



# ADRD

Alzheimer's Disease  
and Related Dementia

---

## ADVISORY COUNCIL REPORT



**STATE OF TENNESSEE  
COMMISSION ON AGING AND DISABILITY**

Andrew Jackson State Office Building  
502 Deaderick Street, 9<sup>th</sup> Floor  
Nashville, Tennessee 37243

James Dunn  
Executive Director

Phone (615) 741-2056  
Fax (615) 741-3309

January 15, 2022

The Honorable Rusty Crowe  
425 Rep. John Lewis Way N.  
Suite 720 Cordell Hull Bldg.  
Nashville, TN 37243

The Honorable Bryan Terry  
425 Rep. John Lewis Way N.  
Suite 646 Cordell Hull Bldg.  
Nashville, TN 37243

Dear Chairman Crowe and Chairman Terry:

Public Chapter 364 (2019) passed by the General Assembly created the Alzheimer's Disease and Related Dementia Advisory Council ("Council") and administratively attached the Council to the Tennessee Commission on Aging (TCAD). The purpose of the Council is to continually assess the current status of Alzheimer's disease and related dementia in the state and to assess the current and future impact of Alzheimer's disease and dementia on Tennessee residents.

The Act also requires an annual report be submitted to the General Assembly that "identifies barriers to Alzheimer's disease care, analyzes service utilization data, and includes recommendations, metrics, and best practices to address gaps in service."

Enclosed you will find a copy of this year's updated report, which accounts for Council actions throughout 2021 and proposes to carry over the Council's goals and recommendations from the previous report submitted in January 2021.

Thank you for your efforts on behalf of Tennessee's aging population.

Sincerely,

A handwritten signature in black ink that reads "James Dunn".

James Dunn  
Executive Director

## Table of Contents

<b>Executive Summary</b> .....	<b>2</b>
<b>Introduction</b> .....	<b>4</b>
<b>Council Members</b> .....	<b>5</b>
<b>Background</b> .....	<b>6</b>
2019 Needs Assessment .....	8
Virtual Townhalls .....	8
Online Survey – State Alzheimer’s Plan Update .....	8
<b>Goals and Recommendations</b> .....	<b>11</b>
<b>Next Steps Informative Document for Medical Providers</b> .....	<b>14</b>
<b>Bibliography</b> .....	<b>15</b>
<i>Appendix A</i> .....	<i>17</i>
<i>Appendix B</i> .....	<i>18</i>

## Executive Summary

In April 2019, the Tennessee General Assembly unanimously passed legislation creating the Alzheimer’s Disease and related Dementia Advisory Council (Chapter 364 of the Public Acts of 2019). The Governor signed the bill on May 10, 2019 (see Appendix A).

This Act established the Advisory Council, administratively attached it to the Tennessee Commission on Aging and Disability (TCAD), and set out the purpose of the council:

- 1) Continually assess the current status of Alzheimer’s disease and related dementia in this state and to assess the current and future impact of Alzheimer’s disease and dementia on Tennessee residents;
- 2) Examine the existing industries, services, and resources addressing the needs of persons, families, and caregivers affected by Alzheimer’s disease and related dementia;
- 3) Develop a strategy to mobilize a state response to matters regarding Alzheimer’s disease and related dementia; and
- 4) Provide recommendations to the governor and to the general assembly on issues related to its work.

Each year more than 3,500 Tennesseans die from Alzheimer’s Disease (12). In 2019, there were approximately 120,000 Tennesseans with Alzheimer’s Disease being cared for by 439,000 informal caregivers. These caregivers were providing approximately 500 million hours of unpaid care in Tennessee at a value of \$6.324 billion annually.

In 2020, there were approximately 444,000 informal caregivers providing approximately 506 million hours of unpaid care in Tennessee at a value of \$6.628 billion annually. These numbers will continue to rise each year as the number of Tennesseans with Alzheimer’s disease is expected to rise 16.7% between 2020 and 2025.

Through focus groups and a statewide online needs assessment, services and resources were one of the primary needs mentioned within the Alzheimer’s State Plan submitted in January 2020<sup>1</sup>. These needs included awareness, availability, and affordability of services and resources. Other findings included a need for workforce education and increased public awareness of the disease.

The Advisory Council was tasked to develop a strategy to mobilize a state response to matters regarding Alzheimer’s disease and related dementia. Through reviewing other states’ plans on Alzheimer’s Disease and related dementias, listening to testimony presented at the Advisory Council meetings, and analyzing data gathered during the needs assessment, the Advisory Council agreed upon four overarching goals for this strategy.

- Goal 1: Educate and Empower Tennessee to be “Dementia-Aware”
- Goal 2: Support and Empower Persons with Dementia and their Caregivers
- Goal 3: Ensure an adequately prepared workforce
- Goal 4: Research

---

<sup>1</sup><https://www.tn.gov/content/dam/tn/aging/documents/Alzheimer%27s%20and%20related%20dementia%20TN%20State%20Plan.pdf>

In 2020, the Council was extended by action of the Tennessee General Assembly for five years. The Council looks forward to continuing this important work and providing recommendations to the General Assembly on issues related to Alzheimer's and related dementias in the State of Tennessee. This report serves as an update to the Alzheimer's State Plan submitted in January 2021.

## Introduction

In April 2019, the Tennessee General Assembly unanimously passed legislation creating the Alzheimer's disease and related Dementia Advisory Council (Chapter 364 of the Public Acts of 2019). The Governor signed the bill on May 10, 2019 (see Appendix A).

This Act established the Advisory Council, administratively attached it to the Tennessee Commission on Aging and Disability (TCAD), and set out the purpose of the council:

- 1) Continually assess the current status of Alzheimer's disease and related dementia in this state and to assess the current and future impact of Alzheimer's disease and dementia on Tennessee residents;
- 2) Examine the existing industries, services, and resources addressing the needs of persons, families, and caregivers affected by Alzheimer's disease and related dementia;
- 3) Develop a strategy to mobilize a state response to matters regarding Alzheimer's disease and related dementia; and
- 4) Provide recommendations to the governor and to the general assembly on issues related to its work.

The Act requires the council to develop and submit an Alzheimer's Disease State Plan to the General Assembly by January 15, 2020 (which was completed) and update the plan and report to the General Assembly on its progress no later than January 15 of each subsequent year. This report to the General Assembly is to identify barriers to Alzheimer's disease care, analyze service utilization data, and include recommendations, metrics, and best practices to address gaps in service. As an ongoing entity, the Council looks forward to continuing this important work and providing recommendations to the Governor and the General Assembly on issues related to Alzheimer's and related dementias in the State of Tennessee. This report serves as an update to the Alzheimer's State Plan submitted in January 2021.

## **Council Members**

Pursuant to statute, certain departments and entities were to be represented on the Council. The following individuals make up the Council:

Senator Rusty Crowe

Representative Sabi Kumar

James Dunn, Tennessee Commission on Aging and Disability

Patti Killingsworth, TennCare

Alicia Robeson, Department of Mental Health & Substance Abuse Services

Sally Pitt, Tennessee Department of Health

Kirk Mason, CEO, Stones River Manor

Dr. Angela Jefferson, Vanderbilt University Medical Center

Janice Wade Whitehead, Alzheimer's Tennessee

Jesse Samples, Tennessee Health Care Association

Elizabeth Bradshaw Scott, Tennessee Nurses Association

Reverend Richard Brown, Payne Avenue Missionary Baptist Church

Dawne Bunn, Alzheimer's Association TN Chapter Executive Director

Gwyn Earl, LeadingAge TN Board of Directors

Laura Musgrave, family caregiver representative

Dr. David Compton, person living with Alzheimer's

## Background

### Alzheimer's and Related Dementias

Dementia is a specific type of degenerative brain disease that is irreversible and gets worse over time. There are various types of dementia; however, Alzheimer's Disease is the most common type of dementia, accounting for approximately 60 to 80 percent of all dementias (1 p. 9). Other dementing illnesses include Parkinson's disease with dementia, Lewy body disease, Frontotemporal dementia, vascular dementia, and a few other, rarer disorders. In older people, vascular disease is often mixed with Alzheimer's disease pathology, and it seems to lower the threshold for dementia to develop. Dementia results in the loss of cognitive functioning such as thinking, reasoning, and remembering. These symptoms of dementia begin when neurons or cells within the brain have been damaged or stop working. However, brain changes begin long before symptoms and may begin up to 20 years prior to symptoms (2; 3; 4; 5).

Although dementia is more common with age, it is not a normal part of aging. Scientists do not currently know exactly what causes a person to develop Alzheimer's disease and related dementia (ADRD) or how to prevent it. However, literature suggests that certain risk factors increase an individual's risk of developing the disease. For instance, some demographic groups such as older black / African Americans and Hispanics are more likely to develop dementia compared to their non-minority counterparts. (1) In addition, people with specific types of intellectual and developmental disabilities (IDD) such as Down Syndrome have a higher risk for Alzheimer's Disease and related dementia (7). Overall, the greatest known risk factor for developing ADRD is age; however, other factors may also increase one's risk of developing dementia. Some of these risk factors such as family history, or genetics are unable to be changed. However, other risk factors such as head injury, obesity, specific cardiovascular diseases (mid-life hypertension, prehypertension, high cholesterol), and diet may be risk factors which are modifiable or able to be changed.

Though research is still evolving, evidence is strong that people can reduce their risk of future dementias by making key lifestyle changes including regular physical exercise, eating a heart-healthy diet, maintaining strong social connections, and keeping mentally active. Finally, there appears to be a strong link between future risk of Alzheimer's and serious head trauma, especially when injury involves loss of consciousness. Therefore, reducing the risk of head injury may also be a strategy to reduce the risk of future dementias.

ADRD is diagnosed by medical professionals; however, this is not done using a single test. Instead, healthcare providers complete a medical assessment including medical history, physical exam, neurological exams, and other diagnostic tools (6).

There is currently no cure for ADRD and no proven way to stop the progression of the disease. However, there are both pharmacological and non-pharmacological treatments to help with symptoms associated with the disease. There are also services available to support family members and caregivers of persons with dementia. For the benefits to be realized, persons with dementia and their caregivers must be aware of these services and how to access them.

### Alzheimer's and related dementias in the United States

Today, an estimated 5.6 million Americans aged 65 and older are living with Alzheimer's disease. This number is expected to grow to as many as 14 million Americans by 2050 (1). These individuals are being cared for by more than 16 million informal caregivers. These caregivers provide approximately 18.5 billion hours of care each year, valued at nearly \$234 billion nationally. ADRD is a leading cause of



disability and the 6<sup>th</sup> leading cause of death (1; 7). Although the impact of this disease is vast, less than half (47 percent) of older adults have ever discussed their thinking or memory abilities with a health care provider. Only 28 percent report ever having received an assessment for cognitive health. And even fewer—16 percent—receive regular cognitive assessments during routine health checkups (1). While almost all older adults (93 percent) say they trust their doctor to recommend testing if needed, less than half of primary care physicians say it is their standard protocol to assess older adults for cognitive impairment. Instead, many physicians wait for patients or their family members to bring the topic up first (1). This issue is further complicated by the well-documented shortage of healthcare professionals specializing in geriatrics and other Alzheimer's related specialties.

Healthcare costs of both individuals living with dementia and their caregivers are significantly higher than their counterparts without dementia (1; 8; 9; 10; 11). In 2019, nationally the cost of caring for those with Alzheimer's and other dementias will total an estimated \$290 billion. The annual out-of-pocket spending incurred by dementia caregivers—including household and personal care expenses—is nearly twice as high as that incurred by caregivers of people with other conditions (1).

### Alzheimer's and Related Dementias in Tennessee

Across the US, Tennessee has the 2nd highest age-adjusted mortality rate from dementia (12). Each year more than 3,500 Tennesseans die from Alzheimer's Disease (12). In Tennessee, there are approximately 120,000 individuals with Alzheimer's Disease being cared for by 444,000 informal caregivers. These caregivers provided approximately 506 million hours of unpaid care in Tennessee at a value of \$6.628 billion annually. These numbers will continue to rise each year as the number of Tennesseans with Alzheimer's disease is expected to rise 16.7% between 2020 and 2025. (2; 14). Many adults in Tennessee report worsening or more frequent confusion or memory loss. This is often one of the earliest noticeable symptoms related to ADRD. In Tennessee, 14% of adults ages 45 and over have experienced these symptoms, yet, less than half of these individuals have talked about these symptoms with a health care provider (13). In addition, healthcare for persons living with dementia is costly to Tennessee's healthcare system through increased healthcare expenditures as well as out-of-pocket healthcare costs (14; 8). In addition, caregivers often have negative health consequences related to their caregiving roles, therefore, caregivers also have higher health care costs. These health care costs are valued at \$291 million in the state of Tennessee (1 p. 37). These health-related costs have increased over the past 5 years and are projected to continue rising for at least the next 5 years as this population continues to grow (1; 15).

## 2019 Needs Assessment

For the Alzheimer's and Related Dementia Advisory Council to gain an understanding of the strengths, challenges, and needs of persons living with dementia, their families, and other stakeholders, an initial needs assessment was conducted and used in the development of the Council's initial [Alzheimer's and Related Dementia State Plan](#). The goal of this needs assessment was to provide policy makers, service providers, and the general population with appropriate data about trends and implications for the current population. The Tennessee needs assessment was based upon similar needs assessments conducted in other states (16; 17). Similar to recent Alzheimer's State Plans in other states, the state needs assessment was based on a mixed-methods approach composed of three main components: (1) focus groups conducted by the Tennessee Department of Health in conjunction with the Tennessee State Health Plan; (2) an online statewide survey of older Tennesseans, advocates, persons with Alzheimer's Disease, Tennessee has the 2nd highest age-adjusted mortality rate from dementia 7 caregivers, and service providers; and (3) analyses of additional data including those presented at meetings of the Tennessee Alzheimer's and Related Dementia Advisory Council.

The Council recognized that future in-depth and representative needs assessment should be conducted, as needed, as the plan continues to evolve.

## Virtual Townhalls

In an effort to gather input from members of the community on the updated Alzheimer's State Plan, the Council hosted (5) five virtual town halls around the state.

- December 2, 2020 – Hosted by Senator Bo Watson
- December 4, 2020 – Hosted by Representative Ryan Williams
- December 7, 2020 – Hosted by Senator Rusty Crowe
- December 7, 2020 – Hosted by Senator Jack Johnson
- December 8, 2020 – Hosted by Senator Raumesh Akbari

During each virtual town hall, participants were encouraged to share comments via unmuting of lines and/or typing in the chat box. Issues mentioned included: increased need for education/information for both community members and providers; increased resources for providers; and increased need for technology. Specifically, participants were asked about any issues related to COVID-19. Participants stated the pandemic has made caring for those with Alzheimer's and dementia very difficult. For example, caregivers are choosing to bring loved one's home, but it can be a challenge to find in-home care providers. Additionally, families are having to provide care themselves while juggling other priorities (ex: kids who are out of school). Some are choosing to put in-home services on hold for fear of contracting COVID-19. Providers are also worried about contracting COVID-19 from providing in-home services. Recommendations provided will be discussed at the next Council meeting and incorporated into the State Alzheimer's Plan.

## Online Survey – State Alzheimer's Plan Update

Additionally, the State Alzheimer's Advisory Council sought public input on Tennessee's plan to address Alzheimer's Disease through an online survey. This online survey was designed to reach a broad segment of Tennessee's population. Specifically, it aimed to include individuals unable to attend virtual Council

meetings or virtual town halls due to caregiving or professional responsibilities. The survey was distributed using both purposive and convenience sampling. Survey respondents were recruited through Council members, Tennessee's Aging Network, professional organizations, support groups, partners, and social media. Surveys were made available via an online link. Respondents were asked to choose the top (3) three priorities under each goal.

During November and December of 2020, an electronic survey was distributed to gather input for the updated Alzheimer's Disease State Plan. Survey participants were asked to choose 3 short-term strategies from each Goal defined by the Advisory Council in the TN Alzheimer's State Plan. Overall, 60 individuals responded to this survey. Of these 60 respondents, 15 were caregivers, 30 were not caregivers, and 11 reported falling into "other" category, most previously caregivers who were not doing so currently.

Within Goal 1 Educate and Empower Tennessee to be "Dementia-Aware" the 3 items most frequently suggested for short-term strategies include:

- Develop a communication strategy to increase awareness, reduce stigma, and increase public understanding of Alzheimer's and other dementias
- Encourage incorporation of brain health, ADRD, and caregivers' needs into plans of state and local government, health and social service organizations, research and educational institutions, businesses and faith communities
- Using culturally appropriate communications, educate Tennesseans and raise awareness about brain health, potential risk reduction strategies, early warning signs, changes to discuss with a health professional, and benefits of early diagnosis of ADRD and mild cognitive impairment

Within Goal 2 Support and Empower Persons with Dementia and their Caregivers, the 3 items most frequently suggested for short-term strategies include:

- Increase access to home and community-based services, including adult day care and respite services, and ensure that those with Alzheimer's and other dementias have access to these services regardless of age, financial status, stage of cognitive impairment.
- Create "one stop shop" or easy to find place for Tennesseans to find information on services available across the State
- Conduct assessment to identify gaps in and barriers to services available in Tennessee including but not limited to those associated with costs

Within Goal 3 Ensure an adequately prepared workforce. the 3 items most frequently suggested for short-term strategies include:

- Educate healthcare professionals on dementia treatment best practices (e.g., behavioral symptom management), including risk/benefit ratio of antipsychotic drug use, "black box" labeled medications, and other medications contraindicated in persons living with dementia Educate healthcare professionals on information related to caregivers, including health risks, available tools and information, and supportive programs and services
- Foster continuing education to improve healthcare professionals' ability and willingness to support early diagnoses and disclosure of dementia, provide effective care planning at all stages

of dementia, offer counseling and referral, and engage caregivers, as appropriate, in care management

- Educate healthcare professionals across sectors about recognizing early signs and symptoms of ADRD among demographic groups (age, gender, socioeconomic status, IDD, etc.) with increased risk of dementia

Within Goal 4 Research, Monitor, and Evaluate. the 3 items most frequently suggested for short-term strategies include:

- Ensure Tennesseans are aware of opportunities and benefits of participation in research studies, clinical trials, and tissue donation procedures
- Identify health disparities in those with dementia in Tennessee through state and local needs assessments (geographic, socioeconomic, racial/ethnic, gender, LGBT older adults, IDD, etc.)
- Identify strategies to increase enrollment of diverse populations to participate in research

## **Goals and Recommendations**

The Council's update report aims to set short-term goals which could be achieved within a 1-2-year time period. These recommendations aim to positively impact a broad range of stakeholders including persons living with dementia, families and caregivers, healthcare providers, policy makers, government agencies, and others. These recommendations and strategies will be achieved through collaborative efforts between not-for-profit organizations, private entities, government agencies, persons with dementia, caregivers, and other stakeholders across the State. Furthermore, the enacting legislation states that the purpose of the Alzheimer's disease and related dementia advisory council is to "(1) Continually assess the current status of Alzheimer's disease and related dementia in this state and to assess the current and future impact of Alzheimer's disease and dementia on Tennessee residents." Therefore, these needs, goals, and recommendations will be continuously reviewed and updated as needed to ensure the highest possible quality of life for Tennesseans with dementia, along with their families and caregivers.

## **Goal 1: Educate and Empower Tennessee to be “Dementia-Aware”**

### *Rationale*

Public awareness of dementia is a challenge in our State. The public is often unaware of the potentially modifiable risk factors that may contribute to the development of dementia. Lack of awareness and understanding of ADRD can create barriers to diagnosis/care and impact families physically, mentally, and financially. Furthermore, lack of awareness and education can increase stigma surrounding dementia and create a more challenging environment for persons with dementia and their caregivers (18; 19; 20) Therefore, education and outreach can promote risk-reduction strategies, increase the likelihood of early diagnosis, and improve quality of life for Tennesseans living with dementia and their caregivers.

### *Recommendations for 2021/2022*

1. Continue meeting, at least quarterly, as the Alzheimer’s and Related Dementia Advisory Council
2. Regularly update and disseminate the Alzheimer’s and Related Dementia State Plan
3. Develop a communication strategy to increase public understanding of Alzheimer’s and other dementias
4. Using culturally appropriate communications, educate Tennesseans and raise awareness about brain health, potential risk reduction strategies, early warning signs, changes to discuss with a health professional, and benefits of early diagnosis.
5. Increase awareness and emphasize the importance of caregivers’ health and wellbeing in as they fulfill the crucial role of supporting individuals living with ADRD
6. Develop resource guides for caregivers, health care professionals, family members of those living with Alzheimer’s disease, and the aging networks
7. Promote education about, and greater use of, care planning and related tools for individuals with ADRD.

## **Goal 2: Support and Empower Persons with Dementia and their Caregivers**

### *Rationale*

There are an estimated 120,000 Tennesseans living with dementia and 444,000 caregivers for Tennesseans living with dementia, resulting in economic, social, and health impacts statewide (2; 14). Results from needs assessment and testimony provided during the advisory council hearing suggest that the current infrastructure is inadequate to support this growing population. However, empowering and supporting persons with dementia and their caregivers, can improve the lives of both Tennesseans with dementia and their caregivers (21).

### *Recommendations for 2021/2022*

1. Provide support and education for dementia caregivers in navigating services
2. Educate Tennesseans and caregivers of those at increased risk of dementia on communicating this concern with health care providers
3. Increase availability, visibility, and referral to support groups and peer-driven support for individuals living with mild cognitive impairment and early forms of ADRD

### **Goal 3: Ensure an adequately prepared workforce**

#### *Rationale*

The number of Tennesseans living with dementia continues to grow. When asked where they would seek out information related to care and resources available for ADRD, 2019 Needs Assessment survey respondents frequently stated they would reach out to a healthcare provider first. However, the respondents were not satisfied with the training of providers and 38% rated this as a pressing ADRD-related need for our State. At taskforce meetings, workforce issues were frequently mentioned as a barrier to care and growing need for our State. Therefore, there must be an adequately prepared and dementia-capable workforce, including healthcare workers, allied professionals, administrators, nurses, social workers, clergy, first responders, and others for our State.

#### *Recommendations*

1. Foster continuing education to improve healthcare professionals' ability and willingness to support early diagnoses and disclosure of dementia, provide effective care planning at all stages of dementia, offer counseling and referral, and engage caregivers, as appropriate, in care management.

### **Goal 4: Research, Monitor, and Evaluate**

#### *Rationale*

There is currently no cure for ADRD and no proven way to stop the progression of the disease. Through increased understanding of ADRD (brain health, prevention, care, and treatments), the Council is committed to the long-term goal of seeing Tennessee one day become a State in which ADRD can be successfully prevented, treated, and/or cured.

#### *Recommendations*

### **Additional strategy related to COVID-19**

#### *Rationale*

COVID-19 has impacted everyone, but it has especially affected older adults. Age increases risk for severe illness, hospitalization, and even death from COVID-19. In fact, 8 out of 10 deaths associated with COVID-19 in the U.S. have been among adults 65 or older (22). Some people living with dementia might be at an even higher risk of infection or severe illness because of their age and/or other underlying medical conditions. For this reason, it has been especially important for older adults and their caregivers to follow CDC guidelines including social distancing, mask wearing, etc (22). Caregivers of those living with ADRD are further impacted by the pandemic due to increased social isolation, stress, and limited access to outside support (adult day, respite, etc) (23). With the understanding that the impacts of COVID-19 on those living with dementia and their caregivers are wide-ranging, the Council proposed this additional strategy.

- Explore and address how those living with Alzheimer's and related dementia and their caregivers are affected by the COVID-19 pandemic including environmental/social/economic changes caused by the pandemic such as limited outside support, social isolation, etc.

The Council will explore and address:

- Effects of COVID-19 pandemic on persons living with dementia and their caregivers
- Long-term COVID-19 complications for persons living with dementia.  
Long-term implications on dementia related risk factors (exercise, diet, chronic condition management, cardiovascular health, etc).

## **Next Steps Document for Medical Providers**

Several members of the Council identified a lack of resources available for Tennesseans newly diagnosed with Alzheimer’s disease or a related dementia. This resulted in the development of a handout that will be electronically distributed to medical providers across the state for ease of use. This handout includes resources for Tennesseans who receive a diagnosis for Alzheimer’s disease or a related dementia. The document will be presented to the Tennessee Board of Medical Examiners early 2022. To view the document, see Appendix B.



## Bibliography

1. **Centers for Disease Control and Prevention. National Center for Health Statistics.** *Alzheimer's Disease Mortality by State*. s.l. : U.S. Department of Health and Human Services, 2019.
2. *2019 Alzheimer's Disease Facts and Figures*. **Alzheimer's Association**. 3, 2019, *Alzheimers and Dementia*, Vol. 15, pp. 321-87.
3. *Clinical and Biomarker Changes in Dominantly Inherited Alzheimer's Disease*. **Xiong, Chengjie, et al.** 2012, *NEJM*, Vol. 367, pp. 795-804.
4. *Spatial patterns of neuroimaging biomarker change in individuals from families with autosomal dominant Alzheimer's disease: a longitudinal study*. **Gordon, BA, et al.** *Lancet Neurology*, pp. 241-250.
5. *Stages of the pathologic process in Alzheimer disease: age categories from 1 to 100 years*. **Braak, H, et al.** 11, Nov 2011, *Journal of Neuropathology and Experimental Neurology*, Vol. 70, pp. 960-969.
6. *Amyloid  $\beta$  deposition, neurodegeneration, and cognitive decline in sporadic Alzheimer's disease: a prospective cohort study*. **Villemagne, VL, et al.** 4, April 2013, *Lancet Neurology*, Vol. 12, pp. 357-67.
7. **Office of the Assistant Secretary for Planning and Evaluation (ASPE).** *IDD and Dementia. US Department of Health and Human Services*. [Online] July 1, 2015. <https://aspe.hhs.gov/report/idd-and-dementia>.
8. **National Institute on Aging.** *Basics of Alzheimer's Disease and Dementia*. [Online] United States Health and Human Services. National Institute on Health. National Institute on Aging, 31 December, 2017. <https://www.nia.nih.gov/health/what-dementia-symptoms-types-and-diagnosis>.
9. *Deaths: Final Data for 2017*. **Centers for Disease Control and Prevention. National Center for Health Statistics, Division of Vital Statistics**. 9, Atlanta : United States Department of Health and Human Services, June 24, 2019, *National Vital Statistics Reports*, Vol. 68.
10. *Risk Factors and Hospitalization Costs of Dementia Patients: Examining Race and Gender Variations*. **Husaini, Baqar, et al.** 4, Oct-Dec 2015, *Indian Journal of Community Medicine*, Vol. 40, pp. 258-263.
11. *The incremental direct costs associated with behavioral symptoms in AD*. **Murman, DL, et al.** 11, Dec 10, 2002, *Neurology*, Vol. 58, pp. 1721-9.
12. **Alzheimer's Association.** *2016 Alzheimer's Disease Facts and Figures. Special Report: The Personal Financial Impact of Alzheimer's Disease on Families*. 2016.
13. **Rainville, Chuck, Skufca, Laura and Mehegan, Laura.** *Family Caregiving and Out-of-Pocket Costs: 2016 Report*. Washington, CD : s.n., 2016.
14. *Alzheimer's Disease Facts and Figures*. **Alzheimer's Association**. 2020.
15. **Centers for Disease Control and Prevention Division of Population Health, National Center for Chronic Disease Prevention and Health Promotion.** *Subjective Cognitive Decline — A Public Health Issue*. 2019.
16. **Centers for Medicaid and Medicare Services.** *Chronic Conditions Utilization/Spending State Level: All Beneficiaries, 2017* . *Chronic Conditions*. [Online] November 27, 2019.

17. **Alzheimer's Association.** *The Impact of Alzheimer's Disease on Medicaid Costs: A Growing Burden for States.* 2015.
18. *A Systematic Review of Dementia-related Stigma Research: Can We Move the Stigma Dial?*  
**Hermann, LK, et al.** 3, March 2018, *American Journal of Geriatric Psychiatry*, Vol. 26, pp. 316-331.
19. *'The stigma attached isn't true of real life': Challenging public perception of dementia through a participatory approach involving people with dementia.* **Reynolds, L, et al.** 2, London : s.n., February 2017, *Dementia*, Vol. 16, pp. 219-226.
20. **Alzheimer's Society.** *Dementia, Out of the Shadows.* London : Alzheimer's Society, 2008.
21. *Translating Evidence-Based Dementia Caregiving Interventions into Practice: State-of-the-Science and Next Steps . 2,* 2015 WHCoA, *The Gerontologist*, Vol. 55, pp. 210-226.
22. **Centers for Disease Control and Prevention.** COVID-19: Older Adults. [Online] December 12, 2020. <https://www.cdc.gov/coronavirus/2019-ncov/need-extra-precautions/older-adults.html>.
23. —. **Caregivers of People Living with Dementia.** [Online] September 11, 2020. <https://www.cdc.gov/coronavirus/2019-ncov/need-extra-precautions/caregivers-dementia.html>.

# Appendix A



# State of Tennessee

## PUBLIC CHAPTER NO. 364

### SENATE BILL NO. 28

By Crowe, Robinson, Kyle, Johnson, Reeves, Dickerson, Bowling, Massey, White, Jackson, Haile, Hensley, Swann, Watson, Yarbrow, Akbari, Roberts; Mr. Speaker McNally; Rose

Substituted for: House Bill No. 37

By Whitson; Mr. Speaker Casada; Hawk, Love, Hazlewood, Helton, Carter, Gant, Weaver, Beck, Hicks, Matthew Hill, Howell, Gloria Johnson, Ogles, Jernigan, Zachary, Dixie, Lamberth, Clemmons, Cooper, Sherrell, Hall, Byrd, Van Huss, Moon, Calfee, Lafferty, Freeman, Terry, Cepicky, Haston, Keisling, Littleton, Miller, Windle, Holsclaw, Ragan, Boyd, Camper, Marsh, Powell, Chism, Powers, Smith, Garrett, Shaw, Hodges, White, Faison, Hakeem, Bricken, Lamar, Hardaway, Cochran, Sanderson, Crawford, Doggett, Timothy Hill, Moody, Kumar, Hurt, Travis, Daniel, Towns, Williams, Coley, Parkinson, Thompson

AN ACT to amend Tennessee Code Annotated, Title 4; Title 68, Chapter 11, Part 14 and Title 71, relative to the creation of the state Alzheimer's disease and related dementia advisory council.

BE IT ENACTED BY THE GENERAL ASSEMBLY OF THE STATE OF TENNESSEE:

SECTION 1. Tennessee Code Annotated, Section 4-29-242(a), is amended by inserting the following as a new subdivision:

( ) State Alzheimer's disease and related dementia advisory council, created by § 71-2-117;

SECTION 2. Tennessee Code Annotated, Title 71, Chapter 2, Part 1, is amended by adding the following as a new section:

#### 71-2-117.

(a) As used in this section:

(1) "Alzheimer's disease" means a progressive degenerative disease of the brain that leads to dementia, and is characterized by the finding of unusual helical protein filaments in nerve cells of the brain; and

(2) "Executive director" means the executive director of the Tennessee commission on aging and disability.

(b) There is created the state Alzheimer's disease and related dementia advisory council, referred to in this section as the "council."

(c)(1) The council shall be composed of no less than eleven (11) and no more than thirteen (13) members, which include:

(A) One (1) member of the health and welfare committee of the senate, to be appointed by the speaker of the senate;

(B) One (1) member of the health committee of the house of representatives, to be appointed by the speaker of the house of representatives;

(C) The commissioner of health, or the commissioner's designee, who serves as an ex officio voting member;

(D) One (1) person to be appointed by the governor;

(E) One (1) licensed medical professional with experience in Alzheimer's disease and related dementia care, to be appointed by the executive director;

(F) One (1) person diagnosed with Alzheimer's disease or related dementia, to be appointed by the executive director;

(G) A representative of Alzheimer's Tennessee, Inc., to be appointed by the executive director;

(H) A representative of the Alzheimer's Association, to be appointed by the executive director;

(I) A representative of the bureau of TennCare, to be appointed by the executive director;

(J) A representative of the Tennessee Health Care Association, to be appointed by the executive director;

(K) A representative of LeadingAge Tennessee, to be appointed by the executive director; and

(L) Any other person possessing relevant experience with Alzheimer's disease and related dementia care, to be appointed by the executive director.

(2)(A) The private citizen members listed in subdivisions (c)(1)(E)-(K) may be appointed by the executive director from lists of qualified nominees submitted by groups involved in the study of Alzheimer's disease and related dementia, including, but not limited to, the Alzheimer's Association, Alzheimer's Tennessee, the department of health, the bureau of TennCare, the Tennessee Health Care Association, the Tennessee Association for Home Care, and the Tennessee Nurses Association.

(B) The executive director shall consult with the interested groups listed in subdivision (c)(2)(A) to determine qualified persons to fill the positions as provided in this subsection (c).

(d)(1) The persons appointed under subdivisions (c)(1)(A) and (B) are nonvoting members of the council. They serve only so long as they remain members of the general assembly. Any legislative vacancy on the council shall be filled by the respective speaker, for the purpose of serving out the remainder of the unexpired term.

(2) The private citizen members appointed under subdivisions (c)(1)(D)-(K) are voting members and are eligible for reappointment to the council. Any vacancy among the private citizen members shall be filled by the respective appointing authority to serve for the remainder of the unexpired term.

(e) Except as provided in subsection (f) for initial appointments, the terms of the members of the council are for three (3) years.

(f)(1) In order to stagger the terms of the newly appointed council members, initial appointments shall be made as follows:

(A) The persons appointed under subdivision (c)(1)(D)-(F) serve an initial term of one (1) year, which expires on June 30, 2020;

(B) The persons appointed under subdivisions (c)(1)(G)-(I) serve an initial term of two (2) years, which expires on June 30, 2021; and

(C) The persons appointed under subdivisions (c)(1)(J) and (K) serve an initial term of three (3) years, which expires on June 30, 2022.

(2) Following the expiration of members' initial terms as prescribed in subdivision (f)(1), all three-year terms begin on July 1 and terminate on June 30, three (3) years later.

(g) The members shall elect a chair and a vice chair, whose duties are established by the council.

(h) In making the appointments under subsection (c), the executive director shall strive to ensure that the council is composed of persons who are diverse in professional or educational background, ethnicity, race, sex, geographic residency, heritage, perspective, and experience.

(i) The council shall fix a time and place for regular meetings and shall meet no less than twice yearly to review the state plan and all related metrics and outcomes. The executive director shall call the first meeting of the council. All other meetings of the council shall be at the call of the chair.

(j) A majority of the voting members of the council constitutes a quorum, and all official action of the council requires a quorum.

(k) The respective appointing authority may remove a private citizen member of the council for misconduct, incapacity, or neglect of duty.

(l)(1) The legislative members of the council shall be reimbursed as members of the general assembly are paid for attending legislative meetings as provided in § 3-1-106.

(2) The private citizen members of the council do not receive travel expenses or compensation for their service.

(m) The purpose of the council is to:

(1) Continually assess the current status of Alzheimer's disease and related dementia in this state and to assess the current and future impact of Alzheimer's disease and dementia on Tennessee residents;

(2) Examine the existing industries, services, and resources addressing the needs of persons, families, and caregivers affected by Alzheimer's disease and related dementia;

(3) Develop a strategy to mobilize a state response to matters regarding Alzheimer's disease and related dementia; and

(4) Provide recommendations to the governor and to the general assembly on issues related to its work.

(n) The council is administratively attached to the commission on aging and disability. The council shall consult and advise the executive director on matters related to the establishment, maintenance, and operation of state initiatives related to Alzheimer's disease and related dementia.

(o) The commission and council shall make best efforts to engage the community at large in making its assessments and recommendations regarding Alzheimer's disease and related dementia.

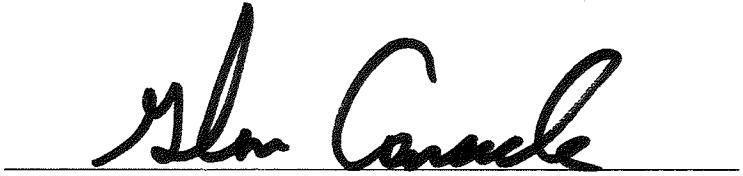
(p) No later than January 15, 2020, the council shall develop and submit an Alzheimer's disease state plan to the chair of the government operations committee of the senate, the chair of the government operations committee of the house of representatives, the chair of the health and welfare committee of the senate, and the chair of the health committee of the house of representatives that identifies barriers to Alzheimer's disease care, analyzes service utilization data, and includes recommendations, metrics, and best practices to address gaps in service. The council shall update the plan and report to the chairs of such legislative committees on its progress no later than January 15 of each year.

SECTION 3. This act shall take effect upon becoming a law, the public welfare requiring it.


SENATE BILL NO. 28

PASSED: April 30, 2019

  
RANDY McNALLY  
SPEAKER OF THE SENATE

  
GLEN CASADA, SPEAKER  
HOUSE OF REPRESENTATIVES

APPROVED this 10<sup>th</sup> day of May 2019

  
BILL LEE, GOVERNOR

# **Appendix B**





# What to Do Next

## After an Alzheimer's or Dementia Diagnosis

A diagnosis of Alzheimer's disease can be difficult but getting accurate information and support can help you know what to expect and what to do next. Use this checklist to help you get started.

1

### Learn about Alzheimer's disease and related dementias

- Tennessee Department of Health [bit.ly/tnalzpatientcare](https://bit.ly/tnalzpatientcare)
- Tennessee Commission on Aging [bit.ly/tnaging](https://bit.ly/tnaging)
- Alzheimer's Tennessee [www.alztennessee.org](https://www.alztennessee.org) 24/7 Helpline 800.259.4283
- Alzheimer's Association Tennessee Chapter [www.alz.org/tn](https://www.alz.org/tn) 24/7 Helpline 800.272.3900
- Understanding Alzheimer's Disease & Dementia [bit.ly/whatisAD](https://bit.ly/whatisAD)
- Living Well with Alzheimer's Disease [bit.ly/tnalzdiagnosis](https://bit.ly/tnalzdiagnosis)
- What You Need to Know: Written by Individuals with a Diagnosis <https://bit.ly/3Fukj0l>

2

### Complete legal, financial and long-term planning

Get information to help you plan. [bit.ly/ADplanning](https://bit.ly/ADplanning)

Review finances, prepare or update your will, living will, health care power of attorney, and financial power of attorney. [bit.ly/ADfutureplans](https://bit.ly/ADfutureplans)

Resources for finding an attorney.

- Tennessee Senior Law Alliance 1-844 HELP4TN <https://las.org/>
- Tennessee Elder Law [bit.ly/tnelderlaw](https://bit.ly/tnelderlaw)

Advance Directives TN [bit.ly/tnadvancedirectives](https://bit.ly/tnadvancedirectives)

Learn about care you may need in the future and how to pay for it:

- LongTermCare <https://acl.gov/ltc>
- Long Term Care in Tennessee [bit.ly/ltcChoices](https://bit.ly/ltcChoices)
- Explore getting help to pay for medicines, housing, transportation, and more. [www.benefitscheckup.org](https://www.benefitscheckup.org)

3

### Obtain Support for Care Partners

- National Family Caregiver Support Program [bit.ly/tncaregiversupport](https://bit.ly/tncaregiversupport)
- OPTIONS for Community Living [bit.ly/tnoptions](https://bit.ly/tnoptions)
- Adult Day Services [bit.ly/tnadultdayservices](https://bit.ly/tnadultdayservices)
- Tennessee Respite Coalition <https://bit.ly/tnrespitcoalition>
- Alzheimer's Tennessee Video Caregiver Academy [www.alztennessee.org/Academy](https://www.alztennessee.org/Academy)

4

### Remain Safe at Home

- Get Home-Safety Tips [bit.ly/caregiversafety](https://bit.ly/caregiversafety)
- Home Safety Checklist [bit.ly/mysafetychecklist](https://bit.ly/mysafetychecklist)
- Falls Prevention [bit.ly/alzpreventfalls](https://bit.ly/alzpreventfalls)

5

### Staying Safe on the Road

Ask your doctor for names of driving evaluators or visit:

- American Occupational Therapy Association [bit.ly/drivingeval](https://bit.ly/drivingeval)
- Driving & Dementia [bit.ly/drivesafe123](https://bit.ly/drivesafe123)



# What to Do Next

## After an Alzheimer's or Dementia Diagnosis

6

### Consider Participating in a Clinical Trial

Ask your doctor about trials or studies.

- Alzheimer's Tennessee Research Connection [bit.ly/joinatrialtn](http://bit.ly/joinatrialtn)
- National Institutes on Health [bit.ly/ADTrials](http://bit.ly/ADTrials)
- Pat Summitt Clinic <https://bit.ly/3FqsnPz-PSC>  
865.305.2273
- University of Tennessee Health Science Center, Memphis, Tennessee <https://www.uthsc.edu/>  
901.448.5500
- Vanderbilt Memory & Alzheimer's Center [www.vanderbiltmemory.com](http://www.vanderbiltmemory.com)  
615.322.8676
- Alzheimer's Association Trial Match <http://alz.org/trialmatch>

7

### Stay Healthy

**Be Active!** Getting exercise helps people with Alzheimer's feel better and helps keep their muscles, joints, and heart in good shape. [bit.ly/ADandexercise](http://bit.ly/ADandexercise)

- Eat a well-balanced diet that includes fruits, vegetables, and whole grains. [bit.ly/eatwell123](http://bit.ly/eatwell123)
- Continue to enjoy visits with family and friends, hobbies, and outings.
- Make regular appointments with your primary care doctor or specialist (neurologist, neuropsychiatrist, geriatric psychiatrist). Ask your primary care doctor for a referral to a specialist.
- Consider going to a memory disorders clinic. Ask your doctor for a referral if desired.
- Care Partners should also pay close attention to health and wellbeing. [bit.ly/healthycaregiving](http://bit.ly/healthycaregiving)

8

### Find Local Services

- Alzheimer's Tennessee Local Office 865.544.6288
- Alzheimer's Association Tennessee Chapter Local Office 615.315.5880
- The Alzheimer's Association and AARP host a comprehensive website [www.CommunityResourceFinder.org](http://www.CommunityResourceFinder.org) Enter your zip code to find medical services, community programs, housing options and other services near where you live.
- Alzheimer's is a disability. TNPathfinder can help navigate resources and care planning. [TNPathfinder.org](http://TNPathfinder.org)
- Area Agencies on Aging & Disability  
Call 866.836.6678 from anywhere in the state to be automatically directed to your nearest Area Agency.  
<https://bit.ly/33lnuu3>

9

### Find Local Support Groups

Alzheimer's Tennessee  
<https://bit.ly/tnalzsupport>  
East Tennessee: 865.544.6288  
Northeast Tennessee: 423.232.8993  
Middle Tennessee: 615.580.4244  
West Tennessee: 731.694.8065  
Cumberlands Tennessee: 931.526.8010  
South Central Tennessee: 931.434.2348

Alzheimer's Association  
[bit.ly/alzcommunitysupportgroups](http://bit.ly/alzcommunitysupportgroups)  
Nashville: 615.315.5880  
Chattanooga: 423.265.3600  
Knoxville: 865.200.6668  
Memphis: 901.565.0011