

2023–2030

Utah Alzheimer's Disease and Related Dementias State Plan

Prepared by the Utah Alzheimer's Disease and Related
Dementias Coordinating Council

Dedication

The 2023-2030 Utah Alzheimer's Disease and Related Dementias State Plan is dedicated to all Utahns affected by dementia, including those living with the disease, informal caregivers, friends, neighbors, families, healthcare professionals, and those fighting to find a cure or treatment.

This plan aims to reduce the burden of dementia in Utah by reducing stigma, increasing awareness, providing education, and supporting our ethnically diverse population throughout our frontier, rural, and urban communities.



Table of contents

Letters of support	1
Executive summary	4
Introduction to the plan	6
How to use the plan.	7
Acronym list	8
2018-2022 plan accomplishments	9
State plan priority summary	11
Priority: Dementia-aware Utah	12
Priority: Dementia-competent workforce	16
Priority: Expand research.	22
Priority: Living Well with dementia	26
Priority: Support & empower caregivers	30
Acknowledgments.	36
Resources	38
Dementia warning signs	44
Risk factors and risk reduction.	45
Glossary	47
References	55

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STATE OF UTAH

SPENCER J. COX
GOVERNOR

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SALT LAKE CITY, UTAH
84114-2220

DEIDRE M. HENDERSON
LIEUTENANT GOVERNOR

Nov. 15, 2022

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 (ADRD) 2023-2030. 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 and has grown over the years. 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 priorities and vision of this plan will continue to advance us towards a healthier Utah.

Alzheimer's disease affects 34,000 individuals in Utah and more than 5 million people in the United States. The disease is projected to have a 23.5% 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 \$185 million in 2020 and those amounts are just projected to increase with an estimated 27% change from 2020 to 2025. Alzheimer's is also a deadly affliction; it is currently ranked as the 4th leading cause of death in Utah leading to 980 deaths in 2019. Nationally, nearly one in every three seniors who die each year have Alzheimer's or another dementia.

The ADRD State Plan provides an action plan for improved detection, diagnosis, risk reduction 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. Together, we can work to improve the lives of our family members, friends and neighbors whose lives have been impacted by dementia. 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 citizens and their families.

Sincerely,

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

Spencer J. Cox
Governor



State of Utah

SPENCER J. COX
Governor

DEIDRE M. HENDERSON
Lieutenant Governor

Department of Health & Human Services

TRACY S. GRUBER
Executive Director

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NATE WINTERS
Deputy Director

November 14, 2022

Dear Fellow Utahns,

On behalf of the Utah Department of Health and Human Services, I would like to offer my support for Utah's State Plan for Alzheimer's Disease and Related Dementias 2023-2030 (State Plan). Across the country, Alzheimer's disease and other dementias are a growing public health crisis. Utah is no different with about one in nine individuals over the age of 65 (over 34,000 Utahns) living with Alzheimer's dementia. By 2025, Utah is projected to have a 23.5% increase in individuals with Alzheimer's (the 10th largest in the United States). We currently do not have the data to inform us just how widespread dementia is outside of Alzheimer's, but we do know overall, Alzheimer's and other dementias are considerably underdiagnosed. This projected increase is a subject that hits home as most already know someone battling some form of dementia and over 97,000 Utahns are serving as Alzheimer's caregivers.

The Utah Department of Health and Human Services is proud to house the State Plan within our Division of Aging and Adult Services and we are committed to advocate for its priorities and strategies as we strongly believe they will lead to Utah becoming a dementia-capable state. The Coordinating Council for the State Plan consists of partners from across the state - healthcare systems, long-term care organizations, public health entities, local businesses, legislators, family caregivers, individuals living with dementia, and concerned citizens - who have worked tirelessly to help develop this plan. The vision and passion they have is visible every day in their commitment to improve the health and outcomes for all Utahns affected by dementia. We would like to thank all of those individuals who give their time and energy so freely in these efforts.

I encourage all of our partners and Utah citizens to review Utah's State Plan for Alzheimer's Disease and Related Dementias 2023-2030 and carefully consider what you as an individual, a community member, a caregiver, or a professional can do to help bring the vision laid out in this plan to light. Those of you who have already contributed, we thank you and ask that you continue with your efforts. We invite those who have not yet had a chance to contribute to join us in making Utah a dementia-capable state. We look forward to working with you.

Sincerely,

Tracy Gruber
Executive Director

Utah Department of Health & Human Services

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January 1, 2023



THE BRAINS BEHIND SAVING YOURS:®

Dear Fellow Utahns,

On behalf of the Alzheimer's Association, Utah Chapter, I am pleased to support the 2023-2030 Utah Alzheimer's Disease and Related Dementias State Plan. The Alzheimer's Association is continuously working to raise public awareness of Alzheimer's disease and related dementias, expand services to those living with the disease, provide support for families and caregivers, improve the capacity and capability of our health and long-term care workforce, and advance local research. This plan supports our current and future work of addressing the impact of dementia within our state. By collaborating with the Utah Department of Health and Human Services, as well as other statewide partners, we are set to take significant steps in providing a greater foundation of resources for all Utahns.

In Utah, dementia is the 4th leading cause of death. From 2020-2025, the number of those with Alzheimer's disease is expected to increase by 23.5%. Currently in Utah, Alzheimer's costs Medicaid \$185 million and our Medicare spending per capita is \$24,093, combined with almost \$2 billion in unpaid care provided by Utah family caregivers. Utah is preparing to meet this public health crisis with an equal force. This state plan details a variety of actionable strategies that will develop Utah into a dementia capable state. Our goals and recommendations ensure implementation of resources, education, and support for all Utahns affected by Alzheimer's disease or other dementias.

Our plan seeks to bring together partners from across Utah to address dementia related issues within our communities. We recognize it takes a coordinated approach to support those affected by dementia and enhance dementia services within our state. We're all in this together and I'm excited for the progress to come with the continued implementation of the 2023-2030 Utah Alzheimer's Disease and Related Dementias State Plan.

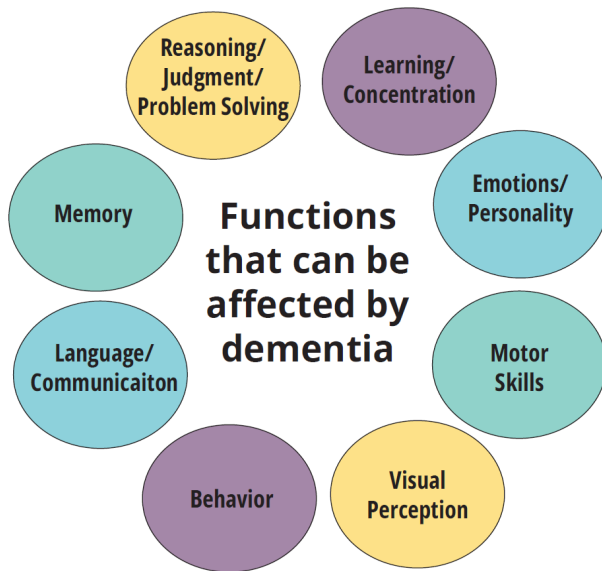
Warm regards,

A handwritten signature in black ink that reads "Stacie Kulp". The signature is fluid and cursive, with the first name "Stacie" being more prominent than the last name "Kulp".

Stacie Kulp
Executive Director

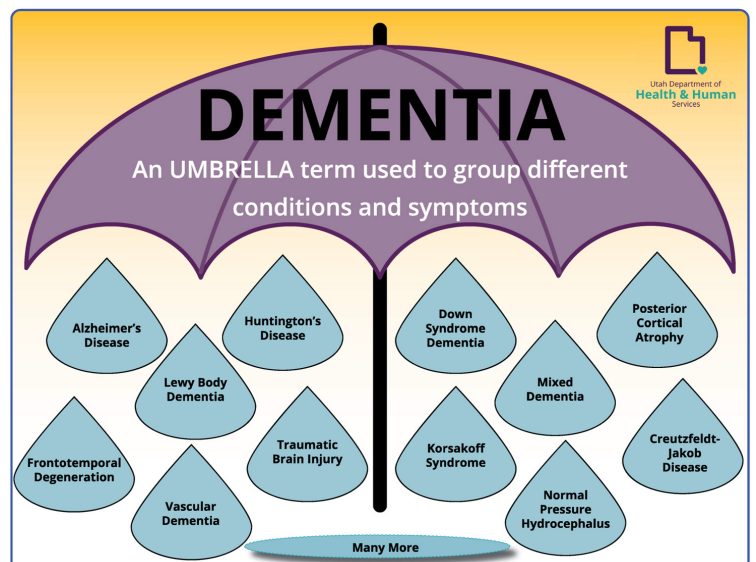
Executive summary

Utah is home to more than 3 million people located in 29 counties, covering 84,000 square miles. More than 350,000 Utahns are aged 65 and older. Approximately one in nine individuals over the age of 65 (over 34,000 Utahns) has Alzheimer's disease. By 2025, this number is expected to increase to 42,000, representing a 23.5% increase (the 10th largest in the United States).³ Unfortunately, we do not have estimates of the total number of Utahns affected by dementia outside of Alzheimer's. We do know that Alzheimer's and other dementias are vastly under-diagnosed.



Dementia is a general term referring to a loss of cognitive function (see image) severe enough to interfere with daily life. Dementia is often referred to as an umbrella term as it covers a broad range of diseases.

The most common forms of dementia are Alzheimer's disease, vascular dementia, frontotemporal degeneration, and Lewy Body dementia. Many also have mixed dementia, which is a condition where brain changes of at least two types of dementia occur simultaneously.³



In Utah, nearly half of all adults provide unpaid care to loved ones, with 22% of them providing care to someone with Alzheimer's or a related dementia. Over 80% of caregivers manage household tasks such as cooking or cleaning and nearly half assist with personal care such as bathing and dressing.¹

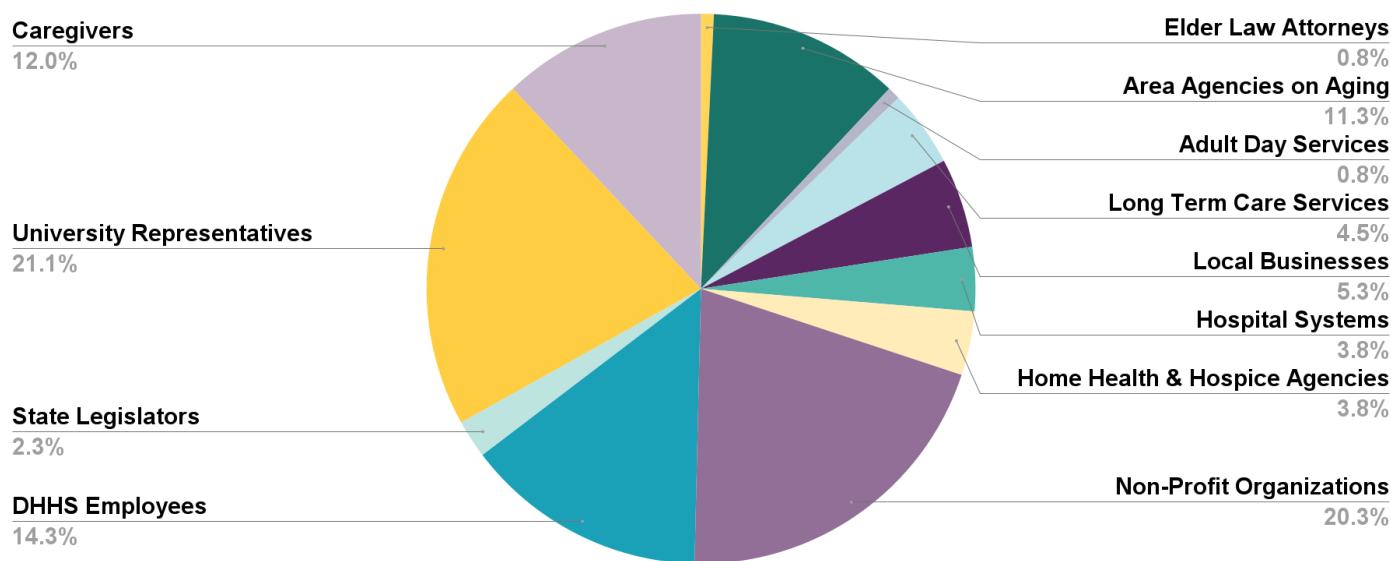
Executive summary

Utah's State Plan Task Force was convened in 2011 to develop the first Utah State Plan for Alzheimer's Disease and Related Dementias addressing the needs of persons with dementia, their caregivers, and professionals. This state plan represents a continuation of the goals, recommendations, and strategies outlined in the 2012-2017 and the 2018-2022 plans. The Coordinating Council, created in 2015 from the seeds of the State Plan Taskforce, identifies current needs and creates the priorities, strategies, targets for change, and action steps detailed in this plan. This plan represents 5 overarching priorities which are:

- Priority 1: Public Awareness — Dementia-aware Utah
- Priority 2: Aging Services — Dementia-competent workforce
- Priority 3: Research — Expand research
- Priority 4: Those living with the disease — Living well with dementia
- Priority 5: Caregiver Resources — Support & empower caregivers

The strategies and recommendations 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. The plan will help coordinate statewide activities to leverage limited resources.

The demographics of the ADRD Coordinating Council can be found below. This council welcomes new members and is open to anyone interested in participating.



Introduction to the plan

Vision

Forge innovative and comprehensive solutions for people affected by dementia.

Mission

To foster individual and community empowerment by increasing visibility, understanding, and resources for those living with cognitive decline or dementia, their caregivers, and the professionals who serve them.

Mission-oriented goals

1. Provide resources and support to individuals, families, and professionals affected by dementia.
2. Collaborate with partners statewide on accomplishing our priorities.
3. Reduce stigma surrounding dementia diagnosis, conversations, and caregiving through education, resources, and public awareness.
4. Advance policy, systems, and environmental (PSE) changes in the state.
5. Collect data to inform our work and priorities.

ADRD plan milestones

2011	ADRD Task Force was convened
2012	Utah Alzheimer's Disease and Related Dementias (ADRD) State Plan unanimously adopted by the Utah Legislature
2015	ADRD State Plan assigned to the Department of Health along with funding for implementation; A state-wide Coordinating Council established to implement the goals and objectives within the state plan
2018	Second edition of the ADRD State Plan published; Letter sent through DoPL to health providers about the AWW and cognitive screening
2019	Silver Alert bill passes; Second letter sent through DoPL to health providers about the AWW and cognitive screening; Launched the ADRD public awareness campaign
2020	Aging Adult Fraud bill passes; Core Competencies created for Assisted Living Facilities
2021	Amended the POLST Act; Passed abuse/neglect against vulnerable adults bill; Passed spousal caregiver support bill
2022	Alzheimer's Disease and Dementia Research Center is legislatively funded and assigned to Utah State University

How to use the plan

The 2023–2030 Utah Alzheimer’s Disease and Related Dementias (ADRD) State Plan concentrates on 5 priorities.

These 5 priorities are:

- Dementia-aware Utah
- Dementia-competent workforce
- Expand research
- Living well with dementia
- Support & empower caregivers

Each priority includes strategies, targets for change, and action steps:

Strategies	Targets for change	Action steps
Methods to equitably reach the priority; intended to benefit all Utahns affected by dementia.	Measurable outcomes expected for Utah upon successfully implementing the strategies.	Examples of specific policy, systems, and environmental (PSE) change initiatives that individuals and organizations can do to equitably implement the strategies.

Please note: Throughout the plan, the targets for change may show as TBD. We do not have current data for all of our targets. This baseline will be collected in 2023 and then updated.

Evaluation of the plan

The ADRD program and coordinating council will evaluate the implementation and impact of the strategies within the ADRD State Plan utilizing several different methods. These methods will produce both qualitative and quantitative data. An annual report will be distributed to stakeholders.



Acronym list

AAA	Area Agency on Aging
APS	Adult Protective Services
ADL	Activity of Daily Living
ADDRC	Alzheimer's Disease and Dementia Research Center
ADRD	Alzheimer's Disease and Related Dementias
AWV	Annual Wellness Visit
BIPOC	Black, Indigenous, People of Color
BRFSS	Behavioral Risk Factor Surveillance System
CDC	Centers for Disease Control and Prevention
CNA	Certified Nursing Assistant
DHHS	Department of Health and Human Services
DNR	Do Not Resuscitate
DoPL	Department of Occupational and Professional Licensing
EAP	Employee Assistance Program
FMLA	Family and Medical Leave Act
FTD	Frontotemporal Degeneration
IADL	Instrumental Activity of Daily Living
MCI	Mild Cognitive Impairment
MMSE	Mini Mental State Examination
OT	Occupational Therapist
PCP	Primary Care Provider
PERS	Personal Emergency Response System
POLST	Provider Order for Life-Sustaining Treatment
PSE	Policy, Systems, and Environmental
SCD	Subjective Cognitive Decline

2018-2022 plan accomplishments

The 2018-2022 ADRD State Plan has had many successes. Although there was a major interruption to our efforts due to the COVID-19 pandemic, we were able to meet over 90% of our objectives from the plan. The following is a highlight of our accomplishments:

- Collaborated with the 12 Area Agencies on Aging (AAAs) to provide dementia/caregiver education, resources, and information on risk reduction.
- Held conferences in partnership with the Utah Department of Health's Bureau of Health Promotion and its programs.
- Identified and promoted current resources to individuals with dementia and their caregivers/ care partners.
- Trained over 100 individuals statewide to offer Dementia Dialogues® who then educated 1,000+ individuals about dementia. This program was also translated into Spanish and provided through community partners.
- Trained 30 individuals to offer the Dealing with Dementia program which reduced wait lists for the program within the AAAs.
- Educated over 200 first responders on dementia.
- Contracted with the University of Utah (U of U) to provide over 800 care consultations through the Department of Neurology's Cognitive Disorders Clinic.
- Contracted with the Alzheimer's Association, Utah Chapter to provide over 80 support group meetings statewide for caregivers and those living with dementia.
- Contracted with the Alzheimer's Association, Utah Chapter to provide over 80 medical care practices with ADRD information.
- Contracted with Comagine Health (formerly Health Insight) to provide 45 clinics (135 providers) with education on the AWW and diagnosing dementia.
- Held community forums around the state to identify needs and areas of focus.
- Sent two letters (2018 & 2019) through the Department of Occupational and Professional Licensing (DoPL) to all providers working with older adults in any capacity. These letters promoted resources and encouraged early diagnosis of dementia.
- Advocated for the Silver Alert Bill, which was passed in the 2019 legislative session to notify the public about missing older adults with cognitive impairments.
- Launched a statewide public awareness campaign in 2019 focused on the Medicare Annual Wellness Visit (AWV). The campaign educated those 30 and older about the signs and symptoms of dementia and the importance of a "brain health check." This campaign had over 6 million impressions via newspapers, social media, digital ads, testimonial videos, radio advertisements/interviews, and TV interviews.

2018-2022 plan accomplishments

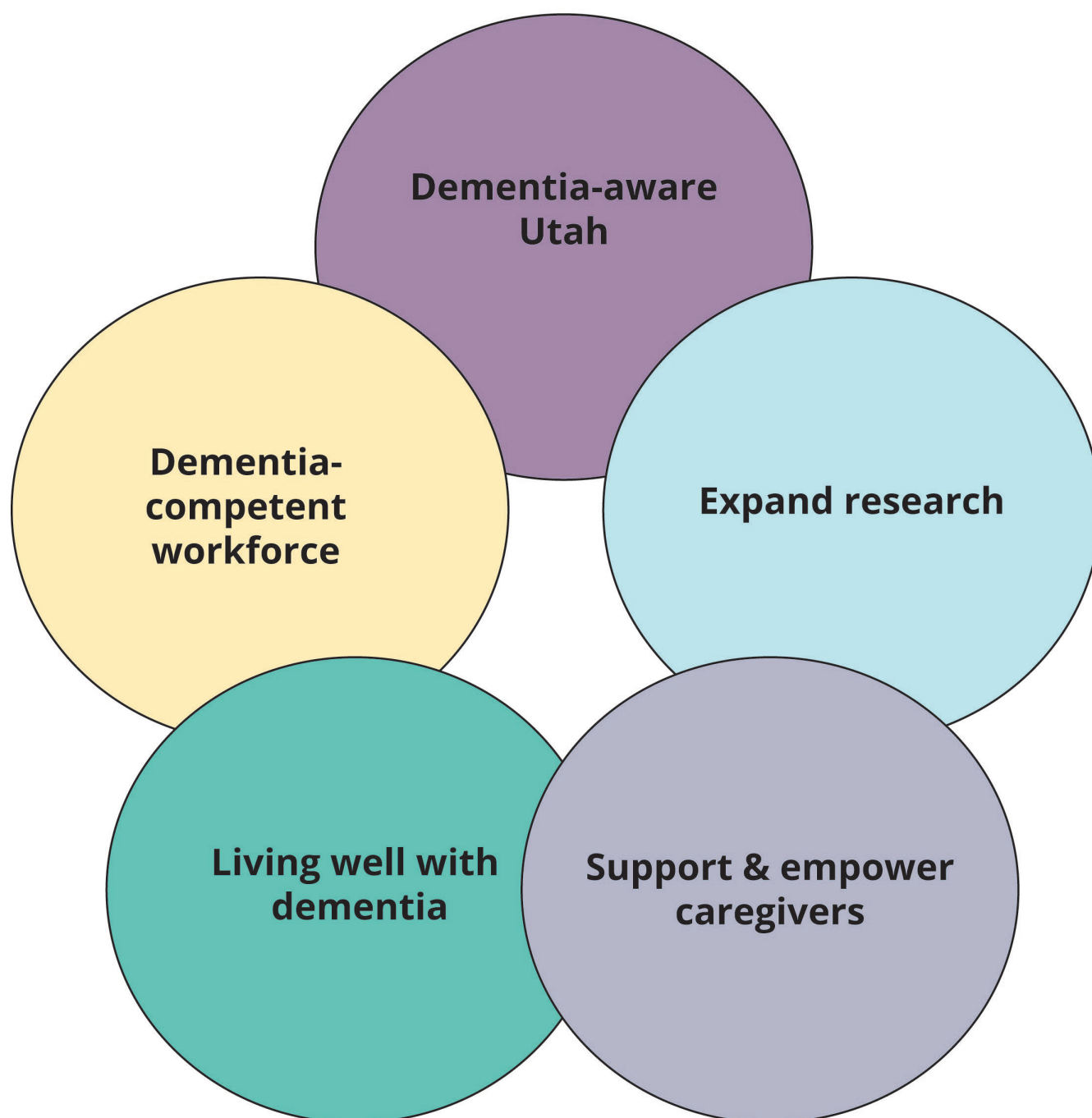
- Collaborated with the Health Facility, Licensing and Resident Assessment Board and its stakeholders to create Core Competency training required for all staff within Assisted Living Facilities. In addition, implemented a dementia education requirement for all administrators.
- Amended the POLST Act in the 2021 legislative session, which implemented a document recognized by other states allowing electronic signatures and verbal confirmation under limited circumstances.
- Passed abuse/neglect against vulnerable adults bills in both the 2021 and 2022 legislative sessions increasing penalties for offenders.
- Passed a bill in the 2022 legislative session establishing a certification process for Community Health Workers.
- Created a listserv of caregiving and dementia researchers to increase statewide research collaboration.
- In 2022, a dedicated Alzheimer's Disease and Dementia Research Center began at Utah State University (USU) to coordinate research efforts statewide with partners and through USU Extension offices.
- Expanded Medicaid New Choices Waiver and Aging Waiver programs in the 2022 legislative session, gaining a 26% increase in funding.



State plan priority summary

The 5 priorities in this plan reflect the vision of the Utah Alzheimer's Disease and Related Dementias Coordinating Council to forge innovative and comprehensive solutions for people living with Alzheimer's and related dementias, their caregivers, and professionals. Utah's priority areas are informed by Healthy People 2030¹⁶, 2022 National Strategy to Support Family Caregivers¹³, the CDC Healthy Brain Initiative⁷, and respective road maps.

2023-2030 Priorities



Dementia-aware Utah



Introduction

Dementia has physical, psychological, social, and economic impacts for people living with the disease, their care partners, families, and society at large. Unfortunately, there is often a lack of awareness and understanding of dementia, resulting in barriers to diagnosis and care, as well as stigma and poor quality of life. Knowledge and appreciation of evidence-based science is key to building a dementia-aware Utah. With information comes empowerment. Through targeted educational programs and carefully crafted media messaging, we can change the perception of dementia and work towards accepting and treating the disease to improve quality of life.

Our public awareness strategy incorporates targeted messaging, in linguistically and culturally competent ways, directed towards those living with dementia, informal caregivers, healthcare professionals, and Utah's workforce as a whole. Messaging is an important tool to educate about the signs/symptoms of dementia, behavioral expressions, communication techniques, speaking to a provider about concerns, and resources available. With this messaging, we aim to create spaces where caregivers and those living with dementia can feel safe, congregate, and be supported statewide.

Sharing information on dementia, caregiving, and resources will influence a community's ability to understand, respond more compassionately, and assist those affected. Bringing resources and education to professionals can enhance recognition of the disease, improve willingness and ability to diagnose, and increase access to treatment and resources. Thereby increasing the knowledge and confidence of those living with cognitive impairment and their caregivers.

"Americans whisper the word Alzheimer's because their government whispers the word Alzheimer's. And although a whisper is better than the silence that the Alzheimer's community has been facing for decades, it's still not enough. It needs to be yelled and screamed to the point that it finally gets the attention and the funding it deserves and needs, if for no other reason than to get some peace and quiet. "

- Seth Rogan, in his address to Congress February 2014¹¹

Strategies

Strategies describe the selected methods to equitably reach the overarching priority. They aim to benefit all Utahns, including those living with dementia, formal and informal caregivers, and healthcare professionals.

Strategy A	Improve public awareness of ADRD through culturally appropriate messages.
Strategy B	Improve public understanding of ADRD through targeted education programs for families, caregivers, state and local leaders, policymakers, and healthcare professionals.
Strategy C	Strengthen statewide collaborations that improve communications among ADRD stakeholders.
Strategy D	Develop action-oriented messages through stakeholder collaboration.
Strategy E	Disseminate action-oriented messages through a media mix that reaches all ADRD stakeholders.










Targets for change

Targets for change represent the measurable outcomes expected for Utah upon successful implementation of the strategies.

Focus groups held		Media exposures	
TBD	TBD	TBD	TBD
Baseline (2023)	Target (2030)	Baseline (2023)	Target (2030)
ADRD Partner Survey Data		ADRD Media Data	
Media impressions		Messages published	
6 Million	18 Million	TBD	TBD
Baseline (2023)	Target (2030)	Baseline (2023)	Target (2030)
ADRD Media Data		ADRD Partner Survey Data	
Overarching vision			
Improve public awareness, reduce stigma, and motivate action regarding ADRD and caregiving.			

Action steps

Action steps provide examples of specific policy, systems, and environmental (PSE) change initiatives that individuals and organizations can do to equitably implement the strategies. The examples listed here do not form a comprehensive list; those who implement the plan are encouraged to partner with others in their community(ies) to identify and pursue appropriate initiatives.

Action steps	
	Create impactful, meaningful and actionable messages focused on awareness, understanding, and de-stigmatization of dementia.
	Utilize statewide partnerships to develop and promote evidence-based knowledge and understanding of risk reduction of cognitive decline. Messages may include: <ul style="list-style-type: none"> • Clear definition of what risk reduction means • Lifestyle focus (all adults) • Management of chronic diseases • Diet • Exercise • Social engagement • Physical environment • Self-risk assessment
	Improve awareness of local research partnerships and opportunities.
	Improve public awareness of risk reduction, mild cognitive impairment (MCI), subjective cognitive decline (SCD), and dementia.
	Promote tools and information to family and professional caregivers to improve their caregiving skills and breadth of knowledge.
	Impact quality of life for those newly diagnosed and living with dementia by improving knowledge of the disease, its progression, and mitigating interventions.
	Ensure that all messages and media are relevant and accessible to culturally and linguistically diverse populations.
	Promote the Medicare Annual Wellness Visit's Cognitive Health Assessment among healthcare providers and the general public.
	Collect and compare data from media campaigns to determine reach and inform future work.
	Coordinate messaging with partners to create a united voice statewide.

Dementia-competent workforce



Introduction

Providing Utahns who are living with dementia the highest quality of care requires an adequate work force of professionals with appropriate skills. High-quality care should be provided from the point of diagnosis through the full spectrum of care providers the individual will encounter. This workforce may include primary care physicians (PCPs) (family medicine, general practice, internal medicine, etc.), specialists (geriatricians, neurologists, geriatric psychiatrists, neuropsychologists, etc.), nurse practitioners, physician assistants, podiatrists, dentists, physical therapists, occupational therapists, speech pathologists, registered nurses, certified nursing assistants, home health aides, and personal care aides.

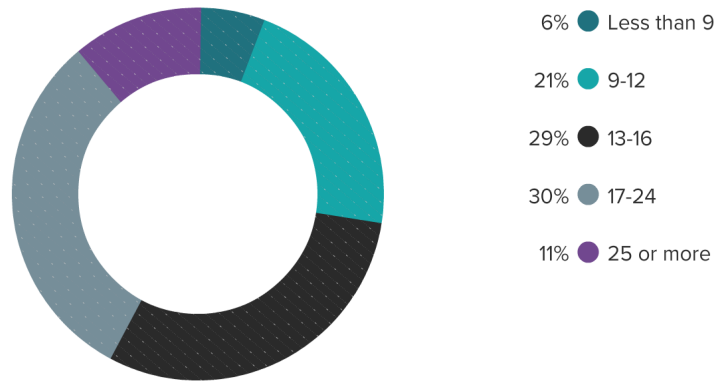
Throughout the course of the disease, those diagnosed with dementia and their family caregivers rely on healthcare professionals for accurate information and education on detection, diagnosis, care, treatment, patient and family resources, and coordination among providers that spans every level of licensure. Further, care must address the complex needs of persons with dementia due to the physical, cognitive, emotional, and behavioral symptoms of the disease along with any coexisting or chronic conditions.

As of early 2022, Utah has 25 geriatricians. This does not include other specialists who also treat geriatric conditions. It is estimated that Utah will need a 356% increase to meet the demands of our older adult population by the year 2050.³ This shortage of specialists creates obstacles to a timely and accurate diagnosis. The absence of a diagnosis may contribute to a delay in treatments, care, supportive services, family and caregiver education, and obtaining the services of legal and financial professionals for future needs. In many cases it robs the individual, family, and friends of the opportunity to share a wholesome relationship while the person with dementia is still able.

There are many types of providers that diagnose dementia including but not limited to: neurologists (44%), psychiatrists (34%), geriatricians (22%), and other specialists (15%). However studies show that 85% of initial dementia diagnoses are made by a non-specialist physician, usually a PCP. In a survey done by the Alzheimer's Association in 2019, 40% of PCPs reported they were "never" comfortable making the diagnosis. Half of the survey respondents stated they did not feel "adequately prepared" to make the diagnosis and 25% responded they were "sometimes or never" comfortable answering questions regarding dementia. Close to 1/3 of those surveyed chose to refer their patients to a dementia specialist, but as previously stated, there are not enough specialists to meet the needs of our older adult population.³ Ensuring PCPs are adequately prepared to deliver dementia care is critically important given this shortage of dementia care specialists.

Providers face many time constraints when meeting with patients. According to a Medscape survey, 59% of all providers spend 13-24 minutes with each of their patients during a single visit. See chart below for total minutes spent with each patient. However, this chart excludes psychiatrists.¹⁰

Minutes Personally Spent With Each Patient



PCPs must triage their time with each patient according to the needs of that particular visit. Medicare provides an Annual Wellness Visit (AWV) for everyone 65 and older. This visit should include a cognitive assessment, but it is often neglected due to lack of time. Fewer than 1/3 of patients receiving their AWV reported they had received a cognitive screening.³ Non-clinical staff could be utilized to provide these screenings in many settings. PCPs and other providers could train their staff on simple, baseline tests such as the Mini-Cog®. While these tests are not to be relied upon solely for a diagnosis, they can be used as a tool during the early screening process by providing a baseline to compare with future screenings. These same non-clinical staff can be instrumental in providing community resources to both patients and caregivers/partner. This would enhance patient satisfaction and create a more positive experience prior to and after diagnosis.

In addition to the need for teams within healthcare systems to become dementia-competent, there is also the same need within the long-term care continuum. Individuals with dementia have more skilled nursing facility stays and more home healthcare visits than other older adults. Individuals with dementia make up 32% of home health clients, 28% of adult day service clients, 34% of individuals in residential care, and 48% of nursing home residents.³ It is imperative for staff within long-term care to have the robust training necessary to support their clients with dementia as the disease progresses.

Personal care aides, home health aides, nursing assistants, and other direct care workers provide most of the formal care in private residences and residential communities such as assisted livings, nursing homes, and other long-term care settings.³ Services provided may include bathing, dressing, housekeeping, and food

preparation. These direct care workers play an important role in the lives of our older adult population allowing them to age at home/age in place, remain as independent as possible, and reduce hospital readmissions. In Utah, a 49% increase in home health and personal care aides is needed by 2028 to meet demand.³

Turnover rates of direct care staff in home and long-term care can be as high as 82% annually¹⁰. Formal caregiving can be very rewarding, but also very taxing on the caregiver. Some of these workers have suggested that high turnover rates are due to gaps in pay, limited benefits such as paid time off or insurance, low staffing ratios, little to no training in some of their specialized duties, and exhaustion. Certified Nursing Assistants (CNAs) and home health aides are federally required to receive at least 75 hours of training, which does not include any dementia-specific topics. There currently is not a federal training requirement for non-certified personal care staff.¹³ The APHA has noted “continued failure to strengthen the dementia care workforce will increasingly limit the ability of people living with dementia to access quality services and supports, adding to health, social, and economic burdens for individuals, families, and society.”¹⁵

In addition to quality healthcare, individuals with dementia would benefit from an educated and prepared workforce across all professions. With a better understanding of dementia comes compassion. A more dementia-competent workforce will assist in reducing stigma, increasing acceptance, and enabling those with dementia and their caregivers to live their best lives possible. Anyone working with the public should be given basic information about dementia, which will create safe and welcoming environments for all.



Strategies

Strategies describe the selected methods to equitably reach the overarching priority. They aim to benefit all Utahns, including those living with dementia, formal and informal caregivers, and healthcare professionals.

Strategy A	Enhance and expand dementia training within licensure, certification, and degree programs.
Strategy B	Improve and support dementia education and resources for healthcare providers.
Strategy C	Collaborate with stakeholders to explore standardization of dementia training and certification throughout the long-term care continuum.
Strategy D	Expand dementia education and resources for all state departments and community-based professionals.
Strategy E	Encourage businesses to become dementia-conscious and supportive.

Targets for change

Targets for change represent the measurable outcomes expected for Utah upon successful implementation of the strategies.

Licensure, certification, and degree programs requiring dementia education		Cognitive assessment and care plan services provided	
TBD	TBD	TBD	TBD
Baseline (2023)	Target (2030)	Baseline (2023)	Target (2030)
ADRD Partner Survey		Chronic Disease Reporting Rule	
Percent of Assisted Living Facilities in compliance with the required Core Competencies		Number of first-line contacts and businesses that receive dementia training	
52%	100%	200	1,600
Baseline (2023)	Target (2030)	Baseline (2023)	Target (2030)
Core Competency Approval Process		ADRD Partner Survey	

Overarching vision

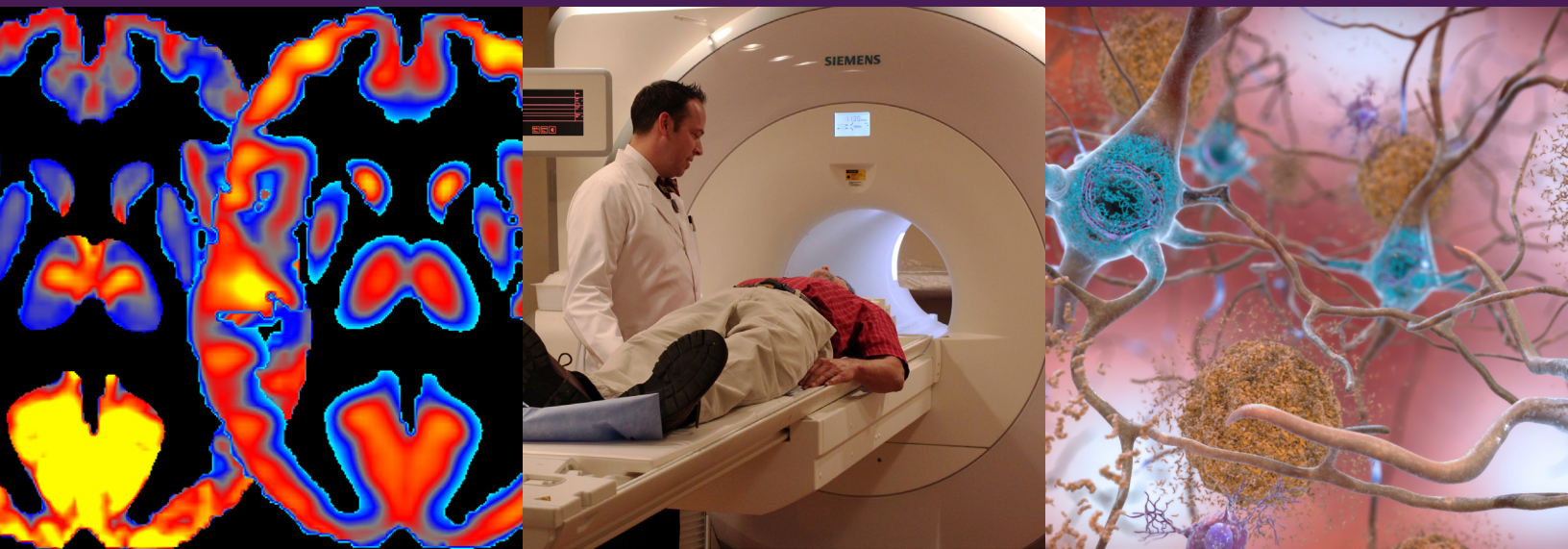
Educate, empower, strengthen, and support a dementia-competent workforce to improve the experiences of those affected by dementia.

Action steps

Action steps provide examples of specific policy, systems, and environmental (PSE) change initiatives that individuals and organizations can do to equitably implement the strategies. The examples listed here do not form a comprehensive list; those who implement the plan are encouraged to partner with others in their community(ies) to identify and pursue appropriate initiatives.

Action steps	
	Work with licensing and certification entities to incorporate approved CME/CEU dementia courses into license/certification renewal for healthcare professionals.
	Promote and support dementia education within certification, licensure, and degree programs across all healthcare disciplines.
	Identify and promote standards of practice for dementia management to include billing/reimbursement, diagnosis, treatment, referrals, and patient/caregiver education.
	Utilize data from the Chronic Disease Reporting Rule to inform areas of focus regarding education and outreach to healthcare providers.
	Educate healthcare professionals on risk reduction, treating comorbidities, and attending to behavioral health needs among people with cognitive decline and dementia.
	Encourage healthcare providers to include dementia in chronic disease management plans.
	Increase recognition of dementia within the providers of substance abuse disorders, developmental disabilities, psychiatry, and mental health.
	Update and refine the Assisted Living Core Competencies and revise the current Dementia Training Approval Process.
	Identify and promote standards of practice and dementia-specific training throughout the care continuum.
	Expand dementia training among first responders statewide.
	Equip businesses to become dementia conscious and supportive to better serve their clients affected by dementia.
	Partner with healthcare systems to encourage Age Friendly Health System designation.

Expand research



Introduction

Utah's ADRD State Plan incorporates research into many of its goals and strategies. For example, strategies related to supporting caregivers, living well with dementia, or providing educational opportunities, are all guided by empirical data and evidence-based best practices. The Coordinating Council and its co-chairs meet regularly to discuss and disseminate current research identified from local, national, and international scientific sources.

ADRD researchers in Utah target efforts across a wide spectrum of disciplines and approaches. These include studies of disease prevention and overall brain health, cognitive interventions for higher-risk populations or those experiencing MCI, and treatment of the various dementia-causing pathologies. Research also includes optimizing quality of life for people living with dementia, as well as care, support, and education for family and paid caregivers. Expertise includes micro-level studies of brain cells up through macro-level epidemiological studies and policy analyses.

Key partners in current and expanded ADRD research include the Utah DHHS Caregiver Support Program; Utah Association of Area Agencies on Aging; AARP Utah; Alzheimer's Association, National and Utah Chapter; Association for Frontotemporal Degeneration (AFTD); Utah Commission on Aging; Memory Matters Utah, and private industries focusing on pharmaceuticals and other innovative product development. The University of Utah houses several departments, divisions, and centers active in dementia research including, but not limited to, the Center on Aging, Department of Neurology's Division of Cognitive Neurology, College of Nursing, Geriatric Internal Medicine's Aging Brain Care Program, and Geriatric Psychiatry Clinic. Brigham Young University and Utah State University are also active in ADRD research across various disciplines and departments.

In July 2022, the state legislature provided funding through a budget appropriation to establish the Alzheimer's Disease and Dementia Research Center (ADDRC). This is housed at Utah State University (USU) and will utilize its extension offices to connect with Utah's frontier and rural areas. The ADRD Coordinating Council co-chairs serve as an external advisory panel for the center. The initial goals of the center are to build infrastructure in ADRD research at USU and foster collaborations through key partnerships within the state. Funding will be used for research equipment, novel and collaborative projects, personnel, and to disseminate research. In addition, efforts may include building university-driven research registries and promoting engagement in clinical trials.

Strategies

Strategies describe the selected methods to equitably reach the overarching priority. They aim to benefit all Utahns, including those living with dementia, formal and informal caregivers, and healthcare professionals.

Strategy A	Engage in a public health approach to address the significant projected growth of ADRD in Utah.
Strategy B	Increase ADRD research funding to Utah.
Strategy C	Promote participation in research studies.
Strategy D	Encourage collaborative research on ADRD.

Targets for change

Targets for change represent the measurable outcomes expected for Utah upon successful implementation of the strategies.











Cognitive assessment codes utilized		Funded grants in the state related to ADRD	
TBD	TBD	TBD	TBD
Baseline (2023)	Target (2030)	Baseline (2023)	Target (2030)
Chronic Disease Reporting Rule		ADRD Partner Survey	
Persons engaging with ADRD-related research in Utah		Researchers participating in ADRD studies	
TBD	TBD	30	60
Baseline (2023)	Target (2030)	Baseline (2022)	Target (2030)
ADRD Partner Survey		ADRD Partner Survey	

Overarching vision

Explore novel research and expand existing research in ADRD in order to better understand best practices in assessment, diagnosis, intervention, and treatment resulting in better quality of life for individuals with dementia and their caregiver/ partners.

Action steps

Action steps provide examples of specific policy, systems, and environmental (PSE) change initiatives that individuals and organizations can do to equitably implement the strategies. The examples listed here do not form a comprehensive list; those who implement the plan are encouraged to partner with others in their community(ies) to identify and pursue appropriate initiatives.

Action steps	
	Apply for funding to support a public health approach to dementia.
	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 and implementation of the ADRD State Plan.
	Increase the surveillance of incidence of ADRD and the impact of caregiving using the BRFSS and other surveys.
	Advocate for continued state and federal funding to support dementia related research within Utah.
	Promote taxpayer contributions through a tax check-off to support ADRD research in the state.
	Support researchers in grant submissions through mentorship opportunities and dissemination of grant opportunities.
	Educate the public on the availability, purpose, and value of research and encourage participation in clinical trials and other studies.
	Collaborate with private, state, and federal partners to increase participation of diverse populations in research studies, including rural areas.
	Leverage social media, websites, and research registries to better advertise and encourage research participation.
	Offer support to researchers studying ADRD topics.
	Encourage research collaborations across institutions and community providers.
	Convene informative and networking events for researchers across institutions.
	Catalog research expertise in the state by topic areas related to ADRD.

Living well with dementia



"There is plenty of life after dementia."
-Ren Willie

Introduction

In the U.S., about 1 in 9 people age 65 and older (6.5 million) has Alzheimer's dementia. In the past decade, it has been estimated as 1 in 10.³ This change demonstrates the increase in prevalence of Alzheimer's we are seeing across the United States. Unfortunately, outside of Alzheimer's, we currently do not have the data to inform us just how widespread dementia is nationwide. In addition, individuals as young as 20 can also develop various forms of dementia. While studies are limited, researchers believe about 110 out of every 100,000 people (about 200,000 Americans) have younger-onset dementia.³

Dementia rates differ by gender and race. More women (4 million or about 2/3) are living with Alzheimer's than men (2.5 million or about 1/3). This is due to the fact that women live longer than men on average. Since age is the greatest risk factor, we see a higher prevalence among women. In addition, older Blacks are about 2 times as likely and older Hispanics are about 1 1/2 times as likely to have dementia compared to older Whites. This difference is explained by disparities such as life experiences, socioeconomic indicators, and health conditions produced by the historic and continued marginalization of Black and Hispanic people in the United States.³

Subjective Cognitive Decline (SCD) is one of the earliest warning signs of dementia and refers to the perceived worsening of cognitive abilities by an individual within themselves. Of those age 45 and older, 10% reported SCD. However, the majority (54%) of those individuals had not consulted a physician about their concerns. While not all experiencing SCD develop Mild Cognitive Impairment (MCI) or dementia, many eventually do.³ Therefore, consulting a healthcare provider is important to determine the cause of these changes.

Currently in Utah, dementia is the 4th leading cause of death. There are 34,000 individuals over the age of 65 living with Alzheimer's disease. By 2025, we expect to see a 23.5% increase (42,000). That is the 10th highest projected rate of increase across the United States. Among the startling number of older adults living with dementia in Utah, there has been an increase in those younger than 65 facing a diagnosis of MCI or dementia and experiencing SCD.³ This has a significant impact, as many are still in the workforce and are providers for their family.

These statistics demonstrate that this public health crisis needs more resources and services dedicated to the individuals living with dementia. Throughout the state of Utah, we are facing under reported and misdiagnosed dementia cases. Our data is limited, and therefore the number of people needing education, support, a dignified diagnosis, and resources is unknown. We recognize through our vision, strategies, targets for change, and action items that this is only a place from which to start. We aim to work closely with community partners to understand what resources and supports already exist and where there are discrepancies among geographic and demographic indicators for people living with dementia, while working toward increasing and enhancing access and awareness.

Strategies

Strategies describe the selected methods to equitably reach the overarching priority. They aim to benefit all Utahns, including those living with dementia, formal and informal caregivers, and healthcare professionals.

Strategy A	Increase the availability and utilization of resources to support people living with dementia throughout the state.
Strategy B	Increase intergenerational programming throughout the state.
Strategy C	Reduce disparities in availability and utilization of resources for BIPOC populations.
Strategy D	Reduce stigma by empowering those with dementia to live a full life with confidence and dignity.
Strategy E	Enhance awareness and expand services available to those with mild cognitive impairment, younger-onset dementia, cognitive decline, and all other dementias.

Targets for change

Targets for change represent the measurable outcomes expected for Utah upon successful implementation of the strategies.















Support groups and education programs for people living with dementia	Social engagement programs for people living with dementia
TBD	TBD
Baseline (2023)	Baseline (2023)
Target (2030)	Target (2030)
ADRD Partner Survey	ADRD Partner Survey
Companies who offer benefits for people living with dementia	Dementia diagnoses throughout Utah
TBD	TBD
Baseline (2023)	Baseline (2023)
Target (2030)	Target (2030)
ADRD Partner Survey	Chronic Disease Reporting Rule

Overarching vision

Empower, support, and expand access to resources for those living with dementia.

Action steps

Action steps provide examples of specific policy, systems, and environmental (PSE) change initiatives that individuals and organizations can do to equitably implement the strategies. The examples listed here do not form a comprehensive list; those who implement the plan are encouraged to partner with others in their community(ies) to identify and pursue appropriate initiatives.

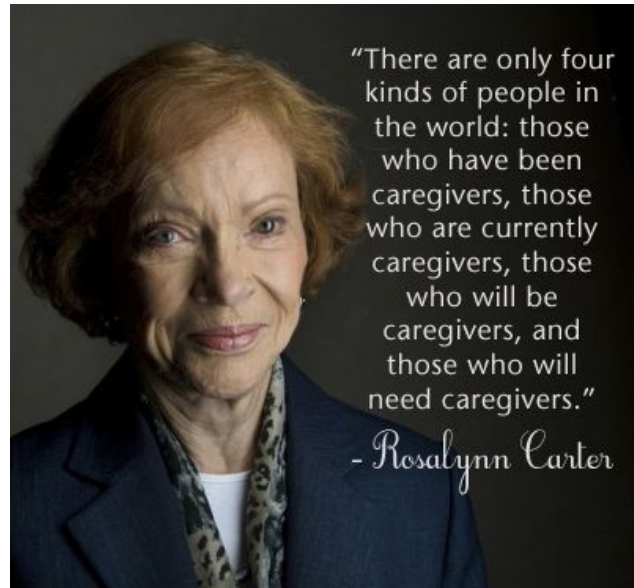
Action steps	
	Empower those living with dementia to advocate for themselves and contribute within their communities.
	Expand awareness of mental health assistance and resources available for persons living with dementia.
	Expand services and support for people living with dementia in frontier, rural, and urban locations.
	Identify services needed in order to be inclusive of the diverse needs of those living with dementia.
	Build trust in BIPOC communities through established community partnerships.
	Create and maintain a list of organizations that provide services and support for those living with dementia.
	Provide and expand education for those recently diagnosed by informing them of their options and resources.
	Train community partners/organizations to engage those living with dementia using best practices which could include Institute for Healthcare Improvement's Age Friendly Health Systems framework.
	Expand intergenerational programming offered through community partners.
	Expand and promote creative arts programs and social engagement groups for persons living with dementia.
	Collaborate with employers, employee assistance programs (EAPs), and human resource representatives to establish, expand, and promote benefits and resources available to support employees developing dementia.
	Identify existing benefits and laws that support people living with dementia, both federally and within Utah.
	Empower individuals with dementia as they learn to cope, manage, and plan ahead to live their best life.
	Improve financial and workplace security for people living with dementia by advocating for and effecting legislative change.

Support & empower caregivers



Introduction

Former First Lady Rosalynn Carter is often quoted from her written testimony before the Senate Special Committee on Aging in 2011 where she said “There are only four kinds of people in the world — those who have been caregivers, those who are currently caregivers, those who will be caregivers and those who will need caregivers.”⁶ Caregiving touches all of us. In fact, according to the Caregiving in the U.S. 2020 report, published by AARP and the National Alliance for Caregiving, “Caregiving



remains an activity that occurs among all generations, racial/ethnic groups, income or educational levels, family types, gender identities, and sexual orientations.”¹ It is the great equalizer.

Family caregivers are the backbone of our long-term services and supports system. Through their efforts countless individuals are able to live and thrive in their homes and communities. In addition, family caregivers also supplement the care provided in residential care settings such as assisted living communities or nursing homes. We simply cannot replace the invaluable work they do.

More than 11 million Americans provide unpaid care for people with Alzheimer’s or other dementias. In Utah, approximately 97,000 caregivers support individuals with dementia providing 119 million hours of unpaid care valued at \$1.985 million. As the cognitive abilities of the person with dementia decline, the value of care provided by dementia family caregivers increases 18% each year.³ Caregivers of individuals with dementia face a difficult journey. They are more likely to assist with activities of daily living (ADLs) and provide help for a larger number of tasks than non-dementia caregivers. They are more likely to exhibit depression and anxiety, experience greater strain, and see a decline in their social network size than other caregivers. In addition, dementia caregivers report more subjective cognitive problems and lower quality of life than non-caregivers.³

Demands on dementia caregivers increase and intensify with the disease progression. At the onset, individuals with dementia require 151 hours of caregiving a month while eight years later that number increases to 283 hours of care per month.³ That is almost the equivalent of working two full-time jobs. The majority of dementia caregivers (60%) work as well. In addition to their caregiving responsibilities, they work an average of 35 hours a week. Caregivers of individuals with dementia are also twice as likely to experience financial difficulties than non-dementia caregivers. This is due to disruptions in employment (working less hours, turning down a promotion, retiring early, etc.) which not

only impacts their immediate salary but also their retirement earnings, or taking on costs (medical care, personal care, household expenses, etc.) for the person with dementia.³

The impact of dementia caregiving differs among genders and races. Female caregivers experience higher levels of burden, impaired mood, depression, and health issues than male caregivers. Compared to White caregivers, we see greater care demands, less use of outside help/formal service, and greater depression among Hispanic, Black, and Asian American caregivers. Hispanic caregivers also indicate lower physical well-being when compared to White caregivers. Ultimately, when family caregivers are in distress or crisis, the individual with dementia experiences increased institutionalization rates, exacerbated behavior/psychological challenges, and increased risk of abuse.¹¹

Because of these challenges and more, 69% of Utahns serving as caregivers to individuals with dementia report at least one chronic health condition, 22.3% report depression, and 10.7% report frequent poor physical health. Dementia caregiving is such a challenging journey, the majority of caregivers (72%) experience relief when their loved one with dementia passes away.³ Caregivers have their own financial, health, and wellness needs. If they are unable to care for themselves, how can they support another? Spousal dementia caregivers are 41% more likely to become frail while caregiving and 18% pass away before their partners.³ If dementia caregivers don't receive support, healthcare providers will soon find themselves with more than one patient. Or worse, their initial patient will become orphaned. What happens then to the person with dementia?

An investment in family caregivers must be a priority among all levels. It stands to reason for the focus to be on the individual in need of healthcare and support. However, more often than not, there is a family caregiver behind that individual who is struggling. As a well-respected colleague, Nancy Madsen-Wilkerson, used to say, "When one needs care, two need help." For the past several decades, we have seen incremental progress on a national level in recognizing and supporting caregivers. Most recently and immediately prior to the publication of Utah's ADRD State Plan, the 2022 National Strategy to Support Family Caregivers was released. This milestone strategy contains almost 350 actions the federal government will take as well as over 150 actions that states, communities, and the private sector can take to support family caregivers.¹⁰ This national strategy will continue to inform the work we do throughout Utah for family caregivers who are supporting individuals with dementia.



A note on language

Throughout this document, and especially this section, the terms “caregiver” or “family caregiver” are used extensively. It is important to note that we recognize not everyone who supports another individual identifies as a caregiver. In fact, if asked most will say, “I am just a daughter” or “I am just helping because they need support.” Because most caregivers don’t identify as such, they can miss connecting to resources that are targeted to them using this identifier. Getting caregivers to self-identify with their role may help them in accessing services. We also recognize some individuals living with dementia prefer the term “care partner” when referring to the person who supports them. Care partner is especially appropriate when the individual with dementia is early in their disease process and takes an active role in their own care needs. As dementia progresses, and the person with dementia takes a more passive role, the term caregiver is typically used. In addition, some cultures do not have a word for this role altogether.

The terms “family caregiver” and “informal caregiver” are often used by professionals to refer to the supportive role family, friends, or others play. Though there is nothing informal about the extensive amount of assistance family caregivers provide, the phrase refers more to unpaid caregivers versus the paid caregiving workforce who are trained in specific care tasks. The term “family” can be used in the broadest sense, including spouses, partners, siblings, children, chosen family, friends, neighbors, etc.

For ease, the term “caregiver” will be used to refer to the role played in support of the person needing assistance. Caregivers may be of any age, gender, race, ethnicity, socioeconomic background, etc. Caregivers may live with the person they support, nearby, or provide care from a distance.

The term “primary caregiver” is used to identify the team leader who oversees the responsibilities for the person needing support. The primary caregiver could be any connection/relationship with the person they are supporting. Most individuals with dementia have more than one person supporting them. In that case, terms such as “secondary caregiver,” “tertiary caregiver,” and so on may be used. Or some families simply say “She’s in charge and I am the backup.”

However one refers to themselves, family caregivers are vital and irreplaceable members of our healthcare system and entitled to resources to support the valuable work they do.

Strategies

Strategies describe the selected methods to equitably reach the overarching priority. They aim to benefit all Utahns including those living with dementia, formal and informal caregivers, and healthcare professionals.

Strategy A	Improve the self-identification and perception of caregivers of persons with dementia.
Strategy B	Increase the visibility, availability, and utilization of resources for caregivers.
Strategy C	Prepare, educate, and support current and future caregivers throughout the course of their caregiving journey.
Strategy D	Empower caregivers to become advocates for the health and wellbeing of themselves and their care recipients.
Strategy E	Improve financial and workplace security available to caregivers.

Targets for change

Targets for change represent the measurable outcomes expected for Utah upon successful implementation of the strategies.

Caregiver support groups		Caregiver educational programs	
TBD	TBD	TBD	TBD
Baseline (2023)	Target (2030)	Baseline (2023)	Target (2030)
ADRD Partner Survey		ADRD Partner Survey	

Employers who offer benefits to support family caregivers		Care consultations	
TBD	TBD	TBD	TBD
Baseline (2023)	Target (2030)	Baseline (2023)	Target (2030)
ADRD Partner Survey		ADRD Partner Survey	

Overarching Vision			
Building hopeful, supported, confident, and empowered caregivers/care partners of persons with dementia who advocate for themselves and for those whom they support.			

Action steps

Action steps provide examples of specific policy, systems, and environmental (PSE) change initiatives that individuals and organizations can do to equitably implement the strategies. The examples listed here do not form a comprehensive list; those who implement the plan are encouraged to partner with others in their community(ies) to identify and pursue appropriate initiatives.

Action steps	
✿	Empower those who support others in identifying with and fostering acceptance of their role as caregivers.
✿	Conduct research on caregiver messaging (i.e. more acceptable terms for “caregiver,” “support group,” etc.) and how to reach caregivers.
✿	Update and maintain a list of community organizations that support and educate caregivers of persons with dementia, engage new organizations within the caregiver support space, and partner to promote all services offered.
✿	Identify locations where there is need for additional services and partner with local organizations to offer services in those areas.
✿	Identify services needed to be inclusive of underserved and underrepresented caregivers (due to language, race, culture, location, access, education, etc.) and collaborate with local organizations in reaching those caregivers through culturally and linguistically appropriate services.
✿	Create and disseminate a simple reference tool to help caregivers navigate and access resources across platforms.
✿	Raise awareness of resources available across platforms to support informal caregivers.
✿	Educate professionals and healthcare providers on resources available throughout the caregiving journey and the importance of connecting caregivers to resources as soon as possible.
✿	Identify existing benefits and laws that support caregivers, both federally and within Utah.
✿	Educate employers, employee assistance programs (EAPs), and human resource representatives on resources available to support caregivers and the importance of connecting employees to these resources.
✿	Collaborate with local organizations to advocate for and effect legislative changes that promote workplace and financial security for caregivers.
✿	Develop a systematic process to collect and measure data that will inform priorities and best practices.

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- Elizabeth Fauth — Expand Research
- Lauren Willie — Living Well with Dementia
- Kate Nederostek —Support & Empower Caregivers

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- Representative Dan Johnson
- Senator Kathleen Riebe
- Rob Ence - Utah Commission on Aging
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- Utah Higher Education Appropriations Subcommittee
- Social Services Appropriations Subcommittee under the direction of Raymond Ward and Senator Jacob Anderegg

We are grateful to Robert Korycinski for sharing his creative gift and template for this plan.





Dementia resources

Alzheimer's Association

www.alz.org

Helpline: 800-272-3900

Association for Frontotemporal Degeneration (AFTD)

www.theaftd.org

Helpline: 866-507-7222

Creutzfeldt-Jakob Disease Foundation

www.cjdfoundation.org

Helpline: 800-659-1991

Huntington's Disease Society of America (HDSA)

www.hdsa.org

Helpline: 800-345-4372

Lewy Body Dementia Association (LBDA)

www.lbda.org

Lewy Line: 800-539-9767

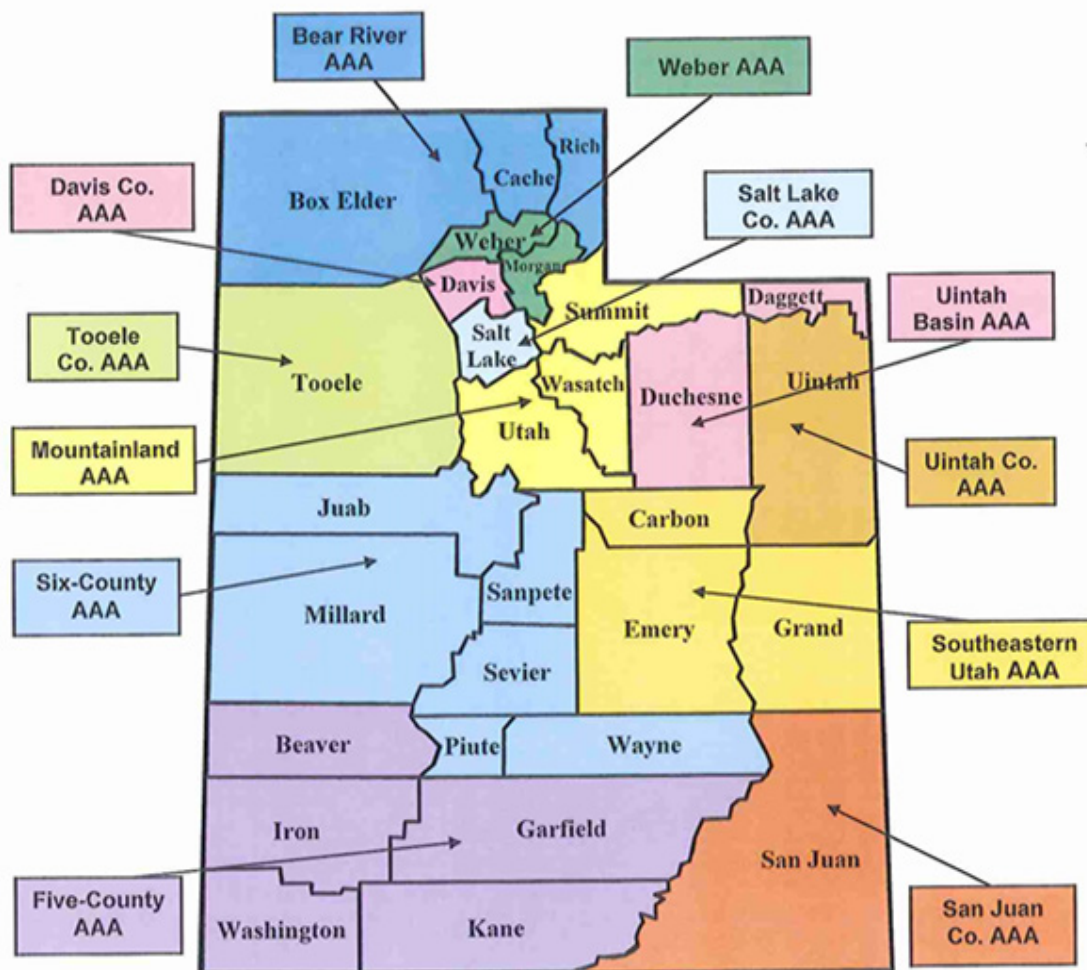
Parkinson's Foundation

www.parkinson.org

Helpline: 800-473-4636



Area Agencies on Aging



Utah AAAs may offer the following services:

- Active aging
- Advocacy & long-term care ombudsman
- Caregiver support
- Health promotion & education
- Home & community based care
- Housing liaison
- Information & assistance
- Legal services
- Meals on wheels
- Medical transportation
- Medicare counseling
- Senior centers
- Volunteer opportunities
- And more

To find information on your local Area Agency on Aging (AAA) visit eldercare.acl.gov or UtahAging.org.

Infographics

UTAH CAREGIVING



2020 Behavioral Risk Factor Surveillance System (BRFSS) Data



Nearly 1 in 5
adults are caregivers

CAREGIVERS provide regular care or assistance to a FRIEND or FAMILY member with a health problem or disability

CAREGIVING CAN BE

LENGTHY
Nearly half have provided care for at least two years



INTENSE
A quarter have provided care for at least 20 hours per week



HOW DO CAREGIVERS HELP?



Over 80% manage household tasks

Nearly half assist with personal care



WHO ARE CAREGIVERS?

58% are women

19% are 65 years old or older

37% are caring for a parent or parent-in-law

22% of caregivers are providing care to someone with dementia



FUTURE CAREGIVERS



Nearly 1 in 7 NON-CAREGIVERS expect to **BECOME CAREGIVERS** within 2 years

alzheimer's
association



For more information: www.alz.org/publichealth

www.cdc.gov/aging

CS 329234-A

February 2022

UTAH

SUBJECTIVE COGNITIVE DECLINE



2020 Behavioral Risk Factor Surveillance System (BRFSS): People Aged 45 Years and Older

1 in 10

people aged 45 years and older are experiencing

Subjective Cognitive Decline



SCD is self-reported **MEMORY PROBLEMS** that have been **GETTING WORSE** over the past year.

76%

of people with SCD have at least one chronic condition



30%

of people with SCD had to give up day-to-day activities



Less than half

of people with SCD have discussed their symptoms with a healthcare provider



Nearly a third

of people with SCD say it interfered with social activities, work, or volunteering



25%

of people with SCD need help with household tasks



alzheimer's 
association



for more
information:

www.alz.org/publichealth

www.cdc.gov/aging

CS 328530-A

December 2021



Utah

Alzheimer's Statistics



Prevalence

NUMBER OF PEOPLE
AGED 65 AND OLDER
WITH ALZHEIMER'S

Year	TOTAL
2020	34,000
2025	42,000

ESTIMATED % CHANGE

23.5%



Workforce

25

of geriatricians

356.0%

% increase needed to meet
the demand in 2050

13,040

of home health and
personal care aides

49%

% increase needed to meet
demand in 2028



Caregiving (2021)

97,000

Number of Caregivers

\$1,985,000,000

Total Value of Unpaid Care

22.3%

% of caregivers
with depression

119,000,000

Total Hours of Unpaid Care

69.0%

% of caregivers
with chronic
health conditions

10.7%

% of caregivers
in poor physical
health



Health Care

HOSPICE (2017)

2,506

of people in hospice
with a primary diagnosis
of dementia

19%

% in hospice with a primary
diagnosis of dementia

HOSPITALS (2018)

1,194

of emergency department
visits per 1,000 people
with dementia

16.7%

dementia patient hospital
readmission rate

MEDICAID

\$185M

Medicaid costs of caring
for people with Alzheimer's
(2020)

27.0%

projected change in costs
from 2020 to 2025

MEDICARE

\$24,093

per capita Medicare spending on people
with dementia (in 2021 dollars)



Mortality

OF DEATHS FROM ALZHEIMER'S DISEASE (2019)

980

186.5% increase in
Alzheimer's deaths since 2000

More than **6 million Americans** are living with Alzheimer's, and over **11 million** provide their unpaid care. The cost of caring for those with Alzheimer's and other dementias is estimated to total **\$321 billion** in 2022, increasing to nearly **\$1 trillion** (in today's dollars) by mid-century.

For more information, view the **2022 Alzheimer's Disease Facts and Figures** report at alz.org/facts.
© 2022 Alzheimer's Association® All Rights Reserved. Alzheimer's Association is a not-for-profit 501(c)(3) organization.

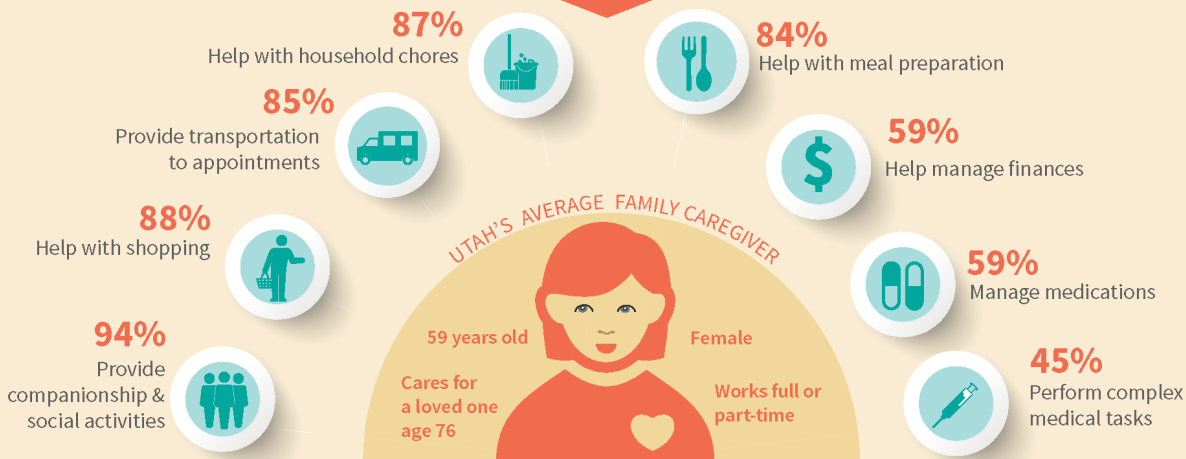


UTAHNS ARE FAMILY CAREGIVERS

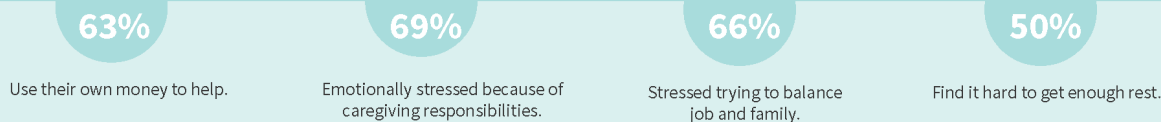
Across Utah family caregivers take on big responsibilities helping their parents, spouses, and other loved ones stay at home. AARP recently surveyed 801 Utah registered voters age 40-plus about caring for their families. Here's what we learned:

48% Current or Former Caregivers **65%** Likely Caregivers in the Future

Utah family caregivers often have huge responsibilities. They:



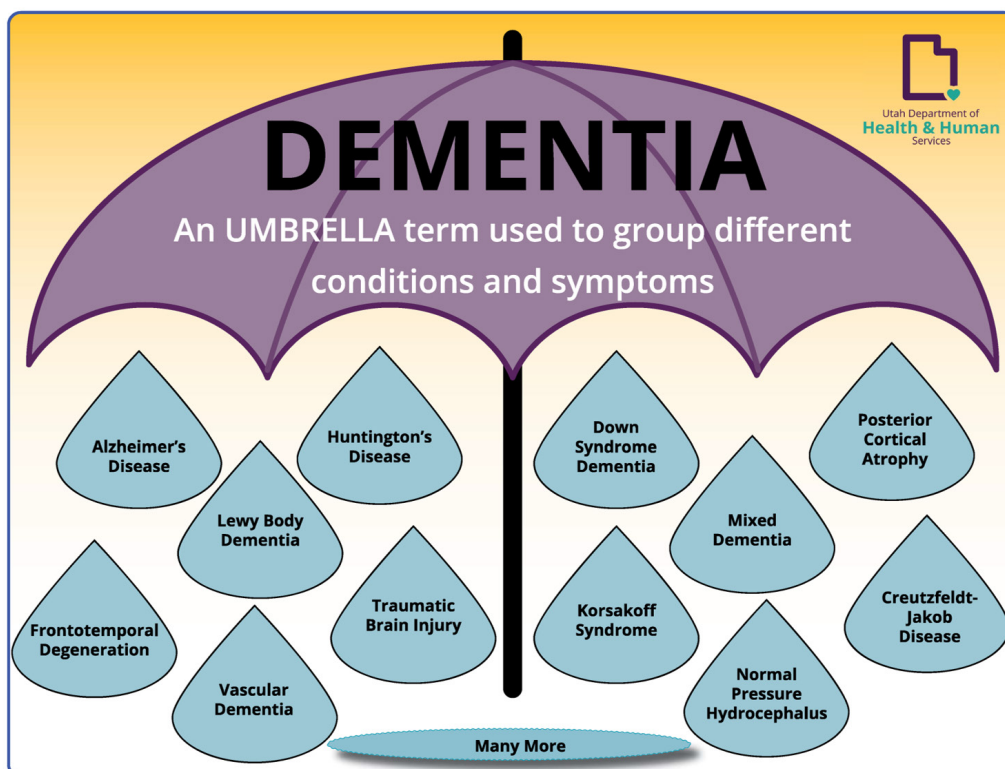
Utah family caregivers believe it's important to help their loved ones live independently at home, but they also face challenges:



Source: September 2018 Survey of 801 Utah Registered Voters Aged 40-plus. Margin of error is $\pm 3.5\%$
<https://doi.org/10.26419/res.00259.009>

I ♥ Caregivers

AARP Real Possibilities





The Association for
Frontotemporal Degeneration
FIND HELP • SHARE HOPE

FTD: TIME TO DIAGNOSIS



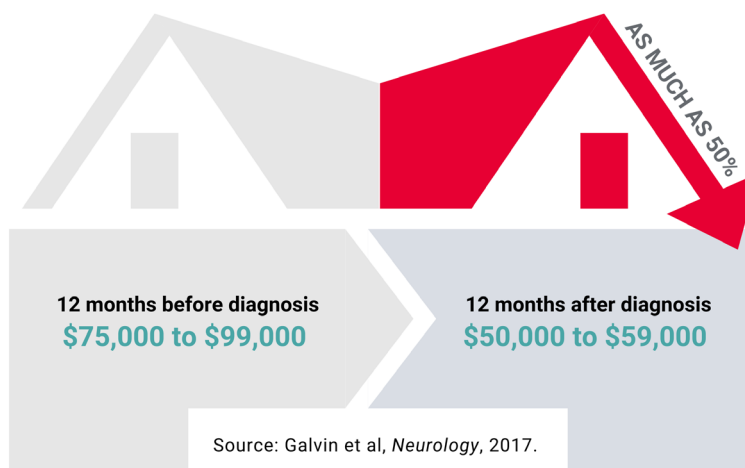
3.6 years is too long - let's change that



ANNUAL COST TO FAMILIES



FTD – IMPACT ON HOUSEHOLD INCOME



Dementia warning signs

NOTE: It's possible for individuals to experience one or more of these signs in varying degrees. It is not necessary to experience every sign in order to raise concern.

Cognitive changes¹²

- Challenges with communicating or finding words
- Confusion and disorientation
- Declining coordination and motor functions
- Issues with reasoning or problem-solving
- Memory loss, which is usually noticed by someone else
- Poor visual and spatial abilities, such as getting lost while driving
- Problems handling complex tasks
- Trouble with planning and organizing

Psychological changes¹²

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

What to do if you notice a sign(s)²:

If you notice one or more signs in yourself or another person it can be difficult to know what to do. It's common to feel uncertain or nervous about discussing these changes with others. Talking about your concerns might make them seem more "real." Or, you may fear upsetting someone by sharing observations about changes in their abilities or behavior. However, these signs are significant health concerns that should be evaluated by a doctor. It's important to actively figure out what's going on.

Dementia risk factors and reduction

Risk factors that cannot be changed¹²

- **Age:** The risk for dementia increases as you age, however, dementia is not a normal part of aging and can occur in younger individuals.
- **Family history:** Having a family history of dementia increases your risk, however, it does not guarantee that you will develop any form of it.
- **Down syndrome:** Many people with Down syndrome develop younger-onset Alzheimer's disease.

Risk factors that you can change¹²

- **Air pollution:** Studies have found that air pollution exposure — particularly from traffic exhaust and burning wood — is associated with greater dementia risk.
- **Cardiovascular risk factors:** These include high blood pressure (hypertension), high cholesterol, buildup of fats in your artery walls (atherosclerosis), and obesity.
- **Depression:** Although not yet well understood, late-life depression might indicate the development of dementia.
- **Diabetes:** Having diabetes may increase your risk of dementia, especially if it's poorly controlled.
- **Diet and exercise:** Research shows that lack of exercise increases the risk of dementia. In addition, a greater incidence of dementia is noted in people who eat an unhealthy diet compared with those who follow a Mediterranean-style diet rich in produce, whole grains, nuts, and seeds.
- **Excessive alcohol use:** Drinking large amounts of alcohol has long been known to cause brain changes.
- **Head trauma:** People who've had severe head trauma have a greater risk of dementia.
- **Medications that can worsen memory:** Try to avoid over-the-counter sleep aids that contain diphenhydramine (Advil PM, Aleve PM) and medications used to treat urinary urgency such as oxybutynin (Ditropan XL).
- **Sleep disturbances:** People who have sleep apnea and other sleep disturbances might be at higher risk of developing dementia.

Dementia risk factors and reduction

- **Smoking:** Smoking might increase your risk of developing dementia and blood vessel diseases.
- **Vitamin and Nutritional Deficiencies:** Low levels of vitamin D, vitamin B-6, vitamin B-12, and folate can increase your risk of dementia.

Risk Reduction Tips¹²

- **Be physically and socially active:** Physical activity and social interaction might delay the onset of dementia and reduce its symptoms.
- **Get enough vitamins:** Some research suggests that people with low levels of vitamin D in their blood are more likely to develop dementia. You can get vitamin D through certain foods, supplements, and sun exposure.
- **Get Good-quality sleep:** Practice good sleep hygiene and talk to your doctor if you snore loudly, have periods where you stop breathing, or gasp during sleep.
- **Keep your mind active:** Mentally stimulating activities such as reading, solving puzzles, playing word games, and memory training might delay the onset of dementia and decrease its effects.
- **Maintain a healthy diet:** A diet such as the Mediterranean diet — rich in fruits, vegetables, whole grains, and omega-3 fatty acids, which are commonly found in certain fish and nuts — might promote health and lower your risk of developing dementia. This type of diet also improves cardiovascular health, which may help lower dementia risk.
- **Manage cardiovascular risk factors:** Treat high blood pressure, high cholesterol, and diabetes. Lose weight if you're overweight. High blood pressure might lead to a higher risk of some types of dementia.
- **Manage mental health conditions:** See your doctor to treat depression or anxiety.
- **Quit smoking:** Some studies have shown that smoking in middle age and beyond might increase your risk of dementia and blood vessel conditions.
- **Treat hearing problems:** People with hearing loss have a greater chance of developing cognitive decline. Early treatment of hearing loss, such as use of hearing aids, might help decrease the risk.

Glossary

Activities of Daily Living (ADLs): A term used by healthcare professionals to refer to the basic self-care tasks an individual does on a day-to-day basis. (ex: walking, bathing, dressing, feeding, toileting, transferring)

Acute care: A branch of secondary healthcare where a patient receives active but short-term treatment for a severe injury or episode of illness, an urgent medical condition, or during recovery from surgery. In medical terms, care for acute health conditions is the opposite from chronic care or longer term care.

Adaptive/Assistive equipment: Devices that are used to assist with completing activities of daily living.

Adult Day services: A professional care setting in which older adults, adults living with dementia, or adults living with disabilities receive individualized therapeutic, social, and health services for some part of the day.

Adult Protective Services (APS): A social services program provided by state and/or local governments nationwide serving older adults and adults with disabilities who are in need of assistance. APS workers investigate cases of abuse, neglect, or exploitation working closely with a wide variety of allied professionals such as physicians, nurses, paramedics, firefighters, and law enforcement officers.

Advance care planning: Making decisions about the care you would want to receive if you become unable to speak for yourself. These are your decisions to make and are based on your personal values and preferences.

Age friendly health system: A designation recognizing a system-wide commitment to improving the health and well-being of older adults and reliably providing a set of four evidence-based elements of high-quality care, known as the “4Ms,” to all older adults in their system: What Matters, Medication, Mentation, and Mobility.

Aging in place: The ability to live in one's own home and community safely, independently, and comfortably regardless of age, income, or ability level.

Alzheimer's disease: Type of dementia that causes problems with memory, thinking and behavior. Symptoms usually develop slowly and get worse over time, becoming severe enough to interfere with daily tasks.

Area Agency on Aging (AAA): A nationwide network of state and local programs that help older adults to plan and care for their lifelong needs. They were created under the federal Older Americans Act.

Assisted living residences: A system of housing and limited care that is designed for senior citizens who need some assistance with daily activities but do not require care in a nursing home.

Care consultations: A meeting with a trained professional who will help navigate difficult caregiving decisions and family issues; assess current needs and anticipate future care challenges; develop an effective care plan; assist with problem solving; and offer supportive listening in a confidential, nonjudgmental environment.

Care manager: As healthcare providers, care managers provide for their patients by matching patient needs with appropriate services. Care managers who act as facility supervisors may be in charge of business operations and oversee patient care at clinics, hospitals, nursing homes, and other healthcare facilities.

Caregiver, family/designated representative, or care partner: Family members, friends, or neighbors who provide unpaid assistance to a person with a chronic illness or disabling condition.

Certified Nursing Assistant (CNA): A person who assists patients with healthcare needs and cares for a patient who is ill or recovering from a surgery or disease. CNA duties are assigned by a registered professional nurse.

Chronic disease: According to the definition by the U.S. National Center for Health Statistics, a chronic disease is one lasting 3 months or more. Chronic diseases generally cannot be prevented by vaccines or cured by medication, nor do they just disappear.

Clinical trials: Research investigations in which people volunteer to test new treatments, interventions, or tests as a means to prevent, detect, treat or manage various diseases or medical conditions. Some investigations look at how people respond to a new intervention and what side effects might occur.

Co-morbidities: The simultaneous presence of two chronic diseases or conditions in a patient.

Cognition: The mental action or process of acquiring knowledge and understanding through thought, experience, and the senses.

Congregate housing: Congregate housing, or congregate living, offers independent living in separate apartments.

Conservator: A guardian or protector.

Continuing care retirement communities: A continuing care retirement community, sometimes known as a life plan community, is a type of retirement community in the U.S. where a continuum of aging care needs (independent living, assisted living, and skilled nursing care) can all be met within the community.

Creutzfeldt-Jakob disease: A fatal degenerative disease affecting nerve cells in the brain, causing mental, physical, and sensory disturbances such as dementia and seizures. It is believed to be caused by prions and hence to be related to Bovine Spongiform Encephalopathy (BSE) and other spongiform encephalopathies such as kuru and scrapie.

Custodial care: Non-medical care that helps individuals with their daily basic care, such as eating and bathing. Custodial care for an individual is recommended by an authorized medical personnel, but providers of custodial care are not required to be medical professionals.

Decubitus ulcers (pressure ulcers, pressure sores, or bedsores): A sore developed due to pressure caused by lying in bed in one position for an extended period of time.

Delirium: An acutely disturbed state of mind that occurs in fever, intoxication, and other disorders and is characterized by restlessness, illusions, and incoherence of thought and speech.

Dementia: A chronic or persistent disorder of the mental processes caused by brain disease or injury and marked by memory disorders, personality changes, and impaired reasoning.

Dementia Dialogues®: An evidence-informed, nationally registered, intervention training program created by the University of South Carolina to designed to educate community members and caregivers about Alzheimer's disease and related dementias.

Do Not Resuscitate (DNR) order: A medical order written by a doctor that instructs healthcare providers not to do cardiopulmonary resuscitation (CPR) if a patient's breathing stops or if the patient's heart stops beating.

Down Syndrome dementia: As they age, individuals affected by Down syndrome have a greatly increased risk of developing a type of dementia that's either the same as or very similar to Alzheimer's disease.

Durable power of attorney for finances: A power of attorney (POA) which typically remains in effect until the death of the principal or until the document is revoked.

Elder abuse: An intentional act or failure to act that causes or creates a risk of harm to an older adult.

Elder law: An area of law that covers a number of different legal issues affecting older adults, their caregivers, and relatives.

Employee Assistance Program (EAP): A voluntary, work-based program that offers free and confidential assessments, short-term counseling, referrals, and follow-up services to employees who have personal and/or work-related problems.

Estate planning: A process involving the counsel of professional advisors who are familiar with your goals and concerns, your assets and how they are owned, and your family structure. It can involve the services of a variety of professionals, including your lawyer, accountant, financial planner, life insurance advisor, banker, and broker.

Executor: A person or institution appointed by an individual to carry out the terms of their will.

Faith based support: Support affiliated with, supported by, or based on a religion or religious group.

Family and Medical Leave Act (FMLA): Entitles eligible employees of covered employers to take unpaid, job-protected leave for specified family and medical reasons with continuation of group health insurance coverage under the same terms and conditions as if the employee had not taken leave.

Formal caregiver: A person trained in providing care and who is paid for their services.

Frontotemporal degeneration (FTD): A group of brain disorders caused by degeneration of the frontal and/or temporal lobes of the brain. FTD is also frequently referred to as frontotemporal dementia, frontotemporal lobar degeneration (FTLD), or Pick's disease.

Functional impairment: Limitations due to an illness.

Geriatric psychiatrist: Psychiatrists that specialize in the diagnosis and treatment of mental conditions affecting older adults over the age of 65.

Geriatrician: An expert in the branch of medicine or social science dealing with the health and care of older adults.

Guardianship: The position of being legally responsible for the care of someone who is unable to manage their own affairs.

Health assessment: A health assessment is a plan of care that identifies the specific needs of a person and how those needs will be addressed by the healthcare system or skilled nursing facility. Health assessment is the evaluation of the health status by performing a physical exam after taking a health history.

Home health agency: A public or private organization that delivers skilled nursing and other therapeutic service to a patient at home.

Home health aide: A trained and certified healthcare worker who provides assistance with personal care (hygiene and exercise), household duties (meal preparation and light housekeeping), and monitors the patient's condition in the patient's home.

Hospice care: Compassionate comfort care (as opposed to curative care) for people facing a terminal illness with a prognosis of six months or less, based on their physician's estimate if the disease runs its course as expected.

Huntington's disease: A hereditary disease marked by degeneration of the brain cells and causing chorea and progressive dementia.

In-home/personal care: Also known as non-skilled care, non-medical care, or companion care, personal care services at home allows you to live in the comfort of your own home for as long as possible. Remaining at home may provide you with an enhanced quality of life that you might not experience in other settings.

Independent living: Communities designed to feel and function like a private residence.

Informal caregiver: Provide regular, unpaid care or assistance to a friend or family member who has a health problem or disability.

Instrumental Activities of Daily Living (IADLs): Self-care tasks that require more complex thinking or organizational skills. (ex: managing finances, transportation, communication, medication management.)

Korsakoff syndrome: A chronic memory disorder caused by severe deficiency of thiamine (vitamin B-1). Korsakoff syndrome is most commonly caused by alcohol misuse, but certain other conditions also can cause the syndrome.

Lewy Body dementia: A disease associated with abnormal deposits of a protein called alpha-synuclein in the brain. These deposits, called Lewy bodies, affect chemicals in the brain whose changes, in turn, can lead to problems with thinking, movement, behavior, and mood.

Living will: A written statement detailing a person's desires regarding their medical treatment in circumstances in which they are no longer able to express informed consent, especially an advance directive.

Long-term care: A variety of services designed to meet a person's health or personal care needs during a short or long period of time. These services help people live as independently and safely as possible when they can no longer perform everyday activities on their own.

Long-distance caregiving: Caregiving for someone an hour or more away from you.

Long-term care Insurance: Reimburse policyholders a daily amount (up to a pre-selected limit) for services to assist them with activities of daily living such as bathing, dressing, or eating.

Long-term care ombudsman: Seeks resolution of problems and advocates for the rights of residents of long-term care facilities to ensure and enhance the quality of life and care of residents.

Medicaid: A public health insurance program that provides healthcare coverage to low-income families and individuals in the United States.

Medicaid-certified: Recognition by a state agency or other such entity administering a particular state's Medicaid program that a healthcare provider or supplier is in compliance with all the conditions of participation set forth in the appropriate state and federal Medicaid Regulations.

Medicare-certified: Offering services at a level of quality approved by Medicare.

Medicare: A federal health insurance for people 65 or older, some younger people with disabilities, or people with End-Stage Renal Disease.

Memory care communities: A kind of specialized care for people living with Alzheimer's and other forms of dementia.

Mild Cognitive Impairment (MCI): A condition in which people have more memory or thinking problems than other people their age. The symptoms of MCI are not as severe as those of Alzheimer's disease or a related dementia. People with MCI can usually take care of themselves and carry out their normal daily activities.

Mini-Cog®: A brief, cognitive screening test that is frequently used to evaluate cognition in older adults in various settings.

Mini-Mental State Examination (MMSE): A set of 11 questions that doctors and other healthcare professionals commonly use to check for cognitive impairment.

Mixed dementia: A condition in which brain changes of more than one cause of dementia occur simultaneously.

National Family Caregiver Support Program: Provides grants to states and territories to fund various supports that help family and informal caregivers care for older adults in their homes for as long as possible.

Normal pressure hydrocephalus: A brain disorder in which excess cerebrospinal fluid (CSF) accumulates in the brain's ventricles, causing thinking and reasoning problems, difficulty walking, and loss of bladder control.

Nursing home: A place for people who don't need to be in a hospital but can't be cared for at home.

Occupational Therapist (OT): Trained professionals who help people participate in their desired occupations with the therapeutic use of everyday activities, based on the client's personal interests and needs.

Palliative care: Compassionate comfort care that provides relief from the symptoms and physical and mental stress of a serious or life-limiting illness. Palliative care can be pursued at diagnosis, during curative treatment and follow-up, and at the end of life.

Personal Emergency Response System (PERS): Also known as Medical Emergency Response Systems, let you call for help in an emergency by pushing a button. A PERS has 3 components: a small radio transmitter, a console connected to your telephone, and an emergency response center that monitors calls.

Posterior cortical atrophy: Gradual and progressive degeneration of the outer layer of the brain (the cortex) in the part of the brain located in the back of the head (posterior).

Provider Order for Life-Sustaining Treatment (POLST): A system to elicit patients' preferences regarding medical treatment, and communicate and honor those preferences by creating portable medical orders.

Respite care: Short-term relief for primary caregivers.

Social Worker: A practice-based profession that promotes social change, development, cohesion, and the empowerment of people and communities.

Support groups: A group of people with common experiences or concerns who provide each other with encouragement, comfort, and advice.

Subjective Cognitive Decline (SCD): The self-reported experience of worsening or more frequent confusion or memory loss.

Sundowning: Restlessness, agitation, irritability, or confusion that can begin or worsen as daylight begins to fade.

Traumatic head injury: A form of acquired brain injury that occurs when a sudden trauma causes damage to the brain.

Vascular dementia: A common form of dementia caused by an impaired supply of blood to the brain, such as may be caused by a series of small strokes.

Wandering: A person living with dementia can become lost or confused about their location due to their inability to recognize familiar places and faces, this can happen at any stage of dementia.

Younger-onset dementia: Any dementia that develops in people under the age of 65.



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