



Arizona Alzheimer's State Plan

A Framework for Action



*Working Together to Address the Growing
Human and Financial Cost of Dementia in Arizona*

November 2016

On behalf of the individuals and families living with and effected by Alzheimer's disease and related disorders, we are honored to share the new **Arizona Alzheimer's State Plan: A Framework for Action.**

Arizona leads the nation in the advancement of research toward a cure and the advancement of quality care and supportive services for Alzheimer's. Arizona is also challenged by the high growth rate of the disease.

This Plan offers a framework for public and private sectors, businesses, organizations, and communities to work together on common goals for Arizona.

- 1. Maximize public awareness and understanding**
- 2. Develop new and enhance existing supports for people with Alzheimer's disease and their families**
- 3. Expand dementia-capable workforce in Arizona**
- 4. Advance and disseminate research**
- 5. Create a dementia-capable system in Arizona**

Our next step as we move toward implementation will also include a call to action for individuals, families, and community members in how each of us can help address the growing need.

Sincerely,

Arizona Alzheimer's Task Force



DOUGLAS A. DUCEY
GOVERNOR

STATE OF ARIZONA
OFFICE OF THE GOVERNOR

EXECUTIVE OFFICE

September 2015

Arizona is home to more than 1.6 million people 60 years of age and older and that number is expected to reach 3 million by 2030. Currently 120,000 Arizonans age 65 and older are diagnosed with Alzheimer's disease, and that number is projected to reach 200,000 by 2025. While Alzheimer's disease is not a typical part of aging, it is the fourth leading cause of death in our state and the top leading cause for women age 65 and older.

There is good news to share. The Arizona Alzheimer's Task Force was launched in 2011 to bring together a wide range of public and private stakeholders throughout the state to address the growing human and financial cost of Alzheimer's disease and related disorders. Thanks to the work of more than 100 community members, a framework for action has been developed.

I urge all Arizonans to review the recommendations and watch for opportunities to get involved. It will take all of us working together to make sure our state effectively manages this growing concern and offers hope for those directly impacted.

Sincerely,

A handwritten signature in black ink that reads "Douglas A. Ducey".

Douglas A. Ducey
Governor
State of Arizona

1700 WEST WASHINGTON STREET, PHOENIX, ARIZONA 85007
602-542-4331 • www.azgovernor.gov



TABLE OF CONTENTS

The Need for a Framework for Action 5

Vision Mission and Guiding Principles 8

Goals, Recommendations and Strategies 10

Appendices

Overview of Alzheimer’s Disease and Related Disorders 23

Glossary of Terms 26

Acknowledgements 28

Contact Information 31



THE NEED FOR A FRAMEWORK FOR ACTION

Alzheimer's disease and related disorders touch every person in Arizona. The impact is very real, whether it is the rising costs of medical and skilled nursing care, sharing roads with drivers with dementia, law enforcement time to search for people with Alzheimer's who wander and become lost, impact of financial exploitation cases, growing health care needs, or – perhaps most importantly - the emotional, physical and financial impact of having or caring for someone with Alzheimer's disease.

Alzheimer's disease is the most common form of dementia. The disease attacks brain cells, causing problems with memory, thinking and behavior. Alzheimer's is not a typical part of aging; it is a progressive disease that worsens over time, with no cure available today.

The Arizona Alzheimer's Task Force was formed to bring together a wide range of public and private stakeholders throughout the state to address the growing human and financial cost of dementia in Arizona. Over 100 community members throughout Arizona have been engaged in the Task Force and its Work Teams to develop the Arizona Alzheimer's State Plan, including professionals from multi-disciplinary fields, government and non-profit agencies, the research community, aging services providers, individuals in the early stage of Alzheimer's disease, and family caregivers. The initial Task Force Planning Group has been a collaboration of the Governor's Office on Aging, the Arizona Department of Economic Security Division of Aging and Adult Services, the Arizona Alzheimer's Consortium, and the Alzheimer's Association Desert Southwest Chapter. This collaboration has provided guidance to the Task Force and helped ensure efforts are in alignment with the State Plan on Aging.

Task Force partners recognize that now is the time to build a plan for Arizona's future. In 2015, there are 120,000 Arizonans age 65 and older who have Alzheimer's disease. This number is expected to increase to 200,000 by 2025, representing the second highest projected growth rate in our nation.¹ Alzheimer's disease is now the fourth leading cause of death in Arizona, and the top leading cause for women age 65 and older. While Arizona's total population is expected to increase about 80% from 2010 to 2050, a growth rate of 174% is expected during this period for Arizonans age 65 and older. In addition to the aging in place of



baby boomers, Arizona continues to have a high in-migration of seniors coming to the state to retire. Given the general prevalence rate that one in nine people at age 65+ and one in three at age 85+ will have Alzheimer's disease¹, Arizona must prepare for a rapid increase in the number of residents with Alzheimer's.

It is not only the person with Alzheimer's disease who is impacted, but also family, friends and communities. In 2014, 314,000 family caregivers provided 357 million hours of unpaid care to people with Alzheimer's disease and related disorders in Arizona. The value of this unpaid care was over \$4.58 billion. During this period, Arizona's family caregivers had a \$155 million higher cost of health care for themselves.¹

This document is intended as Arizona's new collaborative strategic plan framework to address Alzheimer's disease and related disorders. Arizona was one of the first states to include a subcommittee on Alzheimer's disease and related disorders as part of the sunset review process for the Governor's Advisory Council on Aging completed in 1990. Since that time, the Governor's Advisory Council on Aging has worked with a variety of public and private sector partners in the consideration of the needs of Arizona residents experiencing the journey of Alzheimer's disease. Much has been discovered about Alzheimer's disease and its impact over the past 25 years, including many innovations and best practices in policy, research, care and supportive services that have been developed and implemented in Arizona.

The Arizona Alzheimer’s Task Force will continue its important work in the next phase of implementation of the State Plan’s “Framework for Action”. A “Call to Action” plan will be developed, to include suggested calls to action for many diverse stakeholders and community members. We will be able to build on our strengths. We are fortunate in Arizona to have some of the nation’s top researchers and practitioners already committed to working on diagnosis, treatment and finding ways to prevent and treat Alzheimer’s. State agencies and other partners have been awarded federal funding to collaboratively advance our work, including support to develop dementia-capable systems and the Healthy Brain Initiative. We have many health and human service care team members working closely with those diagnosed, their care partners and families to ensure that quality care and supportive services are provided to those in need. Considering current economic challenges, collaboration is no longer a choice but instead a necessity. Many state agencies, local municipalities, and private sector community organizations have already imbedded Alzheimer’s related priorities and actions into their own respective plans. Armed with the new State Plan, Arizona is posed to continue to be a leader in ensuring that until there is an end to Alzheimer’s disease, there will be care and support.





The vision of the Task Force is the elimination of Alzheimer’s disease and related dementia. Until there is a cure, the vision is that there will be quality care and supportive services available, accessible and acceptable throughout Arizona.

MISSION STATEMENT

To address the growing human and financial cost of dementia in Arizona.

GUIDING PRINCIPLES

The Goals, Recommendations and Strategies for programs, services, practice, policy and research related to Alzheimer’s disease in Arizona are intended to:

- Focus on the four “A’s”: Awareness, Availability, Accessibility, and Acceptability.
- Include all aspects of the diversity of our populations and communities throughout Arizona.
- Respond to both Alzheimer’s disease and the related disorders.
- Focus on the individual needs, strengths, preferences and expectations of people living with dementia, their family care partners and professionals who serve them.
- Empower to build resiliency.
- Reduce the stigma often associated with the disease.
- Promote collaboration and leveraging resources.
- Advance a seamless integration of the quality care continuum.

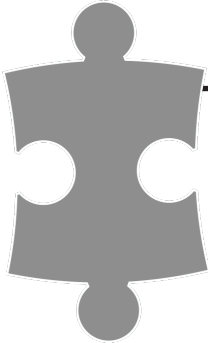
- Include a message of hope.
- Support the engagement of a “Care Team” that is inclusive of the person living with Alzheimer’s, the caregiver/care partner, and health and human service providers. It is recognized that Care Teams can best function within a larger caring community network (for example, neighborhoods, faith based organizations, civic organizations, etc.).
- Promote strategies to preserve cognitive health.
- Recognize that recommendations and strategies to achieve goals require an iterative review process to maximize resources and impact.

The Task Force’s intent is that the Plan’s framework be considered as a whole. The Plan includes recommendations and strategies that could have been placed within additional Goal areas; however, efforts were purposefully made to reduce duplication.



GOAL 1

Maximize Public Awareness and Understanding



Increase public awareness and understanding of Alzheimer’s disease and related disorders, resources for assistance and ways to help in Arizona. In keeping with the Task Force’s Guiding Principles, the recommendations and strategies are intended to be inclusive to all aspects of the diversity of our populations and communities throughout Arizona.

RECOMMENDATION 1.1

Implement A Public Awareness Campaign Focused On Reducing The Stigma Of The Disease

Strategies

- A. Identify public and private sector community partners to collaboratively develop and conduct a statewide awareness campaign focused on Alzheimer’s as a chronic disease that impacts everyone.
- B. Promote realistic, positive and diverse images of people with Alzheimer’s disease and their care partners to improve societal acceptance and integration.
- C. Utilize appropriate public and social media to reach a broad audience.
- D. Partner with educational institutions at all levels to infuse Alzheimer’s disease information into health related curricula.
- E. Develop the “Dementia Friendly” best-practice model as a means to promote awareness through sensitivity training to community members, public and private organizations, and businesses in Arizona.



RECOMMENDATION 1.2

Conduct Community Education Focused On Healthy Lifestyles, Warning Signs And Benefits Of Early Detection

Strategies

- A. Engage community partners in disseminating information and educating their constituents about the differences between memory changes related to aging and potential warning signs of Alzheimer's, risk factors, the importance of early diagnosis, and effective strategies for obtaining a diagnosis.
- B. Integrate Alzheimer's disease awareness training into existing urban and rural public health and community health centers for related chronic diseases.
- C. Coordinate efforts to disseminate evidence-based messages about risk reduction for preserving cognitive health, such as the benefit of exercise, healthy eating, and chronic disease management including of diabetes or hypertension.
- D. Promote cognition as an essential "vital sign" to be assessed during patients' Annual Wellness Visits, including for Medicare, to both the general public and the medical community.



RECOMMENDATION 1.3

Ensure Accessibility To And Acceptability Of Information About The Disease, Available Health Care Resources, Supportive Services, And Research Opportunities

Strategies

- A. Identify, develop and/or update consumer resource materials appropriate for diverse audiences, to be disseminated by community partners.
- B. Promote websites that include evidence-based information on Alzheimer's disease, with linkages to web-based education, assessment tools and community resources.
- C. Ensure appropriate training for health and social service organizations that provide telephone help lines which may receive calls from constituents with dementia-related concerns.
- D. Encourage regional transportation plans to include the needs people with Alzheimer's and their care partners.
- E. Promote the use of technologies to enhance access to services, including expansion of telemedicine programs.
- F. Promote the benefits of and opportunities for participation in research.

RECOMMENDATION 1.4

Encourage Public And Private Sector Partners To Integrate Alzheimer's Priorities Into Their Action Or Operational Plans

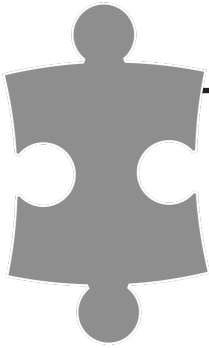
Strategies

- A. Incorporate cognitive health, Alzheimer's disease, and caregiving needs into strategic and action plans of state and local government, health and social service organizations, research and educational institutions, businesses and faith communities.
- B. Develop and disseminate tools kits and provide technical assistance on creating "Dementia Friendly" neighborhoods, communities and organizations.
- C. Engage community gatekeepers, including first responders, pharmacy staff, bank tellers, and utility workers, through training on how to help people with dementia.



GOAL 2

Develop New & Enhance Existing Supports for People with Alzheimer’s Disease and their Families



Ensure the availability, accessibility, and acceptability of supportive resources for people living with Alzheimer’s disease and related disorders and their caregivers in Arizona. In keeping with the Task Force’s Guiding Principles, the recommendations and strategies are intended to be inclusive to the individual and their families to all aspects of the diversity of our populations and communities throughout Arizona.

RECOMMENDATION 2.1

Increase Education And Skill Training Opportunities

Strategies

- A. Expand diverse care management infrastructures that assist families in accepting and understanding the diagnosis, how to access services, identifying and overcoming future challenges and other concerns.
- B. Expand quality educational trainings throughout the state of Arizona to include urban and rural communities for people with Alzheimer’s disease and their caregivers.
- C. Ensure that people living with Alzheimer’s disease and their caregivers have accessible skill training statewide.
- D. Promote the development of innovative tailored service delivery and outcome tactics to address individual, family and cultural needs.

RECOMMENDATION 2.2

Expand The Availability Of Evidence-Based Supportive Services

Strategies

- A. Evaluate support services to ensure the effectiveness for people living with Alzheimer’s disease and their caregivers.
- B. Promote innovative evidence-based supportive services, with a focus on those that help with behavioral symptom management.
- C. Identify areas for programmatic collaboration to enable service expansion statewide.

RECOMMENDATION 2.3

Expand Respite Opportunities To Provide Needed Relief For Unpaid Caregivers To Continue As The Backbone Of The Long-Term Care System

Strategies

- A. Broaden the eligibility requirements for use of respite programs and grants so that more families may benefit regardless of financial status, age or location.
- B. Expand collaborative efforts to offer consumer-directed respite services.



RECOMMENDATION 2.4

Ensure Accessibility Of Resources To People Living With Alzheimer’s Disease And Related Disorders And Their Families By Identifying And Removing Barriers To Engagement

Strategies

- A. Assist people living with Alzheimer’s disease and their caregivers in planning for future care needs, accounting for the cost and impact.
- B. Provide tools for caregivers to request appropriate supportive resources from their employers.
- C. Promote the utilization of available transportation services for individuals living with Alzheimer’s disease who are unable to drive.
- D. Establish social, supportive and recreational activities tailored to special needs and geographically isolated communities.
- E. Promote the availability of community-based services for people living with Alzheimer’s disease and their families statewide.

RECOMMENDATION 2.5

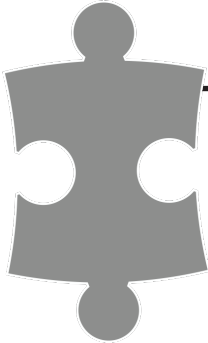
Develop And Promote Access To Services That Protect The Safety Of People Living With Alzheimer’s Disease And Related Disorders

Strategies

- A. Encourage and promote the utilization of best-practice safety programs.
- B. Develop and disseminate toolkits on safety-related prevention for people living with Alzheimer’s disease and their caregivers.
- C. Promote the development of individualized emergency preparedness plans for people living with Alzheimer’s disease and their caregivers.

GOAL 3

Expand Dementia-Capable Workforce in Arizona



Expand the dementia-capable workforce in Arizona through specialized dementia education and training, and the development and implementation of standardized quality measures of dementia care across long-term-care, community health and other healthcare settings. In keeping with the Task Force’s Guiding Principles, the recommendations and strategies are intended to be inclusive to all aspects of the diversity of our populations and communities throughout Arizona.

RECOMMENDATION 3.1

Develop A Dementia-Capable And Culturally Competent Workforce That Cares For Older Adults And People With Alzheimer’s Disease And Related Disorders Throughout The Continuum Of Care

Strategies

- A. Identify and promote best practices related to dementia care across various care settings.
- B. Support certification, licensure, and degree programs for those working with older adults and people with Alzheimer’s disease and their caregivers.
- C. Partner with licensing and certification boards to recommend continuing education on Alzheimer’s and related dementias as a condition of license renewal for doctors, nurses, and other health professionals.
- D. Recommend competency-based training based on the “Principals of Caregiving – Arizona Direct Care Curriculum – Alzheimer’s Disease and Related Disorders Module” (available through www.azdirectcare.org)
- E. Encourage care providers to partner with multicultural coalitions as they develop dementia-capable services for ethnically diverse clients and residents across the continuum of care.
- F. Develop innovative models to address workforce shortages, including recruitment and retention strategies, through education and training programs.



RECOMMENDATION 3.2

Train Professionals In Non-Health Care Fields Who Interface With Families Of People Living With Alzheimer’s Disease And Related Disorders

Strategies

- A. Encourage comprehensive Alzheimer’s disease and related disorders training to first responders, law enforcement, EMTs, fire fighters, emergency preparedness, and search and rescue officials.
- B. Promote innovative evidence-based supportive services, with a focus on those that help with behavioral symptom management.
- C. Promote training on legal issues facing people with Alzheimer’s disease and related disorders and their families, such as guardianship, conservatorship, and powers of attorney.
- D. Promote dementia training for individuals who serve the public, such as mail carriers, meter readers, and meals on wheels volunteers.
- E. Develop new and refine existing training materials for information and referral staff in service agencies.

RECOMMENDATION 3.3

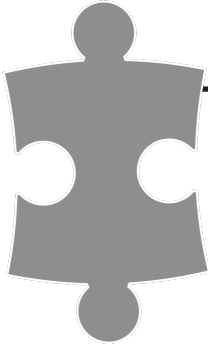
Improve Dementia Care Capacity And Competency Of Health And Human Service Care Teams

Strategies

- A. Develop and disseminate dementia-specific curriculum and training programs tailored to health and human service professionals.
- B. Improve care practices by linking people living with Alzheimer’s disease and related disorders to dementia care managers to coordinate care, manage individual cases, and supplement clinical care with resources on supportive services and community-based agencies that offer specialized expertise, social supports, and mental health services.
- C. Create and disseminate an evidence-based set of guidelines for disease management to improve evaluation, treatment, care coordination, and follow-up support of the person with Alzheimer’s disease or a related disorder, conservatorship, and powers of attorney.
- D. Educate clinicians on the criteria needed to refer and qualify people with dementia for hospice care to ensure that patients receive full benefit of the medical, health services, and social supports offered at end of life.
- E. Promote the Arizona Alzheimer’s Consortium as a tertiary referral resource for the state’s physicians to support diagnosis and management of complex cases.
- F. Incorporate Alzheimer’s educational materials for people with dementia and family caregivers into digital libraries to enable physicians to store and disseminate such information in connection with electronic medical records.
- G. Expand the role of community health workers in dementia education and care in reaching underserved communities.

GOAL 4

Advance and Disseminate Research



Conduct and disseminate **cutting-edge research** in Alzheimer's disease and related disorders including research on its impact on Arizona through increased funding and support, expanded collaborations, and a greater understanding of research and its benefits. In keeping with the Task Force's Guiding Principles, the recommendations and strategies are intended to be inclusive to all aspects of Arizona's diversity.

RECOMMENDATION 4.1

Collect And Share Research Findings About The Impact Of Alzheimer's Disease On Arizona And Its Residents

Strategies

- A. Include cognitive impairment, comorbidities/ co-occurring disorders, stress and caregiving-related questions in the state's BRFSS (Behavioral Risk Factor Surveillance System). Disseminate these findings for use in program and research development to respond to the needs of Arizona residents.
- B. Create an Arizona research exchange or network through Arizona conferences on Alzheimer's disease and related disorders and via mechanisms such as LinkedIn and Research Gate, a social networking site for professionals, scientists and researchers to share papers, ask and answer questions, and find collaborators.
- C. In alignment with the Plan's public information and engagement campaign, seize opportunities through radio, TV and other media outlets for researchers and providers to regularly speak to audiences about Alzheimer's and related topics.
- D. Conduct and distribute yearly review/ summary of relevant Alzheimer's disease and related disorders literature for Arizona communities in order to keep abreast of national and international directions.
- E. Prioritize reduction of the time lag between discovery and research translation to ensure the benefits of increased knowledge can be shared as quickly as possible.
- F. Strengthen the Arizona Alzheimer's Disease Research Priority Agenda by expanding and enhancing cutting edge research that encompasses both medical research and promising clinical drug trials, in addition to essential research on prevention, risk reduction, impact, care and support of people living with Alzheimer's disease and their care partners.

RECOMMENDATION 4.2

Increase Understanding Of The Benefits Of Research

Strategies

- A. Engage and educate health and human service providers on the benefits of referring people impacted by Alzheimer's disease and related disorders to research studies.
- B. Improve care practices by linking people living with Alzheimer's disease and related disorders to dementia care managers to coordinate care, manage individual cases, and supplement clinical care with resources on supportive services and community-based agencies that offer specialized expertise, social supports, and mental health services.
- C. Use testimonials of diverse groups of research participants to describe the benefits of research and assist with research recruitment.
- D. Engage younger audiences in research-related activities through social media.



RECOMMENDATION 4.3

Increase Participation In Research Statewide

Strategies

- A. Develop collaborative strategies among research institutes, health and human service providers, and Arizona's aging network.
- B. Create and support recruitment campaigns such as Banner Alzheimer's Prevention Initiative and Alzheimer's Association TrialMatch.
- C. Encourage research that explores the inter-relationships among Alzheimer's disease and related disorders and other co-occurring disorders/co-morbidities such as depression, diabetes, heart disease, arthritis, etc.
- D. Identify and overcome challenges to engaging participants in Alzheimer's disease and related disorders research, including geographic, socio-economic, cultural or other differences that may discourage participation.

RECOMMENDATION 4.4

Increase Research Funding, Support And Resources

Strategies

- A. Preserve and expand state funding of Alzheimer's research.
- B. Promote increased taxpayer contributions through state approved mechanisms (e.g., a state tax check-off to fund Alzheimer's disease and related disorders research).
- C. Increase sponsorship and support from private and public sectors (including non- and not-for-profit entities as well as individuals) to foster research collaboration.
- D. Identify and take advantage of ways to share resources (time, space, etc.) in research programs and activities.
- E. Explore emerging internet and social media resources and solutions, which may include crowd funding, crowd sourcing and similar opportunities for both funding and participant recruitment.

RECOMMENDATION 4.5

Expand Upon Existing And Develop New Research Collaborations

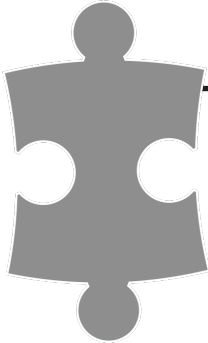
Strategies

- A. Identify and implement best practices and develop new opportunities for increased collaborative research across organizations (e.g., institutes, universities, government, industry, and non- and not-for-profit).
- B. Promote increased taxpayer contributions through state approved mechanisms (e.g., a state tax check-off to fund Alzheimer's disease and related disorders research).
- C. Increase sponsorship and support from private and public sectors (including non- and not-for-profit entities as well as individuals) to foster research collaboration.
- D. Engage and mentor new investigators and those from other fields for collaborative work on Alzheimer's disease and related disorders research.
- E. Build on existing and develop new conference opportunities in Arizona on Alzheimer's research.



GOAL 5

Create a Dementia-Capable System in Arizona



Create and sustain an **innovative dementia-capable system** of home and community-based services that are accessible and acceptable to people with dementia and their caregivers. In keeping with the Task Force's Guiding Principles, the recommendations and strategies are intended to be inclusive to all aspects of the diversity of our populations and communities throughout Arizona.

RECOMMENDATION 5.1

Create And Sustain A Dementia-Capable Home And Community-Based Services System That Is Responsive To The Unique Needs Of People With Alzheimer's Disease And Related Disorders

Strategies

- A. Conduct and evaluate a statewide analysis of service capacity with an added emphasis on unserved and underserved areas and populations in the state.
- B. Remove barriers that keep people with younger-onset Alzheimer's disease and related disorders from receiving services that seniors are eligible to receive.
- C. Provide sufficient public funding and resources for home and community-based services to promote the optimal well-being of people living with Alzheimer's disease and related disorders and their caregivers.
- D. Advocate for palliative and hospice care benefits and services that focus on comfort and dignity.
- E. Ensure that services, supports, and approaches in a dementia-capable system are available, accessible and acceptable regardless of ethnicity, geography, or culture.
- F. Promote quality standards and measurable outcomes for dementia care in Arizona's long-term care, community health, and other health care settings.

RECOMMENDATION 5.2

Establish A “Single Entry Point/No Wrong Door” Access To Services For People With Alzheimer’s Disease And Related Disorders And Their Caregivers

Strategies

- A. Expand accessibility of services through the continued development of the Arizona’s Aging and Disabilities Resource Consortium (ADRC), AZ Links and the Caregiver Resource Line.
- B. Coordinate and conduct Alzheimer’s disease and related disorders training within all of the AZ Links Regional Partnerships, focusing on the developmental disabilities support system and centers for independent living statewide.
- C. Improve access to quality care and services through the expansion of dementia care and behavioral health services and the integration of those services into primary care settings.



RECOMMENDATION 5.3

Improve Rural Health Systems By Expanding Dementia Care And Behavioral Health Services To Improve Access, Reduce Costs And Enhance The Quality And Safety Of Care

Strategies

- A. Support transportation programs to provide rural residents with access to health providers.
- B. Ensure the availability of consumer-directed respite services in rural communities.
- C. Grow the network of skilled nursing facilities and assisted living communities to provide high quality long-term care services to people with Alzheimer’s disease and related disorders in rural areas.
- D. Promote best practice models for rural long-term care, community health and other health care settings that provide care to people with Alzheimer’s disease and related disorders.
- E. Increase the capacity and competency of rural long-term care, community health and other health care settings.
- F. Expand the telehealth network and, when appropriate, the use of technology as a viable way to expand and enhance service availability, accessibility, and acceptability.

RECOMMENDATION 5.4

Ensure Access To A Comprehensive, Sustainable Set Of Quality Services That Are Responsive To The Unique Needs Of People With Alzheimer’s Disease And Related Disorders

Strategies

- A. Promote coordinated care consultation (“Options Counseling”) for families of people living with Alzheimer’s disease and related disorders.
- B. Promote locally coordinated transportation programs that serve people with Alzheimer’s disease and related disorders.
- C. Promote the screening of family caregivers for their needs as routine practice in care planning for people with Alzheimer’s disease and related disorders.
- D. Identify and partner with volunteer non-profit organizations dedicated to assisting those living with Alzheimer’s disease and related disorders and their families, which would offer free services such as transportation, household chores, companionship and respite.
- E. Promote safe and effective transitions between care settings and systems.




RECOMMENDATION 5.5

Foster Innovative Services For People With Alzheimer’s Disease And Related Disorders And Their Caregivers

Strategies

- A. Partner with health insurance providers to recommend that medically appropriate dementia services are clearly identified and addressed in coverage statements and covered in policies, including those for younger-onset dementia.
- B. Promote innovative and multi-disciplinary approaches to help improve the safety of individuals with Alzheimer’s disease who wander.
- C. Increase the use of established, evidence-based best practice programs related to Alzheimer’s disease and related disorders.



APPENDIX

Overview of Alzheimer's Disease and Related Disorders

Alzheimer's (AHLZ-high-merz) disease is named after the late Dr. Alois Alzheimer, a German neuropathologist who first described the disease of the brain about his patient, Auguste D., in 1906. Alzheimer's disease attacks brain cells, causing problems with memory, thinking and behavior. Alzheimer's is not a typical part of aging; it is a progressive disease that worsens over time, with no cure available today.

Alzheimer's disease is the most common form of dementia among older adults. Dementia is a general term for a group of brain disorders that involve mental decline. The term "dementia" may inadvertently create some misunderstandings. The word, "demented" has become synonymous with "wild", "frantic" or even "crazy" in popular language. "Dementia" may sometimes be used by health care and social service providers when the specific cause or disorder such as Alzheimer's disease has not yet been diagnosed. The term may also be used in general to refer to symptoms associated with cognitive impairment and decline. While some forms of dementia or brain disorders are reversible, Alzheimer's disease is not.

Related Disorders

The Arizona Alzheimer's Task Force purposefully uses the term "Alzheimer's disease and related disorders" throughout its recommendations to capture the variety of types and causes of dementia. The "related disorders" that are addressed by the Task Force are a group of brain disorders that cause progressive dementia with a group of symptoms that may interfere with daily living through their impact on thinking and social functioning. The most common related disorders include vascular dementia, mixed dementia, dementia with Lewy bodies, Parkinson's disease, frontal temporal dementia, Creutzfeldt-Jakob disease, normal pressure hydrocephalus and Huntington's disease. Each of these occurs later in adult life and is progressive but not developmental in nature. Other types of neurological conditions, ranging from autism to traumatic brain injury, are not specifically within the scope of the Task Force.

Disease Progression

Alzheimer's is a progressive disease. Its advancement varies by individual. People living with Alzheimer's may not experience the same symptoms nor progress at the same rate. There are multiple models that describe stages of progression that some people experience, including a seven stage framework from no impairment to very severe decline developed by Barry Reisberg, MD (clinical director of New York University School of Medicine's Silberstein Aging and Dementia Research Center).



Practitioners often refer to a three-tiered framework of early stage, mid- or moderate stage, and late or advanced stage, to assist both the person with the disease and the care partner understand the potential progression of symptoms and enable them to better plan for the future.

In 2011, the National Institute on Aging and the Alzheimer's Association proposed new criteria and guidelines for diagnosing Alzheimer's disease. In 2012, new guidelines to help pathologists describe and categorize brain changes associated with Alzheimer's were also proposed. The three stages proposed within the new guidelines are preclinical Alzheimer's disease, mild cognitive impairment due to Alzheimer's disease, and dementia due to Alzheimer's disease. These proposed stages will rely on new technology and biomarker tests to detect changes to the brain, including before cognitive symptoms are apparent.¹

Memory-Related Changes

Some memory and related decline may be expected in the aging process. Other medical conditions may cause symptoms that mimic those of Alzheimer's disease. Individuals who experience any of these concerns are advised to contact their health care providers.

MEMORY CHANGES	
Related to Aging	Potential Signs of AD
Making a bad decision once in a while	Frequent poor judgment and decision making
Missing a monthly payment	No longer able to manage a budget
Temporarily forgetting the day or date, but later remembering	Losing track of the date or season
Losing things from time to time	Misplacing things and being unable to retrace steps to find them

Risk Factor

A risk factor is a quality, attribute or factor associated with an increased risk of disease. Age is the greatest risk factor for Alzheimer’s disease, although advancing age does not cause the disease. Statistically, one in nine people age 65 or older and one in three people age 85 and older will develop Alzheimer’s.¹ Other risk factors may include traumatic brain injury, cardiovascular risk factors (head-heart connection), or specific genetic mutations.

Mild Cognitive Impairment or MCI

This term refers to a subtle but measurable memory disorder. A person with MCI may experience memory problems greater than normally expected with aging, but may not show other symptoms of cognitive impairment such as impaired judgment or reasoning. Research is continuing to learn more about why some individuals with MCI may progress to Alzheimer’s disease while others may not.

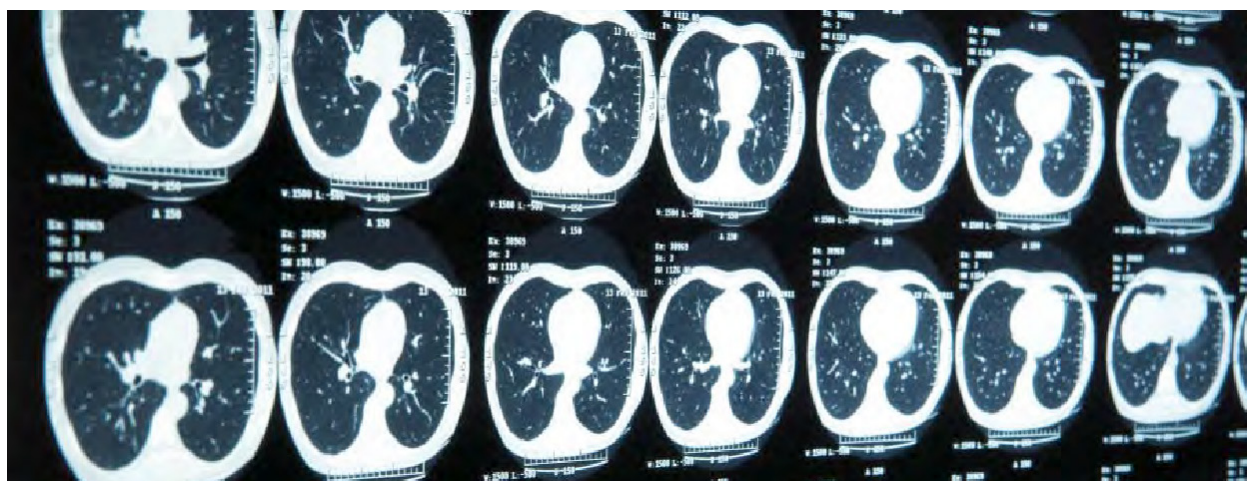
Early Stage


This refers to the initial phases of Alzheimer’s disease and related disorders in which people experience progressive cognitive decline, while still having the capacity to actively participate in many of their prior daily activities including decision making about their future care.

Younger Onset

This refers to people who have Alzheimer’s disease diagnosed under the age of 65. This term is used instead of “early onset” to distinguish it from “early stage”.

(1) Alzheimer’s Association, 2015 Alzheimer’s Disease Facts and Figures, Alzheimer’s and Dementia, 2015 11(3)332+





APPENDIX

Glossary of Terms

Aging and Disabilities Resource Center (ADRC)

Provides a single, coordinated system of information and access for individuals seeking long-term services and supports. The federal initiative is a collaborative effort of the U.S. Administration on Community Living and the Centers for Medicare and Medicaid Services (CMS).

Behavioral Risk Factor Surveillance System (BRFSS)

Established by the Centers for Disease Control and Prevention, the BRFSS is the nation's premier system of health-related telephone surveys that collect state data about U.S. residents regarding their health-related risk behaviors, chronic health conditions, and use of preventive services.

Care Team

The Arizona Alzheimer's Task Force supports the engagement of a "Care Team" that is inclusive of the person living with Alzheimer's disease or a related disorders. Members include:

- **Person with/People living with Alzheimer's Disease** - The Task Force respects that the people who are living with Alzheimer's disease and related disorders are people first. The disease does not define the individual. The term "Alzheimer's patient" is only used in the context of the doctor-patient relationship.
- **Caregiver/Care Partner** - These terms are used to reflect the relationship of family and friends with people living with Alzheimer's disease and related disorders. Philosophically, the term "care partner" is preferred with regard to supporters of people in early stage, who do not require the level of ongoing supervision and care that people in more advanced stages may need. In the early stage of the disease, ideally there is a partnership involved that empowers and includes the person living with the disease.
- **Health and Human Service Providers** - This term is used when describing the broad range of paid professionals and paraprofessionals involved in serving individuals and families impacted by the disease.

Continuum of Care

This term as used in this document refers to a range of health and human services that people living with Alzheimer’s disease or related disorders may need during the course of disease progression. Typically, this may include community-based, in-home and residential care resources.



Dementia-Capable System

This term refers to a health and human service support system that is tailored to meet the unique needs of each person with Alzheimer’s disease or a related disorder.

Dementia-Capable Workforce

Refers to a workforce of health and human service providers in which staff have appropriate training in understanding the unique needs of people living with Alzheimer’s disease and related disorders, are knowledgeable about resources available to assist them, and skilled in knowing how to communicate and address their needs.

Dementia Friendly Communities

This term is used to describe communities, cities, counties and states that are informed, safe and respectful of individuals with Alzheimer’s disease and related disorders and their families and care partners, providing supportive options, and fostering quality of life.

Diversity and Inclusiveness


The Arizona Alzheimer’s Task Force embraces a broad definition of diversity that relates to people, communities, networks and audiences. Culturally responsive care team members work to bridge the gap between their own sociocultural contexts and those of people they serve. Culturally responsive team members acknowledge the sociocultural context and its influence; actively listen to others’ perspectives; and respectfully communicate similarities and differences across contexts and perspectives to foster understanding and maximize the availability, accessibility, and acceptability of practice, programs, services, policies and research endeavors.

Evidence-based or Evidence-informed Practices

These terms refer to interventions that have been tested through reliable evaluation methods to reflect proven best practices based on current knowledge.

“Single Entry Point/No Wrong Door”

This term is used to describe a system of support in which people looking for assistance have easy and comprehensive access to services.



APPENDIX

Acknowledgement

The development of the Arizona Alzheimer's State Plan has been a highly collaborative effort in which many public and private organizations and individuals have contributed their valued time, talents and expertise.

Arizona Alzheimer's Task Force Planning Group Organizations**

- Alzheimer's Association Desert Southwest Chapter
- Arizona Alzheimer's Consortium
- Arizona Department of Economic Security, Division of Community Engagement and Services, Aging and Disability Services Administration formerly Division of Aging and Adult Services
- Arizona Department of Health Services
- Arizona Governor's Office on Aging

Arizona Alzheimer's Task Force Organizations

- AARP Arizona
- Alzheimer's Association Desert Southwest Chapter
- Arizona Alzheimer's Consortium
- Arizona Association of Adult Day Services
- Arizona Association of Area Agencies on Aging
- Arizona Attorney General's Office
- Arizona Department of Economic Security, Division of Community Engagement and Services, Aging and Disability Services Administration formerly Division of Aging and Adult Services
- Arizona Department of Health Services
- Arizona Department of Insurance
- Arizona Development Disabilities Planning Council
- Arizona Direct Care Workforce
- Arizona Governor's Office on Aging
- Arizona Health Care Association
- Arizona Health Care Cost Containment System
- Arizona Hospice and Palliative Care Organization

- Arizona Hospital and Healthcare Association
- Arizona Legislature
- Arizona Non Medical Home Care Association
- Arizona Pharmacy Association
- Arizona State University College of Nursing and Health Innovation
- Assisted Living Federation of America
- Consumer Representation of People Living with Alzheimer’s Disease and Related Disorders and Family Care Partners
- Health Services Advisory Group
- Leading Age Arizona
- Northern Arizona University
- University of Arizona Center on Aging

Volunteers who served on the Task Force or its Work Groups in support of the development of the Arizona Alzheimer’s State Plan Framework for Action


- | | |
|------------------------------------|-----------------------|
| • Jeffrey Alexander | • Vanessa Deatherage |
| • Representative Cecil Ash | • Patti Dorgan |
| • Karla Averill | • Jan Dougherty |
| • Melissa Arzabal | • Ted Evertsen |
| • Sylvia Balistreri | • Mindy Fain, MD |
| • Karen Barno | • Barbara Fanning |
| • Michelle Barth | • Meg Fenzi |
| • Mary Beals-Luedtka | • Dan Fern |
| • Gary Beitel | • James Fitzpatrick** |
| • Pat Beitel | • Lisa Glow |
| • Ann Benson | • Jodi Goalstone |
| • David Besst** | • Alfredo Gonzalez |
| • Debra Boehlke | • Cathy Griner** |
| • Karen Boswell | • Karin Helton |
| • Representative Kate Brophy McGee | • Bob Herbert |
| • Phil Carl** | • Bernadine Hoffman |
| • Representative Heather Carter | • Carolyn Hutchens |
| • Larry Clausen | • Conni Ingallina |
| • Heriberto Contreras | • Don Irish |
| • David Coon, PhD** | • David Jerman |
| • Jane Cox | • Karen Jeselun |
| • Marcella Crane | • Dara Johnson |
| • Cathy De Lisa** | • Kari Johnson |
| • Elisa Davis | |

- Crystal Keenan
- Jacque Keller
- Dana Kennedy
- Kirti Khalsa
- Susan Kilby
- Nicole Kitts Early
- Erin Klug
- Mika Kondo
- LuAnne Lilly
- Emilia Martinez-Brawley
- Carole Mandino
- Auburn McCanta
- Jo-Anne McGowan
- Vicki McAllister
- Laura Michael
- Rachel Minton
- Ed Mitchell
- M. Jane Mohler, PhD
- Babak Nayeri, FACFE, FABMPP
- Evelyn Newton
- Stacey Nseir
- Lisa O'Neill
- Lisa O'Toole
- Kat Pollard
- Kelly Raach
- Carolyn Raper
- Ted Raper
- Eric Reiman, MD
- Kathy Ritchie
- Gillian Romain
- Genny Rose
- Heidi Ross
- Virginia "Ginny" Rountree
- Ramona Rusinak
- Cindy Saverino**
- Deborah Schaus**
- Mary Servin
- Kelly Shackelford
- Mary Pat Sharp
- Helena Smith
- Verne (Smitty) Smith
- Jami Snyder
- Melanie Starns**
- Patricia Talcott
- Thomas Tenkely
- Joanne Thomson
- Lynne Tomasa
- Wayne Tormala**
- Cat Trobaugh
- Shawn Trobia
- Jutta Ulrich
- Johannah Uriri-Glover, PhD
- Cindy Vargo
- Tim Vaske
- Kelly Vaughan
- Traci Wagner
- Hannele Waissi
- Amanda Weiler
- Pete Wertheim
- Mary Wiley
- Kim Woda

Special appreciation is noted for the Vitalyst Health Foundation, formerly known as St. Luke's Charitable Trust, for their grant support of initial efforts and to Representative Heather Carter for helping launch the Calls to Action.

We sincerely apologize if an individual volunteer or an organization was inadvertently misspelled or omitted from this list, which is intended to span involvement from 2011 to 2016. Please notify us of our error so that we may correct this in future publications.

**Denotes Planning Group members



APPENDIX

Contact Information

For more information about the Arizona Alzheimer’s Task Force or the Arizona Alzheimer’s State Plan: A Framework for Action, please contact:

Arizona Governor’s Office on Aging
State Executive Tower
1700 W. Washington St., Suite 240
Phoenix, AZ 85007

Phone Number: (602) 542-4710
Email Address: aging@az.gov



