# THE NEVADA STATE PLAN TO ADDRESS ALZHEIMER'S DISEASE

January 2017

**The Department of Health and Human Services**
**Task Force on Alzheimer's Disease**

# TASK FORCE ON ALZHEIMER'S DISEASE

Senator Valerie Wiener (Ret.), Chair
Peter Reed, Ph.D., Director, Sanford Center for Aging, University of Nevada, Vice Chair
Senator Joseph Hardy
Assemblyman James Oscarson
Charles Bernick, M.D., Associate Medical Director, Cleveland Clinic Lou Ruvo Center for Brain Health
Virginia (Gini) L. Cunningham, M.Ed., Volunteer and Support Group Facilitator, Humboldt Volunteer Hospice and Alzheimer's Association of Northern Nevada
Jacob Harmon, Regional Director, Northern Nevada Alzheimer's Association
Jane Fisher, Ph.D., Department of Psychology, University of Nevada Reno
Wendy Simons, Deputy Director of Wellness, Nevada Department of Veterans Services (NDVS); Owner, Wendy Simons Consulting
Julie Kotchevar, M.A., Deputy Administrator, Aging and Disability Services, Department of Health and Human Services

## ***Former Contributing Member***

Albert Chavez, Ed. S., CFLE, Regional Director, Southern Nevada Region, Desert Southwest Chapter, Alzheimer's Association

# State Plan to Address Alzheimer's Disease
# Nevada Revised Statute 439.5083
# Revised August, 2016

## ***The Impact of Dementia***

Approximately 50 forms of dementia have been identified. Alzheimer's disease is just one form of dementia and comprises about 70 percent of all dementia diagnoses. Currently, one in nine people (11 percent) of those over the age of 65 have Alzheimer's disease. This translates into about 39,000 people in Nevada. To add some perspective, this is a 38 percent increase from ten years ago. Based on current data trends, this number is expected to increase to 64,000 people by 2025. Nationally, Nevada has the third highest growth rate of this disease at 64 percent!

With this explosive need in Nevada, the Task Force on Alzheimer's Disease (TFAD) contributes timely and essential information and insights, through its State Plan, Annual Reports, and bi-monthly meetings. On a continuous basis, TFAD provides focused and crucial information about vital policies, practices, and programs to the Aging and Disability Services Division, which works daily to serve the needs of persons with Alzheimer's disease and other forms of dementia in Nevada.

## ***TFAD Supports:***

- Dementia-Friendly Communities, where those living with Alzheimer's disease and other forms of dementia, along with their care partners, feel and experience the respect, dignity, support, value, and inclusion in everyday community life.

- Innovative ways of thinking that provide opportunities for persons with Alzheimer's disease and other forms of dementia to experience full and meaningful lives.

- Proactive collaborations between health care professionals, first responders, community organizations, the business community, educators, care partners, volunteers, and others to provide dementia-friendly services and support that nurture a full and optimal quality of life for persons with Alzheimer's disease and other forms of dementia.

- Ongoing education and professional development for persons who, directly or indirectly, serve and support persons with Alzheimer's disease and other forms of dementia, as well as their care partners.

- Best practices for all individuals and entities that are making contributions to the quality of life for persons with Alzheimer's disease and other forms of dementia, as well as their care partners.

- Continuous and expansive public awareness activities that promote opportunities for expanding Dementia-Friendly Communities.

## ***Executive Summary***

State Plans to Address Alzheimer’s Disease have been created by both the ACR10 Task Force (2013) and TFAD (2015) and were submitted to both the Governor and the Nevada State Legislature. Nine recommendations from the 2015 State Plan have been moved to Appendix A, because TFAD determined that these particular recommendations have been or are being addressed appropriately. These recommendations will continue to be monitored annually. If TFAD's annual review of these recommendations demonstrates a need to re-address one or more of these recommendations, TFAD can include them in its next State Plan.

Following is a list of the recommendations, approved by the Task Force on Alzheimer’s Disease (TFAD) to be addressed in the 2017 State Plan, and the year they were first included in the State Plan:

### ***Access to Services***

#1: Statewide Information and Referral System (2013)

#2: Telehealth (2013)

#3: Cultural Competency (2013)

#4: Affordability (2013)

#5: Outreach to Physicians (2017)

### ***Quality of Care***

#6: Care Pathways (2013)

#7: Long-Term Care (2013)

#8: Caregiver Services (2013)

#9: Caregiver Support (2017)

### ***Quality of Life***

#10: Volunteers (2013)

#11: Guardianship (2017)

#12: Hospital Practices (2013)

#13: Veterans and Families (2017)

#14: Driving and Dementia (2017)

### ***Public Awareness***

#15: Community Outreach (2013)

#16: Business Outreach (2013)

---

# Access to Services

### ***Recommendation #1: Statewide Information and Referral System*** **(2013)**

Sustain a statewide information and referral system for people living with Alzheimer's disease and other forms of dementia, their caregivers, and their families to enable them to connect with local case managers and support services. It is the expectation that the approaches, content, and messaging within these resources help promote well-being and preserve dignity. Supportive services would include, but are not limited to: Nevada Aging and Disability Resource Centers (ADRC), Family Resource Centers (FRC), and other related informational systems (e.g. websites, helplines, and other technologies).

#### Indicators

Monitor the establishment of a collaboration that includes resource centers, such as Nevada ADRC; Northern California and Northern Nevada Chapter of the Alzheimer's Association; Southern Nevada Region, Desert Southwest Chapter of the Alzheimer's Association; University of Nevada, Reno; and Nevada Caregiver Support Center, to develop plans for an information and referral system. The Aging and Disability Services Division (ADSD) will monitor the number of contacts made by outreach programs and the number of inquiries regarding information or services relating to Alzheimer's disease and other forms of dementia received by the ADRC. In addition, ADRC will monitor the number of "hits" on information sites, such as an expanded nevadaadrc.com, alz.org/NorCal for Northern Nevada and alz.org/dsw for Southern Nevada, nevadacaregiver.unr.edu, and Alzheimers.gov.

#### Potential Funding

Older Americans Act funds. Grants, donations, and/or gifts.

---

## ***Recommendation #2: Telehealth* (2013)**

Support AB292, passed during the 2015 Legislative Session, which expanded access to Telehealth services throughout the state. This includes supporting the Telehealth Consortium in its efforts to improve Telehealth utilization by encouraging collaboration among network providers, physicians, and service recipients. These collaborations should identify and help remove service delivery barriers, as well as educate providers and the public about the existence of, and benefits of Telehealth services, especially in rural and remote communities throughout Nevada.

### **Indicators**

Monitor Telehealth projects across the state to determine if they are: 1) available and accessible, 2) being utilized effectively and efficiently, and 3) providing information/access to follow-up resources. Review evaluation of projects, such as Nevada's Early Stage Dementia Project and the Telehealth Early Phase Patient and Family Support Program (TESP), to assess the processes and outcomes and duplicate the measurements of the success of the projects. Follow the development of the Nevada Broadband Telemedicine Initiative (NBTI), using the Nevada Hospital Association (NHA) goals and evaluation.

### **Potential Funding**

Alzheimer's Disease Supportive Services Program (ADSSP). The State of Nevada. Grants, donations, and/or gifts.

---

## ***Recommendation #3: Cultural Competency* (2013)**

Support efforts to develop and distribute toolkits to assist public and private organizations in their outreach to different cultural communities.

### **Indicators**

Monitor the development and dissemination of toolkits to organizations serving persons living with dementia and their family caregivers, such as ADSD grant-funded partners.

### **Potential Funding**

U.S. Administration on Aging grants. Collaboration with different cultural and ethnic organizations. Grants, donations, and/or gifts.

---

## ***Recommendation #4: Affordability* (2013)**

Address affordability of services for persons with Alzheimer’s disease and other forms of dementia by using national data and explore other cost-sharing mechanisms. This includes the

DHHS Behavioral Rate for skilled nursing facilities.  This rate expands the reimbursement options for facilities that serve persons whose challenging behaviors, resulting from a dementia, once necessitated them to be placed out-of-state for appropriate care.

### Indicators

The Aging and Disability Services Division will monitor, track and analyze national data and make a recommendation of equitable reimbursement rates based on this analysis.

### Potential Funding

Medicaid expansion.  Grants, donations, and/or gifts.

---

## *Recommendation #5:  Outreach to Physicians* (2017)

### *Background*

According to the Alzheimer’s Association, primary care physicians are the gatekeepers to assessment and treatment, as well as potential links and referrals to community resources.  These vital resources can provide support, services, and education for patients, caregivers, and families.

Through focused outreach efforts, organizations that serve persons with Alzheimer’s disease and other forms of dementia should form significant collaborations with physicians.  These working relationships have the potential to maximize a seamless two-way referral process, which can decrease obstacles to care.  Physicians, working with other health care providers and organizations, should provide an effective navigation continuum, from diagnosis, through early, middle, and late stages of the disease, to end-of-life. This same continuum of care, with appropriate resources and ongoing communication, can eliminate service gaps.

### Recommendation

Support collaborations between medical professionals and medical associations to adopt and promote use of best-practice diagnostic guidelines for Alzheimer’s disease and other forms of dementia.  Support a meaningful and effective communication continuum between these professionals and community-based service organizations, including referrals to community-based resources.

### Indicators

Data gathered by the Alzheimer’s Association.

### Potential Funding

Alzheimer’s Association.  Grants, donations, and/or gifts.

---

# Quality of Care

## ***Recommendation #6: Care Pathways* (2013)**

Support the adoption of specialized care pathways. Encourage the Nevada Hospital Association (NHA) to develop a best-practice care plan for the management of patients with cognitive impairment entering the hospital. The NHA is strongly encouraged to develop this plan in collaboration with subject matter experts from: the Alzheimer's Association; research and educational organizations; first responders; and healthcare organizations. In addition, TFAD supports the CARE Act, which helps caregivers when those for whom they care are hospitalized. TFAD will also serve in an advisory capacity and provide necessary testimony to the Legislative Subcommittee to Conduct a Study of Post-Acute Care.

### Indicators

Monitor through regulatory and hospital associations how many hospitals establish a best-practices care plan.

### Potential Funding

In-kind contributions from potential participants, such as the Cleveland Clinic Lou Ruvo Center for Brain Health, Touro University Nevada, Nevada System of Higher Education (NSHE), and other educational institutions in Nevada. Federal Alzheimer's research grants. Private-sector foundation grants. Other grants, donations, and/or gifts.

---

## ***Recommendation #7: Long-Term Care* (2013)**

Continue to review current funding and funding streams to support the development of quality long-term care options for people living with Alzheimer’s disease and other forms of dementia in Nevada. Provide funding or incentives to encourage long-term care providers to increase capacity for placement of individuals with Alzheimer’s disease and other forms of dementia. Also emphasize person-centered planning that helps promote well-being and preserves dignity, as well as helping patients, their families, and caregivers, feel and experience respect, dignity, support, value, and inclusion in everyday community life.

### Indicators

Monitor the number of long-term care options for persons with Alzheimer's disease and other forms of dementia across the state.

### Potential Funding

Medicaid expansion through Home- and Community-Based Services Waiver. Expansion through the DHHS Behavioral Rate for skilled nursing facilities. Increased supplemental SSI rate. Tax incentives. Grants, donations, and/or gifts.

---

## ***Recommendation #8: Caregiver Services* (2013)**

Provide caregivers with access to evidence-based education and support services that promote knowledge and understanding of Alzheimer's disease and other forms of dementia and how to best support people living with dementia. Provide and expand respite services for family and informal caregivers of persons with Alzheimer's disease and other forms of dementia. Broaden the eligibility requirements for use of respite programs and grant funding so that more families may benefit from them regardless of financial status or age.

### **Indicators**

ADSD will annually monitor waitlists, number of consumers, and hours of caregiver support services provided in the ADSD-funded programs.

### **Potential Funding**

Fund for a Healthy Nevada. Retired and Senior Volunteer Program (RSVP). Older Americans Act funding (Title III). The Alzheimer's Association. Grants, donations, and/or gifts.

---

## ***Recommendation #9: Caregiver Support* (2017)**

### ***Background***

Caregivers of people with Alzheimer's disease and other forms of dementia frequently report high levels of stress, which can be emotionally, physically, and psychologically harmful to them. According to the Latest Facts and Figures Report from the Alzheimer's Association, 15.9 million family members and friends provided 18.1 billion hours of unpaid care to those with Alzheimer's and other forms of dementia in 2015. That care had an estimated economic value of $221.3 billion. Approximately two-thirds of caregivers are women, and 34 percent are age 65 or older. 41 percent of caregivers have a household income of $50,000 or less. On average, care contributors lose more than $15,000 in annual income as a result of reducing or quitting work to meet the demands of caregiving.

Alzheimer's disease takes a devastating toll on caregivers. Nearly 60 percent of Alzheimer's and dementia caregivers rate the emotional stress of caregiving as high or very high; about 40 percent suffer from depression. One in five care contributors cut back on their own doctor visits because of their care responsibilities. And, among caregivers, 74 percent report they are "somewhat" to "very" concerned about maintaining their own health since becoming a caregiver.

### **Recommendation**

Support caregivers with information and resources about caring for persons with Alzheimer's disease and other forms of dementia. Provide caregivers with information about, as well as access to, programs, services, and resources that promote their own well-being. These services include, but are not limited to: family care consultation, caregiver support groups, educational programs and services, respite programming, and evidence-based programs. Support efforts to promote and fund comprehensive caregiver services that are provided by many organizations, including, but not limited to: AARP, Alzheimer's Associations, Catholic Charities, the Cleveland Clinic Lou Ruvo Center for Brain Health, Nevada Caregiver Support Center, and Nevada Senior Services.

Support the Dementia-Friendly America initiative and the work of the state's Dementia-Friendly Champion Groups in northern and southern Nevada. In addition, support the establishment of a key partners' network, which would create a system of referrals to appropriate services.

### Indicators

Aging and Disability Services Division will track and compile data it collects, along with data provided by the key partners' network and other dementia-related organizations. ADSD will monitor Dementia-Friendly Champions, including sector teams, in northern and southern Nevada.

### Potential Funding

Older Americans Act. Grants, donations, and/or gifts.

---

# Quality of Life

## ***Recommendation #10: Volunteers* (2013)**

Recruit and train community volunteers through collaborations with various organizations, including nonprofits, service organizations, healthcare institutions, and universities, which have existing programs, education, and practices that address Alzheimer's disease and other forms of dementia. Through these collaborations, volunteers will have the opportunity to expand their own knowledge and awareness about all forms of dementia and learn how to effectively participate in the care and support of persons with Alzheimer's disease and other forms of dementia, their families, and their caregivers. In supporting age- and dementia-friendly communities, volunteers will learn how to promote each person's well-being, as well as preserve their dignity and respect in everyday community life. Also, by implementing "Train the Trainer" programs, volunteer outreach opportunities can be expanded.

### Indicators

Monitor nonprofits, service organizations, healthcare institutions, and universities that recruit volunteers for the number of volunteers they recruit, the types of training they offer, how many volunteers they train, and what other services are provided. Determine which additional trainings and services might be needed to expand volunteer education and opportunities.

**Potential Funding**

Grants, donations, and/or gifts.

---

## ***Recommendation #11: Guardianship* (2017)**

Support the development and implementation of the Guardianship "Bill of Rights," which was created by the Commission to Study the Administration of Guardianships in Nevada's Courts. In particular, support the specific protections for individuals with Alzheimer's disease and other forms of dementia.

**Indicators**

Monitor activities of the Commission to Study the Administration of Guardianships in Nevada's Courts and any subsequent legislative proposals.

**Potential Funding**

Grants, donations, and/or gifts.

---

## ***Recommendation #12: Hospital Practices* (2013)**

Ensure best-practice hospital transitional care programs that include information on community resources for caregivers and persons with dementia. Investigate federal funding opportunities, through Medicare Innovations or Centers for Medicare and Medicaid Services, to develop a transitions planning program, which would also include provisions, when appropriate, for non-hospital care, such as a mobile dementia team approach.

**Indicators**

Monitor the number of hospital transitional care programs that employ best-practice discharge policies.

**Potential Funding**

Collaboration between Nevada ADSD, Nevada DHCFP, DPBH, and other appropriate State agencies. Grants, donations, and/or gifts.

---

## ***Recommendation #13: Veterans and Families* (2017)**

### ***Background***

It is estimated that more than 300,000 veterans live in Nevada, and the vast majority of these veterans do not know what services are available to them or how to access them. Such services include: skilled care facilities, residential care/assisted living facilities, community-based care services, veteran burial benefits, and others.

It is important to advise and educate veterans and their families about potentially untapped Federal VA benefits that could assist them. With changing regulations, many aging veterans and their families do not know about their eligibility for benefits that were not previously available. Also, many facilities are challenged when working with veterans, because they do not understand how prior military service can affect veterans in the aging process. This is especially significant for veterans who have Alzheimer’s disease and other forms of dementia.

### **Recommendation**

Support the development and implementation of the Veterans in Care (VIC) initiative, being created and implemented by Nevada Department of Veterans Services. In particular, support the specific provisions that relate to individuals with Alzheimer’s disease and other forms of dementia and their families.

### **Indicators**

Monitor the development of the VIC initiative.

### **Potential Funding**

Nevada Department of Veteran Services. Grants, donations, and/or gifts.

---

## ***Recommendation #14: Driving and Dementia* (2017)**

### ***Background***

Physical safety is a prerequisite for a healthy and positive quality of life. Cognitive disorders, such as Alzheimer’s disease and other forms of dementia, affect several abilities necessary for safe driving, including visual perception and processing, sustained attention, working memory, and judgment. As persons with dementia progress to moderate impairment, both their ability to drive competently and their insights about their own skill level are highly compromised. According to several studies, persons with dementia commonly continue to drive after their cognitive abilities have been so compromised that they are no longer safe drivers. Also, individuals with moderate impairment often do not recall that their driving privileges have been revoked or voluntarily surrendered.

Cessation of driving privileges can result in the loss of independence and autonomy for an individual with dementia and restrict that person's access to social activities, health care, and other needed services. The following recommendation, provided by the TFAD Subcommittee on Driving and Dementia, is based on input gathered from: a) town hall meetings and surveys, involving stakeholders from across Nevada, including persons with dementia, their families, and their care partners, as well as social service, health care, and public safety professionals; b) review of evidence-based approaches to the assessment of driving competence in persons with dementia; c) discussions with the Nevada Department of Motor Vehicles; and d) a survey of driver safety evaluation programs across the United States. From the cumulative data gathered by the Subcommittee, it is clear that the manner in which impaired driving is being addressed within Nevada varies significantly.

## Recommendation

Standardize the system of driver evaluation and improve the infrastructure, services, and support for persons with dementia whose driving ability may be compromised. This includes: implementing a uniform set of evidence-based screening tools for health care providers and first responders, as well as a standardized evidence-based evaluation tool for use by the Department of Motor Vehicles (DMV).

Support the dissemination of information regarding driving safety and dementia. This information should convey how to address the multi-faceted needs and concerns of persons with dementia and those who care for them. Specific information should include signs that an individual's driving ability might be compromised and how to access relevant resources to address this concern. Such information should be available on websites, as well as be distributed in printed materials, to: health care and social service providers, first responders, families, care partners, and the general public. Engage health care providers and first responders to evaluate the utility of the recommended screening tools.

Promote age- and dementia-friendly communities, which provide alternate transportation resources, through volunteerism and public-private partnerships, to maximize an individual's independence and assure public safety.

## Indicators

ADSD will monitor input from health care providers and first responders about the utility of recommended screening tools. ADSD will monitor the number of accidents and fatalities by the age of driver, the number of referrals by health care providers and first responders to the DMV, and the number of evaluations conducted by the DMV following referral. ADSD will assess the distribution of informational materials related to driving and dementia and how the distribution of information can be expanded and/or improved. ADSD will monitor the number and usage of alternative transportation resources.

**Potential Funding**

Federal funding. DMV. Nevada Department of Transportation (NDOT). Regional Transportation Commission (RTC). ADSD grants. Grants, donations, and/or gifts.

---

# Public Awareness

## *Recommendation #15: Community Outreach* (2013)

Foster the development of Dementia-Friendly Communities awareness campaigns to provide information about early signs of dementia and to advance Dementia-Friendly Communities across the state. The campaigns should include updates about current research and prevention trials that can delay progression, as well as information about how earlier diagnosis and intervention can lead to a more productive and meaningful life. The campaigns should be designed to help citizens feel better supported and hopeful, as well as encourage access to available services. The campaigns should be promoted through public service announcements, broadcast and print interviews, as well as articles in newspapers and magazines, website, and Internet venues. The respective target audiences for each public awareness campaign may include, but are not limited to:

a. Allied health professionals, bankers, emergency first responders, financial planners, lawyers, and other professionals who may have contact with persons with dementia.

b. Caregivers and family members of persons with dementia. This campaign should focus on creating and supporting Dementia-Friendly Communities, where those living with Alzheimer's disease and other forms of dementia, along with their care partners, can feel and experience the respect, dignity, support, value, and inclusion in everyday community life. This campaign should also focus on ways to help alleviate the fear, stress, and stigma surrounding dementia, which includes educating and informing caregivers about support group opportunities and other available supportive services that will help them care for themselves and their family member.

c. The general public. This campaign should also focus on creating, supporting, and sustaining Dementia-Friendly Communities.

**Indicators**

Monitor the instances of media attention through public service announcements, interviews, and stories. Monitor: the number of professionals and professional organizations contacted; the number of visits to the Nevada ADRC website; and the level of progress in developing and sustaining public awareness campaigns in cooperation with the State Grants Office and DHHS Outreach Services.

## Potential Funding

Alzheimer's Associations. Professional licensing boards and organizations. Nevada Broadcaster's Association. Nevada ADSD. Grants, donations, and/or gifts.

## *Recommendation #16: Business Outreach* (2013)

Encourage the business community to implement established employee assistance programs and dementia-friendly activities that encompass education and training for employees, including those who are caregivers. Specifically, foster partnerships with other organizations that are also affected by Alzheimer's disease and other forms of dementia, such as diabetes, stroke, and heart organizations, to help promote information about services and care for those who have symptoms of dementia.

### Indicators

Monitor the number of employee assistance programs with caregiver education and training. Monitor the number of partnerships with other dementia-related organizations.

### Potential Funding

Employers and employer organizations. Grants, donations, and/or gifts.