2025 ALZHEIMER'S DISEASE ADVISORY COMMITTEE

Annual Report





ELDERAFFAIRS.ORG

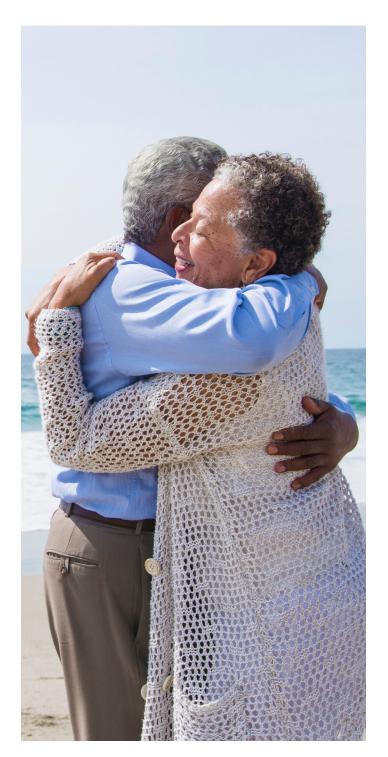


Table of Contents

Section 1 Introduction to Alzheimer's Disease and Related Dementias
Section 2 Alzheimer's Disease and Related Dementias Infrastructure in Florida11
Section 3 Department Advancements in Alzheimer's Disease and Related Dementias
Section 4 Policy Advancements in Alzheimer's Disease and Related Dementias
Section 5 Alzheimer's Disease Advisory Committee 19
Section 6 Executive Summary of Recommendations for 2024-202521

2025 FLORIDA

ALZHEIMER'S STATISTICS

PREVALENCE

Number of People Aged 65 and Older with Alzheimer's (2020)

579,900

% of Adults Over 65 with Alzheimer's

12.5%

WORKFORCE

of Geriatricians in 2021

418

Increase Needed to Meet 2050 Demand

168.2%

of Home Health and Personal Care Aides in 2022

72,410

Increase Needed to Meet 2032 Demand

22.6%

CAREGIVING

of Caregivers

870,000

Total Hours of Unpaid Care

1.4B

Total Value of Unpaid Care

\$29.4B

Caregivers with Chronic Health Conditions

66.4%

Caregivers with Depression

28.6%

Caregivers in Poor Physical Health

13.6%

HEALTH CARE

of People in Hospice (2017) with a Primary Diagnosis of Dementia

19,897

Hospice Residents with a Primary Diagnosis of Dementia

15%

of Emergency
Department Visits per
1,000 People with
Dementia (2018)

1,552

Dementia Patient Hospital Readmission Rate (2018)

23.0%

Medicaid Costs of Caring for People with Alzheimer's (2025)

\$3.7B

Per Capita Medicare Spending on People with Dementia in 2024 Dollars

\$35,223

Americans are living with Alzheimer's, and nearly 12 million provide their unpaid

More than 7 million

care. The cost of caring for those

with Alzheimer's

and other dementias

is estimated to total

\$384 billion in 2025,

increasing to nearly

\$1 trillion

(in today's dollars) by mid-century.

For more

information, view

the 2025 Alzheimer's

Disease Facts and

Figures report at

alz.org/facts.



© 2025 Alzheimer's Association® All Rights Reserved. Alzheimer's Association is a not-for-profit 501(c)(3) organization.

MORTALITY

of Deaths from Alzheimer's Disease (2022)

6,397

Section 1

Introduction to Alzheimer's Disease and Related Dementias

Alzheimer's disease is a progressive and irreversible brain disorder that slowly destroys memory, thinking skills, and the ability to carry out everyday tasks. It is the most common cause of dementia, accounting for 60% to 80% of all cases. Dementia is a general term for a decline in mental ability severe enough to interfere with daily life. While aging can bring mild memory changes, Alzheimer's is not a normal part of aging.

Alzheimer's disease begins with damage to brain cells (neurons), particularly in areas involved in memory and learning. But Alzheimer's disease is much more complex than struggling with memory. Over time, brain cell death spreads to other regions, leading to significant cognitive and physical decline. The disease progresses gradually but inevitably leads to death.

Key characteristics:

- Caused by damage to nerve cells in the brain.
- Progressive, with symptoms worsening over time.
- Begins with mild memory loss and can lead to loss of communication, independence, and awareness and eventually impedes the body's ability to perform its most basic functions (e.g., breathing, swallowing, and regulating the heartbeat.)
- Irreversible the damage cannot be undone.

Prevalence

- Globally, more than 50 million people are living with Alzheimer's disease and related dementias (ADRD).
- In the United States, approximately 6.2 million people are affected by Alzheimer's.
- In Florida, around 580,000 residents aged 65 and older are currently living with the disease.

• The number of people affected is projected to grow significantly. By 2060, the number of Americans with Alzheimer's is expected to reach nearly 14 million.

Who Is at Risk?

- Age is the strongest known risk factor. Most people with Alzheimer's are 60 years or older.
- Early-onset Alzheimer's (appearing in people as young as their 40s or 50s) is less common.
- Other risk factors include:
 - » Lifestyle factors (e.g., years of formal education, history of traumatic brain injury, smoking, exercise, diet.)
 - » Genetics and family history
 - » Environmental influences

Signs and Symptoms

While symptoms vary, there are commonly recognized signs that can help alert loved ones of warning signs. These signs are referred to as the "10 Warning Signs" and can include:

- 1. Memory loss that disrupts daily life.
- 2. Challenges in planning or solving problems.
- 3. Difficulty with familiar tasks.
- 4. Confusion with time and/or place.
- **5.** Trouble understanding visual images and special relationships.
- 6. Problems with words (speaking or writing)
- **7.** Poor judgment or decision-making.
- **8.** Misplacing things and being unable to retrace steps.
- 9. Withdrawal from work or social activities.
- 10. Changes in mood, personality, or behavior.

Having one or more of these symptoms does not necessarily mean a person has Alzheimer's. A person might have obvious changes with all these skills, or it might only be noticeable in one or two areas. A proper medical evaluation is essential.

Diagnosis and Progression

Research shows that Alzheimer's-related brain changes may begin 20 years or more before symptoms appear. Early detection is crucial for planning and management.

As the disease progresses:

- Independence decreases.
- Physical health and cognition decline.
- Care needs increase.
- The disease ultimately becomes fatal.

Treatment and Care

There is currently no cure for Alzheimer's disease, but a combination of medical treatment, personalized care strategies, and ongoing support can help manage symptoms and improve quality of life for those affected.

Treatment Approaches

Treatment strategies focus on:

- Supporting brain health through lifestyle changes, cognitive stimulation, and medical management.
- Managing behavioral symptoms such as agitation, sleep disturbances, anxiety, and depression.
- Delaying symptom progression, particularly in the early and middle stages of the disease.

Medications

The U.S. Food and Drug Administration (FDA) has approved several medications to treat Alzheimer's symptoms. These drugs may:

- Help patients cope with memory loss and confusion.
- Slow the rate of decline in thinking and daily functioning.
- Be most effective when introduced in the early to moderate stages.
- Vary in effectiveness between individuals and often become less effective as the disease progresses.

However, it's important to note that:

- These medications do not stop the disease or reverse its effects.
- They can be costly and may cause side effects such as nausea, dizziness, or appetite loss.
- Because their benefits are limited, medication should be only one part of a comprehensive care plan.

The Importance of Caregiving and a Strong Care Plan

Given the progressive nature of Alzheimer's and the limited effectiveness of current drug treatments, knowledgeable caregiving and a well-structured care plan are essential.

Trained and informed caregivers play a critical role in managing day-to-day needs, recognizing changes in behavior or health, and providing emotional and physical support. A strong care plan should address not just medical treatment, but also provide guidance on:

- Safety and daily living support.
- Legal and financial planning.
- Advance care directives.
- Support for caregivers, including respite care and mental health resources.

As the disease advances, individuals may lose the ability to communicate their needs or make decisions. Early planning allows families to honor the wishes of the person with Alzheimer's and adapt care as their needs evolve.

Caregiving can be emotionally and physically demanding. Without proper support, caregivers are at high risk for burnout, depression, and health problems. A strong care plan provides structure and resources, helping caregivers cope with the challenges and maintain their own well-being while providing quality care.

Alzheimer's Disease in Florida

Florida has the second highest prevalence of Alzheimer's Disease (AD) in the country and the highest prevalence in the country, per capita. Currently, Florida is home to approximately 580,000 individuals over 65 with AD and 870,000 caregivers¹. Since age is the most prominent risk factor for developing AD, Florida likely will continue to lead the nation, as approximately 23 percent of its population is over 65², and an estimated 30% of Florida's population will be over 60 years of age by 2030³. In 2050, the number of people in America ages 65 and older with AD is projected to reach 14 million, with Florida having the highest projected rate of increase in the country⁴. The Miami-Dade region, along with Baltimore, MD, and Bronx County, NY, currently have the highest estimated AD rates in the country.

The economic impact of this disease is astounding. In 2025, ADRD will cost the nation \$3.7 billion – not including the value of unpaid caregiving. Costs of health care and long-term care for individuals living with ADRD are substantial, and dementia is one of the costliest conditions to society.

These costs are reflected in all areas of health care delivery:

- People living with ADRD have twice as many hospitalizations per year as other older people.
- Medicare beneficiaries with ADRD are more likely than those without dementia to have other chronic conditions, such as heart disease, diabetes, and kidney disease.

- Older people living with ADRD have more skilled nursing facility stays and home health care visits per year than other older people; and
- People living with ADRD make up a large proportion of all elderly people who receive adult day services and nursing home care.

And yet, despite the enormous cost to healthcare and government infrastructure, families ultimately bear approximately 70% of the caregiver costs. These costs do not reflect the increased health care needs often felt by caregivers, who experience a decline in mental and physical health as a result of their caregiving responsibilities to their loved one.

2025 Alzheimer's Association Facts and Figures⁵

The 2025 Alzheimer's Association Facts and Figures Report4 provides an overview of the latest national statistics and information on Alzheimer's prevalence, incidence, mortality and morbidity, costs of care, and caregiving. These staggering numbers illustrate the importance of prioritizing this illness.

- Approximately 7 million Americans aged 65 and older live with AD in 2025; by 2050, this number is projected to rise to nearly 13 million.
- Approximately 580,000 Floridians are currently living with AD.
- Florida has the second highest prevalence of AD in the nation.
- AD is the sixth leading cause of death in Florida.
- About 1 in 9 people age 65 and older has Alzheimer's
- 1 <u>alz.org/media/Documents/alzheimers-facts-and-figures.pdf</u>
- 2 census.gov/programs-surveys/acs/data/data-tables.html
- $3\ \underline{flhealthcharts.gov/ChartsDashboards/rdPage.aspx?islCounty=69\&rdReport=AgingInFlorida.Profile\&tabid=Report$
- 4 <u>cdc.gov/alzheimers-dementia/about/alzheimers.html?CDC_AAref_Val=https://www.cdc.gov/aging/aginginfo/alzheimers.htm</u>
- 5 <u>alz.org/alzheimers-dementia/facts-figures</u>

- The lifetime risk for Alzheimer's at age 45 is 1 in 5 for women and 1 in 10 for men.
- Health and long-term care costs for people living with dementia are projected to reach \$384 billion in 2025 and nearly \$1 trillion in 2050.
- Nearly 12 million Americans provide unpaid care for people with Alzheimer's or other dementias.
- In 2024, unpaid caregivers provided an estimated more than 19 billion hours of care valued at more than \$413 billion.
- 92% of Americans would want to take a medication that could slow the progression of Alzheimer's.
- Nearly 4 in 5 Americans would want to know if they had Alzheimer's disease before having symptoms, or before those symptoms interfered with their activities.
- Nearly 3 in 5 Americans said they would accept moderate or very high levels of risk with taking medication to slow the progression of Alzheimer's disease
- African Americans are two times more likely to develop AD than their white counterparts.
- Hispanic Americans are one-and-a-half times more likely to AD than their white counterparts.

Caregiving⁶

Eighty-three percent of the help provided to older adults in the U.S. comes from family members, friends, or other unpaid caregivers.

- Nearly 12 million Americans provide unpaid care for a family member or friend with dementia. The value of these unpaid hours is valued at \$413.5 billion — nearly 16 times the total revenue of McDonald's in 2023.
- About 30% of caregivers are age 65 or older.

- Approximately two-thirds of caregivers are women; more specifically, over one-third of dementia caregivers are daughters.
- Most caregivers (66%) live with the person with dementia in the community.
- Most caregivers (66%) live with the person with dementia in the community.

Care Navigation⁷

Family caregivers are the backbone of the ADRD infrastructure. Their contributions reflect an enormous price tag that has, so far, not been tallied in the cost of healthcare delivery. However, family caregivers are often untrained and unfamiliar with resources that can improve their caregiving experience. Care Navigation services are a logical form of support that can increase skills and knowledge, improve access to care, and improve health outcomes for the caregiver and their loved ones. The following statistics are taken from the Alzheimer's Association 2024 Special Report on Caregiving.⁸

- Only 14% of U.S. dementia care facilities had dedicated care navigators in 2024, up from 11% in 2020.
- Two-thirds of families (66%) report feeling overwhelmed and lost navigating dementia care services, a significant increase from 60% in 2020.
- Dementia care navigators play a crucial role in guiding families through complex health and social systems, enhancing care coordination and resource access.
- 45% of primary care physicians (PCPs) report feeling "never" or "only sometimes" comfortable diagnosing Alzheimer's or other dementias, an increase from 40% in 2020.
- 55% of PCPs say they feel inadequately prepared to care for individuals with ADRD, compared to 50% in 2020.

6 <u>alz.org/alzheimers-dementia/facts-figures</u>

7 <u>alz.org/getmedia/a7390c29-e4c0-4d3c-b000-377b6c112eea/alzheimers-facts-and-figures-special-report.pdf</u>

 $8 \ \underline{alz.org/getmedia/a7390c29-e4c0-4d3c-b000-377b6c112eea/alzheimers-facts-and-fig-\underline{ures-special-report.pdf}$

- 30% of PCPs report being "only sometimes" or "never" comfortable answering questions about dementia, up from 25% in 2020.
- 1.4 million additional direct-care workers are projected to be needed between 2023 and 2033 to care for the growing dementia population, compared to 1.2 million projected between 2020 and 2030.
- Challenges include a lack of standardized care navigation models, leading to varied quality and access. Only 20% of care facilities follow a standardized care navigation model.

The Department of Elder Affairs Care Navigation program, which serves as the cornerstone of the Florida Alzheimer's Center of Excellence (FACE), was established in acknowledgment of the significant benefits this type of support provides. The FACE Care Navigation program represents a significant effort to address the challenges noted in the Alzheimer's Association Special Report.

National Cost of Care for ADRD

- This year, health and long-term costs for people living with dementia and Alzheimer's are expected to reach \$384 billion (not including the value of unpaid care)⁹. This cost, when factoring the value of unpaid care, climbs to \$781 billion¹⁰.
- Costs affecting family caregivers are compounded by a loss of income valued at approximately \$8 billion ¹¹.
- Medicaid costs for a person living with dementia are 22 times higher than for older adults without dementia. Medicare costs are 3 times higher ¹².

- People living with Alzheimer's or other dementias have twice as many hospital stays per year as other older people.
- Medicare beneficiaries with Alzheimer's or other dementias are more likely than those without dementia to have other chronic conditions, such as heart disease, diabetes and kidney disease.
- AD is currently the most expensive disease in America, costing more than cancer or heart disease.

Workforce Shortage

Florida is confronting a mounting crisis in geriatric and Alzheimer's care, driven by a severe shortage of caregivers across the spectrum of workers. This shortage is present in every setting – from direct assistance in nursing homes, assisted living, and in-home care settings and the way to neurologists and gerontologists.

As the state's enormous Baby Boomer generation continues aging, demand for memory-care and dementia services is rising sharply. However, the ranks of Certified Nursing Assistants (CNAs), Licensed Practical Nurses (LPNs), and Registered Nurses (RNs) remain depleted—FHCA surveys report that over 90% of Florida's long-term care facilities face staffing challenges, with nearly half limiting admissions due to insufficient personnel¹³.

Financial pressures are another serious obstacle—low Medicaid reimbursement rates make it hard for care facilities to offer competitive wages, and many depend on expensive agency staff to fill critical gaps, driving

9 alz.org/alzheimers-dementia/facts-figures

10 schaeffer.usc.edu/wp-content/uploads/2025/04/The-Cost-of-Dementia-in-2025.pdf

11 <u>alz.org/getmedia/c65b6229-48cf-4a7b-a447-328fdf05e35d/alzheimers-facts-and-figures-2024.pdf</u>

12 <u>alz.org/getmedia/c65b6229-48cf-4a7b-a447-328fdf05e35d/alzheimers-facts-and-figures-2024.pdf</u>

13 <u>mcknights.com/news/more-than-half-of-florida-providers-reducing-admissions-due-to-staff-ing-challenges-survey</u>

up operational costs¹⁴. This leads to burnout among existing caregivers and poor retention: despite wage increases of 20–25% for CNAs, LPNs, and RNs, 95% of operators report difficulty recruiting and retaining staff¹⁵. In private pay settings (as in the case of most Assisted Living Facilities), companies report that it is difficult to increase wages for direct care workers without increasing the cost to the resident¹⁶.

The challenge is especially acute in Alzheimer's care, where continuity, familiarity, and specialized training are essential—and where frequent turnover undermines quality. Many dementia patients require consistent, patient-centered support; understaffing can lead to increased medical errors, neglect, and a decline in emotional well-being. Meanwhile, the burden shifts onto unpaid family caregivers—Florida ranks among the states in "critical" or "high risk" status due to a shortage of paid home-health aides (only ~16 aides per 1,000 seniors versus a national average of ~64), meaning dementia care increasingly falls on families with limited support¹⁷.

Florida's geriatric and Alzheimer's care system is under strain: a rapidly aging population, a shrinking workforce pipeline, insufficient compensation, and systemic underfunding are collectively threatening the state's ability to deliver dignified, high-quality care.

Ongoing Research

Scientists continue to investigate the causes, prevention, and treatment of Alzheimer's. Efforts in Florida and worldwide focus on understanding risk factors, identifying interventions to slow or stop the disease, and identifying biomarkers that can help make

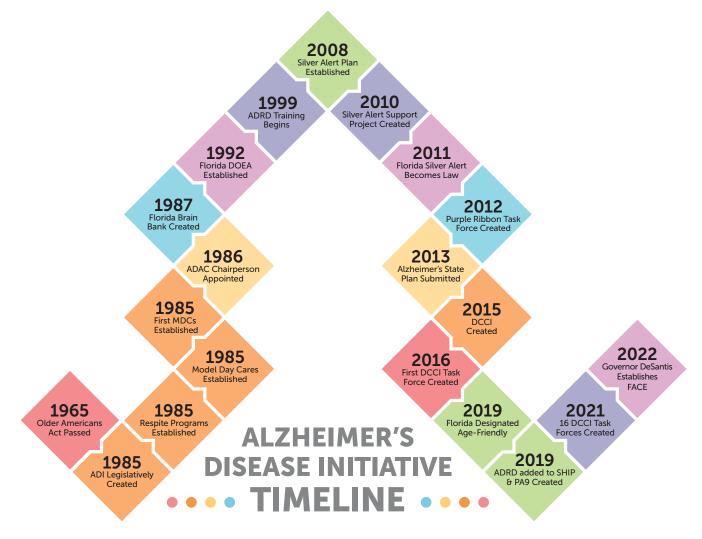
the diagnostic process faster and more cost-effective.

Treatment Breakthroughs

- New Drug Approvals and Advances:
 - » Lecanemab (Leqembi): This drug, approved in early 2023, is a monoclonal antibody targeting amyloid-beta plaques, which are associated with Alzheimer's disease. Clinical trials have shown it can slow cognitive decline in patients with early Alzheimer's.
 - » Donanemab: Another monoclonal antibody targeting amyloid plaques, it has shown promise in clinical trials for slowing the progression of Alzheimer's. The FDA granted accelerated approval for this drug in 2024.
- Tau Protein Research:
 - » Advances in targeting tau protein, another hallmark of Alzheimer's pathology, have been significant. Researchers are developing therapies that aim to reduce tau tangles, which contribute to neuronal damage and cognitive decline.
- Gene Therapy and Genetic Research:
 - » Progress in gene therapy aims to address genetic risk factors associated with Alzheimer's. Research into gene editing tools like CRISPR has explored their potential in modifying genes linked to Alzheimer's, such as the APOE gene.
- Early Detection and Diagnosis:
 - » Development of more sensitive biomarkers and imaging techniques, including advances in PET scans and blood tests, are improving early

CONTINUED ON PAGE 11

- 14 <u>floridadaily.com/fhca-warns-legislators-about-long-term-care-facilities-worsening-work-force-and-economic-crisis</u>
- 15 fhca.org/media_center/entry/who_will_care_for_floridas_growing_senior_population
- 16 <u>mcknights.com/news/more-than-half-of-florida-providers-reducing-admissions-due-to-staff-ing-challenges-survey</u>
- 17 <u>marketwatch.com/story/family-caregivers-struggle-the-most-in-these-states-whats-being-done-to-help-dd7c50b8</u>



1965

The Older Americans Act was passed and created the Area Agency on Aging.

1985

Alzheimer's Disease Initiative (ADI) was legislatively created in 1985 to provide a continuum of services to meet the changing needs of individuals and families affected by Alzheimer's Disease and Related Dementias.

The start of the ADI respite programs and model day care services.

The First Memory Disorder Clinics (MDCs) established at USF, UF, and UM.

1986

The Alzheimer's Disease Advocate Committee (ADAC) established and the first chairperson was appointed.

1987

The Florida Brain Bank was created at Mt. Sinai Medical Center in Miami by Dr. Ranjan Duara.

1992

Department of Elder Affairs (DOEA) established.

1999

ADRD training program established.

2008

Florida Silver Alert Plan was established through Executive Order 08-211 by Governor Charlie Crist.

2010

Silver Alert coordination and support project started.

2011

Florida Silver Alert became state law under Florida Statute sections 937.021 and 937.0201*.

2012

HB 473 passed that created the Purple Ribbon Task Force (PRTF) housed within DOEA.

2013

Submitted Florida Alzheimer's Disease State Plan to the Governor and Legislature. The PRTF adjourned following the submission.

2015

DOEA announced the Dementia Care and Cure Initiative (DCCI).

2016

Tallahassee announced as the first DCCI pilot task force.

2019

Florida became the 4th designated Age-Friendly State.

ADRD placed into the State Health Improvement Plan and Priority Area 9 created.

2021

16th DCCI task force created.

2022

Governor Ron DeSantis highlighted record funding for Alzheimer's and related dementias and established the Florida Alzheimer's Center of Excellence (FACE).

^{*}Florida Statute

detection. For instance, new bloodbased biomarkers have been validated to detect Alzheimer's-related changes before significant symptoms appear.

- Combination Therapies:
 - » Research into combining different types of treatments, such as amyloid-targeting drugs with tau-targeting therapies or anti-inflammatory agents, is gaining momentum. The idea is to address multiple pathways involved in Alzheimer's simultaneously.
- Surgical Interventions:
 - » Researchers are exploring surgical procedures, such as lymphovenous bypass, to reduce lymphatic fluid buildup in the brain. These interventions aim to restore or improve the brain's natural waste clearance pathways, which may be impaired in individuals with dementia. By enhancing lymphatic drainage, the goal is to reduce neuroinflammation and improve cognitive function. While still under investigation, these procedures represent a promising area of research into how surgical methods might support brain health and slow the progression of neurodegenerative diseases like Alzheimer's.
- Lifestyle and Behavioral Interventions:
 - » Studies continue to highlight the impact of lifestyle factors on Alzheimer's progression. Research into diet, exercise, and cognitive training interventions shows that these can have a meaningful impact on slowing disease progression or improving quality of life.

These advancements reflect a need for the state's ADRD infrastructure to contain a multifaceted approach, with attention to immediate needs affecting today's patients, caregivers, and care providers as well as the upstream responses that have the most promising impacts in the future.

Section 2

Alzheimer's and Related Dementias Infrastructure

Governor DeSantis has prioritized addressing Alzheimer's Disease (AD) in Florida due to its extensive impact across the health care industry and beyond. Florida is a national leader in this space by integrating efforts into programs focused on research, risk reduction, workforce development, and caregiver support.

The Alzheimer's Disease Initiative (ADI) represents Florida's key infrastructure for caregiver support, encompassing clinical services, diagnosis, support services, education, and research, and fostering collaboration among community partners to identify gaps and provide recommendations. Under Governor DeSantis's leadership, funding for these comprehensive services has significantly increased.

The ADI includes four main funded components specified in Florida statute: the Alzheimer's Disease Advisory Committee (ADAC), respite and support services, Memory Disorder Clinics (MDCs), and the Florida Brain Bank. Additional advancements include Florida's Silver Alert system, an ADRD Priority Area on the State Health Improvement Plan (SHIP), and 17 Dementia Care and Cure Initiative Task Forces statewide (a new rural DCCI taskforce was added in early 2025). DOEA works with partners through the 11 Area Agencies on Aging (AAAs) to address ADRD concerns, provide community resources, and more.

Additionally, Florida is home to two federally funded Alzheimer's Disease Research Centers that act as ADRD hubs and supports state-based research funding through the Ed and Ethel Moore Research Grant Program (housed at Florida Department of Health).

Governor DeSantis' Five Point Dementia Action Plan

1

Included Alzheimer's and related dementias as a priority within the State Health Improvement Plan (SHIP).

Alzheimer's is the sixth leading cause of death in Florida but was not previously directly addressed by the SHIP

2

Challenge local communities to expand the Dementia Care and Cure Initiative (DCCI) in their areas.

Eight out of 11 AAAs are engaged in DCCI programs, including 16 area-specific DCCI Task Forces.

3

Challenge Florida institutions to match funding for their in-house Memory Disorder Clinics (MDC).

The State of Florida has designated and funded 17 MDCs located in medical schools, teaching hospitals, and similar institutions.

4

Increase funding for the Alzheimer's Disease Initiative (ADI).

Governor DeSantis' Freedom First Budget included \$12 million in funding to support the ADI and supportive services for people living with ADRD, their families, and caregivers.

5

Governor DeSantis requests the development of a Center of Excellence pursuant to the Federal BOLD Act. Announced the Florida Alzheimer's Center of Excellence to promote evidence-based treatment and prevention, awareness and education about ADRD, and to connect families with resources.

The Role of the Department of Elder Affairs

DOEA is responsible for administering human services and long-term care programs, including programs funded under the Federal Older Americans Act of 1965 and other programs assigned to it by law, 430.04, F.S. (2019). For the service provision and policy development as it relates to persons who are in the early stages of AD, who have younger-onset AD, or who have a related form of dementia, DOEA administers the ADI, Home Care for the Elderly (HCE), Respite for Elders Living in Everyday Families (RELIEF), and the federally funded Family Caregiver Support Program. All these programs provide caregiver support; however, only the ADI is designed to provide dementia-specific services. Over the years, ADI has taken up new initiatives

to better serve persons with dementia and their caregivers.

Secretary Michelle Branham continues to serve as the agency head for DOEA following her initial appointment by Governor DeSantis in December 2021. Under her leadership, the Department serves Florida's 6.1 million seniors aged 60 and older, providing services and supporting initiatives through Florida's Aging Network to help seniors live well and age well in the state. In 2023, Secretary Branham expanded the role of the Dementia Director to include leadership over a new Division of Alzheimer's and Brain Health, converging all Department efforts related to brain health within a dedicated team. The Department's efforts are outlined in the following section.



1 PSA 1

Northwest Florida Area Agency on Aging

5090 Commerce Park Cir. Pensacola, FL 32505 Phone: (850) 494-7101

Elder Helpline: (866) 531-8011

nwflaaa.org

2 PSA 2

Advantage Aging Solutions

414 Mahan Dr.

Tallahassee, FL 32308 Phone: (850) 488-0055

Elder Helpline: (866) 467-4624

advantageaging.org

3 PS

PSA 3

Elder Options

100 S.W. 75th St., Ste. 301 Gainesville, FL 32607 Phone: (352) 378-6649

Elder Helpline: (800) 262-2243

agingresources.org

4

PSA 4

ElderSource

10688 Old St. Augustine Rd. Jacksonville, FL 32257 Phone: (904) 391-6600

Elder Helpline: (888) 242-4464

myeldersource.org

5

PSA 5

Area Agency on Aging of Pasco-Pinellas

9549 Koger Blvd. Gadsden Bldg., Ste. 100 St. Petersburg, FL 33702 Phone: (727) 570-9696

Elder Helpline: (727) 217-8111

agingcarefl.org

6

PSA 6

Senior Connection Center

2

Wakulla

8928 Brittany Way Tampa, FL 33619

Phone: (813) 740-3888

Elder Helpline: (800) 336-2226 seniorconnectioncenter.org

7

PSA 7

Senior Resource Alliance

3319 Maguire Blvd., Ste. 100

Orlando, FL 32803

Phone: (407) 514-1800

Elder Helpline: (407) 514-0019 seniorresourcealliance.org

8

PSA 8

Area Agency on Aging for Southwest Florida

15201 N. Cleveland Ave., Ste. 1100 North Fort Myers, FL 33903 Phone: (239) 652-6900

Elder Helpline: (866) 413-5337

aaaswfl.org

9

PSA 9

Area Agency on Aging of Palm Beach/Treasure Coast, Inc.

4400 N. Congress Ave.

West Palm Beach, FL 33407 Phone:

(561) 684-5885

Elder Helpline: (866)684-5885

aaapbtc.org

10

PSA 10

Area Agency on Aging of Broward County

5300 Hiatus Rd. Sunrise, FL 33351 (954) 745-9567

Phone: (954) 745-9567

Elder Helpline: (954) 745-9779

adrcbroward.org

11

PSA 11

Clav

Putnan

Alachua

Hernando

Dixie

3

5

4

7

9

Martin

Palm Beach

Broward

Volusia

Orange

De Soto

Charlotte

8

10

Alliance for Aging

760 NW 107th Ave #214 Miami, FL 33172

Phone: (305) 670-6500

Elder Helpline: (305) 670-4357

allianceforaging.org

County coloring represents area served by the corresponding Area Agency on Aging.

PSA - Planning and Service

Area

Caregiver Support and Respite Services in Florida

The Alzheimer's Disease Initiative (ADI) is a statewide program within the Department of Elder Affairs that provides services to individuals and families affected by ADRD. ADI includes three components:

- 1. Supportive services such as counseling, consumable medical supplies, and respite for caregiver relief.
- 2. Memory Disorder Clinics (MDCs) to provide diagnosis, education, training, research, treatment, and referrals, and
- **3.** The Florida Brain Bank to support research.

Community Care for the Elderly (CCE)

Program provides community-based services organized on a continuum of care to help functionally impaired elders live in the least-restrictive yet most cost-effective environment suitable to their needs.

Research in Florida:

The Ed & Ethel Moore Grant Program, created in 2014, supports the development of innovative research in the prevention, assessment, and treatment of progressive dementia. The program is managed by the Department of Health. The long-term objectives include the following:

- Improving the health of Floridians through research on prevention, treatments, diagnostic tools, and cures for ADRD.
- Expanding the foundation of knowledge relating to the prevention, diagnosis, treatment, and cure of Alzheimer's disease and related dementias; and
- Stimulating economic activity in areas related to research on ADRD.

Alzheimer's Disease Research Centers serve as hubs of translational science that focus on preventing and treating ADRD. They play a pivotal role in fostering enrollment for industry-sponsored clinical trials and ensuring advances in evidence-based care for ADRD are disseminated efficiently and rapidly to community-based medical practices. There are two federally funded Research Centers in Florida: 1) Mayo Clinic Jacksonville and 2) 1Florida (an ADRD consortium of universities and health science centers).

Resources in Florida:

Memory Disorder Clinics (MDCs) are state-funded and statutorily established to conduct research and training in a diagnostic and therapeutic setting for persons living with ADRD. The MDCs also provide an annual report. There are 17 MDCs currently in Florida. They participate in funded research projects, and as part of their contractual agreement, must partner with research programs focusing on dementia and dementia care. All clinics work with DOEA to develop metrics that reflect their impact to the state and local communities and to contribute to the body of knowledge about Alzheimer's disease and related dementias.

Area Agencies on Aging (AAAs) are

organizations that serve seniors and individuals with disabilities in the community. The AAAs serve as a trusted resource to advocate, educate, and empower seniors, adults with disabilities, and caregivers, which promotes independence in partnership with the community. They strive to provide seniors, adults with disabilities, and caregivers with the resources and services needed to maintain independence, promote healthy aging, and live an optimal quality of life. The AAAs are considered the gateway to senior services. They perform all intake assessments for home and community-based services such as the ADI respite funding and the Community Care for the Elderly funding (CCE).

Dementia Care and Cure Initiatives (DCCIs)

Dementia Care and Cure Initiative task forces engage communities across Florida to be more dementia-caring, promote better care for Floridians affected by dementia, and support research efforts to find a cure. Being a dementia-caring community means services and supports are in place to make that community hospitable to those living with dementia, their caregivers, families, and loved

Alzheimer's ADI Disease Respite Care Advisory Program Committee Memory Brain Disorder Bank Clinics **PROGRAM** COMPONENTS ALZHEIMER'S DISEASE INITIATIVE **SUPPORTING COMPONENTS** Alzheimer's Disease Florida Related Silver Alert Dementias Training State Health Improvement Dementia Care & Cure . Plan PA9 Initiative

The ADI Respite Care Program is a collaborative effort with the Area Agencies on Aging. SHIP and Priority Area 9 are a collaborative effort with Florida Department of Health and Alzheimer's Association.



ones. Each interaction with the community should be a positive one, created out of respect and understanding, with the purpose of giving individuals with dementia the opportunity to continue playing a vital role within their communities.

Section 3

Department Advances in Alzheimer's Disease and Related Dementia

Florida Alzheimer's Center of Excellence (FACE): FACE's core initiatives are dedicated to individuals with dementia and their family caregivers. Through consultations with Care Navigators, family members receive guidance on effective lifestyle interventions for caregiving. These Care Navigators provide comprehensive support, including legal and financial planning, home safety, caregiving skills, access to community resources, education, and emotional support. They also facilitate connections to local experts for services requiring professional-level intervention, such as medical care and legal planning. The primary role of the Care Navigator is to act as a reliable resource and guide, ensuring that care plans adapt to the evolving needs of the individual.

In 2022, FACE began collaborating with the Navigating Aging Needs (NAN) program. NAN, a key clinical partner, provides the assessment and care plan protocol used by the FACE Care Navigation team. The NAN protocol was featured at the Alzheimer's Association International Conference in Amsterdam in July 2023 and was also selected for presentation in 2024. Data from the NAN protocol highlights significant improvements: in 2023, the program achieved a 75% reduction in falls and a 68% reduction in hospitalizations. By 2024, these figures had improved to an 86% reduction in falls and an 81% reduction in hospitalizations.

The second phase of FACE's efforts focuses on recognizing direct-care settings that excel in staff training and support. The third phase involves acknowledging industry leaders in ADRD clinical care and research. This model, inspired by the Department of Health's Cancer Centers of Excellence, establishes benchmarks and best-practice standards. Recognition as a FACE Partner helps families identify

CONTINUED ON PAGE 18



2

The legislature has authorized 17 memory disorder clinics (MDCs) operating in 13 distinct service areas that provide comprehensive diagnostic and referral services for persons with Alzheimer's disease and related dementias. The clinics also conduct service-related research and develop caregiver training materials and educational opportunities.

and the Florida Brain Bank

Memory Disorder Clinic at Medical Center Clinic

8333 N. Davis Hwy Bldg. 1, Floor 3 Pensacola, FL 32514 (850) 474-8353

1

Tallahassee Memorial HealthCare **Memory Disorder Clinic**

2473 Care Drive, Ste. 102 Tallahassee, FL 32308 (850) 431-5001

Mayo Clinic Jacksonville **Memory Disorder Clinic**

3 4500 San Pablo Rd. Jacksonville, FL 32224 (904) 953-7103

University of Florida Memory Disorder Clinic

3009 SW Williston Rd. Gainesville, FL 32608 (352) 294-5400

Orlando Health Center for Aging and Memory Disorder Clinic

32 West Gore Street Orlando, FL 32806 (321) 841-9700

AdventHealth Memory Disorder Clinic

265 E. Rollins Street, 6th Floor Orlando, FL 32803 (407) 392-9237

Health First Memory Disorder Clinic

3661 S. Babcock St. 6 Melbourne, FL 32901 (321) 434-7612

Morton Plant Madonna Ptak Center for Alzheimer's Research and Memory Disorders Clinic

430 Morton Plant St., Ste. 401 Clearwater, FL 33756 (727) 298-6025

University of South Florida Memory Disorder Clinic

8 3515 E. Fletcher Ave. Tampa, FL 33613 (813) 974-3100

Putnar

Hardee

De Soto

11

4

5

7

8

10

Hillsborough

3

6

9

12

Broward

St. Mary's Medical Center Memory Disorder Clinic at Palm Beach Neuroscience Institute

901 Village Blvd., Ste. 702 West Palm Beach, FL 33409 (561) 990-2135 8756 Boynton Beach Blvd., Ste. 2500 Boynton Beach, FL 33472 (561) 990-2135

Florida Atlantic University Louis and Anne Green Memory and Wellness Center

777 Glades Rd., Bldg. AZ-79 Boca Raton, FL 33431 (561) 297-0502

Sarasota Memorial Memory Disorder Clinic

1515 S. Osprey Ave., Ste. A-1 Sarasota, FL 34239 (941) 917-7197

Lee Memorial LPG Memory Care

11 12600 Creekside Lane, Ste. 4 & 7 Fort Myers, FL 33919 (239) 343-9220

Broward Health North Memory Disorder Center

201 E. Sample Rd.
Deerfield Beach, FL 33064
(954) 786-7392

Mt. Sinai Medical Center Wien Center for Alzheimer's Disease and Memory Disorders

4302 Alton Rd., Ste. 650 Miami Beach, FL 33140 (305) 674-2543 ext. 55725

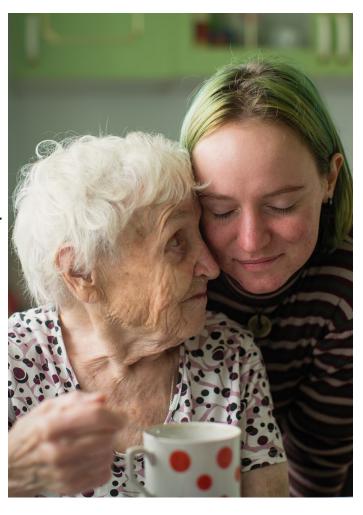
13

University of Miami Center for Cognitive Neuroscience and Aging

13 1695 N.W. 9th Ave., Ste. 3202 Miami, FL 33136 (305) 355-9065

Frank C. & Lynn Scaduto MIND Institute at Miami Jewish Health

5200 NE 2nd Avenue Miami, FL 33137 (305) 514-8652



Brain Bank Locations

State of Florida Brain Bank- Satellite Office Orlando Alzheimer's and Dementia Resource Center

1410 Gene Street Winter Park, FL 32789 (407) 436-7755

State of Florida Brain Bank Wien Center for Alzheimer's Disease and Memory Disorders

> 4302 Alton Road, Suite 650 Miami Beach, FL 33140 (305) 674-2018

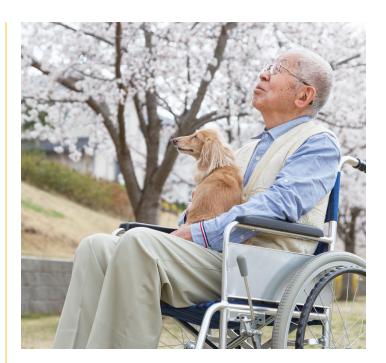
NOTE: County coloring represents area served by the corresponding Memory Disorder Clinic. top professionals in the field and elevates care standards. The second phase of the FACE model began in 2025 by working with Specialized Adult Day Care centers to address workforce shortages and explore efforts to provide more support for families and create great efficiencies with the Specialized ADC fee and reimbursement schedule.

ADRD Curriculum and Training Provider Evaluation: The Department of Elder Affairs is responsible for establishing and publishing education requirements for direct care workers in licensed care settings, as well as certifying training providers and evaluating training curricula. Applications for training providers and curricula have been digitized and are now accessible via the Department's website. The Agency for Health Care Administration (AHCA) then ensures compliance with ADRD training requirements during its routine site visits. To streamline AHCA's monitoring process, certificates of completion for the initial training offered by the Department have been standardized, an intake protocol for learners who are requesting reissued certificates has been established. Additionally, a new Learning Management System is planned the launch in in late 2025. The new platform will faster and easier to use, and will create more learning opportunities for users.

To date, more than 200,000 users have accessed the 1-hour training program.

State Health Improvement Plan, Priority Area ADRD: Florida is a leader in ADRD efforts and acknowledges the critical importance of ADRD through the State Health Improvement Plan (SHIP). In 2019, Governor DeSantis called on the Department of Health to add ADRD as a Priority Area, making Florida the first and only state to have ADRD as a standalone priority.

In May 2019, ADRD became the ninth priority area of the state's 2017-2021 SHIP cycle. ADRD continues as a Priority Area for the 2022-2026 cycle. The SHIP Priority Area Workgroups address the following primary functions:



- Develop goals and measurable objectives for each priority area.
- Create implementation plans to drive action.
- Monitor and provide quarterly progress updates on State Health Improvement Plan objectives and activities.
- Compile recommended revisions to State Health Improvement Plan goals and objectives for approval by the State Health Improvement Plan Steering Committee; and
- Serve as champions for the State Health Improvement Plan by increasing awareness and engagement within respective networks.

The goals of ADRD Priority Area Workgroups include:

- Strengthen the capacity to address Alzheimer's disease and related dementia.
- Ensure a competent ADRD workforce; and
- Enhance support services for those living with ADRD and their caregivers.

The ADRD Priority Area Workgroup is a potential avenue to implement the Alzheimer's Disease Advisory Committee recommendations and highlight best-practice guidelines.

Section 4

Policy Advancements in Alzheimer's Disease and Related Dementia

During the most recent legislative session, there were no statutory or regulatory changes made to Alzheimer's Disease and Related Dementias (ADRD) policy in Florida. However, the session still yielded positive outcomes in funding, reflecting continued state-level support for the growing needs of this population.

Funding Achievements

All minimum funding requests submitted by ADAC and its partners were fully met, ensuring the continuation of essential programs and services across the state. In recognition of Florida's increasing aging population and the expanding reach of ADRD, the legislature also approved additional appropriations to support:

- Expansion of community-based services
- Increased staffing and resources within Memory Disorder Clinics (MDCs)
- Growth and operations of the Florida Alzheimer's Centers of Excellence (FACE)

These increases will enhance the state's capacity to respond to the evolving demands of ADRD care and research and will allow for expanded outreach, training, and family support initiatives.

Member Projects

In addition to core appropriations, several "member projects" funding initiatives submitted by individual legislators to address local or regional needs—were successfully approved. These projects reflect strong community and legislative engagement with ADRD issues and will contribute to locally tailored solutions and pilot programs that can inform statewide strategies.

While no new legislation was enacted this cycle, the support for ADRD-related funding illustrates a growing recognition among lawmakers of the importance of continued investment in dementia care and infrastructure. Looking ahead, the ADAC remains committed to advocating for codification of critical programs, such as FACE, and revisiting policy proposals to strengthen workforce training, care coordination, and research participation.

Section 5

The Alzheimer's Disease Advisory Committee

ADAC - Section 430.501, Florida Statutes

Established by the Florida Legislature in 1986 as part of the broader Alzheimer's Disease Initiative, the Alzheimer's Disease Advisory Committee (ADAC) serves as a vital advisory body addressing the growing impact of Alzheimer's disease and related dementias (ADRD) throughout Florida. In response to the increasing prevalence and significant impact of ADRD within the state, the Legislature expanded ADAC's membership in 2019 from 10 to 15 members to enhance its capacity and expertise.

The committee's composition includes eleven members appointed by the Governor, alongside two members each appointed by the President of the Senate and the Speaker of the House of Representatives. This statutory framework established the committee's primary mission: to "advise the Department regarding legislative, programmatic, and administrative matters that relate to persons living with Alzheimer's disease and their caretakers."

To ensure comprehensive representation, the ADAC statute encourages membership from diverse stakeholder groups, including law enforcement professionals, Area Agencies on Aging representatives, individuals living with dementia, and Florida Department of Health officials.

Committee Responsibilities

As defined in the 2019 legislative updates, ADAC's core responsibilities encompass:

- Annual Reporting: Preparing and submitting comprehensive annual reports to the Governor, the President of the Senate, the Speaker of the House of Representatives, and the Secretary of DOEA
- **State Plan Development:** Proposing strategic updates to the Alzheimer's Disease State Plan
- Policy and Program Recommendations:
 Developing recommendations addressing
 AD policy and research initiatives, clinical care standards, and institutional, homebased, and community-based programming
- Federal Coordination: Providing essential input and support for Florida's implementation of federal BOLD Act requirements

Statutory Reporting Requirements

In accordance with section 430.501, Florida Statutes, the committee's annual report must comprehensively address:

- Strategic information and evidence-based recommendations regarding Alzheimer's disease policy development
- Detailed documentation of all state-funded initiatives in Alzheimer's disease research, clinical care delivery, institutional care, home-based services, and communitybased programs, including comprehensive outcome assessments
- Strategic proposals for updates to the Alzheimer's Disease State Plan

Committee Activities and Engagement

Throughout each year, ADAC conducts quarterly meetings that bring together ADRD specialists and healthcare providers from across Florida. These collaborative sessions enable the committee to systematically evaluate the multifaceted challenges affecting individuals with ADRD and their families, including public safety considerations, educational and training

requirements, support service delivery, financial resource needs, service capacity limitations (particularly extensive waiting lists), research advancement, ethical and legal considerations, and legislative priorities.

Meeting Schedule 2024-2025

During 2024-2025, ADAC convened on the following dates:

- Wednesday, October 30, 2024 (Q3)
- Tuesday, December 3, 2024 (Q4)
- Wednesday, March 19, 2025 (Q1)
- Wednesday, June 4, 2025 (Q2)

Research and Educational Presentations

Throughout 2024-2025, ADAC facilitated research presentations designed to provide committee members and the public with cutting-edge insights into academic developments and emerging research opportunities. These presentations fostered meaningful dialogue about current service delivery gaps and innovative research directions in ADRD care.

Featured presentation topics included:

- Alzheimer's Association International Conference Update Keith Gibson provided a comprehensive overview of the 2024 AAIC, highlighting breakthrough advancements in early detection through blood testing, promising treatments like Donanemab, and innovative risk reduction strategies. Gibson emphasized the conference's global impact with over 14,443 attendees from 101 countries and showcased the growing involvement of young scientists in Alzheimer's research.
- Respite for All Foundation Daphne
 Johnston presented on RFA's volunteer driven, social-based respite program
 operating across 15 states and 51 ministries.
 The program provides relief for individuals
 with dementia and caregivers through
 small group activities emphasizing social

engagement, relationship building, and community inclusion in a supportive, no-fail environment.

- The Healthy Aging Company Dr. Christian Bréchot discussed THAC's innovative biopharmaceutical approach to age-related diseases, featuring their flagship therapy ALF-5755. This recombinant peptide targets insulin resistance as the root cause of diabetes while addressing both diabetic neuropathy and cognitive decline associated with Alzheimer's disease.
- **GUIDE Dementia Care Benefit** Dr. Adam Perry presented on this new eight-year Medicare pilot program launched in July 2024. The initiative provides coordinated care through four core elements: care navigation, caregiver support and training, respite care, and clinical harm reduction to improve quality of life while reducing institutionalization.
- McKinsey Research on Alzheimer's & Related Dementias McKinsey Health Institute shared comprehensive research projecting significant growth in ADRD cases, with Florida expected to have one of the highest concentrations of older adults by 2040. The presentation outlined future treatment landscapes and emphasized the need for coordinated prevention, screening, and specialized care approaches.
- Art in Mind Natalie Lemke highlighted the successful Pasco-Pinellas Dementia Care and Cure Initiative's community engagement events, which have attracted over 30 participants monthly since 2023. The program provides appropriate communitybased activities for people with memory loss and their care partners while educating community partners on better service delivery.

Section 6

Executive Summary of Recommendations for 2024-2025

Effectively addressing Alzheimer's Disease and Related Dementias (ADRD) in Florida demands a comprehensive, coordinated approach across multiple sectors. This includes policy development, scientific research, clinical care, institutional systems, and community-based services. The recommendations presented here form a strategic framework to strengthen Florida's response to the growing and evolving impact of ADRD.

This report has been developed by the Alzheimer's Disease Advisory Committee (ADAC) with insights gathered from researchers, healthcare professionals, caregivers, community organizations, and individuals living with ADRD throughout the state. The action items are designed to improve care quality, foster innovation in research, and build a more supportive and responsive system for individuals and families affected by ADRD. These goals are centered around five key pillars:

Policy

Policy recommendations call for stronger legislative and regulatory action to address workforce readiness, early detection, and care standards. This includes mandatory ADRD-specific training for healthcare providers, ongoing support for state health initiatives, and expanded efforts to raise public awareness. Embedding ADRD priorities into Florida's broader health policy ensures that systems are better equipped to meet current and future needs.

PILLAR 2
Research

PILLAR 3
Clinical Care

PILLAR 4
Institutional Care

PILLAR 5
Home and CommunityBased Services

Research

Research recommendations emphasize the importance of increasing state and private investment in ADRD research. This includes supporting interdisciplinary collaborations, improving data collection and sharing, and expanding public education around research participation. By fostering a more robust research infrastructure, Florida can contribute to breakthroughs in diagnosis, treatment, and prevention, and position itself as a leader in dementia science.

Clinical Care

Clinical care recommendations focus on enhancing early detection, diagnosis, and ongoing management of ADRD. This involves promoting standardized screening protocols, integrating dementia care into primary and specialty care settings, and providing continuing education for clinicians. Expanding access to high-quality, evidence-based care will lead to better health outcomes and a more coordinated care experience for patients and caregivers.

Institutional Care

Recommendations for institutional care highlight the need for consistent training, improved care practices, and innovative therapeutic approaches in long-term care facilities. Emphasis is placed on creating dementia-friendly environments, supporting staff development, and incorporating non-pharmacological therapies like music and reminiscence therapy. These efforts will elevate the quality of care and improve the well-being of residents in institutional settings.

Home and Community-Based Services

Home and community-based services play a vital role in supporting individuals with ADRD and their families. Recommendations focus on expanding access to respite care, enhancing caregiver training, and strengthening community partnerships. The continued use of therapeutic programs and culturally responsive education will help individuals remain safely and independently at home for as long as possible, while also reducing caregiver burden.

A united, cross-sector strategy is essential to meet the complex challenges of Alzheimer's Disease and Related Dementias (ADRD). By implementing these evidence-informed recommendations across policy, research, clinical care, institutional systems, and community services, Florida can significantly improve quality of life for individuals with ADRD and their caregivers. This multifaceted approach not only addresses today's needs but also prepares the state for the future, serving as a model for comprehensive dementia care nationwide.

Pillar 1: Policy

Effective policy development is essential for strengthening Florida's response to Alzheimer's Disease and Related Dementias (ADRD). The following recommendations support a coordinated legislative and advocacy strategy that advances the goals of Florida's State Health Improvement Plan (SHIP) while reinforcing the mission of the Alzheimer's Disease Advisory Committee (ADAC).

1. Launch a State-Supported Public Awareness Campaign

A statewide public awareness campaign, backed by the Florida Department of Health and other key agencies, would significantly increase understanding of ADRD, promote early detection, and reduce stigma. This effort would align with SHIP goals around health equity and access, and support broader objectives related to caregiver support and community education.

2. Advocate for Codification of the FACE Program

The Florida Alzheimer's Center of Excellence (FACE) program plays a critical role in improving access to high-quality care and resources for individuals with ADRD and their caregivers. Continued advocacy is needed to codify the FACE program into state statute, ensuring its long-term sustainability and integration into Florida's healthcare infrastructure.



3. Expand Supportive Services for Caregivers

Policymakers should evaluate and implement opportunities to expand wraparound services and supports for caregivers, including respite care, mental health services, and caregiver training. These services reduce caregiver burnout and improve quality of life for both caregivers and individuals living with ADRD.

4. Develop and Distribute an Advocacy Toolkit

To strengthen stakeholder engagement, an advocacy toolkit should be created for use by ADAC members and community advocates. This toolkit would include talking points, fact sheets, district-specific data, and guidance for engaging with legislators and community leaders.

5. Empower Grassroots Legislative Advocacy

Encourage committee members and community stakeholders to engage in grassroots advocacy by writing letters to legislators and participating in public comment opportunities. A template letter or general advocacy form should be provided to make these efforts more accessible and impactful.

6. Bundle Related Legislative Items

To improve efficiency and legislative impact, ADRD-related bills should be bundled under a unified legislative package, with clearly defined implementation dates. This approach supports better coordination across programs and facilitates long-term planning and funding.

7. Use Data to Drive Local Engagement

Utilize district-specific ADRD data to inform legislators and community leaders about the local impact of Alzheimer's and related dementias. Tailoring messaging and policy priorities to specific regions can strengthen advocacy efforts and lead to more targeted, responsive solutions.

8. Align Advocacy with Budget Timelines

Review previous-year budget items to identify opportunities for strategic funding requests during the current legislative session. This proactive approach ensures that advocacy efforts are timely, data-driven, and aligned with the state's fiscal planning cycle.

Pillar 2: Recommendation for ADRD Research

Alzheimer's disease research in Florida is at a critical juncture, with significant opportunities to expand innovation, improve participation in clinical studies, and align resources with the growing needs of the population. The following recommendations focus on enhancing research funding, increasing accessibility, and strengthening infrastructure and partnerships to support cutting-edge discovery and care.

1. Increase Funding Through the Ed and Ethel Moore Program

To keep pace with rising demand and scientific opportunity, state funding for Alzheimer's research must be increased. While other diseases like cancer have seen dramatic funding growth, Alzheimer's research funding through the Ed and Ethel Moore program has remained relatively flat over the past decade. Strategic investments in this program would support high-impact studies across prevention, diagnosis, treatment, and caregiver support, and allow Florida to remain competitive in the national research landscape.

2. Expand Access to Clinical Trials Through Trial Matching

Clinical trial recruitment remains a major barrier to advancing Alzheimer's research. Florida should work to develop a state-supported trial matching platform modeled after the Alzheimer's Association's TrialMatch system. This could be embedded within the existing infrastructure of the Florida Alzheimer's Centers of Excellence (FACE), which are already engaged with Memory Disorder Clinics (MDCs), healthcare providers, and the ADRD community.

FACE is uniquely positioned to:

 Match eligible individuals and families to appropriate trials.

- Coordinate with MDCs, neurologists, and primary care providers to raise awareness about available studies.
- Bridge the gap between researchers and diverse patient populations, ensuring more equitable participation in clinical research.

3. Improve Trial Design for Caregivers and Persons Living with Dementia

Recruiting home-based caregivers and individuals living with dementia requires flexible, accessible research design. Programs must minimize participant burden by:

- Offering shorter, modular interventions instead of multi-week time-intensive programs.
- Utilizing online, asynchronous content to accommodate caregivers' schedules.
- Providing clear, supportive communication that explains the study's goals, safety measures, and potential benefits—not only for the participant, but for the broader community.

Researchers are encouraged to integrate caregiver-centered design principles early in study planning to improve recruitment and retention.

4. Strengthen Partnerships with Medical and Professional Associations

Collaborating with professional associations is key to expanding research awareness and clinician engagement. Partnerships should be formalized with organizations such as:

- Florida Medical Association
- Florida Osteopathic Medical Association
- State and regional Neurological Societies

These partnerships can help:

- Promote clinical trials to physicians and encourage referrals.
- Disseminate educational materials about ongoing research.
- Engage providers in shaping research priorities and dissemination.

5. Support Innovation in Therapeutics and Technology

Ongoing support should be directed toward emerging areas of ADRD research, including:

- Focused ultrasound therapies
- Pharmaceutical innovations
- Non-pharmacological interventions such as digital therapeutics and caregiver tools

Encouraging collaborative research publications from Florida's MDCs—leveraging their large and diverse patient populations—will strengthen the state's contribution to global Alzheimer's research.

6. Bring Research to the Participant

To overcome common participation barriers—such as transportation, scheduling, and awareness, Florida should invest in community-based research engagement strategies.

Strategies can include:

- "Research-to-you" models that bring trials directly into homes or community centers.
- Layered educational outreach that explains the purpose, safety, and potential benefits of participating in research.
- Building trust through culturally appropriate messaging and consistent, transparent communication.

Pillar 3: Clinical Care

High-quality clinical care for individuals with Alzheimer's Disease and Related Dementias (ADRD) requires a proactive, informed, and standardized approach across all healthcare settings. As science and treatment options rapidly evolve, Florida must prioritize access to current information, specialized training, and coordinated care models. The following recommendations aim to strengthen the clinical care infrastructure across the state.

1. Improve Access to Up-to-Date Clinical Information for Healthcare Providers

The field of Alzheimer's research and treatment is advancing rapidly. To ensure that primary care physicians and other frontline providers remain informed, Florida should develop a system for disseminating timely, evidence-based updates on ADRD diagnosis, treatment options, and care models

Strategies can include:

- Regular electronic bulletins to providers
- Updates delivered through continuing medical education (CME) programs
- Integration with electronic health record systems

An information app or online portal specifically designed for healthcare professionals would offer a centralized, accessible resource for staying current on best practices and clinical guidelines.

2. Develop a Statewide Repository of Best Practices

To support continuous learning and improvement in clinical dementia care, Florida should establish a centralized repository of clinical best practices, hosted and maintained by the Florida Alzheimer's Centers of Excellence (FACE). This dynamic, digital platform would serve as a "one-stop shop" for:



- Clinical guidelines and updates
- Care coordination tools
- Multidisciplinary care models
- Shared resources from across the state's Memory Disorder Clinics (MDCs)

Disseminated electronically and through educational forums, this repository would be an essential tool for clinicians seeking the most current, effective care strategies.

3. Expand Specialized Certification in Dementia Care

Encouraging widespread specialized certification for dementia care can elevate the quality of care across all settings. Programs such as the Certified Dementia Practitioner (CDP) credential offer structured, evidence-based training for healthcare professionals.

Strategies can include:

- Promote dementia-specific certification for healthcare workers, including physicians, nurses, and allied health professionals
- Incentivize participation through professional development credits or reimbursement programs

 Collaborate with FACE and MDCs to provide certification opportunities statewide

These certifications would ensure a skilled, dementia-informed workforce capable of providing high-quality, person-centered care.

4. Standardize Clinical Pathways Across the State

To reduce variability in care and improve patient outcomes, FACE should lead efforts to develop and roll out a standardized patient care pathway for individuals with ADRD. In collaboration with MDCs, primary care teams, and specialists, this model would:

- Define clear roles and responsibilities across the care team
- Ensure timely referral, diagnosis, and management
- Integrate medical, behavioral, and social supports

Standardized pathways would promote continuity of care, reduce system fragmentation, and support earlier intervention.

5. Promote Culturally Responsive Care and Engagement

To improve care equity, efforts must be made to engage and support underrepresented populations, particularly African American and Hispanic communities, who often face barriers to ADRD diagnosis and care.

Strategies can include:

- Partnering with statewide African American physician organizations to co-develop and disseminate educational materials
- Ensuring cultural relevance in provider education and patient communication
- Engaging community leaders and organizations in outreach and training efforts

Pillar 4: Institutional Care

As Florida's aging population grows, the need for high-quality, dementia-informed care in institutional settings—such as long-term care facilities, assisted living centers, and skilled nursing homes—continues to rise. Ensuring that facilities are staffed with well-trained, compassionate professionals is critical to improving outcomes for individuals living with Alzheimer's Disease and Related Dementias (ADRD). The following recommendations aim to strengthen the workforce pipeline, support ongoing professional development, and enhance the overall quality of institutional dementia care.

1. Address the Direct Care Workforce Shortage

Florida has made significant strides in training direct care workers, but the demand for a steady, well-prepared workforce continues to outpace supply.

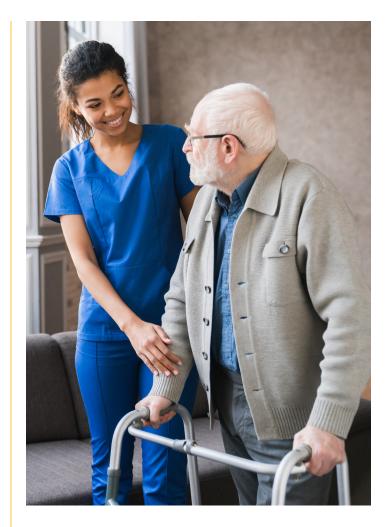
Strategies can include:

- Develop partnerships with stakeholders across healthcare, education, and workforce development to strategically address shortages.
- Expand FACE's role in facilitating placement matching between newly certified professionals and institutional care facilities in need of staffing.
- Promote careers in dementia care through outreach campaigns that highlight job stability, impact, and growth opportunities.

2. Promote Certification and Continuing Education

Quality institutional care depends on an informed and continually updated workforce. Strategies can include:

 Encourage widespread adoption of certifications such as the Certified Dementia Practitioner (CDP) credential.



- Review and advocate for strengthened continuing education (CE) requirements for those working in institutional care, including aides, nurses, and administrative staff.
- Codify ongoing training standards through the return of key legislation—such as previous AHCA-related proposals—during the 2026–2027 legislative cycle.

3. Create Alternative Entry Pathways into the Dementia Care Field

To expand and diversify the workforce, Florida should explore alternative pathways into the field.

Strategies can include:

 Collaboration with trade schools to develop accelerated dementia care certification programs.



- FACE-led marketing and outreach promoting trade school careers in dementia care to high school graduates, adult learners, and career switchers.
- Engagement with immigration programs, helping legally residing individuals with international healthcare backgrounds transition into Florida's dementia care workforce—offering them a meaningful alternative to underemployment in unrelated sectors.

4. Strengthen Partnerships with Educational Institutions

Building a sustainable workforce requires strong collaboration with Florida's state colleges, private institutions, and vocational training programs. These partnerships can:

- Ensure dementia-specific training is embedded in all relevant healthcare curricula.
- Connect students with internship and job placement opportunities in long-term care settings.
- Encourage faculty development around dementia care competencies and emerging best practices.

Pillar 5: Home and Community Based Services

As most individuals living with Alzheimer's Disease and Related Dementias (ADRD) remain in their homes or community settings throughout most of the disease progression, access to well-organized, easily navigable support services is critical. Home and community-based services (HCBS) not only reduce the burden on institutional care systems but also improve quality of life and independence for individuals with ADRD and their caregivers. The following recommendations aim to strengthen Florida's HCBS network by improving access, awareness, and coordination through the leadership of the Florida Alzheimer's Centers of Excellence (FACE).

1. Develop a Centralized HCBS Information Hub via FACE

To improve public access to community-based dementia resources, Florida should invest in the creation of a dedicated FACE website and companion mobile app. This centralized digital hub would:

- Serve as a repository of HCBS offerings, including respite care programs, caregiver support groups, adult day services, and therapeutic programs.
- Include links to 501(c)(3) partner organizations, allowing for direct donations and community support.
- Offer up-to-date information on local providers, eligibility, and access instructions.
- Provide navigation support to help families identify the right services for their needs.

This platform would also connect with Institutional Care efforts (Pillar 4), acknowledging the overlap in caregiver and patient needs between community and residential care environments.



2. Promote and Expand Successful Respite Programs

Programs like "Respite for All" offer a scalable, inclusive model of respite care that can provide much-needed relief to caregivers across the state. Strategies can include:

- Support the replication and expansion of this model in partnership with nonprofit and community organizations.
- Advocate for sustainable funding to support inclusive, community-based respite services that are affordable and accessible.

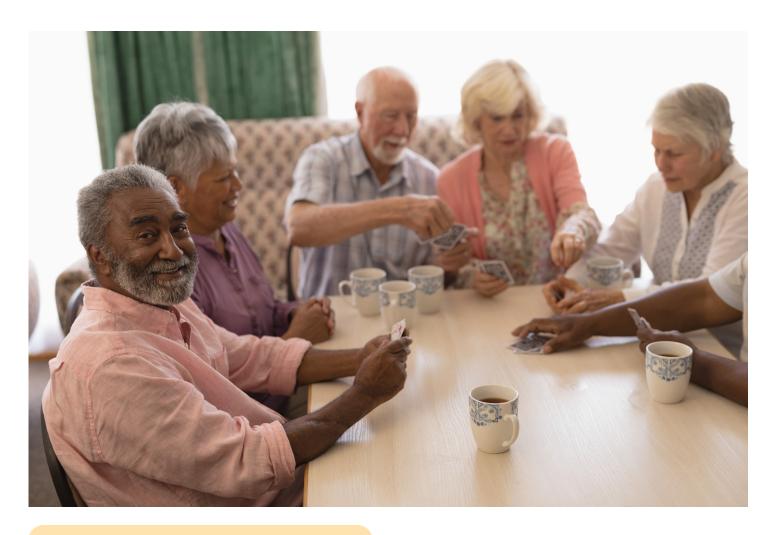
These programs are vital for reducing caregiver burnout and supporting the long-term ability of families to care for loved ones at home.

3. Increase Visibility and Utilization of Care Navigators

Care Navigators play a critical role in connecting families to appropriate services and resources.

Strategies can include:

- Make Care Navigator contact information more readily available, distributing it through dementia clinics, neurology practices, primary care providers, and community centers via direct mail, email campaigns, and print materials.
- Encourage in-person engagement, allowing navigators to participate in local events or service delivery, so families can put a face to the name and build trust.
- Advocate for additional funding to expand FACE's navigator program, ensuring sufficient staffing and training to serve communities across the state.



4. Support Technology Access and Innovation

Technology plays an increasingly vital role in dementia care—from remote monitoring and safety devices to caregiver support platforms.

Strategies can include:

- Create and maintain a repository of dementia-related technologies, hosted on the FACE website, highlighting current tools on the market as well as emerging innovations.
- Identify and promote technology companies offering promising ADRD solutions through curated listings and provider reviews.
- Encourage partnerships between FACE, MDCs, and technology developers to pilot and evaluate tools in real-world settings, improving access and usability for families.

Closing

Florida is at a critical crossroads in its response to Alzheimer's Disease and Related Dementias (ADRD). With a rapidly growing aging population and increasing demand for services across the care continuum, the state must remain proactive, coordinated, and innovative in its efforts. This report outlines a comprehensive set of recommendations rooted in five strategic pillars: Policy, Research, Clinical Care, Institutional Care, and Home and Community-Based Services.

From expanding clinical trial access and building a certified, culturally responsive workforce to strengthening caregiver supports and modernizing care coordination through technology, these recommendations reflect the collective input of stakeholders, professionals, and families throughout Florida. They emphasize the importance of centralized information systems, standardized care

pathways, specialized training, and community engagement as foundational elements in delivering high-quality, person-centered dementia care

Central to these efforts is the continued support and expansion of the Florida Alzheimer's Centers of Excellence (FACE), which are uniquely positioned to bridge gaps between research, clinical care, policy implementation, and family support. Codifying FACE in state statute, securing sustainable funding, and empowering it to lead digital innovation and workforce development will ensure a more resilient and responsive ADRD infrastructure statewide.

Alzheimer's disease is not a challenge that can be solved in silos. It demands collaboration across sectors, disciplines, and communities. With bold leadership, ongoing advocacy, and commitment to equity and innovation, Florida can set a national standard for comprehensive, compassionate dementia care.

By implementing the strategies outlined in this report, Florida can significantly improve outcomes for individuals living with ADRD and their caregivers – enhancing quality of life today, while laying the foundation for a better future for all Floridians



ELDERAFFAIRS.ORG

4040 Esplanade Way Tallahassee, Florida 32399-7000

Phone: (850) 414-2000 | Fax: (850) 414-2004