Rhode Island Alzheimer's Disease and Related Disorders

2024-2029 State Plan

OFFICE OF THE LIEUTENANT GOVERNOR

RHODE ISLAND DEPARTMENT OF HEALTH

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Dear Colleagues, Friends, and Rhode Islanders,

We are thrilled to present the Rhode Island Alzheimer's Disease and Related Disorders State Plan 2024-2029. This plan outlines more than nine strategic objectives that will empower all Rhode Islanders, regardless of age, race, ethnicity, cognitive ability, or ZIP code, to embrace brain healthy lifestyles; understand dementia and cognitive decline; and achieve an optimal quality of life as they age in Rhode Island. Health equity and social determinants of health remain at the forefront as a cross-cutting theme in this State Plan.

According to the Alzheimer's Association, there are more than 24,000 Rhode Islanders living with some form of dementia. Given the state's aging population, we know this number is expected to increase by at least 12.5% by 2025. Communities of color are disproportionally impacted—Black/African American populations are two times more likely to develop some form of dementia than their White counterparts, while Hispanic populations are one-and-a-half times more likely to develop some form of dementia than their White counterparts.

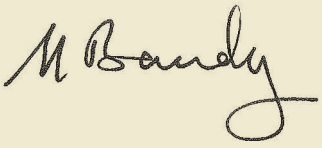
Although we think of dementia as a condition that most commonly impacts older adults, early- or young-onset can affect individuals in their thirties and forties. The 2019 Behavioral Risk Factor Surveillance System (BRFSS) indicates that 1 in 9 Rhode Islanders ages 45 and older are experiencing Subjective Cognitive Decline (SCD), a self-reported memory problem that has gotten worse in the past year. Only half of the individuals with SCD have discussed their symptoms with a healthcare professional.

Alzheimer's disease and other forms of dementia have an enormous impact on informal, unpaid caregivers. In Rhode Island, more than 36,000 unpaid caregivers provide more than 51 million hours of unpaid care. More than half of these caregivers live with their own chronic health conditions.

The Centers for Disease Control and Prevention (CDC) has developed the Healthy Brain Initiative Roadmap that aligns action items to address Alzheimer's disease and other forms of dementia with the Essential Services of Public Health. The Rhode Island Department of Health (RIDOH) has adopted the Healthy Brain Initiative Roadmap through the Rhode Island Alzheimer's Disease and Related Disorders Program. This Program has received CDC funding to build diverse partnerships, convene subject matter experts, engage people with lived experience, and lead initiatives that aim to implement the strategies within this State Plan.

We look forward to continued collaboration with all Rhode Islanders who have developed and will be impacted by the goals, objectives, and strategies within this State Plan. Thank you for your partnership and dedication to supporting those living with and caring for people with dementia in our state.

Sabina Matos
Lieutenant Governor



Utpala Bandy, MD, MPH
Interim Director of Health

Acknowledgements

Convened since December 2019, the Rhode Island Advisory Council on Alzheimer's Disease and Related Disorders meets regularly with the goal of providing oversight into activities outlined in the Rhode Island State Plan on Alzheimer's Disease and Related Disorders (ADRD).

The following is a list of appointed Council members and their representing agency. Each member brings their own unique perspective and expertise to monthly Council meetings and the State Planning process. Their tireless dedication to promoting brain health and supporting those living with dementia and their caregivers in Rhode Island is celebrated in the spirit of this State Plan.

Rhode Island Alzheimer's Disease and Related Disorders Advisory Council

Representing Agency	Designee	Appointment Description
Aging in Community Sub-Committee of the Long-Term Care Coordinating Council (LTCCC)	Maureen Maigret	Speaker of the House Appointee
Alzheimer's Association – Rhode Island Chapter	Donna McGowan	Governor's Appointee – Representative from an Alzheimer's disease organization that funds research and has demonstrated experience in care and patient services
Alzheimer's Disease and Memory Disorders Center, Rhode Island Hospital	Terry Fogerty	Governor's Appointee – Alzheimer's disease patient advocate
Brown Geriatrics	Thomas Bayer	Governor's Appointee – Representative from the adult primary care community
Butler Hospital Memory and Aging Program	Meghan Riddle	Governor's Appointee – Researcher with Alzheimer's-related expertise in basic, translational, clinical and drug development science
Butler Hospital Memory and Aging Program	Tara Tang	Governor's Appointee – Representative from an Alzheimer's advocacy organization that provides services to families and professionals, including information and referrals, support groups, care consultation, education, and safety services
CareLink Rhode Island	Christine Gadbois	Governor's Appointee – healthcare professional
Leon Mathieu Senior Center	Herb Weiss	Senate President Appointee
Lt. Governor's Office	Grace Sneesby	Lt. Governor, Designee
Lt. Governor's Office - LTCCC	Lt. Governor Sabina Matos	Chair of the Long-Term Care Coordinating Council
Office of Healthy Aging (OHA)	Dana McCants-Derisier	Director, Office of Healthy Aging, Designee
Person with Lived Experience, Caregiver	Karen Friend	Governor's Appointee – Alzheimer's disease caregiver
Rhode Island Assisted Living Association	David Bodah	Governor's Appointee – Representative from the long-term care industry
Rhode Island College	Marianne Raimondo	Governor's Appointee – Representative from an organization focused on Alzheimer's workforce development
Rhode Island Department of Health	Nancy Sutton (Chair)	Director, Rhode Island Department of Health, Designee
United Healthcare	Christine West	Governor's Appointee – Representative of a health care insurer
United Way of Rhode Island	Sylvia Bernal	Lt. Governor Appointee – Sole appointment with no reference to list
	To be determined	Lt. Governor Appointee – Two individuals with experience as caregivers selected from a list of five names submitted by the Speaker of the House. Selected appointees should reflect diverse back-grounds, including diversity in race and ethnicity
	To be determined	Lt. Governor Appointee – Two individuals with experience as caregivers selected from a list of five names submitted by the Senate President. Selected appointees should reflect diverse backgrounds, including diversity in race and ethnicity

Introduction

Background

Rhode Island has an aging population.

Over the past decade, Rhode Island has shown trends of an aging population. In 2020, 23.0% of the State's population were ages 60 and older[1]. Rhode Island must utilize this demographic data to inform public health decision-making and build a framework to prioritize the health needs of its aging population. The overall risk and health burden of Alzheimer's disease and related disorders (ADRD) has been prominent for Rhode Islanders within this age range. In 2020, an estimated 24,000 adults in Rhode Island ages 65 and older were living with ADRD[2]. This makes Rhode Island the state with the third highest percentage of Alzheimer's disease in New England.

Socioeconomic factors impact people living with dementia and caregivers.

Some communities in Rhode Island have seen higher rates of ADRD among people ages 65 and older, including Providence, Pawtucket, Central Falls, and Woonsocket—with Central Falls having the highest rates at 20.0%[3]. The communities with the largest burden of ADRD have statistically had trends of growing Black and Hispanic populations as well as higher percentages of families living below the federal poverty line[4]. For instance, Central Falls has the highest Hispanic population ages 65 and older in the state at 30.0%. This population is also recognized as one of the most affected by ADRD[3]. In Central Falls, 85.7% of the population live below the federal poverty line[3]. These economic trends remain consistent for Pawtucket (67.0%), Woonsocket (66.0%), and Providence (62.0%)—where Black and Hispanic populations are also most prevalent, and burden of disease is higher[3,4].

Economic disparities between racial groups contribute to gaps in caregiver burden. In some communities, those with ADRD face increased financial challenges and limited access to home and community-based resources such as adult day services and respite care. Compared to White caregivers, Black caregivers are more likely to provide more than 40 hours of care per week (54.0% versus 39.0%) and 69.0% less likely to use respite services than White caregivers[2]. Poverty, low income, job instability, and low economic opportunity have negative impacts on caregivers' abilities to care for their loved ones affected by ADRD. Caregivers with limited financial resources may resort to other means for covering necessary expenses by taking on debt, giving up assets, or deprioritizing the treatment needed to manage their own health conditions[5].

There are lifestyle modifications that can be made to reduce the risk of dementia.

There are many cited risk factors for dementia, including age, genetics, gender, and family history. A new CDC report identifies eight modifiable risk factors, including 1) hypertension, 2) not getting enough physical exercise, 3) obesity, 4) diabetes, 5) depression,6) smoking, 7) hearing loss, and 8) binge drinking, and their prevalence among adults 45 and older. The report indicates that adults experiencing Subjective Cognitive Decline were more likely to report at least four of the risk factors (34.0%) than those without cognitive decline (13.0%), and the modifiable risk factors were more common among African American, Hispanic, American Indian, and Alaska Native populations[6].

The Rhode Island workforce will need to expand to meet the needs of people living with dementia.

Workforce shortages across the state may have an impact on the quality and availability of care for people living with dementia and their caregivers. There are currently 33 geriatricians and 7,390 home health and personal care aides in Rhode Island who are facing challenges with increasing workforce demands[2]. It is estimated that there will need to be a 46.0% increase of geriatricians and 28.0% increase of home health and personal care aides by 2050 to adequately care for people living with dementia in Rhode Island. This poses new opportunities for specialty training and continued workforce development.

History of the Plan

A State plan to address ADRD has been active in Rhode Island since 2013. This statewide focus began in 2012, when a joint resolution directed the Lt. Governor's Long-Term Care Coordinating Council (LTCCC) to serve as the organizational umbrella to oversee the development of an Alzheimer's State Plan for Rhode Island.

An updated State Plan was released in 2019 by the Lt. Governor's Office. It was developed in partnership with an LTCCC Executive Board on Alzheimer's which included subject matter experts and people with lived experience. Nearly 200 surveys and 23 local meetings were facilitated to identify and understand current challenges impacting people living with dementia and caregivers. Forty-five key person interviews were also conducted to inform the 2019 State Plan.

A top recommendation was to allocate one position within RIDOH to coordinate implementation of actions in the State Plan through the activities of public health and in close collaboration with the Lt. Governor's Office, the Office of Healthy Aging (OHA), and the Alzheimer's Association – Rhode Island Chapter. This recommendation was achieved in 2019, when RIDOH received CDC "Building our Largest Dementia" (BOLD) Funding which supports the RIDOH ADRD Program.

In collaboration with the statewide ADRD Advisory Council, the RIDOH ADRD Program launched a revision process of the 2019 ADRD State Plan. Key partners were convened at an ADRD Stakeholder Summit and through community forums with the Alzheimer's Association – Rhode Island Chapter, to inform and update State Plan recommendations. In alignment with the CDC Healthy Brain Initiative Roadmap, the revised State Plan includes goals, objectives, and strategies to guide the RIDOH ADRD Program and its partners in continuing to support people living with dementia and their caregivers.

Timeline of ADRD State Plan Development

2012

Long-Term Care Coordinating Council convenes a work group to oversee the development of an Alzheimer's State Plan for Rhode Island

2013

Lt. Governor's Office finalizes and widely distributes the first State Plan on Alzheimer's Disease and Related Disorders

2015

Lt. Governor's Office convenes an Executive Board on Alzheimer's disease to revise the State Plan

2018

Lt. Governor's Office and the Alzheimer's Association Rhode Island Chapter secure grant funding to update the State Plan

2019

An updated State Plan is published by the Lt. Governor's Office

2019

Rhode Island General Assembly passes bill creating the statewide ADRD Advisory Council, and the RIDOH ADRD Program is established

2019

RIDOH is awarded a three-year CDC BOLD funding opportunity to address dementia through a public health approach

2021

ADRD Advisory Council launches review process of the 2019 Rhode Island ADRD State Plan

2022

Alzheimer's Association – Rhode Island Chapter hosts eight Community Forums throughout the state with more than 100 registrants. Results inform the State Plan revision.

2022

RIDOH ADRD Program hosts the first-ever ADRD Stakeholder Summit with more than 100 attendees. Feedback from attendees informs the State Plan revision.

2023

RIDOH ADRD Program is awarded a five-year CDC BOLD funding opportunity to continue efforts in addressing dementia through a public health approach and maintain the RIDOH ADRD Program

2023

RIDOH ADRD Program hosts an interactive strategic planning process with nearly 40 community partners to draft Goals, Objectives, and Strategies

2023

Rhode Island launches the ADRD State Plan 2024-2029 in alignment with the CDC Healthy Brain Initiative Roadmap

Accomplishments

The 2019 ADRD State Plan includes a total of 34 Recommendations. From those, the following three recommendations were prioritized:

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.**
2. **Promote ADRD research opportunities of all types.**
3. **Include brain health in existing publicly funded health promotion and chronic disease management activities.**

Through a collaborative process, the ADRD Advisory Council, key partners, and the RIDOH ADRD Program have achieved the Top 3 Recommendations by taking the following steps:

1. **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. **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. **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."**

Plan Framework

The Healthy Brain Initiative (HBI) Roadmap was developed to guide public health departments in recommending action items to address Alzheimer's disease and other forms of dementia. There are 24 Roadmap Action Items included in the HBI Roadmap that can be implemented through a "life-course approach," meaning that interventions can be implemented at any stage in the disease process, including a focus on dementia risk reduction and prevention. The 24 Roadmap Action Items are categorized within four domains (see Figure 1).

While reading through the Strategies in this State Plan, notice the alignment of each Strategy with one of the four domains from the HBI Roadmap. This alignment provides a seamless connection to the public health activities outlined in the HBI Roadmap action items.

The four domains are reflected again in Figure 2: Conceptual Framework for the Healthy Brain Initiative Roadmap. The Rhode Island ADRD State Plan will continue to center health equity as reflected in the Conceptual Framework. To that end, the implementation of activities in the State Plan will intentionally utilize culturally and linguistically appropriate language; include people with lived experience; and collaborate with a diverse group of key partners.

On the outer ring of the Conceptual Framework, the four domains are surrounded by areas of practice across the life-course that can impact the domains including 1) Risk Reduction, 2) Early Detection and Diagnosis, 3) Caregiving, and 4) Community-Clinical Linkages. These areas of practice will be closely considered as the State Plan is implemented.

Figure 1 Domains for Roadmap Action Items

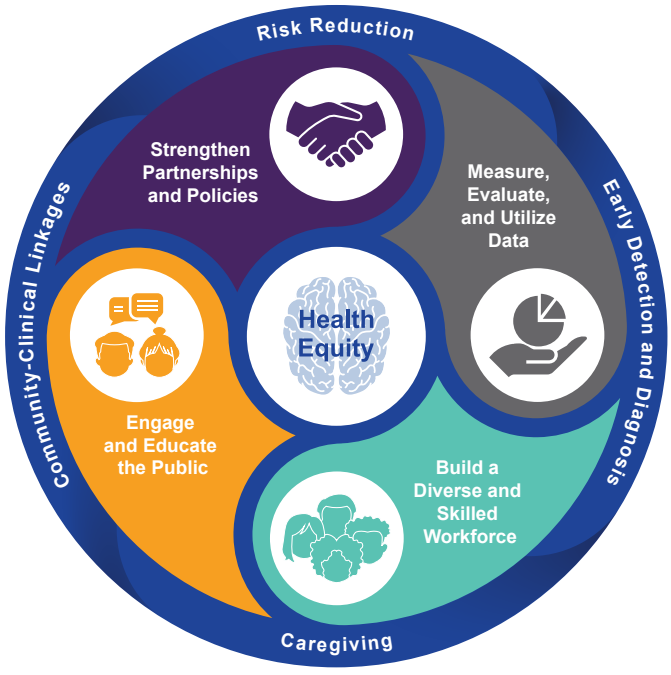
STRENGTHEN PARTNERSHIPS AND POLICIES:
Public health strengthens, supports, and mobilizes community partnerships to improve brain health. It also creates, champions, and implements supportive policies and plans.

MEASURE, EVALUATE, AND UTILIZE DATA:
Public health monitors health status to identify and solve community health problems and evaluates effectiveness, accessibility, and quality of personal and population-based health services. Findings are translated into data-informed programs and policies to improve brain health across the life course.

BUILD A DIVERSE AND SKILLED WORKFORCE:
Public health trains and prepares the public health and healthcare workforce to educate their constituents and provide the best care to people at risk for or living with dementia while supporting caregivers.

ENGAGE AND EDUCATE THE PUBLIC:
Public health engages with diverse communities to understand how messages are best delivered and what information to convey to specific populations. Public health communicates effectively to educate people about factors that influence brain health and ways to maintain or improve their cognitive health and quality of life.

Figure 2 Conceptual Framework for the Healthy Brain Initiative Roadmap



Plan Restructuring and Revision

In early 2023, RIDOH contracted with Health Resources in Action, Inc. (HRiA) to facilitate a process to produce the 2024-2029 ADRD State Plan. The purpose of this process was to reformat the existing Plan to make it more accessible and easier to track progress. HRiA worked with RIDOH, the Rhode Island ADRD Advisory Council, and key partners to develop vision and mission statements and update the structure and content. This collaborative process provided an opportunity to gather input about the overall vision and mission for the Rhode Island ADRD State Plan as well as the plan elements. The stakeholders that were engaged included people with lived experience as caregivers as well as agencies and people who work in community-based settings.

In July 2023, HRiA facilitated an in-person Strategic Discussion with the ADRD Advisory Council and an expanded group of stakeholders to gather input on the draft vision and mission statements and the revised plan contents. See Appendix C for the full list of stakeholders. Attendees were engaged through interactive methods to provide input on what they liked, what they would change, and what they would add to the presented material. Participants were also encouraged to provide potential partners and resources as well as ideas for future consideration which were collected as part of a "parking lot," where information that did not specifically align with the State Plan elements can be referenced. *See Appendix B for the list of Future Considerations.*

The input gathered was then recorded, reviewed, and utilized to revise the vision and mission statements and the plan elements. These revised materials were shared with Strategic Discussion participants for an additional round of electronic feedback. That feedback was consolidated, reviewed, and incorporated into the final version of the plan that is presented in this report.

Vision and Mission

Vision: Rhode Island empowers all individuals impacted by dementia to achieve their best quality of life.

Mission: Engage Rhode Island community, workforce, health systems, and public health stakeholders to ensure all Rhode Islanders have the resources, education, and services they need to support those impacted by dementia.

Rhode Island ADRD State Plan Snapshot

Sector Area	Goal Statement	Objectives
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.	1.1 Increase supports and services for people with ADRD through 4 interventions that will improve quality of life by 2029. 1.2 Increase supports and services for families and caregivers through the promotion and awareness of resources and materials by 2029. 1.3 Implement 5 initiatives to promote information and resources about ADRD and brain health to all Rhode Islanders by 2029.
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.	2.1 Expand ADRD outreach and services for communities that are disproportionately impacted by ADRD by 20% by 2029. 2.2 Promote and support 5 initiatives to educate and train the Rhode Island health and human service workforce on ADRD and dementia care by 2029.
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.	3.1 Implement 7 initiatives that will increase access to care for those living with ADRD in Rhode Island by 2029. 3.2 Promote research and educational opportunities that will improve ADRD care throughout the Rhode Island health system by 2029.
Public Health	Rhode Island will lead the nation in addressing dementia through a public health approach.	4.1 Implement 4 initiatives to increase the capacity of Rhode Island to address ADRD as a public health and health equity issue. 4.2 Promote and support 3 efforts to elevate ADRD as a public health issue in the state.

Plan Elements by Sector Area

Alignment with the CDC Healthy Brain Initiative Roadmap

As described in the Plan Framework, each of the strategies in this plan aligns with a domain from the CDC Healthy Brain Initiative Roadmap. The icons below note which of the four domains of the Healthy Brain Initiative Roadmap a strategy is addressing.

Strengthen partnerships and policies

Build a diverse and skilled workforce

Measure, evaluate, and utilize data

Engage and educate the public

Sector 1: Community

Goal 1:

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.

Objective 1.1:

Increase supports and services for people with ADRD through 4 interventions that will improve quality of life by 2029.

Strategy 1.1.1: Work with at least two communities with high prevalence of ADRD to develop action plans that promote age and dementia friendly resources and information that identify local supports for people with dementia and their caregivers.

Strategy 1.1.2: Engage the AARP, the Alzheimer's Association, and the Department of Motor Vehicles in conversations about assessing and improving the medical driving fitness of people with ADRD.

Strategy 1.1.3: Promote collaboration between OHA and other entities to assist community programs with promotion and outreach of the program and ADRD awareness.

Strategy 1.1.4: Create more accessible neighborhoods for people living with dementia in their communities including walkable sidewalks, greater access to healthy food options, and safer public spaces.

Objective 1.2:
Increase supports and services for families and caregivers through the promotion and awareness of resources and materials by 2029.

Strategy 1.2.1: Promote dementia specific caregiver support programs to increase awareness of available resources in Rhode Island.

Strategy 1.2.2: Develop relationships with community-based organizations, particularly those that serve priority populations, to support them in offering dementia specific programs.

Strategy 1.2.3: Support community education about caregiver health and rights under the Coronavirus Aid, Relief, and Economic Security (CARES) Act.

Strategy 1.2.4: Promote availability and knowledge of respite services for family caregivers.

Objective 1.3
Implement 5 initiatives to promote information and resources about ADRD and brain health to all Rhode Islanders by 2029.

Strategy 1.3.1: Develop and maintain web and offline information about ADRD.

Strategy 1.3.2: Promote all Rhode Island Alzheimer's disease prevention registries more widely to persons with healthy cognitive functioning.

Strategy 1.3.3: Host educational sessions in communities throughout Rhode Island to teach people living with dementia, their caregivers, and the public about brain health, the signs and progression of dementia, caregiver support options, and available resources/services.

Strategy 1.3.4: Create user-friendly data briefs to disseminate in communities across Rhode Island that highlight the prevalence of dementia in Rhode Island and the risk reduction efforts that can be promoted.

Strategy 1.3.5: Develop and disseminate Brain Health Guide that recommends health actions for people diagnosed with mild cognitive impairment and/or early-stage Alzheimer's disease.

Potential Partners and Resources

- Age-Friendly Rhode Island
- Alzheimer's Association Community Resource Finder
- Carney Institute for Brain Science
- Center for Southeast Asians
- Community-based resources such as: community centers, ethnic clubs, farmers markets, food pantries, public libraries, and senior centers
- Department of Administration, Division of Stateside Planning
- Farm Fresh Rhode Island
- Health Equity Zones
- Providence Streets Coalition
- Real Access Motivates Progress (RAMP)
- Rhode Island Elder Info
- Rhode Island Minister's Alliance
- RIDOH Healthy Eating and Active Living Program
- United Way of Rhode Island

Sector 2: Workforce

Goal 2:
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.

Objective 2.1:
Expand ADRD outreach and services for communities that are disproportionately impacted by ADRD by 20% by 2029.

Strategy 2.1.1: Add dementia issues to the portfolio of community health educators (such as Community Health Workers (CHWs), State Health Insurance Assistance Program (SHIP) workers) who work throughout the state and build their capability to identify persons with cognitive impairment.

Strategy 2.1.2: Recruit linguistically and culturally diverse volunteer educators who represent disproportionately impacted populations to promote awareness of dementia.

Objective 2.2:
Promote and support 5 initiatives to educate and train the Rhode Island health and human service workforce on ADRD and dementia care by 2029.

Strategy 2.2.1: Encourage collaboration among Rhode Island College (RIC), University of Rhode Island (URI), and Community College of Rhode Island (CCRI) health and human service programs and collaborate on a concentration in dementia care and services in these or health and aging services majors.

Strategy 2.2.2: Outreach to program directors to advocate for the delivery of Dementia Competence training within curriculum content prior to clinical rotations that are required for students entering the healthcare workforce.

Strategy 2.2.3: Convene meetings between specialty high school programs graduating certified nursing assistants, junior college, and college nursing programs to create a career track in dementia care.

Strategy 2.2.4: Create incentive opportunities to encourage participation in dementia specific training particularly for direct care workers who may not receive reimbursement for continuing education.

Strategy 2.2.5: Promote accessible training such as Project Extension of Community Healthcare Outcomes (Project ECHO) for interdisciplinary healthcare teams to learn from subject matter experts and colleagues on dementia-specific topics.

Potential Partners and Resources

- Brown University and the Warren Alpert Medical School of Brown University
- Community Health Worker Association of Rhode Island
- Home care agencies
- Healthcare profession associations (medical, nursing, etc.)
- Johnson and Wales University
- LTCCC
- Oasis International
- RIDOH Oral Health Program
- Providence College Nursing School
- Real Jobs Rhode Island
- Rhode Island Elder Info
- Rhode Island College Institute for Education in Healthcare
- Rhode Island Nurses Institute Middle College Charter School
- University of Rhode Island, Rhode Island Geriatric Education Center, Rhode Island Geriatric Workforce Enhancement Program

Sector 3: Health System

Goal 3:

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.

Objective 3.1:

Implement 7 initiatives that will increase access to care for those living with ADRD in Rhode Island by 2029.

Strategy 3.1.1: Implement healthcare facility operational/education plans to improve care delivery across healthcare settings for people living with dementia and their caregivers.

Strategy 3.1.2: Promote advancements in use of technology (e.g., remote patient monitoring, workflow claims reimbursement for telehealth) to maintain the independence of people with dementia in their home as they age.

Strategy 3.1.3: Promote increased use of screening tools embedded within electornic medical records (EMRs) to detect dementia within primary care.

Strategy 3.1.4: Increase collaboration across the care continuum (such as with community-based organizations and through promotion of community health worker initiatives) to meet the health-related social needs/social determinants of health for patients living with dementia.

Strategy 3.1.5: Consider referral mechanisms (such as Unite Us) to implement within health systems to assist patients living with dementia and their caregivers in finding resources to meet their needs.

Strategy 3.1.6: Promote awareness of Home and Community Based Services (HCBS) to support people with dementia living in the community.

Strategy 3.1.7: Advocate for the Medicaid waiver provision that includes respite as a long-term support core service for Medicaid recipients.

Objective 3.2:
Promote research and educational opportunities that will improve ADRD care throughout the Rhode Island health system by 2029.

Strategy 3.2.1: Encourage public/private partnerships to support neuroscience, clinical, translational, and health services research and propose new actions to increase support of state-based life science investments in brain research.

Strategy 3.2.2: Integrate information about participation in research opportunities into existing educational materials.

Potential Partners and Resources

- Adult day care centers
- Alzheimer's Association Health Care Systems Director
- Healthcare professionals, ADRD specialists
- Emergency responders
- Local housing authorities
- Long-Term Care Coordinating Council
- Non-profits that provide case management to Long-Term Services and Supports recipients
- RIDOH Tobacco Control Program
- Surveillance data to identify barriers, identify gaps, identify cultural/ population-specific challenges

Sector 4: Public Health

Goal 4:
Rhode Island will lead the nation in addressing dementia through a public health approach.

Objective 4.1:
Implement 4 initiatives to increase the capacity of Rhode Island to address ADRD as a public health and health equity issue.

Strategy 4.1.1: Utilize the RIDOH health equity framework to ensure health disparities in risk and burden of ADRD be addressed.

Strategy 4.1.2: Implement and analyze public health surveillance by using data such as the caregiving and cognitive health related modules available for the BRFSS and the All-Payers Claims Database.

Strategy 4.1.3: Build sustainability to support initiatives of the Rhode Island State Plan on ADRD and the work of the RIDOH ADRD Program (e.g., federal funding such as CDC BOLD, state funding, cross agency support, public-private partnership).

Strategy 4.1.4: Convene an equity workgroup focused on elevating and addressing issues of health equity and dementia.

Objective 4.2:
Promote and support 3 efforts to elevate ADRD as a public health issue in the state.

Strategy 4.2.1: Implement recommendations outlined in the CDC and the Alzheimer's Association Healthy Brain Initiative Road Map to advance cognitive health as an integral component of public health.

Strategy 4.2.2: Include brain health in existing publicly funded health promotion and chronic disease management activities.

Strategy 4.2.3: Advocate for CHW services that support people with ADRD to be reimbursed by Medicaid.

Potential Partners and Resources

- Rhode Island Department of Behavioral Healthcare, Developmental Disabilities & Hospitals
- Brown University School of Public Health
- Emergency Services
- Rhode Island Executive Office of Health and Human Services
- Geriatric Resource Center
- Health Equity Zones
- Rhode Island Office of the Health Insurance Commissioner
- Public communications
- Rhode Island Public Health Association

Next Steps – Implementation Phase

The components included in this Plan guide the ADRD Advisory Council, the RIDOH ADRD Program, and key partners in implementing action items to achieve each strategy. The Council will create an Action Plan of the State Plan to prioritize activities and identify champions to implement the work. The identified champions will represent a group of diverse partners from various sector areas, agencies, and populations served. The ADRD Advisory Council and the RIDOH ADRD Program look forward to continued efforts in building programs that are accessible by all Rhode Islanders and align with the Mission and Vision of the State Plan.

Appendices

Appendix A: ADRD Infographics

Appendix B: Future Considerations

Appendix C: Strategic Discussion Attendees

Appendix D: Glossary of Terms

Appendix E: Acronyms

Appendix F: References

2020 Rhode Island Healthy Aging Data Report

Older Adult Health in Every Community

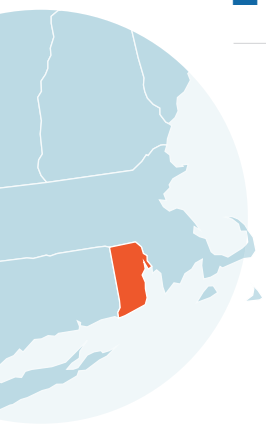
CHANGES SINCE 2016

Older Rhode Islanders Are More Diverse; Population Is Growing

243,523 People age 60+
23% of the population

65+ population increasingly diverse:

- **+0.6%** Black
- **+0.3%** Asian
- **+1.2%** Hispanic/Latinx

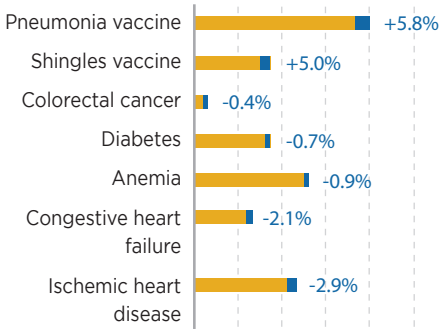


Highest %
Of older people age 85+ in **NEW ENGLAND**

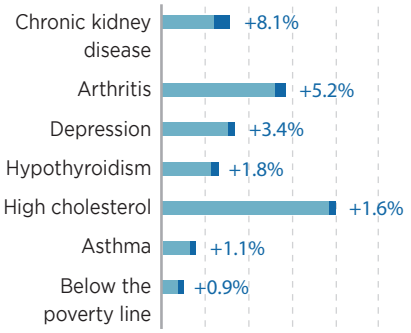
3rd Highest %
Of older people age 85+ in the **UNITED STATES**

Twice
As many 85+ women as men

Making Progress
Rates Improved For



More Work to be Done
Rates Worsened For



Race Matters

52 Health Indicators
have evident disparities

Older Black people
had higher rates than older Asians, Hispanics, and Whites in

25 indicators

Including:

- Diabetes
- Hypertension
- Stroke
- Glaucoma
- Congestive heart failure
- Prostate cancer

Older Hispanic people
had higher rates than older Asians, Blacks, and Whites in

8 indicators

Including:

- Alzheimer's disease
- Liver disease
- Depression

Gender Matters

Women are more likely to	Men are more likely to
Eat recommended fruits and veggies daily	Meet CDC guidelines for physical activity and screening guidelines
Stress about buying food	Have heart disease
Have falls	Have chronic kidney disease
Have depression	Have diabetes

Where You Live Matters

Most people don't live in long-term care settings

<5% of adults 65+ live in long-term care settings

31% of people 65+ live alone

70% of people 60+ own their home

Diagnosis of indolent chronic diseases are more prevalent in communities with **MORE EDUCATION, HIGHER INCOMES, AND GOOD ACCESS TO MEDICAL CARE**

Serious, complex chronic diseases are more prevalent in communities with **LESS EDUCATION AND LOWER INCOMES**

COVID-19 EXACERBATES EXISTING DISPARITIES
in communities of color

Understand

1. Download community profile
2. Read the Highlights Report to understand how your community compares to the statewide trends
3. Learn about programs and resources
   - Call The POINT at 401-462-4444
   - Visit RI Office of Healthy Aging at www.oha.ri.gov

Engage

1. Encourage people you know and community leaders to engage in age-friendly movement
2. Connect with Age-Friendly RI at www.agefriendlyri.org
3. Recommend changes for healthy aging

Act

1. Get involved in local efforts to promote healthy aging
2. Use data to prioritize community needs
3. Collaborate with diverse partners
4. Create opportunities for civic engagement and social connection
5. Identify and build upon what's working

Gerontology Institute
John W. McCormack Graduate School of Policy and Global Studies
UMASS BOSTON

TUFTS Health Plan FOUNDATION

Learn more at healthyagingreports.org/rhode-island

Appendix B: Future Considerations

The ideas listed below were generated by participants in the Strategic Discussion that took place in July 2023. Some of the input that was provided did not fit into the existing plan objectives and strategies and was placed in a "parking lot." Many of the parking lot suggestions could be addressed in other State Plans such as the Rhode Island State Plan on Aging or the Rhode Island State Plan on Caregiving. As the current strategies are achieved, these ideas may be considered for inclusion in the plan, with input from stakeholders.

Sector Area 1: Community

- Establish a single point of contact (e.g., The Point) to the Rhode Island Alzheimer's Association (RIAA) to help patients and caregivers navigate the journey.
- Increase the number of Village Commons.
- Address financial and legal planning needs, including information on the following topics: power of attorney; financial education and planning; living wills; and health directives.
- Increase awareness of the cost of care and mechanisms for paying for care.
- Increase access to supports based on data of areas with higher prevalence of ADRD.
- Explore peer-to-peer support programs.
- Advocate for the inclusion of this Plan's community goal in municipal planning.
- Explore community programs providing respite support.
- Engage community members through regular focus groups.
- Explore tutoring opportunities that pair high school tech students with seniors who need basic skills utilizing the internet.
- Encourage housing partners to strengthen resources to help Rhode Islanders age in place (e.g., Accessory Dwelling Unit (ADU) grants).
- Include people living with dementia on the RI Special Needs Emergency Registry.

Sector Area 2: Workforce

- Engage select facilities to pilot and assess training for all staff.
- Establish training for first responders on identifying persons with cognitive impairment.
- Establish a training and education program for primary care that is inclusive of community health centers as well as private practices.
- Provide training for dental providers and include training for dental care for those w/ ADRD.
- Collaborate on the development of a leadership role for Certified Nursing Assistants (CNAs) and direct care workers with a dementia certification (with increased salary).
- Explore ways to address workforce shortage and burnout issues among paid caregivers.
- Explore ways to improve pay for caregivers, including higher minimum wage and career paths.
- Train volunteers to provide respite services for caregivers.

Appendix B: Future Considerations

Sector Area 3: Health System

- Increase awareness of Veteran benefits for those who would be eligible.
- Include CHWs as reimbursable by insurance beyond Medicaid to increase access.
- Promote completion of healthcare power of attorney and advanced directives at diagnosis (or soon after).
- Partner with cities and towns' Emergency Medical Technicians (EMTs) and Emergency Medical Assistance (EMAs) to increase access to monitoring in home.
- Advocate for medical waiver provision to include payment for remote patient monitoring (not currently covered by Medicaid).
- Be aware of new initiatives that are defining model dementia care.
- Work across state agencies to improve RIDOH regulations for healthcare facilities that serve people with dementia.

Sector 4: Public Health

- Explore ways to collect, analyze, and use existing data to support and improve ADRD efforts. For example, improve the identification of health disparities through improved demographic data collection and utilization of that data around key measures; improve qualitative data collection to gather input from people with lived experience at the local level.
- Advocate for the Rhode Island Department of Behavioral Healthcare, Developmental Disabilities & Hospitals (BHDDH) reporting system for healthcare professionals to include caregiver data for care recipients.
- Develop and promote a Rhode Island brain health advertising campaign across all health systems.

Appendix C: Strategic Discussion Attendees

The following individuals have been instrumental in providing State Plan feedback and attended the July 2023 interactive planning session:

1. Annie Murphy, Alzheimer's Association – Rhode Island Chapter
2. Donna McGowan, Alzheimer's Association – Rhode Island Chapter
3. Geraldine Mitchell, Alzheimer's Association – Rhode Island Chapter
4. Tara Tang, Butler Hospital Memory and Aging Program
5. Colleen Mellor, Caregiver, Author
6. Kathleen Gerard, Caregiver, Alliance for Better Long-Term Care
7. Chris Gadbois, CareLink
8. Sandra Fournier, CareLink
9. Susanne Campbell, Care Transformation Collaborative
10. Suzanne Herzberg, Care Transformation Collaborative
11. Heidi Ross, Community Member
12. Herb Weiss, Leon Mathieu Senior Center, Author
13. Grace Sneesby, Lieutenant Governor's Office
14. Sabina Matos, Lieutenant Governor
15. Dana McCants Derisier, Office of Healthy Aging
16. Kristina Nagel, Office of Healthy Aging
17. Nicole Arias, Office of Healthy Aging
18. Jennifer Pencifel, PACE-Rhode Island
19. Kriss Auger, PACE-Rhode Island
20. Michelle Lupoli, PACE-Rhode Island
21. David Bodah, Rhode Island Assisted Living Association
22. Marianne Raimondo, Rhode Island College
23. Tonya Glantz, Rhode Island College
24. Cali McAtee, Rhode Island Department of Health, Diabetes, Heart Disease, and Stroke Program
25. Kirsten Skelly, Rhode Island Department of Health, Tobacco Control Program
26. Sadie DeCourcy, Rhode Island Department of Health, Oral Health Program
27. Deb Burton, Rhode Island Elder Info
28. Terry Fogerty, Rhode Island Hospital Alzheimer's Disease and Memory Disorders Center
29. Sylvia Bernal, United Way of Rhode Island
30. Cristina Amedeo, United Way of Rhode Island/The Point

Rhode Island Department of Health ADRD Program Staff:

1. Nancy Sutton, Center for Chronic Care and Disease Management
2. Victoria O'Connor, ADRD Program Manager
3. Haita Ndimbalan, ADRD Program Coordinator

Facilitators:

Amanda Henry, Health Resources in Action
Eliza Campbell, Health Resources in Action

Appendix D: Glossary of Terms

ALZHEIMER'S DEMENTIA: the dementia stage in the Alzheimer's continuum.

ALZHEIMER'S DISEASE: an irreversible, progressive brain disorder that slowly destroys memory and thinking skills and, eventually, the ability to carry out the simplest tasks. Symptoms usually develop slowly and get worse over time, becoming severe enough to interfere with daily tasks.

BRAIN HEALTH: a concept that involves making the most of the brain's capacity and helping to reduce some risks that occur with aging. Brain health refers to the ability to draw on the strengths of the brain to remember, learn, play, concentrate, and maintain a clear, active mind.

CAREGIVER: spouses, partners, adult children, other relatives, and friends providing unpaid help to people living with dementia who have at least one limitation in their activities of daily living and reside in the community. Caregivers often assist with diverse activities of daily living such as personal care; household management; medication and healthcare management; and coordination of financial matters.

COGNITION: the mental functions involved in paying attention, thinking, understanding, learning, remembering, solving problems, and making decisions. Cognition is a fundamental aspect of an individual's ability to engage in activities, accomplish goals, and successfully negotiate the world. It can be viewed along a continuum—from optimal functioning to mild cognitive impairment to Alzheimer's and severe dementia.

COGNITIVE IMPAIRMENT: trouble remembering, learning new things, concentrating, or making decisions that affect everyday life.

DEMENTIA: the loss of cognitive functioning—thinking, remembering, and reasoning—and behavioral abilities to such an extent that it interferes with a person's daily life and activities. These functions include memory, language skills, visual perception, problem solving, self-management, and the ability to focus and pay attention. Alzheimer's is the most common cause of dementia. Other types include vascular dementia, dementia with Lewy bodies, and frontotemporal dementia.

MILD COGNITIVE IMPAIRMENT: a slight but measurable decline in cognitive abilities that includes memory and thinking. A person with mild cognitive impairment is at an increased risk of developing Alzheimer's or another dementia.

SUBJECTIVE COGNITIVE DECLINE: self-reported confusion or memory loss that is happening more often or is getting worse.

Appendix E: Acronyms

AARP	American Association of Retired Persons
ADRD	Alzheimer's Disease and Related Disorders
BHDDH	Department of Behavioral Healthcare, Developmental Disabilities & Hospitals
BOLD Act	Building Our Largest Dementia Infrastructure for Alzheimer's Act
BRFSS	Behavioral Risk Factor Surveillance System
CARES Act	Coronavirus Aid, Relief, and Economic Security Act
CCRI	Community College of Rhode Island
CDC	Centers for Disease Control and Prevention
CHW	Community Health Workers
DOA	Department of Administration
ECHO	Extension of Community Healthcare Outcomes
EMR	Electronic Medical Records
EOHHS	Executive Office of Health and Human Services
FTE	Full-time employee
HBI	Healthy Brain Initiative
HCBS	Home and Community Based Services
HEAL	Healthy Eating and Active Living
HEZ	Health Equity Zones
JWU	Johnson and Wales University
LTCCC	Long-Term Care Coordinating Council
LTSS	Long-Term Services and Supports
OHA	Office of Healthy Aging
OHIC	Office of the Health Insurance Commissioner
RAMP	Real Access Motivates Progress
RIAA	Rhode Island Alzheimer's Association
RIC	Rhode Island College
RIDOH	Rhode Island Department of Health
RINI	Rhode Island Nurses Institute Middle College Charter School
RITCP	RIDOH Tobacco Control Program
SCD	Subjective Cognitive Decline
SHIP	State Health Insurance Assistance Program
URI	University of Rhode Island

Appendix F: References

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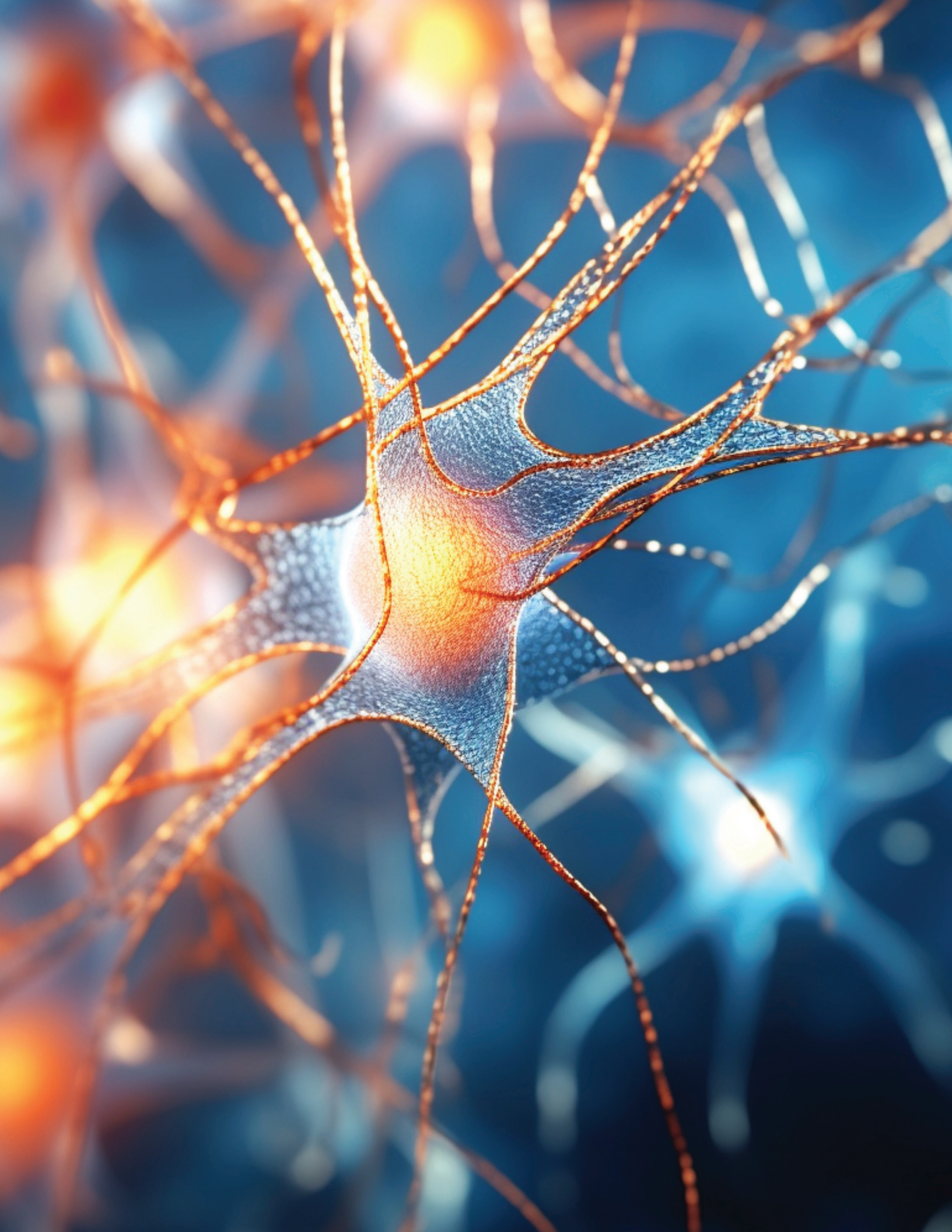

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