

2023 to 2028

South Carolina Statewide Plan to Address Alzheimer's Disease & Related Dementias (ADRD)

EXECUTIVE SUMMARY



Developed by: The Division of Injury and Substance Abuse Prevention at SC DHEC; The South Carolina Department on Aging's Alzheimer's Resource Coordination Council and Center (ARCC) and The Weathers Group

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South Carolina
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February 1, 2023

To the Honorable Members of the South Carolina General Assembly:

The South Carolina Department on Aging's Alzheimer's Resource Coordination Center Advisory Council is pleased to present the 2023 to 2028 South Carolina State Plan to Address Alzheimer's Disease and Related Dementias.

Our statewide plan to address dementia has not been updated since 2009, when the Purple Ribbon Task Force published their findings and recommendations for action to address the current and future impact of Alzheimer's Disease within the state in a report titled *Conquering the Specter of Alzheimer's Disease in South Carolina*. The Task Force was housed in what was then called the Lieutenant Governor's Office on Aging and was convened through the passage of Senate Concurrent Resolution 1333 by the South Carolina General Assembly in 2008. In the fourteen years following the report's publication, the landscape of Alzheimer's Disease and Related Dementias (ADRD) has changed dramatically, and our citizens need a revised, updated plan of action to address the ever-increasing statistics and concern around ADRD.

The 2023 to 2028 South Carolina State Plan was developed via an intensive six-month strategic planning and data collection process led by the South Carolina Department of Health and Environmental Control's (SCDHEC) Division of Injury and Substance Abuse Prevention. The Alzheimer's Resource Coordination Center Advisory Council (ARCC) served as the representative coalition of experts and stakeholders from throughout South Carolina and provided essential expertise, data analysis, and support throughout the process.

According to the SC Alzheimer's Disease Registry, at least 111,818 individuals are currently living with ADRD in South Carolina. At the state level, we have an Alzheimer's crisis. In 2015, South Carolina had the highest Alzheimer's death rate in America, and it remains in the top 5 causes of death in SC today. In 2020, Medicaid costs for South Carolinians with Alzheimer's amounted to \$652 million — and those costs are expected to increase 25% in just four years.

And then there's the impact on caregiving families. There are an estimated 197,000 caregivers in South Carolina providing almost 300 million hours of unpaid care. That unpaid care provided by family members or friends is valued at over \$4.4 billion. Caregivers of people with dementia indicate substantial financial, emotional, and physical health difficulties. We also know that 1 in 3 dementia caregivers in our state are "sandwich generation" caregivers — meaning that they care not only for someone with dementia, but also for at least one child or grandchild.

These statistics are daunting in their weight and impact, but the picture they paint is unmistakable: Dementia is a large and growing public health crisis for South Carolina, and those facing a dementia diagnosis and their caregivers need support. We cannot afford to ignore this. What can we do as a state to curb the impact of this growing burden on families? While each state has its own unique gaps and needs, South Carolina is uniquely poised to make a huge impact for families facing a dementia diagnosis through collaboration between state agencies, community-based organizations, long term care providers, home and community-based services, research institutions, and health systems. This plan is our new commitment to addressing ADRD through collaboration, data-driven programming decisions, and health equity.

Our strategic planning and stakeholder feedback process has shown us that we must work with our community-based care providers, both long term care and community resources, to improve delivery of dementia informed education to improve outcomes across all settings. Input from stakeholders highlighted the fact that a critical element is missing from South Carolina's current and previous efforts to provide quality care and resources for people affected by and living with dementia – a public health framework. Research shows us that by prioritizing risk reduction, we can prevent people from progressing beyond a mild cognitive impairment into dementia. This, along with early detection and early diagnosis, can help families have longer with their loved one to prepare for care, financially, mentally, and legally. The strategies for action outlined in this plan, along with the collaboration of state agencies to implement and prioritize dementia as a public health issue and a costly problem facing our great state, will help improve the health outcomes, quality of care, and caregiver health for everyone touched by Alzheimer's and other forms of dementia.

Respectfully submitted,

A handwritten signature in cursive script that reads "Taylor Wilson".

Taylor Wilson

Director of Government Affairs, Alzheimer's Association South Carolina Chapter
Chair, Alzheimer's Resource Coordination Center Advisory Council

Acknowledgements

Thank you to the dedicated individuals and agencies who played an integral role in developing the 2023 to 2028 South Carolina Statewide Plan to Address Alzheimer’s Disease and Related Dementias (ADRD), including:

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Overview

In the fall of 2021, the South Carolina Department of Health and Environmental Control's (SCDHEC) Division of Injury and Substance Abuse Prevention began the process of developing a five-year statewide strategic plan to address and prevent the impact of Alzheimer's Disease and Related Dementias (ADRD) - hereafter referred to as the "SC Statewide Plan to Address ADRD." This process is part of the Centers for Disease Control and Prevention's (CDC) directive to award funds to state public health agencies under the Building Our Largest Dementia (BOLD) Infrastructure for Alzheimer's Act, passed into law on December 31, 2018.

The South Carolina Department of Health and Environmental Control worked closely with the South Carolina Department on Aging and relevant public health coalitions and organizations to ensure the plan included input from ADRD stakeholders statewide. To this end, the South Carolina Department on [Aging's Alzheimer's Resource Coordination Center Advisory Council](#) (ARCC or Council) was pulled in as a convener and lead partner to ensure that a variety of diverse and representative stakeholders had a voice in guiding the development of the strategic plan. The SC Statewide Plan to Address ADRD is a blueprint for how our healthcare systems, long term care providers, state agencies, community partners, and people and families impacted by dementia will continue to address the growing crisis of Alzheimer's Disease and Related Dementias throughout South Carolina. The objectives and strategies outlined in the plan will allow South Carolina to promote risk reduction and early detection and diagnosis of ADRD, as well as build the infrastructure and accountability necessary to build dementia-capable programs and services for the growing number of people impacted by ADRD every year.



A Public Health Framework to Address ADRD

The following plan was guided by the recommendations put forward by the Healthy Brain Initiative's [State and Local Public Health Partnerships to Address Dementia, The 2018-2023 Road Map](#), ("Healthy Brain Roadmap") as well as data from research and academic entities across the state. The Healthy Brain Roadmap promotes a comprehensive public health approach described in the Conceptual Framework visual below.

The SC Statewide Plan to Address ADRD uses a public health framework to address upstream factors that may be modified and the systems and environments that can impact risk factors for Alzheimer's Disease and Related Dementias. Since our strategic plan development and shift to a public health framework was guided by the Healthy Brain Roadmap, it not only addresses the current care and treatment needs of people impacted by dementia, but also prepares for the future by developing strategies and objectives that address risk reduction and improve early detection and diagnosis for ADRD

Using a public health framework to address ADRD also requires stakeholders to consider and promote efforts that address primary, secondary, and tertiary prevention of ADRD. Within the context of ADRD, primary prevention efforts are those that accelerate risk reduction, specifically, promoting prevention of modifiable risk factors for developing dementia. These risk factors include traumatic brain injury, smoking, diet, physical activity, cardiovascular risk, and other modifiable factors that also correspond with an overall healthy lifestyle and improved quality of life. Secondary prevention for ADRD includes improving rates of early detection and diagnosis of dementia and recognition of cognitive impairment. Tertiary prevention efforts are those that ensure safety and quality of care for all people with dementia and/or that provide support and improve health of all types of caregivers and care partners.

It is important to note that although stakeholders across South Carolina are supportive of using a prevention framework for our plan to address ADRD over the next five years, the primary data and input from stakeholders across the state did not always place a high priority on primary and secondary prevention strategies to address ADRD. As our state moves from planning to implementation, however, there will be a commitment to the inclusion of not only tertiary prevention efforts and improvements to accessing quality care, but also promote efforts and programs that reduce risk of mild cognitive impairment and increase early detection and diagnosis of ADRD across the lifespan.



This figure of the Healthy Brain Roadmap Conceptual Framework outlines how we can use the four Essential Services of Public Health (Domains) - assure a competent workforce (W), monitor and evaluate (M), develop policies and mobilize partnerships (P), and educate and empower (E) the nation - to develop strategies to address ADRD. Action within each of these four domains is guided by three core principles: 1) to best eliminate health disparities, 2) collaboration across multiple sectors, and 3) leverage resources for sustained impact.

Conceptual Framework Source: Alzheimer's Association and Centers for Disease Control and Prevention. Healthy Brain Initiative, State and Local Public Health Partnerships to Address Dementia: The 2018-2023 Road Map. Chicago, IL: Alzheimer's Association; 2018

The 2023 to 2028 SC Statewide Plan to Address ADRD

VISION, MISSION, & VALUES

Our VISION:

All people in South Carolina have the opportunity to live the highest quality of life throughout their life course.

Our MISSION:

To catalyze statewide collaboration to promote a comprehensive approach to risk reduction, early detection and diagnosis, high-quality dementia services, and a coordinated and equitable continuum of care across South Carolina for Alzheimer's Disease and Related Dementias.

Our VALUES:

Dignity - is at the core of what we do.

We respect and support the health and well-being of the whole person throughout their life course, regardless of diagnosis or progression of disease.

Integrity - is foundational to all our work.

In order to ensure our efforts to address ADRD do no harm and maintain the highest of ethical standards, we are committed to continually learning, protecting vulnerable populations, and reducing barriers to education and resources.

Equity - guides our approaches and practices.

We engage in our work with intentionality, recognizing that systemic inequities exist and significantly impact access to information about risk reduction, early detection, and barriers to quality care and support.

Community - is essential to our success.

We build trust and collaborate with a wide range of partners, including researchers, providers, and local organizations, to ensure that all community members have access to the education, services, care, and resources they need to achieve the highest quality of life possible.

Information - is critical to the development of data-driven programs, policies, and procedures.

We must **be transparent with our partners and share information freely.** Equitable access to information is key to risk reduction and other health promotion efforts. Information from stakeholders, statistics, research and current data allow us to align with best practices, develop culturally relevant programming for caregivers, care partners, health care systems, and persons diagnosed with and at risk for ADRD.



SOUTH CAROLINA STATE PLAN GOALS & OBJECTIVES

Five Categories for Action as Defined by the ARCC's Strategic Work Group:

1. Education for Healthcare Providers and Community
2. Advocacy and Policymaking
3. Access and Connection to Care
4. Caregiver Support
5. Data and Resources

CROSS CUTTING Elements: Multi-Sector Collaboration, Equity, and Public Health Framework

Goal 1: Education for Healthcare Providers & Community

Healthy Brain Initiative Roadmap Domain(s): E, W

Improve knowledge, understanding, and awareness of ADRD by educating and empowering all South Carolinians, including every person engaged in the continuum of care.

(Continuum of care roles include: healthcare professionals, public health professionals, first responders, caregivers and care partners, families, policymakers, and the community at-large)

Goal 2: Advocacy & Policymaking

Healthy Brain Initiative Roadmap Domain(s): E, P

Support policy and advocacy efforts that improve the health and wellbeing of all people in South Carolina.

Goal 3: Access & Connection to Care

Healthy Brain Initiative Roadmap Domain(s): E, W

Improve the quality of ADRD care and ensure all people in South Carolina are able to access the resources, healthcare, and support they need for reducing risk and all other issues related to ADRD.

Goal 4: Caregiver Support

Healthy Brain Initiative Roadmap Domain(s): P

Improve, expand, and develop multidimensional support and health promotion programs for professional and family caregivers and care partners.

Goal 5: Data & Resources

Healthy Brain Initiative Roadmap Domain(s): M

Improve access to, coordination, and use of ADRD data and resources statewide.

KEY FOR HEALTHY BRAIN ROADMAP DOMAINS:

E = Educate and Empower

M = Monitor and Evaluate

P = Develop Policies and Mobilize Partners

W = Competent Workforce



Need Additional Information?

Please contact the SC Department of Health & Environmental Control's Division of Substance Abuse & Injury Prevention via email at whitehe@dhec.sc.gov or SC Department on Aging at slewis@aging.sc.gov