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South Carolina
**DEPARTMENT
ON AGING**

Alzheimer's Resource Coordination Center

REPORT
JULY 1, 2021 – JUNE 30, 2022

To Governor Henry McMaster and members of the South Carolina General Assembly,

In the United States today, more than 6 million people are living with Alzheimer's disease. That number is growing rapidly as ten thousand baby boomers turn 65 each day, the age at which the risk of dementia increases.

At the state level, we have an Alzheimer's crisis. According to the South Carolina Alzheimer's Disease Registry, the most comprehensive population-based registry of its kind in the nation, over 111,000 South Carolinians are living with Alzheimer's or related dementia. By the numbers, the effects on our state are staggering:

- Based on projections in the Alzheimer's Association 2022 Alzheimer's Disease Facts and Figures, every state across the country will experience at least a 6.7% in the number of residents living with Alzheimer's. South Carolina is projected to see an increase of more than 26%.
- In 2015, South Carolina had the highest Alzheimer's death rate in America. According to the latest CDC data (2017), South Carolina still ranks sixth highest in Alzheimer's deaths, and Alzheimer's is the sixth leading cause of death in our state.
- South Carolina is the third largest neurology desert in the nation, facing a massive projected shortage of neurologists by 2025 for our dementia population.
- 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.

We can't ignore 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 \$4.3 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.

By prioritizing a public health approach to science-backed risk reduction, we can help South Carolinians take steps to modify their risk factors and promote healthy behaviors. This can reduce the risk of cognitive decline, possibly reduce the risk of dementia, and protect cognitive health. These interventions, along with early detection and early diagnosis, can help families have longer with their loved one to prepare for care, financially, mentally, and legally.

We also know that we can work with our community-based care providers, including both long term care and community resources, to improve delivery of dementia-informed education to improve outcomes across all settings. This work, along with the collaboration of state agencies to prioritize dementia as a costly public health issue 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.

The Alzheimer's Resource Coordination Center (ARCC) serves as an essential foundation for this important work. Established by South Carolina law (SECTION 44-36-310) in 1994, the mandate of the ARCC and its Advisory Council members is to "provide statewide coordination, service system development, information and referral, and caregiver support services to individuals with Alzheimer's disease and related dementia, their families, and caregivers."

Duties of ARCC Advisory Council member roles are specified by statute and appointed by the Governor, including a slate of several new appointees in 2021. Their duties include attending quarterly Council meetings, participating in efforts to update South Carolina's Alzheimer's State Plan, recommending policy initiatives, advising the work of the SC Alzheimer's Registry, reviewing grants for Alzheimer's community education and caregiver support, and collaborating with Council members to advance services and supports for families facing Alzheimer's disease and related dementia in our state.

The work of the ARCC is overseen by our state Dementia Coordinator at the SC Department on Aging. In October 2022, South Carolina was one of the select states that attended the Dementia State Coordinator Summit in Washington, DC. This provided an invaluable opportunity for our Dementia Coordinator to expand her expertise by connecting with and learning from officials in other states who are similarly tasked with developing, supporting, and implementing dementia-specific policies across state agencies.

The ARCC has also been serving as a stakeholder group, most recently, with the aid of The Weathers Group, crafting an Alzheimer's state strategic plan, which was completed in March 2023. This plan provides a much-needed update to our state's previous Alzheimer's state plan of 2009 while also fulfilling the requirements of the Building Our Largest Dementia Infrastructure (BOLD) grant awarded to SC DHEC in September 2021 by the CDC. Stakeholder surveys and stakeholder focus groups have informed the plan's goals and objectives, charting a vital course to address the dementia crisis our state faces.

With all of this momentum through the ARCC, South Carolina is now poised to make a major impact on brain health, dementia support services, caregiving respite, and beyond – thanks to the wisdom of the SC General Assembly to invest in our state agencies and create the essential role of a Dementia Coordinator to lead these efforts at the SC Department on Aging.

As we all hope for the cure or prevention that cannot come soon enough, 197,000 caregiving South Carolinians and their 95,000 loved ones struggling with this disease urgently need our support. With your continued foresight and leadership, the SC General Assembly can help impacted families care for their loved ones at home longer, keep our caregivers healthier, and reduce the burden of cost of care for taxpayers in South Carolina.

Respectfully submitted,

A handwritten signature in black ink that reads "S. Taylor Wilson". The signature is written in a cursive, flowing style.

Chairperson, Alzheimer's Resource Coordination Center (ARCC)

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South Carolina Statistics

The 2021 Annual Report of the South Carolina Alzheimer's Disease Registry reports that 111,818 individuals were living with Alzheimer's or Related Dementia (ARD) in 2017. The Registry tracks information from January 1, 2017, through December 31, 2017, the most current years with available and comprehensive data.

In 2021, in South Carolina, approximately 197,000 persons cared for these individuals (based on statistics provided by the Alzheimer's Association "2022 Alzheimer's Disease Facts and Figures"). The Alzheimer's Association report projects a 51% increase in the number of persons affected by Alzheimer's disease and other related dementia between 2017 and 2050.

Caregiving Information

In the United States, more than 11 million Americans provided unpaid care in 2021 ("2022 Alzheimer's Association Disease Facts and Figures"). These caregivers provided an estimated 16 billion hours of unpaid care, valued at \$27.6 billion. The estimated value of care by family and unpaid caregivers in South Carolina alone was over \$4 million in 2021 ("2022 Alzheimer's Association Facts and Figures").

The physical, emotional, and financial demands on unpaid caregivers are huge, especially for those caring for a person with dementia. In South Carolina, nearly 22% of caregivers suffer from depression, 54% have chronic health conditions, and 11.8% are in poor physical health ("2022 Alzheimer's Association Disease Facts and Figures"). Families want to keep their loved ones at home. However, the absence of supportive services which enable families to care for their loved ones at home may lead to premature placements in an institutional setting, thereby increasing the economic cost to the state and the psychological cost to the family caregivers.



Beginning in 1995, the Legislature has addressed this need by allocating \$150,000 in state funds to the ARCC each year to develop community-based respite programs, caregiver education and training, and other supportive services to support caregivers and those living with ADRD. Grant programs include group respite, adult day services, education programs, and innovative programs that support family caregivers and those living with ADRD. Others have included persons with Alzheimer's disease, the medical community, colleges and universities, first responders, such as police, fire, and emergency medical personnel, and the general public. Recipients of the grants are awarded up to \$20,000 in the first year and \$10,000 in the second year. Grantees are required to equally match state grant funds through community funding and in-kind resources.

The ARCC is the only entity in South Carolina that awards grants to start dementia-specific respite and education programs in communities. It monitors and provides technical assistance to grantees to ensure that the standards remain at the highest level.

It offers information and resources to the grantees as well as the general public. The ARCC continues to encourage and support grantees after their grant award has ended by offering technical assistance to encourage the sustainability of their programs.

Alzheimer's disease is one of the costliest and most uninsured health risks South Carolina families are likely to face. The U.S. Census Bureau projects that in 2030, South Carolina will be home to 1.1 million people over the age of 65, potentially propelling South Carolina to a ranking of 15th in the nation for the highest percentage of adults 65+ residents.

Increasing age is a leading risk factor for Alzheimer's disease, and South Carolina's rapidly growing older population presents a challenge to families, communities, and those who plan and deliver services for the state. By preparing for the future now and providing the much-needed supportive services for families caring for loved ones at home, South Carolina will be ready to meet the challenges of Alzheimer's disease and related dementia with programs and services in place, rather than trying to handle the epidemic after it has started.

Supportive Services Provided by First and Second-Year ARCC Grantees in 2021-2022:

Supportive Services Provided by First and Second-Year ARCC Grantees in 2021-2022:

Number of Unduplicated Respite Participants	243
Hours of Respite Provided	12,178
Number of Support Group Meetings	52
Number of Educational Participants	1,573
Numbers of Hours of Education	4,114
Number of Innovative Programs	6

Eight grants were awarded in 2021-2022, comprised of five respite programs, one education program, and two innovative programs. All ARCC grant awards are equally matched with community funding and in-kind resources. A plan for sustainability is required for the continuation of the program after grant funding has ended. Standardized reporting for all grant programs is required to aid in ensuring fidelity to the objectives as outlined in the grant application.

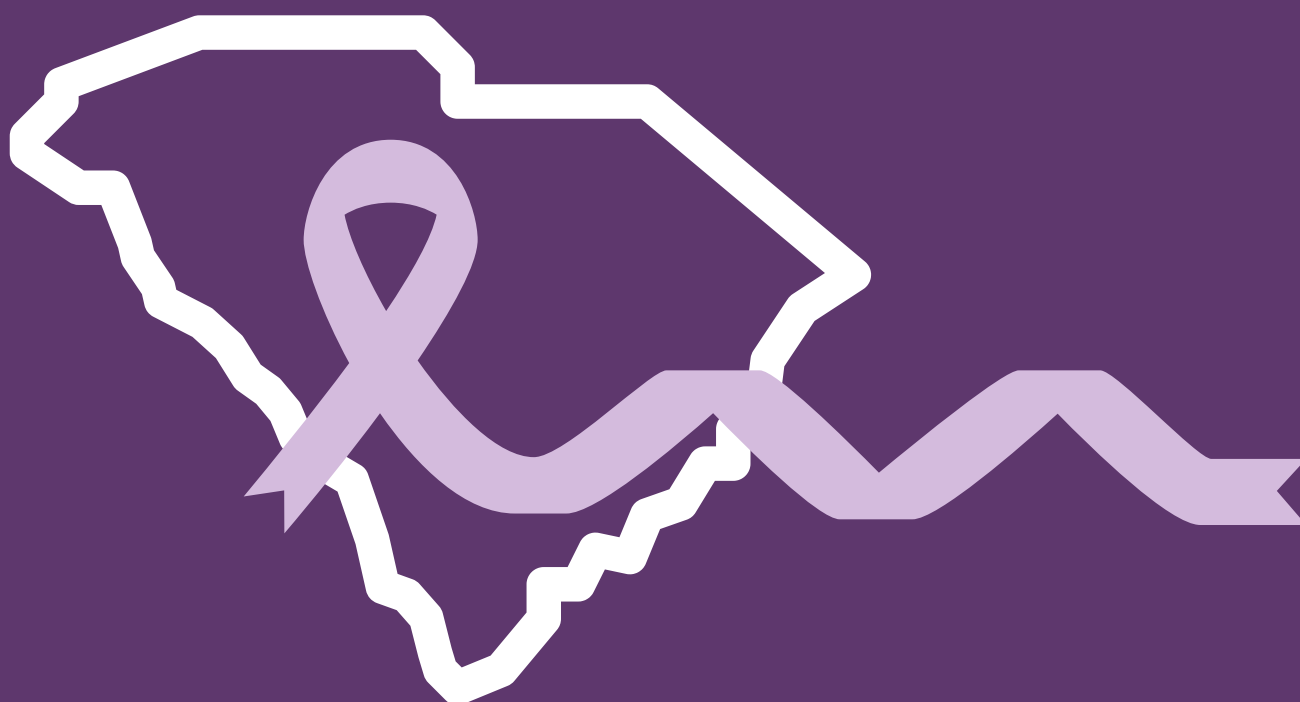
As part of the grant process, the ARCC sponsored a pre-proposal workshop for prospective grantees in February 2021 and a grant procedures workshop for new grant recipients in June 2021. The Dementia Coordinator leads quarterly grantee meetings in order to unite grantees and share better practices. Additionally, ARCC grant information is made available at www.aging.sc.gov.



Providing the much-needed supportive services for families caring for loved ones at home can prevent or delay the much higher cost of assisted living or nursing home placement. Substantial cost savings are realized for both the state and its taxpayers when home- and community-based services are adequately funded and available for utilization. Support from our state's leaders is imperative in combating the costs associated with these diseases.

By acting proactively, our state will spend less money and serve more persons living with Alzheimer's and related dementias. If our leadership fails to act, taxpayers will be forced to foot the bill for the huge differences in costs. We thank the South Carolina Legislature for its support in providing relief, respite, and education to South Carolinians with Alzheimer's disease and related dementias and their caregivers, and we believe further investigation of the savings our state will see by supporting home and community-based services is warranted.

Due to the unprecedented growth of the senior population in our state, it is vital to our state's welfare, our citizens, and our economy that our leadership study these potential savings that could very well avert a crisis in our state.



A. Enabling Legislation

The Alzheimer's Resource Coordination Center was created in the Division on Aging Act of the South Carolina Legislature effective April 20, 1994, and is now housed in the South Carolina Department on Aging. The purpose of the Center is to "provide statewide coordination, service system development, information and referral, and caregiver support services to individuals with Alzheimer's disease and related disorders, their families, and caregivers."

B. Responsibilities Assigned by Legislation

According to the SC Code of Laws Section 33-36-320, the center shall:

- (1) Initiate the development of systems, which coordinate the delivery of programs and services;
- (2) Facilitate the coordination and integration of research, program development, planning, and quality assurance;
- (3) Identify potential users of services and gaps in the service delivery system and expand methods and resources to enhance statewide services;
- (4) Serve as a resource for education, research, and training and provide information and referral services;
- (5) Provide technical assistance for the development of support groups and other local initiatives to serve individuals, families, and caregivers;
- (6) Recommend public policy concerning Alzheimer's Disease and related disorders to state policymakers;
- (7) Submit an annual report to the Joint Legislative Committee on Aging and to the General Assembly.

C. Community Grants

According to the SC Code of Laws Section 44-36-325, the Alzheimer's Resource Coordination Center was further directed to "develop a grant program to assist communities and other entities in addressing problems relative to Alzheimer's disease and other related disorders. In awarding grants, consideration must be given to recommendations made by the advisory council to the center on priority needs and criteria for selecting grant recipients. As a condition to receiving a grant, the community or other entity shall provide matching funds or an in-kind contribution equal to the amount of funds awarded in the grant." This act took effect July 1, 1996.

III. ADVISORY COUNCIL

The ARCC is supported by an advisory council appointed by the Governor including, but not limited to, representatives of:

1. Alzheimer's Association – SC Chapter
2. AARP
3. Clemson University
4. Department of Disabilities and Special Needs
5. Department of Health and Environmental Control
6. Department of Mental Health
7. Department of Social Services
8. Department of Health and Human Services
9. Medical University of South Carolina
10. National Association of Social Workers, South Carolina Chapter
11. South Carolina Adult Day Services Association
12. South Carolina Association of Area Agencies on Aging
13. South Carolina Council on Aging Directors
14. South Carolina Association of Nonprofit Homes for the Aging
15. South Carolina Association of Residential Care Homes
16. South Carolina Health Care Association
17. South Carolina Home Care Association
18. South Carolina Hospital Association
19. South Carolina Medical Association
20. South Carolina Nurses Association
21. South Carolina Alzheimer's Disease Registry
22. South Carolina State University
23. University of South Carolina
24. Coastal Carolina University
25. Family Caregiver
26. SC Silver Haired Legislature
27. SCALA

The Advisory Council meets quarterly and Sub-Committees meet as needed.

Appendix A – ARCC Advisory Council Members

Alzheimer’s Association–SC Chapter –
Ms. Taylor Wilson (Chair)

AARP –
Mr. Joseph Meyers

Clemson University –
Dr. Nicole Davis

Coastal Carolina University –
Dr. Cynthia Port

Consumer/Caregiver 1 –
Ms. Angela Sanders

Consumer/Caregiver 2 –
Dr. Scott Habakus

Department of Disabilities and Special
Needs –
Mr. Robert McBurney

Department of Health and Environmental
Control –
Ms. Emma Kennedy

Department of Health and Human Services –
Ms. Margaret Alewine

Department of Mental Health –
Dr. Miroslav Cuturic

Department of Social Services –
Ms. Kelly Cordell

Medical University of South Carolina –
Dr. Steve Carroll

Medical University of South
Carolina/Veterans Health Administration –
Dr. Jessica Broadway

National Association of Social Workers, South
Carolina Chapter –
Ms. Sara English

South Carolina Adult Day Association –
Pending

South Carolina Association of Area Agencies
on Aging –
Ms. Janae Stowe

South Carolina Council on Aging Directors –
Mr. Andrew Boozer

Leading Age/South Carolina Association of
Nonprofit Homes for the Aging –
Ms. Vicky Moody

South Carolina Association of Residential
Care Homes –
Ms. Denise Kish (Vice–Chair)

South Carolina Health Care Association –
Ms. Melissa Gilliam

South Carolina Home Care Association –
Ms. Mary Peck

South Carolina Hospital Association –Pending

South Carolina Medical Association–
Dr. Terry Dodge

South Carolina Nurses Association –
Pending

South Carolina Silver–Haired Legislature –
Ms. Rebecca Smith

South Carolina Statewide Alzheimer’s Disease
Registry –
Dr. Maggi Miller

South Carolina State University –
Dr. Miriam Evans

University of South Carolina –
Ms. Megan Byers (Secretary)

Staff: Ms. Jennifer Brewton, Ms. Sheila Lewis

Appendix B – Grants Awarded in July 2021 for FY 2021-2022

Alzheimer’s Family Services of Greater Beaufort Respite Beaufort County	\$10,000
Golden Corner Respite Respite Oconee County	\$20,000
Leeza’s Care Connection Education & Innovative Lexington & Richland Counties	\$20,000
Magnolia Memory Care Respite York County	\$18,744
Midlands Development Corporation Education & Innovative Richland County	\$30,000 ¹
Mother DeVeaux Adult Day Care Respite Richland County	\$16,500
Respite Care Charleston Respite Charleston County	\$10,000
The Ark of SC Education Charleston County	\$20,000
TOTAL GRANT AWARDS IN FISCAL YEAR 2021-2022	\$145,244

Includes \$10,000 from the ARCC 2019-2020 fiscal year carried forward due to inability to start programming as planned due to COVID-19 delays.

South Carolina Department on Aging
Alzheimer's Resource Coordination Center

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