

## Chapter Three: Raising Awareness About Alzheimer’s Disease and Related Dementias

**C**rucial to helping state stakeholders and individuals address the growing problem of Alzheimer’s disease and related dementias in our state are accurate information about symptoms, diagnosis, disease progression, and relationships to other aspects of preventive health care, as well as guidance and resources for the logistical aspects of dementia, such as caregiver concerns, financial planning, legal protections, and options for long-term care.

The Task Force envisions a collective, statewide effort toward raising awareness and supporting North Carolinians with Alzheimer’s disease or related dementias and their families and caregivers. This effort should also build upon the existing work of the many state stakeholders currently working to promote messages around Alzheimer’s disease and related dementias and ensure that North Carolinians have the information needed to face the challenges of these conditions. The Task Force sought to develop actionable recommendations around raising awareness of many important aspects of Alzheimer’s disease and related dementias for individuals, families, and policymakers, including promoting brain health, early detection and diagnosis of dementia, and collective efforts toward developing dementia-capable North Carolina communities.

**“ Stigma has a negative influence on both individuals with Alzheimer’s or related dementias and their caregivers, including discrimination and rejection.**

### ***Promoting Awareness and Education about Alzheimer’s Disease and Related Dementias***

While the term “Alzheimer’s disease” and some related symptoms and disease characteristics are generally known, many misperceptions remain. These misperceptions include that memory loss or other cognitive symptoms are always a normal part of aging; that only older individuals develop Alzheimer’s; or that there are no effective treatments for Alzheimer’s disease. Also, because Alzheimer’s and related dementias are poorly understood and often feared, there is often stigma surrounding individuals and families who are coping with Alzheimer’s.<sup>1</sup> Studies have shown that the effects of stigma have a negative influence on both individuals with Alzheimer’s or related dementias and their caregivers, including discrimination and rejection for the person with the disease. This stigma can also contribute to caregiver burden.<sup>2,3</sup> Decreasing this stigma can help families better prepare for the emotional, physical, and financial costs of Alzheimer’s disease or related dementias, as well as benefit from community support and medical research.<sup>4</sup>

Many advocacy and research organizations support general messaging around the importance of healthy behaviors and lifestyle choices that can improve brain health and potentially have an impact on the likelihood of developing Alzheimer’s disease or related dementias. Other behavior messages focus on the importance of social engagement and participating in cognitive activities such as reading and completing puzzles.<sup>5,6</sup> Many organizations encourage integrating these messages into broader state and local public health promotion efforts, ensuring that messages are culturally sensitive and relevant to diverse groups, and incorporating appropriate partnerships and collaborations in order to increase awareness of Alzheimer’s disease and related dementias as a public health challenge.<sup>7</sup>

Promotion of available resources and information for families dealing with Alzheimer’s disease or related dementias must also be incorporated into awareness and education campaigns. There is a wealth of information and resources in North Carolina (see Chapters 4 and 5), however families often face difficulty in accessing this information when they need it and also in understanding eligibility for services. Families need information about health care providers, long-term care, home- and community-based services, insurance coverage, financial assistance and planning, legal protections, family communication, caregiving roles and tasks, caregiver coping, respite, day-to-day symptom management, and self-care. As health and service providers develop materials for public outreach and education, they should ensure the inclusion of dementia-specific information and resources.

The Task Force examined many examples of the important work currently being done to promote public health messages related to heart and brain health. The Task Force recognized the opportunity to incorporate dementia-specific information into this health promotion work and emphasized the value of collaboration, partnerships, and a shared commitment to raising awareness about Alzheimer’s disease and related dementias.

**Recommendation 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.**

In order to increase awareness and promote education about Alzheimer’s disease and related dementias, organizations should establish a partnership (and/or build on existing public/private partnerships) to explore the incorporation of Alzheimer’s disease and related dementias information into current health promotion/education programs and social marketing/health promotion materials. Information should include:

- a) Connection between brain health and other preventable risk factors and health behaviors.
- b) Support for early detection and accurate diagnosis, and information about prevention and clinical trial registries.
- c) Resources/referrals for home- and community-based services, health care providers (including specialists), caregiver support services, home safety, and long-term care.
- d) Financial planning information, including available insurance coverage for different types of care and advanced care planning, legal protections (including information on fraud, guardianship, and Adult Protective Services), care transitions, and employee resources.
- e) Strategies to reduce stigma around Alzheimer’s disease and related dementias.
- f) Resources for underserved populations including individuals with intellectual/developmental disabilities, minority populations, homeless, and rural communities.

Partners: Including, but not limited to, North Carolina Division of Aging and Adult Services, North Carolina Division of Public Health, North Carolina Division of Mental Health, Developmental Disabilities, and Substance Abuse Services, the state Medicaid agency, North Carolina Department of Public Instruction, Area Agencies on Aging, North Carolina Office of Rural Health, county social and human services agencies, county Departments of Public Health, providers of mental health services, academic programs for professionals in health and human services, philanthropic organizations, North Carolina Chamber of Commerce, businesses/employers, health professional associations, managed care organizations, private payers, faith-based communities, and advocacy organizations.

**Early Detection and Diagnosis**

Less than 50% of people with diagnosed Alzheimer’s disease or related dementia report being told of their diagnosis. When caregivers (instead of diagnosed individuals) were asked about being told if their family member had Alzheimer’s or dementia, only 50-53% reported that they had been informed of the diagnosis. The current health professional consensus is that individuals and families should always be informed when Alzheimer’s disease or related dementia is detected.<sup>8</sup>

Early recognition of Alzheimer’s and related dementia symptoms and subsequent appropriate diagnosis can be helpful for families facing the challenges of Alzheimer’s disease or related dementias. Normal aging is the most common reason for memory loss, but detection tools can identify whether there are additional behavioral or cognitive markers that indicate Alzheimer’s disease or other forms of dementia.<sup>9</sup> There are currently a number of tools in use by health care providers to appropriately identify and diagnose Alzheimer’s disease and related dementias.<sup>10</sup> One of the most common tools is the mini mental state examination. This tool consists of a short series of questions and tasks.<sup>10</sup> The Mini-Cog™ test is another brief and validated screening test for dementia.<sup>11</sup> Cognitive changes identified by these tests should be interpreted in the context of the person’s medical history, medications, mood symptoms, and concurrent medical concerns.

If a test indicates possible Alzheimer’s disease or a related dementia, the health care provider may perform or refer the person for additional evaluation.<sup>9</sup> For individuals over the age of 65 who receive insurance coverage through Medicare, the annual wellness visit must include a cognitive assessment. Because there is no universally accepted assessment tool, Medicare does not specify which tool providers should use or how to conduct the tests.<sup>12</sup> Instead, they are required to “assess the beneficiary’s cognitive function by direct observation, with due consideration of information obtained via beneficiary reports and concerns raised

**“ Only 47% of primary care physicians in the U.S. believe that their practice is properly trained and prepared to handle the care needs of people with dementia. ”**

by family members, friends, caretakers, or others.”<sup>13</sup> This may consist of reviewing a patient’s other health risks, questioning the patient and/or family members about behavior, and/or using standardized cognitive tests.<sup>12</sup> For individuals with Down’s syndrome, assessment is generally recommended at an earlier age and providers use assessment tools to measure baseline cognitive ability as well as new or ongoing behavioral symptoms. For individuals with Down’s syndrome, behavioral changes are more common early symptoms of Alzheimer’s disease than memory loss or forgetfulness.<sup>14,15</sup> (See Chapter 7 for additional information about individuals with intellectual or developmental disabilities.)

The costs and benefits to universal screening for Alzheimer’s disease and related dementias remain unclear. The United States Preventive Services Task Force studied the use of diagnostic tools for dementia and found that, while many tools are useful for identifying dementia, there is inadequate evidence for the benefits of universal dementia screening for adults over 65 with no cognitive symptoms.<sup>16</sup> There are a limited number of medications or therapies that aim to treat dementia by managing symptoms, but clinical outcomes are inconclusive and many patients experience adverse side effects.<sup>17</sup>

Beyond therapeutic approaches, there still may be benefits of early detection and diagnosis of dementia for individuals and families. Early detection may allow families the opportunity to plan – financially, logistically, and legally – for challenges they might face in dealing with the diagnosis. They may be able to receive referrals to home- and community-based services, and clinical trial registries. Early detection may also be helpful in preventing loss of income or assets from bad decisions, losing or breaking personal property, and other consequences of early Alzheimer’s disease or related dementias. In part because of the potential planning benefits for families, the United States Preventive Services Task Force suggests that health care providers conduct assessments for cognitive impairment whenever there are symptoms that may indicate dementia or mild cognitive impairment.

In order for providers to adequately conduct dementia screening and diagnosis when indicated, there is a strong need for enhanced training in specific assessment tools, the application of those tools in appropriate contexts, and in best practices for connecting patients to needed additional care and resources. Recent research shows that only 47% of primary care physicians in the U.S. believe that their practice is properly trained and prepared to handle the care needs of people with dementia.<sup>18</sup>

Researchers from the University of North Carolina at Chapel Hill analyzed a community-based pilot dementia training program conducted with primary care providers. Providers were in family practice and internal medicine, and 21% of participating physicians had a geriatrics subspecialty. The program was a joint project between Carolina Alzheimer’s Network (an educational outreach program of the University of North Carolina at Chapel Hill), three North Carolina Area Agencies on Aging, and Project C.A.R.E. (a caregiver resource and support program implemented through the North Carolina Division of Aging and Adult Services). Both physicians and other primary care staff participated in a one-day training program, focused on detection tools, diagnosis, management, and patient and caregiver resources. Participating providers also received post-training follow up.<sup>19</sup>

Physician participants (n=29) completed a baseline interview, a post-training questionnaire, and an additional follow up six months after completing the training program. These tools identified whether and how physician participants’ confidence in their practice of dementia detection and diagnosis changed. At the six-month follow up, most participants showed an increase in confidence in dementia detection skills, with the best results evident in distinguishing Alzheimer’s from other forms of dementia, patient and caregiver education about dementia, and referring patients and caregivers to community resources. Follow up also showed increased use of dementia assessment tools.

The Task Force examined current protocols for dementia detection, Medicare requirements, and evidence-based recommendations, as well as initiatives to increase primary care providers’ capacity and skill in brief standardized assessment tools. Because of the need for improved systems of care for individuals and families who receive a diagnosis of dementia, the Task Force acknowledged potential downsides to families receiving a dementia diagnosis without also having access to quality dementia care and services. Therefore, the Task Force did not recommend universal screening, but instead focused its early detection and

**Figure 3.1: Early Signs of Alzheimer’s Disease**

- Memory loss that disrupts daily life**
- Changes or challenges in ability to solve problems**
- Difficulty with familiar tasks**
- Confusion about place or time**
- Vision problems such as judging distance or determining colors**
- Problems with vocabulary and conversation**
- Frequently losing items**
- Poor decision-making or judgment**
- Withdrawal from professional and leisure activities**
- Personality and mood changes**

Source: Alzheimer’s Association. Ten early signs and symptoms of Alzheimer’s. Alzheimer’s Association website. [http://www.alz.org/alzheimers\\_disease\\_10\\_signs\\_of\\_alzheimers.asp](http://www.alz.org/alzheimers_disease_10_signs_of_alzheimers.asp). Accessed September 21, 2015.

diagnosis recommendations on enhanced training for health care providers, particularly around detection and assessment tools, potential benefits of early detection, referrals to services, and the importance of improved care systems for people with dementia.

**Recommendation 3.2: Enhance training for health care providers on the benefits and best practices for Alzheimer’s disease and related dementias detection, diagnosis, and services referrals.**

Offer pre-service and in-service training in the early detection of Alzheimer’s disease and related dementias. Training should include validated brief assessment and diagnostic tools, and should be tailored to all populations. Training should focus on:

- a) Incorporating specific tools for early detection in all populations, including individuals with limited English proficiency and those with intellectual or developmental disabilities.
- b) How to meet Medicare annual wellness visit requirements for cognitive assessment using validated tools and a functional approach to assessment.
- c) Benefits of early detection for families and caregivers, including family support, advance planning, symptom and care management strategies, non-pharmacological interventions for improving functional and behavioral symptoms, medication options, and need to incorporate family feedback in identifying cognitive impairment.
- d) Referral resources (to include hard copies provided at time of visit, if requested) for additional medical assessment, diagnostic testing, treatment services, and services for caregivers for those with signs of cognitive impairment.
- e) Information about care and available services and supports, including specific additional training or ongoing education for care managers or other staff.

Lead: North Carolina Area Health Education Centers (AHEC)

Partners: Including, but not limited to, the North Carolina Medical Society, the North Carolina Psychiatric Association, the North Carolina Hospital Association, the North Carolina Nurses Association, and academic health science centers.

**Collective Impact for a Dementia-Capable Community**

The Task Force identified the importance of collaborative work to address dementia in North Carolina, as well as the need for a multi-stakeholder process to achieve the Task Force goals. Collective impact is a method of multi-stakeholder collaboration that meets the following criteria:<sup>20</sup>

- Common agenda
- Shared measurement system
- Mutually reinforcing activities
- Continuous communication
- Backbone support organization

In order to have the greatest success, a collective impact process must have a dedicated organization and staff to serve as infrastructure through the course of the initiative. The backbone organization must commit to handling the logistic and administrative work of the collective impact process, as well as mediate conflicts and oversee technical issues, inter-organization communication, data collection, and analysis/reporting.

Many types of organizations can serve as appropriate backbone organizations. Government agencies, nonprofit organizations (either new or existing), and funder-based organizations can all be effective backbone organizations, and there are pros and cons to each type of entity fulfilling this role, including varying levels of transparency, neutrality/conflicts of interest, sustained funding, and existing infrastructure. Backbone organizations also generally require staff to serve as project director/manager, data manager, and facilitator.<sup>21</sup>

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*ACT on Alzheimer’s: Collective Impact at the State Level*

The state of Minnesota provides a useful example of collective impact in action to address Alzheimer’s disease. In 2009, state legislation tasked the Minnesota Board on Aging with establishing the Alzheimer’s Disease Working Group and developing recommendations to address the increasing challenges of Alzheimer’s in the state. The Working Group recommendations were released in 2011, and ACT on Alzheimer’s (originally called Prepare Minnesota for Alzheimer’s 2020) was created to oversee the implementation of the state recommendations.<sup>22</sup> The ACT on Alzheimer’s “collective action” initiative now consists of more than 400 individual members and 60 organizations, including private, non-profit, and government groups. Between 2013 and 2015, ACT on Alzheimer’s received \$750,000 in state funding and raised an additional \$2 million in funding from philanthropic organizations, advocacy organizations, federal grants, academic institutions, and health care systems.<sup>23</sup>

The goals of ACT on Alzheimer’s include:

- Identify and invest in promising approaches that reduce costs and improve care.
- Increase detection of Alzheimer’s disease and improve ongoing care and support.
- Sustain caregivers by offering them information, resources, and in-person support.
- Equip communities to be “dementia capable” to support residents who are touched by Alzheimer’s disease.
- Raise awareness and reduce stigma by engaging communities.<sup>22</sup>

In working towards these goals, ACT on Alzheimer’s emphasizes principles of health equity and aims to include broad community buy-in from those traditionally involved in dementia work and those new to such projects.

ACT on Alzheimer’s has used qualitative evaluation methods to assess the initiative’s progress in four primary areas: enhanced capacity of providers, organizations, and institutions to provide care and supports for people with Alzheimer’s and their families; influence on state guidelines and policies that affect Alzheimer’s and dementia within communities; enhanced support to caregivers; and community capacity to engage in the initiative.<sup>24</sup> The evaluation found that the collective action initiative is succeeding in bringing people together to begin planning and ACT on Alzheimer’s resources are being used by state and local agencies. There are also many aspects of the initiative that have been identified as needing improvement, including the importance of effective coordinators/leaders at the local level, the need for systematic and consistent communication to stakeholders about the initiative’s progress, and the necessity of having people with dementia and their caregivers as active contributing stakeholders.<sup>24</sup>

*Dementia Friendly America and a Model Initiative in Orange County*

Building on the work of Minnesota’s ACT on Alzheimer’s initiative, the Dementia Friendly America Initiative (DFA) announced funding for 15 pilot projects to implement collective impact efforts to address dementia and the creation of dementia-friendly communities. Community partners include local business representatives, faith-based organizations, health care providers, residential facilities, legal and financial services, home- and community-based services providers, and government agencies.

Sponsored and funded by over 50 organizations, including AARP, the Alzheimer’s Association, CVS/Caremark, the International Association of Chiefs of Police, the National League of Cities, and US Against Alzheimer’s, the Dementia Friendly America initiative seeks to leverage community resources and stakeholder partnerships to create communities that “are informed, safe, and respectful of individuals with dementia and their families, provide supportive options, and foster quality of life” for all residents.<sup>25</sup>

In looking at the objectives and anticipated partners for the Dementia Friendly America initiative, the Task Force decided that the term “dementia capable” captured the goals and ideals of DFA, and addressed the needs of a state population dealing with the cognitive, physical, and emotional challenges of residents

**Figure 3.2: ACT on Alzheimer’s Dementia-Friendly Community Resources**



Source: ACT on Alzheimer’s. Dementia-friendly resources. ACT on Alzheimer’s website. <http://www.actonalz.org/communities-action-resources>. Accessed October 14, 2016. Reprinted with permission from ACT on Alzheimer’s.

with dementia and their caregivers. Dementia-capable communities and systems consider the impact of dementia on all aspects of the community, including services eligibility, information distribution and access, caregiver services, safety, workforce training, family decision-making and planning, daily interactions for workers and other community members, and community preparedness.<sup>26</sup>

In 2015, the Orange County Department on Aging received grant funding of \$900,000 from the U.S. Department of Health and Human Services' Administration for Community Living to enhance its community supports and services with the goal of becoming a fully coordinated and effective dementia-capable community. Community, organizational, and individual initiatives will include a business and government training program to improve knowledge and understanding about living with or caring for someone with dementia; a skills-based dementia training program for direct care workers in the home; and new or expanded services for individuals with dementia and their caregivers, such as in-home services, support groups, and respite.<sup>27</sup>

The program has also incorporated several measurable outcomes into their planning process, largely focused on caregiver quality of life.<sup>27</sup> The program will also conduct a process evaluation, using a control group of caregivers currently receiving services, and an intervention group of caregivers receiving the services. The evaluation aims to determine whether the intervention was effectively implemented and to use feedback to improve the interventions and inform similar projects.<sup>27</sup>

In late 2015, UNC's Jordan Institute for Families issued a request for information for communities interested in being considered for the Institute's Adult Network of Care pilot programs. Focused on Alzheimer's disease and related dementias and adult guardianship, these pilot projects will provide technical assistance and guidance to several communities across the state as they engage in collective impact initiatives aimed at improving community life for people with Alzheimer's disease or related dementias, or in improving resources and procedures for adult guardianship.<sup>28</sup>

The Task Force on Alzheimer's Disease and Related Dementias examined the principles of collective impact and their application through ACT on Alzheimer's, Dementia Friendly America, and the Orange County project. The Task Force determined that a collective impact approach to creating dementia-capable communities would be appropriate for our state.

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**Recommendation 3.3: Create a collective impact partnership to develop and establish dementia-capable pilot communities.**

Using the resources and toolkits available from the Dementia Friendly America and ACT on Alzheimer's projects, partners should develop a collective impact partnership which will work toward the development and establishment of three to four Alzheimer's disease and related dementia-capable pilot communities in North Carolina.

- a) The collective impact partnership should be supported by staff from North Carolina Division of Aging and Adult Services, who will oversee collaboration, establish a statewide advisory committee made up of stakeholders, and facilitate technical assistance.
- b) Philanthropic partners should develop a targeted grant process to identify appropriate communities for initial and/or continuing funding.
- c) The pilot community projects should lead to the development of a sustainable and replicable model that can be disseminated to additional North Carolina communities and serve as a foundation for dementia-capable communities.
- d) The local collective impact pilots will require a full-time staff person to champion and organize local efforts. Resources will be required for facilitation, data planning/analysis, and meeting expenses. The estimated annual budget for each pilot is \$125,000.
- e) Pilots should include evaluation of the costs and benefits of this approach for developing a dementia-capable community.

Lead: North Carolina Division of Aging and Adult Services

Partners: Including, but not limited to, philanthropic organizations, county social and human services agencies, Area Agencies on Aging, Association of County Commissioners, UNC's Jordan Institute for Families, local providers of care (including behavioral health, medical health, and human services), and other academic institutions.

**Recommendation 3.4: Establish statewide coordinated leadership to oversee the state plan on Alzheimer's disease and related dementias.**

Establish a statewide coalition on Alzheimer's disease and related dementias to oversee the implementation of this plan. The coalition should be coordinated by the state Alzheimer's disease specialist. The coalition should be charged with:

- a) Developing the collective impact strategy, including assisting funding agencies in selecting communities for collective impact and convening local collective impact efforts to support shared learning, and, if successful, for scale up of collective impact efforts to other communities.
- b) Coordinating implementation of the plan.
- c) Reporting yearly progress on implementation to the Secretary of Health and Human Services (and/or the Senate and House Committees on Aging).
- d) Support other workgroups charged with implementations of specific recommendations.
- e) Serve in an advisory capacity to the North Carolina Division of Aging and Adult Services to support additional recommendations (i.e., the development of a toolkit).

Lead: The North Carolina Division of Aging and Adult Services

Partners: Including, but not limited to, North Carolina Division of Mental Health, Developmental Disabilities, and Substance Abuse Services, North Carolina Division of Social Services, the state Medicaid agency, the North Carolina Division of Public Health, the North Carolina Division of Health Services Regulation, Alzheimer's North Carolina, Alzheimer's Association, members of the North Carolina General Assembly, the Governor's Council on Aging, the Duke Endowment, AARP North Carolina, LeadingAge North Carolina, North Carolina Area Health Education Centers, local Area Agencies on Aging, the North Carolina Coalition on Aging, the Geriatrics Workforce Enhancement Program, local providers of care (including behavioral health, medical health, and human services), media representatives, and caregivers for people with Alzheimer's disease and related dementia, with special attention to ensure diversity and statewide representation.

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