



# Caregiver Engagement – What, How and Why?

Victoria O'Connor, Alzheimer's Disease and Related Disorders Program Manager



# Introduction

Alzheimer's Disease and Related Disorders Program

Rhode Island Department of Health

Federal Funding: Center for Disease Control and Prevention funding, "BOLD" grant

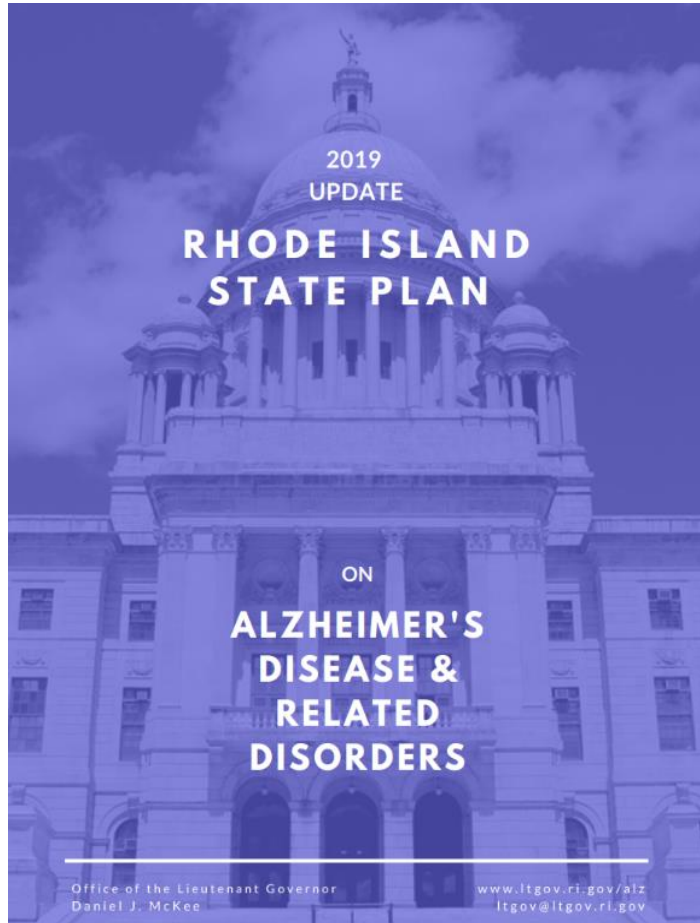
\$500,000 per year

Current funding cycle: 9/30/2023-9/29/2028



*Grammy Louise*

# 2019 Rhode Island State Plan on Alzheimer's Disease and Related Disorders



- Created by then Lieutenant Governor (now Governor) Daniel McKee and the "Executive Board on Alzheimer's Disease"
- 34 Recommendations
- 20/34 recommendations achieved or in-progress
- Laid the foundation for Rhode Island Department of Health to apply for federal funding

# 2019 State Plan – Top 3 Recommendations

1. Allocate one director-level position within RIDOH to coordinate implementation of actions in this State Plan in and through the activities of public health, in close collaboration with the Lt. Governor’s office, Office of Healthy Aging, and other agencies.
  - Utilizing BOLD funding to support at least one grant-funded full-time employee (FTE) within RIDOH to convene key partners, with the goal of achieving Rhode Island ADRD State Plan recommendations.
2. Promote ADRD research opportunities of all types.
  - Collaborating across Rhode Island ADRD research institutions (i.e., Butler Hospital Memory and Aging Program; Alzheimer’s Disease and Memory Disorders Center at Rhode Island Hospital; and the Mood and Memory Center) to promote ADRD research opportunities with a specific goal of increasing the diversity of research participants in both clinical and non-clinical trials.
3. Include brain health in existing publicly funded health promotion and chronic disease management activities.
  - Cross-collaborating with existing chronic disease programs (i.e., the Diabetes, Heart Disease, and Stroke Program, Tobacco Control Program) to promote messaging around shared and protective risk factors for dementia by utilizing terms such as “What’s good for your heart is good for your brain.”

# 2019 State Plan Accomplishments

In addition to achieving the top three recommendations, the following recommendations were also achieved:

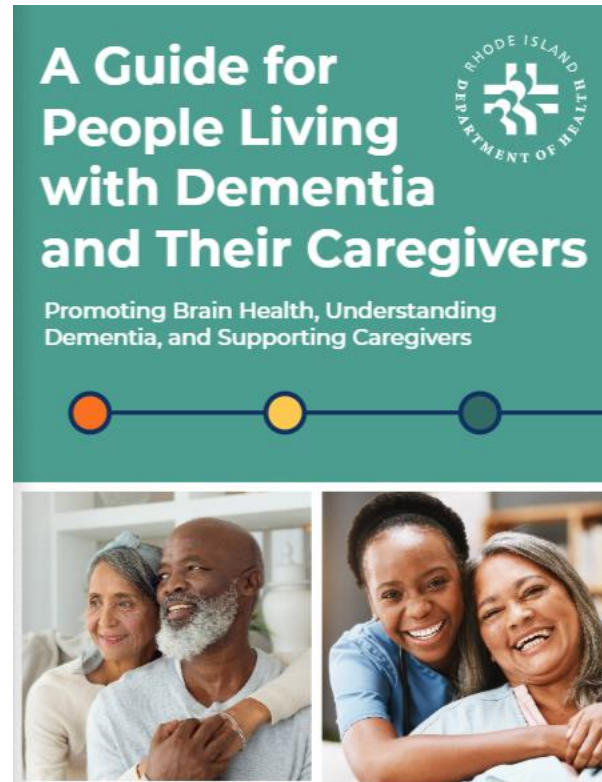
- Implement and analyze public health surveillance data through the caregiving and cognitive health related modules available from the Behavioral Risk Factor Surveillance System
- Increase collaboration between state universities and consider a concentration in dementia care
  - Rhode Island College Dementia Certificate Program – *“Building Dementia Competence: Advanced Skills for Effective Care and Support”*
- Develop and maintain web and offline information about ADRD
  - Visit the Rhode Island Department of Health table for helpful resources

# A Guide for People Living with Dementia and Their Caregivers

Promoting Brain Health, Understanding Dementia, and Supporting Caregivers

## This guide can help with:

- Understanding changes in memory and thinking
- Identifying risk factors for dementia
- Knowing the different stages of memory loss
- Learning about emerging treatments
- Finding resources and support
- Forming an action plan



## How can I get this free guide?

Visit [health.ri.gov/ribrainhealthguide](https://health.ri.gov/ribrainhealthguide)

Scan this QR code for a digital version:



Contact The Alzheimer's Association  
24/7 Helpline for more assistance:

1-800-272-3900

# 2024-2029 Rhode Island State Plan on Alzheimer's Disease and Related Disorders



Rhode Island  
Alzheimer's Disease  
and Related Disorders

2024-2029 State Plan



- Created by the Rhode Island Department of Health and the statewide Alzheimer's Disease and Related Disorders Advisory Council
- 4 Sector Areas
  - Community
  - Workforce
  - Health System
  - Public Health
- 36 Strategies

# Plan Elements by Sector Area

- Sector 1: Community
  - Rhode Islanders of all ages and abilities, particularly high-risk populations, will have access to information, resources, and tools that promote knowledge of brain health; improve quality of life for people who are living with dementia and their caregivers; and support people as they navigate the stages of the disease.
- Sector 2: Workforce
  - The Rhode Island workforce will be knowledgeable about and connected to opportunities to expand their skillset to serve people with dementia and their caregivers, will be encouraged to collaborate with key stakeholders across the care continuum, and will be confident in their ability to serve ADRD populations across various settings.



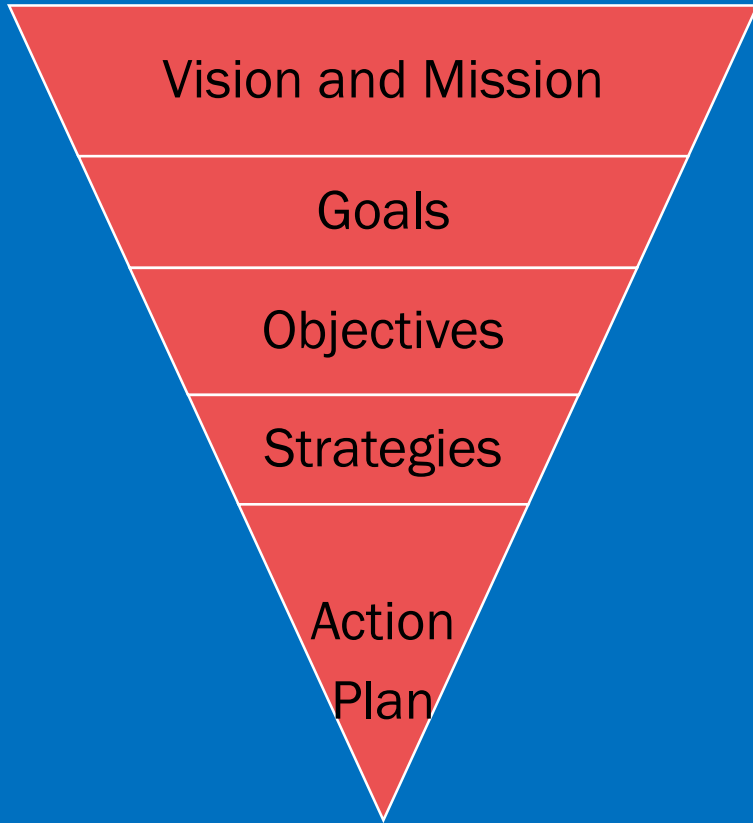
# Plan Elements by Sector Area

- Sector 3: Health System
  - The Health System will be equipped to provide the right care, at the right time, in the right setting for people living with dementia and their caregivers in Rhode Island.
- Sector 4: Public Health
  - Rhode Island will lead the nation in addressing dementia through a public health approach.



# How can you participate in State Plan activities?

# Action Planning Sessions



Sign up to participate at the Rhode Island Department of Health table!

1

Session 1:  
4/23/24  
8:30-10:30am

2

Session 2:  
5/8/24  
2:00-4:00pm

3

Session 3:  
5/15/24  
12:00-2:00pm



# Why should you participate?

Your voice matters!

# What do we know about caregiving?

## Nation-wide

- 83% of help provided to older adults in the United States comes from family members, friends, or other unpaid caregivers.
- 48% of caregivers who provide help to older adults do so for someone with Alzheimer's or another dementia.
- More than 11 million Americans provide unpaid care for people with Alzheimer's or other dementias
- In 2023, caregivers of people with Alzheimer's or other dementias provided an estimated 18.4 billion hours of unpaid care valued at \$346.6 billion.
  - This is 57% of the net value of Walmart's total revenue in 2023 (\$611.3 billion) and nearly 15 times the total revenue of McDonald's in 2022 (\$23.3 billion).

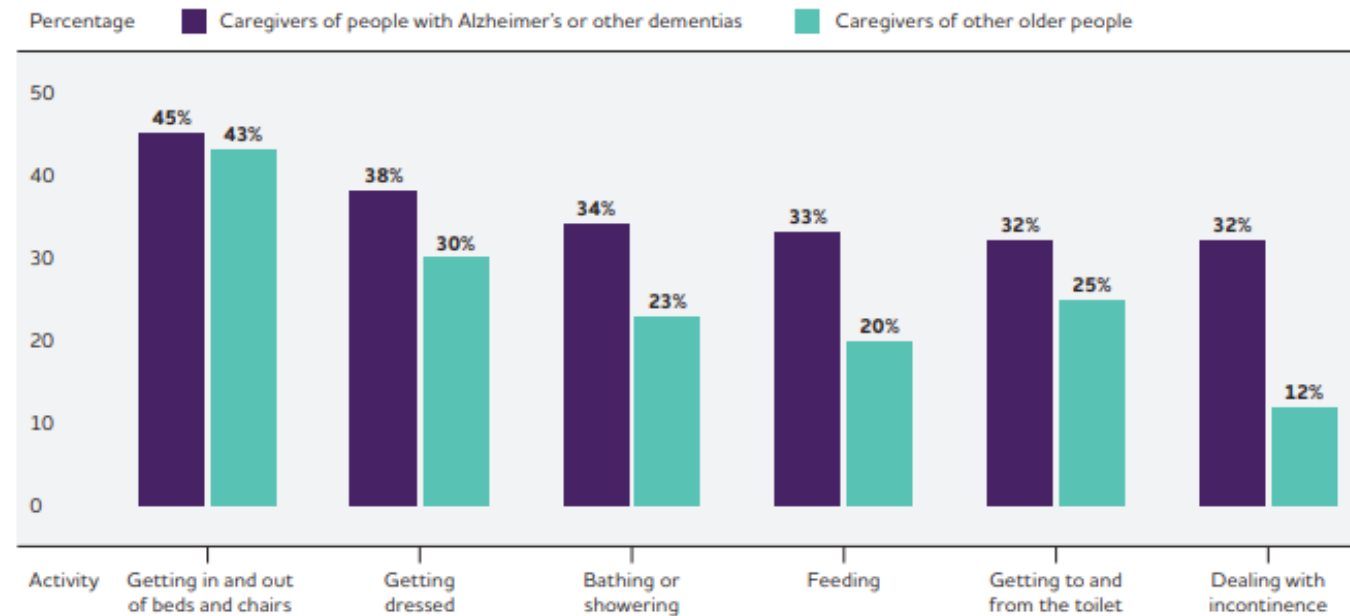
## Rhode Island

- 36,000+ total number of caregivers
- 51,000,000 hours of unpaid care
- 54.2% experience chronic health conditions
- 41.0% experience depression
- 11.5% report poor physical health

# Caregiving Tasks – Activities of Daily Living

Figure 9

Proportion of Caregivers of People with Alzheimer's or Other Dementias Versus Caregivers of Other Older People Who Provide Help with Specific Activities of Daily Living, United States, 2015



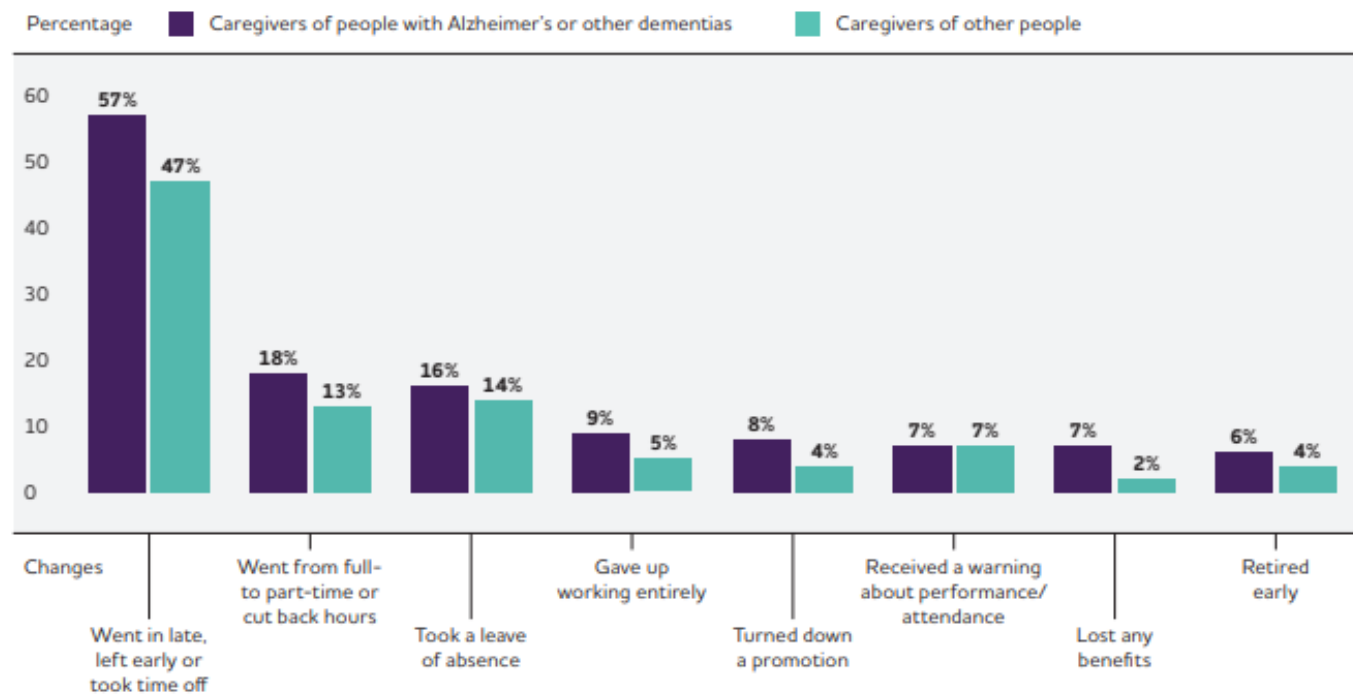
Created from data from the National Alliance for Caregiving in Partnership with the Alzheimer's Association.<sup>442</sup>



# Caregiving and Economic Burden

Figure 11

Work-Related Changes Among Caregivers of People with Alzheimer's or Other Dementias Who Had Been Employed at Any Time Since They Began Caregiving



Created from data from the National Alliance for Caregiving in Partnership with the Alzheimer's Association.<sup>442</sup>



# Homework

- **Connect at the Rhode Island Department of Health table**
- **Take home the Rhode Island Brain Health Guide**
- **Sign up for an Action Planning Session**
- **Inform the Rhode Island State Plan on Alzheimer's Disease and Related Disorders**
- **Engage with the Alzheimer's Association – Rhode Island Chapter for support and resources**
- **Connect with each other**
- **Enjoy the day**