

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

2018
to
2022

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Writing provided by Karen Nellist of KTEN Writing and Evaluation Services.

Suggested citation:

Utah's State Plan for Alzheimer's Disease and
Related Dementias 2018-2022. Version 1.0.
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of Health



Utah's State Plan for Alzheimer's Disease and Related Dementias is the result of many individuals who devoted their time and effort to the creation of this plan. This endeavor could not have happened without the hard work and commitment of private, non-profit, public entities, and individuals who participated in workgroups representing specific topics. The Coordinating Council, comprised of the chairperson of each workgroup and a representative from the Utah Department of Health, managed the process to create this state plan.

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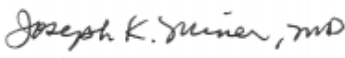
Dear Fellow Utahns,

On behalf of the Utah Department of Health, I would like to offer my support for Utah's State Plan for Alzheimer's Disease and Related Dementias 2018-2022. Utah has a higher rate of Alzheimer's disease than almost any other state. Already 30,000 people in our State have the disease, with a projected increase of forty percent in the next eight years. This is a subject that hits home for many Utahns as most of us know someone close to us who battles some form of dementia. We are committed to advocate the principles and goals laid out in this state plan as we strongly believe they will continue to bring further resource improvement and educational outreach for Alzheimer's and other related dementias.

The Coordinating Council for the Alzheimer's state plan consists of partners from many organizations, teams, and concerned citizens who have worked tirelessly to help develop this plan and provide resources to all of our dementia caregivers. The vision and passion they have is visible every day, as they continuously engage new ideas to help bring better health to all afflicted Utahns and their families. The Utah Department of Health would like to thank all of those individuals who give their time and effort so freely to help create the strategies found in this state plan. Implementing these strategies will benefit all Utah citizens.

I encourage all of our partners and Utah citizens to review Utah's State Plan for Alzheimer's Disease and Related Dementias and carefully consider what you as an individual, a community member, or a caregiver, can do to help bring the visions laid out in this plan to light. Those of you who have already contributed, we thank you to continue with your efforts. We invite those who have not yet had a chance to contribute to review this plan and discover how you can join forces to make Utah a dementia-capable state. We look forward to working with you.

Sincerely,


Joseph K. Miner, M.D.



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Spencer J. Cox
Lieutenant Governor

March 26, 2018

Dear Fellow Utahns,

It is my pleasure to present and offer my support for Utah's State Plan for Alzheimer's Disease and Related Dementias 2018-2022. The purpose of this plan is to create an awareness of Dementia in Utah, support individuals with dementia and their family caregivers, have a dementia competent workforce and expand Alzheimer's and Dementia research. The Alzheimer's State Plan Task Force was established in 2011 for Alzheimer's Disease and Related Dementias. Already an exponential growth of improvements has been seen within local resources available statewide. Despite the hard work that has already been accomplished, there is still a need for more development in this field and I am confident the goals and vision of this plan will continue to advance us towards a healthier Utah.

Alzheimer's Disease affects 30,000 individuals in Utah and over 5 million people in the United States. The disease is projected to have a 40 percent change by 2025 affecting 42,000 people in Utah. Alzheimer's is also a costly condition with the Medicaid costs of caring for people with Alzheimer's listed at \$152 million in 2017 and those amounts are just projected to increase with an estimated 50.5 percent change from 2017 to 2025. Alzheimer's is also a deadly affliction; it is currently ranking as the 6th leading cause of death in Utah leading to 584 deaths in 2014. Nearly one in every three seniors who die each year have Alzheimer's or another dementia.

The Alzheimer's State Plan provides an action plan for improved detection, diagnosis and treatment. By following the plan, caregivers will be empowered, trained, and supported to better care for their loved ones and handle their ongoing responsibilities as a caregiver. My hope is that all Utahns will rely on and become educated on the principles provided in the plan as I believe they are critical to improving the well-being and health of our senior citizen and their families.

Sincerely,

A handwritten signature in black ink, appearing to read "Spencer J. Cox".

Spencer J. Cox

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January 1, 2018

THE BRAINS BEHIND SAVING YOURS.™

Dear Fellow Utahns,

On behalf of the Alzheimer's Association, Utah Chapter, I am pleased to support Utah's State Plan for Alzheimer's Disease and Related Dementias 2018–2022. We have worked closely with the Alzheimer's and Related Dementias Program in the Utah Department of Health, and this plan supports our current and future work. We are continuously working toward raising public awareness of Alzheimer's disease, to help provide support for family and caregivers, and to support the advancement of local research. By collaborating with the Utah Department of Health and other statewide partners, we are taking significant steps towards providing a greater foundation of resources for all Utahns.

The senior population is on the rise, and is expected to continue growing. As these seniors age, we expect the number of people with Alzheimer's disease or a related dementia to continue growing. We need to prepare for this upcoming increase and meet Alzheimer's disease with an equal force. The Utah State Plan details a variety of actionable strategies which will help Utah reach the goal of becoming a Dementia-capable state. This plan outlines the goals and recommendations to ensure that Utah implements resources, education, and provide support for all Utah residents affected by Alzheimer's disease or other dementias. This plan helps focus and bring together local partners across the state with similar visions and missions to address dementias.

We look forward to working with all individuals, community members, and partners, including the Utah Department of Health's Alzheimer's Disease and Related Dementias Program to accomplish the goals set out in this plan to help reach our combined vision of becoming a Dementia-capable State.

Sincerely,

A handwritten signature in black ink, appearing to read "RD", written over a light blue horizontal line.

Ronnie Daniel,
Executive Director

The State Plan Task Force, which created the 2012-2017 Utah's State Plan for Alzheimer's Disease and Related Dementias, met with citizens throughout Utah to gather feedback on priority areas of need. This experience also shaped the development of this plan, with the following guiding directives:

- **To combat the stigma and increase awareness of Alzheimer's disease and related dementias.** Dementia is associated with a decline in memory and other mental disabilities severe enough to interfere with daily life. It is caused by physical changes in the brain. Common forms of dementia include Alzheimer's disease, vascular dementia, frontotemporal degeneration, and dementia with Lewy bodies.
- **To emphasize person-centered care that responds to individual needs and strengths.** Develop healthcare practices and societal responses that emphasize the strengths and abilities people with dementia have, not just their losses. In particular, people in early stage of dementia would be better served when their health care wishes, desires for self-determination, and continued independence are equally respected to those with other chronic illnesses or disabling conditions.
- **To anticipate and address the broadening cultural, ethnic, racial, socio-economic, and demographic diversity of Utah.** Rural access to dementia diagnostic services has become increasingly problematic. The prevalence of dementia among Hispanics and African-Americans is disproportionately greater than among Whites older than 65. These populations are growing in our state. Broad disparity in access to services is addressed in the plan.



Listing of Individuals who Contributed to the Development of the State Plan

Utah's State Plan for Alzheimer's Disease and Related Dementias 2018-2022 was a collaborative effort in which many individuals as well as private, non-profit, and public organizations gave time and expertise. All contributors are owed a huge debt of gratitude for providing their suggestions and insights on addressing Alzheimer's disease and related dementias in Utah and for providing feedback on this plan.

With special recognition to Ronnie Daniel, Executive Director of the Alzheimer's Association, Utah Chapter for his persistent efforts and continuing support of Utah's State Plan for Alzheimer's Disease and Related Dementias. And in addition, we appreciate his contributions as Co-Chair of the Alzheimer's Disease and Related Dementias Coordinating Council.

With deep appreciation for the time and energy contributed by the Co-Chairs of the four Coordinating Council workgroups:

- **Anne Asman** for leading the Dementia Aware Utah Workgroup.
- **Nancy Madsen** for leading the Supported and Empowered Caregivers Workgroup.
- **Kate Nederostek** for leading the Dementia Competent Workforce Workgroup.
- **Elizabeth Fauth** for leading the Expanded Research in Utah Workgroup.

With gratitude to the Utah Department of Health, Bureau of Health Promotion for their ongoing support and commitment.



Utah is home to more than 3 million people located in 29 counties, covering 84,000 square miles. More than 300,000 Utahns are aged 65 and older and approximately 30,000 of these people have Alzheimer's disease. By 2025, the number of Utahns aged 65 and older with Alzheimer's disease is expected to increase to 42,000, representing a 40% increase. Unfortunately, there are no estimates of the total number of Utahns with other related dementias.

In Utah, nearly half (46.7%) of all adults provide unpaid care to loved ones with Alzheimer's or related dementias and have been doing so for two or more years. More than three-quarters of caregivers (77.4%) manage household care such as cleaning or cooking and 61% manage personal care such as feeding or bathing.

Utah's State Plan Task force was convened in 2012 to develop the first Utah's State Plan for Alzheimer's Disease and Related Dementias. This plan addressed the needs of the person who has dementia as well as the needs of their caregivers. The current state plan represents a continuation of the goals, recommendations, and strategies outlined in the 2012-2017 plan. The Coordinating Council, established by the first state plan, reviewed the original plan and previous accomplishments to identify current needs and create the goals, recommendations, and strategies detailed in this plan.

This plan represents four overarching goals supported by recommendations and specific strategies. The four overarching goals are:

Goal 1: Public Awareness – Dementia Aware Utah

Goal 2: Aging Services – Dementia Competent Workforce

Goal 3: Helping People with Dementia – Supported and Empowered Caregivers

Goal 4: Research – Expanded Research in Utah

The recommendations and strategies in this plan will be accomplished through the joint efforts of private organizations, non-profit entities, local and state government agencies, as well as interested stakeholders and individuals. The plan will help to coordinate statewide activities to leverage limited resources.

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What is Dementia?

Dementia is a general term referring to a loss of cognitive function (remembering, thinking, and reasoning) severe enough to interfere with daily life. The characteristic symptoms of dementia are difficulties with memory, language, problem-solving, and other cognitive skills that affect a person's ability to perform everyday activities. These difficulties occur because nerve cells (neurons) in parts of the brain involved in cognitive function have been damaged or destroyed. This damage interferes with the ability of brain cells to communicate with each other. When brain cells cannot communicate normally, thinking, behavior, and feelings can be affected. Though Alzheimer's disease is the dementia most commonly known, other dementia diagnoses include vascular dementia, dementia with Lewy bodies, and frontotemporal degeneration.

Dementia is more common as people age; however, many people live into their 90s and beyond without any signs of impairment. Dementia symptoms vary depending on the cause, but common signs and symptoms may include, but are not limited to:

Cognitive changes

- Memory loss that disrupts daily life
- Challenges in planning or solving problems
- Difficulty completing familiar tasks at home, work, or at leisure
- Confusion with time or place
- Trouble understanding visual images and spatial relationships
- New problems with words in speaking or writing
- Misplacing things and losing the ability to retrace steps
- Decreased or poor judgment
- Withdrawal from work or social activities
- Changes in mood and personality

Psychological changes

- Personality changes
- Depression
- Anxiety
- Uncharacteristic behavior
- Paranoia
- Agitation
- Hallucinations

Why is a state plan needed?

It is estimated that in Utah in 2017, there were 30,000 adults aged 65 and older with Alzheimer's disease, with a projected increase of 40.0% by 2025. These figures do not include the other degenerative neurological dementias for which there are no estimates (Utah's State Plan for Alzheimer's Disease and Related Dementias, 2012-2017).

The number of Utahns with Alzheimer's disease and related dementias will grow each year as the proportion of the Utah population aged 65 and older continues to increase; the oldest Baby Boomers turned 65 years old in 2011. As Baby Boomers age, there is an increased need for more awareness, training, and research. Aging is the greatest risk factor for Alzheimer's disease and related dementias.

There is no long-term strategic plan for the growing population of older adults in Utah. In 2005, the University of Utah Center for Public Policy and Administration published "The Utah Aging Initiative" that discussed projected demographics and the impact of the so-called "senior boom." That same year, the Utah State Legislature created the Commission on Aging to increase understanding of the needs of the aging population. In 2006, Governor Jon Huntsman initiated the Utah 2030 project to encourage state agencies to design plans to address the best ways of serving the growing older adult population, but no programs were implemented (Utah Foundation, 2015). In 2012, the State Plan Task Force was convened to write the first state plan to address Alzheimer's disease and related dementias. This plan covered the years 2012-2017.

As a result of implementing this plan, private, non-profit, public entities, and individuals, have worked together to address the five goals identified in the 2012-2017 plan:

1. To create a dementia-aware Utah.
2. To establish health and dignity for all with dementia and those at risk.
3. To enable supported and empowered family caregivers.
4. To create a dementia competent workforce.
5. To expand dementia research in Utah.

The current state plan (2018-2022) builds on accomplishments from the first. This document summarizes the accomplishments from the 2012-2017 state plan. The 2018-2022 Utah's State Plan for Alzheimer's Disease and Related Dementias will coordinate and support the work of private, non-profit, public entities, stakeholders, and individuals for the next five years.

What is the focus of the 2018-2022 state plan?

The 2018-2022 Utah's State Plan for Alzheimer's Disease and Related Dementias focuses on four overarching goals with specific strategies to accomplish those goals. The four overarching goals are:

1. To create a dementia aware Utah.
2. To create a dementia competent workforce.
3. To enable supported and empowered caregivers.
4. To expand dementia research in Utah.

The 2012-2017 goal, "To Establish health and dignity for all with dementia and those at risk" was merged into the four overarching goals above to ensure this is addressed within each of the overarching goals. This is consistent with the "Healthy Brain Initiative: The Public Health Road Map for State and National Partnerships", developed by the Alzheimer's Association and the Centers for Disease Control and Prevention.

How do I use this plan?

This plan is organized to allow for multiple uses.

The **burden section** describes national and statewide data that demonstrate the burden of Alzheimer's disease and related dementias using prevalence and mortality data. Additionally, this section summarizes cognitive decline and the dementia caregiving burden in Utah. This data should be shared and used to build a case for needed services.

The State of Utah **vision and framework** sections describe the Coordinating Council's vision of where we are going and how private, non-profit, and government agencies will collaborate to accomplish the goals and recommendations set forth in this plan.

The **accomplishments section** describes the achievements that have taken place that fulfilled the initiatives of the previous plan (2012-2017). These should be used as a basis for moving forward to accomplish the goals of the current plan (2018-2022).

The **goal areas, recommendations, and strategies sections** of the plan detail the targeted way in which private, non-profit, public entities, and individuals can work together to accomplish the four overarching goals set out in this plan.

Finally, the **appendix section** includes information and tools that will be helpful to those working in the field of dementia as well as for dementia caregivers.

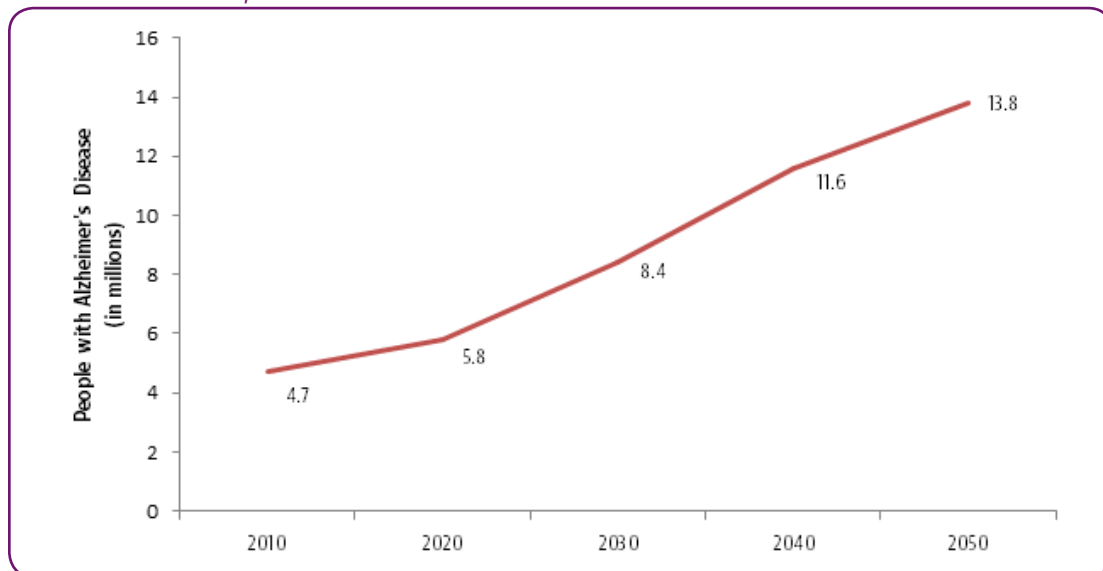
Burden

National Data

In the U.S. in 2017, approximately 5.3 million adults aged 65 and older were living with Alzheimer's disease (Herbert et al, 2013).

The Baby Boomer generation is the largest percentage of adults aged 18 and older in the U.S. The first of the Baby Boomers turned 65 years old in 2011 and the end of the cohort will be turning 65 years old in 2029. Due to medical advances and social and environmental conditions, it is expected that the number of Americans who will live to 80 or older will increase dramatically in the coming years (Ortman, et al, 2014). This will have the unintended consequence of almost tripling the number of Americans who will develop Alzheimer's disease or another dementia by the year 2050 (Figure 1).

Figure 1: Projected Number of People Aged 65 and Older in the U.S. with Alzheimer's Disease, 2010 to 2050

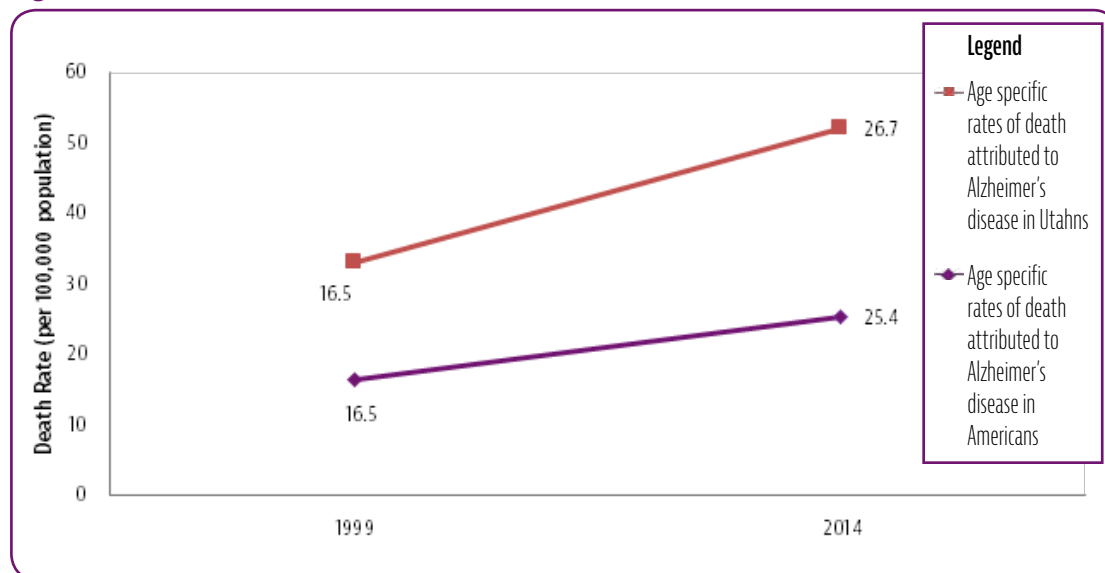


Source: Herbert et al, 2013.

Mortality

From 1999 to 2014, age-specific rates of deaths attributable to Alzheimer's disease demonstrated a statistically significant increase among Americans from 16.5 to 25.4 per 100,000 population (Taylor et al, 2017). In that same time period, age-specific rates of deaths attributable to Alzheimer's disease increased among adults aged 75 to 84 from 129.5 to 185.6 per 100,000 population and among adults aged 85 and older from 601.3 to 10,006.8 per 100,000 population. The largest increase in the rates of Alzheimer's deaths among adults aged ≥ 85 years occurred from 1999 to 2005 compared with 2005 to 2014 ($p < 0.001$). Since 2005, although the mortality rate has continued to increase, the rate of increase was not as large as from 1999 to 2005.

Figure 2: Utah Death Rate for Alzheimer's Disease Over Time, Utah, 1999-2014



Alzheimer's disease deaths in the National Vital Statistics System mortality file were identified using underlying cause of death International Classification of Disease Tenth Revision codes G30.0, G30.1, G30.8, and G30.9.

Age-adjusted death rates were standardized to the 2000 projected U.S. standard population.

Source: Taylor et al, 2017.

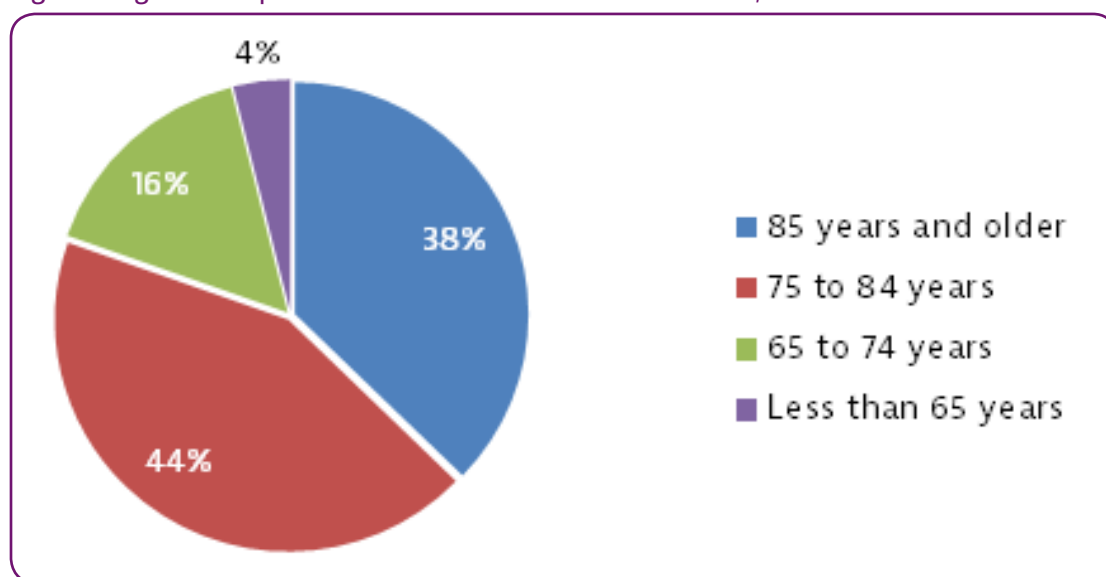
Risk Factors

Risk factors for Alzheimer's disease include, but are not limited to: age, sex, and race/ethnicity. With age being the number one risk factor for developing the disease.

Age

The percentage of adults with Alzheimer's disease increases with age. Thirty-eight percent (38%) of adults aged 85 and older have Alzheimer's disease compared to 4% of adults aged 64 or younger (Figure 3).

Figure 3: Ages of People with Alzheimer's Dementia in the U.S., 2017



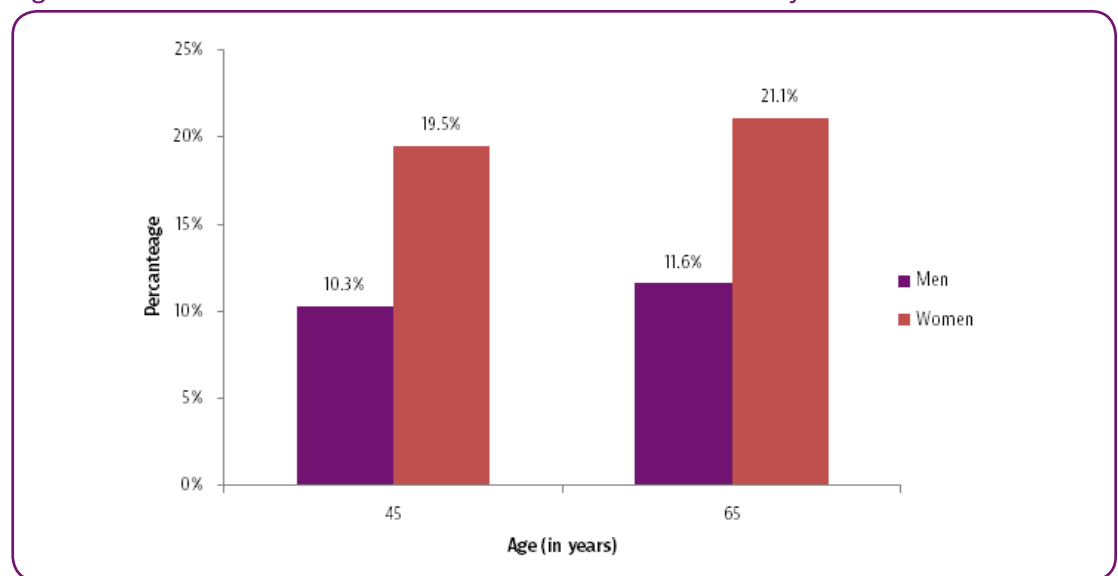
Percentages do not total 100% because of rounding.

Source: Herbert et al, 2013.

Gender

Lifetime risk for Alzheimer's disease is the probability that a person of a specific age will develop the disease during his or her remaining life span. Data from the Framingham Heart Study showed that females aged 45 have a lifetime risk of Alzheimer's disease of 19.5% compared to 10.3% for males the same age, representing a difference of 89%. Though the estimated lifetime risk for Alzheimer's disease at age 65 increased for both females and males, females continued to have an increased risk compared to males (Figure 4).

Figure 4: Estimated Lifetime Risk for Alzheimer's disease in U.S. by Sex

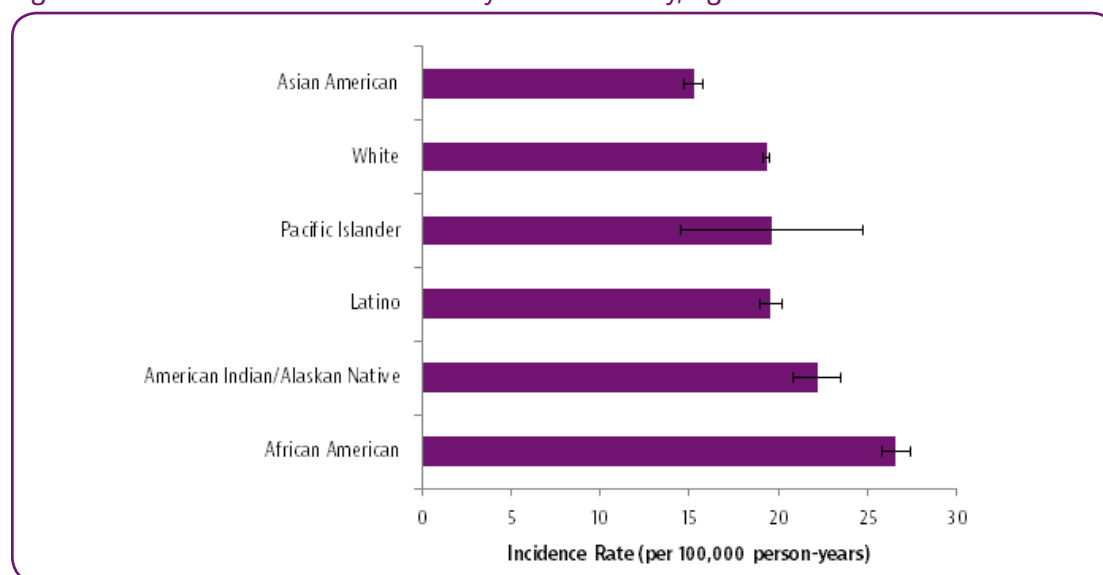


Source: Chene et al, 2015.

Race and Ethnicity

In a study of 274,283 members of the Kaiser Permanente Northern California health plan age 60 and older from 2000 to 2013, the dementia incidence was 59,555 members. When examined by race/ethnicity the results showed that the dementia incidence rate was highest for African Americans (26.6 dementia cases per 1000 person-years) and American Indians/Alaskan Native (22.2 cases per 1000 patient-years). The dementia incidence rate was intermediate for Latinos (19.6 cases per 1000 person-years), Pacific Islanders (19.6 cases per 1000 person-years), and Whites (19.3 cases per 1000 person-years). The lowest dementia incidence rate was among Asian Americans (15.2 cases per 1000 person-years) (Mayeda et al, 2016) (Figure 5).

Figure 5: Incidence Rate for Dementia by Race/Ethnicity, Aged 60 Years and Older



Dementia incidence for Kaiser Permanente Northern California members aged 60 and older from 2000 to 2013 (n=18,778 African American, n=4543 American Indian/Alaskan Native, n=21,000 Latino, n=440 Pacific Islander, n=206,490 White, n=23,032 Asian American).

Age-adjusted to the 2000 U.S. Census.

Source: Mayeda et al, 2017.

Burden on Caregivers

An analysis was performed using data from the 2011 National Health and Aging Trends Study and its companion study, the National Study of Caregiving, to investigate the role of dementia in caregiving. In 2011, 3.6 million adults aged 65 and older with dementia were in residential settings other than nursing homes and 77.2% were receiving assistance with self-care and household activities for health and functioning reasons. This is in contrast to only 20.3% of older adults without dementia needing similar help (Table 1) (Kasper et al, 2015).

Table 1: Assistance with Activities Received by Adults Aged 65 and Older Not Residing in Nursing Home, by Dementia Status, 2011

	Dementia	No Dementia	All
All Older Adults			
Number (millions)	3.6	33.4	37.0
Percent	9.7%	90.3%	100.0%
Types of Assistance			
Any self-care activities	53.1%	10.7%	14.9%
Any household activities	73.9%	17.0%	22.7%
Self-care and household activities	77.2%	20.3%	26.1%

Data from the 2011 National Health and Aging Trends Study and the National Study of Caregiving.

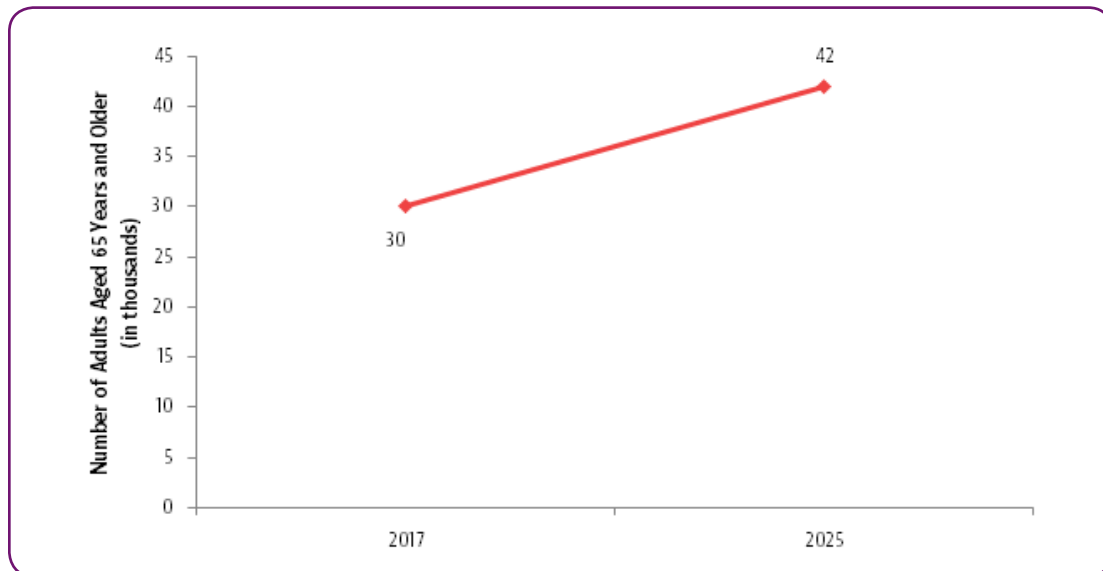
Source: Kasper et al, 2015.

Utah Data

Burden of Alzheimer's Disease in Utah

In Utah in 2017, there were approximately 30,000 adults aged 65 and older with Alzheimer's disease. This number is projected to increase to 42,000 adults aged 65 years and older by 2025; representing a 40% increase (Figure 6). Compared to the U.S., the percentage of increase ranged from a low of 14.1% in Iowa to a high of 54.9% in Vermont, with the majority (84.0%) of states having a projected increase of 36.1% or lower (Alzheimer's Association, 2017).

Figure 6: Projections of Total Number of Utahns Aged 65 and Older with Alzheimer's Disease, 2017 and 2025



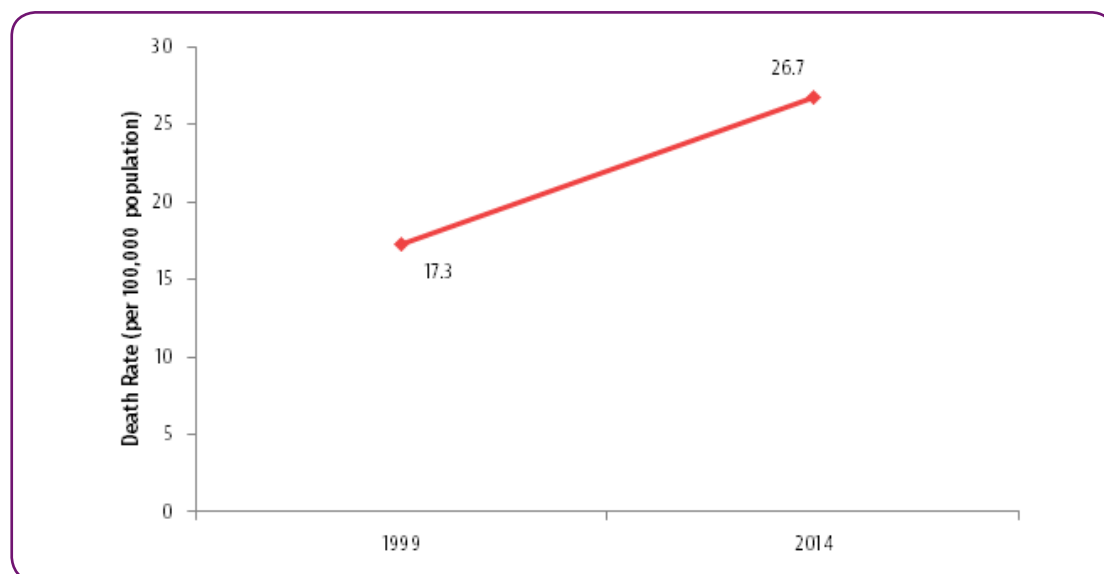
Created from data provided to the Alzheimer's Association by Weuve et al, 2015.

Source: Alzheimer's Association 2017 Alzheimer's Disease Facts and Figures. *Alzheimer's Dementia* 2017;13:325-373.

Mortality in Utah

From 1999 to 2014, age-specific death rates attributable to Alzheimer's disease increased among Utahns from 17.3 to 26.7 per 100,000 population, which represents a statistically significant increase of 54.8% (Figure 7). Comparatively, the state with the lowest death rate increase was Maine which experienced a statistically significant decrease of 23.5% (29.6 per 100,000 population in 1999 compared to 22.7 per 100,000 population in 2014). The state with the highest death rate increase was Mississippi which experienced a statistically significant increase of 164.1% (13.3 per 100,000 population in 1999 compared to 35.2 per 100,000 population in 2014) (Taylor et al, 2017).

Figure 7: Annual Alzheimer's Death Rate Over Time, Utah, 1999-2014



Alzheimer's disease deaths in the National Vital Statistics System mortality file were identified using underlying cause of death International Classification of Disease Tenth Revision codes G30.0, G30.1, G30.8, and G30.9.

Age-adjusted death rates were standardized to the 2000 projected U.S. standard population.

Source: Taylor et al, 2017.

Cognitive Decline in Utah

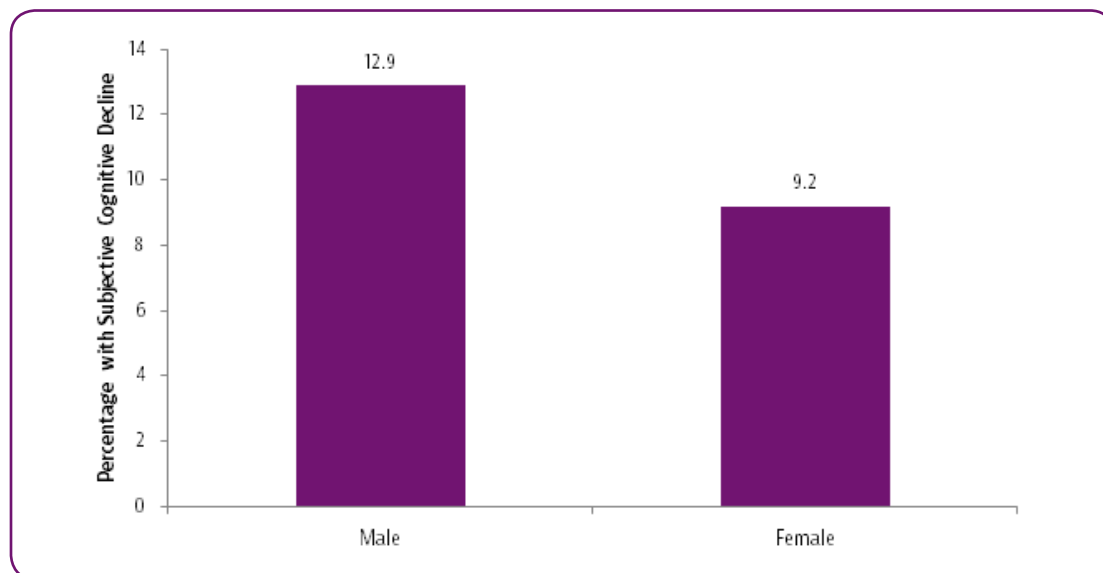
In Utah, 11.0% of adults aged 45 and older reported subjective cognitive decline. Subjective cognitive decline is defined as experiencing confusion or memory loss that is happening more often or is getting worse (Behavioral Risk Factor Surveillance Survey [BRFSS] 2015 cognitive decline module). More than half of these adults (59.4%) had not spoken with a healthcare provider about this issue.

For those with worsening memory problems, 36.3% say that it has created functional difficulties (i.e., caused them to give up day-to-day activities and/or interfered with work or social activities).

Subjective Cognitive Decline by Sex in Utah

In Utah, more males (12.9%) experienced subjective cognitive decline compared to females (9.2%) (Figure 8).

Figure 8: Subjective Cognitive Decline by Sex, Utah, 2015

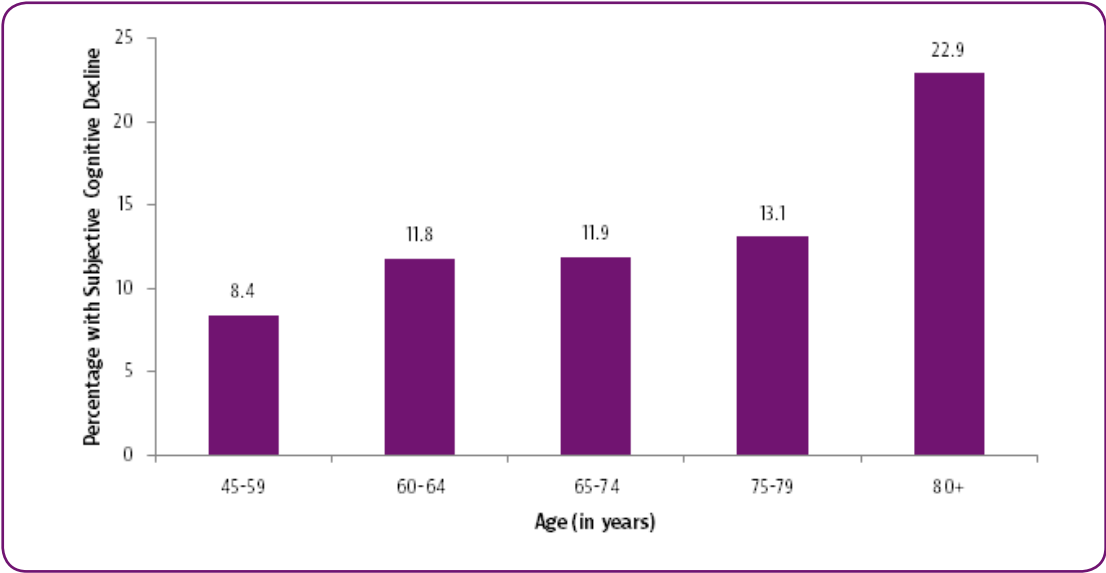


Source: Alzheimer's Association *Cognitive Decline in Utah*; BRFSS Cognitive Decline Module, 2015.

Subjective Cognitive Decline by Age in Utah

In Utah, the highest percentage of subjective cognitive decline (22.9%) was seen in adults aged 80 years and over and the lowest percentage (8.4%) is seen in adults aged 45 to 59 years. Between ages 60 to 79 years, the percentage of subjective cognitive decline was essentially unchanged and ranged from 11.8% to 13.1% (Figure 9).

Figure 9: Subjective Cognitive Decline by Age, Utah, 2015

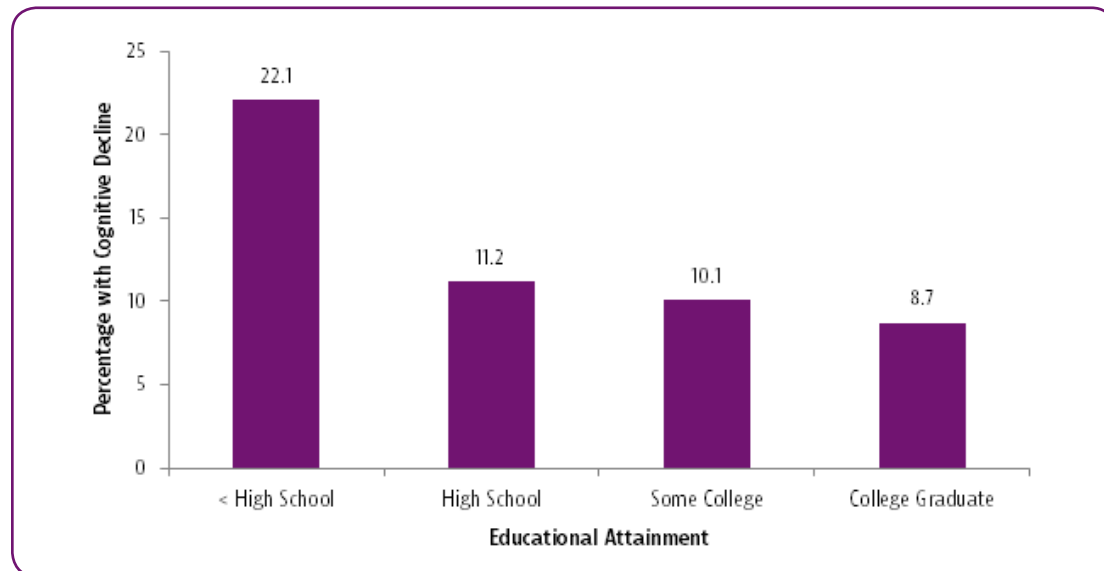


Source: Alzheimer’s Association Cognitive Decline in Utah; BRFSS Cognitive Decline Module, 2015.

Subjective Cognitive Decline by Educational Attainment in Utah

In Utah, the highest percentage of subjective cognitive decline (22.1%) was seen in adults who had not graduated from high school and the lowest percentage (8.7%) was seen in adults with a college degree. Subjective cognitive decline ranged from 10.1% to 11.2% for high school graduates and those with some college education (Figure 10).

Figure 10: Subjective Cognitive Decline by Educational Attainment, Utah, 2015



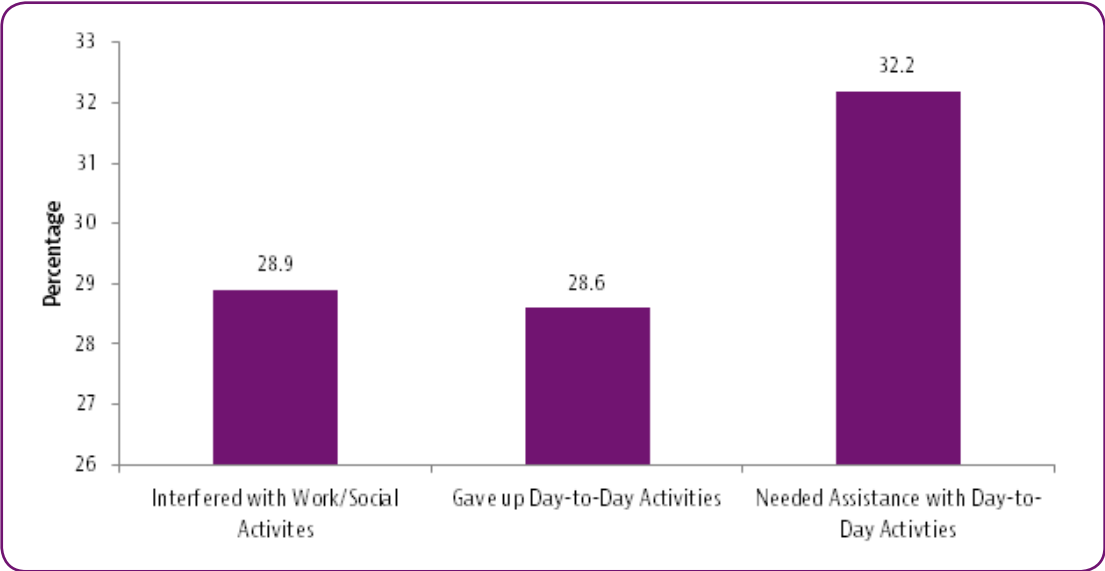
Source: Alzheimer's Association Cognitive Decline in Utah; BRFSS Cognitive Decline Module, 2015.

Memory Problems and Daily Life in Utah

Just under one-quarter (23.2%) of Utah adults with memory problems live alone and almost two-thirds (74.0%) of Utah adults with memory problems have at least one other chronic condition (defined as arthritis, asthma, chronic obstructive pulmonary disease, cancer, cardiovascular disease, or diabetes).

In Utah, 32.2% of adults with memory problems reported that they needed assistance with day-to-day activities, 28.6% reported they had to give up day-to-day activities, and 28.9% reported that memory loss problems had interfered with work/social activities (Figure 11).

Figure 11: Percent of Adults with Memory Problems who Say it Created Difficulties and Burden, Utah, 2015



Source: Alzheimer’s Association Cognitive Decline in Utah; BRFSS Cognitive Decline Module, 2015.

Dementia Caregiving in Utah

In Utah, nearly half (46.7%) of all adults providing unpaid care to loved ones with Alzheimer's disease or other dementia had been doing so for two or more years.

Caregivers are more likely to be female (63.1%) compared to male (36.9%). Nearly half of Alzheimer's disease and dementia caregivers (48.5%) provided nine or more hours of care per week. Among Alzheimer's disease and dementia caregivers, more than one-third (36.0%) provided care to their parent or their parent-in-law (Alzheimer's Association Dementia Caregiving in Utah; BRFSS Caregiving Module, 2015).

More than three-quarters of caregivers (77.4%) manage household care such as cleaning or cooking and 61.0% manage personal care such as feeding or bathing (Alzheimer's Association Dementia Caregiving in Utah; BRFSS Caregiving Module, 2015).



State of Utah Vision

The vision for Utah is to forge innovative and comprehensive solutions for people living with Alzheimer's and related dementias and their caregivers.

Framework of how work will progress

The Alzheimer's Disease and Related Dementias State Plan Coordinating Council represents private, non-profit, public entities, and individuals. This Coordinating Council was formed to implement the strategies in the 2018-2022 plan and will continue to be the conduit to accomplish the strategies as outlined in the current plan. The Coordinating Council is comprised of workgroups that coordinate specific strategies designed to accomplish the four overarching goals of the plan. See the diagram for examples of partners represented on the Coordinating Council.

Through implementation of the state plan strategies, we envision that people with dementia and their caregivers will have clear and ready access to an integrated system that offers a comprehensive set of high-quality healthcare services and social supports that are evidence-based and support the self-determination, dignity, and protection of people with Alzheimer's disease and related dementias.



Accomplishments from Utah's State Plan for Alzheimer's Disease and Related Dementias for 2012-2017

In 2011 the State Plan Task Force met with Utahns statewide to develop the first Utah's State Plan for Alzheimer's Disease and Related Dementias. Below is a summary of the many accomplishments that have come from implementing the 2012-2017 state plan, which identified five goals, 18 broad recommendations, and nearly 100 specific strategies.

Accomplishments within the Dementia Aware Utah goal include:

- The Utah Department of Health, Bureau of Health Promotion hired an Alzheimer's State Plan Specialist.
- Established an Alzheimer's Disease and Related Dementias Coordinating Council.
- Established collaboration between the Utah Department of Health; Utah Department of Human Services, Caregiver Support Program; Utah Association of Area Agencies on Aging; AARP; Alzheimer's Association-National and Utah Chapters; Utah Commission on Aging; Court Guardianship Monitoring Program for vulnerable adults; and Center for Alzheimer's Care, Imaging and Research (CACIR) at the University of Utah.
- Developed a media plan to create awareness on the 10 warning signs of Alzheimer's disease.
- Received a grant from the National Alzheimer's Association to implement specific action items in the "Healthy Brain Initiative: The Public Health Road Map for State and National Partnerships."
- Collected and distributed Alzheimer's disease and related dementias resource guides statewide.
- Facilitated Dementia Dialogues® trainings, in both English and Spanish, throughout the state.
- Raised awareness and promotion of the Alzheimer's Association 24/7 Helpline, which offers reliable information and support in more than 240 different languages and dialects.
- Raised awareness and promotion of the Alzheimer's Association online education programs available in English and Spanish.
- Participated in and promoted the Alzheimer's Workplace Alliance (AWA).
- Coordinated local and statewide media regarding increased awareness of dementias.
- Promoted the "Healthy Habits for a Healthier You: Tips from the Latest Research education program and their 10 Ways to Love your Brain campaign."

Accomplishments within the Health and Dignity for all With Dementia and Those at Risk goal include:

- The Alzheimer's Association provided education to healthcare providers on cognitive assessments during annual wellness visits, the importance of early diagnosis of dementia, and other topics at local physician summits.
- Developed and utilized a survey to ascertain priorities for the goals and objectives outlined in the state plan.
- The Utah Department of Health funded HealthInsight to develop a report on physicians' use of cognitive assessments during Medicare annual wellness visit.
- Updated Utah administrative code (R432-270) to strengthen dementia specific training for all employees and facility administrators.
- The Alzheimer's Association developed a statewide online community resource database accessible 24/7.
- Healthcare provider dementia trainings provided statewide both in-person and online.
- Police departments and first responders began using the Alzheimer's Association "Approaching Alzheimer's: First Responder Trainings and Dementia Dialogues®."
- The Alzheimer's Association trained Utah search and rescue organizations on how to locate lost people with dementia.
- The Alzheimer's Association Medic Alert Safe Return program and other related programs were promoted to the community and first responders.
- The Alzheimer's Association created and disseminated a toolkit to assist clinicians in providing and being reimbursed for cognitive and functional assessment and care planning for people with cognitive impairment.
- Since 2014, the Alzheimer's Association has held 250 meetings with state government officials to educate and advocate for the needs of individuals affected by dementia.
- The Alzheimer's Association worked closely with federal legislators to strengthen the commitment for funding research and working services.

Accomplishments within the Supported and Empowered Caregivers' goal include:

- Dementia resources are available on the Utah Department of Health website at www.livingwell.utah.gov.
- Dementia Dialogues® was presented to more than 500 caregivers and health care professionals.
- Over 49 trainers attended a two-day train-the-trainer program and conducted Dementia Dialogues® throughout the state at Area Agencies on Aging (AAA), assisted living facilities, independent living/retirement communities, memory care centers, home healthcare, non-medical home healthcare, senior services, and skilled nursing facilities.
- Dementia Dialogues® was translated into Spanish and presented to Spanish-speaking caregivers and community health outreach workers.
- Dementia Dialogues® was presented at the Generations Conference targeting healthcare professionals.
- The Utah Caregiver Support program within the AAA provides information and resources, case management, caregiver education, support groups, assistive technology, etc. to caregivers statewide.
- REACH-RCI, a family caregiver training program, was initiated in five AAAs.
- Caregiver conferences were held in Lindon, St. George, Ogden and Logan in collaboration with the University of Utah and the Alzheimer's Association.
- The Alzheimer's Association received 8,339 calls to its 24/7 Helpline from Utahns.
- Since 2014, the Alzheimer's Association provided 249,038 service contacts to Utahns, including information and referrals, case management, education programs, support groups, etc.

Accomplishments within the Dementia-Competent Workforce goal include:

- Developed the Southern Utah Advisory Committee; three town hall meetings were conducted to gather input from community members on the needs in Southern Utah and to provide resources to the community.
- A town hall meeting was held in Northern Utah to gather input from the community and provide local resources to attendees.
- The University of Utah Gerontology Interdisciplinary Program, within the College of Nursing, offers a variety of certificates and degrees in Gerontology and Aging Studies.
- Dementia training is available as continuing medical education (CME)/ continuing education unit (CEU) credit for healthcare professionals.
- Dementia Dialogues® trainings are available in Spanish and English and, are now being offered to the hearing-impaired community through the use of interpreters and one hearing-impaired Dementia Dialogues® trainer.
- Collaborated with HealthInsight to better understand the extent to which cognitive assessments were being conducted in Utah by providers who bill for these services and to identify needs or gaps in knowledge and resources for cognitive assessment, diagnosis, and referral of patients with symptoms of dementia and related disorders. A final report of the findings, “Cognitive Assessments during Medicare Annual Wellness Visits,” was released in June 2016.
- HealthInsight developed a Medicare Annual Wellness Visit toolkit for primary care physicians.
- Utah healthcare companies and the Alzheimer’s Association created diagnosis and treatment plans for dementia.
- Information and resources from AAAs and the Utah Caregiver Support Program was disseminated to healthcare providers and communities.
- Co-sponsored a physician’s summit with the Alzheimer’s Association.
- The Utah Department of Health provided a statewide recommendation that was sent to all primary care physicians on the benefits of early and accurate diagnosis and recommendations for cognitive screening tools.
- Promotion of EssentiALZ certification to long-term care companies in order to improve quality of care to individuals with dementia.
- The Alzheimer’s Association created an Alzheimer’s disease pocket card and a mobile and desktop app to assist the entire clinical team on how manage Alzheimer’s disease with confidence.

- The Alzheimer's Association created and disseminated a toolkit to primary care physicians on assessing cognitive

impairment during the Medicare annual wellness visit.

Accomplishments within the Expanded Research in Utah goal include:

- Highlighting ongoing Utah dementia-related research and clinical trials at the Coordinating Council meetings.
 - Listing of clinical trials associated with Alzheimer's disease in Utah within the Alzheimer's Association TrialMatch program database, which educates local physicians on the program and the benefits of patient and caregiver participation in clinical trials.
 - The Alzheimer's Association promoted the TrialMatch program to people with dementia, caregivers, physicians, etc.
- in an effort to increase participation in dementia research. Since 2012, TrialMatch saw an increase of 2,736 points, which is representative of profiles created by individuals willing to participate in research studies.
 - Alzheimer's Association sponsored the Alzheimer's Research Symposium with researchers from Utah and the National Alzheimer's Association and have hosted numerous dementia research presentations throughout the state.



This section details the recommendations and strategies that will be used to accomplish the four overarching 2018-2022 goals in the plan. Corresponding workgroups are tasked with implementing the recommendations and strategies of each goal. The members of these workgroups represent individuals from private, non-profit, and public entities as well as other stakeholders.

GOAL 1: A Dementia-aware Utah

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

Short Term Goals (1 Year)

1. Continue meeting quarterly as the Alzheimer's and Related Dementias Coordinating Council.
2. Partner with Utah Department of Health, Bureau of Health Promotion to share program resources devoted to Alzheimer's disease and related dementias.
3. Collaborate with Utah Department of Health, Office of Health Disparities to develop and disseminate culturally appropriate print, radio, television, and social media campaigns to raise awareness of Alzheimer's disease and related dementias.

Intermediate Term Goals (2-3 Years)

4. Utilize specific initiatives to overcome barriers to services by targeting unique challenges associated with reaching and educating caregivers in Utah (i.e. rural areas, Spanish-speaking, other non-English-speaking, and Native American tribal communities).

Long Term Goals (5+ Years)

5. Partner with the Utah State Board of Education to offer curriculum in schools (grades K-12) to educate young Utah citizens on the facts of aging with sensitivity to those family members with cognitive impairment and family care giving needs.
6. Educate and enlist the faith-based community as a key resource that can reach out to and support caregivers.
7. Heighten public awareness of resources, such as the 2-1-1 information line; SAFE-UT; Silver Alert, Alzheimer's Association 24/7 Helpline; Area Agencies on Aging (AAAs); Aging and Disability Resource Centers; Veterans' clinics; the University of Utah Center for Alzheimer's Care, Imaging and Research (CACIR); and establish metrics to measure awareness and impact.

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

Short Term Goals (1 Year)

1. Develop electronic links within state-supported websites to ensure that reliable information from state agencies and community organizations is disseminated.

Intermediate Term Goals (2-3 Years)

2. Conduct qualitative research to develop the messages needed.

Long Term Goals (5+ Years)

3. Disseminate public education messages through accessible websites, mobile apps, libraries, senior centers, and physician offices with standardized Alzheimer's disease and related dementia content. (Funding contingent)
4. In collaboration with the Alzheimer's Association, 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 Prevention and other evidence-based sources on behaviors that might lower the risk of cognitive decline.
5. Provide access to and education about 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 through public libraries, resource centers, hospitals, assisted living facilities, and easily accessible websites.
6. Ensure information and educational materials are offered at appropriate literacy, language, and legibility (ADA best practices for print materials).

Recommendation 1C: Provide Utah citizens with the best evidence on how to reduce their own risk for cognitive decline.

Long Term Goals (5+ Years)

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 cognitive decline.

2. Promote the Centers for Disease Control and Prevention “The Healthy Brain initiative: A National Public Health Road Map to Maintaining Cognitive Health”.
3. Target the higher prevalence of Alzheimer’s disease among older African-Americans and Hispanic women through education on diabetes, cardiovascular disease, and other known risk factors more common in these populations.

Recommendation 1D: Coordinate standardized information throughout state and local governments.

Long Term Goals (5+ Years)

1. Increase participation of state and local agencies to identify programs and services relevant to aging individuals with cognitive decline, even if not currently so identified, and advise on how awareness would enhance community impact.
2. Facilitate workplace education for employees of state and local governments about memory loss, Alzheimer’s disease, and related dementias.

Recommendation 1E: Improve access to a timely diagnosis, differential treatment, and supportive services.

Short Term Goals (1 Year)

1. Promote use of Medicare preventive service benefits for the detection of cognitive decline and/or impairment, which commenced in 2011 under the Patient Protection and Affordable Care Act.

Goal 2: Support and Empower Family and Other Informal Caregivers

Recommendation 2A: Advocate and promote education on the vital role of informal caregivers with guidance on quality care and the best utilization of resources throughout the process of the disease.

Short Term Goals (1 Year)

1. Identify and document the resources available to support and educate caregivers regarding Alzheimer’s disease and related dementias.

Intermediate Term Goals (2-3 Years)

2. Determine an effective dissemination system for caregiver resources.

Long Term Goals (5+ Years)

3. Disseminate resource information and measure the effectiveness of methods used.

Recommendation 2B: Increase the utilization of existing caregiver education programs and support systems.

Short Term Goals (1 Year)

1. Identify existing caregiver education programs and support systems to create a baseline of these services.

Intermediate Term Goals (2-3 Years)

2. Translate caregiver education and support systems into culturally and linguistically appropriate programs (funding contingent).

Long Term Goals (5+ Years)

3. Increase the number of caregivers that have been impacted through educational programs and support systems.

Recommendation 2C: Address the needs of working caregivers.

Short Term Goals (1 Year)

1. Identify existing workplace benefits and laws that support working caregivers.

Intermediate Term Goals (2-3 Years)

2. Develop awareness and best practice caregiver support materials for employers, employee assistance programs (EAPs), and working caregivers.

Long Term Goals (5+ Years)

3. Actively engage with human resource professionals and Employee Assistance Program to train and disseminate materials to employees.

Goal 3: Dementia-Competent Workforce

Recommendation 3A: Develop a dementia-capable and culturally competent professional healthcare workforce who cares for older adults and people with dementia throughout the continuum of care.

Short Term Goals (1 Year)

1. Encourage professionals to identify and support certification, licensure, and degree programs that work with older adults, including people with dementia and their informal caregivers to expand the geriatric workforce.
2. Provide education and updates to healthcare professionals on insurance reimbursement for cognitive evaluation and care planning (including, but not limited to, evaluations as part of annual wellness visits or as indicated).
3. Encourage partnerships with multicultural coalitions to develop and expand dementia-supportive services for ethnically diverse clients and residents across the continuum of care (including, but not limited to, adult day care centers, home-based providers, assisted living communities, skilled nursing facilities, and specialized dementia care entities).

4. Educate healthcare professionals on the benefits of early referral of patients and their families to dementia resources in order to educate, support, and guide care planning.

Intermediate Term Goals (2-3 Years)

5. Work with appropriate licensing and certification agencies to improve dementia competency by requiring a standard level of dementia sensitivity and disease education.

Long Term Goals (5+ Years)

6. Work with appropriate licensing and certification agencies to require continuing dementia education as a condition of license/certification renewal for healthcare professionals.

Recommendation 3B: Improve dementia care capacity, competency, and proficiencies of healthcare providers.

Short Term Goals (1 Year)

1. Disseminate guidelines based on best practices for Alzheimer's and related dementia diagnosis and disease management to improve assessment, treatment, care coordination, and follow-up support for the patients and caregivers.
2. Educate healthcare providers on the criteria needed to refer and qualify dementia patients for hospice care to ensure they receive the full benefit of services and social supports provided for end of life care.
3. Educate healthcare providers on the benefits of early referral of patients and their families to dementia resources in order to educate, support, and guide care planning.
4. Provide education and updates to healthcare providers on insurance reimbursement for cognitive evaluation and care planning (including, but not limited to, evaluations as part of annual wellness visits or as indicated).
5. Continue to partner with HealthInsight to conduct brief, in person dementia-specific trainings of primary care settings across Utah.

Intermediate Term Goals (2-3 Years)

6. Advocate for dementia-specific topics to be included as a percentage of the annual continuing education hours required for license renewal of healthcare providers.
7. Advocate for dementia-specific curriculum to be required for all medical and allied healthcare professionals prior to initial certification or licensure.
8. Educate healthcare providers on the importance of providing person-centered care to patients and their caregivers.

9. Advocate for financial opportunities (including, but not limited to, grants, tuition assistance, and stipends) to increase the number of healthcare professionals pursuing education and training in gerontology and geriatrics.

Long Term Goals (5+ Years)

10. Connect clinics without support services to community organizations that supplement clinical care through resources such as case management, specialized expertise, social supports, and neuropsychological and mental health services.
11. Encourage healthcare providers to store and disseminate dementia related information and educational materials for patients and their caregivers through digital libraries.

Recommendation 3C: Train professionals in non-healthcare fields who interface increasingly with people who have dementia.

Short Term Goals (1 Year)

1. Educate first responders through programs such as, “Approaching Alzheimer’s: First Responder Training” offered by the Alzheimer’s Association or Crisis Intervention Training (CIT) available to state agencies.
2. Advocate for a statewide Silver Alert program.
3. Educate Adult Protective Services workforce to become more dementia competent.

Intermediate Term Goals (2-3 Years)

4. Partner with state regulators, court administrators, judicial officials, and the Utah Bar Association for training on legal issues facing people with dementia and their families such as guardianship, conservatorship, powers of attorney, and related medical standards.

Recommendation 3D: Coordinate efforts and improve communication between healthcare professionals, healthcare providers, and professionals in non-healthcare fields that interact with individuals with dementia

Short Term Goals (1-2 Years)

1. Investigate bi-directional database systems implemented in other states.

Intermediate Term Goals (2-3 Years)

2. Coordinate any dementia-related initiatives brought forth by the Utah State Legislature.
3. Continue educating community health workers on Alzheimer’s disease and related dementias.

Long Term Goals (5 + Years)

4. Advocate for a statewide database to house all legal documents related to healthcare (including, but not limited to, power of attorney, guardianship, advanced directives, and POLST forms).

Goal 4: Expanded Research in Utah

Recommendation 4A: Engage in a public health approach to address the significant projected growth in Alzheimer's disease and related dementias in Utah.

Long Term Goals (5+ Years)

1. Collect and use data to drive public health service development and delivery. Use available data to assist in program improvement, grant submissions, and collaborative opportunities with other researchers.
2. Increase surveillance of incidence of Alzheimer's disease and related dementias and the impact of caregiving using the Behavioral Risk Factor Surveillance System (BRFSS) and other surveys (funding contingent).
3. Use available surveillance data to assist in program improvement, grant submissions, collaborative opportunities with other researchers, and implementation of the Utah Alzheimer's Disease and Related Dementias State Plan.

Recommendation 4B: Advocate for research funding.

Short Term Goal (1-2 Years)

1. Advocate to support the expansion and collaboration, recruitment, and retention of world-class researchers.

Intermediate Term Goals (2-3 Years)

2. Advocate for funding to support dementia related research by entities within Utah.
3. Promote taxpayer contributions through a tax check-off to support Alzheimer's disease and other related dementia research at Utah research universities.

Long Term Goals (5+ Years)

4. Pursue federal funding to support dementia related research by entities within Utah.
5. Ensure that the most promising evidence-based research projects are advanced and sustainable, including but not limited to research on prevention, treatment, and finding a cure for Alzheimer's disease and related dementias.

Recommendation 4 C: Promote participation in research and clinical trials.

Short Term Goals (1-2 Years)

1. Educate the public on the availability, purpose, and value of research, and encourage participation in clinical trials and other studies.
2. Collaborate with private, state, and federal partners to increase participation of diverse populations in research studies.

Long Term Goals (5+ Years)

3. Empower families to advocate for clinical postmortem diagnostic services and tissue banking to invest in the future health of their families.
4. Educate families on the importance of accurate death certificate data which should include information obtained through postmortem diagnostic examinations.



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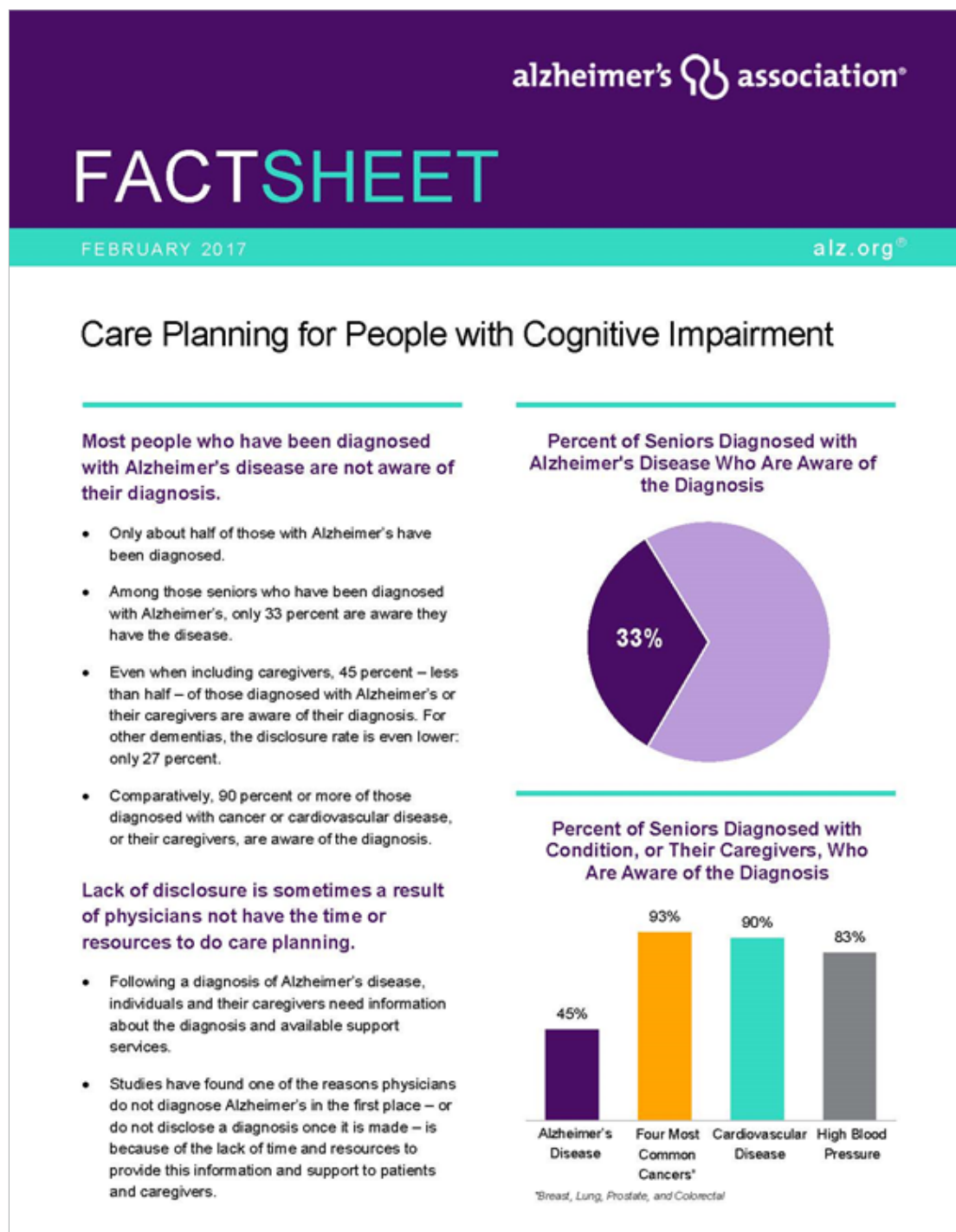
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A diagnosis – and disclosure of that diagnosis – is necessary before care planning can occur, which is crucial in improving outcomes for the individual.

- Care planning allows newly-diagnosed individuals and their caregivers to learn about medical and non-medical treatments, clinical trials, and support services available in the community – resulting in a higher quality of life for those with the disease.
- Individuals receiving care planning specifically geared toward those with dementia have fewer hospitalizations, fewer emergency room visits, and better medication management.
- Alzheimer's complicates the management of other chronic conditions. Care planning is key to care coordination and managing those other conditions.

The HOPE for Alzheimer's Act

The new G0505 billing code implements the core provision of the Health Outcomes, Planning, and Education (HOPE) for Alzheimer's Act and is consistent with the recommendations of the *National Plan to Address Alzheimer's Disease*.

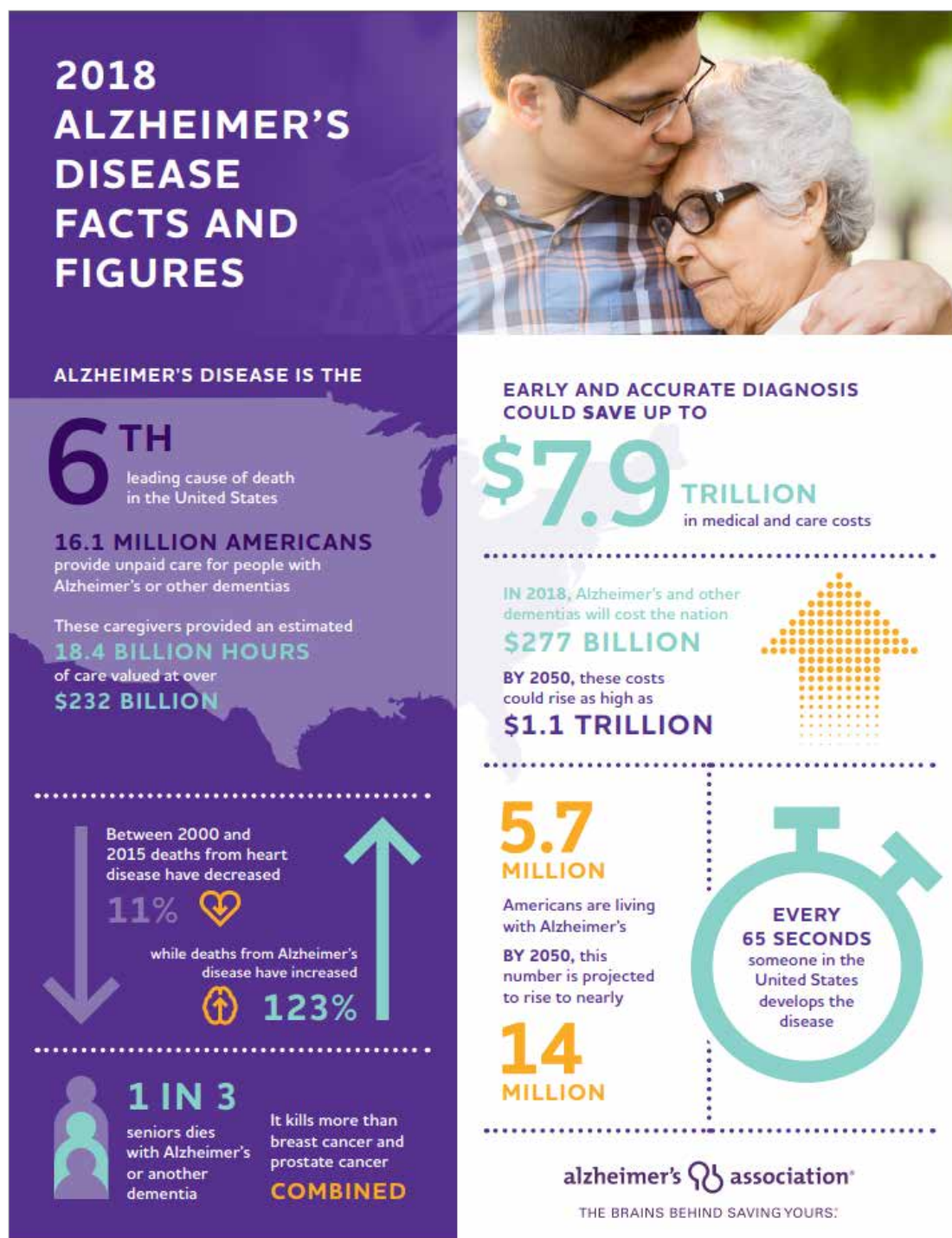
First introduced in 2009, the bipartisan HOPE for Alzheimer's Act was designed to provide comprehensive care planning services following a dementia diagnosis, with the services available to both the diagnosed individual and his or her caregiver. A total of 12 House members cosponsored the first version of the bill. By 2016, when the Centers for Medicare and Medicaid Services (CMS) proposed the new billing code, support had grown to more than two-thirds of Congress – 310 cosponsors in the House and 57 in the Senate.

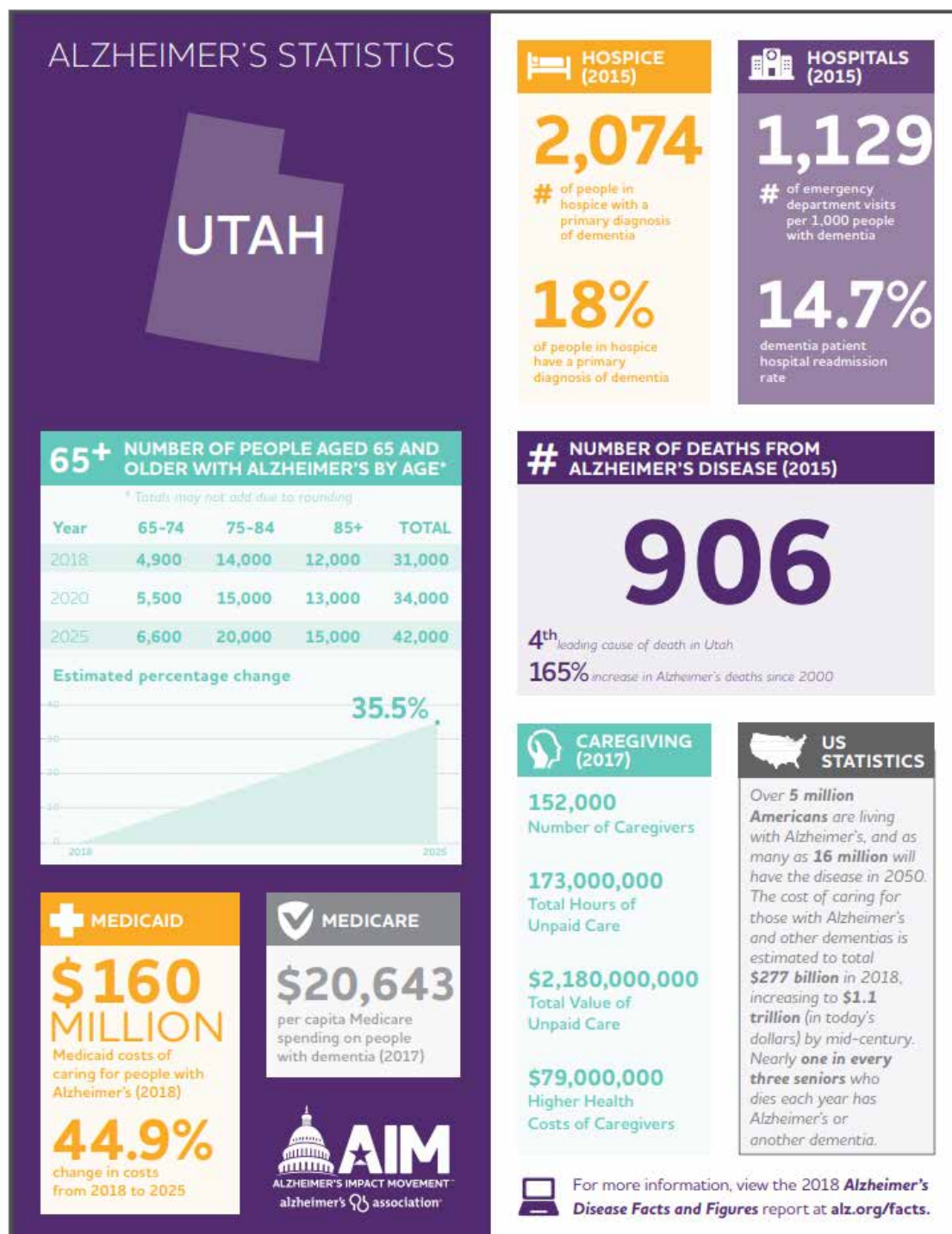
A new Medicare billing code – known as G0505 – now allows clinicians to be reimbursed for providing care planning to cognitively impaired individuals.

- Effective January 1, 2017, the billing code – known as G0505 in the Medicare Physician Fee Schedule – is available to clinicians treating Medicare beneficiaries with cognitive impairment, including Alzheimer's disease.
- Physicians, physician assistants, nurse practitioners, clinical nurse specialists and certified nurse midwives can currently be reimbursed under G0505.
- With this code, clinicians will have the time and resources to provide a comprehensive set of care planning services to people with cognitive impairment and their caregivers.

G0505 requires clinicians to provide detailed, person-centered care planning.

- The new code requires clinicians to provide several services, including:
 - evaluating cognition and function
 - measuring neuropsychiatric symptoms
 - evaluating safety (including driving ability)
 - identifying and assessing a primary caregiver
 - helping develop advance care directives
 - planning for palliative care needs.
- All of these services are ultimately used under the code to develop a detailed care plan – including referrals to community resources – that is shared with both the beneficiary and his or her caregiver.





appendix E: Aging and Dementia Resources

Alzheimer's Association	www.alz.org/utah
Administration for Community Living	www.acl.gov
Alzheimer's Foundation of America (AFA)	www.alzfdn.org
The Association for Frontotemporal Degeneration	www.theaftd.org
American Society on Aging	www.asaging.org
Centers for Medicare and Medicaid	www.cms.gov
Dementia Friendly America	www.dfamerica.org
Dementia Society of America	www.dementiasociety.org
The Gerontological Society of America	www.geron.org
Huntington's Disease of Society of America	www.hdsa.org
Memory Matters	www.memorymatterutah.org
National Institute on Aging	www.nia.nih.gov
National Parkinson's Foundation	www.parkinson.org

Utah Department of Human Services, Division of Aging and Adult Services

Website: www.daas.utah.gov

- Food and nutrition
- Transportation
- Utah Caregiver Support Program
- Home and community-based services

The Alzheimer's Association, Utah Chapter

Website: www.alz.org/utah

- Local offices
- 24 hour Helpline
- Caregiver center
- Community resource finder
- Support groups
- Facts and figures 2018

University of Utah Alzheimer's Center (CACIR)

Website: uuhsc.utah.edu/cacir

- Conduct clinical resources and deliver the latest brain imaging technology
- Helps raise standards for dementia care and research
- Works for early diagnosis

Living Well Utah

Website: www.livingwell.utah.gov

- Increase knowledge and awareness of signs and symptoms of Alzheimer's and related dementias
- Resources, home care, support groups, education, and events for caregivers
- Improve the dignity and quality of life with dementia and their families

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