Chapter Two: Overview of Alzheimer's Disease and Related Dementias

What is Alzheimer's Disease and Related Dementia?

Dementia is a set of symptoms caused by underlying brain malfunction that typically includes memory loss, language difficulty, and impaired judgment.[1] Alzheimer's disease is the most common (and arguably the most well-known) of several brain disorders that cause dementia. According to the Alzheimer's Association, 60-80% of dementia cases are attributable to Alzheimer's disease.[2] Alzheimer's disease can be confirmed only upon autopsy by the presence of amyloid plaque and neurofibrillary tangles of tau protein in the brain. In life, Alzheimer's is diagnosed through cognitive testing, but the diagnosis is not definitive.[3] Alzheimer's disease is a terminal illness, and the only top 10 cause of death that cannot be cured, prevented, or slowed.[4]

> **"Alzheimer's disease is a terminal illness, and the only top 10 cause of death that cannot be cured, prevented, or slowed.**

For the purposes of this report, both "Alzheimer's disease" and "dementia" will be used, as well as "Alzheimer's disease and related dementias." These phrases can be understood to encompass Alzheimer's disease as well as forms of dementia that present symptoms similar to those of Alzheimer's disease.

Figure 2.1: Most Common Types and Symptoms of Dementia

Type of Dementia	Description	Symptoms
Alzheimer's Disease	Alzheimer's disease damages nerve cells in the brain, and symptoms worsen over time as more cells are damaged. It is characterized by the presence of amyloid plaques and tau tangles in the brain. Both early- and late-onset Alzheimer's have a genetic component.	Severe forgetfulness Changes in mood Confusion Difficulty concentrating or multitasking Getting lost in familiar places
Cerebrovascular/ Vascular Dementia	Cerebrovascular dementia happens when clots block blood flow to the brain and kill brain cells. People with this type of dementia may also have high blood pressure, heart disease, high cholesterol, and/or diabetes. It is considered the second most common type of dementia.	Memory loss Difficulty focusing/concentrating Confusion Symptoms often occur suddenly, then stabilize before occurring again
Mixed Dementia	Experts estimate that up to 45% of people with dementia have both Alzheimer's disease and vascular dementia.	Memory loss Difficulty focusing/concentrating Confusion Symptoms often occur suddenly, then stabilize before occurring again
Lewy Body Disease/ Dementia with Lewy Bodies (DLB)	DLB occurs when abnormal proteins called Lewy Bodies form in nerve cells in the brain.	Memory loss Confusion Difficulty with movement Excessive sleepiness Hallucinations
Frontotemporal Lobar Degeneration/ Frontotemporal Dementia (FTD)	This rare type of dementia occurs in the front and sides of the brain, and tends to occur in younger people and progress more quickly than Alzheimer's disease.	Personality changes Difficulty with judgment and social skills Poor financial or personal decisions Feelings of disconnectedness

Source: Alzheimer's Association. Aging, Memory Loss, and Dementia: What's the Difference? Chicago, IL: Alzheimer's Association. http://www.alz.org/mnnd/documents/aging_memory_loss_and_dementia_what_is_the_difference.pdf. Accessed July 27, 2015.
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Often, early symptoms of Alzheimer's disease or related dementias are confused with symptoms of normal aging. Symptoms of normal aging include occasional confusion or forgetfulness, such as forgetting someone's name or the day of the week (and remembering later), or losing an item every now and then. Alzheimer's disease, by contrast, is progressive and degenerative, meaning symptoms get worse over time.

Unlike in normal aging, Alzheimer's disease and related dementias are accompanied by physiological changes in the brain that result in severe mental deterioration that far exceeds normal cognitive decline.[2] Early signs and symptoms of Alzheimer's disease include: memory loss that disrupts daily life, changes or challenges in ability to solve problems, difficulty with familiar tasks, confusion about familiar places or time, vision problems, problems with vocabulary and conversation, frequently losing items, poor decision-

making or judgment, withdrawal from professional and leisure activities, and personality and mood changes.[5,6]

"North Carolina is projected to have 210,000 residents over the age of 65 living with Alzheimer's disease in 2025.

There is growing evidence that Alzheimer's disease begins with structural changes in the brain that occur years before symptoms arise.[7] Symptoms begin during the phase of Mild Cognitive Impairment (MCI) or early Alzheimer's disease. Daily functioning is unaffected in people with MCI, but higher-level cognitive skills begin to erode. Some people that develop MCI never develop Alzheimer's disease.[8] For those that do develop Alzheimer's, the disease progresses through stages as symptoms develop and worsen, resulting in the loss of cognitive ability and increased dependence on caregivers. The middle stage of the disease is often characterized by a loss of ability to perform an increasing number of tasks including driving, grocery shopping, and paying bills. In the terminal stages of Alzheimer's disease or related dementias, a person may lose all ability to learn, speak, eat, use the toilet, and recognize their loved ones.[7]

Prevalence of Alzheimer's Disease and Related Dementias

While it is difficult to estimate overall prevalence of dementia, the U.S. Preventive Services Task Force estimates that up to 5.5 million Americans have dementia (including Alzheimer's disease), with rates increasing with age. Five percent of people ages 71 to 79 years have dementia. This number jumps to 24% for those ages 80 to 89 years, and 37% for those older than 90 years.[8]

It is estimated that 5.3 million Americans have Alzheimer's disease, and Alzheimer's disease is the sixth leading cause of death nationally. [9] In North Carolina, over 160,000 people are estimated to be living with Alzheimer's disease. [9] Alzheimer's disease is the fifth leading cause of death in North Carolina, and was responsible for 2,872 deaths in 2012. [10] Americans are now living longer than ever before, and particularly as the baby boomer generation ages, the United States will have to contend with a rapidly growing population of people with Alzheimer's disease or related dementias. For people over the age of 65, the rate of Alzheimer's doubles every five years.[7] One in three people over 85 has Alzheimer's disease.[11] The Alzheimer's Association projects that by 2025, 7.1 million Americans will have Alzheimer's. North Carolina is projected to have 210,000 residents over the age of 65 living with Alzheimer's disease in 2025, an increase of 31.3%.[9] This figure will represent nearly 1 in 10 of the over-65 population. Because Alzheimer's disease is underdiagnosed, up to half of the estimated number of people with Alzheimer's may not know they have it.[12]

Who is at Risk for Alzheimer's Disease and Related Dementias?

Age is the primary known risk factor for dementia, including late onset Alzheimer's disease.[13] As noted above, the rates of Alzheimer's disease and related dementias increase as people get older. Genetic predisposition, or family history, is another significant risk factor for developing Alzheimer's disease or related dementia, and there is evidence to suggest that gene expression – the process by which genes are "switched" on or off due to environmental or behavioral factors – may also play a role in the development of Alzheimer's.

There are other potential risk factors for Alzheimer's disease and related dementias that may be modifiable through behavior and lifestyle changes. Modifiable risk factors that have been linked to Alzheimer's disease include physical activity, educational attainment, occupation, diabetes, cardiovascular disease, hypertension, obesity, depression, and social and cognitive engagement, among others.[14]

A small percentage (approximately 200,000) of the 5.3 million Americans with Alzheimer's disease have young onset Alzheimer's disease. This disease is diagnosed before age 65 and individuals may get it as young as 30 or 40 years old. The symptoms are the same and preparation needs to be made for long-term care. The young onset form of Alzheimer's disease occurs as a result of mutations in one of three specific and rare genes – the gene for the amyloid precursor protein (APP), and the genes for the presenilin1 and presenilin 2 proteins. Individuals who inherit a mutation to any of these are guaranteed to develop Alzheimer's disease well before age 65. This type of Alzheimer's is called familial Alzheimer's and many family members in multiple generations can be affected.[a]

History of traumatic brain injury is another risk factor for dementia. Studies have shown that a moderate or severe traumatic brain injury can result in a two- to four-fold increase in dementia risk. While it is unclear if mild traumatic brain injuries result in an increased risk of dementia, there is some evidence that individuals who experience multiple mild traumatic brain injuries, such as repeated minor concussions of

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the sort often experienced by boxers and football players, may be at increased risk for dementia later in life.[15] Traumatic brain injury among older adults, even when seemingly mild, can contribute to cognitive decline.[a]

"Latinos, African Americans are at a higher risk for developing Alzheimer's disease.

Compared to non-Latino whites, Latinos and African Americans are at a higher risk for developing Alzheimer's disease.[16] In the 65-74 age group, African Americans have the highest prevalence of Alzheimer's disease at 9.1%, compared to 7.5% for Latinos and 2.9% for non-Latino whites. For individuals over 85, Latinos have a prevalence rate of 62.9%, compared to 58.6% among African Americans, and 30.2% among non-Latino whites.[17] Women are twice as likely to develop Alzheimer's as men.[17] While the full reasons for the gender disparity are unknown, experts agree that the primary reason is that women tend to live longer than men; age-specific incidence estimates of Alzheimer's and dementia (i.e. new cases) show no significant difference between rates for men and rates for women.[12]

Individuals with Down's syndrome also have a three- to five-times higher risk for Alzheimer's disease than the general population. Alzheimer's tends to develop at a younger age (40s or 50s) for people with Down's syndrome than for other adults. Autopsy results have shown that nearly all people with Down's syndrome have markers in the brain that are associated with Alzheimer's disease.[18]

Caring for People with Alzheimer's Disease or Related Dementias

People with Alzheimer's disease or related dementias require increasingly intensive care as their disease progresses. Children and spouses are often the primary caregivers for people with Alzheimer's or related dementias. In 2014, roughly 448,000 North Carolinians provided $6.2 billion in unpaid care for loved ones with dementia (approximately 2-3 unpaid caregivers for each person with dementia). [10]During the early stages of Alzheimer's, caregivers often assist with financial planning and major decision-making, but as the disease progresses they may also need to monitor wandering, behavioral problems, and be increasingly involved in activities of daily living. The intensive care needs associated with Alzheimer's often require that caregivers take time off of work, hire additional help, and sometimes seek a care setting that offers around-the-clock skilled care. Caregivers experience high incidences of stress, anxiety, and depression and are more likely to incur higher medical costs themselves.[19]

Figure 2.2: Caregiver Costs in North Carolina: Number of Alzheimer's and dementia caregivers, hours of unpaid care, and costs of caregiving

Year	Number of Caregivers	Total Hours of Unpaid Care	Total Value of Unpaid Care	Higher Health Costs of Caregivers
2012	437,000	497,000,000	$6,132,000,000	$245,000,000
2013	442,000	504,000,000	$6,272,000,000	$252,000,000
2014	448,000	510,000,000	$6,208,000,000	$263,000,000

Source: Alzheimer's Association. North Carolina Alzheimer's statistics. Chicago, IL: Alzheimer's Association: 2015. http://www.alz.org/documents_custom/facts_2015/alz_ff_northcarolina.pdf?type=interior_map&facts=undefined&facts=facts. Accessed September 21, 2015.

There are a variety of home- and community-based support services available to people caring for people with Alzheimer's disease or related dementias. Meal services, adult day care, senior centers, caregiver support groups, and respite services are available in certain areas to assist caregivers.[7] Access to community services can alleviate caregiver stress and help prolong community living for individuals with Alzheimer's or related dementias. Unfortunately, caregivers are not always aware of home- and community-based care options, and many communities have long waiting lists for such services. Certain caregiver interventions have demonstrated that connecting caregivers with community resources can extend the amount of time that caregivers are able to care for their loved one in the home rather than in a more costly care facility.[20] In some states, low-income caregivers can access a Medicaid waiver that will pay for these services. North Carolina's Community Alternatives Program for Disabled Adults (CAP/DA) waiver covers home- and community-based services, but long waiting lists and limited availability (by county) make the waivers difficult to access for thousands of North Carolinians.[21]

Currently in North Carolina, the ratio of potential caregivers (people aged 45-64) to those who need care (over the age of 80) is 8:1. By 2030, there will only be four potential caregivers for every older adult in the state.[22] For a disease that requires intensive caregiving, the declining ratio of potential caregivers to potential dementia patients may mean that nursing homes and residential facilities will play an increasingly large role in caring for those with Alzheimer's disease and related dementia.

Economic Impact of Alzheimer's Disease and Related Dementias

The combination of formal and informal care that Alzheimer's disease and related dementias require makes it an extraordinarily costly disease. The total annual cost of Alzheimer's disease in the United States was between $157 and $215 billion in 2014. By 2040, if no vaccine, treatment, or cure is developed, Alzheimer's disease is projected to cost the nation between $1.2 and $1.6 trillion annually.[7]

"By 2040, if no vaccine, treatment, or cure is developed, Alzheimer's disease is projected to cost the nation between $1.2 and $1.6 trillion annually.

Because they primarily afflict individuals over the age of 65, Alzheimer's disease and related dementias are especially costly to state budgets. Medicare, which is federally financed, pays for much of the medical care for those over 65. In North Carolina, for those who are eligible, Medicaid pays for most long-term services and supports in an institutional setting—a service that three-quarters of individuals with dementia rely on at some point. Because the average annual cost of care in a skilled nursing facility (commonly known as a nursing home) in North Carolina exceeds $75,000,[23] many families cannot afford this care. Often, individuals of family members of those with Alzheimer's disease or related dementia will "spend down" assets to become eligible for Medicaid. In fact, Medicaid is the primary payer for two-thirds of nursing home residents.[7] Delaying placement in nursing homes or other long-term care facilities can have a great impact on Medicaid spending. (See Chapter 4 for additional information on long-term services, supports, and payment for medical and non-medical services.)

Individuals with Alzheimer's disease or related dementias also incur higher medical costs than their peers—costs that are largely borne by Medicare or Medicaid. The cognitive decline associated with the disease creates difficulty for patients managing multiple health conditions. People with Alzheimer's are hospitalized two to three times more frequently than their peers without Alzheimer's disease.[7] In particular, people with Alzheimer's are more likely to experience potentially avoidable hospitalizations related to a comorbid condition such as diabetes or heart disease.[25,26] The combined likelihood of hospitalization and institutionalization means that people with Alzheimer's are more costly to both Medicare and Medicaid than other older adults. Individuals with Alzheimer's that are eligible for both Medicare and Medicaid (known as "dual-eligibles," see Chapter 5) are 3 times as costly to Medicare and 19 times as costly to Medicaid as their peers who do not have dementia.[25]

Recent research has shown that the average total cost of dementia (including out of pocket costs, Medicare and Medicaid costs, private insurance, and costs of informal care) during an individual's last five years of life is $287,038. Heart disease is the next most costly condition, at $175,136. Out-of-pocket spending was 81% higher for people with dementia than for people without dementia: $61,522 vs. $34,068.[26] The spending burden also disproportionately affects certain demographic groups. While out-of-pocket spending for all people with dementia was 32% of assets compared with 11% for people without dementia, for African Americans, the proportion of assets was 84%, and for people with less than a high school education it was 48%. Unmarried or widowed women spent 58% of their assets on out-of-pocket costs for dementia.[26]

National and State Action on Alzheimer's Disease and Related Dementia

In December 2010, Congress unanimously passed the National Alzheimer's Project Act (NAPA), which President Obama signed into law in January 2011 (42 U.S.C. § 11201). NAPA establishes a National Alzheimer's Project housed in the Department of Health and Human Services that is charged with coordinating national efforts for research, treatment, and caregiving. NAPA requires an annual update to the national plan, an annual set of national recommendations, an annual evaluation of all federally-funded Alzheimer's initiatives, and the creation of an Advisory Council on Alzheimer's Research, Care, and Services composed of 22 experts and stakeholders at the federal and state level. NAPA aims to effectively treat or prevent Alzheimer's by 2025; optimize care quality and efficiency; expand supports for people with Alzheimer's and their families; enhance public awareness and engagement; and track progress and drive improvement.[27]

In 2013, the National Institutes of Health (NIH) launched an Alzheimer's disease research plan, with the intended goal being the fulfillment of the NAPA recommendation to prevent and treat Alzheimer's disease by 2025.[28] The primary steps of the research plan included meeting milestones for research on nonpharmacological interventions, biomarkers, public health surveillance, infrastructure, and treatment and prevention study participation and recruitment.[28] While an initial $50 million outlay in 2012, followed by an additional $40 million in 2013 and $100 million in 2014, was allotted by Congress for Alzheimer's funding, experts estimate that such funding increases must continue in order for research goals to be met by 2025.[28]

In late 2015, increased attention to Alzheimer's disease and dementia and their impact on individuals and families resulted in a proposed increase of $350 million for fiscal year 2016 (a 59.7% increase over FY2015) for NIH's Alzheimer's disease and related dementia research funding. [29]

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The 2015 NAPA update includes several new initiatives. As part of the 2015 update, the federal Department of Health and Human Services is working to design curricula for workforce training and family caregivers, and has launched a $4 million brain health awareness campaign. In addition, the Dementia Friendly America Initiative, modeled on Minnesota's ACT on Alzheimer's Program, announced that it will begin pilot programs in 15 communities throughout the country by 2016.[30] (See Chapter 3 for additional information.)

While very few states had comprehensive Alzheimer's plans prior to NAPA, 39 states and Washington, DC, had published Alzheimer's state plans as of July 2015. Including North Carolina, seven more states have convened task forces or working groups that are working to develop Alzheimer's disease and related dementia state plans.[31] North Carolina's statewide Task Force on Alzheimer's and Related Dementia included 45 stakeholders and experts from throughout the state that met monthly over the course of one year. The efforts of the Task Force have culminated in the recommendations detailed in this report.

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