



Texas State Plan for Alzheimer's Disease 2024- 2028

**As Required by
Texas Health and Safety Code, Sections
99A.001 and 99A.004**



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Executive Summary

[Texas Health and Safety Code, Section 99A.001](#), directs the Texas Department of State Health Services (DSHS) to develop and implement a state plan for education on, and treatment of, Alzheimer’s disease and related dementias (ADRD). DSHS must review and modify the state plan at least once every five years. [Texas Health and Safety Code, Section 99A.004](#), requires DSHS submit to the legislature a biennial update on state plan activities.

The following Texas State Plan for Alzheimer’s Disease 2024-2028 (state plan) builds off the [Texas State Plan for Alzheimer’s Disease 2019-2023](#) and presents strategies across 10 priority areas:

- Public education and awareness;
- Risk reduction;
- Coordinated care and support;
- Partnerships and engagement;
- Professional training;
- Early detection and diagnosis;
- Quality care and support;
- Family dementia caregiving;
- Surveillance and evaluation; and
- Research advances.

The priority areas and strategies emphasize risk reduction, the role of primary care providers (PCPs) in early detection and diagnosis, and the importance of including family caregivers in care planning. The 2024-2028 state plan encourages a coordinated effort among stakeholders to address the needs of people living with ADRD and the families that care for them.

Introduction

Alzheimer's Disease

Dementia is a general term for cognitive changes such as memory loss, behavior and personality changes, and changes to other cognitive functions. Alzheimer's disease, the most prevalent form of dementia, is an age-related, progressive, and irreversible brain disease characterized by a steady decline in cognitive, behavioral, and physical abilities. Alzheimer's and related dementias are severe enough to interfere with daily life.

Alzheimer's is thought to begin 20 years or more before symptoms develop. Hallmark symptoms of Alzheimer's are memory loss, disorientation, and diminished thinking ability followed by a downward spiral that includes problems with verbal expression, analytical ability, frustration, irritability, and agitation. As the disease progresses, physical manifestations include loss of strength and balance and the inability to perform simple tasks and physical activities. As cognitive and functional abilities decline, individuals are rendered totally dependent on others for care. As more of the brain becomes affected, areas that control basic life functions like swallowing and breathing become irreversibly damaged, eventually leading to death. Currently, there is no effective treatment or cure for Alzheimer's. There is evidence that hypertension control, physical activity, and measures to promote heart health may help prevent, reduce, or delay the effects of dementia.

Though Alzheimer's is the most common cause of dementia, there are many other types, including Creutzfeldt-Jakob disease, Lewy body dementia, frontotemporal dementia, Huntington's disease, mixed dementia, normal pressure hydrocephalus, Parkinson's disease, vascular dementia, and Korsakoff syndrome.¹

For more information on the signs and symptoms of Alzheimer's, go to [alz.org/alzheimers-dementia/10_signs](https://www.alz.org/alzheimers-dementia/10_signs). For information on related dementias, go to nia.nih.gov/health/alzheimers-and-dementia/what-dementia-symptoms-types-and-diagnosis.

¹ Alzheimer's Association. Alzheimer's Disease Facts and Figures. <https://www.alz.org/media/Documents/alzheimers-facts-and-figures.pdf>. 2024. Accessed March 28, 2024.

In 2024, an estimated 6.9 million Americans aged 65 years and older were living with Alzheimer's. Approximately 4.2 million were women and approximately 2.7 million were men.² Women are more likely to develop Alzheimer's and other dementias. In 2020, approximately 460,000 Texans aged 65 years and older were living with Alzheimer's. In terms of absolute numbers, Texas ranks fourth in the nation in Alzheimer's cases and second in Alzheimer's deaths.

In 2023, approximately one million unpaid caregivers provided care to Texans with Alzheimer's.³ This equates to an estimated 1.5 billion hours of unpaid care at a cost of approximately \$23.9 billion per year. In 2024, the economic burden of caring for people with Alzheimer's and other dementias (including health care, long-term care, and hospice care) was projected to reach approximately \$360 billion. Total annual payments for health care, long-term care, and hospice care for individuals with Alzheimer's and other dementias are projected to increase from approximately \$360 billion in 2024 to nearly \$1 trillion in 2050 (in 2024 dollars).

Research continues to expand scientific understanding of Alzheimer's disease causes, treatments, and prevention. Scientists have identified genetic and biological changes that occur with Alzheimer's, allowing them to pinpoint possible targets for treatment. Advances in pharmacologic treatment may stabilize and delay progression of Alzheimer's symptoms. Delayed progression helps contain medical and long-term care costs, eases caregiver burden, and allows the individual with Alzheimer's to participate more fully in life and postpone dependency.

Alzheimer's is a major public health and research challenge because of its detrimental effects on the health and well-being of the nation's population. Because there is no cure for Alzheimer's, the importance of early detection becomes even more critical. The earlier the diagnosis is made, the more likely the individual may respond to treatment. Despite its importance, significant barriers remain to early detection. A missed or delayed diagnosis of Alzheimer's can lead to unnecessary burdens on the individual and their caregivers.

Ongoing research efforts to find causes and identify risk factors to delay onset of, prevent, and cure Alzheimer's are imperative. As methodologies are refined, scientists and clinicians will be able to investigate and understand the earliest pathological and clinical signs of Alzheimer's, perhaps 10 to 20 years before a clinical diagnosis. Drug development to block the progression of symptoms and

² Ibid.

³ Ibid.

eventually prevent Alzheimer's is critical to decreasing disability and death, containing health care costs, and protecting individuals and families.

Increased support for individuals with Alzheimer's and their caregivers is crucial. Stakeholders should continue to support community and home-based care as well as community supports for caregivers. This would provide caregivers assistance for those caring for their loved ones at home. Expediting statewide, coordinated action to address Alzheimer's remains critical as the prevalence of the disease continues to climb, exacting huge human and economic burdens.

Recognizing the importance of developing partnerships made up of diverse Alzheimer's stakeholders, the Centers for Disease Control and Prevention (CDC) and the Alzheimer's Association developed the [Healthy Brain Initiative, State and Local Public Health Partnerships to Address Dementia: The 2023-2027 Road Map](#).⁴

Update on 2019-2023 State Plan Activities

In 2019, the legislature directed DSHS to develop and implement a state plan for the education on and treatment of ADRD. As required by [Texas Health and Safety Code, Section 99A.002](#), DSHS consulted with the interested parties to develop the state plan by holding meetings with the Alzheimer's Disease Partnership, a stakeholder group established by DSHS. The Partnership includes more than 200 individuals, including providers, advocates, researchers, members of the public, and state agency representatives. Taking stakeholder input into account, DSHS published and submitted the [Texas State Plan for Alzheimer's Disease 2019-2023](#) in September 2019.

The 2019-2023 state plan included eight priority areas:

- Education and awareness;
- Coordinated systems of care and support;
- Partnerships and engagement;
- Training;
- Quality care and support;

⁴ Alzheimer's Association and Centers for Disease Control and Prevention. Healthy brain initiative, state and local public health partnerships to address dementia: the 2023-2027 road map. <https://www.cdc.gov/aging/pdf/roadmap/HBI-State-and-Local-Road-Map-for-Public-Health-2023-2027-508-compliant.pdf>, 2024.

- Family inclusion;
- Importance of data collection and evaluation; and
- Advance research and collaboration.

Stakeholder Meetings

DSHS sought regular input on the 2019-2023 state plan by convening the Alzheimer's Disease Partnership. DSHS completed the following activities during Partnership meetings:

- DSHS provided opportunities for stakeholders to offer input on 2019-2023 state plan;
- A representative from the Health and Human Services Commission (HHSC) Office of Aging Services Coordination presented on available services and resources to inform the activities of individual Partnership organizations and encourage collaboration; and
- Partners discussed possible ways to develop educational content and organize community resources.

Legislative Appropriations

In the [2022-2023 General Appropriations Act, Senate Bill 1, 87th Legislature, Regular Session, 2021 \(Article II, DSHS, Rider 35\)](#), the legislature appropriated \$1 million to DSHS for Alzheimer's disease activities. DSHS used this appropriation to continue an Alzheimer's disease public awareness campaign launched in August 2020.

In the [2024-2025 General Appropriations Act, House Bill 1, 88th Legislature, Regular Session, 2023 \(Article II, DSHS, Rider 31\)](#), the legislature increased funding to DSHS for Alzheimer's disease activities to \$5.5 million over the biennium. The legislature provided direction on how DSHS should use these funds and provided one full time equivalent (FTE) employee to manage Alzheimer's program initiatives. In line with the rider language, DSHS is using resources available for Alzheimer's disease to:

- Continue the public awareness campaign;
- Create an additional awareness campaign for health care professionals on early detection and treatment;

- Coordinate with stakeholders and other agencies on developing and implementing the state plan;
- Operate a competitive grants program to provide direct caregiver support and promote early detection and diagnosis; and
- Add cognitive decline and caregiving-related questions in the [Texas Behavioral Risk Factor Surveillance System](#) (BRFSS) for 2024 and 2025.⁵

Alzheimer’s Disease Awareness Campaign

DSHS supports a public awareness campaign that includes public service announcement messages for paid media (statewide television, radio, digital, and print ads). The goal of the campaign is to help Texans recognize the signs of Alzheimer’s disease in their loved ones and start a conversation on seeking care. The campaign generated more than 47 million impressions in fiscal year 2022, and more than 72 million impressions in fiscal year 2023.⁶

DSHS also developed an educational booklet titled [A Family’s Guide to Alzheimer’s](#). The booklet is for community-based organizations and providers and includes information for families on:

- Early detection;
- Starting a conversation when individuals notice the signs of dementia;
- Getting a diagnosis; and
- How to find community resources.

⁵ Texas Department of State Health Services. Texas behavioral risk factor surveillance system (BRFSS). Texas Department of State Health Services website. <https://www.dshs.texas.gov/texas-behavioral-risk-factor-surveillance-system-brfss>. Accessed June 26, 2024. The Texas BRFSS is a telephone survey of randomly selected adult Texans conducted monthly to collect data on health behaviors that contribute to the leading causes of death and chronic disease. The BRFSS Cognitive Decline Module asks about subjective cognitive decline, the potential difficulties it may cause with everyday activities, and whether people have discussed their memory challenges with a health care professional. The Caregiver Module includes questions about caregiving status and the caregiving situation, care recipient’s health issues, and prospects for future caregiving needs.

⁶ A media impression is a measure of the number of times content is consumed.

DSHS is expanding the public awareness campaign to include educational modules regarding early detection and diagnosis for health care professionals. The modules will be available in fall 2024.

Data Collection

DSHS included the Caregiver Optional Module and Cognitive Decline Optional Module in the 2023 and 2024 BRFSS surveys. The results of these surveys will be available in fall 2024 and fall 2025. DSHS will incorporate results into [Texas Health Data](#) dashboards, share the data with the Partnership and the Texas Council on Alzheimer's Disease and Related Disorders, and include the data in future Alzheimer's-related reports.

The CDC BOLD Grant Award

In 2023, DSHS received funds from the CDC "Building Our Largest Dementia Infrastructure" (BOLD) grant. The five-year grant supports the following DSHS activities that align with the 2019-2023 state plan as well as the 2024-2028 state plan:

- Leveraging existing and new partnerships to provide education to the public and health care professionals through community education events and awareness campaigns;
- Conducting a needs assessment to analyze the gaps in community organizations and clinical systems of care;
- Increasing community-clinical linkages to provide direct caregiver support and promote early detection and diagnosis;
- Enhancing Alzheimer's Disease Partnership participation to develop an implementation plan; and
- Conducting data collection through BRFSS and a survey of Partnership members.

To implement these activities, DSHS has hired two staff and executed two contracts, one to provide education about ADRD and one to conduct a community needs assessment.

Unpaid Caregiver Survey and Report

DSHS developed and implemented the 2021 Texas Alzheimer’s Disease and Related Dementias Caregiver Survey in collaboration with the Partnership.

Results of the English-language 2021 Texas Alzheimer’s Disease and Related Dementias Caregiver Survey were published in the November 2023 issue of the Journal of Long-Term Care with the title [“The Most Difficult ‘Job’ There Is” – Characteristics and Challenges of Unpaid Caregivers of Persons with Alzheimer’s and Related Dementias in Texas](#). DSHS launched a survey for Spanish-speaking unpaid caregivers and a second distribution of the English survey in July 2024. Results are expected in fall 2024.

State Plan for Alzheimer's Disease 2024-2028

In 2023, DSHS reviewed the 2019-2023 state plan and sought input on revisions from the Alzheimer's Disease Partnership, the Texas Council on Alzheimer's Disease and Related Disorders, and the [Aging Texas Well Advisory Committee](#). HHSC administers the Aging Texas Well Advisory Committee, which includes representation from local and state agencies. The results of this review and stakeholder input informed the updates to the 2024-2028 state plan. DSHS also reviewed issues and recommendations outlined in the revised [Healthy Brain Initiative, State and Local Public Health Partnerships to Address Dementia: The 2023-2027 Road Map](#) (Road Map) developed by the Alzheimer's Association and CDC.⁷

The 2024-2028 state plan is not a comprehensive list of all possible actions to address ADRD but rather highlights areas that could empower people living with ADRD, family caregivers, and community members to take part in care planning and support quality care. The state plan is also a resource for professionals and stakeholders connected to health care and related services, such as medical professionals, health systems, public health professionals, state agencies, community-based organizations, and academic and research institutions.

Public Health Approach

The 2024-2028 state plan uses a public health approach to address ADRD. This means addressing challenges among aging individuals and the wider population based on a life course approach. Priority areas are designed to intersect with individuals and their communities at multiple points throughout the lifespan.

The 2024-2028 state plan emphasizes the role of PCPs in early detection and diagnosis. Early detection helps patients and their families receive adequate care, learn about treatment options, and develop care plans. The updated plan also stresses risk reduction and the importance of targeting populations at higher risk for ADRD:

⁷ Alzheimer's Association and Centers for Disease Control and Prevention. Healthy brain initiative, state and local public health partnerships to address dementia: the 2023-2027 road map. <https://www.cdc.gov/aging/pdf/roadmap/HBI-State-and-Local-Road-Map-for-Public-Health-2023-2027-508-compliant.pdf>, 2024.

- African Americans;
- Hispanics;
- Women;
- People with developmental disabilities;
- Rural populations;
- People who are uninsured or underinsured; and
- People who are socially isolated, live alone, or are experiencing homelessness.

Stakeholders can use the 2024-2028 state plan to:

- Inform activities;
- Prioritize needs;
- Share ideas and education with others; and
- Encourage collaboration and partnerships.

Priority Areas

To address the needs of ADRD, the 2024-2028 state plan outlines key strategies across ten priority areas for people living with ADRD, family caregivers, community members, providers, and stakeholders to consider:

- Public education and awareness;
- Risk reduction;
- Coordinated care and support;
- Partnerships and engagement;
- Professional training;
- Early detection and diagnosis;
- Quality care and support;
- Family dementia caregiving;
- Surveillance and evaluation; and
- Research advances.

Priority Area 1: Public Education and Awareness

Efforts to educate and raise public awareness of ADRD support open conversations and encourage individuals to discuss their cognitive health with their families and providers, including PCPs. Public education and awareness activities should be evidence based, culturally appropriate, and take a life course approach. Educating individuals from a young age to implement healthy lifestyle behaviors to support brain health and reduce the risk of ADRD is crucial.

Strategies

- 1.1 Provide and promote public education and awareness campaigns on the following ADRD topics:
 - ▶ Signs and symptoms;
 - ▶ Risk reduction;
 - ▶ Diagnosis;
 - ▶ Available resources;
 - ▶ Stigma reduction;
 - ▶ Brain health and cognitive decline;
 - ▶ Approaches to enhancing well-being when living with ADRD; and
 - ▶ Support for family and other unpaid caregivers.
- 1.2 Collaborate to include ADRD and risk reduction information in education systems (K-12 and post-secondary).

Priority Area 2: Risk Reduction

Some ADRD risk factors such as age, family history, and genetics cannot be changed.⁸ However, certain actions can help reduce risk factors, including:

- Being physically active;
- Not smoking;

⁸ Alzheimer's Association. Alzheimer's disease. Alzheimer's Association website. https://www.alz.org/alzheimers-dementia/what-is-alzheimers/causes-and-risk-factors?utm_source=google&utm_medium=paidsearch&utm_campaign=google_grants&utm_content=dementia&gad_source=1&gclid=EA1aIQobChMI3cfLtb-PhQMVJSfUAR3E9QAIEAAYASAAEgIZovD_BwE. Accessed March 22, 2024.

- Controlling weight;
- Eating a healthy diet;
- Controlling diabetes;
- Controlling midlife hypertension (high blood pressure);
- Protecting against head injury; and
- Reducing harmful use of alcohol.⁹

Strategies

- 2.1 Engage with communities, especially those at highest risk, to address healthy lifestyle choices and non-medical drivers of health that may impact the risk for cognitive decline.
- 2.2 Embed cognitive decline risk factors into evidence-informed health promotion and chronic disease prevention awareness and education campaigns, and jurisdictional dementia plans.¹⁰
- 2.3 Promote the role of PCPs in discussing the impact of healthy lifestyle choices from an early age on brain health, and identifying and treating all chronic conditions that may put individuals at risk for cognitive decline.

Priority Area 3: Coordinated Care and Support

Gaps in health care services and community-clinical linkages create barriers for people living with ADRD and their caregivers to access timely diagnosis, treatment, community services, quality health care, and support over the lifespan. Barriers include:

- Inadequate availability of standardized professional training;
- Insufficient coordination of dementia care between specialists and PCPs; and

⁹ Alzheimer's Association. Risk reduction messaging for health education. <https://www.alz.org/media/Documents/Risk-Reduction-Messaging-for-Health-Education.pdf>. Accessed March 22, 2024.

¹⁰ Dementia plans aim to improve quality of life, health care, community support, and long-term care support for people living with dementia and their family caregivers by promoting public awareness and covering a range of issues that may include dementia education, priority areas, and stakeholder actions for a given jurisdiction.

- Lack of formal linkages between professionals and community-based programs.

Family caregivers often have little knowledge about available services to support their need of respite and financial support. This gap can be better addressed when collaboration and connections occur among public health and medical professionals, clinics, community-based organizations, insurance companies, state agencies, and family caregivers.

Strategies

- 3.1 Identify and address gaps in services, community clinical linkages, access to services, and priority needs of people living with ADRD and family caregivers.
- 3.2 Promote collaboration between PCPs and dementia specialists (such as behavioral neurologists and social workers) to support PCPs in diagnosing dementia and providing care management over time.
- 3.3 Support existing or emerging best practice models of care coordination between physicians, hospitals, and long-term facility care professionals to reduce errors and duplication of services, improve outcomes, and minimize hospital readmissions.
- 3.4 Increase the number of community health workers and expand their role in providing education on ADRD to underserved communities.

Priority Area 4: Partnerships and Engagement

Improving outcomes for Texans with ADRD and their families requires a diverse group of stakeholders to collaborate and share information on best practices and lessons learned. Collaborative approaches help people living with ADRD remain in their communities longer and maintain a life of dignity and value.

Strategies

- 4.1 Encourage community organizations, state agencies, and health care organizations to collaborate and share information on the impact of ADRD on family caregivers and communities, areas in the state with the highest prevalence, high risk populations, and the role of public health to address these issues.
- 4.2 Partner with state agencies, community-based organizations, law enforcement, and first responders to:

- ▶ Promote the [Texas Department of Public Safety’s \(DPS\) Silver Alert Program](#) for people over age 65 years with dementia and for people with early onset dementia who are at risk for wandering;¹¹ and
- ▶ Prepare for situations involving people living with ADRD, including the 40-hour education and training program created by [House Bill 568, 88th Legislature, Regular Session, 2023](#), which requires training for law enforcement professionals regarding interacting with people living with ADRD.

Priority Area 5: Professional Training

Comprehensive up-to-date provider training improves person-centered care for people living with ADRD and their family caregivers. All professionals interacting with older adults should know the symptoms and stages of Alzheimer’s disease, the unique symptoms of dementia types, and aspects of disease management and caregiving as changes occur over time. This includes knowing what resources are available to patients and their family. Knowing what to look for in ADRD, and where to make referrals, increases opportunities for early diagnosis and better disease management.

PCPs are the most likely professionals to diagnosis ADRD because of their existing and trusted relationships with their patients. However, PCPs may assume that only a specialist can provide diagnosis and doubt their own ability to diagnose, treat, and support patients over time. With a lack of dementia specialists like neurologists and long wait times for appointments, PCPs must be trained and empowered to diagnose and treat ADRD, working with specialists as needed.¹² The following recommendations primarily impact training and education centers, as well as professional associations.

Strategies

- 5.1 Provide evidence-informed training and educational resources to PCPs on types of dementia, their unique symptoms, diagnostic screening tools, treatment options, family care planning, community support resources, and

¹¹ Silver alert. Texas Department of Public Safety website. <https://www.dps.texas.gov/section/intelligence-counterterrorism/silver-alert>. Accessed January 30, 2024.

¹² Alzheimer’s Association. Alzheimer’s Disease Facts and Figures - Special Report. <https://alz.org/media/Documents/alzheimers-facts-and-figures-special-report-2020.pdf>. Accessed August 14, 2024.

the importance of early detection to assist families in accessing treatment options and to plan for future care needs.

- 5.2 Train PCPs to use validated assessment tools and standards of diagnosis according to national guidelines. Incorporate assessments into Medicare annual “Wellness” visits and educate providers on Medicare reimbursement coding for family conferences and care planning meetings.^{13,14}
- 5.3 Train current and future public health professionals (such as health department staff, community health workers, nutritionists, social workers, epidemiologists, health educators, and researchers) on:
 - ▶ The best available evidence on brain health, ADRD, warning signs, diagnosis, caregiving, and the role of public health; and
 - ▶ Risk factors and ways to address them in other chronic disease prevention strategies.
- 5.4 Train non-medical professionals (such as administrative staff of medical offices, non-medical staff in facilities and hospitals, community support organizations, long-term care employees, and state agencies) on the types of dementia, their unique symptoms, community resources, and how to respectfully interact with people when noticing symptoms.
- 5.5 Increase awareness of, and support for certification, licensure, and degree programs that encourage working with older adults and ADRD populations.

Priority Area 6: Early Detection and Diagnosis

Early and accurate ADRD diagnosis helps patients and their families:

- Understand cognitive changes and how they may evolve over time;
- Learn about available and emerging treatment options; and
- Access clinical trials.

With an early diagnosis, patients can participate in planning their own future alongside their families. This includes making decisions about their own medical,

¹³ United States Centers for Medicare and Medicaid Services. Yearly wellness visits. Medicare.gov website. <https://www.medicare.gov/coverage/yearly-wellness-visits>. Accessed January 18, 2024.

¹⁴ Alzheimer’s Association. Cognitive assessment and care planning services: Alzheimer’s Association expert task force recommendations and tools for implementation. <https://www.alz.org/careplanning/downloads/cms-consensus.pdf>, 2018.

legal, financial, and long-term care. Because neurologists and other specialists can be difficult to find and may involve long wait times for an appointment, PCPs should feel empowered make a dementia diagnosis, work with specialists, and provide person-centered care over the course of the disease. The following strategies primarily impact medical professionals, including PCPs.

Strategies

- 6.1 Evaluate cognitive symptoms early using nationally validated standards of diagnosis with family input.
- 6.2 Have direct and supportive conversations with people with ADRD and their families to help them know what to expect over time and maintain quality of life as long as possible.
- 6.3 Discuss and create detailed care plans with family caregivers at the time of diagnosis. Care plans address caregiver concerns over time by addressing information on the diagnosis, treatment options, community resources, when to visit the doctor, and coordination of care with other providers.
- 6.4 At the point of diagnosis, discuss with the family issues of personal safety before a wandering incident occurs. This includes explaining the DPS Silver Alert program and providing information on ADRD medical identification options that ensure first responders have immediate access to the patient's medical details.

Priority Area 7: Quality Care and Support

When medical professionals and related service providers understand best practices for diagnosis, treatment, and care management over time, they can better provide person-centered, quality health care. Quality care and support includes addressing cognitive, behavioral, and psychological symptoms, including family caregivers, and considering the needs of different populations. The following strategies are primarily directed towards medical institutions and professionals, including PCPs.

Strategies

- 7.1 Monitor and manage changes in symptoms together with family and caregivers. Use best practices that prioritize quality of life, create safe environments, and support social engagement.

- 7.2 Incorporate non-pharmacologic and pharmacologic treatment options and interventions as appropriate. Ensure appropriate diagnosis when using pharmacological interventions to avoid situations like unnecessary use of antipsychotic medications.
- 7.3 Adopt and promote the use of the [Alzheimer’s Association’s Dementia Care Practice Recommendations](#), and modify inpatient medical and behavioral health services guidelines to ensure they address people with ADRD.¹⁵

Priority Area 8: Family Dementia Caregiving

Family caregivers, as well as friends and neighbors, are often referred to as unpaid or informal dementia caregivers.¹⁶ They are a vital part of helping people living with ADRD live life well and receive quality care over time. Most people with ADRD can live in their homes with family care during the early to middle stages of disease progression. The needs of family caregivers change over time and can include financial support, respite, and psychological and emotional support. Medical professionals can help caregivers understand their role in providing care, what support and resources are available to them, and the importance of maintaining their own health and well-being.

Strategies

- 8.1 Include families in all aspects of care planning. Address the needs of family caregivers over time.
- 8.2 Encourage family members to connect with other people living with ADRD and their families to share experiences and navigate services.
- 8.3 Support the needs of long-distance family caregivers, younger caregivers, and caregivers for people with early onset dementia.
- 8.4 Encourage hospitals to use care models that include family caregiving in discharge planning with specific discharge instructions to the family.

¹⁵ Dementia care practice recommendations. Alzheimer’s Association website.

https://www.alz.org/professionals/professional-providers/dementia_care_practice_recommendations. Accessed January 18, 2024.

¹⁶ The term family caregiver includes all types of unpaid caregivers regardless of their relation to the patient.

- 8.5 Encourage employers to adopt recommendations for family caregivers from national reports such as the [National Academy of Medicine’s Families Caring for an Aging America](#).¹⁷

Priority Area 9: Surveillance and Evaluation

Surveillance and evaluation help public health programs focus on populations most in need, ensure that interventions are based on the best available evidence, and inform program improvements. There are barriers to collecting population based ADRD data at both the national and state levels. Some of these barriers include underreporting on death certificates, misclassification in diagnosis, and methodological differences when reporting statistics. The following strategies primarily impact DSHS and academic institutions.

Strategies

- 9.1 Collaborate with relevant groups to evaluate surveillance systems to identify ongoing data needs, surveillance gaps, common data elements, uniform collection methods, and reporting formats for ADRD priorities.
- 9.2 Use the cognitive assessment that is part of Medicare annual “Wellness” visits to develop better statewide prevalence data on cognitive impairment.
- 9.3 Incorporate evaluation and sustainability into caregiving support programs.

Priority Area 10: Research Advances

Ongoing research and research collaboration on ADRD are vital components to finding cures and discovering ways to reduce risk and prevent dementia. Emerging treatment options for early-stage Alzheimer’s disease are examples of new possibilities. To be successful, clinical trials should be more accessible and include a variety of populations. Additionally, research that focuses on family caregivers is critical to understanding the resources needed to provide care and the impact of caregiving on health and well-being. Clinical and non-clinical research outcome information helps the community understand emerging trends, ways to improve disease management and treatment options, and how to best use education and community-based services.

¹⁷ National Academies of Sciences, Engineering, and Medicine. Families caring for an aging America. Washington, DC: The National Academies Press. 2016. https://www.johnhartford.org/images/uploads/reports/Family_Caregiving_Report_National_Academy_of_Medicine_IOM.pdf. Accessed January 30, 2024.

Strategies

- 10.1 Sustain and support ongoing coordinated research for ADRD and increase the number of Alzheimer’s Disease Research Centers in Texas.¹⁸
- 10.2 Focus clinical and non-clinical research on the 10 priority areas.
- 10.3 Promote and improve access to active research studies for a variety of populations through PCP education and community outreach.

¹⁸ The National Institute on Aging funds [Alzheimer's Disease Research Centers](#) (ADRC) at major medical institutions across the United States. Researchers at these centers are working to translate research advances into improved diagnosis and care for people with ADRD, as well as to find ways to treat and possibly prevent these diseases. The ADRC in Texas is the [Biggs Institute for Alzheimer’s and Neurodegenerative Diseases at UT Health San Antonio](#).

Conclusion

The 2024-2028 state plan provides priority areas and strategies regarding education on and treatment of ADRD. Developed with stakeholder input, the 2024-2028 state plan builds on the 2019-2023 state plan. It describes a public health approach to address these conditions.

The collective action of many partners can help address the challenges of daily living with ADRD as well as the cost and burden on family caregivers. The 2024-2028 state plan serves as a resource for stakeholders in determining the role and direction of their organizations as part of a coordinated effort to ensure the health and well-being of all Texans.