

**New Hampshire Alzheimer's Disease
and Related Dementias
State Plan Executive Summary & Areas of Focus**

**Prepared by the statewide Professionals and Families State Plan
Workgroups in conjunction with the New Hampshire Health and Human
Services and Elder Affairs Sub-Committee**

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Document Outline

A. Executive Summary.....p.1
B. Introduction.....p.2
C. Areas of Focus.....p.4

A. Executive Summary

New Hampshire Alzheimer's Disease and Related Dementias State Plan Recommendations

The following document presents recommendations, goals and strategies that comprise a framework for a New Hampshire Alzheimer's Disease and Related Dementias State Plan ("*State Plan*"). It was developed at the request of the Health and Human Services and Elder Affairs Joint Committee of the New Hampshire State Legislature, in partnership with the New Hampshire offices of the Alzheimer's Association, Massachusetts and New Hampshire Chapter ("*Alzheimer's Association*") with statewide professionals and families workgroups as well as New Hampshire Fisheries and Wildlife, local and state law enforcement and the New Hampshire Department of Health and Human Services.

The recommendations, goals and strategies are the result of research and deliberation by the statewide workgroups of families and professionals, persons with dementia, healthcare and other service providers, first responders, physicians, elder law attorneys and various other sources pertinent to Alzheimer’s disease and related dementias in the Granite State.

The recommendations are intended to be implemented over the next 5 years by the Department of Health & Human Services (DHHS), ServiceLink and the Alzheimer’s Association of New Hampshire in conjunction with other stakeholders through the establishment of an Alzheimer’s Committee. As a public/private partnership, this Committee will utilize existing resources within the state of New Hampshire and the Alzheimer’s Association while seeking other private and federal funding as necessary. The Alzheimer's Committee will be convened and will be chaired by Representative Pat Long and by the Alzheimer’s Association. The Committee will be convened using current members of the Workgroups, the Sub-Committee, as well as other state, local, private and public health reform stakeholders identified by DHHS, ServiceLink and the Alzheimer's Association.

The Committee began work on a draft work plan, which includes specific action steps and timelines on various aspects of the report that will be used as the basis for future taskforce work. The Committee will review the draft work plan with the workgroups and revise it accordingly. Wherever possible, DHHS, ServiceLink, the Alzheimer's Association and other stakeholders will integrate the recommended action steps into their standard scope of services and activities. When necessary, DHHS, ServiceLink and the Alzheimer's Association will work with stakeholders to identify and secure additional private and federal funding in order to implement recommended action steps.

These recommendations represent a road map to help New Hampshire improve the quality of life for the thousands of families affected by Alzheimer's and to minimize the public and private costs of this devastating disease.

B. Introduction

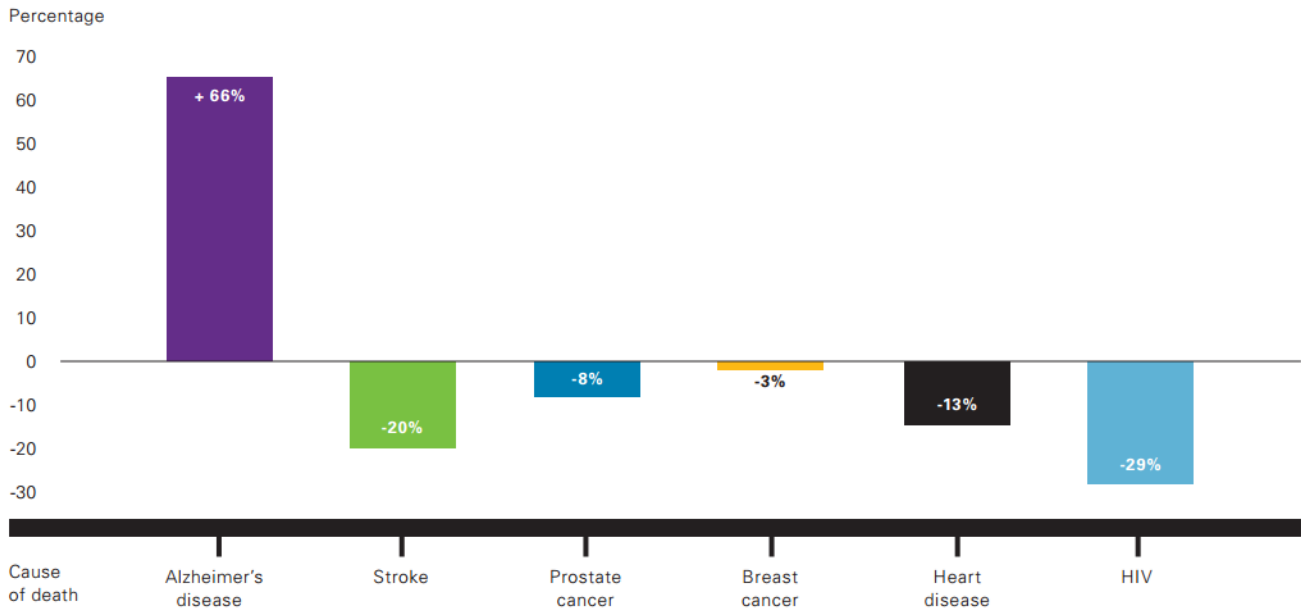
Alzheimer's disease is a fatal, degenerative disease of the brain that slowly diminishes a person's ability to reason, remember, respond to their environment and, eventually, carry out even the most basic tasks. There is currently no cure.

An estimated 5 million Americans of all ages have Alzheimer's disease. This figure includes 5.2 million people aged sixty-five and olderⁱ and two hundred thousand (200,000) individuals under age sixty-five who have younger-onset Alzheimer's.ⁱⁱ

Alzheimer's disease is the most common type of dementia-causing illness, accounting for sixty to eighty percent of incidents.* Other types of dementia account for at least one million additional cases nationwide. Studies also indicate that as many as ten to twenty percent of people aged sixty-five and older have Mild Cognitive Impairment (MCI),^{iii, iv, v} which may in some cases represent a transitional state between normal aging and the earliest symptoms of Alzheimer's. Nearly half of all people who have visited a physician about MCI symptoms will develop dementia in three or four years.^{vi}

Every sixty-eight seconds, another American develops Alzheimer's disease. It is the sixth leading cause of death in the United States and the fifth leading cause of death for those aged sixty-five and older. Between 2000 and 2008, deaths attributed to Alzheimer's disease increased sixty-six percent, while those attributed to other major chronic illness—stroke, heart disease, breast cancer, prostate cancer and HIV—have all declined.^{vii, viii}

Percentage Changes in Selected Causes of Death (All Ages) Between 2000^a and 2008^b



^a National Center for Health Statistics. *Deaths: Final Data for 2000*.¹⁶⁰

^b National Center for Health Statistics. *Deaths: Preliminary Data for 2008*.¹⁷⁹

* For the purposes of this document, the word "Alzheimer's," unless otherwise noted, will indicate Alzheimer's disease and related dementia-causing illnesses.

In New Hampshire, more than twenty thousand (20,000) individuals age sixty-five and older have Alzheimer's disease.^{ix} This number does not include those with related dementias.

There are now more than sixty-four thousand (64,000) unpaid caregivers in New Hampshire caring for someone with Alzheimer's disease. 66.1% of these caregivers are women and the average age of caregiver is eighty-two but more than 55% percent are over the age of eighty-five. Of those being cared for, 67.9% are a parent or parent-in-law of the caregiver. The number of New Hampshire residents affected by Alzheimer's disease expected to increase 37% percent by 2025 if no cure is found.^x

In response to this impending crisis the Health and Human Services and Elder Affairs Committee at the behest of Representative Pat Long, in partnership with the Alzheimer's Association (*Alzheimer's Association*), began the development of a New Hampshire Alzheimer's Disease and Related Dementias State Plan. In response the Alzheimer's Association convened statewide workgroups, consisting of people with Alzheimer's, family members, and representatives from state and local health and human service agencies, senior centers, day programs, elder law attorneys, the VNA, universities, hospitals, public safety agencies, professional caregivers and AARP.

The Alzheimer's Association sought to gather first-hand the concerns and needs of New Hampshire citizens affected by Alzheimer's disease. Three major areas of focus were identified:

1. Access to Services
2. Minimal Education Standards for Professionals
3. Public Health and Safety

The Advisory Committee convened two workgroups, one composed of families and people with Alzheimer's disease and one of professionals who work in the field with those coping with Alzheimer's disease. In all, over one hundred experts and advocates contributed to this report through these workgroups. Each workgroup met a minimum of three times between March and May, 2013, and identified areas of expertise in the field and gaps in the delivery of training and services in New Hampshire.

C. Areas of Focus

1. Access to Services

A diagnosis of Alzheimer’s or a related dementia thrusts both the person with the disease and his loved ones into a stressful and confusing new world.

While families provide the vast majority of supportive care and services to people with Alzheimer’s disease and related dementias, they often must seek community or residential supportive services.

Unfortunately, people with Alzheimer’s and their families often do not know where to turn for the information necessary to make critical decisions about the legal, medical and support services they need. Even when such programs exist and information is readily available, it is not easily found by families or known by those to whom they turn for help, such as primary care physicians, senior centers, home care nurses and adult day health programs. For families living with a loved one with younger-onset (under age sixty-five) Alzheimer’s disease, the challenges of finding services and support are magnified.

Physicians, nurses, lawyers, bankers, financial planners, emergency first responders, allied health professionals including but not limited to pharmacists and dentists and ancillary service providers such as meals-on-wheels and congregate meal centers as well as community, homecare and long term care providers could more effectively help consumers by better understanding Alzheimer’s disease, the services available, and reliable sources of advice and support.

Better access to and knowledge of services can help caregivers to provide a higher quality of care to loved ones as the disease progresses, often postponing the need for more costly long term institutional care. Wider availability of affordable services can help people with Alzheimer’s disease and related dementias, both with and without caregiver support; reside in the community for as long as possible.

Encouraging expansion and accessibility of home and community-based services reflects the expressed desire of people with Alzheimer’s disease to age in place. This is consistent with evolving federal and state long term support policies emphasizing community-based care as a potentially cost-effective alternative to institutional care.^{xi,xii}

Most care for people with Alzheimer’s and related dementias is delivered at home by family members.

As Alzheimer’s disease progresses and cognitive decline ensues, individuals with Alzheimer’s disease and related dementias often experience changes in personality and behavior, as well as increased dependence on others to meet their needs. Without guidance, caregivers often wait until crises occur before reaching out for information, resulting in costly and unnecessary hospitalizations, emergency room visits, and premature placement in nursing homes. Family caregivers often suffer from both physical and mental exhaustion. 33% of family caregivers of people with Alzheimer’s disease report symptoms of depression^{xiii, xiv} and 61% of caregivers report that the emotional stress of caregiving was high to very high.^{xv}

This hardship can be alleviated when caregivers are given clear, simple information about the disease, steps they should take following diagnosis or onset of symptoms, progression of disease and symptom management and the benefits of using supportive services in the community. Data suggests that improving access to caregiver interventions can improve caregiver health and, as a result, decrease reliance and financial strain on New Hampshire's health and social service systems.

Respite services may also provide a short term break from the typical 24/7 care that is required for someone with mid and late stage Alzheimer's disease or a related dementia. Access to affordable and appropriate respite options can greatly facilitate aging in place and enhance the health of caregivers. Respite services such as adult day health, supportive day programs and in-home care also provide those with Alzheimer's and related dementias with the therapeutic benefits of social engagement, physical activity and mental stimulation.

Respite services are not affordable or accessible for the majority of families in the Granite State. The therapeutic benefits of respite services for the person with Alzheimer's disease or a related dementia are not defined as "medically necessary" by federal, state or private insurers.

In an aging population, Alzheimer's can bankrupt any society's medical, insurance and elder care systems.

Alzheimer's disease diminishes a person's ability to manage medication for any chronic illness, often leading to profoundly negative outcomes, including unnecessary hospitalizations. Early recognition, treatment, and coordination of care for dementia, starting at the primary care point of entry, can mitigate the growing social and financial burdens on our health care systems, and on care partners.

The lack of management of Alzheimer's disease and other dementias due to late recognition reduces quality of life and compounds the costs of medical care. Efficiency and quality of care is further reduced by poor understanding of common medical conditions that elevate risk for dementia, reduced access to care of many types in rural settings and lack of communication among consumers, their families, and their providers.

Families need a reliable source of information to help them find qualified physicians for the diagnosis and ongoing treatment of this unique disease. As the trajectory of incidence continues to rise above 35% by 2025, New Hampshire will need more highly skilled physicians and diagnostic centers to manage this growing population and the physical, emotional and financial burden of Alzheimer's disease. New Hampshire needs increased opportunities and incentive to recruit and retain these highly skilled physicians throughout the entire state.

Medicare now covers an Annual Wellness Visit, which includes a health risk assessment to detect cognitive impairments. Medical centers, community health centers and state agencies should consider leveraging this opportunity to promote early detection and diagnosis by facilitating outreach and education to primary care physicians and to Medicare recipients in the community.

2. Public Health and Safety

The greatest risk-factor for Alzheimer’s disease is age.

While the greatest risk factor of Alzheimer’s disease is advancing age, several chronic diseases and health risks—high cholesterol, Type 2 diabetes, high blood pressure, physical inactivity, smoking and obesity, are associated with a higher risk of developing Alzheimer’s disease and related dementias.^{xvi, xvii, xviii, xix, xx} Some evidence suggests that exercise may directly benefit brain cells by increasing blood and oxygen flow.^{xxi} Diets that include relatively little red meat and emphasize whole grains, fruits and vegetables, fish, shellfish, nuts, olive oil and other healthy fats, may also improve cardiovascular and brain health.^{xxii} A number of studies indicate that maintaining strong social connections and keeping mentally active as we age might lower the rate of cognitive decline and Alzheimer’s disease.^{xxiii} While none of these lifestyle changes will eliminate the possibility of getting Alzheimer’s disease, continued and expanded public education efforts regarding the potential of a healthy, active lifestyle could delay the onset and reduce the severity of symptoms for thousands of individuals.

People with Alzheimer’s disease and their families face increased potential for physical, emotional, and financial harm due to several specific risks, including driving, financial fraud and wandering behavior.

Alzheimer’s disease affects judgment, shortens attention span and reaction time, impairs visual-spatial ability, sequencing and cognitive mapping skills. Even in its early stages, the disease can increase risk of vehicular accidents and risk of becoming lost, either while driving or on foot.

Wandering is one of the most life-threatening risks associated with Alzheimer’s disease. Six out of ten people with Alzheimer’s disease will wander from their homes or care facilities and become lost at some point in their illness. If not found within 24-hours, most will suffer serious injury, and nearly half will lose their lives.^{xxiv}

Impaired judgment and vision can also turn ordinary household items and situations into potential hazards. Rugs, clutter, electrical cords, poor lighting, lack of handrails, and sharp, breakable or flammable materials are all potential sources of major accidents.

Moreover, one of every five citizens over the age of sixty-five has been defrauded.^{xxv} The National Institutes of Health report that people with Alzheimer’s are especially at risk for fraud, and that a loss of ability to manage one’s finances is one of the first signs of Alzheimer’s disease.^{xxvi} Indeed, financial planners, who work closely with clients, often for many years, may be among the first to notice warning signs on bank and credit card statements that suggest a person’s financial skills are deteriorating.^{xxvii, xxviii}

3. Minimal Education Standards for Professionals

Alzheimer’s disease and related dementias are unique conditions that require professionals be given appropriate ongoing training to deliver effective care.

The American Medical Association describes quality of care as “care that consistently contributes to the improvement or maintenance of quality and/or duration of life.”^{xxix} Quality of care can be maintained and improved by well designed, engaging, interactive dementia education for staff and supervisors in a number of care settings including community-based and residential locations. Staff equipped with the appropriate skills have greater longevity in their positions, have a higher degree of job satisfaction, have better overall morale, an improved sense of teamwork, and a sense of empowerment.^{xxx, xxxi,} With community based programs, dementia training for staff enables consumers to remain in their homes for longer or avoid institutional care altogether.^{xxxii}

Training of professional caregivers and other staff with direct contact with families and persons with the disease improves outcomes and reduces challenging symptoms and, often, the need for psychoactive medications to control behavior. Training reduces falls and improves the overall health of clients through better medications compliance, personal hygiene and nutrition.^{xxxiii, xxxiv}

Stage-appropriate, purposeful, cognitively stimulating daily activity has also proven effective in helping people will reduce challenging behavioral symptoms, reduce the need for psychoactive medications, promote better sleep, maintain independence, improve mood and morale, and reduce falls.^{xxxv}

Thoughtful interior design can help a person with dementia compensate for cognitive losses and remain independent longer.^{xxxvi} Ample lighting, elimination of glare and reflective surfaces, clear pathways, handrails, and contrasting colors can all help improve mood, reduce challenging behaviors, reduce falls, promote self-care and keep people safe.

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