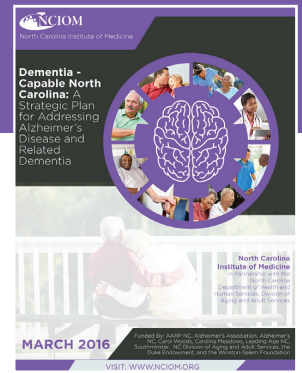


Dementia-Capable North Carolina

PROGRESS REPORT 2020



What is Dementia-Capable?

Dementia-Capable is interpreted as an ability, through a combination of staff knowledge, skills, and competency as well as available programs and services, to fulfill the needs of people living with dementia and their caregivers. This term is used in the U.S. national dementia plan and relevant documents (HHS, 2012a, 2013b).

What is Alzheimer's Disease and Related Dementia?

Dementia is a general term for memory loss and other cognitive decline serious enough to interfere with daily life. Dementia is not a normal part of aging. Alzheimer's disease is a type of dementia and the most commonly diagnosed. Alzheimer's disease accounts for 60-80 percent of dementia cases and is an irreversible, progressive brain disorder. (NIH)

The Task Force on Alzheimer's Disease and Related Dementias

In March 2015, the North Carolina Institute of Medicine (NCIOM), in partnership with the North Carolina Department of Health and Human Services Division of Aging and Adult Services, convened a statewide, multi-stakeholder Task Force on Alzheimer's Disease and Related Dementias. Through a mandate from the North Carolina General Assembly, Senate Bill 744 (2014), the Task Force was charged with developing an actionable strategic plan for the state of North Carolina.

The Task Force was funded by AARP NC, the Alzheimer's Association, Alzheimer's NC, Carol Woods, Carolina Meadows, the Duke Endowment, LeadingAge NC, the North Carolina Department of Health and Human Services Division of Aging and Adult Services, Southminster, and the Winston-Salem Foundation.

The full Dementia-Capable North Carolina Strategic Plan can be downloaded at <http://nciom.org/dementia-capable-north-carolina-a-strategic-plan-for-addressing-alzheimers-disease-and-related-dementias/>

Notable Progress in NC's Five Focus Areas

The Dementia-Capable North Carolina Strategic Plan (the Plan) is organized around the following five focus areas:

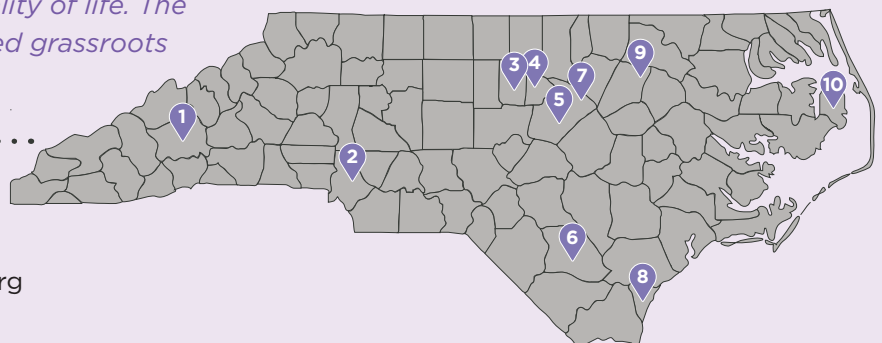
1. Raising Awareness About Alzheimer's Disease and Related Dementias
2. Having Supportive Options That Foster Quality of Life
3. Supporting Caregivers and Families Touched by Alzheimer's Disease or Related Dementias
4. Promoting Meaningful Participation in Community Life
5. Reaching Those Who Are Underserved

Examples of notable progress are described below by Focus Area. Reference to specific Strategic Plan Recommendations are indicated in parentheses. For a full list of the recommendations, see Appendix A.

What is a dementia friendly community? *A dementia friendly community is a town, city, county, or region that is informed, safe and respectful of individuals with dementia and their families and caregivers and provides supportive options that foster quality of life. The areas listed here are engaging in a locally led grassroots process to become more dementia friendly.*

Dementia Friendly Communities as of 2020

1. Dementia Friendly Western NC
2. Dementia Friendly Charlotte-Mecklenburg
3. Dementia Friendly Orange
4. Dementia Inclusive Durham
5. Dementia Friendly Cary
6. Dementia Friendly Bladen
7. Dementia Friendly Wake Forest/SING



8. Dementia Friendly Southeast NC
9. Dementia Friendly Nash
10. Dementia Friendly Outer Banks

FOCUS AREA 1: Raising Awareness About Alzheimer’s Disease and Related Dementias

A. Local and statewide groups are working actively to raise awareness about and promote Alzheimer’s Disease and related dementias, as well as the Plan.

- As part of its goal to strengthen service delivery and capacity, the 2019-2023 North Carolina State Plan on Aging includes Objective 4.3: “Provide effective leadership for Dementia-Capable North Carolina, a strategic plan for addressing Alzheimer’s disease and related dementias.” The Coalition for a Dementia-Capable North Carolina assists with and oversees progress on the Plan’s 33 recommendations. The Coalition includes representatives from the public and private sectors. **(3.4)**
- The Dementia Friendly Communities Statewide Workgroup (now called the Dementia Friendly Communities and Hospitals Collaborative) fosters the development and growth of dementia friendly community efforts across the state. This Workgroup includes representatives from those active community projects that are underway. **(3.3)**
- Representatives from UNC Hospitals, Vidant Health, Chesapeake Regional Health Care, Carolina East Health Systems, Carteret Health Care, and more than 16 Dementia Friendly community initiatives have joined the NC Dementia Friendly Communities and Hospitals Collaborative led by NC DAAS to mentor one another and foster a growing statewide Dementia Friendly movement. **(3.4)**
- In 2019, NC DAAS formed a Dementia Friendly Communities Baseline Standards Task Force consisting of representatives from Area Agencies on Aging, dementia friendly communities and hospitals, NC Alzheimer’s Association, and NC Dementia Alliance. This team developed a brief navigational document for North Carolina that addresses common questions about dementia friendly communities, Dementia Friends Information Sessions and Dementia Friendly Hospitals. **(3.1)**



- Carol Woods Retirement Community has presented its initiative, The Quest Upstream, at Leading Age conferences, Dementia Action Alliance and other national conferences, as well as published a blog at changingaging.org, contributed articles and podcasts for Leading Age and Commission on Accreditation of Rehabilitation Facilities, and participated in a documentary film to be released in late 2020 by Virginia Public Media. **(3.1, 3.2)**
- New Hanover County Senior Resource Center is in the process of developing a 5-year Master Aging Plan, which will include a dementia friendly initiative. **(3.1)**
- Lower Cape Fear LifeCare in Wilmington has started a Dementia Care Specialty Program, serving more than 115 families prior to 2020 and provided Dementia Friends Information Sessions to more than 350 attendees across their 10-county area. **(3.1)**
- Dementia Inclusive Durham received a grant in 2019 from the U.S. Administration on Community Living to support their efforts to develop community-involved strategies for individuals living with dementia. Dementia Inclusive Durham was formed in 2016 and is one of the state’s first dementia friendly community initiatives. **(3.3)**
- Mecklenburg County was recognized with a 2019 Aging in Action award for its role in the Dementia Friendly Charlotte-Mecklenburg and helping adults age with choice, dignity, and independence. **(3.3)**

FOCUS AREA 2: Having Supportive Options that Foster Quality of Life

B. Providers of long-term services and supports recognize the need for specialized training and increased capacity for supporting people with Alzheimer’s or related dementia.

- Carol Woods Retirement Community’s participatory action research initiative, The Quest Upstream, is designed to support the inclusion of people living

with dementia and the wellbeing of all community members. This project has improved their capacity to problem-solve as a team and reduce distress and increase well-being among residents living with dementia in their higher levels of support. **(4.6)**

- Since 2016, Wake AHEC has offered an annual “Join the Team! A Person/Family Centered

Approach to Alzheimer’s Disease and Related Dementia Care” for healthcare providers, caregivers, families and patients to learn from, with, and about each other’s role in Alzheimer’s Disease and Related Dementia. **(4.6)**

- The North Carolina Association of County Directors of Social Services Road Map for Program Improvement: Addressing the Needed Improvements in Aging and Disabled Adults calls for comprehensive training for facility staff to effectively manage needs of residents with dementia. **(4.10)**
- The NC Culture Change Coalition in conjunction with the Centers for Medicaid and Medicare Services (CMS) issues grants to certified nursing homes for programs that benefit the residents, such as: music and art programs, sensory gardens, intergenerational programs, and Compassionate Touch®. **(4.10)**

C. Several hospital systems have adopted Dementia Friendly practices and have joined the Dementia Friendly Communities Statewide Working Group, now known as the Dementia Friendly Communities and Hospitals Collaborative.

- In 2017, the Outer Banks Hospital was named the First Dementia Friendly Hospital in North Carolina. The staff are trained in best care practices that include a sensitivity to and an awareness of the difficulties faced by those with dementia and their caregivers, and has grown

into a versatile program that touches several patient-facing departments at the hospital. **(4.9)**

- In 2018, the UNC Center for Healthy Aging received a 3-year grant from the Duke Endowment for a Dementia Friendly Hospital Initiative (DFHI). **(4.9)**
- Five UNC Health hospitals are participating in the DFHI: UNC Hospitals – Hillsborough Campus (pilot); Wayne UNC Health Care; NC Memorial Hospital; Pardee UNC Health Care; and Chatham Hospital. As of May 31, 2020, 1,240 UNC Health employees have been trained. **(4.9, 4.10)**
- DFNI is working with the NC Division of Aging and Adult Services (NC DAAS) and the Area Agencies on Aging in the participating hospitals’ service areas to ensure that patients and their caregivers are aware of available community resources. **(4.1, 4.8)**
- NC Governor Roy Cooper declared September 26, 2019 to be “Dementia Friendly Hospitals Day.” **(4.9)**
- In February 2020, the UNC Dementia Friendly Hospital Initiative (DFHI) received the Triangle Business Journal’s “Health Care Hero Community Impact Award.” **(4.9)**
- The NC Health and Human Services’ Office of Rural Health has supported Chowan and Outer Banks Hospitals, both part of Vidant Health System, with funding, technical assistance and consultation. **(4.9)**

FOCUS AREA 3: Supporting Caregivers and Families Touched by Alzheimer’s Disease or Related Dementias

D. Many are prioritizing support for caregivers of people with dementia.

- The NC Senior Tar Heel Legislature’s 2020 Priorities include increasing funding for Project C.A.R.E. (Caregivers Alternatives to Running on Empty) by \$500,000 in 2019-20 and in future years increasing funding by 10% annually for expected growth. **(5.2)**
- No Wrong Door, in collaboration with NC 2-1-1, provided training and a long-term services and supports specialist in 2019. **(5.3)**
- NCCare360, a robust statewide resource directory, which provides a No Wrong Door approach and is powered by NC 2-1-1, is now available in all 100 counties in NC. **(5.3)**
- The NC Coalition on Aging’s legislative priorities include conducting a comprehensive study about how the state can better support family

caregivers, particularly caregivers who are in the workforce so they can continue to work. **(5.4)**

- Pending approval by the Centers for Medicare and Medicaid Services the NC Community Alternatives Program for Disabled Adults (CAP-DA) program will enhance client and caregiver choice and broaden the types of support beneficial to people with dementia. These include: **(5.6)**
 - Establishment of a Comprehensive Integrated Assessment Entity (CIAE) to provide integrated access to services
 - Expansion of Programs of Inclusive Care for the Elderly (PACE) across the state
 - A beneficiary resource line made available by the CIAE
 - More support for family caregivers under the new CAP-DA waiver
 - Consumer direction so that beneficiaries can hire family members

FOCUS AREA 4: Promoting Meaningful Participation in Community Life

E. A network of local and statewide efforts to address elder abuse has grown.

- NC Partnership to Address Adult Abuse promotes safe communities through prevention, recognition, protection and prosecution of adult abuse, neglect and exploitation. **(6.1)**
- The UNC School of Government hosted the Elder Abuse Multi-Disciplinary Team Workshop, in September 2019. The workshop brought together diverse stakeholders from around North Carolina to begin the process of forming and developing multi-disciplinary teams (MDTs) to address elder abuse in their respective communities. **(6.2)**



- Guilford County's Family Justice Center launched "Friends Against Fraud," an initiative aimed at protecting adults with dementia. This has been shared in other communities across the state and is being implemented in Buncombe County. **(6.4)**

FOCUS AREA 5: Reaching Those Who are Underserved

F. Several efforts are underway to reach those populations that are disproportionately affected by Alzheimer's disease and related dementia.

- The NC Registry for Brain Health, launched in June 2019, is the first registry of its kind in the State of North Carolina. The Registry is designed to increase awareness of Alzheimer's disease and related disorders and to connect North Carolinians of all ages to research opportunities designed to improve brain health. A large percentage of registry participants are from underserved groups. **(7.1)**
- The NCDHHS' Division of Aging and Adult Services (DAAS) was awarded a grant in 2020 from the Centers for Disease Control and Prevention (CDC) to help promote a public health approach to Alzheimer's disease and related dementias. **Building Our Largest Dementia Infrastructure for North Carolinians (BOLD NC)**, will assist the divisions of Aging and Adult Services and Public Health in increasing the focus on brain health and cognitive decline risk factors, as well as help to meet the needs of people with dementia and

their caregivers. Program activities will align with the *Healthy Brain Initiative State and Local Public Health Partnerships to Address Dementia: The 2018-2023 Road Map and the Road Map for Indian Country*. **(7.1)**

- A Caregiver Module was included in the 2017 NC Behavioral Risk Factor Surveillance System (BRFSS) and the Cognitive Impairment/Decline Module, which was included in 2011, was also included in the 2020 BRFSS. **(7.2)**
- The Coalition for a Dementia-Capable NC determined that death certificates need to more consistently cite dementia as the cause of death, as Alzheimer's and Related Disorders are now the 4th leading cause of death in North Carolina in adults age 65 and older. It is the 5th leading cause of death among all North Carolina adults. **(7.3)**
- The NC Health and Human Services Office of Rural Health's Medication Assistance Program for the uninsured and underinsured contains dementia medications in its formulary.



The following updates cross Focus Areas 1, 2, 3 and 4.

G. The statewide initiative Rethinking Guardianship promotes the use of less restrictive alternatives to guardianship and works to improve the current guardianship system in North Carolina.

- A brochure, available in English and Spanish, describes options and alternatives to guardianship and is distributed widely through the Rethinking Guardianship network. **(3.1, 6.1, 6.2)**
- The website <http://rethinkingguardianshipnc.org> includes relevant data, articles and educational materials. **(6.1)**
- An educational video aimed particularly at families, titled “Understanding Guardianship” is posted on the Rethinking Guardianship website. **(3.1, 5.7, 6.1)**
- Work is underway to redraft NC General Statute 35A to ensure greater rights and protections for adults under guardianship. **(6.3)**
- Data, stories and findings from Rethinking Guardianship were submitted to the US Senate Special Committee on Aging for the report, “Ensuring Trust: Strengthening State Efforts to Overhaul the Guardianship Process and Protect Older Adults.” **(6.1, 6.2)**
- Rethinking Guardianship has been presented at numerous professional conferences for organizations such as the NC Bar Association, Elder Law and Special Needs Section and Area Health Education Centers. **(4.1, 4.10, 6.1, 6.2)**
- A Rethinking Guardianship Summit was held in 2019 with over 300 guardianship stakeholders to build awareness and engage participants in national and state action to protect elders and people with disabilities from fraud, abuse and exploitation. **(6.1, 6.2)**

APPENDIX A: Dementia-Capable NC Strategic Plan Recommendations

Focus Area 1: Raising Awareness and Transforming Attitudes

- 3.1 – Increase awareness and promote education about Alzheimer’s disease and related dementias and available resources through incorporating Alzheimer’s disease and related dementia-specific information in current health promotion and education programs.
- 3.2 – Enhance training for health care providers on the benefits and best practices for detection, diagnosis, and services referrals of Alzheimer’s disease and related dementias.
- 3.3 – Create a collective impact partnership to develop and establish dementia-capable pilot communities.
- 3.4 – Establish statewide coordinated leadership to oversee the state plan on Alzheimer’s disease and related dementias.

Focus Area 2: Having Supportive Options that Foster Quality of Life

- 4.1 – Promote appropriate care settings for people with Alzheimer’s disease and related dementia, including home- and community-based settings, institutional settings, and hospice and palliative care when appropriate.

- 4.2 – Examine methods of reimbursement and incentives for Alzheimer’s disease and related dementia care through new models of care, including care management services and palliative care before people with Alzheimer’s disease and related dementia are hospice eligible.
- 4.3 – Assess health system capacity for people with Alzheimer’s disease and related dementias.
- 4.4 – Improve telehealth services for people with Alzheimer’s disease and related dementias.
- 4.5 – Increase access to medical and community services for people with Alzheimer’s disease and related dementia through improved transportation services through an inter-departmental working group.
- 4.6 – Apply principles of person-centered care to the care processes and protocols at health care providers and facilities for people with Alzheimer’s disease and related dementias.
- 4.7 – Improve quality of care and care coordination for people with Alzheimer’s disease and related dementia through improved ratings systems and dementia-specific indicators.
- 4.8 – Improve care coordination for people with Alzheimer’s disease and related dementia through new models of care.



- 4.9 – Expand the Dementia Friendly Hospital initiative.
- 4.10– Promote Alzheimer’s disease and related dementia-specific training for health professionals and community workforce.
- 4.11 – Incentivize entry into geriatric and gerontology specialization and additional training in dementia care.
- 4.12– Increase compensation based on Alzheimer’s disease and related dementia-specific training and certification.

Focus Area 3: Supporting Caregivers and Families

- 5.1 – Promote integration and accessibility of dementia-specific resources through a comprehensive caregiver toolkit and virtual resource center.
- 5.2 – Ensure adequate funding for family caregiver support services including dementia specific respite through NC Project C.A.R.E.
- 5.3 – Continue No Wrong Door Initiative through a collaboration with NC 2-1-1.
- 5.4 – Enhance employer policies to support family caregivers.
- 5.5 – Examine outcomes and impact of home- and community-based services programs.
- 5.6 – Expand the Medicaid Home and Community Based Services Waiver Program.
- 5.7 – Implement best practices for the integration and coordination of home- and community-based services.

Focus Area 4: Promoting Meaningful Participation in Community Life

- 6.1 – Increase awareness of legal protections and vulnerabilities of people with Alzheimer’s disease and related dementia.
- 6.2 – Incorporate legal protection issues specific to people with Alzheimer’s disease and related dementias into health, legal, and financial professional training.
- 6.3 – Examine state statutes to determine adequate legal safeguards and protections for people with Alzheimer’s disease and related dementia.
- 6.4 – Integrate elder fraud and abuse data to improve services for people with Alzheimer’s disease and related dementia.
- 6.5 – Improve home safety resources and workforce capacity.
- 6.6 – Enhance public safety and law enforcement outreach around Alzheimer’s disease and related dementia.

Focus Area 5: Reaching Those Who Are Underserved

- 7.1 – Support Alzheimer’s disease and related dementia research through the establishment of a statewide collaborative registry
- 7.2 – Continue periodic inclusion of cognitive impairment and caregiver modules of the Behavioral Risk Factor Surveillance System.
- 7.3 – Improve prevalence data through accurate death certificate completion.
- 7.4 – Improve data on Alzheimer’s disease and related dementia prevalence through implementing a statewide data reporting system.

