

# Texas Council on Alzheimer's Disease and Related Disorders Biennial Report 2024

As Required by Texas Health and Safety Code, Section 101.010

September 2024

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## **Executive Summary**

The Texas Council on Alzheimer's Disease and Related Disorders (TCADRD) developed the following report in compliance with <u>Texas Health and Safety Code</u>, <u>Section 101.010</u>. The report is due before September 1 of each even-numbered year to the Governor, Lieutenant Governor, the Speaker of the House of Representatives, and members of the Legislature. The report documents TCADRD activities during fiscal years 2023 and 2024, as well as its recommended actions for fiscal years 2025 and 2026.

TCADRD conducted the following highlighted activities during fiscal years 2023 and 2024:

- Elected a vice chair;
- Developed this biennial report;
- Established a subcommittee to identify future activities; and
- Drafted an issue brief on Alzheimer's disease (Alzheimer's) and social isolation.

In March 2024, TCADRD identified the following recommendations for fiscal years 2025 and 2026:

- Support ongoing coordinated Alzheimer's research, including research into improving the lives of persons with Alzheimer's and other dementias, specifically historically disadvantaged communities, as well as the lives of families and caregivers of persons with Alzheimer's and other dementias.
- Continue support for quality care for persons with Alzheimer's and related dementias and their caregivers.
- Engage in strategic collaborations.
- Expand local caregiver services and supports.

## Introduction

<u>Texas Health and Safety Code, Section 101.010</u>, requires TCADRD to submit a report on its activities and recommendations to the Governor, Lieutenant Governor, Speaker of the House of Representatives, and members of the Legislature by September 1 of each even-numbered year.

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.<sup>1</sup>

For more information on the signs and symptoms of Alzheimer's, go to <u>alz.org/alzheimers-dementia/10 signs</u>. For information on related dementias, go to

<sup>&</sup>lt;sup>1</sup> 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.

<u>nia.nih.gov/health/alzheimers-and-dementia/what-dementia-symptoms-types-and-diagnosis</u>.

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.<sup>2</sup> 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. 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, prevent, and cure Alzheimer's are imperative. As methodologies are refined,

<sup>&</sup>lt;sup>2</sup> Ibid.

<sup>&</sup>lt;sup>3</sup> Ibid.

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 is made. Drug development to block the progression of symptoms and 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.

## **Council Activities**

Texas Health and Safety Code, Section 101.007, requires TCADRD to:

- Advise the Texas Department of State Health Services (DSHS) and recommend needed action for the benefit of persons with Alzheimer's and related disorders and for their caregivers;
- Coordinate public and private family support networking systems for primary family caregivers;
- Disseminate information on services and related activities for persons with Alzheimer's and related disorders to the medical and health care community, the academic community, primary family caregivers, advocacy associations, and the public;
- Coordinate a volunteer assistance program primarily for in-home and respite care services;
- Encourage research to benefit persons with Alzheimer's and related disorders;
- Recommend to DSHS disbursement of grants and funds available for the Council; and
- Facilitate coordination of state agency services and activities relating to persons with Alzheimer's and related disorders.

TCADRD has 15 members, including 12 voting members appointed by the Governor, Lieutenant Governor, and Speaker of the House of Representatives. The Health and Human Services Commission (HHSC) and DSHS also appoint three non-voting state agency members. For a list of members, see the <u>TCADRD online roster</u>.

Per statute, TCADRD meets twice per year. The <u>TCADRD webpage</u> details each meeting in fiscal years 2023 and 2024, including agendas and webcasts. TCADRD engaged in the following activities in fiscal years 2023 and 2024:

- Re-elected Dr. Eddie Patton, Jr., as Vice Chair.
- Established a subcommittee to develop the 2024 biennial report.

  Subcommittee members gave input and met to consolidate recommendations and feedback from other members before submitting for member review.

- Established an activities subcommittee to discuss possible TCADRD activities for member review.
- Drafted an issue brief on Alzheimer's and social isolation to be published in fall 2024.
- Received scientific updates from the <u>Texas Alzheimer's Research and Care Consortium</u> (a collaboration among 11 of the state's leading medical research institutions working to improve early diagnosis, treatment, and prevention of Alzheimer's).

## **Council Recommendations**

TCADRD submits the following recommendations for fiscal years 2025 and 2026.

**Recommendation 1:** Support ongoing coordinated Alzheimer's research, including research into improving the lives of persons with Alzheimer's and other dementias, specifically historically disadvantaged communities, as well as the lives of families and caregivers of persons with Alzheimer's and other dementias.

- Continue recognition and support of coordinated statewide research. Financially support the recruitment of expertise in research and clinicians from all over the world to Texas institutions.
- Support research on Alzheimer's and other types of dementia, both basic science, clinical, public health, and health systems research, focusing on:
  - Early detection and prevention;
  - ▶ Differentiation between Alzheimer's and other dementias:
  - Identification of all contributing and modifiable risk factors underlying each patient's dementia including diet, physical activity, and social implications (such as loneliness);
  - Understanding the biological and environmental factors that contribute to cognitive dysfunction;
  - Treatment, care, and support for persons living with dementia; and
  - ▶ The well-being and support of caregivers for persons with dementia including physical health, mental health, and financial impact.
- Support the incorporation of the Cognitive Decline and the Caregivers
   Modules in the annual <u>Texas Behavioral Risk Factor Surveillance System</u>
   (BRFSS).<sup>5</sup>

<sup>4</sup> Agency for Healthcare Research and Quality. Health systems research. Agency for Healthcare Research and Quality website.

https://www.ahrq.gov/healthsystemsresearch/index.html. Accessed June 26, 2024.

<sup>&</sup>lt;sup>5</sup> The Texas BRFSS is a monthly telephone survey of randomly selected adult Texans 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

- Support efforts to bring to Texas additional National Institute on Agingfunded Alzheimer's Disease Research Centers, and other similar national organizations.
- Promote a statewide brain banking system that reflects the demographic diversity of Texas and includes participation from minority populations.<sup>6</sup>
- Explore ways to highlight information and links to resources listing clinical trial opportunities for physicians, medical researchers, and patients.
- Continue to provide continuing education through specially trained healthcare providers.

**Recommendation 2:** Continue support for quality care for persons with Alzheimer's and related dementias and their caregivers.

- Promote interdisciplinary education of health professionals, first responders, and other essential personnel on how to interact with persons with dementia, management of behaviors (anxiety, aggression, wandering, etc.) through behavior modification, environmental modifications, medication use, and promoting the concepts of dementia friendly communities.<sup>7</sup>
  - ▶ Work with city and county officials to promote the concept of dementia friendly cities and communities.
  - ▶ Support programs that center on education of police, first responders, and other essential personnel on how to help persons with dementia.
- Support the development of quality care tailored to the needs of persons with dementia and the inclusion of family caregivers in decision making.
   Recognize and accommodate the needs of diverse populations, including the effects of culture, language, and socioeconomic background.

includes questions about caregiving status, care recipients' health issues, and prospects for future caregiving needs.

<sup>&</sup>lt;sup>6</sup> Brain banking refers to the collection and storage of brains donated after death for research. Brain donation provides an opportunity to help researchers learn more about how types of dementia affect the brain and how to better treat and prevent them.

<sup>&</sup>lt;sup>7</sup> Dementia friendly communities increase understanding of dementia and reduce stigma by empowering, supporting, and including people living with dementia and their family caregivers within all areas of their communities.

- Promote the most recent <u>Alzheimer's Association's Dementia Care Practice</u>
   <u>Recommendations</u> for quality care practices based on current evidence, best practices, and input from subject matter experts.
- Support DSHS activities regarding awareness and education campaigns for physicians and caregivers on early detection and diagnosis, caregiver wellbeing, and caregiver support as funded by:
  - ▶ The five-year funding opportunity through the Centers for Disease Control and Prevention (CDC), "Building Our Largest Dementia Public Health Programs to Address Alzheimer's Disease and Related Dementias," also known as the BOLD grant; and
  - ▶ 2024-2025 General Appropriations Act, House Bill 1, 88th Legislature, Regular Session, 2023 (Rider 31).
- Continue recognition and support of ongoing enhancements to the DSHS website to include information for caregivers and health care providers.
- Include information about different types of dementia and their associated symptoms in required dementia training for staff in care facilities. Types of dementia and their distinguishing symptoms should include Alzheimer's, cerebrovascular disease, frontotemporal dementia, Lewy body disease, Parkinson's disease, and mixed dementia.

#### **Recommendation 3:** Engage in strategic collaborations.

- Encourage partnerships between state and county health professional organizations and other stakeholders to promote research and awareness campaigns with an emphasis on geographic areas with the greatest need.
- Promote the Alzheimer's Association and CDC <u>Healthy Brain Initiative, State</u>
   and Local <u>Public Health Partnerships to Address Dementia: The 2023-2027</u>
   <u>Road Map</u> to promote brain health as a vital component of public health, and to increase the number of Texans who recognize the direct impact physical health can have on cognitive health.
- Support and promote the revised Texas State Plan for Alzheimer's Disease 2024-2028 (state plan). <u>Texas Health and Safety Code</u>, <u>Section 99A.001</u>, directs DSHS to develop and implement a state plan for education on and treatment of Alzheimer's and other dementias. The state plan is reviewed and modified as necessary at least once every five years.

• Support DSHS collaboration on education, community clinical linkages, and caregiver supports as funded by the BOLD grant and Rider 31.

#### **Recommendation 4**: Expand local caregiver services and supports.

- Support DSHS and its role in providing support and resources for persons living with the disease, caregivers, and health care professionals through activities such as those funded by the BOLD grant, Rider 31, and other funding opportunities.
- Continue to enhance the DSHS website by making it more user-friendly with links and references to Alzheimer's state and community services.
- Ensure that services provided by Texas Health and Human Services agencies are directed to and evaluated for underserved and diverse populations.

# Conclusion

TCADRD continues to dedicate time and effort to highlighting the needs of persons living with Alzheimer's and other dementias, their family caregivers, and related professionals.

TCADRD's recommendations for fiscal years 2025 and 2026 include supporting ongoing coordinated Alzheimer's research and quality care to improve the lives of persons with Alzheimer's and other dementias and their caregivers, engaging in strategic collaborations, and expanding local caregiver services and support.