health care professionals and community partners.

Most people do not think about or plan for any Alzheimer's services or support until they are diagnosed with the disease. At both the 2010 and Alzheimer's listening sessions, families expressed their frustration with learning too late about actions they could have taken for their loved ones with Alzheimer's. This includes addressing driving and safety concerns, taking care of legal and financial matters and discussing long term care options to ensure their loved one's needs and preferences are respected. People specifically requested a road map that would help guide their decision making and planning.

A workgroup comprised of task force members, practicum students, professionals in the field of aging, and consumers convened to develop a road map framework. The workgroup focused on three critical areas that individuals and families need the most direction in: health and wellness, safety, and legal and financial matters. The topics were then addressed for mild, moderate, and severe stages of Alzheimer's. The workgroup aimed to develop a straightforward road map that would help individuals and families address the most critical issues in a timely manner.

Concurrently, the Alzheimer's Association announced the development of the Alzheimer's Navigator, an online assessment program to help caregivers and individuals with dementia evaluate their needs, execute action steps and connect with local programs and services. Under this program, users complete a set of focused questions and receive a customized action plan detailing next steps and suggested resources to approach Alzheimer's. The Navigator works in conjunction with a newly developed online search engine that enables individuals and caregivers to locate community programs, services and resources. The website will be alzheimersnavigator.org.

With the anticipated launch of Alzheimer's Navigator in early 2012, the task force recommended postponing the development of a state Road Map in order to evaluate the Navigator as an adequate alternative to a road map.

III. Services and Support

Goal: Provide a wide array of community and home based services that may offer more cost-effective options for the rapidly increasing number of Missourians with Alzheimer's or related disorders and their caregivers.

Methods:

- Examine existing MO HealthNet programs for gaps in service that may limit the ability to utilize home and community based care.
- Identify and disseminate information on respite programs and advocate for expanded respite funding.
- Enhance awareness of the benefits of long term care insurance such as Missouri's Long Term Care Partnership Program and Missouri's new premium refund law.
- Identify the opportunities for Missouri to secure federal and non-federal funding to advance home and community based options for those with Alzheimer's and other related dementia.

In Missouri, during 2010, more than 300,000 family members and friends provided over 300 million hours of unpaid care, valued at \$4 billion dollars, to those with Alzheimer's and other dementias.

Caring for a person with Alzheimer's or dementia is often difficult and as a result many unpaid caregivers experience depression and high levels of emotional stress. Families often experience declining health, financial difficulties and even job loss. At the Alzheimer's listening sessions families expressed their strong desire to keep their loved ones at home and the need for caregiver support such as respite assistance.

During the 2011 and 2012 legislative sessions, the task force has supported appropriations for Alzheimer's Service Grants that fund respite care programs across the state. Some areas have waiting lists of up to a year for their respite programs. To address the great need for respite care, the task force is urging an appropriation in FY13 of \$300,000 for these programs. This amount is needed to serve current respite recipients as well as those on a waiting list, and is still forty percent less than the 2009 state funding for respite care.

Given the high costs of private long-term care service, many people cannot afford it for the duration of the disease. People live an average of four to eight years after diagnosis of Alzheimer's disease. However, some individuals live as long as twenty years after their diagnosis. A range of public and private resources are necessary to support persons with Alzheimer's disease. Personal savings can rapidly be exhausted by the expense of supporting victims of Alzheimer's. Long term care insurance, including insurance coverage for services ranging from in-home assistance to adult daycare to extended stays in nursing homes is an important source of support for persons with Alzheimer's, and for their families.

Area	Avg. Daily Nursing Home	Avg. Daily Nursing Home	Avg. Monthly in Assisted Living	Home Health Aide Avg.	Homemaker Services Avg.	Adult Day Services
	Rate: Private	Rate: Semi- Private	Facility	Hourly Rate	Hourly Rate	Daily Rate
Kansas City	\$ 158.00	\$ 143.00	\$ 2,433.00	\$ 18.00	\$ 18.00	\$ 72.00
St. Louis	\$ 178.00	\$ 151.00	\$ 3,863.00	\$ 19.00	\$ 19.00	\$ 71.00
Rest of MO	\$ 146.00	\$ 131.00	\$ 3,032.00	\$ 18.00	\$ 18.00	\$ 68.00
MO Avg.	\$ 157.00	\$ 140.00	\$ 2,948.00	\$ 18.00	\$ 18.00	\$ 70.00

Source: National Clearinghouse for Long Term Care Information

Insurance coverage for long term care is readily available, but accounts for less than 2% of the total market for medical insurance products in Missouri. Long Term Care (LTC) coverage is commonly perceived as too expensive, and the reasons for having the coverage are commonly misunderstood. Options may be available to public policymakers to stimulate the purchase of LTC insurance. Additional information about the market for LTC insurance coverage appears as Appendix I to this report.

Insurance	Number of Insureds
Individual LTC	125,959
Group LTC	54,947
Total LTC	180,906
Total MO Accident & Health	11,102,602

Source: MO Department of Insurance, <http://insurance.mo.gov/consumers/LongTerm/FAQ.php>

When a person's private resources become exhausted, Medicaid is often used to pay for the Alzheimer's care. As the number of individuals with Alzheimer's is rapidly increasing, so is the need for more Medicaid funding. In recognizing this impending problem, the task force examined existing MO HealthNet programs as well as dementia specific waiver programs implemented in other states.

The MO HealthNet programs provided medical services to 18,212 participants with Alzheimer's or other dementias at a cost of \$191,641,741 in state fiscal year 2011. The majority of expenditures (82.6%) for Alzheimer services are the result of nursing home care. The following table shows the top four categories that comprise 98.3% of all MO HealthNet expenditures for care related to Alzheimer or other dementias.

Category of Care	Participant Count	SFY 2011 Costs
Nursing Home Care	8,057	\$ 158,254,138
Pharmacy*	14,147	\$ 17,797,139
Community Based Services	1,122	\$ 10,401,192
Hospital	1,698	\$ 1,871,170

*Only includes pharmaceutical costs not covered by Medicare Part D.

As the population continues to age, costs will increase. Community based services provide a cost effective means to prevent or delay institutionalization in either a nursing home, intermediate care facility for the developmentally disabled, or a hospital. Missouri currently provides community based services through the Medicaid state plan (personal care, adult day health care, and home health) and through nine (9) 1915c Home and Community Based Waivers. While an expansive array of services is available through the waivers for individuals with a developmental disability, there are limited services for the aged or physically disabled population. An identified gap in coverage exists in the areas of respite, companion care, and skilled nursing services.

The task force recommends that upon approval of funding from the General Assembly, Missouri seek approval from the Centers for Medicare and Medicaid Services (CMS) for a 1915c Home and Community Based waiver as a more cost effective alternative to institutional care that addresses the gap in services for individuals with Alzheimer's and related dementias.

IV. Delivering Improved Dementia Care

Goal: Ensure a sufficient, dementia conscious, quality workforce at all levels of the care continuum.

Methods:

- Review current dementia training requirements for ways to improve the quality of dementia services across the care continuum.
- Design a system to review the transfers and discharges of individuals receiving care for Alzheimer’s disease or related dementias.
- Alzheimer’s care facilities and programs must demonstrate that their staff is trained to provide appropriate behavioral interventions and medications.
- Design a career ladder guide for employees that includes accredited dementia training.
- Develop and implement ongoing in-service training on Alzheimer’s disease and related dementia for first responders through programs such as Missouri Peace Officer Standards and Training.
- Develop a pilot demonstration project that incorporates dementia specialists for hospital and behavioral health settings.

Across the care continuum, from physicians, to hospitals, to hospice, there is an urgent need for more training on delivering quality dementia care. At Alzheimer’s listening sessions, families expressed the desire for persons delivering care to individuals with dementia to be trained in dementia care.

Since 2001, Missouri has had dementia training requirements for individuals employed by in-home agencies, home health agencies, adult day centers, assisted living facilities, residential care facilities and nursing homes (660.050.RSM0). However, statutory requirements are inconsistent and implementation varies from provider to provider and across different provider groups. Therefore, the task force appointed a workgroup to evaluate Missouri’s current dementia training regulations.

Concurrently in August of 2011, CMS issued a mandate in Section 6121 of the Affordable Care Act for Nurse Aide Training in Nursing Homes. The mandate stipulates that initial training requirements for new nurse aides include two topics in each nurse aide’s yearly training program: 1) How to care for residents with dementia; 2) How to prevent resident abuse.

As part of this project, CMS will consult with experts and national stakeholder groups to ensure that new products promote person-centered care as well as the current clinical standards, principles and practices. In an effort to assist facilities with complying with these provisions, the CMS memo lists training programs such as:

- CARES Program™ an online dementia care training program produced by HealthCare Interactive, Inc. consisting of ten 1-hour modules
- Foundations of Dementia Care – a classroom training program produced by the Alzheimer’s Association

While CMS focuses on nurse aide training, the memo states that it is their intent for facilities to expand the scope of training to include other direct and non-direct care staff. Missouri law requires training for direct and non-direct care staff as well as training for providers across the care continuum.

Upon review of the new CMS requirements and the analysis of Missouri's regulatory language for dementia training, the task force recommends that the Department of Health and Senior Services address current inconsistencies and strengthen regulatory language to ensure compliance with 660.050.RSMO and Section 6121 of the Affordable Care Act.

V. Missouri as a Leader in Alzheimer's Research

Goal: Maintain Missouri's status as a leader in Alzheimer's disease and related disorders research.

Methods:

- Restore state funding to Missouri based researchers for the Alzheimer's Disease and Other Related Disorders Program.
- Partner with academic institutions across the state to develop a research summit with the dual goals of fostering scientific collaboration and disseminating current research to the general public.

The Alzheimer's Disease Research and Related Disorders Program (ADRDP), established by legislation in 1987, focuses on advancing new research initiatives and bringing new researchers into the field. The program is administered by the Board of Curators at the University of Missouri. Since inception, the ADRDP has experienced a high return on its investment. The program supports an average of eight projects each year. For each dollar expended on these projects, more than ten dollars in subsequent support comes to the state from national granting agencies. Yet, the ADRDP has not been funded by the state since 2006. The task force strongly supports the reinstatement of funding to the ADRDP and passage of SB482 and HB1216, which would increase individual research grants from \$30,000 to \$50,000.

In 2011, approximately \$22 million in federal and foundation grants were awarded to Missouri Alzheimer's researchers. Current research can be divided into four broad categories: longitudinal studies and centers (~\$8 million), brain imaging (~\$3 million), mechanisms of disease (~\$10 million), and psychosocial factors (~\$1 million). Research in each of these categories is driven by the goal of earlier and improved diagnosis of Alzheimer's disease.

Highlights of Missouri Alzheimer's research:

- Washington University; Senior Author = Dr. John C. Morris – Researchers measured amyloid deposition in the brains of cognitively normal individuals using PET imaging. This study is the largest of its kind examining amyloid at two different time points (average of 2.5 years apart) in the same individuals; it strongly suggests that the major growth in amyloid deposition in the brain occurs prior to the onset of clinical symptoms of Alzheimer disease.
- Washington University; Senior Author = Dr. Randy Bateman – In this study, researchers measured the levels of amyloid in the spinal fluid in real time over a 36-hour period. They found that amyloid rises and falls in the spinal fluid in a daily pattern that echoes the sleep cycle; the brain's relative inactivity during sleep may provide an opportunity to clear amyloid, which can form plaques in the brain if not cleared. This data suggests that better sleep may be helpful in reducing the risk of Alzheimer's disease.
- University of Missouri-Columbia; Senior Authors = Drs. James Lee and Grace Sun – Researchers investigated how the components of the cell membrane can affect amyloid precursor protein, the source of amyloid. Their results indicated that certain unsaturated fatty acids could increase cleavage of amyloid

precursor protein in a way that **prevents** amyloid production. Since these fatty acids are ingredients in food, information derived from this study should provide potential dietary strategies for the prevention of Alzheimer disease.

- University of Missouri-Columbia; Senior Author = Dr. Lorraine Phillips – The purpose of this study was to test the effect of a storytelling program on communication, neuropsychiatric symptoms, and quality of life in long-term care residents with dementia. Researchers found that creative storytelling positively affected quality of life and improved communication skills in persons with moderate dementia.
- Saint Louis University; Senior Author = Dr. George Grossberg – This study was an analysis of a large, international, trial of the rivastigmine (Exelon) patch in patients with mild-to-moderate Alzheimer disease. The data suggested that patch doses higher than the commonly used 9.5 mg/24 hr (in particular, 13.3 mg/24 hr) may provide additional cognitive benefit without sacrificing safety or tolerability.

Appendix

Department of Insurance Summary

Long Term Care is medical and non medical care for people who have a chronic disease, serious accident, sudden illness, or cognitive impairment such as Alzheimer's disease. This care can be provided at someone's home, in a nursing home or other setting. This care can be given by either a health care professional, like a nurse or home health aide, other paid personal care providers, or family members. LTC differs from regular medical care in that the focus of LTC is not necessarily to improve the medical condition of the insured but to maintain the insured's quality of life. To better define LTC, six activities of daily living are used to decide if an individual needs long term care assistance.¹

The six activities of daily living are bathing, continence, dressing, eating, toileting and transferring. Bathing is defined as the ability to wash oneself and includes getting into and out of a tub or shower. Continence is the ability to maintain control over one's bladder and bowel functions. Dressing involves the putting on and off of all articles of clothing and necessary braces, fasteners or artificial limbs. Eating includes the ability to feed oneself by getting food into the body from a receptacle. Toileting is defined as getting onto and off, and to and from, the toilet and performing the associated personal hygiene. Transferring is moving into or out of a bed, chair or wheelchair.¹

LTC Insurance provides insurance coverage for the cost of LTC beyond a predetermined point. It pays for the support services that are associated with treating and giving LTC. Medicare and other types of health insurance generally do not cover LTC. LTC policies vary in the amount and scope of services they cover and in the settings in which the services are provided.

To encourage more people to buy LTC Insurance, the Federal and State governments enacted laws establishing the Long Term Care Partnership program. The LTC partnerships provide a mechanism for individuals to qualify for Medicaid coverage without first being required to exhaust all of their assets. This is done by allowing an individual to protect a certain amount of assets when applying for Medicaid coverage, determining Medicaid eligibility, determining the amount of any Medicaid payment, or recovery by the state of a payment for medical services. The amounts of assets being protected have to equal the insurance benefits amount in a LTC insurance policy. For example, if an individual purchased a LTC Partnership policy that has benefits of \$200,000 then that individual can protect up to \$200,000 worth of assets. For a policy to qualify as a partnership policy certain criteria have to be satisfied.¹

Those criteria are firstly, the insured person has to be a resident of the partnership state when the coverage first becomes effective. Secondly, the policy must meet the IRS definition of a qualified long term care policy, which means that the policy benefits are not taxable. Thirdly, the coverage must meet the requirements of the Deficit Reduction Act of 2005. Fourthly, the coverage must contain inflation protection not less favorable than the following: if the individual is less than 61 at the time of purchase then the policy must contain compound inflation protection; if the individual is older than 61 and less than 76, the policy must contain some level of inflation protection; and for anyone older than 76, inflation protection may be offered but is not

required. Lastly, the policy must meet specific rules as established by the National Association of Insurance Commissioners (NAIC).¹

Individuals purchase LTC insurance for a variety of reasons. The first reason would be to protect their assets from having to be sold off to pay for long term care. Medicare, Medicaid and other private insurance plans don't cover the full cost of LTC. Long Term Care Insurance helps cover the costs of an individual's LTC needs that are not covered by Medicare, Medicaid or any other private insurance plan. The second reason for purchasing LTC insurance is to preserve financial independence; insurance helps an individual to not have to rely on family, friends or government programs for financial support. The next reason is that it allows an individual to not have to rely on family members for care. The fourth reason is that long term care insurance guarantees the affordability of services. The last reason is that the individual is conscious of the increasing costs of LTC insurance. Individuals are aware that as they get older the cost of LTC insurance will increase so the decision to purchase today is a better decision than waiting until getting older to purchase LTC insurance.¹

The costs associated with dealing with LTC needs as well as the cost of long term care insurance can be quite expensive and LTC insurance premiums are increasing. According to data from the National Clearinghouse for Long Term Care Information, the 2008 average monthly premium for LTC Insurance in the United States ranges from \$134 for someone under the age of 30 to \$1,928 for someone 65 or older. To go along with the high premium rates the cost of LTC is higher. The cost of staying in a nursing home ranges from \$4,200 to \$4,710 per month depending on if the individual wants a private or a semi-private room. The cost of staying in an assisted living facility averages about \$2,948 per month. The data in this section are in tables 1 & 2 below.¹

Even though data on the characteristics of purchasers of LTC insurance in Missouri is relatively difficult to come across, there have been studies published on the LTC insurance buyers across the country which helps infer who buys LTC insurance in Missouri. Additionally, there is data on the LTC partnership program in Missouri and this data is useful to help infer who purchases LTC insurance in Missouri. The two most useful data sources are the AHIP study *Who Buys Long Term Care Insurance? A 15-Year Study of Buyers and Non-Buyers, 1990-2005* and data gathered by Thomson Reuters on Long Term Care partnerships. The data shows the location, gender and age of buyers.

The two data sources have the age groups broken down in different ways but they both show that the vast majority of purchasers are between the ages of 50-70. The AHIP data shows that the average age of purchasers is 61 and 45% of purchasers are from the age range of 55-64. The second largest age group is 65-69 with 17% of purchasers and 50-54 age group is the next largest at 15%. Combined these age groups comprise nearly 80% of the market. The Thomson Reuters data show that the largest group of LTC partnership purchasers is from the age group of 61-70. The second largest age group of purchasers is 51-60. These two age groups make up nearly 80% of the market. Both studies show that roughly 57% of consumers are female. Unfortunately the AHIP report does not provide any statistics on what type of area consumers live in but the Thomson Reuters data does illustrate the type of county of individuals who buy LTC partnerships. The counties are a metropolitan, micropolitan or rural county. Metropolitan counties are those counties that are part of metropolitan area. A metropolitan area has at least one urbanized area that has a population of at least 50,000. Some examples of a metropolitan area are the St. Louis and Kansas City areas. Micropolitan counties are those counties that are part of a micropolitan area. A micropolitan area has an urban area that has at least a population of 10,000 but less than 50,000. Some examples of a micropolitan area are the Branson and

Sedalia areas. A county not classified as being part of either a metropolitan or micropolitan area is considered to be a rural county. The overwhelming majority, with nearly 82% of consumers, reside in counties that are considered metropolitan. Rural county residents are about 10% of consumers and micropolitan residents composed the rest of consumers at 8%. The data in this paragraph are in Tables 3, 4 and 5 below and it is data for LTC partnerships.¹

Data from the Missouri Department of Insurance website tells us the size of the LTC insurance market. For the year of 2010 there were 125,959 insureds in the individual LTC insurance market and 54,947 insureds in the group LTC insurance market. This totals 180,906 insureds in the LTC insurance market while the total number of insureds in the Accident and Health Insurance market in Missouri in 2010 was 11,102,602. (Note this is nearly double the population of the state. It is understood that the total A&H market reflects the fact that any person in the market may be there more than once – they may have a health insurance policy, a long term care policy, a supplemental disability policy, etc.) LTC insurance makes up less than 2% of the overall Accident and Health market. The above numbers and percentages indicate that in Missouri the LTC insurance market is very small and this mirrors the conditions of the LTC insurance market across the whole country. Data for this paragraph is in Table 6 below.¹

There are ways to educate Missourians about the need for LTC planning and encouraging the consideration of LTC insurance. The following are some ideas to consider in helping to educate Missourians on LTC.

Many people wrongly think that Medicare will cover the costs of LTC. This is only partly true; Medicare will pay for LTC if an individual requires skilled nursing or rehabilitative care for a short period of time but not the non skilled associated with the activities of daily living. Medicare will only provide care if an individual has spent at least three days in the hospital and the individual is admitted to a Medicare certified nursing facility within 30 days of the individual's prior stay. Medicare will pay for full coverage for the first 20 days and only partial coverage from the 21st-100th days. After the 100th day the individual pays for all of the costs of staying in a skilled nursing facility.

LTC Insurance premiums are relatively inexpensive compared to the cost of LTC services. LTC Insurance premiums in Missouri are on average \$816 per month. This is roughly a fifth of the cost of staying in a nursing facility, which averages from \$4,200 to \$4,700 per month. The premiums are roughly a quarter the cost of paying a home health aide or homemaker service, which is about \$4,320 per month (based on 8 hour day, 30 days in a month).

Long Term Care Partnerships provide the chance for individuals to protect their savings from being exhausted before they can be eligible for Medicaid. This allows individuals to keep their life savings intact while they take care of their LTC needs. The LTC partnership gives individuals the peace of mind knowing that they will not be left in financial ruin after paying for LTC. A number of insurance companies sell LTC Partnerships in Missouri, a list of those companies can be found at <http://insurance.mo.gov/consumers/LongTerm/#>.

Consumers can educate themselves from a number of resources. Most of those resources can be accessed through the Department of Insurance's website on Long Term Care at <http://insurance.mo.gov/consumers/LongTerm/#> or the website of the National Clearinghouse for Long Term Care Information which is www.longtermcare.gov . If a consumer has concerns or questions regarding LTC

insurance they can contact the department’s Insurance Consumer Hotline at 800-726-7390, or by email to consumeraffairs@insurance.mo.gov.

Table 1

Area	Avg. Daily Nursing Home	Avg. Daily Nursing Home	Avg. Monthly in Assisted Living	Home Health Aide Avg.	Homemaker Services Avg.	Adult Day Services
	Rate: Private	Rate: Semi- Private	Facility	Hourly Rate	Hourly Rate	Daily Rate
Kansas City	\$ 158.00	\$ 143.00	\$ 2,433.00	\$ 18.00	\$ 18.00	\$ 72.00
St. Louis	\$ 178.00	\$ 151.00	\$ 3,863.00	\$ 19.00	\$ 19.00	\$ 71.00
Rest of MO	\$ 146.00	\$ 131.00	\$ 3,032.00	\$ 18.00	\$ 18.00	\$ 68.00
MO Avg.	\$ 157.00	\$ 140.00	\$ 2,948.00	\$ 18.00	\$ 18.00	\$ 70.00

Source: National Clearinghouse for Long Term Care Information

Table 2

Age Group	Avg. Monthly Premium (\$)	Range of Premiums (\$)
Under 30	134	91 - 1,110
30-39	245	151 - 1,328
40-49	476	513 - 1,634
50-59	837	508 - 2,130
60-64	1,278	766 - 2,258
65 and older	1,982	1,355 - 4,077

Source: National Clearinghouse for Long Term Care Information

Table 3

Age Group	Percent of Policyholders
0-40	2.06%
41-50	8.16%
51-60	34.16%
61-70	44.98%
71+	10.64%

Source: Thomson Reuters

Table 4

Gender	Percent of Policyholders
Female	57.15%
Male	42.85%

Source: Thomson Reuters

Table 5:

Type of County	Number of Policyholders	Percent of Policyholders
Metropolitan	4,025	81.59%
Micropolitan	417	8.45%
Rural	491	9.95%
Total	4,933	100%

Source: Thomson Reuters

Table 6:

Insurance	Number of Insureds
Individual LTC	125,959
Group LTC	54,947
Total LTC	180,906
Total MO Accident & Health	11,102,602

Source: Missouri DIFP

¹ MO Department of Insurance, <http://insurance.mo.gov/consumers/LongTerm/FAQ.php>

¹ 20 CSR 400-4.100(3)(D)(F)(G)(H)(O)(P)

¹ MO Dept of Insurance

¹ 20 CSR 400-4.110(1)(A)

¹ Who Buys Long Term Care Insurance? A 15 year study 1990-2005, prepared for AHIP by LifePlans Inc., www.ahipresearch.org/PDFs/LTC_Buyers_Guide.pdf pgs. 55-56

¹ National Clearinghouse for LTC Information, www.longtermcare.gov/LTC/Main_Site/Tools/Paying/Private-Financing/LTC_Insurance/Buying.aspx#Cost & www.longtermcare.gov/LTC/Main_Site/Tools/State_Costs.aspx

¹ Who Buys LTC? Thomson-Reuters, <http://w2.dehpg.net/LTCPartnership/Reports.aspx>

¹ MO Department of Insurance, <http://insurance.mo.gov/reports/suppdata/>

factsheet

MARCH 2011

alz.org

2011 Alzheimer's Disease Facts and Figures

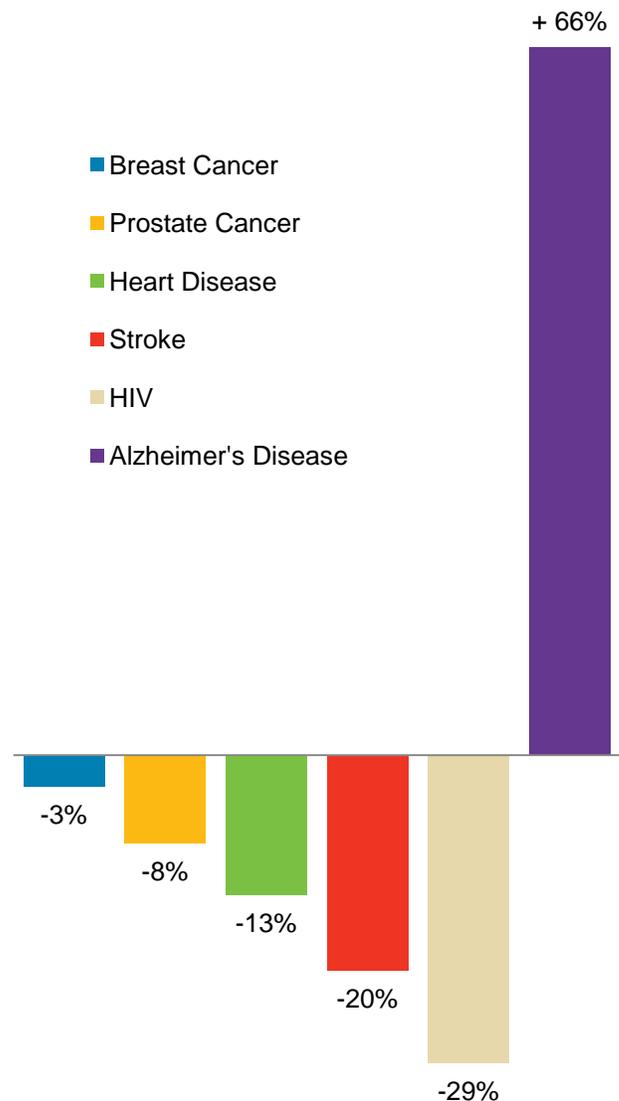
With Alzheimer's, it is not just those with the disease who suffer. It's also their caregivers.

- In 2010, 14.9 million family and friends provided 17 billion hours of unpaid care to those with Alzheimer's and other dementias.
- The economic value of the unpaid care provided to those with Alzheimer's and other dementias totaled \$202.6 billion in 2010.
- More than 60 percent of Alzheimer's and dementia caregivers rate the emotional stress of caregiving as high or very high; one-third report symptoms of depression.

Alzheimer's is not just memory loss. Alzheimer's kills.

- Alzheimer's disease is the 6th leading cause of death in the United States and the 5th leading cause of death for those aged 65 and older.
- Alzheimer's is the only cause of death among the top 10 in America without a way to prevent, cure, or even slow its progression.
- Deaths from Alzheimer's increased 66 percent between 2000 and 2008, while deaths from other major diseases, including the number one cause of death (heart disease), decreased.

Change in Number of Deaths Between 2000 and 2008



Based on preliminary 2008 mortality data

The number of Americans with this devastating and heartbreaking disease is growing – and fast.

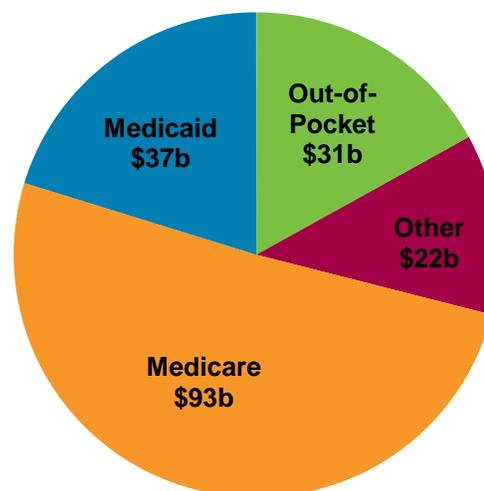
- Today, 5.4 million Americans are living with Alzheimer's disease – 5.2 million aged 65 and over; 200,000 with younger-onset Alzheimer's. By 2050, as many as 16 million Americans will have the disease.
- Two-thirds of those with the disease – 3.4 million – are women.
- Of Americans aged 65 and over, 1 in 8 has Alzheimer's, and nearly half of people aged 85 and older have the disease.
- Another American develops Alzheimer's disease every 69 seconds. In 2050, an American will develop the disease every 33 seconds.
- Most people survive an average of four to eight years after an Alzheimer's diagnosis, but some live as long as 20 years with the disease.
- On average, 40 percent of a person's years with Alzheimer's are spent in the most severe stage of the disease – longer than any other stage.
- Four percent of the general population will be admitted to a nursing home by age 80. But, for people with Alzheimer's, 75 percent will be admitted to a nursing home by age 80.

Facts in Your State

The *2011 Alzheimer's Disease Facts and Figures* report also contains data on the impact of the disease in every state across the nation.

Find the full report and information on your state at www.alz.org/facts

2011 Cost of Alzheimer's = \$183 Billion



Alzheimer's disease has profound implications for government budgets.

- In 2011, the cost of caring for those with Alzheimer's to American society will total an estimated \$183 billion. This is an \$11 billion increase over last year – a rate of increase more than four times inflation.
- Average per person Medicare payments for those with Alzheimer's and other dementias are three times higher than for those without these conditions. Medicaid spending on seniors with Alzheimer's and other dementias is nine times higher.
- Unless something is done, the costs of Alzheimer's to Americans in 2050 will total \$1.1 trillion (in today's dollars).
- Between now and 2050, Medicare spending on those with Alzheimer's will increase nearly 600 percent, and Medicaid spending will increase nearly 400 percent.



Missouri

ALZHEIMER'S STATISTICS

In the United States, an estimated **5.4 million people** are living with Alzheimer's disease, and someone develops the disease every **69 seconds**. Unless something is done, as many as **16 million** Americans will have Alzheimer's in 2050 and someone will develop the disease every **33 seconds**. In 2010, **14.9 million** family members and friends provided **17 billion hours** of unpaid care to those with Alzheimer's and other dementias – care valued at **\$202.6 billion**.

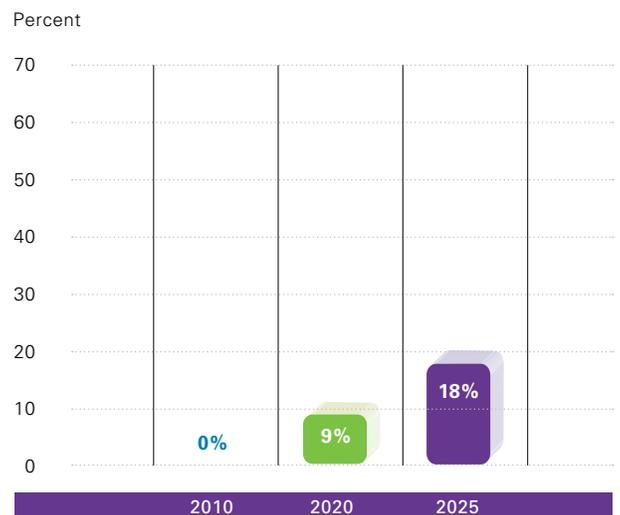
Number of People Aged 65 and Older with Alzheimer's by Age

Year	65-74	75-84	85+	Total	% change from 2000
2000	6,500	55,000	48,000	110,000	
2010	5,600	53,000	55,000	110,000	0%
2020	7,200	53,000	57,000	120,000	9%
2025	8,300	63,000	58,000	130,000	18%

Number of Alzheimer's and Dementia Caregivers, Hours of Unpaid Care, and Economic Value of Care

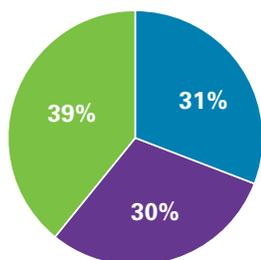
Year	Number of Caregivers	Total Hours of Unpaid Care	Total Value of Unpaid Care
2008	180,997	156,236,940	\$1,734,230,037
2009	202,662	230,791,080	\$2,654,097,424
2010	304,448	346,705,485	\$4,136,196,441

Percentage Change in Number with Alzheimer's Disease Compared to 2000



Cognitive Impairment in Nursing Home Residents, 2008

Total Nursing Home Residents **79,422**



- Level of Cognitive Impairment
- severe/moderate
 - mild/very mild
 - none

Number of Deaths Due to Alzheimer's Disease in 2007

1,681

