



**Texas Council on
Alzheimer's Disease and
Related Disorders Biennial
Report 2022**

**As Required by
Texas Health and Safety Code, Section
101.010**

**Texas Council on Alzheimer's Disease
and Related Disorders
September 2022**

**Administrative Support Provided by
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Executive Summary

The Texas Council on Alzheimer's Disease and Related Disorders (Council) was established in 1987. [Texas Health and Safety Code, Section 101.010](#) requires the Council to submit to the Governor, Lieutenant Governor, Speaker of the House of Representatives, and members of the Legislature a biennial report of activities and recommendations.

This report documents the activities of the Council during fiscal years 2021-2022, as well as recommended actions for 2023-2024.

The following are highlights of the Council's activities during fiscal years 2021-2022.

- The Council elected Dr. Eddie L. Patton, Jr., as Council Vice Chair.
- The Council Chair, Dr. Marc Diamond, appointed Dr. Vaunette Fay, Dr. Sudha Seshadri, Dr. Eddie L. Patton, Jr., and himself to a four-person workgroup for the *2022 Texas Council on Alzheimer's Disease and Related Disorders Biennial Report* (2022 biennial report) to be convened by the Department of State Health Services (DSHS).
- Workgroup members provided input for the 2022 biennial report via individual email. DSHS convened the four-person 2022 biennial report workgroup to condense duplicate recommendations and consolidate member input to send to the Council for review.
- The Council Chair appointed Dr. Eddie L. Patton, Jr., Mr. Byron Cordes, Dr. Sudha Seshadri, and Mr. Michael Gayle to a four-person standing workgroup to discuss possible Council activities.
- DSHS convened the activities workgroup multiple times to discuss possible activities and send ideas to the Council for review. The workgroup did not have a quorum of the Council at the meetings and did not vote on any matter.
- The Council voted to proceed with the development of an issue brief on the topic of dementia and social isolation and to explore possibilities for creating a video with information for persons with Alzheimer's disease (Alzheimer's) and their family caregivers.
- The Council discussed and made changes to the draft 2022 biennial report recommendations. DSHS staff provided administrative support to update the draft recommendations with Council input.

In March 2022, the Council identified the following recommendations for fiscal years 2023-2024.

- Support ongoing coordinated Alzheimer’s research, including research into improving the lives of persons with Alzheimer’s and other dementias as well as the lives of families and caregivers of those persons.
- 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.

1. Introduction

As directed by [Texas Health and Safety Code, Section 101.007](#), the Texas Council on Alzheimer's Disease and Related Disorders shall engage in the following activities:

- Advise the Department of State Health Services (DSHS) and recommend needed action for the benefit of persons with Alzheimer's disease 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 disease 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 disease 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 disease and related disorders.

As required by [Texas Health and Safety Code, Section 101.010](#), before September 1 of each even-numbered year, the Council shall submit a biennial report of the Council's activities and recommendations to the Governor, Lieutenant Governor, Speaker of the House of Representatives, and members of the Legislature.

This report outlines the activities of the Council in fiscal years 2021-2022 and their recommendations for fiscal years 2023-2024.

The 87th Texas Legislature removed the requirement in [Texas Health and Safety Code, Section 101.008](#) for the department to maintain a population data base of persons with Alzheimer's disease and related disorders in Texas.

2. Background

In 2022, an estimated 6.5 million Americans age 65 and older are living with Alzheimer’s disease.¹ In 2020, approximately 400,000 Texans age 65 and older were living with Alzheimer’s disease.¹ Recognizing this public health issue, the Texas Legislature established the Texas Council on Alzheimer’s Disease and Related Disorders. For additional information about the Alzheimer’s disease burden in Texas, see [Appendix A](#).

As directed by statute, the Council is composed of 15 members, including 12 voting members who are appointed by the Governor, Lieutenant Governor and Speaker of the House. Three non-voting members are appointed by the Health and Human Services Commission and the Department of State Health Services. For a list of Council members, see [Appendix B](#).

¹ Alzheimer’s Association. Alzheimer’s Disease Facts and Figures. <https://www.alz.org/media/Documents/alzheimers-facts-and-figures.pdf>. 2022. Accessed April 11, 2022.

3. Council Activities – Fiscal Years 2021-2022

The Council must meet at least twice each calendar year and at the call of the chairman. Due to COVID-19, the Council met virtually on October 12, 2020, and March 23, 2021, and used a hybrid meeting format with in-person webcasting and virtual participation on October 25, 2021, and March 23, 2022.

Council member appointments over the 2021-2022 biennium include:

- June 2020: Dr. Kelly Fegan-Bohm, Department of State Health Services (DSHS) representative
- February 2022: Mr. Joe A. Evans, Jr. (reappointed), and Dr. Eddie L. Patton, Jr. (reappointed)

The following describes Council activities in fiscal year 2021.

- The Council voted to elect Dr. Eddie Patton, Jr., as Council Vice Chair for one year.
- The Council Chair, Dr. Marc Diamond, appointed Dr. Vaunette Fay, Dr. Sudha Seshadri, Dr. Eddie L. Patton, Jr., and himself to a four-person workgroup for the *2022 Texas Council on Alzheimer's Disease and Related Disorders Biennial Report* (2022 biennial report) to be convened by the DSHS.
- Workgroup members provided input for the 2022 biennial report via individual email. DSHS convened the four-person 2022 biennial report workgroup via conference call on August 11, 2021, to condense duplicate recommendations and consolidate member input to send to the Council for review. The workgroup did not have a quorum of the Council and did not vote on any matter.
- The Council Chair appointed Dr. Eddie L. Patton, Jr., Mr. Byron Cordes, Dr. Sudha Seshadri, and Mr. Michael Gayle to a four-person standing workgroup to discuss possible Council activities.
- DSHS convened the activities workgroup on January 14, 2021, and September 3, 2021, to discuss possible activities and send ideas to the Council for review. The workgroup suggested the Council create an issue brief on the topic of dementia and social isolation and explore possibilities for creating a video with information for persons with Alzheimer's disease and

their family caregivers. The workgroup did not have a quorum of the Council at the meetings and did not vote on any matter.

The following describes Council activities in fiscal year 2022.

- The Council voted to elect Dr. Eddie Patton, Jr., as Council Vice Chair for one year.
- The Council voted to proceed with the development of an issue brief on the topic of dementia and social isolation.
- The Council voted to explore possibilities for creating a video with information for persons with Alzheimer's disease and their family caregivers.
- The Council discussed and made changes to the draft 2022 biennial report recommendations. DSHS staff provided administrative support to update the draft recommendations with Council input and emailed a draft of the recommendations to the Council on January 31, 2022, and the entire draft of the 2022 biennial report on March 9, 2022.
- DSHS convened the activities workgroup on March 18, 2022, to discuss the issue brief on the topic of dementia and social isolation and explore possibilities for creating an educational video. The workgroup will create an outline for the issue brief and begin researching and writing the brief. The workgroup will gather more information about the resources needed to produce the educational video. The workgroup did not have a quorum of the Council and did not vote on any matter.
- Dr. Marc Diamond, Council Chair, was unable to attend the March 23, 2022, Council meeting and designated Council member Dr. Kelly Fegan-Bohm to serve as the presiding officer. The Council voted on four recommendations for the 2022 biennial report.

4. Council Recommendations – Fiscal Years 2023-2024

The Council respectfully submits the following recommendations.

Recommendation 1: Support ongoing coordinated Alzheimer’s disease (Alzheimer’s) research, including research into improving the lives of persons with Alzheimer’s and other dementias 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.
- Support research on Alzheimer’s, both basic science research and clinical 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 diverse biological and environmental factors (including social determinants of health) that contribute to cognitive resilience and dysfunction;
 - ▶ Treatment, care, and support for persons living with dementia; and
 - ▶ Well-being and support of caregivers for persons with dementia including physical health, mental health, and financial impact.
- Support the incorporation of the Alzheimer’s optional modules in the annual Texas Behavioral Risk Factor Surveillance System. The two Alzheimer’s modules are the *Caregiver Optional Module* and the *Cognitive Decline Optional Module*.
- Support efforts to bring to Texas more National Institute on Aging-funded Alzheimer’s Disease Research Centers and other similar national organizations.

- Establish a statewide brain banking system that reflects the demographic diversity of Texas and includes participation from minority populations.²
- Explore ways to highlight information and links to resources listing clinical trial opportunities for physicians, patients, and medical researchers.

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 (e.g., anxiety, aggression, wandering, etc.) through behavior modification, environmental modifications, and medication use, and promoting dementia friendly concepts.
 - ▶ 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 deal with 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.
- Promote the [Alzheimer’s Association’s 2018 Dementia Care Practice Recommendations](#).³ The *Dementia Care Practice Recommendations* outline recommendations for quality care practices based on a comprehensive review of current evidence, best practices, and expert opinions.
- Promote the Alzheimer’s awareness campaign as funded (\$1 million) by the [2022-23 General Appropriations Act, Senate Bill 1, 87th Legislature, Regular Session, 2021](#).

² 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.

³ Fazio S, Pace D, Maslow K, Zimmerman S, Kallmyer B. Alzheimer’s Association Dementia Care Practice Recommendations. *The Gerontologist*. 2018;58(Supplement 1):S1–S9. <https://www.alz.org/media/Documents/alzheimers-dementia-care-practice-recommendations.pdf>.

- Continue recognition and support of ongoing enhancements to the DSHS website with information for caregivers and health care providers, such as the 2020-2021 biennium additions of
 - ▶ A flyer highlighting the connection between heart health and brain health,
 - ▶ A survey on the experiences of unpaid caregivers who provide care for someone with dementia in Texas, and
 - ▶ Materials from the Alzheimer’s awareness campaign to encourage starting a conversation after noticing signs of Alzheimer’s.

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 Centers for Disease Control and Prevention’s [*Healthy Brain Initiative, State and Local Public Health Partnerships to Address Dementia: The 2018-2023 Road Map*](#), 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 brain/cognitive health.⁴
- Support and promote the [*Texas State Plan for Alzheimer’s Disease 2019-2023*](#) (state plan).⁵ [*Texas Health and Safety Code, Section 99A.001*](#) directs DSHS to develop and implement a state plan for education on and treatment of Alzheimer’s and other dementias. The state plan will be reviewed and modified as necessary at least once every five years.
 - ▶ Increase funding for DSHS for implementation activities from the state plan.
- Invite local representatives to speak at Council meetings about how they are implementing the state plan.

⁴ Alzheimer’s Association and Centers for Disease Control and Prevention. *Healthy Brain Initiative, State and Local Public Health Partnerships to Address Dementia: The 2018-2023 Road Map*. Centers for Disease Control and Prevention. <https://www.cdc.gov/aging/pdf/2018-2023-Road-Map-508.pdf>. Published 2018.

⁵ Texas Department of State Health Services. *Texas State Plan for Alzheimer’s Disease 2019-2023*. Texas Department of State Health Services. <https://www.dshs.texas.gov/legislative/2019-Reports/Alzheimers-Disease-State-Plan-2019-2023.pdf>. Published September 2019.

Recommendation: 4: Expand local caregiver services and supports.

- Strengthen DSHS and its role in providing support and resources for persons living with the disease, caregivers, and health care professionals.
- 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.

5. Conclusion

The Council 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.

The Council’s recommendations for fiscal years 2023-2024 include supporting ongoing coordinated Alzheimer’s research, including research into improving the lives of persons with Alzheimer’s and other dementias as well as the lives of families and caregivers of persons with Alzheimer’s and other dementias. These recommendations also include continuing support for quality care for persons with Alzheimer’s and related dementias and their caregivers, engaging in strategic collaborations, and expanding local caregiver services and support.

List of Acronyms

Acronym	Full Name
DSHS	Department of State Health Services

Appendix A. Alzheimer's Disease – An Urgent National Health and Research Priority

The Burden of Alzheimer's Disease

Alzheimer's disease (Alzheimer's) is an age-related, progressive, and irreversible brain disease characterized by a steady decline in cognitive, behavioral, and physical abilities severe enough to interfere with daily life. 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 all their 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 prevention, treatment, or cure for Alzheimer's. Alzheimer's is thought to begin 20 years or more before symptoms develop.

In 2022, an estimated 6.5 million Americans age 65 and older are living with Alzheimer's disease.¹ In 2020, approximately 400,000 Texans age 65 and older were living with Alzheimer's.¹ In 2020, COVID-19 was the third-leading cause of death in the U.S.¹ This moved Alzheimer's from the sixth-leading cause of death to the seventh-leading cause of death for 2020 and 2021.¹ In 2022, the economic burden of caring for people with Alzheimer's and other dementias is projected to reach approximately \$321 billion.¹ In terms of absolute numbers, Texas ranks fourth in the nation in the number of Alzheimer's cases and second in the number of Alzheimer's deaths.¹ Approximately 4 million of the estimated 6.5 million people age 65 and older with Alzheimer's are women and approximately 2.5 million are men.¹ Women are also more likely to have other dementias.¹

In 2021, there were more than 11 million unpaid caregivers in the U.S., most of whom were family members.¹ In Texas, approximately 1.09 million unpaid caregivers provided care to Texans with Alzheimer's in 2021.¹ This equates to an estimated 1.77 billion hours of unpaid care at a cost of approximately \$25.9 billion per year.¹ 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 \$321 billion in 2022 to nearly \$1 trillion in 2050 (in 2022 dollars).¹

Texas data are highlighted here: [2022 Alzheimer's Disease Facts and Figures \(Texas\)](#).⁶

Progress Through Research and Advocacy

Research continues to expand our understanding of the causes of, treatments for, and prevention of Alzheimer’s.⁷ 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. This delay in progression helps contain costs associated with medical and long-term care, eases caregiver burden, and allows the individual with Alzheimer’s the opportunity to participate more fully in life and postpone inevitable dependency.

Public Health Challenge and Research Priority

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, 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

⁶ Alzheimer’s Association. Alzheimer’s Disease Facts and Figures - Texas. <https://www.alz.org/media/Documents/texas-alzheimers-facts-figures-2022.pdf>. 2022. Accessed April 11, 2022.

⁷ U.S. Department of Health and Human Services. National Plan to Address Alzheimer’s Disease: 2021 Update. <https://aspe.hhs.gov/sites/default/files/documents/66904c18bb1f0843c3c113d7099e98c1/napa-national-plan-2021-update.pdf>

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 must continue to advocate for community and home-based care and community supports for caregivers because these programs give caregivers the assistance they need to help care for their loved ones at home. Expediting statewide, coordinated action to address Alzheimer's in Texas remains critical as the prevalence of the disease continues to climb, exacting huge human and economic burdens on Texans and resources.

Appendix B. Texas Council on Alzheimer's Disease and Related Disorders Member Roster, 2021-2022

Byron Cordes, LCSW, C-ASWCM, CMC San Antonio	Laura DeFina, MD Dallas
Marc Diamond, MD, Chair Dallas	Joe A. Evans, Jr. Beaumont
Vaunette Fay, PhD Houston	Ana Guerrero Gore Galveston
Char Hu, PhD Austin	Eddie L. Patton, Jr., MD, Vice-Chair Sugar Land
Mary Ellen Quiceno, MD, FAAN, FANA Dallas	Sudha Seshadri, MD, DM San Antonio
Terrence Sommers Amarillo	Angela Turner Normangee
Kelly Fegan-Bohm, MD, MPH, MA Texas Department of State Health Services	Valerie J. Krueger Texas Health and Human Services Commission
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