

# Utah's State Plan for Alzheimer's Disease and Related Dementias

Action Plan for 2012-2017



50 thousand Utah  
citizens affected

50

nation's highest  
growth rate 127%

127

132 thousand  
family caregivers

132

80% of dementia  
patients live at home

80

prevalence is nearly  
2 times greater among  
older minorities

2x

\$1.8 billion of unpaid  
caregiving in Utah

1.8

# “With this State Plan,

Utah can fight the growing Alzheimer’s crisis head-on. The plan is a blueprint for unified action through coordinated public-private partnerships. The Task Force has focused on three pillars:

- 1) To improve the dignity and quality of life for people with dementia and their families;
- 2) To mobilize government, health professionals and families around the fight against Alzheimer’s and related dementias; and
- 3) To support and advance research.

The Plan is comprehensive and lists 5 goals, 18 broad recommendations and nearly 100 specific strategies. These strategies for the most part can be implemented through existing budgets and systems, if better coordinated, and will improve outcomes and cost-effectiveness of efforts on behalf of Utah’s families coping with this crisis daily. For them, *now* is the time to act.”



– **Norman L. Foster, M.D.**  
Director, The University of Utah  
Center for Alzheimer's Care,  
Imaging and Research

STATE OF UTAH  
OFFICE OF THE LIEUTENANT GOVERNOR



GREG BELL  
LIEUTENANT GOVERNOR

January 25, 2012

The Alzheimer State Plan Task Force was created in 2011 for Alzheimer's disease and related dementias. This 20-member task force held meetings and worked diligently throughout the year to develop a state plan. Hundreds of citizens participated in the process and many shared their in-depth personal stories and provided valuable input. From Logan to St. George, from Clearfield to Price, the task force crisscrossed the state and met with citizens from the Salt Lake Valley as well.

The task force learned that persons struck by Alzheimer's disease or a related neurodegenerative dementia cannot be stereotyped. Individuals across the state suggested policies should be developed that will enhance self-determination, strengthen families, improve dementia professional training, expand research, and above all, inform all Utah citizens about the facts, risks and options associated with this disease.

The Alzheimer State Plan sets forth principles for state agencies, stakeholders, and committed citizens who are already invested in the success of this plan, to lay out subsequent steps for improved detection, diagnosis and treatment. Through this plan, caregivers will be empowered, trained, and supported to better care for and handle their challenges

I urge you to study the ideas, goals, recommendations, and strategies set forth in the Alzheimer State Plan. Together we can work to improve the lives of our family members, friends and neighbors whose lives have been impacted by this disease.

Respectfully,

A handwritten signature in blue ink that reads "G Bell".

Greg Bell  
Lieutenant Governor

# GUIDING PRINCIPLES

The State Plan Task Force met with citizens throughout the state, and from that experience emphasized the following guiding principles in the development of a Utah State Plan for Alzheimer's disease and related dementias:



- Combat stigma and increase awareness regarding Alzheimer's disease. In addition to Alzheimer's, related dementias caused by degenerative neurological diseases are a serious concern. Alzheimer's disease is the predominant cause of the constellation of symptoms we refer to as dementia, but other dementia diagnoses, include vascular dementia, frontotemporal dementia, Lewy bodies dementia, and so on, are included in the Plan.



- Emphasize person-center care that responds to individual needs and strengths. We can develop health care practices and societal responses that emphasize the strengths and abilities people with dementia have, not just their losses. In particular, persons in early stage would be better served when their health-care wishes, desires for self-determination and continued independence are respected equally to those with other chronic illness or disabling conditions.



- Anticipate and address the broadening cultural, ethnic, racial, socio-economic, and demographic diversity of Utah. Rural access to diagnostic services is increasingly problematic. The prevalence of dementia among Hispanics and African-Americans is disproportionately greater than among whites past the age of 65, and these populations are growing in our state. Broad disparity in access to services is addressed in the plan.



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# Utah's State Plan

## SUMMARY OF GOALS AND RECOMMENDATIONS

### GOAL 1 A Dementia-aware Utah RECOMMENDATIONS

- 1A: Raise broad public awareness of Alzheimer's disease and related dementias through culturally appropriate education campaigns
- 1B: Ensure that reliable, up-to-date disease and care information is disseminated
- 1C: Provide Utah citizens with the best evidence on how to reduce or delay their own risk for Alzheimer's disease.
- 1D: Coordinate standardized information throughout state and local governments

### GOAL 2 Health & Dignity for All with Dementia and Those at Risk RECOMMENDATIONS

- 2A: Engage a public health approach to confront Utah's significant projected growth in Alzheimer's disease.
- 2B: Improve access to a timely diagnosis, differential treatment and supportive services for persons with Alzheimer's disease and Related dementias.
- 2C: Provide access to behavioral health services and person-centered in-home care that includes evidence-based, non-pharmacological interventions rather than more costly inpatient treatment
- 2D: Secure the safety, independence, and mobility of persons with Alzheimer's disease and related dementias with appropriate responses and policies for each stage of the disease
- 2E: Enhance the self-determination of persons with memory loss and in the early-stage of Alzheimer's disease and related dementias.
- 2F: Implement a statewide strategy to coordinate, integrate, deliver and monitor long-term care and services



# for Alzheimer's Disease and Related Dementias

## **GOAL 3 Supported and Empowered Family Caregivers**

### **RECOMMENDATIONS**

- 3A: Acknowledge and invest in the vital role of family caregivers with guidance on quality care and the best utilization of family financial resources throughout the disease course
- 3B: Empower caregivers through a supportive network that is better coordinated and culturally competent, and by expanding affordable respite care
- 3C: Ensure that all families have access to clinical post-mortem diagnostic services and tissue banking to invest in the future health of their families

## **GOAL 4 A Dementia-competent Workforce**

### **RECOMMENDATIONS**

- 4A: Strengthen the multidisciplinary workforce that cares for older adults and with dementia throughout the continuum of care
- 4B: Improve dementia care capacity and competency of primary care providers.
- 4C: Train professionals in other, non-health care fields that interface increasingly with persons who have dementia

## **GOAL 5 Expanded Research in Utah**

### **RECOMMENDATIONS**

- 5A: Recruit and retain world-class researchers, and attract research investments that generate economic multipliers to create jobs and drive innovation
- 5B: Hasten development of promising new treatments with increased patient research participation and more federal, state and private research dollars

# Why Is a State Plan Needed?

**Utah** has the highest per capita prevalence increase of Alzheimer's among all states. Prevalence is the number of existing cases of a disease in a population at a given time. Utah will grow by 127% in its cases of Alzheimer's disease – from 22,000 cases in 2000 to 50,000 cases in 2025. These figures do not include the other 30% to 40% of degenerative neurological dementias for which we lack projection data. Thus, along with 32,000 cases of Alzheimer's disease in Utah today, the number of diagnosable cases of Alzheimer's disease and related dementias is close to 50,000. The combined number of Alzheimer's disease and related dementia cases in Utah could approach 100,000 by the year 2025.

Why will Utah experience a doubling or more of Alzheimer's disease and related dementias? The number of Utahns with Alzheimer's disease and related dementias will grow each year as the proportion of Utah's population that is over age 65 continues to increase. The number will escalate rapidly in coming years as the baby boom generation ages. With population growth, life expectancy, retirees coming to the state, Utah is about to experience an aging tsunami in the next decade. Age is the greatest risk factor for Alzheimer's disease and related dementias; thus, Utah will see unprecedented prevalence growth.

This unprecedented growth will have a marked impact on Utah's healthcare

system, not to mention families and caregivers. The impact is already noted, for example, Utah's Area Agencies on Aging report that upwards of 70% of families and caregivers they serve through the Caregiver Support Program are coping with Alzheimer's disease, a related dementia, or undiagnosed cognitive impairment. These Agencies provide information and referrals and are impacted with increasing case loads helping caregivers deal with complicated dementia symptoms and the stress of caregiving.

The cost of caring for someone with Alzheimer's disease and related dementias is staggering. Families provide almost 80% of care for Utahns living with the disease estimated to be worth \$1.8 billion annually. An estimated 132,000 Utah family caregivers provided over 150 million hours of care at home. These are 2010 figures. Yet, the State also incurs huge costs in managing the complexities of dementia. Most of these costs are driven by skilled nursing home expenditures. Arguably, these costs could be reduced by an investment in home and community-based care on behalf of family caregivers.

Families and government are not alone in shouldering the rising cost of Alzheimer's care. Utah's business community faces as much as \$1.4 million in lost productivity per year, as many employed caregivers must miss work, reduce their work hours, or change jobs. This, in turn, puts



the caregiver at risk of losing health insurance and vital financial resources for his or her own future.

The impact of Alzheimer's disease and related dementias was noted by the Utah State Plan Task Force in its meetings throughout the state, and the coming increase of aging baby boomers means the worst is yet to come. Nationally, the U.S. Congress, the National Institutes of Health, the Centers for Disease Control and the Administration on Aging, among others, are working with the Alzheimer's Association – the leading voluntary health organization in Alzheimer's care and support and the largest, private nonprofit funder of Alzheimer's research – to reduce the risk of dementia through the promotion of brain health and to improve care and support for all who are affected. AARP Utah; the Center for Alzheimer's Care, Imaging and Research; the Utah Division of Aging and Adult Services and the Alzheimer's Association Utah Chapter have developed similar programs in Utah.

The Utah Task Force also noted that simultaneous with Utah legislation to develop a Utah State Plan, the Congress passed legislation to develop a National Plan to Address Alzheimer's Disease. The Task Force believes the Draft Framework for the National Plan to Address Alzheimer's Disease released in January, 2012, by the U.S. Department of Health and Human Services offers a comprehensive

outline of goals and strategies that must be addressed in the nation's first-ever strategic plan for Alzheimer's.

Such efforts can support and bolster the state's own careful planning as Utah joins dozens of other states in developing its own State Plan for Alzheimer's Disease and Related Dementias. Utah's Plan is an action plan for the next half decade, 2012–2017, and should be kept evergreen as a framework for change and a gauge for progress.



# Action Plan 2012–2017

It has been one year since the first wave of Utah's baby boomers turned age 65. The "silver tsunami" has begun. The number of Utahns with Alzheimer's disease and related dementias will grow each year as the proportion of Utah's population that is over age 65 continues to increase. The number will escalate rapidly in the coming years as Utah's baby boom generation ages.

Prevalence, as mentioned above, is the number of existing cases of a disease in a population at a given time. Incidence is the number of new cases of a disease in a given time period. The estimated annual incidence (rate of developing disease in a one-year period) of Alzheimer's disease increases dramatically with age, from approximately 53 new cases per 1,000 people aged 65 to 74, to 170 new cases per 1,000 people aged 75 to 84, to 231 new cases per 1,000 people over age 85 (the "oldest-old").

An estimated 5.4 million Americans of all ages were coping with Alzheimer's disease in 2010, among them 32,000 Utahns with Alzheimer's. Statistics reveal that:

- One in eight people aged 65 and older (13 percent) has Alzheimer's disease.
- Nearly half of people aged 85 and older (43 percent) have Alzheimer's disease.

- Of those with Alzheimer's disease, an estimated 4 percent are under age 65, 6 percent are 65 to 74, 45 percent are 75 to 84, and 45 percent are 85 or older.

As mentioned, Utah's aging tsunami will have its greatest impact in the next ten to fifteen years, and that correlates with the state's highest per capita growth of Alzheimer's disease and related dementias compared with all other states.

Utah's growth in Alzheimer's and related dementias is also associated with its growing ethnic and racial diversity. While most people in the United States living with Alzheimer's and related dementias are non-Hispanic whites, older African-Americans and Hispanics are proportionately more likely than older whites to have Alzheimer's disease and other dementias. Data indicate that in the United States, older African-Americans are probably about twice as likely to have Alzheimer's and other dementias as older whites, and Hispanics are about one and one-half times as likely to have Alzheimer's and other dementias as older whites. Persons of Hispanic origin are projected to double as a percent of population from 1995 to 2025 in Utah. African Americans will also increase as a percent of population in Utah. As Utah's diverse populations increase and age and the correlated impact of Alzheimer's and related dementias increases, more effective means of

serving health care needs of diverse populations will be needed.

As thousands of Utahns turn age 65, 75, and 85, increasing mild cognitive impairment and the question, “Is it Alzheimer’s?” will become an issue. As a result, their children and grandchildren will raise their awareness and support. Similarly, religious, social, private and public institutions will provide a significant measure of care and advocacy. The Utah Commission on Aging found that a key to success in dealing with the age tsunami will be Utah’s high priority on community, family and independence. It concluded there will be a need to support the most vulnerable of aging Utahns. It stated that Utah, “must continually strive to assure that every public dollar spent on aging individuals provides the maximum benefit to the recipient at the most reasonable cost to the State.”

In the coming years, thousands of Utah families will be working through the challenges of cognitive impairment due to degenerative neurological diseases. In the early stages, many will be working through the challenge of the driving dilemma faced by aging Utahns, and conversations about safe driving can evoke strong emotional reactions. As the disease progresses and these challenges continue, they will impact on personal independence, managing day-to-day activities, legal and financial preparedness, the ability to obtain an accurate and dignified



diagnosis of Alzheimer’s disease or a related diagnosable dementia, effective medical treatment, and long-term care options.

Considering the number of Utahns and their families dealing with these challenges on a daily basis, a public health crisis looms in our state that compels policy leaders and key stakeholders to act. Many people with Alzheimer’s suffer from multiple chronic conditions, and the need for support is great. As Utah confronts its “silver tsunami” and a doubling of its cases of Alzheimer’s disease and related dementias, there is a significant, urgent need for a comprehensive strategic plan. In 2011, the Utah State Legislature acted to fill that gap by creating a Task Force. Herewith are the resulting goals, recommendations and strategies set forth by the Utah State Plan Task Force.



# Utah State Plan

for Alzheimer's Disease and Related Dementias:  
An Action Plan for 2012–2017

GOALS, RECOMMENDATIONS and STRATEGIES

## GOAL 1 A Dementia-aware Utah

### RECOMMENDATIONS:

**1A: Raise broad public awareness of Alzheimer's disease and related dementias through culturally appropriate education campaigns**

### STRATEGIES:

1. Establish an ADRD Coordinating Council to... Seek public, private, corporate and philanthropic funding for broad-based, statewide education campaigns
2. Partner with the Bureau of Health Promotion, Utah Department of Health, to establish a program with health resource guides devoted to Alzheimer's disease and related dementias
3. Collaborate with the Center for Multicultural Health, Utah Department of Health, to develop and disseminate culturally appropriate print, radio and television media campaigns for awareness of Alzheimer's disease and related dementias
4. Target Utah's unique challenges associated with reaching and educating caregivers in rural areas, Spanish-speaking, other non-English-speaking, and Native American tribal communities with specific initiatives to overcome barriers to services
5. Promote realistic and positive images of people with Alzheimer's disease and related dementias and their caregivers to overcome existing public stigma and misperceptions
6. Advocate adoption of the Alzheimer's Disease Early Detection Alliance (AEDA) of the Alzheimer's Association by businesses, faith-based organizations, and community service groups to spread awareness among their constituencies
7. Partner with the State Office of Education to offer curriculum in schools to educate young Utah citizens on the facts of aging with sensitivity to those with cognitive impairment and family caregiving
8. Educate and enlist the faith-based community as a key resource that can reach out to and support family caregivers
9. Heighten public awareness resources, such as the 2-1-1 information line, 24/7 Alzheimer's helpline, Area Agencies on Aging, Aging and Disability Resource Centers, veterans clinics, and the Center for Alzheimer's Care, Imaging and Research, and establish metrics of awareness with the Division of Aging and Adult Services

**1B: Ensure that reliable, up-to-date disease and care information is disseminated**

**STRATEGIES:**

1. Disseminate public education campaign messages through accessible websites, mobile apps, libraries, senior centers, and physician offices with standardized Alzheimer's disease and related dementia content
2. Assemble content for public awareness campaigns to address a wide range of issues and audiences, including, but not limited to:
  - Early warning signs and effective strategies for obtaining diagnosis, treatment and support
  - Cost of long-term care, limits of Medicare, personal responsibility, importance of financial planning, and the limits and availability of community resources
  - Information from the Centers for Disease Control and other reliable sources on behaviors that might lower the risk of developing Alzheimer's disease and related dementias
3. Develop electronic links within state-supported websites to ensure that reliable information from state agencies is disseminated
4. Provide state-approved forms such as Durable Power of Attorney for Healthcare, Physician Orders for Life Sustaining Treatment (POLST) and other documents with helpful instructions and Frequently Asked Questions at no cost to the consumer via public

libraries, resource centers and easily accessible websites

5. Ensure information and educational materials are offered at appropriate literacy, language, and legibility (font size) for a diverse population

**1C: Provide Utah citizens with the best evidence on how to reduce their own risk for Alzheimer's disease and related dementias**

**STRATEGIES:**

1. Encourage a wellness agenda for Utah that includes a brain-healthy lifestyle, inclusive of exercise, nutrition, cognitive activity, and social engagement as key protective factors against Alzheimer's disease and related dementias
2. Promote the Center for Disease Control's Healthy Brain Initiative: A National Public Health Road Map to Maintaining Cognitive Health developed through a partnership including the Alzheimer's Association, National Institutes of Health, Administration of Aging, AARP, and many others at the national, state and local levels
3. Support the Cognasium (gymnasium for the brain) movement in Utah, which encourages Utah citizens to take personal responsibility for brain health and develop their own Individualized Cognasium Plan
4. Emphasize heart, brain, and physical benefits of healthy recreation, senior games, fitness in the park programs, multigenerational activities, service to community, healthy aging, and senior center programs
5. Target the higher prevalence of

Alzheimer’s disease and related dementias among older African–Americans and Hispanics – twice that of older whites – through education on diabetes and high blood pressure, conditions more common in these populations, and known risk factors for dementia

**1D: Coordinate standardized information throughout state and local governments**

**STRATEGIES:**

1. Coordinate with the Division of Aging and Adult Services on a continuing role of the State Plan Task Force as an Advisory Group to meet systematically with state and local agencies to identify programs and services relevant to older individuals with memory loss and dementia, even if not currently so identified, and advise on how dementia awareness would enhance performance
2. Enlist state and local governments to facilitate customer training about memory loss, Alzheimer’s disease and related dementias for employees of government units interacting frequently with patients and families, such as the Division of Motor Vehicles, Adult Protective Services, Area Agencies on Aging, Community Mental Health Centers and County Health Departments

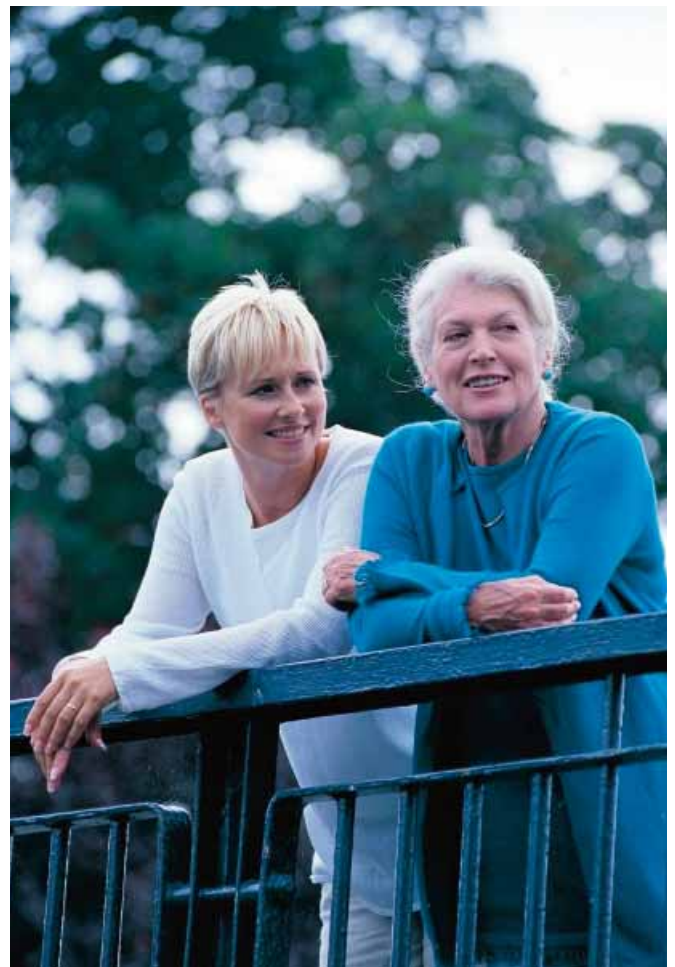
**GOAL 2  
Health and Dignity for All with  
Dementia and Those at Risk**

**RECOMMENDATIONS:**

**2A: Engage in a public health approach to confront Utah’s significant projected growth in Alzheimer’s disease and related dementias**

**STRATEGIES:**

1. Empower public health officials and health care providers to promote disease prevention by addressing risk factors such as caregiving, ethnicity, diabetes, and heart disease
2. Promote brain health initiatives to reduce risk factors, especially in ethnically diverse communities
3. Collect and use data to drive public health service development and delivery
4. Recognize caregiving as a health risk factor that warrants public health attention to incentivize health professionals to acknowledge and address the issue
5. Increase surveillance of incidence of Alzheimer’s disease and the impact of





caregiving through the Behavioral Risk Factor Surveillance System (BRFSS) and other surveys

6. Use available data to assist in program improvement, grant submissions, and implementation of Utah's Alzheimer's Disease State Plan

**2B: Improve access to a timely diagnosis, differential treatment, and supportive services**

**STRATEGIES:**

1. Encourage accurate and dignified diagnosis and proactive treatment, differentiating Alzheimer's disease and related dementias, and promote continuing medical education for physicians and medical practitioners
2. Promote use of the Medicare preventive service benefit for the detection of cognitive impairment, which commenced in 2011 under the Patient Protection and Affordable Care Act
3. Expand the application of the Utah Telehealth Network and increase the number of physicians certified in the Network to treat patients with cognitive impairment in rural Utah
4. Provide a statewide comprehensive resource database and directory that includes information about the range of medical and other providers, programs, and services related to diagnosis, treatment, and support for persons with dementia
5. Pursue federal funding for evidence-based replication projects, including U.S. Administration on Aging grants to states for development of a statewide "dementia-capable," sustainable service delivery system

**2C: Provide access to behavioral health services and person-centered in-home care that includes evidence-based, non-pharmacological interventions rather than more costly inpatient treatment.**

**STRATEGIES:**

1. Improve behavioral health services through the recruitment and specialized training of physicians, nurses, and therapists to provide such services for persons with dementia that are covered through Medicare, Medicaid, and/or private insurance
2. Ameliorate neuropsychiatric symptoms of persons with dementia cared for at home by enhanced training and support of family caregivers on effective behavioral interventions that are designed to modify such symptoms, reduce caregiver distress, and delay nursing home placement
3. Support the development of senior behavioral services commensurate with growth in long-term care and assisted living, including an outpatient geriatric psychiatry consultation program through collaboration of the Office of Higher Education and the Department of Human Services, Division of Substance Abuse and Mental Health, and expand board-certified geriatric psychiatric care in both the private sector and community mental health senior behavioral health services
4. Extend person-centered care in rural Utah with evaluations and consultations for persons with dementia and their family caregivers by dementia specialists and an outpatient geriatric psychiatry consultation program through the Utah Telehealth Network

**2D: Secure the safety, independence, and mobility of persons with Alzheimer’s disease and related dementias with appropriate responses and policies for each stage of the disease**

**STRATEGIES:**

1. Develop a Utah endangered person advisory system through the voluntary partnership of law enforcement, broadcasters, media and community organizations in which cases are initiated by law enforcement and an investigation is made on the missing person’s whereabouts immediately
2. Support widespread and early enrollment of those with memory loss who tend to wander in the MedicAlert+Safe Return™ program of the Alzheimer’s Association and encourage the use of cost-effective cellular and GPS tracking technologies to enable families to prevent wandering
3. Address the unique transportation needs of persons in the early stage of Alzheimer’s disease and related dementias, improve driving cessation policies, and promote available resources such as the Alzheimer’s Association Driving Resource Center ([www.alz.org/safetycenter](http://www.alz.org/safetycenter)) and the National Center on Senior Transportation
4. Partner with Adult Protection Services, law enforcement, the banking industry, and the court system to recognize ongoing or potential financial abuse of elders with dementia, protect those at risk, and curb ongoing exploitation
5. Expand CIT training of law enforcement throughout the state on aging issues

and identification of those with dementia, particularly, in early stage and with behavior disturbance

**2E: Enhance the self-determination of persons with memory loss and mild dementia, and prevent financial exploitation and abuse**

**STRATEGIES:**

1. Enhance self-determination by encouraging persons with dementia and their families to assess management of assets early with the help of elder law specialists or Utah Legal Services, effective draw-down of assets, and avoidance of costly court proceedings
2. Facilitate the independence of early-stage persons with dementia by improving public and private transportation options, working with mobility managers, and training transportation providers and drivers
3. Explore from multidisciplinary perspectives a justice center system for elder and vulnerable adults to ensure timely and appropriate prosecution of those who exploit persons with cognitive impairment
4. Support guardianship and conservator policies that align with national standards, that respect the rights and needs of persons with dementia, and that minimize the burden on families and the legal system
5. Employ health care provider and community agency education to encourage widespread and early use of advanced health care directives

**2F: Implement a statewide strategy to coordinate, integrate, deliver and monitor long-term care and services**

**STRATEGIES:**

1. Establish mechanisms to coordinate among state and local agencies, government departments, voluntary



health organizations, and private long-term care providers to better serve the aging and disabled population. For example, promote cross-training and joint visits by state regulators, and identify more efficient and effective regulatory oversight

2. Create an integrated state long-term care financing approach that provides incentives for people to receive care in home- and community-based settings and enables Utah to retain and reinvest cost savings back into the state's long-term care infrastructure

3. Provide regular training to regulators on best practices in dementia care to improve consistency and continuity between settings
4. Prioritize funding for medical care and long-term services and support through alternative financing mechanisms such as expansion of the use of Medicaid waivers or "provider fees"

**GOAL 3  
Supported and Empowered  
Family Caregivers**

**RECOMMENDATIONS:**

**3A: Acknowledge and invest in the vital role of family caregivers with guidance on quality care and the best utilization of family financial resources throughout the disease course**

**STRATEGIES:**

1. Support, fund and expand the availability of professional guidance to help family caregivers navigate and manage myriad safety and behavioral issues through an array of services such as caregiver assessment, care consultation, counseling, care management, respite care, support groups, assistive technologies and other effective interventions
2. Increase participation in educational programs among diverse caregivers through culturally and linguistically appropriate offerings
3. Secure foundation, corporate and nonprofit funding for effective statewide family caregiver training programs
4. Provide health education early in the



disease through medical providers, voluntary agencies, and the Caregiver Support Program of the Area Agencies on Aging that includes information about disease course, services needed at different disease stages, and how they are paid for

5. Encourage the financial community to provide information about financial planning for chronic illness, the use of long-term care insurance, and other financial instruments
6. Partner with health insurance providers to ensure that medically appropriate dementia services are clearly identified and addressed in coverage statements and covered in policies, including those for younger-onset dementias

**3B: Empower caregivers through a supportive network that is better coordinated, and by expanding affordable respite care**

#### **STRATEGIES:**

1. Recognize and address the financial burden of caregiving and work to protect spouses from impoverishment at all levels of care
2. Encourage businesses and other workplace sites to offer family caregiver support services, e.g. flexible work hours, referrals and counseling through Employee Assistance Programs and other employee initiatives
3. Advocate for state and federal tax credits, similar to the child care tax credit, for frail spousal and working adult offspring caregivers paying for direct care services to encourage the use of early intervention and support services, such as adult day and respite care

4. Research, disseminate, and expand private insurance and cafeteria plans that coverage supportive services for caregivers such as adult day
5. Evaluate the reimbursement rate for adult day care service and provide recommendations to bring the current rate in line with the actual cost of providing the service, based on analysis of:
  - The efficacy of early-stage dementia day care to support independent functioning for as long as possible
  - The possible value of setting rates for different levels of day care, acknowledging unique needs of persons with advancing dementia
  - The effectiveness of adult day service as a less costly alternative to state and federally funded permanent residency in long-term care
6. Consider the potential reallocation of Medicaid dollars between home and community-based programs and nursing home care, and the expansion of 1915c waiver programs to provide additional home- and community-based support to caregivers of home-dwelling persons with dementia as well as save state and federal dollars

**3C: Ensure that all families have access to clinical post-mortem diagnostic services and tissue banking to invest in the future health of their families**

#### **STRATEGIES:**

1. Partner with hospitals as part of their public service mission to provide access to high-quality postmortem diagnostic services for individuals with Alzheimer's disease and related dementias

2. Encourage family-centered biobanking and linkage with the Utah Population Database so families can develop their own family health history based upon genealogical medical and genetic records
3. Mandate the death certificate data include information obtained through postmortem diagnostic examinations



## GOAL 4 A Dementia-competent Workforce

### RECOMMENDATIONS:

**4A: Develop a dementia-capable and culturally competent workforce that cares for older adults and persons with dementia throughout the continuum of care**

### STRATEGIES:

1. Support certification, licensure, and degree programs that encourage working with older adults and persons with Alzheimer's disease and their caregivers. Require a standard level of dementia sensitivity and disease education for all trainees in health-related fields at the student and residency levels
2. Partner with licensing boards to mandate continuing education on Alzheimer's and related dementias as a condition of license renewal for doctors, nurses, and other health professionals
3. Mandate competency-based training based on the Foundations of Dementia Care, developed nationally by the Alzheimer's Association and more than two dozen national organizations, for employees in various settings (e.g., hospitals, nursing homes, assisted living, home care workers, care managers, agency caregiver support staff, and social workers), recognizing there are different strategies for different disciplines, settings, levels of skill and licensure
4. Provide guidance to care managers, advocates, and providers on the Medicare benefit that reimburses for an annual cognitive exam
5. Encourage care providers to partner with multicultural coalitions as they develop "dementia friendly services" ethnically diverse clients and residents across the continuum of care, including adult day care, in-home respite, assisted living, long-term care, and specialized dementia care
6. Create financial incentives (through tuition assistance, loan forgiveness, housing subsidies, and stipends) to increase the number of health care professionals who pursue education and training in gerontology and geriatrics, and particularly, those who make a commitment to work in low-income, uninsured, rural, and ethnic communities with higher disease prevalence
7. Educate providers on the use of Medicare coding to reimburse physicians and allied health professionals for family conferences and care consultation that

educate and support family caregivers, guide future decisions, and enhance the quality of medical care and support services

#### 4B: Improve dementia care capacity and competency of primary care providers

##### STRATEGIES:

1. Explore, endorse, and disseminate dementia-specific curriculum and training programs tailored to primary care physicians, geriatricians, internists, general practitioners, physician assistants, and nurse practitioners
2. Create and disseminate an evidence-based set of guidelines for Alzheimer's and related dementias disease management to improve evaluation, treatment, care coordination, and follow-up support of the patient
3. Improve primary care practices by linking them 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
4. Train nurses, counselors, health professionals and direct care workers to develop person-centered one-on-one care to dementia patients of color and their families
5. Protect and promote Utah's Center on Alzheimer's Care, Imaging and Research as a tertiary referral resource for the state's physicians to support diagnosis and management of complex cases
6. Incorporate Alzheimer's educational materials for patients and family care-

givers into digital libraries to enable physicians to store and disseminate such information in connection with electronic medical records

7. Educate clinicians on the criteria needed to refer and qualify dementia patients for hospice care to ensure that patients receive full benefit of the medical, health services, and social supports offered at end of life

#### 4C: Train professionals in other, non-health care fields that interface increasingly with persons who have dementia

##### STRATEGIES:

1. Educate law enforcement on the MedicAlert+Safe Return™ program of the Alzheimer's Association to quickly identify and return to safety persons with Alzheimer's or related dementias
2. Support efforts of adult protective officials on detecting, addressing, and preventing fraud, abuse, neglect and self-neglect of persons with dementia in the community or in institutions of care
3. Partner with state regulators, court administrators, and the Utah Bar Association for training on legal issues facing persons with Alzheimer's and related dementia and their families such as guardianship, conservatorship, powers of attorney, and the medical standards related to each
4. Provide comprehensive Alzheimer's and related dementia training to first responders, law enforcement, EMT, fire fighters, emergency preparedness, and search and rescue officials

## GOAL 5 Expanded Research in Utah

### RECOMMENDATIONS:

**5A: Recruit and retain world-class researchers, and attract research investments that generate economic multipliers to create jobs and drive innovation**

### STRATEGIES:

1. Collaborate with industry and the life and biosciences sector to increase research infrastructure
2. Ensure that the most promising evidence-based research projects are advanced and made sustainable, including research on prevention, treatment, and finding a cure for Alzheimer's disease
3. Promote research focused on the development of assistive technology, including both high and low tech assistive devices that adapt everyday environments for people with Alzheimer's
4. Engage community physicians in research toward early recognition of memory problems as well as other dementia symptoms, and rapid referrals to clinical trials

**5B: Hasten development of promising new treatments with increased patient research participation and more federal, state and private research dollars**

### STRATEGIES:

1. Promote taxpayer contributions through a tax check-off to support Alzheimer's disease and related dementia research



at Utah universities as administered through existing mechanisms at the Utah Center on Aging

2. Educate the public on the availability, purpose, and value of research, and encourage participation in clinical trials and other studies. Promote the Alzheimer's Association's TrialMatch™ as a resource for increasing participation in clinical trials
3. Collaborate with private, state, and federal partners to increase participation of diverse populations in research studies
4. Encourage the Utah Science Technology and Research (USTAR) Initiative to support a new investigative team in neurodegenerative disease at the University of Utah
5. Generate rapid commercialization and spin-off companies based upon promising and innovative dementia research at Utah universities through their Offices of Technology Development and industry partnerships
6. Collaborate with private, state and federal partners to increase participation of diverse populations in research studies



# Utah's Vision: Becoming a Dementia-capable State

## Creating a Dementia-capable Service System for Persons with Dementia and Their Family Caregivers

Through implementation of the State Plan Strategies, the Task Force envisions that persons with dementia and their family caregivers will have clear and ready access to an integrated system that offers a comprehensive set of high quality health care services and social supports that are evidence-based and support the self-determination, dignity and protection of persons with Alzheimer's disease and related dementias.

Creating this system involves enlisting, informing, building upon and integrating existing programs (1) between state agencies, providers and communities; (2) across the state's Health and Human Services systems; and (3) among non-health related services, i.e., law enforcement, first responders, transportation, legal, and so on.

State Plan Strategies encourage effective dialogue on and development of the following objectives:



**Objective 1: Coordinate the integration of a statewide set of programs, already in existence, that could incorporate a Single Entry Point/No Wrong Door access for individuals with Alzheimer's disease and related dementias and their caregivers**

Such a statewide system would mean persons with dementia and their family caregivers anywhere in the state will have streamlined access to the full array of public and private sector programs and services that enhance home- and community-based care, medical care, long-term care, legal, financial and social supports.

**Objective 2: Ensure access to a comprehensive, sustainable set of high quality services critically needed by persons with Alzheimer's disease and related dementias throughout the state.**

This objective would ensure that persons with dementia and their caregivers will have access to a comprehensive set of high quality services that are (1) evidence-based (2) informed and certified as dementia-capable, not only in primary care, long-term care and human services; but also, in non-health related services, i.e., transportation, law enforcement, safety, legal and financial services.

Utah state agencies operate based on strategic plans. The Task Force encourages Utah state agencies to use these plans to inform their role in the state's operation of a comprehensive, integrated system for persons with Alzheimer's disease and related dementias.

# References



The Utah State Plan Task Force frequently referenced data, charts and figures from Alzheimer's Association *Alzheimer's Disease 2011 Facts and Figures Report*. This report is provided annually each spring and delivered to members of Congress. The full report is available at: [www.alz.org/alzheimers\\_disease\\_facts\\_and\\_figures.asp](http://www.alz.org/alzheimers_disease_facts_and_figures.asp).

1. Alzheimer's Disease Early Detection Alliance, a positive force to improve the health of Utah companies, organization and communities and part of a nation-wide network of organizations that are addressing the Alzheimer's crisis, accessed online at: <http://www.alz.org/aeda/aeda.asp>.
2. Fact Sheet, March, 2011, Find the full report and information on Utah at [www.alz.org/facts](http://www.alz.org/facts). The *2011 Alzheimer's Disease Facts and Figures* report also contains data on the impact of the disease in every state across the nation.
3. Foundations of Dementia Care, classroom training program field-tested to help professional care organizations achieve longer-lasting, more consistent results in dementia patient care, accessed online at: [http://www.alz.org/professionals\\_and\\_researchers\\_foundations\\_of\\_dementia\\_care.asp#practical](http://www.alz.org/professionals_and_researchers_foundations_of_dementia_care.asp#practical)
4. Physicians Orders for Life Sustaining Treatment (POLST) approved by the Utah Department of Health for patient wishes and medical indications for life-sustaining treatment, accessed online at: <http://health.utah.gov/hflcra/forms/POLST/POLSTForm2010.pdf>
5. Principles for a Dignified Diagnosis, published by the Alzheimer's Association in 2009, but may be distributed by unaffiliated organizations and individuals, accessed online at: [http://www.alz.org/national/documents/brochure\\_dignified\\_diagnosis.pdf](http://www.alz.org/national/documents/brochure_dignified_diagnosis.pdf).
6. Senate Resolution, No. 48, the resolution set forth a Utah State Plan Task Force for Alzheimer's Disease and Related Dementias, passed in the 2011 legislative session and signed by Governor Gary Herbert.
7. Senate Joint Resolution, No. 1, sponsored by Senator Karen Morgan for introduction in the 2012 legislative session, expresses support for a Utah State Plan for Alzheimer's disease and related dementias.
8. TrialMatch™, Alzheimer's Association Clinical Studies Matching Service, accessed online at [www.alz.org/Trial-Match](http://www.alz.org/Trial-Match)
9. Utah Facts and Figures, for more information, view the *2011 Alzheimer's Disease Facts and Figures* report, accessed online at: [alz.org/facts](http://alz.org/facts).

# Appendices

## Dementia: Definition and Specific Types\*

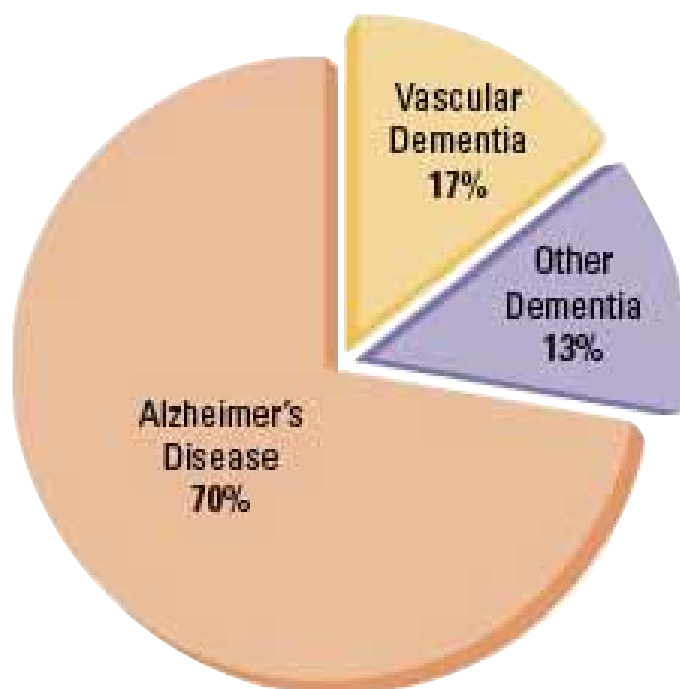
Dementia is caused by various diseases and conditions that result in damaged brain cells or connections between brain cells. When making a diagnosis of dementia, physicians commonly refer to the criteria given in the *Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition (DSM-IV)*. To meet DSM-IV criteria for dementia, the following are required:

- Symptoms must include decline in memory and in at least one of the following cognitive abilities:
  - 1) Ability to generate coherent speech or understand spoken or written language;
  - 2) Ability to recognize or identify objects, assuming intact sensory function;
  - 3) Ability to execute motor activities, assuming intact motor abilities, sensory function and comprehension of the required task; and
  - 4) Ability to think abstractly, make sound judgments and plan and carry out complex tasks.
- The decline in cognitive abilities must be severe enough to interfere with daily life.

It is important for a physician to determine the cause of memory loss or other dementia-like symptoms. Some symptoms can be reversed if they are caused by treatable conditions, such as depression, delirium, drug interaction, thyroid problems, excess use of alcohol or certain vitamin deficiencies.

When dementia is not caused by treatable conditions, a physician must conduct further assessments to identify the form of dementia that is causing symptoms. Different types of dementia are associated with distinct symptom patterns and distinguishing microscopic

brain abnormalities. The most common types are: Alzheimer's disease, vascular dementia, mixed dementia, frontotemporal dementia, dementia with Lewy bodies, Parkinson's disease, Creutzfeldt-Jakob disease, and Normal pressure hydrocephalus.



Source: Plassman, BL; Langa, KM; Fisher, GG; Heeringa, SG; Weir, DR; Ofstedal, MB, et al. "Prevalence of Dementia in the United States: The Aging Demographics, and Memory Study. *Neuroepidemiology* 2007; 29:125-132.<sup>31</sup>

In 2011, the Alzheimer's Association's journal, *Alzheimer's and Dementia: The Journal of the Alzheimer's Association*, published new criteria and guidelines for the diagnosis of Alzheimer's disease. These were developed by the Association and the National Institute on Aging (NIA) of the National Institutes of Health (NIH). For more information, see page 24, *New Diagnostic Criteria and Guidelines for Alzheimer's Disease*.

\*Portions of this definition are based on the *Alzheimer's Association, 2011 Alzheimer's Disease Facts and Figures, page 5*.



# Utah

## 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

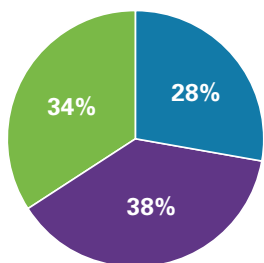
Year	65–74	75–84	85+	Total	% change from 2000
2000	1,400	12,000	8,800	22,000	
2010	1,600	15,000	16,000	32,000	45%
2020	2,400	19,000	20,000	41,000	86%
2025	3,000	24,000	23,000	50,000	127%

### 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	90,283	77,932,159	\$865,046,968
2009	101,151	115,191,322	\$1,324,700,201
2010	132,991	151,450,408	\$1,806,803,372

### Cognitive Impairment in Nursing Home Residents, 2008

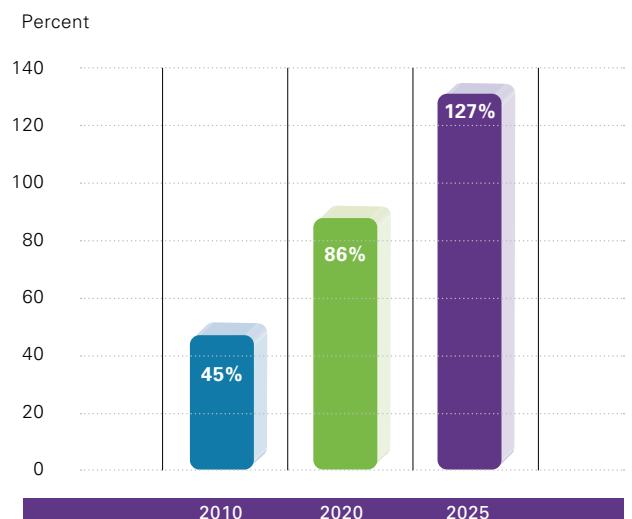
Total Nursing Home Residents **17,743**



Level of Cognitive Impairment

- severe/moderate
- mild/very mild
- none

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



### Number of Deaths Due to Alzheimer's Disease in 2007

# 393



# New Diagnostic Criteria and Guidelines for Alzheimer's Disease

*The Utah State Plan Task Force strongly urges support of Utah-based research initiatives (see Goal 5). New diagnostic criteria include biomarkers for use in research settings and are a work in progress to evolve as knowledge advances. Therefore, now is the time for Utah to develop strategies for Utah-based research.*

The criteria and guidelines for diagnosing Alzheimer's disease have been updated to incorporate new brain imaging and biochemical tests that could signal the disease before symptoms appear. This historic update, which is the first in 27 years, stems from mounting evidence that the degeneration of nerves deep within the brain starts years or even decades before memory loss and other cognitive changes are noticeable.

The significance of this development is that it brings us closer to earlier detection and treatment, and ultimately leads to effective disease-modifying therapies. There have been no new drug treatments for Alzheimer's disease in nearly a decade.

The new criteria open the door for research into the earliest stages of the disease and the development of drugs that may slow or stop the degenerative process before the damage is done. Their release follows a report that brain areas affected by Alzheimer's disease start shrinking up to a decade before symptoms appear.

**The new diagnostic criteria and guidelines are now available, and include the following key elements:**

- Updates to widely-used existing guidelines for Alzheimer's disease originally established in 1984.
- Refinements to existing guidelines for diagnosing mild cognitive impairment (MCI). People with MCI experience a decline in memory, reasoning or visual perception that's measurable and noticeable to themselves or to others, but not severe enough to be diagnosed as Alzheimer's or another dementia.
- Expansion of the conceptual framework for thinking about Alzheimer's disease to include a "preclinical" stage characterized by signature biological changes (biomarkers) that occur years before any disruptions in memory, thinking or behavior can be detected. Promising investigational biomarkers include brain imaging strategies and certain proteins in spinal fluid.
- Establishment of a framework for eventually adding biomarker benchmarks to the diagnosis of Alzheimer's disease in all of its stages.

# Principles for a Dignified Diagnosis

*This is the first statement of its kind written by people with dementia on the subject of the Alzheimer and related dementia diagnosis experience.\**

From a 2008 report, *Voices of Alzheimer's Disease: A Summary Report on the Nationwide Town Hall Meetings for People with Early Stage Dementia*, these principles are their insights on how to make that experience better.

- **Talk to me directly, the person with dementia.**

I am the person with the disease, and though my loved ones will also be affected, I am the person who needs to know first.

- **Tell the truth.**

Even if you don't have all the answers, be honest about what you do know and why you believe it to be so.

- **Test early.**

Helping me get an accurate diagnosis as soon as possible gives me more time to cope and live to my fullest potential and to get information about appropriate clinical trials.

- **Take my concerns seriously, regardless of my age.**

- **Deliver the news in plain but sensitive language.**

This may be one of the most important things I ever hear. Please use language that I can understand and is sensitive to how this may make me feel.

- **Coordinate with other care providers.**

- **Explain the purpose of different tests and what you hope to learn.**

- **Give me tools for living with this disease.** Please don't give me my diagnosis and then leave me alone to confront it. I need to know what will happen to me, and I need to know not only about medical treatment options but also what support is available through the Alzheimer's Association and other resources in my community.
- **Work with me on a plan for healthy living.**
- **Recognize that I am an individual and the way I experience this disease is unique.**
- **Alzheimer's is a journey, not a destination.**

\*This is an excerpt of a document published by the Alzheimer's Association. Contact the Utah Chapter for the full document at 800-272-3900.



# Glossary of Terms

## **Alzheimer's Disease Supportive Services Programs**

A series of programs funded by U.S. Administration on Aging grants to the State of Utah and the Alzheimer's Association Utah Chapter to create community-based health-related and social support services for underserved populations in targeted locations. The model partners the Division of Aging and Adult Services, the Alzheimer's Association Utah Chapter, Area Agencies on Aging and community providers to develop evidence-based and culturally competent services to persons with Alzheimer's disease and related dementias.

## **Assisted Living**

Assisted living is a licensed residential setting that provides 24-hour care and supervision to seniors who need assistance, but do not require around the clock nursing care. Assisted living communities provide assistance with Activities of Daily Living (ADLs), medication management, social activities, housekeeping, meals, transportation, and may offer dementia care programs or health-related services. For more information, contact the Utah Assisted Living Association.

## **Caregiver**

The term caregiver refers to anyone who provides assistance to someone else who is, in some degree, incapacitated and needs help: a husband who has suffered a stroke; a wife with Parkinson's disease; a mother-in-law with cancer; a father with Alzheimer's disease; a son with traumatic brain injury; a partner with AIDS. **Informal caregiver** and **family caregiver** are terms that refer to unpaid

individuals such as family members, friends, neighbors and congregational members who provide care. This becomes the circle of care. These individuals can be primary or secondary caregivers, full time or part time, and can live with the person being cared for or live separately. For more information, contact the Utah Coalition for Caregiver support.

## **Cognasium**

Cognasium is to the brain what the gymnasium is to the body, and focuses on brain health. Dementia is universally viewed as a diminishment of the person affected. This translates to a stress-burden model of caregiving. The Cognasium approach focuses on the remaining strengths and abilities of the person with dementia which often outweigh the losses. Not only physical activity; but also, activities in visual arts, music and socialization are hugely successful. A recent documentary film demonstrated such discoveries worldwide with dementia patients, captured in its title, "I Remember Better When I Paint." The caregiver develops an Individualized Cognasium Plan (ICP) with the loved one with dementia. The ICP focuses on appropriate exercise, proper nutrition, cognitive activity and social engagement. The caregiver is trained to administer this program in the home. The care recipient regularly attends a Cognasium Support Group with other early stage persons while the caregiver attends a Caregiver Support Group that focuses on disease awareness, problem-solving, mutual support and respite.

The March, 2009, *Journal of Nursing Gerontology* described, in numerous studies, how (1) the early stage brain when challenged



reorganizes after damage and experiences functional improvements, (2) person-centered activities afford better symptom management tools to caregivers, and (3) such programs support the need for an expanding evidence base through research. For more information, contact the Alzheimer's Association Utah Chapter.

### **Hospice Care**

Designed to give supportive care to people in the final phase of a terminal illness and focus on comfort and quality of life, rather than cure. The goal is to enable patients to be comfortable and free of pain, so that they live each day as fully as possible. Aggressive methods of pain control may be used. Hospice programs generally are home-based, but they sometimes provide services away from home in free-standing facilities, in nursing homes, or within hospitals. The philosophy of hospice is to provide support for the patient's emotional, social, and spiritual needs as well as medical symptoms as part of treating the whole person. Supportive services also extend to family members. For more information, contact the Utah Hospice and Palliative Care Organization.

### **Long-Term Care**

This term refers to a variety of services that includes medical and non-medical care to people who have a chronic illness or disability. Long-term care helps meet health or personal

needs. Most long-term care is to assist people with support services such as activities of daily living like dressing, bathing, and using the bathroom. Long-term care can be provided at home, in the community, in assisted living or in nursing homes. It is important to remember that you may need long-term care at any age. A study by the U.S. Department of Health and Human Services says that people who reach age 65 will likely have a 40 percent chance of entering a nursing home. About 10 percent of the people who enter a nursing home will stay there five years or more. For more information, contact the Utah Health Care Association.

### **Respite Care**

Respite care is a constellation of services provided on behalf of a dependent family member so that he or she can remain safely in the home. In Utah, eligible persons over 65 years of age, or disabled (including disabled children), or blind may receive respite care counseling, support, and funding as available, through Area Agencies on Aging, the Veterans Administration, Jewish Family Services, the Alzheimer's Association and the Utah Coalition for Caregiver Support's Lifespan Respite Care Program. Each of these organizations serves specific populations in need within the lifespan, not the entire lifespan. Respite care is generally considered an alternative to out-of-home care, such as nursing homes or board and care facilities. The types of services which can be authorized as respite are housecleaning, meal preparation, laundry, grocery shopping, personal care services (such as bowel and bladder care, bathing, grooming and paramedical services), accompaniment to medical appointments, and protective supervision for the cognitively impaired.



# Resources for Families in Utah

## Alzheimer's Association Dementia Care Service Centers

The Alzheimer's Association is the leading voluntary health organization in Alzheimer care, support and research. Its mission is to eliminate Alzheimer's disease through the advancement of research; to provide and enhance care and support for all affected; and to reduce the risk of dementia through the promotion of brain health.

The core services of the Alzheimer's Association are:

- Information & Referral
- Family Care Consultation
- Medic Alert® + Safe Return® wanderer's registry & I.D.
- Caregiver Education
- Support Groups
- Professional Training
- Early Stage Programs



### Service Center Locations and the Areas They Serve

#### *Northern Rural Utah*

##### **Logan Service Center**

BRAG Area Agency on Aging  
170 North Main Street  
Logan, UT 84321  
(435) 752-7242

#### *Northern Wasatch Front*

##### **Clearfield Service Center**

Located in Clearfield Senior Center  
42 South State Street  
Clearfield, UT 84015  
(801) 525-5057

#### *Central Wasatch Front*

##### **Murray Service Center**

855 East 4800 South, Suite 100  
Murray, UT 84107  
(801) 265-1944

#### *Southern Wasatch Front*

##### **Orem Service Center**

Located in Mountainland  
Area Agency on Aging  
586 East 800 North  
Orem, UT 84097  
(801) 347-0074

#### *Southern Utah*

##### **Care Consultation and Respite Care**

Located in St. George Senior Center  
245 North 200 West  
St. George, UT 84770  
(800) 272-3900

For questions and support throughout Utah:  
Contact the 24/7 Helpline at  
(800) 272-3900

# Acknowledgments

Utah's Alzheimer's Disease and Related Dementias State Plan was a collaborative effort in which many individuals and both public and private organizations contributed precious time, financial resources and valued expertise. The leaders who made this Plan possible are:

## SENATE BILL 48 SPONSOR

Senator Karen Morgan

## HOUSE SPONSOR

Representative Carol Spackman Moss

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Nick Zullo, Program Director,  
Alzheimer's Association  
Utah Chapter

## 2011 ALZHEIMER'S FACTS & FIGURES

*Annual Report to Congress  
by the Alzheimer's Association,  
March, 2011*

Utah has the highest per capita growth rate in Alzheimer's disease prevalence, projected at 127% from 2000 to 2025.

32,000 Utah citizens have Alzheimer's disease and another 14,000 have a related dementia (vascular, Frontotemporal, Dementia with Lewy Bodies, etc.).

132,000 family members (spouses or adult children) care for their dementia loved-ones at home.

In gratitude to the 2011 Legislature that created the Utah State Plan Task Force on March 13, 2011

## FOR FURTHER INFORMATION

Alzheimer's Association Utah Chapter  
855 East 4800 South Salt Lake City, Utah 84117  
(801) 265-1944 • [www.Alz.org/utah](http://www.Alz.org/utah)  
800-272-3900 – 24/7 Helpline



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At Equitable we have a responsibility to be of service to the people of Utah. For over 75 years the spirit of caring has been a fundamental part of who we are. We value the strong partnership we have with the Alzheimer's Association Utah Chapter and are proud to do our part to support its mission . . . because **We Care!**

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