

State Plan for Alzheimer's Disease and Related Dementias in Maine



Aging and Disability
Services

An Office of the
Department of Health and Human Services

Paul R. LePage, Governor

Mary C. Mayhew, Commissioner

ACKNOWLEDGEMENTS

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This is Maine's first-ever State Plan for Alzheimer's Disease and Related Dementias. Recommendations vary in scope, cost and impact and include actions in the near term as well as mid- and long-range goals. Each will require numerous actions to achieve and will require engagement of a diverse group of public and private sector stakeholders. As this plan was developed during a period in which our country's first National Alzheimer's Plan was also being crafted, it will be important, as the state plan moves to implementation phase, that federal implementation be monitored to ensure activities strategically align to maximize outcomes and funding for priority Maine initiatives.

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EXECUTIVE SUMMARY

Now is the time to make Alzheimer's disease a priority in Maine and across the country. As of 2012, more than 5 million Americans have the disease; by 2050, that number grows to 16 million. In Maine alone, the number of individuals living with Alzheimer's will increase from 37,000 individuals today to over 53,000 individuals by 2020. One in eight people aged 65 and older has Alzheimer's disease, and Maine's 65-74 year old age group is forecast to grow by 77% in the next ten years. The annual cost of Alzheimer's today is \$183 billion; by mid-century, the disease could cost our country over a trillion dollars per year. Most importantly, behind every statistic, there is a person. Millions of people are enduring the devastation of this disease that steals memories, independence, control, time, and ultimately, life. Family members and friends struggle to provide or ensure exhaustive, round-the-clock care as their loved ones succumb to the disease.

The Maine State Plan on Alzheimer's Disease and Related Dementias will help guide our response to meeting the needs of individuals and their families affected by mild cognitive impairment and Alzheimer's disease or related dementia today, tomorrow and into the next decade. The plan is a result of a state taskforce that was convened by the Maine Department of Health and Human Services pursuant to LD 859, legislation sponsored by State Sen. Margaret Craven of Lewiston, which was signed into law by Gov. Paul LePage in June 2011. Maine's Office of Elder Services partnered with the Alzheimer's Association, Maine Chapter to recruit additional stakeholders to serve on workgroups to develop the plan over an 11-month period. Individuals from across the state were involved, including family and professional caregivers; individuals living with the disease; representatives of the Maine Center for Disease Control & Prevention and the Maine Association of Area Agencies on Aging; medical providers; health and social service representatives; representatives from home care organizations, assisted living and long-term care facilities; the Long-term Care Ombudsman, public health officials, hospital administrators, directors from health care focused nonprofits, elder law, and finance organizations; as well as representatives from higher education and businesses. Public input sessions provided additional feedback to inform the plan.

The plan engages state agencies, local businesses, the private sector, and philanthropic groups to make Alzheimer's disease a top priority in Maine. A comprehensive state strategy to address the needs of individuals with Alzheimer's disease will provide a mechanism to consider all of these issues collectively. This public health crisis will then be addressed with a thoughtful, integrated and cost-effective approach that is easier for individuals and families to navigate. Twenty-three states across the country already have Alzheimer's Disease plans in place. The Maine plan was crafted at the same time a first-ever National Alzheimer's Plan was being drafted under the direction of the U.S. Department of Health & Human Services. We now have a significant opportunity to change the course of Alzheimer's disease through the strategic and coordinated implementation of these plans. The national plan is comprehensive and seeks to achieve critical elements that individual states alone could not, such as federal research to better understand and treat the disease, and ultimately, to find a cure. There are many initiatives that states like Maine will need to move forward on, leveraging resources on all levels to help our friends and neighbors struggling with the disease.

Based on all the input and experiences shared over the last 11 months, here is what we agreed we must do here in Maine:

Increase awareness about Alzheimer's disease and its impact. Despite the number of people affected, many Mainers still know very little about this disease, which often remains in the shadows, discussed in whispers if at all. We must bring Alzheimer's fully into the open, explain the warning signs, address misplaced anxieties, correct misconceptions and overcome the stigma that too often makes a terrible disease even more of a hardship.

Provide more timely diagnosis, treatment and higher quality care. We must improve the quality of care provided to those with Alzheimer's. Currently, care is often fractured and ineffective, falling short of what is needed. Detection and diagnosis - the foundation of good care - often happens far too late, if at all. As a result, many facing the disease today are left without adequate opportunity to plan ahead. In addition, patients experience poor care coordination and face further complications from coexisting conditions.

Offer better support to caregivers. We must change the fact that we are very poorly equipped to support those with Alzheimer's and their caregivers in our homes and communities. Caregivers are too often isolated and uninformed about effective support strategies. Little government support is provided to help those who want and choose to keep their loved ones at home longer, even if this option is less expensive overall.

Enhance long-term care access and quality. Maine's service infrastructure has significant capacity gaps, which exacerbate challenges for those living in an older, rural state affected by a high rate of chronic disease. To meet the needs of today and tomorrow, we need to appropriately fund a sustainable infrastructure that supports what is done well, empowers choices to do things we know we can do better, and enhances capabilities with innovative new cost-effective models of care delivery that have proven successful in providing quality, evidence-based care where it is needed. The present reality is that even long-term care facilities are often not fully equipped to meet the intense demands of caring for those in the middle and later stages of the disease. We need to do a better job at recruiting, educating, and training our workforce across all settings that make up the care continuum.

We learned many things from Maine people who came together to develop and inform this plan. The most important is that those living with and affected by Alzheimer's disease are desperate for decisive and meaningful action. We need a transformational plan, and we need it now. It's time to roll up our sleeves, to reach beyond the statistics and make sure Mainers suffering from the effects of Alzheimer's Disease know they are not alone and to let them know there are resources in place that will ease their burden.

2011-2012 PROCESS, TIMELINE AND MILESTONES

Milestone

Date/Period

Phase I

LD 859, sponsored by Sen. Margaret Craven, signed into public law

June 2011

Phase II

Joint LD65/LD 859 Task Force meetings convened by Maine DHHS (4)

October 14 – November 18, 2011

Workgroups work sessions convened by Alzheimer's Association
Maine Chapter

Nov. 1, 2011 – April 11, 2012

- Met once in November 2011
- Met twice a month in Jan., Feb. and March
- Met once in April to finalize workgroups' draft
- Location: Augusta, with call-in available
- All workgroups met same day, consecutively
- Alzheimer's Association Maine Chapter staffed
(Research, materials, agenda, minutes, drafting/revising of documents, facilitation)

Meeting dates/times: Back-to-back, one-hour work sessions of the three workgroups were held Wednesdays on Nov. 30, Jan. 11, Jan. 25, Feb. 8, Feb. 22, March 14, March 28, April 11 from 10 a.m. to 2:00 p.m. with a one-hour break for lunch from 12 noon to 1 p.m. prior to the third group's session. Locations: Nov. 30 meeting was held at 32 Blossom Lane, Marquardt Rm 1A. The meetings scheduled to take place during legislative session listed above January-April were held in Cross Office Building, Room 600, Augusta.

Last day of work sessions

April 11, 2012

Draft completed

April 19, 2012

Public input sessions to be held

Late April / Early May 2012

Draft Resource Directory Appendix to be completed

Mid-May, 2012

Revised draft of complete State Plan to be delivered to
Task Force Members for final review

Mid-May, 2012

Final State Plan Report to be delivered to DHHS

Early June, 2012

DHHS presentation to HHS Committee of State Legislature

TBA

Phase III and IV

Work together to promote plan, translate into policy and implementation phases as appropriate to strategically coordinate multi-year, multi-policy issue campaigns successfully implement the recommendations

Starting early fall 2012 prior to swearing in of the to 126th Maine Legislature and ongoing

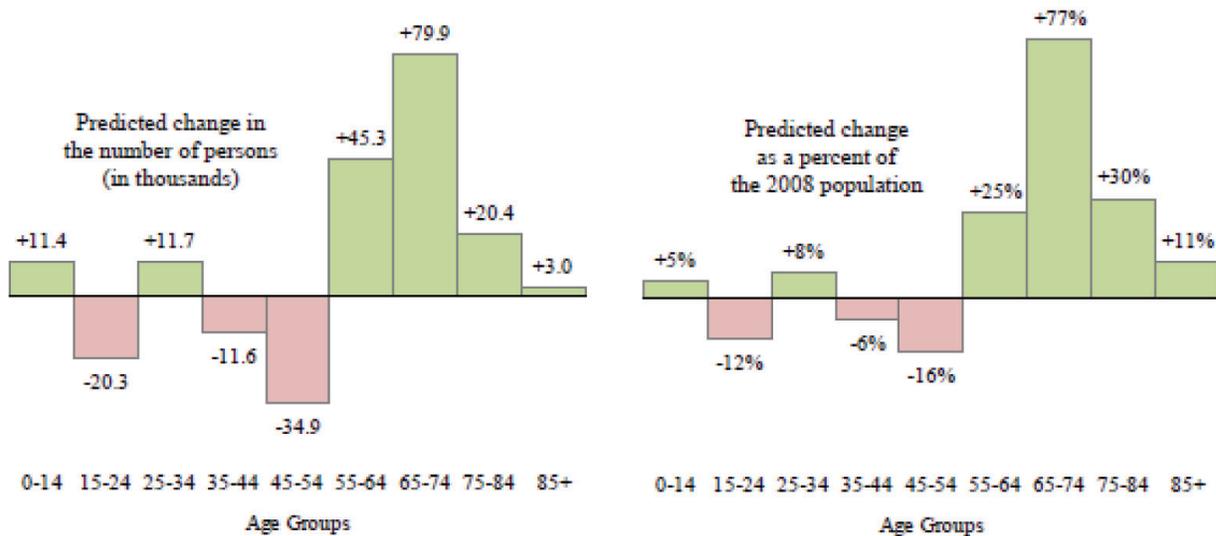
Revisit and re-evaluate plan, establish priorities based on impact, cost, feasibility

Annually in early fall in advance of cloture deadlines for upcoming legislative sessions

I. STATE PLAN STRUCTURE AND PROCESS

By the middle of this century as many as 16 million Americans will have Alzheimer's disease. As of 2012, more than 5 million Americans have the disease. In Maine, the number of individuals with Alzheimer's disease will dramatically increase from the 37,000 individuals today to over 53,000 by 2020, yet there has been no plan in place to accommodate growing needs. Between now and 2020, Maine's long-term care system will need to accommodate the varied needs of an additional 103,000 persons age 65-or-older. While all Maine age groups over age 55 are projected to grow between 2008 and 2020, Maine's 65-to-74 year-old age group is forecast to grow by 77% over 12 years, the fastest of any age group. This represents a total increase of 80,000 (77%) over 12 years. The number of Mainers age 85-and-above, the age group with the highest demand for long-term care, will grow by 3,000 persons, an 11% increase between 2008 and 2020. (Source: Woods and Poole Economics, Inc., "2008 New England State Profile: State and County Projections to 2040," and U.S. Census Bureau, Population Division, "Interim State Population Projections," 2008).

Figure 1-2
Maine's older population is projected to grow quickly between 2008 and 2020



Source: Woods and Poole Economics, Inc., "2008 New England State Profile: State and County Projections to 2040", and U.S. Census Bureau, Population Division, "Interim State Population Projections", 2008

The State Plan for Alzheimer's Disease and Related Dementias in Maine presents a roadmap for the creation of an infrastructure necessary to build dementia-capable programs for the growing number of people with the disease.

A comprehensive state strategy to address the needs of individuals with Alzheimer's disease provides a mechanism to consider all of these issues collectively. The Alzheimer epidemic can then be addressed with a thoughtful, integrated and cost-effective approach.

Enactment of LD 859 was Phase I of a four-phase process:

- I. The mandate,
- II. The plan,
- III. The policy, and
- IV. The implementation (immediate, mid-term and long-term) over the next two decades.

Phase II involves the development of the plan with recommendations as mandated by LD 859.

This phase included/will include:

- The Commissioner of the Maine Department of Health & Human Services appointed task force members. Office of Elder Services convened initial meetings in October and November 2011.
- Participation was expanded and diversified through formation of workgroups (*See also “A” below*), which were convened by the Alzheimer’s Association Maine Chapter from November 2011 through April 2012. All pertinent issues within the scope of LD 859 were discussed—from primary prevention to end-of-life-care.
- A consensus-built plan report was drafted through the efforts of the workgroups.
- Three community forums were held to receive public input (*See also “B” below*).

Next:

- Final revisions will be made and a final review by the LD 859 task force will be completed.
- The report, which will be put in final publication design format and provided to the Office of Elder Services and the Maine Department of Health & Human Services for presentation to the Joint Standing Committee on Health and Human Services, will include meaningful, strategic recommendations for improving Maine’s capacity to address Alzheimer’s and related dementias.

A. Formation of workgroups and draft plan development

Three workgroups, covering the broad topics of Public Awareness, Public Health & Safety; Home and Community-Based Care; and Facility-Based Long-Term Care Services, were formed to develop the plan, including recommendations that correspond with the plan elements articulated on the plan outline, items III through VIII.

B. Community forums

Conducting community forums to hear comments allowed caregivers, family members, health and social service providers, and other community members, to share stories and experiences about caring for and providing services to individuals with Alzheimer’s disease and other dementias and further inform the plan. Individuals with Alzheimer’s disease and other dementias were also encouraged to share their experiences at the forum. Following is a list of proposed questions that acted as a guide for those who wished to speak:

All Participants

- What supportive and healthcare services are needed in your community?
- What is working well in your community that could be shared across the state?
- What creative approaches would you recommend to better serve people in your community?

Caregivers

- What are the most critical needs you face as a caregiver? How could those needs be better met?
- What assistance and support are most important to you, your family and other caregivers?

Providers

- What services do you or your organizations provide to individuals in the community?
- What are the most critical needs you face as a service provider? How could those needs be better met?

Public Input Sessions

Date/Time: Friday, April 27, 11 a.m. – 12 noon

Location: PeoplesChoice Credit Union, 23 Industrial Park Road, Saco

Date/Time: Wednesday, May 2, 11:30 a.m. – 12:30 p.m.

Location: First United Methodist Church, 703 Essex Street, Bangor

Date/Time: Tuesday, May 8, 12 noon – 1 p.m.

Location: St. Mary's D'Youville Pavilion, 102 Campus Avenue, Lewiston

Date/Time: Friday, November 9, 9:00 a.m. – 10:30 a.m.

Location: Mid Coast Senior Health Center, 58 Baribeau Drive, Brunswick

Comments also were also invited to be e-mailed to the Alzheimer's Association Maine Chapter.

Phase III and IV will begin the process of translating the vision of the state plan into actual policy.

Multi-year plan implementation leaders will include: Office of Elder Services - Maine Dept. of Health & Human Services, Maine Centers for Disease Control and Prevention, Alzheimer's Association Maine Chapter, Area Agencies on Aging, and other health, social service, public and community organizations, centers, individuals and businesses.

All will work together to promote the plan, translate into policy, and strategically coordinate multi-year, multi-policy issue campaigns to successfully implement plan recommendations. The plan will be revisited and re-evaluated annually in early fall, to establish priorities based on impact, cost and feasibility.

II. DISEASE BACKGROUND INFORMATION

A. What is Alzheimer's Disease?

Alzheimer's disease (AD) is a progressive brain disorder that destroys brain cells, causing a steady decline in memory, mental abilities and the ability to perform usual activities of daily living. As the disease progresses, it affects one's ability to remember, reason, learn and imagine. Alzheimer's disease is the most common form of dementia which includes a broad spectrum of brain disorders that cause memory loss severe enough to interfere with the normal routines of daily living. Loss of cognitive function caused by Alzheimer's disease is qualitatively different from that related to normal aging. On average, individuals with Alzheimer's disease live for eight to 10 years once a diagnosis has been established. The national Alzheimer's Association has identified seven stages through which an individual with AD passes.

Stage 1 No impairment, normal functioning.

Stage 2 Very mild cognitive decline (may be normal age-related memory lapses).

Stage 3 Mild cognitive decline. Early-stage AD can be diagnosed in some but not all individuals with associated symptoms.

Stage 4 Moderate cognitive decline, diagnosable early-stage AD. An informed medical interview will detect clear deficiencies in memory, decreased capacity to perform complex tasks, reduced memory of one's personal history and tendency to withdraw socially or from mentally challenging situations.

Stage 5 Moderate severe cognitive decline (mid-stage AD). Major gaps in memory and deficits in cognitive functioning emerge. Assistance with activities of daily living becomes essential. Very common facts such as current address and telephone number cannot be recalled upon medical examination, individual is confused about place and time, simple math is difficult, retaining knowledge about self is lost, and individual usually needs assistance with toileting and eating.

Stage 6 Severe cognitive decline; can be severe, moderate or mid-stage AD upon diagnosis. Memory loss accelerates, personality changes emerge and more intense help with activities of daily living are needed. Wandering is common in this stage of the disease.

Stage 7 Very severe cognitive decline; severe or late-stage AD. This is the final stage of the disease; individuals lose their ability to respond to their environment, the ability to speak and ultimately, the ability to control movement.



B. State Demographics

i. Number of Persons with Alzheimer's

Prevalence of Alzheimer's Disease and Other Dementias

Alzheimer's disease currently afflicts approximately 5.4 million Americans. This figure includes 5.2 million people aged 65 and older and 200,000 individuals under age 65 who have younger-onset Alzheimer's. Because the incidence of Alzheimer's disease is highly correlated with age, the aging of the population has significant implications for the resources needed to care for individuals with Alzheimer's disease. Population aging is expected to result in a significant increase in the prevalence of Alzheimer's disease—by 2050, the number of individuals with Alzheimer's disease is projected to be as high as 16 million.

- One in eight people aged 65 and older (13%) has Alzheimer's disease.
- Of those with the disease, an estimated 4% are under age 65, 6% are 65 to 74, 45% are 75 to 84, and 45% are 85 or older.
- Alzheimer's disease was the sixth-leading cause of death across all ages in the United States; the fifth-leading cause of death for those age 65 and older. In 2007, for the US as a whole, the mortality rate from Alzheimer's disease was 24.7 deaths per 100,000 individuals; in Maine, it was 35.7.
- The average annual per-capita Medicare expenditures for a beneficiary with Alzheimer's disease or other dementia is three times that of one without Alzheimer's disease or other dementia.
- Individuals 85 and older (the age group in which Alzheimer's is most likely to occur) who live in households with incomes less than 200 percent of the federal poverty level spend 30 percent of their household income on out-of-pocket health expenditures, compared to 11 percent of individuals 85 and older in all other income categories.



Duration of Illness from Diagnosis to Death

Studies indicate that people 65 and older survive an average of 4 to 8 years after a diagnosis of Alzheimer's disease (AD), yet some live as long as 20 years with Alzheimer's. This indicates the slow, insidious nature of the progression of AD, with the loss of memory and thinking abilities, as well as the loss of independence over the duration of the illness. On average, a person with AD will spend more years (40% of the total number of years with AD) in the most severe stage of the disease than in any other stage. And much of this time will be spent in a nursing home, as nursing home admission by the age of 80 is expected for 75% of the people with AD, compared with only 4% of the general population.

In all, an estimated two-thirds of those dying of dementia do so in nursing homes, compared with 20% of cancer patients and 28% of people dying from all other conditions. Thus, in addition to AD being the 6th leading cause of death, the long duration of the illness may be an equally telling statistic of the public health impact of the disease.

Deaths from Alzheimer's Disease

Alzheimer's disease (AD) is becoming a more common cause of death as the populations of the United States and other countries age. While other major causes of death continue to experience significant declines, those from AD have continued to rise. Between 2000 and 2008 (preliminary data) deaths attributed to AD increased 66%, while those attributed to the number one cause of death, heart disease, decreased 13%.

The increase in the number and proportion of death certificates listing AD reflects both changes in patterns of reporting deaths on death certificates over time as well as an increase in the actual number of deaths attributable to Alzheimer's.

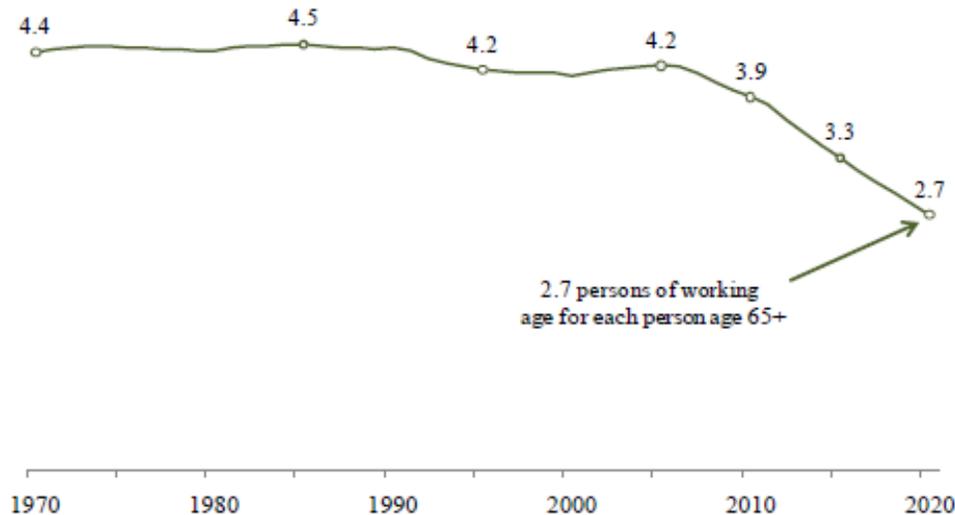
The different ways in which dementia eventually ends in death can create ambiguity about the underlying cause of death. Severe dementia frequently causes such complications as immobility, swallowing disorders and malnutrition. These complications can significantly increase the risk of developing pneumonia, which has been found in several studies to be the most commonly identified cause of death among elderly people with AD and other dementias. The situation has been described as a "blurred distinction between death with dementia and death from dementia." Regardless of the cause of death, 61% of people with AD at age 70 are expected to die before 80 compared with 30% of people at age 70 without AD.

ii. Number of Caregivers

Unpaid Caregivers

Unpaid caregivers are primarily family members, but they also include other relatives and friends. In 2010, they provided 17 billion hours of unpaid care, a contribution to the nation valued at over \$202 billion.

Figure 3-1
Maine's elderly dependency ratio
The Number of Persons of Working Age (20-64) for Each Person Age 65+



Although Maine's elderly dependency ratio held fairly steady from 1970 to 2005, it is projected to be in steady decline through 2020. While Maine had an estimated number of 4.2 working age

(20-64) persons in 2005 for each person age 65-or-above, the ratio is projected to decline to just 2.7 working age persons in 2020 for each person age 65-or-above.

Eighty percent of care provided at home is delivered by family caregivers; fewer than 10% of older adults receive all of their care from paid workers. Caring for a person with Alzheimer's or another related dementia is often very difficult, and many family and other unpaid caregivers experience high levels of emotional stress and depression as a result. Caregiving may also have a negative impact on the health, employment, income and financial security of caregivers. However, a variety of interventions have been developed that may assist individuals with the challenges of caregiving.

Sixty percent of family caregivers and other caregivers of people with Alzheimer's and other dementias are women. Most caregivers are aged 55 or older (56%), are married (66%), have obtained less than a college degree (67%) and are white (70%). Over half are the primary breadwinners (55%), and nearly half are employed full or part time (44%). Fifty percent of these unpaid caregivers live in the same household as the person for whom they provide care. Twenty-six percent of family caregivers have children under 18 years old living with them. These caregivers are sometimes referred to as the "sandwich generation" because they simultaneously provide care for two generations.

Paid Caregivers

Paid caregivers who provide care to older adults with Alzheimer's or related dementias include direct-care workers and professionals. Direct-care workers comprise the majority of the formal healthcare delivery system for older adults and include nurse aides, home health aides, and personal- and home-care aides. Professionals who receive special training in caring for older adults include physicians, physician assistants, nurses, social workers, pharmacists, case workers, and others.

Direct-care workers provide most of the paid care to older adults, including assistance with bathing, dressing, housekeeping and food preparation. Turnover rates are high, and recruitment and retention are persistent challenges.

It is projected that the United States will need an additional 3.5 million healthcare providers by 2030 just to maintain the current ratio of healthcare workers to the population. The need for healthcare professionals trained in geriatrics is escalating, but few providers choose this career path. In 2007, the number of physicians certified in geriatric medicine totaled 7,128; those certified in geriatric psychiatry equaled 1,596. By 2030, an estimated 36,000 geriatricians will be needed. Some have estimated that the increase from current levels will amount to less than 10%, while others believe there will be a net loss of physicians for geriatric patients. Other professions also have low numbers of geriatric specialists: 4% of social workers and less than 1% of registered nurses, physician assistants and pharmacists identify themselves as specializing in geriatrics.



III. PUBLIC AWARENESS, PUBLIC HEALTH AND SAFETY

A. Public Awareness and Public Health

The inclusion of Alzheimer's disease in *Healthy People 2020* – the nation's health prevention and promotion goals for the next decade – confirms that Alzheimer's is a pivotal public health issue, requiring bold action before the crisis worsens.

General misunderstandings regarding Alzheimer's and related dementias and the dementia care system persist in Maine and across the country. Myths and public misperceptions about dementia perpetuate stigma and fear, and the most fundamental information and messages have not been incorporated into public dialogue regarding dementia:

- Dementia is a disease and not a normal process of aging.
- Knowing signs and symptoms of dementias and risk factors can lead to early detection.
- Early detection of cognitive decline and early intervention and planning helps individuals, families and caregivers in significant ways that better enable positive experiences for those living with Alzheimer's and related dementias.
- One in eight older Americans has Alzheimer's disease. Policymakers and other leaders need to better understand the public health implications of the disease in order to inform choices to better prepare our currently ill-equipped infrastructure and systems of care to manage the increasing prevalence of the disease. (*2012 Alzheimer's Disease Facts and Figures*, Alzheimer's Association).



Maine people, as elsewhere, have a limited understanding of the signs and symptoms associated with the diagnosis and treatment of Alzheimer's disease. Issues range from a basic knowledge of early warning signs of the disease to recognizing a lost or endangered person. Public information campaigns will be an important element in creating a ground swell of awareness to dispel myths, overcome the psychological barriers or denial and stigma that can inhibit accurate understanding of the disease, mobilize individuals and communities into action, and change the current paradigm regarding dementia.

In Maine, there is great potential to expand the dissemination of information and use of public education campaigns regarding dementia. Significant consideration should be given to campaigns and communication methods which use broad-based, consistent messages and an array of media approaches. In addition, alternative methods should build the capacity of prominent individuals, community leaders and organizations so that they too can communicate strategic messages to the public, press and peers. Relationship building will be vital to the success of both a broad-based, grassroots campaign and the type of participatory communication approaches which resonate with specific segments of the public. For example, the approaches for employers, young adults, spouses or partners and children of people with dementia should be tailored to obtain the greatest impact and effect.

Maine families, consumers and communities all need to become more involved in and part of the solution to increase public awareness and reduce risk. Providing them opportunities to name what they need and advocate for their interests will allow them to access appropriate needed resources, services, and work in partnership with other community stakeholders. Empowerment and advocacy are increasingly important tools in engaging people with dementia and their families. New research demonstrates the links between empowerment, advocacy and improved quality of life.

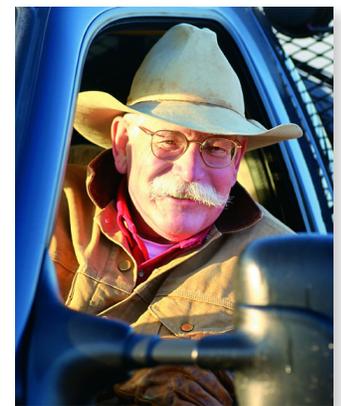
With the increasing population of Mainers over 65 and the parallel increases in the prevalence of dementia, strong consideration should be given to including this population in designing, evaluating and directing how their needs can best be met. Given the potential for early detection of dementia, engaging people frequently, as well as early in the disease process, is entirely feasible. With the expected increase in the number of people with dementia, we can anticipate an increase in the number of families and friends acting as caregivers, who similarly should have a voice in the design of a dementia-informed system of care.

B. Risk Reduction

Wandering is one of the most significant risks involving people with Alzheimer’s disease—nearly 60 percent wander at some point during the course of their illness. Approximately half of wanderings lead to injury if the individual is not found within 24 hours. Several programs have been designed to reduce the risk of wandering and ensure a safe return if wandering occurs. The ability of law enforcement to respond swiftly to reported cases of wandering in Maine was widely expanded in 2011 when the state implemented a coordinated “Silver Alert” response system similar to the “Amber Alert” for missing children. Like Amber Alert, information is sent to designated media outlets including radio and television stations which issue an alert at designated intervals. Two programs that mitigate the risks associated with wandering include MedicAlert + Safe Return and Comfort Zone. MedicAlert + Safe Return is a national emergency response service for individuals with Alzheimer’s disease or related dementia. Individuals in the program are issued a personalized identification bracelet or medallion. Family members can report a missing person to the hotline and initiate a response from local Alzheimer’s Associations and law enforcement agencies. Comfort Zone allows families and caregivers to set up a designated perimeter with family members alerted if the enrollee leaves this designated area.

Another challenge that is often presented is that individuals with Alzheimer’s disease who are wandering, lost or otherwise in a dangerous situation are not immediately recognizable as at risk; that is, the warning signs are not readily apparent. Because the general public is unaware of the situations and signs that put an individual at risk, appropriate community responses cannot be expected.

Another significant safety risk for individuals with Alzheimer’s disease is diminished ability to drive. This is a complex issue, and considerable anxiety exists around telling individuals that they should no longer be driving. Currently, the Maine Department of Motor Vehicles has the authority to cancel, deny or deny reissuance of a license for several reasons, including the inability to operate a motor vehicle because of physical or mental incompetence. The written medical opinion of a licensed physician, physician’s assistant or optometrist may be used for the renewal, suspension, revocation or cancellation of drivers’ licenses.



Public Awareness, Public Health And Safety Recommendations

Goal: Mainers are adequately informed regarding dementia and participate as active stakeholders in the system of dementia care.

Objectives should include activities which create messages to increase awareness, change attitudes which perpetuate the idea that dementia is a natural and acceptable course of the aging process, increase help-seeking behavior, recognition and improve self management. Messages should be targeted to specific populations (e.g., spouses, family members, medical community and employers).

Objective 1: Design a broad-based dementia and brain health public information campaign that includes grass-roots initiatives.

Strategies:

- 1. Collaborate with and leverage the national Alzheimer’s Association’s dementia public awareness campaign and related efforts to encourage the utilization of public service announcements through local radio and television stations, as well as other public awareness venues (traditional print media as well as web, social media and other online forums).** For example, utilize the national Alzheimer’s Association public awareness campaign (with print ads and television commercials) to educate the public about the 10 warning signs of Alzheimer’s disease and the benefits that accrue from increased awareness, early detection and intervention in order to better enable positive experiences for those living with Alzheimer’s and related dementias and their families. These communications initiatives and messages should also be utilized by the Office of Elder Services of the Maine Department of Health and Human Services, the Maine Center for Disease Control and Prevention’s nine public health districts, federally qualified health centers in Maine and older adult service organizations including Area Agencies on Aging and others to ensure that the national awareness campaign is widely disseminated in Maine. Along with the national campaign, local public awareness campaigns should be enhanced and further developed, through public service announcements and other information dissemination outlets. Personal stories and images of caregivers and those living with Alzheimer’s should be emphasized in communications as they are especially impactful. These should include those with younger onset. Special efforts should be made to ensure coverage of rural or other hard-to-reach and/or underserved communities in the state, including native communities, immigrant and other diverse communities. Outreach should also serve to increase awareness of the prevalence of those living with Alzheimer’s who also have other special needs or disabilities, including those with intellectual disabilities (FMI: <http://www.aaid.org/index.cfm>). The U.S. Dept. of Health & Human Services intends to convene one or more groups of experts, both within and outside of the government, to take steps to address the unique challenges faced by people with younger-onset Alzheimer’s disease, racial and ethnic minorities, and people with Down syndrome and other intellectual disabilities. (See *action 2.H.1. of National Alzheimer’s Plan* at <http://aspe.hhs.gov/daltcp/napa/index.shtml#DraftNatlPlan>). Maine’s efforts specific to these populations should align with recommendations emerging from these national task force(s).
- 2. Leverage strategies identified by “The Healthy Brain Initiative,”** collaboratively developed by the national Alzheimer’s Association and the Centers for Disease Control and Prevention, which offers a national public health road map that incorporates a positive and hopeful perspective to maintaining cognitive health, as a means to enhance the public awareness campaign in promoting the latest science.
- 3. Distribute materials available or developed through the above initiatives** via the Maine CDC and Department of Health and Human Services to the public, at senior centers, resource centers and libraries, provider offices, and community health centers that share a common focus of information dissemination and community wellness. Provide materials to insurance companies and health plans in Maine to disseminate to their enrollees.
- 4. Develop training pre-service and in-service curricula related to dementia and cognitive health for continuing professional education of health and human services professionals.** The level of understanding of practicing professionals must be raised to better enable them to assist the public in assessing evidence-based approaches versus those with less proven outcomes, as well as to ensure they have complete information regarding resources and services available at the community level to assist the public in meeting their needs.
- 5. Develop dementia volunteer programs that train lay people to give presentations as health promoters and information disseminators in the community at forums** such as Rotary, Chamber and other service organization events. Engage a diverse group of stakeholders in this effort, including family members, faith-based institutions, high schools

and colleges, the Alzheimer's Association Maine Chapter, AAAs, the Retired Seniors Volunteer Program (RSVP), health centers and other natural partners to increase awareness and understanding of dementia and to expand supports to people with dementia and their families.

6. **Increase outreach to public officials to better inform them of the challenges of dementia and increase understanding of cognitive health.** Better informed policy makers will make more strategic decisions on related program and funding decisions and may serve as champions in the legislative and public arenas.
7. **Convene local forums for the public and for people with, or affected by dementia.** This will enable them to support one another, learn how to advocate for themselves and others, and receive education and information about locally available resources and services to inform them of care options choices, safety strategies, as well as information on accessing insurance coverage, long-term care insurance, legal and financial resources and services, clinical trials and more. This will also offer an opportunity to receive ongoing information from caregivers about continued challenges and new concerns and provide venues to engage their participation in other initiatives.
8. **Engage naturally occurring outreach organizations** such as faith-based communities, senior centers, tribal communities, immigrant and other diverse communities in the state to further expand reach.
9. **Engage the legal community and probate court officials** to better inform them of the challenges of dementia and of the legal services and/or other counseling that may be needed by individuals living with the disease and their families. This should include engaging Maine attorneys in helping to educate the public on legal decisions to consider around Durable Power of Attorney, Advance Directives, etc., as well as what instruments may need to be executed as part of advance planning to advocate on behalf of their loved one to secure services and benefits needed. In addition to state forms, this should also include federal forms (as applicable) which may be overlooked, e.g., VA Advance Directive Durable Power of Attorney for Health Care and Living Will at <http://www.va.gov/vaforms/medical/pdf/vha-10-0137-fill.pdf> and the Appointment of Individual as Claimant's Representative at: <http://www.vba.va.gov/pubs/forms/VBA-21-22A-ARE.pdf>; as well as the Social Security Appointment of Representative form at: <http://www.ssa.gov/online/ssa-1696.html>).
10. **Integrate into the primary and secondary school health and human development curriculums content related to healthy aging versus disease.**
11. **Engage high schools and colleges that require community service projects** as part of their requirements for matriculation or graduation.

Objective 2: Establish or expand strategic initiatives and resources that support active involvement in advocacy, care, self management and safety.

Strategies:

1. **Support and fund increased state-based surveillance through the Behavioral Risk Factors Surveillance System (BRFSS).** Obtaining a more definitive picture of Alzheimer's is essential to any successful strategy to combat the disease. The program of the national Centers for Disease Control and Prevention enables states to collect data on the impact of Alzheimer's disease using the existing state BRFSS, utilizing a de-identified telephone survey that has existed since 1984. BRFSS surveys are conducted annually by state health departments, with funding and technical assistance from the CDC. Surveillance is used to develop data on the incidence, prevalence, and risk factors for particular diseases. Effective surveillance will produce state information about the number of people with cognitive impairment, the number of family caregivers who are taking care of someone with Alzheimer's or another dementia, and the age,

income, living arrangements, health problems, and other characteristics of people with cognitive impairment and their family caregivers. The data developed from surveillance tools support strategies to effectively intervene where resources are needed most, provide the research, caregiving and public health communities a better understanding of people with cognitive impairment and Alzheimer's, and identify opportunities for reducing the impact of this devastating disease. In Maine, the current survey can reach anyone in the state that has a telephone, but does not reach those in facility care. It is self-reporting and 4,000 to 12,000 people are contacted in any given year. Two modules of particular relevance are available: A Cognitive Impairment Module and a Caregiver Module. Questions from both modules will be included in the 2012 BRFSS, and it is anticipated that the release of data findings will be available in mid-2013. Additional support, coordination and funding, however, should be provided to ensure that meaningful, consistent multi-year surveillance and data analysis that includes the cognitive health module questions will be conducted and that continued synthesis and reporting of findings will occur. BRFSS is one, but not the only way, of collecting data about dementia. As Maine is unique in collecting all payer data based on outpatient, hospital and ER visits – which provides robust surveillance of who's being treated for Alzheimer's and related dementias, where, and how – other state data sources should be considered to inform practices and policies as well. Additionally, there should be outreach to members of the patient medical home initiative who are focused on the development of a Behavioral Health Metric tool to inform informed decisions of community coordinated care teams to assess with them whether cognitive health could be included. Another data source that could be considered is death certificates, which may require evaluation of how cause of death is recorded at the clinical level.

2. **Support, fund and promote the re-establishment of a comprehensive state public health plan** to include cognitive health in its strategies or recommendations where appropriate.
3. **Establish and support consumer and family involvement in public advocacy** through advocacy training and financial supports such as travel reimbursement and funding for respite care. Explore opportunities to connect funds where they are needed most with respect to limited resources, while offering as much flexibility as possible to meet the objective of attaining more active involvement.
4. **Engage policy makers in ongoing discussions** with consumers and families regarding state policies and regulations.
5. **Conduct a gap analysis to identify new and existing opportunities to enhance and adequately fund state policies and programs regarding benefits and subsidies to family caregivers**, which promote active involvement of families in dementia care. These incentives can be in the form of monetary incentives, tax incentives, health care coverage or deferred income incentives (retirement) as well as non-monetary incentives such as eligibility to obtain counseling and support for family caregivers through state or locally sponsored programs.
6. **Conduct a gap analysis to identify new and existing opportunities to enhance and adequately fund state policies and programs regarding subsidies for adult day programs** (for example, Partners in Caring), similar to those for child care settings, which support, enable and supplement active caregiving by families and friends in order to encourage the ability to sustain home-based care, which is more cost-effective than residential-based alternatives. Diverse funding stream sources should be considered and evaluated to reflect the needs of a growing population, with emphasis on early intervention strategies and offering families options and choices appropriate to the unique care needs of individuals living with the disease.
7. **Establish a broad network of partners in the areas of business, education, manufacturing, and other community-based employers and organizations** such as YMCAs to promote brain health and wellness programs in the workplace and help educate the public on the importance of early detection of dementia, available resources for people with dementia, and caregiver support.

8. Promote programs which:

- Ensure home safety through falls prevention programs, home safety assessments, and home monitoring devices.
- Help people with dementia and their families prepare for care and services in the event of a disaster or emergency.
- Develop employer-supported dementia caregiver training and other employer-supported programs.

9. Increase safety in the community by improving the visibility and utilization of locator devices and programs such as the Alzheimer's Association Safe Return Program. A public awareness campaign that includes the Maine Department of Public Safety and law enforcement training academies and other state and community organizations focused on safety should be launched to educate the public about the relative effectiveness of locator devices with the goal of increasing their utilization (such as the Alzheimer's Association *Comfort Zone* GPS tracking locator device.)

10. Launch an education and outreach campaign to inform family members and health care providers about ways to address driving issues. The outreach campaign should include physician residency programs in Maine, medical societies, nurse associations, other medical professional societies, hospitals and assisted-living facilities. The Maine Chapter of the Alzheimer's Association should work with continuing medical education providers to include a curriculum module about safety issues associated with patients with Alzheimer's disease and other dementias. (*See also, Diagnosis & Treatment section of plan*).

11. Explore whether a gatekeeper model of case finding should be implemented throughout the state to identify individuals with Alzheimer's disease who are at risk in the community. This model trains community members such as bank tellers, mail carriers, housing managers and other employees of businesses and organizations that are likely to come into contact with older adults to identify those in need of assistance. Trained community members then make referrals to a centralized point-of-contact at DHHS where the individual is triaged to an appropriate agency for assessment and referral. The Maine chapter of the Alzheimer's Association, the AAAs, as well as large employers in Maine and others could offer a short training module for employees about recognizing the signs of wandering and/or lost individuals. Evaluation of whether such a model should be implemented should include considerations of health confidentiality. During the evaluation of this model, a State Registry model could also be evaluated for feasibility and effectiveness and similarly consider complex concerns with respect to health care confidentiality and stigma that can create fear and discomfort in some individuals and families that can become counterproductive to their moving forward to access needed services. It should be evaluated whether benefits are already achieved in existing programs (i.e. Elder Abuse in which banks and others offer a DHHS curriculum to employees) and other new strategies recommended in this plan that make a gatekeeper model and/or State Registry unnecessary, such as new service delivery models, increased collaborations, innovative ways of reaching individuals and families to help them navigate the system in a coordinated way, as well as data collection and surveillance via BRFSS.

12. Encourage and enhance adequate training for first responders about medical and behavioral issues related to Alzheimer's disease and related dementias when responding to an emergency involving these individuals. First responders play an important role in keeping individuals with Alzheimer's disease safe. When an individual with Alzheimer's disease has gone missing or finds himself/herself in a difficult situation, it is often a first responder's job to diffuse the situation and/or provide required supervision and protective services. It is important for first responders to have the knowledge and tools at their fingertips to respond appropriately when needed. The Alzheimer's Association has developed a short curriculum to train first responders in four content areas: 1) wandering; 2) driving, firearms and shoplifting; 3) abuse and neglect; and, 4) disaster response. It is recommended that police departments, fire departments and hospital emergency departments provide dementia training to all first responders. Materials for the training are available through the Maine Chapter of the Alzheimer's Association. Additionally, the Maine CDC funds a program that is currently under development as an EMS pilot program in conjunction with Northern Maine Medical Center to educate paramedics to enhance their knowledge of various health concerns, which could include Alzheimer's disease and related dementias and serve as a model that could be expanded.

IV. DIAGNOSIS AND TREATMENT

Diagnosis of Alzheimer's Disease (Source: *Alzheimer's Association's 2012 Alzheimer's Disease Facts and Figures* report)

A diagnosis of Alzheimer's disease is most commonly made by an individual's primary care physician. The physician obtains a medical and family history, including psychiatric history and history of cognitive and behavioral changes. Ideally, a family member or other individual close to the patient is available to provide input. The physician also conducts cognitive tests and physical and neurologic examinations. In addition, the patient may undergo magnetic resonance imaging (MRI) scans to identify brain changes, such as the presence of a tumor or evidence of a stroke, that could cause cognitive decline.

In 2011, the National Institute on Aging (NIA) and the Alzheimer's Association recommended new diagnostic criteria and guidelines for Alzheimer's disease. The new criteria and guidelines update, refine and broaden guidelines published in 1984 by the Alzheimer's Association and the National Institute of Neurological Disorders and Stroke. The new criteria and guidelines result from work that began in 2009, when more than 40 Alzheimer's researchers and clinicians from around the globe began an indepth review of the 1984 criteria to decide how they might be improved by incorporating scientific advances from the last three decades.

It is important to note that these are recommended criteria and guidelines. More research is needed, especially biomarker research, before the new criteria and guidelines can be used in clinical settings, such as in a doctor's office.

Differences Between the Original and New Criteria

The 1984 criteria were based chiefly on a doctor's clinical judgment about the cause of a patient's symptoms, taking into account reports from the patient, family members and friends; results of cognitive testing; and general neurological assessment. The new criteria and guidelines incorporate two notable changes:

- **1 They identify three stages of Alzheimer's disease**, with the first occurring before symptoms such as memory loss develop and before one's ability to carry out everyday activities is affected. In contrast, the 1984 criteria require memory loss and a decline in thinking abilities severe enough to affect daily life before Alzheimer's disease can be diagnosed.
- **2 They incorporate biomarker tests.** A biomarker is something in the body that can be measured and that accurately indicates the presence or absence of disease, or the risk of later developing a disease. For example, blood glucose level is a biomarker of diabetes, and cholesterol level is a biomarker of heart disease risk. Levels of certain proteins in fluid (for example, levels of beta-amyloid and tau in the cerebrospinal fluid and blood) are among several factors being studied as possible biomarkers for Alzheimer's.

The Three Stages of Alzheimer's Disease Proposed by the New Criteria and Guidelines for the Diagnosis of Alzheimer's Disease

The three stages of Alzheimer's disease identified in the new criteria and guidelines are preclinical Alzheimer's disease, mild cognitive impairment (MCI) due to Alzheimer's disease and dementia due to Alzheimer's disease. These stages are different from the stages now used to describe Alzheimer's. Currently, the stages of Alzheimer's are often described as mild/early-stage, moderate/mid-stage or severe/late-stage. The new criteria propose that Alzheimer's disease begins before the mild/early-stage and that new technologies have the potential to identify Alzheimer's-related brain changes that

occur before mild/early-stage disease. When these very early changes in the brain are identified, an individual diagnosed using the new criteria would be said to have preclinical Alzheimer's disease or MCI due to Alzheimer's. The third stage of the new criteria, dementia due to Alzheimer's disease, encompasses all stages of Alzheimer's disease as described today, from mild/early-stage to severe/late-stage.

Preclinical Alzheimer's disease — In this stage, individuals have measurable changes in the brain, cerebrospinal fluid and/or blood (biomarkers) that indicate the earliest signs of the disease, but they have not yet developed symptoms such as memory loss. This preclinical or pre-symptomatic stage reflects current thinking that Alzheimer's begins creating changes in the brain as many as 20 years before symptoms occur. Although the new criteria and guidelines identify preclinical disease as a stage of Alzheimer's, they do not establish diagnostic criteria that doctors can use now. Rather, they state that additional biomarker research is needed before this stage of Alzheimer's can be diagnosed.

MCI due to Alzheimer's disease — Individuals with MCI have mild but measurable changes in thinking abilities that are noticeable to the person affected and to family members and friends, but that do not affect the individual's ability to carry out everyday activities. Studies indicate that as many as 10 to 20 percent of people age 65 and older have MCI. It is estimated that as many as 15 percent of people whose MCI symptoms cause them enough concern to contact their doctor's office for an exam go on to develop dementia each year. From this estimate, nearly half of all people who have visited a doctor about MCI symptoms will develop dementia in three or four years.

This estimate is higher than for individuals whose MCI is identified through community sampling (and not as a result of a visit to a doctor because of cognitive concerns). For these individuals, the rate of progression may reach 10 percent per year. Further cognitive decline is more likely among individuals whose MCI involves memory problems than in those whose MCI does not involve memory problems. Over one year, most individuals with MCI who are identified through community sampling remain cognitively stable. Some, primarily those without memory problems, experience an improvement in cognition or revert to normal cognitive status. It is unclear why some people with MCI develop dementia and others do not. When an individual with MCI goes on to develop dementia, many scientists believe the MCI is actually an early stage of the particular form of dementia, rather than a separate condition.

The new criteria and guidelines recommend biomarker testing for people with MCI to learn whether they have brain changes that put them at high risk of developing Alzheimer's disease or other dementias. If it can be shown that changes in the brain, cerebrospinal fluid and/or blood are caused by physiologic processes associated with Alzheimer's, the new criteria and guidelines recommend a diagnosis of MCI due to Alzheimer's disease. Before doctors can make such a diagnosis, however, researchers must prove that the biomarker tests accurately indicate risk.

Dementia due to Alzheimer's disease — This stage is characterized by memory, thinking and behavioral symptoms that impair a person's ability to function in daily life and that are caused by Alzheimer's disease-related processes.

Biomarker Tests

The new criteria and guidelines identify two biomarker categories: (1) biomarkers showing the level of beta-amyloid accumulation in the brain and (2) biomarkers showing that nerve cells in the brain are injured or actually degenerating.

Researchers believe that future treatments to slow or stop the progression of Alzheimer's disease and preserve brain function (called "disease-modifying" treatments) will be most effective when administered during the preclinical and MCI stages of the disease. In the future, biomarker tests will be essential to identify which individuals are in these early stages and should receive disease-modifying treatment when it becomes available. They also will be critical for monitoring the effects of treatment.



DIAGNOSIS AND TREATMENT RECOMMENDATIONS

Goal: All citizens of Maine, regardless of their geographical location or financial status will receive the best possible care for dementia, starting with a timely and dignified diagnosis. This should include developing capacity to coordinate care at the primary care level.

- Develop strategies to coordinate care across health care settings through early recognition and management of Alzheimer's and related dementias that include raising awareness of common medical conditions and health disparities that elevate risk for Alzheimer's and exacerbate its effects.
- Expand use of the Patient Centered Medical Home (PCMH) health care model as a means to integrate and coordinate dementia care within primary care practices. Connect with each practice's Community Care Team in order to connect people with community resources that will assist them through all phases of the disease. Recognizing the essential role of primary care in our healthcare system, the Maine Quality Forum (MQF), Maine Quality Counts, and the Maine Health Management Coalition have been working together to lead the Maine Patient Centered Medical Home (PCMH) Pilot. Twenty-six practices were selected to participate in 2009, and the pilot officially started on January 1, 2010. These practices are working diligently to implement the PCMH model as a first step in ultimately achieving the goal of statewide implementation of the model. By January 1, 2013, an additional 50 practices will be participating in the pilot.
- Establish protocol regarding warm referrals from PCMH practices and primary care providers to community agencies such as Area Agencies on Aging and the Alzheimer's Association (i.e. expand Community Links program).

Goal: Clinicians adopt best practices and follow guidelines for early detection and diagnosis utilizing screening as part of the Medicare Annual Wellness Visit.

- Develop plans for multilingual, multicultural awareness campaign for consumers and professionals regarding the Medicare Annual Wellness Visit and the inclusion of the "detection of any cognitive impairment" requirement.
- Work with governmental agencies, medical associations, medical providers, health and community support providers and insurers to identify and/or create improved screening tools for dementia and coordination of medical care and referral for community support and services.

Goal: Implement a continuing education track for physicians and other clinicians in all appropriate provider settings about Alzheimer's disease and related dementias and relevant safety issues.

- Continue to partner with appropriate state agencies and professional medical associations to develop approaches and curricula surrounding continuing medical education regarding Alzheimer's disease and related dementias and management of safety risks.

Comprehensive Roadmap for Dementia Diagnosis and Treatment in Maine

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Overview

Over the next 10 years, the number of individuals living in Maine who are older than 65 years of age will increase by 43% from the current 37,000 to over 53,000. During this time the 65 to 74 year old group will grow by over 70% and the number of Mainers aged 85 and above will grow by 11%, or 3,000 additional persons. With age being the greatest risk factor for dementia, Maine clinicians will be confronted with an ever enlarging population of patients experiencing cognitive and functional decline.

The current health delivery system, ranging from the ambulatory care of independent older persons to the provision of care to persons residing at the nursing home level, is already stretched. Ongoing financial constraints will limit the ability of the State and Federal governments to provide sufficient resources to deal with this unfolding health crisis. Under these circumstances it will be essential for health care providers in Maine to provide the best possible care to this aging population to minimize the morbidities and escalating costs of dementia on individuals, families, and the community. This will require early detection of cognitive decline and effective care to persons who become symptomatic with dementia.

This document is offered as a means for clinicians in Maine to provide a uniformly high standard of care for dementia. All citizens of Maine, regardless of their geographical location or financial status, can and should receive the best possible care for dementia and its sequelae. The guidelines provided here represent the most up-to-date studies and best practices in an effort to guide clinicians statewide in our effort to minimize the terrible impact of this health crisis. It is our hope that clinicians can agree to follow these guidelines and assist in their future development as new information becomes available.

A Review of Dementia

Mild cognitive impairment and dementia can be diagnosed with simple office tests and routine studies. Yet the opportunity to diagnose remains complicated by many factors including reluctance to report cognitive problems due to fear and embarrassment, a lack of sensitive and efficient office tools to assist with cognitive assessment, a confusing lexicon for dementia and the diseases that cause dementia, and therapeutic nihilism on the part of clinicians who do not feel that existing treatments are useful.

The diseases that commonly cause dementia include amyloidopathies (neuritic plaques) and/or tauopathies (neurofibrillary tangles), synucleinopathies (Lewy bodies), prionopathies (spongiform degeneration), or strokes (cerebrovascular disease). These pathological entities destroy cortical and subcortical grey matter and produce impairment in various cognitive domains depending primarily on which specific areas are damaged. Cognitive impairments usually present in patterns and these patterns, or syndromes, are identifiable in the office. The earliest signs of dementia are in the form of mild cognitive impairment and personality changes such as becoming more irritable or apathetic. When the threshold of dementia is crossed, the cognitive impairments are obvious. The final stage is the loss of abilities to independently perform basic activities of daily living such as toileting, hygiene, dressing, and eating.

Each syndrome has its own particular name or diagnosis. Thus we have Dementia of the Alzheimer Type, Frontotemporal dementia, Dementia with Lewy bodies, Progressive Aphasias, Subcortical Dementia, or Vascular Dementia. The nomenclature for these syndromes is non-uniform in that we have conditions named after people (Alzheimer, Lewy), locations of pathology (frontotemporal, subcortical, vascular), pathological findings (Lewy bodies), or symptoms (aphasias). Further confusing the picture is the fact that the syndromes are not entirely predictive of the pathologies. For instance, Dementia of the Alzheimer Type is often, but not always caused by neuritic plaques and neurofibrillary tangles (Alzheimer's disease).

The following table is a highly simplified illustration of the most common presentation for various dementia syndromes.

DEMENTIA SYNDROME	PRIMARY CLINICAL FEATURES
Dementia of the Alzheimer Type	Slowly progressive onset of memory loss plus at least one additional cognitive domain such as praxis, mathematical ability, organizational abilities, or naming problems.
Frontotemporal Dementia	Progressive degradation of functional capacity involving a loss of organizational abilities (dysexecutive variant) and/or proper social comportment (behavioral variant). Apathy and/or disinhibited aggression are common.
Dementia with Lewy Bodies	An Alzheimer or Frontotemporal type dementia occurring in the context of progressive parkinsonism. Patients often experience visual hallucinations (not to be confused with Charles Bonnet Syndrome).
Progressive Aphasias	Progressive acquisition of a Broca's or Wernicke's type aphasia in the absence of focal injury such as stroke. Patients often eventually develop a Frontotemporal Dementia syndrome.
Subcortical Dementia	Mental sluggishness and memory problems in the setting of parkinsonian signs and symptoms. Cortical cognitive functions such as language, praxis, and mathematical abilities remain intact.
Vascular Dementia	Cognitive impairment closely linked by time and location to stroke. This is often overdiagnosed in patients with other dementias who also have a history of strokes.

The task of ruling out medical causes of cognitive impairment and diagnosing specific dementia syndromes is beyond the scope of these guidelines. They are intended to serve as a template for the diagnosis and treatment of dementia syndromes of any degenerative, vascular etiology, or mixed variety.

Routine Screening for Mild Cognitive Impairment

Mild Cognitive Impairment (MCI) is the clinical term delineating the transition from normal cognition to dementia, which designates a level of severity that causes significant impairment in social or occupational functioning and represents a significant decline from a previous level of functioning. It is a pathological state that represents the earliest signs of a neurodegenerative disorder.

Most standardized office assessments of cognition are designed to diagnose dementia and not sensitive enough to confidently detect MCI. However, the symptoms of MCI, such as trouble with memory, are quite apparent to patients and their family members. Thus a simple screening question such as *“Have you noticed any changes in your (or in your parent’s) memory recently?”* actually offers value in identifying individuals at risk. Furthermore, executive cognition can decline while memory is spared. Thus a second screening question such as *“Are you (or is your parent) less well organized than in the past?”* can help identify possible incipient executive cognitive decline.

We propose that all Mainers 65 and older are asked these questions once yearly. Individuals answering in the affirmative should be followed more closely for progression of memory or any other mild cognitive symptom.

Accurate Staging of Dementia

Patients having Mild Cognitive Impairment are at high risk for progressing to dementia. By 8 years, most patients diagnosed with Mild Cognitive Impairment have declined to this level. At this point it is important to accurately track the dementia using a standardized staging tool. This will assist in planning for future needs and transitions. There are several such tools available. However, utilizing a single instrument will greatly aid efforts to monitor the prevalence of dementia and treatment outcomes statewide.

We propose that the Global Deterioration Scale (Exhibit 1) offers a simple and efficient means of tracking the severity of dementia over time and recommend that this be updated at least annually by the clinician.

Annual Cognitive Assessment

Cognition can be tracked with simple, validated instruments such as the Mini Mental State Examination. However, the most commonly used instruments do not screen all cognitive domains, resulting in false negative evaluations. This is particularly true for executive cognition, which is difficult to test in the office but is commonly impaired.

We propose that the Montreal Cognitive Assessment (Exhibit 2) offers the best balance between efficiency and sensitivity to both Dementia of the Alzheimer Type and Frontotemporal dementia syndromes. We recommend that this assessment be given at least once yearly to individuals either already identified as being at risk for dementia because of MCI or to anyone expressing concerns about cognition in the office.

It is not unusual for physicians and patients to find this to be an uncomfortable subject. Further, patients having MCI often have associated irritability and diminished frustration tolerance. This can lead to refusal to participate in the examination. The following are some hints and statements that may make it easier to accomplish this goal with more challenging patients:

“I’d like to test your attention and memory now.”

It is best not to comment on how odd or easy the questions are in case the patient struggles with them. Simply interact with them in a positive manner and tell them they are doing fine and putting in a good effort.

“It looks like your memory is not as reliable as it used to be.”

“We should follow this. You have plenty of memory function left and we should protect it from getting worse over time.”

“There are some things you can do, including lifestyle changes and medications that can protect your memory.”

Treatment of Cognitive Decline

Patients and families consistently identify dementia as a condition that is best managed by a physician. The cognitive protective agents are but one part of a holistic treatment of dementia that encompasses biological, psychological, and social aspects of the disease process. Evidence has shown that engaging in physical activity such as exercise, social activities, and intellectual activities can be beneficial for patients with dementia.

A recent review has shown modest benefit from approaches that provide cognitive stimulation to people with dementia. Cognitive stimulation is an intervention for people with dementia which offers a range of enjoyable activities providing general stimulation for thinking, concentration and memory usually in a social setting, such as a small group.

Clinicians are aware of the evidence based treatments for stroke prevention. However, there are currently no cures for the causes of cortical degenerative dementia. Evidence-based treatments do exist for blunting the inevitable cognitive decline with cholinesterase inhibitors such as donepezil, galantamine, and rivastigmine, along with the NMDA receptor partial antagonist memantine. These reviews are available online at www.cochrane.org.

The three cholinesterase inhibitors are efficacious for mild to moderate Alzheimer's disease. Despite the slight variations in the mode of action of the three cholinesterase inhibitors there is no evidence of any differences between them with respect to efficacy. The evidence from one large trial shows fewer adverse events associated with donepezil compared with rivastigmine.

Memantine is a well-tolerated drug that has been shown to be efficacious for moderate-to-severe Alzheimer's disease. This drug can be combined with cholinesterase inhibitors at this stage of the disease.

Annual Functional Status Assessment

Tracking functional levels helps clinicians assess the patient's current and evolving needs for support in the home while also identifying safety concerns. We recommend the Katz Index of Independence in Activities of Daily Living (Exhibit 3) as a simple and useful tool that should be completed at least annually or any time the clinician suspects functional changes have occurred.

Annual Neuropsychiatric Symptom Assessment

Psychiatric sequelae are common and distressing aspects of dementia. These symptoms present safety risks to both patients and caregivers and are a major cause of caregiver burnout and need for placement at higher levels of care. Patients experiencing these symptoms have poor quality of life. It is imperative to carefully identify the presence of neuropsychiatric symptoms and to treat them effectively.

The Neurobehavioral Rating Scale (Exhibit 4) is a validated and thorough instrument that can identify and classify undesirable psychiatric symptoms and can direct the initiation and monitoring of effective treatment. We recommend that this instrument be completed at least annually or any time the physician identifies neuropsychiatric symptoms. The instrument should be used to track the severity of target symptoms to assess the efficacy of the treatment.

Management of Neuropsychiatric Symptoms

There are unfortunately very few acceptable studies for treatment of neuropsychiatric symptoms in dementia. Unless the patient or caregiver is endangered by the symptoms, the initial intervention should always be non-pharmacological. Such interventions include such measures as optimizing sleep, adequately treating pain, providing proper social, physical, and intellectual stimulation, and ruling out constipation or urinary tract infections.

When these measures are not completely successful or a safety issue exists, then pharmacological measures should be initiated. The Cochrane library contains useful reviews of various medications trials in the setting of dementia. These reviews are available online at www.cochrane.org.

As a general rule, it is best to avoid benzodiazepines such as lorazepam (Ativan), alprazolam (Xanax), or diazepam (Valium). These agents interfere with gait and cause excessive sedation and confusion. There are no published reviews of the benzodiazepine class and thus these are not evidence-based treatments. First generation antipsychotics such as haloperidol (Haldol) or thioridazine (Mellaril) should also be avoided due to an increased risk of mortality in the absence of adequate evidence of efficacy. These drugs also cause Parkinsonism and akathisia, or motor restlessness, further complicating the clinical picture.

The serotonin-specific reuptake inhibitors (SSRI) sertraline 25-200 mg and citalopram 20-30 mg were associated with a reduction in symptoms of agitation when compared to placebo in two studies. One study of trazodone compared to placebo showed no difference in outcome. Both SSRI's and trazodone appear to be tolerated reasonably well when compared to placebo, typical antipsychotics, and atypical antipsychotics.

Should treatment with sertraline or citalopram not succeed then atypical antipsychotics are an appropriate second line choice. Sixteen placebo-controlled trials have been completed with atypical antipsychotics although only nine had sufficient data to contribute to a meta-analysis and only six have been published in peer reviewed journals. There was a significant improvement in aggression with risperidone 0.5-2.0 mg and olanzapine 5-10 mg treatment compared to placebo. There was a significant improvement in psychosis among risperidone 0.5-2.0 mg treated patients.

The overall odds ratio for deaths in patients treated with atypical antipsychotic drugs compared with placebo was 1.54. However, the mortality risks of first generation antipsychotic drugs is even higher and thus atypical antipsychotic medications represent an improvement in risk from the traditional use of first generation drugs.

At this time valproate preparations are ineffective in treating agitation among demented patients. Valproate therapy is associated with an unacceptable rate of adverse effects. On the basis of current evidence, valproate therapy cannot be recommended for management of agitation in dementia.

Annual Screening for Depression

Depression is an illness that remains underdiagnosed and undertreated in the elderly. The elderly tend to display more disturbances in sleep, appetite, and cognitive disturbances than younger individuals. They also tend to report less subjective dysphoria. Thus the diagnosis is often missed. In general, the treatment of depression is similar to that for younger patients. While there may be some increased sensitivity to side effects, there is no evidence that elderly patients respond adequately to lower doses of antidepressant medication.

The Cornell Depression Scale (Exhibit 5) is a logical and efficient rating instrument for depression in the elderly that is recommended for annual screening for depression.

Safety Counseling

As dementia progresses, the home environment often presents safety hazards or impedes the ability to perform activities of daily living. Families should be advised regularly on these issues. When appropriate, a home safety evaluation can be arranged through the local providers of Home Health Services. These agencies are listed at www.maine.gov/dhhs/oes/home_care/home-health.html.

Safety concerns include:

- Fall risk
- Financial management
- Aggression
- Access to firearms or other weapons
- Being left alone
- Driving
- Suicidality
- Medication management
- Fire hazard from cooking or smoking
- Wandering
- Access to hazardous materials
- Inability to respond rapidly to emergencies
- Operation of hazardous equipment
- Abuse or neglect

Families can be directed to the Alzheimer's Association website for helpful safety information at www.alz.org/safetycenter/we_can_help_safety_center.asp.

Driving Risk Counseling

Patients and their caregivers should prepare for the likelihood of driving cessation as dementia severity increases. Even mild dementia increases the risk of motor vehicle accidents. Physicians should inquire at least annually about any driving concerns or issues. Caregiver appraisals are more useful than patient's self-ratings.

The American Medical Association, acting in concert with the National Highway Traffic Safety Administration, has developed the *Physician's Guide to Assessing and Counseling Older Drivers*. This useful document is available at:

www.ama-assn.org/ama/pub/physician-resources/public-health/promoting-healthy-lifestyles/geriatric-health/older-driver-safety/assessing-counseling-older-drivers.page?

Maine physicians can file a Certificate of Examination with the Medical Review Coordinator at the Bureau of Motor Vehicles in Augusta. This report can be filed if the physician has concerns as to the possibility that the patient's ability to drive a motor vehicle safely is compromised by dementia. A physician acting in good faith is immune from any damages claimed as a result of the filing of a certificate of examination pursuant to 29-A MRSA Section 1258 (6). This form can be downloaded as a PDF File from this web address: www.maine.gov/sos/bmv/forms/CR24.pdf.

End of Life Counseling and Advance Care Planning

Aggressive medical treatment for patients with advanced dementia is expensive and often ineffective. It wastes limited resources and can cause unnecessary suffering.

Advance care directives should be established early enough in the course of the dementia to permit the patient to participate in a meaningful manner. The care plan should address preferences for survival, maintenance of function, and comfort. A healthcare surrogate should be designated.

Maine physicians are encouraged to complete a Physicians Orders for Life Sustaining Treatments (POLST) form that will coexist with advance directives. A POLST form is a set of medical orders, which is based on a patient's preferences for care and is signed by the patient's healthcare provider. It follows a patient across settings of care. POLST complements conventional advance directives that may not anticipate specific treatment options that may arise and may not be readily translated into orders. A POLST form can be downloaded at <http://www.mehca.org/QualityRegs/Maine%20POLST%204-15-09%20final.pdf>.

The National Hospice and Palliative Care Organization provides useful resources and information on end-of-life care at www.caringinfo.org.

Caregiver Education and Support

The vast majority of patients with dementia are cared for at home by family members. Studies have shown that greater caregiver knowledge of dementia management was associated with higher care quality. However, the role and responsibility of being a caregiver is associated with significant mental and physical health risks. Caregivers should thus be well informed about basic principles of care including:

- Recognizing declines in capacity and adjusting expectations appropriately.
- Bringing sudden declines in function and emergence of new symptoms to the attention of the clinician.
- Keeping requests and demands on the patient relatively simple.
- Deferring requests if the patient becomes agitated.
- Not confronting the patient about their deficits.
- Remaining calm, firm, and supportive with redirection.
- Being consistent.
- Providing frequent reminders, explanations, and orientation.

We recommend the AMA Caregiver Tool as a readily accessible, easily administered rating scale for caregiver burden. It can be accessed at www.ama-assn.org/resources/doc/public-health/caregiver_english.pdf.

Diagnosis & Treatment: Exhibit 1

GLOBAL DETERIORATION SCALE

NAME:

MRN:

DATE:

Stage 1. No cognitive decline

Clinical: Patients appear normal; they have no complaints of memory deficits, and a clinical interview does not elicit evidence of memory deficit.

Neuropsychologic: Memory test scores are average or above for the patient's age.

Stage 2. Very mild cognitive decline.

Clinical: This is the phase of forgetfulness. The patient complains of forgetting names and misplacing objects and is appropriately concerned about symptoms. There is no evidence of memory deficit in the clinical interview and no objective evidence of deficits in employment or social situations.

Neuropsychologic: The patient performs below average for age.

Stage 3. Mild cognitive decline

Clinical: Memory deficits are evident during an intensive interview by a knowledgeable examiner. The patient forgets names of people recently met and may retain little information read from a book. Decreased performance is evident in work and social situations. The patient may become lost in unfamiliar surroundings. Denial of symptoms and anxiety may be present.

Neuropsychologic: Patients may still be fully oriented, but on memory tests they score at least one standard deviation below the performance predicted by their age.

Stage 4. Moderate cognitive decline

Clinical: Deficits are obvious during the clinical interview. Abnormalities are evident in serial subtraction, knowledge of history and recent events, and personal history. Independent travel and management of personal finances curtailed. Familiar faces are recognized and the patient remains oriented in familiar surroundings. Denial and withdrawal from challenging situations is evident.

Neuropsychologic: Errors are evident on standard orientation questions.

Stage 5. Moderately severe cognitive decline

Clinical: Patients can no longer recall relevant personal information (address, telephone number, names of family members, high school or college where they were educated). Patients know their own names and may know their spouse's name. No help is needed in toileting or eating. Assistance may be required in choosing clothes and dressing.

Neuropsychologic: Errors are evident on standard mental status questionnaire (e.g., MMSE).

Stage 6. Severe cognitive decline

Clinical: Patients may forget the name of their spouse and are unaware of all recent events and experiences in their lives. Patients are disoriented and disturbances of diurnal rhythm may occur. They may be unable to distinguish familiar and unfamiliar individuals. Delusions, repetitive behaviors, or anxiety may be evident.

Neuropsychologic: Patients miss approximately half of the questions on a standard mental status questionnaire.

Stage 7. Very severe cognitive decline

Clinical: All coherent verbal abilities are lost. The patients are incoherent and require assistance in toileting and eating. They may be unable to walk.

Neuropsychologic: Patients are able to answer few or none of the questions on a standard mental status questionnaire.

Diagnosis & Treatment: Exhibit 2

MONTREAL COGNITIVE ASSESSMENT (MOCA)
Version 7.1 Original Version

NAME : _____
Education : _____ Date of birth : _____
Sex : _____ DATE : _____

VISUOSPATIAL / EXECUTIVE							POINTS		
		Copy cube	Draw CLOCK (Ten past eleven) (3 points)			_____/5			
NAMING									
						_____/3			
MEMORY	Read list of words, subject must repeat them. Do 2 trials, even if 1st trial is successful. Do a recall after 5 minutes.	[]	FACE	VELVET	CHURCH	DAISY	RED	No points	
		1st trial							
		2nd trial							
ATTENTION	Read list of digits (1 digit/ sec.).	Subject has to repeat them in the forward order			[]	2 1 8 5 4			
		Subject has to repeat them in the backward order			[]	7 4 2		_____/2	
Read list of letters. The subject must tap with his hand at each letter A. No points if ≥ 2 errors		[] FBACMNAAJKLBFAFAKDEAAAJAMOF AAB					_____/1		
Serial 7 subtraction starting at 100		[]	93	[]	86	[]	79	[]	
		[]	72	[]	65	4 or 5 correct subtractions: 3 pts , 2 or 3 correct: 2 pts , 1 correct: 1 pt , 0 correct: 0 pt		_____/3	
LANGUAGE	Repeat : I only know that John is the one to help today. []								
		The cat always hid under the couch when dogs were in the room. []							_____/2
Fluency / Name maximum number of words in one minute that begin with the letter F		[] _____ (N ≥ 11 words)					_____/1		
ABSTRACTION	Similarity between e.g. banana - orange = fruit [] train - bicycle [] watch - ruler							_____/2	
DELAYED RECALL	Has to recall words WITH NO CUE	FACE	VELVET	CHURCH	DAISY	RED	Points for UNCUED recall only	_____/5	
		[]	[]	[]	[]	[]			
Optional	Category cue								
		Multiple choice cue							
ORIENTATION	[] Date [] Month [] Year [] Day [] Place [] City							_____/6	
© Z.Nasreddine MD		www.mocatest.org			Normal ≥ 26 / 30		TOTAL	_____/30	
Administered by: _____		Add 1 point if ≤ 12 yr edu							

Diagnosis & Treatment: Exhibit 3

Katz Index of Independence in Activities of Daily Living

Activities Points (1 or 0)	Independence (1 Point) NO supervision, direction or personal assistance	Dependence (0 Points) WITH supervision, direction, personal assistance or total care
BATHING Points: _____	(1 POINT) Bathes self completely or needs help in bathing only a single part of the body such as the back, genital area or disabled extremity	(0 POINTS) Need help with bathing more than one part of the body, getting in or out of the tub or shower. Requires total bathing
DRESSING Points: _____	(1 POINT) Get clothes from closets and drawers and puts on clothes and outer garments complete with fasteners. May have help tying shoes.	(0 POINTS) Needs help with dressing self or needs to be completely dressed.
TOILETING Points: _____	(1 POINT) Goes to toilet, gets on and off, arranges clothes, cleans genital area without help.	(0 POINTS) Needs help transferring to the toilet, cleaning self or uses bedpan or commode.
TRANSFERRING Points: _____	(1 POINT) Moves in and out of bed or chair unassisted. Mechanical transfer aids are acceptable	(0 POINTS) Needs help in moving from bed to chair or requires a complete transfer.
CONTINENCE Points: _____	(1 POINT) Exercises complete self control over urination and defecation.	(0 POINTS) Is partially or totally incontinent of bowel or bladder
FEEDING Points: _____	(1 POINT) Gets food from plate into mouth without help. Preparation of food may be done by another person.	(0 POINTS) Needs partial or total help with feeding or requires parenteral feeding.

Total Points: _____

Score of 6 = High, Patient is independent.

Score of 0 = Low, patient is very dependent.

**Slightly adapted. Katz S., Down, TD, Cash, HR, et al. (1970) progress in the development of the index of ADL. *Gerontologist* 10:20-30. Copyright The Gerontological Society of America. Reproduced by permission of the publisher.

Diagnosis & Treatment: Exhibit 4

NEUROBEHAVIORAL RATING SCALE

1 Not present

3 Mild

5 Moderately severe

7 Extremely severe

2 Very mild

4 Moderate

6 Severe

Inattention/Reduced alertness

1 2 3 4 5 6 7

fails to sustain attention, easily distracted; fails to notice aspects of environment, difficult directing attention, decreased alertness

Somatic concern

1 2 3 4 5 6 7

volunteers complaints or elaborates about somatic symptoms (e.g. headache, dizziness, blurred vision), and about physical health in general

Disorientation

1 2 3 4 5 6 7

confusion or lack of proper association for person, place, or time

Expressive Deficit

1 2 3 4 5 6 7

word finding disturbance, anomia, pauses in speech, effortful and agrammatic speech, circumlocution

Emotional Withdrawal

1 2 3 4 5 6 7

lack of spontaneous interaction, isolation, deficiency in relating to others

Conceptual Disorganization

1 2 3 4 5 6 7

thought processes confused, disconnected, disorganized, disrupted; tangential social communication, perseverative

Disinhibition

1 2 3 4 5 6 7

socially inappropriate comments and/or actions, including aggressive/sexual content, or inappropriate to the situation, outbursts of temper

Guilt Feelings

1 2 3 4 5 6 7

self-blame, shame, remorse for past behavior

Memory Deficit

1 2 3 4 5 6 7

difficulty learning new information, rapidly forgets recent events, although immediate recall (forward digit span) may be intact

Agitation

1 2 3 4 5 6 7

motor manifestations of overactivation (e.g. kicking, arm flailing, picking, roaming, restlessness, talkativeness)

Inaccurate Insight & Self-appraisal

1 2 3 4 5 6 7

poor insight, exaggerated self-opinion, overrates level of ability and underrates personality change in comparison with evaluation of clinicians and family

Depressive Mood

1 2 3 4 5 6 7

sorrow, sadness, despondency, pessimism

Hostility/uncooperativeness <i>animosity, irritability, belligerence, disdain for others, defiance of authority</i>	1 2 3 4 5 6 7
Decreased Initiative/Motivation <i>lacks normal initiative in work or leisure, fails to persist in tasks, is reluctant to accept new challenges</i>	1 2 3 4 5 6 7
Suspiciousness <i>mistrust, belief that others harbor malicious or discriminatory intent</i>	1 2 3 4 5 6 7
Hallucinatory Behavior <i>perceptions without normal external stimulus correspondence</i>	1 2 3 4 5 6 7
Fatiguability <i>rapidly fatigues on challenging cognitive tasks or complex activities, lethargic</i>	1 2 3 4 5 6 7
Motor Retardation <i>slowed movements or speech (excluding primary weakness)</i>	1 2 3 4 5 6 7
Unusual Thought Content <i>unusual, odd, strange, bizarre thought content</i>	1 2 3 4 5 6 7
Blunted Affect <i>reduced emotional tone, reduction in normal intensity of feelings, flatness</i>	1 2 3 4 5 6 7
Excitement <i>heightened emotional tone, increased reactivity</i>	1 2 3 4 5 6 7
Poor Planning <i>unrealistic goals, poorly formulated plans for the future disregards prerequisites (e.g. training), fails to take disability into account</i>	1 2 3 4 5 6 7
Lability of Mood <i>sudden change in mood which is disproportionate to the situation</i>	1 2 3 4 5 6 7
Tension <i>postural and facial expression of heightened tension, without the necessity of excessive activity involving the limbs or trunk</i>	1 2 3 4 5 6 7
Comprehension Deficit <i>difficulty in understanding oral intake instructions on single or multistage commands</i>	1 2 3 4 5 6 7
Speech Articulation Deficit <i>misarticulation, slurring or substitution of sounds which affect intelligibility (rating is independent of linguistic content)</i>	1 2 3 4 5 6 7

TOTAL _____

Diagnosis & Treatment: Exhibit 5

CORNELL DEPRESSION SCALE

NAME:

MRN:

DATE:

Scoring System: **a** = unable to evaluate **0** = absent **1** = mild to intermittent **2** = severe

Ratings should be based on signs and symptoms occurring during the week prior to the interview. No score should be given if symptoms result from physical disability.

A. Mood-Related Signs

- | | | | | |
|--|---|---|---|---|
| 1. ANXIETY
<i>anxious expression, ruminations, worrying</i> | a | 0 | 1 | 2 |
| 2. SADNESS
<i>sad expression, sad voice, tearfulness</i> | a | 0 | 1 | 2 |

B. Behavioral Disturbance

- | | | | | |
|---|---|---|---|---|
| 1. LACK OF REACTIVITY TO PLEASANT EVENTS | a | 0 | 1 | 2 |
| 2. IRRITABILITY
<i>easily annoyed, short-tempered</i> | a | 0 | 1 | 2 |
| 3. AGITATION
<i>restlessness, hand-wringing, hair pulling</i> | a | 0 | 1 | 2 |
| 4. RETARDATION
<i>slow movements, slow speech, slow reactions</i> | a | 0 | 1 | 2 |
| 5. MULTIPLE PHYSICAL COMPLAINTS
<i>(score 0 if GI symptoms only)</i> | a | 0 | 1 | 2 |
| 6. LOSS OF INTEREST
<i>less involved in usual activities within past 4 weeks</i> | a | 0 | 1 | 2 |
| 7. APPETITE LOSS
<i>eating less than usual</i> | a | 0 | 1 | 2 |
| 8. WEIGHT LOSS
<i>(score 2 if greater than 5 lbs. in one month)</i> | a | 0 | 1 | 2 |
| 9. LACK OF ENERGY
<i>fatigues easily, unable to sustain activities within past 4 weeks</i> | a | 0 | 1 | 2 |

C. Cyclic Functions

- | | | | | |
|---|---|---|---|---|
| 1. DIURNAL VARIATION OF MOOD
<i>symptoms worse in the morning</i> | a | 0 | 1 | 2 |
| 2. DIFFICULTY FALLING ASLEEP
<i>later than usual</i> | a | 0 | 1 | 2 |
| 3. MULTIPLE AWAKENINGS DURING SLEEP | a | 0 | 1 | 2 |
| 4. EARLY MORNING AWAKENING
<i>earlier than usual for this individual</i> | a | 0 | 1 | 2 |

D. Ideational Disturbance

- | | | | | |
|--|---|---|---|---|
| 1. SUICIDE
<i>feels like life not worth living, suicidal ideas, suicide attempt</i> | a | 0 | 1 | 2 |
| 2. SELF-DEPRECIATION
<i>self-blame, poor self-esteem, feelings of failure</i> | a | 0 | 1 | 2 |
| 3. PESSIMISM
<i>anticipation of the worst</i> | a | 0 | 1 | 2 |
| 4. MOOD-CONGRUENT DELUSIONS
<i>delusions of poverty, illness, or loss</i> | a | 0 | 1 | 2 |

Score _____

V. HOME- AND COMMUNITY-BASED SERVICES

A. Quality service delivery in dementia-capable communities

Approximately 147,000 Alzheimer's and dementia unpaid caregivers in Maine provide care valued at over \$900 million in our state. Caregivers report experiencing high levels of stress due to the emotional toll and financial burden of providing quality care. Long-term care and support for people living with Alzheimer's is demanding, and caregivers often put their own health and well-being at risk in order to provide for their loved ones. Many caregivers tell us that they need help to continue providing care safely at home.



Caregivers, including those living with Alzheimer's and caring for themselves, are often challenged with getting the information they need on what to expect after a diagnosis. Many families receiving a diagnosis leave their doctor's office without adequate preparation. They have unanswered questions on where to learn more about Alzheimer's, what is needed to provide proper care and what steps to take in order to prepare for the changes they will face. Without appropriate guidance and with little to no information, most people, many of whom have never accessed the system before, have to set out on their own to identify critical services they don't even know they'll need yet. This is a challenge for all, but can be

particularly difficult for those in rural areas where resources are limited. Many caregivers describe their frustration with trying to learn to navigate a complex health care system and put together a care plan for a loved one without a road map or guidance while taking care of the individual at the same time.

Adding to caregivers' confusion is the unpredictable duration of Alzheimer's disease. There's no concrete timeline as to how stages will progress, which makes it difficult for caregivers to know what to expect from day to day and month to month. On average, a person 65 or older lives with Alzheimer's four to eight years but can live as long as 20 years. The prolonged duration of Alzheimer's places increasingly intense demands on the family members and friends who provide care. Consequently, people living with Alzheimer's disease and their caregivers face a long, challenging road of questions, financial burden and emotional distress.

To counter the confusion and stress of dealing with Alzheimer's, people with the disease and their caregivers benefit from education on Alzheimer's disease. Caregivers and families need information on the types of quality supportive services available in their communities. Caregivers have also expressed the expectation that their physicians and health care providers would provide information on where to get additional help. (*See also Diagnosis and Treatment plan section*).

In collaboration with more than 30 prominent national organizations, including all major care industry groups, the national Alzheimer's Association's Quality of Care Campaign focuses on the dual goals of enhancing quality of life for individuals with dementia and improving the quality of care they receive. The Association has released the evidence-based dementia care practice recommendations in four phases, three for assisted-living facilities and nursing homes and one for home-based care. Many consider these to be "the gold standard" for use by caregivers and providers as they evaluate and seek to improve dementia care. (*See "Dementia Care Practices Recommendations for Professionals Working in a Home Setting" online at http://www.alz.org/professionals_and_researchers_dementia_care_practice_recommendations.asp*)

Many individuals living with Alzheimer's express the desire to live at home as long as safely possible. However, they and family members describe how barriers to accessible, affordable, quality home and community services that support independence and long-term care at home often force those with Alzheimer's into facility care settings sooner than wanted or needed.

Maine is challenged by a shortage of affordable and accessible respite care and adult day center services. Caregiving at home is an around-the-clock job. Respite care provides a safe, temporary break from daily caregiving responsibilities and can strengthen a caregiver's ability to continue home care for a loved one with Alzheimer's. Respite care services can be brought into the home or found outside the home in the form of adult day centers, which also offer social interaction, structured activities and other services for individuals with Alzheimer's who might otherwise be confined to the safety of their homes and isolated for periods of time. Unfortunately, in many communities respite and adult day services may not be available, or may be too far away to be practical. This is problematic, not only due to the increased expense associated with facility settings that individuals may end up entering before they wish or need to, but also due to the shortage of open slots. Continued work on infrastructure expansion and overcoming barriers to access is needed.



Maine people with dementia and their families are eager for solutions to develop a coordinated and more easily accessible system of care in our state. It would be ideal to have access to the spectrum of needed home and community-based supportive services, acute care, specialty care and long-term care in or nearby the communities in which people live. Although this may not always be possible, Maine does need to explore efficient integrated approaches to the provision of dementia care. Given the number of low-income elders in our state, it is also essential that solutions that are developed and invested in be federally compliant and Medicaid-eligible, sustainable and inclusive. There is a lack of adequate services, particularly in rural Maine, where there are problems with both the breadth of services available to support a continuum of care for people with dementia and their families, as well as a depth of services where capacity is lacking to meet the needs of the population.

In some cases, services (both community-based social services as well as conventional medical care) are available in some regions of Maine but travel and cost can be problematic or interfere with family caregivers' schedules and ability to work. The lack of adequate public transportation for individuals and families, the need for affordable senior housing with dementia-informed staff, and the need to increase capacity of the adult day system are also shortcomings of the existing dementia care infrastructure.

As there are multiple portals to dementia-related support services, a common desire expressed by family caregivers is for a system that triages cases while providing timely information so families are not left to guess about available services, resources and support that will assist them in preparing for not only current needs, but future needs based on disease progression.

Diverse communities also face an additional challenge in accessing services. The pervasive misunderstanding that Alzheimer's disease is a "normal part of aging" regrettably rings especially true in ethnic and minority populations. A better understanding of the importance of language and cultural beliefs can assist older adults affected by Alzheimer's from these diverse communities in Maine. Among the challenges that ethnic and minority populations face are the lack of



awareness of the disease and the stigma still associated with Alzheimer's and related dementias. While these issues exist for all living with Alzheimer's, cultural norms and values can keep members of diverse communities from seeking and obtaining outside assistance. These, in turn, make increasing awareness and delivering services especially difficult among ethnic and minority groups. Ethnic or cultural differences can also compound barriers to addressing the care needs of those diagnosed with Alzheimer's disease. While it can be challenging for everyone to identify resources about Alzheimer's disease and care management needs, it can be even more difficult for individuals who face additional challenges accessing our health care system.

Those living with Alzheimer's disease and related dementias are extremely vulnerable to exploitation. Financial, physical or emotional abuse is a concern in Maine as it is in other states across the country. State agencies such as Adult Protective Services respond to reports, and assess and assist in resolving alleged abuses that can occur in the home, community, or facilities. Additionally, the Maine Long-Term Ombudsman Office and other advocates can help address issues related to potential abuse and neglect. There are opportunities to expand outreach in this area of shared concern utilizing home- and community-based care level channels.

B. Cost to families

One of the biggest challenges for people living with Alzheimer's and their caregivers is the financial burden of care. This includes the costs of treatments, doctor visits, custodial care services, respite services and facility-based care. Every stage of the disease has costs associated with it that can become difficult to manage over time.

Cost of services significantly contributes to the issue of overall access. Services that are partially covered or not covered through insurance policies or the state present barriers. It is difficult for Maine people and represents a significant commitment of time to navigate the channels of payment and reimbursement systems. Many caregivers experience a significant economic impact on themselves when circumstances require them to leave a full-time job to take care of a loved one. The second significant barrier to access is the availability of services. After individuals become informed of available services, they often find obtaining and maintaining the continuity of these services an even bigger challenge.

People living with Alzheimer's disease often rely heavily on government programs such as Medicare and Medicaid to mitigate these costs. Unfortunately, too often Medicare and Medicaid are inadequate, and the overwhelming costs of this disease exceed available personal funds, leaving families affected by Alzheimer's in the difficult position of having to balance sufficient care for their loved ones without impoverishing themselves.

In-home support and community-based day services can range widely depending on needs, services and providers. Professional home health aide private-pay hourly rates in Maine range from a low of \$19 per hour to a high of \$30 per hour. "Homemaker" or companion private-pay hourly rates in the state range from a low of \$16 per hour to a high of \$30 per hour. Private-pay adult day services in Maine range from a low of \$51 per day to a high of \$165 per day. (Source: *Market Survey of Long-Term Care Costs: The 2011 MetLife Market Survey of Nursing Home, Assisted Living, Adult Day Services and Home Care Costs.*)



An overwhelming number of people who live at home or maintain in-home care requested additional home health services through Medicare. Medicare currently offers in-home health coverage to homebound individuals for skilled services such as nursing care or physical therapy. However, families affected by Alzheimer's disease currently must pay out of pocket for personal care support at home or in a nursing facility, the costs of which mount over time. Many people described assistance with custodial care such as bathing or dressing a loved one as an immediate need, particularly for caregivers who have other full-time commitments or who need help with the physical aspects of caregiving.

The prolonged duration of Alzheimer's places increasingly intense demands on family members and friends who provide care. Over time, many families become too overwhelmed with the physical and emotional requirements of providing care and are forced to seek the type of round-the-clock care that can only be found in facilities. These families learn that costs for these types of facilities can quickly deplete financial resources and become unaffordable. Medicaid is the only federal program that covers long nursing home stays, but beneficiaries must be financially and medically eligible to receive coverage. For some people, the challenge of finding affordable facility care that adequately meets the needs of individuals with Alzheimer's is insurmountable.

Government programs, such as Medicaid or Veterans Administration benefits, provide additional avenues of financial assistance. However, people affected by Alzheimer's disease and their caregivers face barriers in meeting eligibility criteria. For example, many people who seek Medicaid assistance to help with the costs of caregiving find income constraints related to the coverage gap problematic. The strict guidelines for Medicaid require individuals with Alzheimer's to "spend down" most of their income, assets or both in order to qualify for assistance. The lengthy and complicated process for requesting government assistance can be a barrier to access as well. Family members commonly describe frustration with the process because they may be unaware of all of the steps involved, the need to fill out a variety of forms, and the wait time for a response.

Despite the financial strain and barriers to access, some are able to navigate this process successfully and benefit from home- and community-based programs that alleviate the burden of caregiving and keep loved ones with Alzheimer's at home—programs that could help others if they were expanded.



HOME- AND COMMUNITY-BASED SERVICES RECOMMENDATIONS

Goal: All Mainers impacted by Alzheimer's disease and related dementias have equitable access to care in dementia-capable communities through a variety of quality home- and community-based service options that meet their unique needs.

Objective: The home- and community-based infrastructure and systems of care in Maine should be expanded and enhanced to provide quality, accessible, coordinated, affordable services to meet a growing population of those living with Alzheimer's disease and related dementias and their caregivers.

Strategies:

1. **Critical to achieving this objective, it is essential that the strategies outlined in Section III of this plan related to Public Awareness, Public Health & Safety be implemented.**
2. **Identify best practices in home care** such as the Alzheimer’s Association’s “Dementia Care Practice Recommendations for Professionals Working in a Home Setting” (See http://www.alz.org/professionals_and_researchers_dementia_care_practice_recommendations.asp) which provides evidence-based best practice recommendations for medical and non-medical care. Ensure that care quality is measured accurately and that quality improvement tools are implemented. Educate family members about best practices.
3. **Develop a state public recognition program to enable consumer choice of home- and community-based provider based on quality.** Include a system of certification and incentive-based options or rewards for dementia competency, including dementia care that is culturally competent.
4. **Ensure Alzheimer’s disease and related dementias are identified as one of the chronic conditions under the Affordable Care Act and other funding sources’ criteria that are used to identify people eligible for services, including home health services.** Develop guidelines for medical homes and community health teams in the assessment, diagnosis, and support of people with dementia and their families — including training for medical homes on availability of community supports; caregiver resources; and use of/development of practice based care coordinators who are focused specifically on needs of people with dementia.
5. **Create a “Maine Dementia-Capable Community” standard of excellence program:**
 - Develop a workable definition of “Dementia-Capable Community” and create and disseminate a list of key elements a community should have to support those with Alzheimer’s and their caregivers.
 - Outreach to municipalities to urge Maine communities to adapt this list for their use.
 - Create “action kits” for communities that help them assess their status and progress toward developing these key elements.
6. **Develop, enhance and improve the variety and supply of formal and informal supports for caregivers of persons with Alzheimer’s,** including supports appropriate for elders and their caregivers in ethnic, immigrant and tribal communities.
7. **Support, fund and promote increased broadband coverage across the entire state** that will enable alternative models of peer, informational, and educational support to be accessible to every home in Maine to reach remote and/or mostly homebound family caregivers using 21st technology mediums including telephone and online support methods, telemedicine, video conferencing, Maine Library Services and other forms of remote communications and outreach.
8. **Conduct a gap analysis to identify existing and new opportunities to enhance and adequately fund state policies and programs regarding benefits and subsidies to family caregivers,** which promote active involvement of families in dementia care. These incentives can be in the form of monetary incentives, tax incentives, health care coverage or deferred income incentives (retirement) as well as non-monetary incentives such as eligibility to obtain counseling and support for family caregivers through state or locally sponsored programs.



9. **Conduct a gap analysis to identify existing and new opportunities to enhance and adequately fund state policies and programs regarding subsidies for adult day programs** (for example, Partners in Caring) similar to those for child care settings, which support, enable and supplement active caregiving by families and friends in order to encourage the ability to sustain home-based care, which is more cost-effective than residential-based alternatives. Diverse funding stream sources should be considered and evaluated to reflect the needs of a growing population, with emphasis on early intervention strategies and offering families options and choices appropriate to the unique care needs of individuals living with the disease.

10. **Identify and promote the adoption of flexible, innovative respite care programs that respond to the diverse and changing needs of people with dementia and their families.**

11. **Enhance existing and explore new innovative, user-friendly models that would further develop the infrastructure to care for people with dementia in collaboration with specialists and primary care providers.** For example, regional organizations designated as dementia care networks could include designated social service agencies, AAAs, adult day centers or other regional dementia care providers or centers. Evaluation of models considered should include the opportunity to hear and learn from other states and/or communities who have practicing models in place and those who are receiving services.

12. **Explore models of community-based care that would offer multidisciplinary care coordination capabilities and improve capacity and access to community or home-based care services for all Mainers who need it.** Care coordination should include the significantly growing population of those with dementia, the choice to age and receive care “in place,” and offer individuals and families informed options early in the process related to home, community, residential and nursing home environments, as well as hospitals and hospice programs, and such as the Program of All-Inclusive Care for the Elderly (PACE), and Support and Services at Home (SASH). Similarly, explore whether there are models tailored to rural areas utilizing nursing homes or other community centers where day care could be offered to accommodate local needs if funding and rules permitted. Regularly evaluate existing and new home- and community-based service delivery models to identify and promote best practices to foster replication and innovation to meet emerging needs.



13. **Support access to dementia care for rural and remote regions of Maine through the development of regional care teams** that provide for the evaluation, consultation, specialty care and outreach through a hub and spokes model, such as coordinating services between regional dementia centers and Area Agencies on Aging.

14. **Support, fund and promote the expansion of increased access to geriatric and neuropsychiatric care through telemedicine, video conferencing and internet-based consultation** in cases that are clinically appropriate. In addition to expanding capacity to enable those who could utilize the technology to do so, also identify and support those who already have the capability to expand reach.

15. **Work with municipalities to increase statewide the availability of dementia-informed transportation services** through assisted transportation and improved integration and coordination of public and social service transportation.

16. **Collaborate with state agencies, nursing homes and home and community-based providers to increase the capacity of the long-term care system to serve people with severe neuropsychiatric symptoms associated with**

dementia. Increased capacity includes specially trained staff using evidence-based models of dementia-informed care and services.

17. **Improve safety of people with dementia and the general public** through the implementation of education and safety programs for older drivers.
18. **Improve the coordination and delivery of care** by emphasizing strong links and relationships between medical, mental health, other home- and community-based services, long-term care facilities, EMS and other health care agencies. This should include working with regional medical centers and community hospitals to improve assessment, referral and care coordination for people with dementia who are treated in emergency departments.
19. **Work with hospital systems to enhance inpatient programs to become fully dementia-capable for both neuro psychiatric and medical admissions** and to improve hospital-based care management services to assist in care coordination for people with dementia, in ambulatory care, hospital and community settings, including home health, rehabilitation, residential and nursing homes. Educate hospitals about the special needs of patients with dementia to inform hospital policies and procedures so that hospitals are both well prepared to serve people with dementia and to ensure effective transitions back into the community.
20. **Support care transitioning programs which help patients move from one health care setting to another:** For example from hospital to home or to a long-term care facility. A primary cause of hospital readmission can be linked to poorly coordinated transitions when patients do not know specific care instructions and cannot easily follow treatment recommendations and/or when individuals are not ready to move to a new setting. Care transitioning programs offer patients support to manage their own care and avoid costly or avoidable readmissions. Under the Affordable Care Act, HHS will work with the Centers for Medicare & Medicaid Services to implement the Community-Based Care Transition Program, a pilot program that aims to reduce hospital readmissions by educating patients to manage their own health and health care.
21. **Work with social service providers, medical and other health care providers, and other service providers across the interdisciplinary care continuum to improve the capacity and supply of community-based case management services and to develop a truly user friendly system to help families navigate care needs.**
22. **Enhance the state 2-1-1 information line's ability to be an effective channel** for Maine people seeking access to resources related to Alzheimer's disease and other dementias by ensuring the system has access to up-to-date contact information for resources in each county. This should be a shared responsibility of state agencies, Area Agencies on Aging, Alzheimer's Association Maine Chapter and other resources affiliated with statewide entities.
23. **Identify and expand the availability of professional guidance options to help family caregivers** navigate and manage the myriad of safety and behavioral issues through an array of services such as caregiver assessment, care consultation, counseling, care management, respite care, support groups, assistive technologies and other effective interventions. This should include a gap analysis to identify priority areas of need. Similarly, identify and expand the reach of public and not-for-profit training programs run by organizations and agencies with expertise in Alzheimer's disease to inform, educate, and offer care giving strategies and interventions to empower family members and/or friends of those living with individuals with Alzheimer's at home (Examples: *"Know the 10 Signs," "Living with Alzheimer's," "Alzheimer's Basics," "Savvy Caregiver"*). Options identified should be included in a comprehensive dementia-focused resource directory that should be developed based on Appendix A of this plan and made available online and kept up-to-date.

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24. **Increase participation in educational programs among diverse caregivers through culturally and linguistically appropriate trainings and materials**, such as those currently being developed by the Maine Centers for Disease Control and Prevention. Customize outreach tailored to immigrant and other diverse communities in Maine and where possible, recruit participation of native language speakers to deliver programs.
 25. **Educate and enlist the faith community as community resources that can help reach out to and support family caregivers**. Invite faith leaders to applicable trainings and also utilize them as a resource to disseminate information and materials.
 26. **Encourage businesses and other workplace sites to offer family caregiver support services**, such as flexible work hours, referrals and counseling through Employee Assistance Programs and other employee initiatives. Invite employers to applicable trainings and also utilize them as a resource to disseminate information and materials.
 27. **Ensure that entities that are specifically involved in the prevention of elder abuse**, such as the Maine Council on Elder Abuse and Prevention and others, are mindful of legal protections with regard to the vulnerable population of those with dementia. Include related resources in the dementia-focused online resource directory.
 28. **Ensure state-approved forms such as Durable Power of Attorney for Healthcare, Physician Orders for Life Sustaining Treatment (POLST) and other documents with helpful instructions and Frequently Asked Questions are available at no cost to the consumer** at public libraries, resource centers and include related resources in the dementia-focused online resource directory.
 29. **Preserve and expand established home- and community-based programs that effectively serve people with dementia and support their caregivers, including adult day programs and in-home supportive services**. This should also include existing or new short-term programs offered in nursing homes or other facilities.
 30. **Support, fund and explore existing or emerging MaineCare programs** that would strengthen and better enable care coordination and management so as to encourage the use of cost- and quality-effective home- and community-based services.
 31. **Promote the importance of establishing meaningful activities across the care continuum that are specifically adapted for the person with dementia**. This may include vocational, rehabilitative, social and recreational activities.
 32. **Evaluate demonstration projects that are available or become available under federal programs to expand adult day services for those with Alzheimer's and home health care for the purpose of preserving the abilities and independence of persons with dementia as long as possible**. One possible example: The new Independence at Home Demonstration project (made possible through the [Patient Protection and Affordable Care Act](#) Section 3024 in late December 2011) that will test a payment incentive and service delivery model that uses primary care teams led by physicians or nurse practitioners to deliver timely, in-home primary care to Medicare beneficiaries with multiple chronic illnesses and functional impairments. Other examples include: The Care Transition Model, Coleman model of care navigation. In instances where Alzheimer's disease or related dementias are not currently listed among eligible conditions of various programs, advocate that they be named eligible.

VI. FACILITY-BASED LONG-TERM CARE SERVICES

Note: For purposes of this document, “facilities,” “long-term care providers” or “long-term care settings” is intended to represent all such types of service providers in non-family home settings where individuals with dementia reside, including: Nursing facilities, dementia care units, residential care facilities, Private Non-Medical Institutions, adult family care homes, retirement communities that also provide services either directly or indirectly, other assisted living communities (including the state-funded affordable assisted care communities), and other long-term care settings.

A. Quality care

High quality, person-centered care is needed for those living with Alzheimer’s disease and related dementias from the time of diagnosis through end-of-life and across all settings, including homes, physician offices, adult day settings, hospitals, residential facilities and others.



People with dementia represent 58% percent of the population of nursing homes in Maine, and 46% of PNMI residential care facilities (Source: *Older Adults and Adults with Disabilities: Population and Service Use Trends in Maine, Muskie School of Public Service, 2010*), and the numbers are growing every day.

Families are often challenged with evaluating and navigating entry into an appropriate long-term care facility for their loved ones. Those who may have success in identifying a facility of choice can still face the frustration of lack of bed availability. This can be an even greater challenge for males given the majority of nursing facility and residential care facility residents in Maine are female (71% and 70%, respectively), which makes finding an appropriately compatible room sometimes difficult. (Data Source: *Older Adults and Adults with Disabilities: Population and Service Use Trends in Maine, Muskie School of Public Service, 2010*). Finding and accessing appropriate facility-based dementia care is difficult across the state, but often even more so in rural areas where options are more limited. This can force long commutes on family members who would prefer their loved ones be closer to home so they can visit more frequently and stay more involved in their loved one’s care.

When they do find a match, family members can be unprepared for the transition. Such a significant move can be overwhelming because of the natural emotional stress of change, but also because of the lack of understanding of the steps involved with regard to intake and admissions, assessment, how best to participate in the development of an appropriate care plan for a loved one, and how to effectively work with facility staff.

Smooth transitions between care settings and coordination among health and long-term care service providers is also essential to ensure high quality, efficient care, particularly given the complexities of Alzheimer’s disease and related dementias.

In addition to meeting the potentially complex medical needs associated with dementia and often co-occurring chronic conditions, facilities also care for the non-medical needs of people with Alzheimer’s, such as needed supervision and assistance with activities of daily living. Many people who have had experiences with care facilities express frustration with the lack of dementia knowledge some providers demonstrate in caring for their loved ones with Alzheimer’s disease, and comment on the need for appropriate training and education in these settings. (*See plan section VIII. Education and Training*).

Overall, there have been fewer quality standards specific to dementia care in the long-term facility setting. The state’s role in regulating quality of care is primarily from a medical and public safety oversight perspective (including licensing and facility inspections). The Maine Long-Term Care Ombudsman’s Office offers valuable services responding to complaints and occurrence-reporting including unexplained deaths or missing persons and more. The National Quality Forum

and the Centers for Medicare and Medicaid Services include some general metrics used by long-term care facilities, and as mentioned previously, the national Alzheimer's Quality of Care Campaign, which many consider to be "the gold standard," focuses on the dual goals of enhancing quality of life for individuals with dementia and improving the quality of care they receive.

B. Cost to families

After a diagnosis of Alzheimer's or related dementias paying for care needed can be an overwhelming concern for individuals, and their families. Possible expenses include: Treatment for dementia, treatment for other medical problems, prescription drugs, personal care items, adult day care, in-home care and/or full-time residential care. These costs can be enormous (*See also, "Cost to families," Home and Community Care Services section of plan*). Families can benefit from planning a long-term budget and discussing how they will meet everyday financial responsibilities, such as paying bills, arranging for benefits, making investments and preparing tax returns.

Getting a diagnosis of Alzheimer's or dementia doesn't always mean a person is unable to make decisions about the future. A person with Alzheimer's should participate as much as possible in planning for the future. Individuals and families benefit from beginning the planning process as early as possible, which better enables discussions leading to decisions about health care choices, finances and paying for care, and legal planning around issues such as advance directives, and will and estate planning.

Some individuals may have retirement benefits and personal savings and assets to help pay for care. Due to the high cost of care, however, most families quickly expend their personal resources and must turn to public programs for assistance.

- **Assisted living.** In 2011, the average cost, nationally, for basic services in an assisted living facility was \$3,477 per month, or \$41,724 per year. Seventy-two percent of assisted living facilities provided care to people with Alzheimer's disease and other dementias, and 52 percent had a specific unit for people with Alzheimer's and other dementias. In facilities that charged a different rate for individuals with Alzheimer's and other dementias, the average rate was \$4,619 per month, or \$55,428 per year, for this care (Source: *MetLife Mature Market Institute. Market Survey of Long-Term Care Costs: The 2011 MetLife Market Survey of Nursing Home, Assisted Living, Adult Day Services, and Home Care Costs. New York, N.Y.: Metropolitan Life Insurance Company, 2011*).
- **Nursing homes.** In 2011, the average cost, nationally, for a private room in a nursing home was \$239 per day, or \$87,235 per year. The average cost of a semi-private room in a nursing home was \$214 per day, or \$78,110 per year. Eighty percent of nursing homes that provide care for people with Alzheimer's disease charge the same rate. In the few nursing homes that charged a different rate, the average cost for a private room for an individual with Alzheimer's disease was \$12 higher (\$251 per day, or \$91,615 per year) and the average cost for a semi-private room was \$8 higher (\$222 per day, or \$81,030 per year). Thirty-six percent of nursing homes had separate Alzheimer's special care units. (Source: *MetLife Mature Market Institute. Market Survey of Long-Term Care Costs: The 2011 MetLife Market Survey of Nursing Home, Assisted Living, Adult Day Services, and Home Care Costs. New York, N.Y.: Metropolitan Life Insurance Company, 2011*).

The private-pay cost of a private room at a nursing home in Maine ranges from \$212 per day to \$370 per day; the private-pay cost for a semi-private room at a nursing home in Maine ranges from \$205 per day to \$303 per day. Private-pay assisted living base rates range from \$1,775 per month to \$6,631 per month (Data Source: *Market Survey of Long-Term Care Costs: The 2011 MetLife Market Survey of Nursing Home, Assisted Living, Adult Day Services and Home Care Costs*.) Caring for individuals with Alzheimer's or related dementias can be significantly higher than average base rates of

the broader population of residents. (See also, *Financing Long-Term Care section of plan for information regarding cost of care as well as the impact of reimbursement shortfalls on long-term care facilities.*)

Insurance options currently available for those eligible includes government programs such as Medicare and Medigap, disability insurance from an employer-paid plan or personal policy, a group employee plan or retiree medical coverage, life insurance and long-term care insurance. Government assistance may include Social Security Disability Income (SSDI) for workers under age 65, Supplemental Security Income (SSI), Medicaid for those who meet certain requirements, Veterans Benefits, or tax deductions and credits such as the Household and Dependent Care Credit.

Additional work is needed to detail the enormous financial costs of Alzheimer's on individuals and families and to identify what options might reduce this burden. With increased prevalence, caring for individuals with Alzheimer's and other dementias will take a huge financial toll. Projections for the future indicate that nationally total payments for healthcare, long-term care and hospice are projected to increase from \$200 billion nationally in 2012 to \$1.1 trillion in 2050, in 2012 dollars. This dramatic rise includes a seven-fold increase in Medicare payments and a five-fold increase in payments from Medicaid and out-of-pocket and other sources such as private insurance, HMOs, other managed care organizations and uncompensated care. (Source: *2012 Alzheimer's Disease Facts and Figures, Alzheimer's Association*).

FACILITY-BASED LONG-TERM CARE SERVICES RECOMMENDATIONS

Goal: Maine people with Alzheimer's and related dementias who choose care in long-term settings have access to quality, person-centered care.

Strategies:

- 1. Integrate into public awareness and educational campaigns the message of the need to plan ahead to better enable thoughtful decisions about health care choices, finances and paying for care, and legal planning around issues such as advance directives, will and estate planning.** Due to the infrastructure shortage of both home- and community-based and long-term care facility services, inform families of the need to plan ahead and identify multiple options that could meet their loved ones needs. Publicize the true and total cost of Alzheimer's, as the public and policymakers may not fully understand the financial burden the disease represents, and with increased prevalence, the level to which it is projected to grow. (See also, *plan section III. Public Awareness, Public Health and Safety*).
- 2. Educate family caregivers and individuals with dementia to recognize and choose quality dementia care.** Examples of educational tools include the Alzheimer's Association CareFinder™ online at <http://www.alz.org/carefinder>.
- 3. Educate family members about how to work with facility staff to ensure the needs of their loved ones are met.** This should include anticipated guidance regarding the intake and admissions process, assessment, care plan development and conferences, resident and/or family councils as well as ongoing more informal interaction during visits. This should also include anticipatory guidance on how family caregivers can help support their loved ones to prepare for the change of setting, as well as guidance on how to prepare themselves.
- 4. DHHS, with continued stakeholder input, should continue to explore all possible alternatives that would prevent harm to individuals living with dementia who reside in Private Non-Medical Institutions to ensure access to needed care and services** (including personal care and medication management) and housing are preserved. In addition to meeting needs that the short-term challenge presents, solutions should also be mindful of the necessity to increase capacity of a sustainable long-term care infrastructure in the mid-and long-term.
- 5. Inventory and evaluate the state's current long-term care facility infrastructure across settings to identify gaps and shortages in service delivery capacity.** Work with industry and other stakeholders to identify strategies that

would provide appropriate reimbursement and/or other incentives to increase the number of dementia care units and qualified workforce as needed across the state.

6. **Identify and implement existing or emerging best practice residential care models to measure care quality accurately and institute quality improvement tools** such as the Alzheimer's Association Quality Residential Care™ recommendations focused on person-centered care practices (*See http://www.alz.org/professionals_and_researchers_dementia_care_practice_recommendations.asp*). This includes Phase I practice recommendations which focus on the fundamentals of quality dementia care, as well as the care areas of food and fluid consumption, pain management and social engagement. Phase 2 focuses on the care areas of wandering, falls and physical restraints. Phase III focuses on end-of-life care practice recommendations including communication and decision-making strategies, assessment and care of physical and behavioral symptoms, psychosocial and spiritual support of residents and family, staff training and more. Other models include: Guidelines should consider care modifications needed in cases involving co-occurring chronic conditions in people with Alzheimer's disease. Care practices should include a best-practice model related to the process of medical decisionmaking in circumstances where no family members are involved and individuals are not under state guardianship. Quality improvement tools should track whether recommended care in all practice areas is being provided.
7. As the percentage of individuals needing more acute-level care continues to grow with the significant increase in prevalence of those having Alzheimer's and related dementias (as well as other more care-intensive conditions), **evaluate required direct care staff ratios of long-term care settings to ensure the ability to maintain quality person-centered care is achieved.**
8. **Identify and support existing or emerging best practice models of care coordination between physicians, hospitals and other providers with long-term facility care providers** to reduce errors and/or duplication, improve outcomes, and minimize costly hospital readmissions for those with dementia and/or behavioral health conditions and the challenges transitions can represent.
9. **Identify and implement existing or emerging best practice competency-based models for training long-term care facility staff to provide quality dementia care** in assisted living, nursing homes and dementia units. (*See "Education and Training" section of plan for recommendations.*)
10. **Evaluate and enhance current state policies regulating licensing/certification**, both pre-employment and continuing education requirements, for the long-term care facility workforce. This should include identifying and implementing competency-based evaluation requirements for personal care attendants, CNAs, LPNs, RNs and others who are care providers. (*See "Education and Training" section of plan*).
11. **Through ongoing awareness and advocacy campaigns, work with family caregivers, professional caregivers, long-term care service providers, other stakeholders and policy makers to incorporate recommendations into dementia care practices and policies.**
12. **Develop a state public recognition program to enable consumer choice of long-term care facility provider based on quality.** Include a system of certification and incentive-based options or rewards for dementia competency, including dementia care that is culturally competent.
13. **Establish or expand initiatives that guide and support facilities in both medical and non-medical quality improvement efforts** (such as the Local Area Network for Excellence program and the Advancing Excellence Campaign.) This should also include establishing Family Councils to supplement input facilities receive from Resident Councils, and informing families of the opportunity to participate.

VII. FINANCING LONG-TERM CARE SERVICES

A. Funding efficiency, cost containment

Funding is a key underlying issue that impacts access to services and quality of care, care options and settings for individuals with Alzheimer's and related dementias. All forms of funding, both public and private, must be utilized efficiently.

Aggregate payments for health care, long-term care and hospice for people with Alzheimer's disease and other dementias are projected to increase from \$200 billion nationally in 2012 to \$1.1 trillion in 2050 (in 2012 dollars). (Source: *2012 Alzheimer's Disease Facts and Figures*, Alzheimer's Association). Medicare and Medicaid cover about 70 percent of the costs of care.

Cost-containment strategies such as avoiding premature placement in long-term care facilities need to be considered among the highest of priorities. An estimated 60 to 70 percent of older adults with Alzheimer's disease and other dementias live in the community compared with 98 percent of older adults without Alzheimer's disease and other dementias. (Sources: *2012 Alzheimer's Disease Facts & Figures*, Alzheimer's Association, based on data from the Medicare Current Beneficiary Survey for 2008; MetLife Mature Market Institute. *Market Survey of Long-Term Care Costs: The 2011 MetLife Market Survey of Nursing Home, Assisted Living, Adult Day Services, and Home Care Costs*. New York, N.Y.: Metropolitan Life Insurance Company, 2011).

Of those with Alzheimer's disease and other dementias who live in the community, 75 percent live with someone and the remaining 25 percent live alone (Source: *2012 Alzheimer's Disease Facts & Figures*, Alzheimer's Association, based on data from the Medicare Current Beneficiary Survey for 2008). As their dementia progresses, they generally receive more and more care from family and other unpaid caregivers (Source: Seshadri S, Beiser A, Kelly-Hayes M, Kase CS, Au R, Kannel WB, et al. *The lifetime risk of stroke: Estimates from the Framingham Study*. *Stroke* 2006; 37(2): 345–50).

Many people with Alzheimer's and other dementias also receive paid services at home; in adult day centers, assisted living facilities or nursing homes; or in more than one of these settings at different times in the often long course of their illness. Given the high average costs of these services (e.g., adult day center services, \$70 per day; assisted living, \$41,724 per year; and nursing home care, \$79,110 to \$87,235 per year), individuals often spend down their assets and eventually qualify for Medicaid (Source: MetLife Mature Market Institute. *Market Survey of Long-Term Care Costs: The 2011 MetLife Market Survey of Nursing Home, Assisted Living, Adult Day Services, and Home Care Costs*. New York, N.Y.: Metropolitan Life Insurance Company, 2011). Medicaid is the only public program that covers the long nursing home stays that most people with dementia require in the late stages of their illness.



Average Annual Per-Person Payments for Health Care and Long-Term Care Services, Medicare Beneficiaries Age 65 and Older, with and without Alzheimer's Disease and Other Dementias and by Place of Residence

Beneficiaries with Alzheimer's Disease/Other Dementias by Place of Residence				
	Overall	Community-Dwelling	Residential Facility	Those without Alzheimer's Disease/Dementia
Medicare	\$19,820	\$17,651	\$22,849	\$7,521
Medicaid	10,120	222	23,953	527
Uncompensated	273	392	107	308
HMO	994	1,543	227	1,450
Private insurance	2,262	2,485	1,948	1,521
Other payer	906	164	1,942	143
Out-of-pocket	9,368	3,167	18,035	2,284
Total*	\$43,847	\$25,804	\$69,066	\$13,879

Source: 2012 Alzheimer's Disease Facts & Figures, Alzheimer's Association. Note: Payments from sources do not equal total payments exactly due to the effect of population weighting. Payments for all beneficiaries with Alzheimer's disease and other dementias include payments for community- dwelling and facility dwelling beneficiaries. Created from unpublished data from the Medicare Current Beneficiary Survey for 2008.

Education and support is paramount in enabling caregivers to care for loved ones and manage the challenges they face, while helping to prevent premature more costly acute and long-term care facility admission. As noted previously in this plan, family members also find evaluating, accessing and piecing together a myriad of distinct home- and community-based services needed to meet the needs of their family member both time-consuming and problematic to navigate. New, innovative and coordinated program alternatives are needed.

People with Alzheimer's disease and other dementias have more than three times as many hospital stays as other older people. (Source: 2012 Alzheimer's Disease Facts & Figures, Alzheimer's Association, based on data from the Medicare Current Beneficiary Survey for 2008). Moreover, the use of health care services for people with other serious medical conditions is strongly affected by the presence or absence of Alzheimer's and other dementias. In particular, people with coronary heart disease, diabetes, chronic kidney disease, chronic obstructive pulmonary disease, stroke or cancer who also have Alzheimer's and other dementias have higher use and costs of health care services than do people with these medical conditions but no coexisting Alzheimer's and other dementias. (Source: 2012 Alzheimer's Disease Facts & Figures, Alzheimer's Association, based on data from the Medicare Current Beneficiary Survey for 2008).

Today's emerging "health care home" model of care, in concert with a growing movement that is shifting long-term care services from facility-based care to "managed care at home," provides a team approach to care coordination. Utilizing

the health care home model to support individuals and families dealing with dementia promises to be a key solution to providing quality, cost-efficient care. Typically consisting of a team of physicians, social workers, physical and occupational therapists and other specialists, this coordinated care model is proving to be a more successful way to manage care and improve health outcomes for individuals across settings (at home and/or in adult day care centers and during medical visits) and results in decreased medical and long-term care costs and lower hospital admission and readmission rates. The growth of such programs, currently available in 29 states, is expanding quickly (A Shift from Nursing Homes to Managed Care at Home, *New York Times*, Feb. 23, 2012, http://www.nytimes.com/2012/02/24/nyregion/managed-care-keeps-the-frail-out-of-nursing-homes.html?_r=1&pagewanted=all). The success of this type of model will be important to achieving access and quality of care while containing costs and should be supported and appropriately funded. Lack of or inadequate reimbursement has presented a barrier that has prevented or delayed many physicians from adopting this model within their practices.

B. Long-term care insurance, other private funding

Few individuals with Alzheimer's disease and other dementias and their families have sufficient long-term care insurance or can afford to pay out-of-pocket for long-term care services for as long as the services are needed.

- Income and asset data are not available for people with Alzheimer's or other dementias specifically, but 50 percent of Medicare beneficiaries had incomes of \$21,774 or less, and 25 percent had incomes of \$13,116 or less in 2010 (in 2011 dollars). Two hundred percent of the federal poverty level was \$21,780 for a household of one and \$29,420 for a household of two in 2011. (Sources: *Kaiser Family Foundation Program on Medicare Policy. Projecting Income and Assets: What Might the Future Hold for the Next Generation of Medicare Beneficiaries?* Menlo Park, Calif.: Henry J. Kaiser Family Foundation, 2011; U.S. Department of Health and Human Services. *The 2011 HHS Poverty Guidelines*).
- Fifty percent of Medicare beneficiaries had retirement accounts of \$2,095 or less, 50 percent had financial assets of \$30,287 or less, and 50 percent had total savings of \$52,793 or less, equivalent to less than one year of nursing home care. (Sources: *Kaiser Family Foundation Program on Medicare Policy. Projecting Income and Assets: What Might the Future Hold for the Next Generation of Medicare Beneficiaries?* Menlo Park, Calif.: Henry J. Kaiser Family Foundation, 2011).

Two-thirds of Americans fear they will not be financially prepared for retirement, according to a recent Gallup Survey. Sixty percent are worried they will not be able to pay medical costs for a serious illness or accident. (Source: *Lack of Retirement Funds Is Americans' Biggest Financial Worry*, Elizabeth Mendez, June 15, 2011, <http://www.gallup.com/poll/148058/lack-retirement-funds-americans-biggest-financial-worry.aspx>). Over 47 percent of our oldest baby boomers are considered "at risk of not having sufficient retirement resources to pay for basic retirement expenditures and uninsured health care costs." (Source: *The EBRI Retirement Readiness Rating:™ Retirement Income*, July 2011, Issue Brief #344).

Despite these concerns a recent survey on retirement health care of middle-income Americans found long-term care to be the least understood. Some 27% of pre-Medicare age Boomers (those born between 1946 and 1964) were not able to "venture a guess as to how much they think they will pay for healthcare once on Medicare versus what they pay today," and one in seven (13%) of Boomers under age 65 were found to falsely believe that Medicare is free. (Source: *Retirement Healthcare for Middle-Income Americans*, Center for a Secure Retirement, January, 2012, <http://www.centerforsecureretirement.com/studies.aspx>).

Fewer than 10 percent of older adults have purchased long-term care insurance policies. (Source: *The New Old Age: Caring and Coping*, *New York Times*, <http://newoldage.blogs.nytimes.com/2010/03/24/a-new-long-term-care-insurance-program/>).

Most families are simply not focused on how to pay for long-term care until they're directly faced with the challenge, with approximately one-third of those people without long-term care insurance reporting that "it's just not something they've ever thought about." (Source: *Kaiser HealthPoll Report*, *Kaiser Family Foundation*, http://www.kff.org/healthpollreport/june_2005/11.cfm).

Increased outreach is needed to educate individuals on the need to plan ahead and prepare, in advance of Alzheimer's disease or disability, to pay for long-term care services they may need. In addition to planning early to secure long-term care insurance, other existing or new innovative investment strategies should be considered and encouraged to help prepare individuals and families well in advance of disease onset.

The Community Living Assistance and Supportive Services Act (CLASS Act), which was proposed as a new federal public-private partnership for employer-based long-term care insurance, was viewed by many as a way of encouraging personal investment to meet the future long-term care needs of those with cognitive or physical disabilities. Concerns about the financial sustainability of the program as it was structured, however, prevented the initiative from moving forward at this time, which is unfortunate as many were hopeful that it would help people living with Alzheimer's disease stay in their home as long as possible, avoiding premature admittance to more expensive long-term care facilities. Innovative programs that meet broader quality of life and funding efficiency goals should be explored and successful models supported and implemented.

Other ways to encourage individual savings include using tax credits or pre-tax dollars for caregiver support services. Many people are unaware that an Employer's Internal Revenue Code Section 125, Cafeteria plan can be used for dependent care (including distributions to pay long-term care services) as well as child care (Source: <http://www.irs.gov/govt/fslg/artilce/0,,id=112720,00.htm>).

Reverse home mortgages have been used by some individuals as a means to use their home equity to help pay for in-home support services or other needed assistance, but the option can be less appealing as it is unaffordable for some to pursue. Some have suggested that if public funding were to be made available to help cover closing costs, which are often a major expense, that this type of investment would be more attractive for those who can avoid reliance on state and federal support.

Innovative private sector support from corporate philanthropy, foundations, and employers of all sizes could also be considered to support needed services. For example, funding of qualified nonprofit organizations to build upon caregiver training programs already in place and increasing ability to organize volunteers to help provide services.

Existing public programs are also functioning under capacity; private funds could boost funding needed to expand services. Federal matching funds for state expenditures for assistance payments are based upon the Federal Medical Assistance Percentages; a complex formula calculated annually (Source: *The Social Security Act, Section 1905(b)*). The resulting federal and state payment does not cover the full cost of care. The "Medicaid shortfall" – the difference between payments and cost – was \$21.21 per resident per day for calendar year 2011 (Source: *A Report on Shortfalls in Medicaid Funding for Nursing Home Care*, *Eljay, LLC for the American Health Care Association, Table 1: State by State Comparison of Rates and Costs (2011 Projections), December 2011*).

Employers with a strong connection to their communities could be recruited to underwrite local programs. As corporate or foundation funding can be difficult to sustain over the long-term, funding short-term initiatives such as public awareness campaigns or to launch pilot projects may be found to be most strategic.

The issue of presenteeism—when employees are working but distracted by the pressures of caregiving—will become a growing challenge in an increasingly aging state faced with an increased prevalence of Alzheimer’s disease and related dementias. Employers would benefit from participating in such programs as the Alzheimer’s Early Detection Alliance (AEDA), a group of organizations dedicated to raising awareness of Alzheimer’s among their employees and the public, and from providing employee benefits such as care coordination counseling and referral services through an Employee Assistance Program that help with the challenges of Alzheimer’s caregiving.

C. Medicare and Medicaid and other public funding

Medicaid covers nursing home care and other long-term care services in the community for individuals who meet program requirements for level of care, income and assets. To receive coverage, beneficiaries must have low incomes or be poor. Most nursing home residents who qualify for Medicaid must spend all of their Social Security income and any other monthly income, except for a very small personal needs allowance, to help pay for nursing home care. Medicaid only makes up the difference if the nursing home resident cannot pay the full cost of care or has a financially dependent spouse. The federal and state governments share responsibility in managing and funding the program.

Medicaid plays a critical role for people with dementia who can no longer afford to pay for their long-term care expenses on their own. In 2008, 58 percent of Medicaid spending on long-term care was allocated to facility-based care, and the remaining 42 percent was allocated to home and community-based services (Source: *Kaiser Commission on Medicaid and the Uninsured. Medicaid and Long-Term Care Services and Supports No. 2168–207, Washington, D.C.: Henry J. Kaiser Family Foundation, 2010*). In 2008, total per-person Medicaid payments for Medicare beneficiaries age 65 and older with Alzheimer’s and other dementias were 19 times as great as Medicaid payments for other Medicare beneficiaries. Much of the difference in payments for beneficiaries with Alzheimer’s and other dementias is due to the costs associated with long-term care (i.e., nursing homes and other residential care facilities, such as assisted living facilities). Medicaid paid \$23,953 (in 2011 dollars) per person for Medicare beneficiaries with Alzheimer’s and other dementias living in a long-term care facility compared with \$222 for those with the diagnosis living in the community and \$527 for those without the diagnosis (Source: *2012 Alzheimer’s Disease Facts & Figures, Alzheimer’s Association. Created from unpublished data from the Medicare Current Beneficiary Survey for 2008*).

Consideration should be given to models of thoughtfully structured, financially integrated, coordinated care programs that would achieve the dual goals of improving care and services to individuals and caregivers while reducing premature or inappropriate, more expensive facility-based care. States such as Connecticut have begun to move in this direction, by participating in Medicaid waiver programs that allow them to combine all of their long-term care dollars (with funds moving with the individual), tightening eligibility criteria for nursing homes, and expanding home- and community-based services.

The PACE Program (Program of All-Inclusive Care for the Elderly) has been applauded in other states as a successful model for coordinating care services with efficient use of Medicare and Medicaid dollars. Programs such as PACE that integrate services and funding, should be evaluated for implementation in Maine. In a state facing infrastructure shortages in home- and community- based as well as facility-based long-term care services – as well as federal compliance challenges to its current Private Non-Medical Institutions (PNMI) structure – there will be a great need for new and/or expanded options and choices for families that are cost and quality effective and funding-eligible.

Innovative opportunities encouraging the development and evaluation of models of service delivery, financing and staffing that have emerged from the passage of the Affordable Care Act health reform law should be fully explored and implemented strategically in Maine. The Centers for Innovation under the Centers for Medicaid and Medicare Services (CMS)

are sponsoring initiatives that have particular emphasis on managing chronic illnesses effectively and efficiently for which a large portion of health care dollars are spent, including Alzheimer's disease.

With 58% percent of the population of nursing homes and 46% of PNMI residential care facilities populated by individuals living with dementia, it is also critical that reimbursement shortages be addressed to ensure the sustainability of facilities across the state. (Data source: *Older Adults and Adults with Disabilities: Population and Service Use Trends in Maine, Muskie School of Public Service, 2010*). According to the Maine Health Care Association, the unfunded allowable cost per day for nursing facilities climbed to \$18.69, and to \$10.04 for residential care facilities in the state (Source: *Five Year Comparisons of Average Allowable Cost Per Day to Average Rate Paid, Nursing Facilities and Residential Care Facilities, Berry, Dunn, McNeil & Parker, 2008*). Providing quality, person-centered care to those with dementia is expensive, and facilities need support to ensure Maine individuals needing the option will be able to access facility-based long-term care.

FINANCING LONG-TERM CARE SERVICES RECOMMENDATIONS

- 1. Better inform the public on how to plan for the financing, insuring and legal issues associated with meeting long-term care needs.** Options for individuals and families to consider include: private long-term care insurance, the Maine Partnership for Long-Term Care, IRS code section 125 cafeteria plans and other investments strategies that will help to pay for care. Legal planning around issues such as advance directives, will and estate planning should also be included. Public awareness campaign should include PSA radio and television outreach to inform the public of resources designed to help family caregivers locate appropriate source(s) of guidance as well as awareness initiatives to promote educational sessions. (*See also, Public Awareness, Public Health & Safety section of plan*).
- 2. Research the true financial cost of Alzheimer's and related dementias on individuals living with the disease, families, communities and the state.** This should include analysis of the cost of caring for those with dementia covered by MaineCare, comparing people with dementia and people without by setting and service. This could also include an analysis of the cost of caring for individuals with dementia who also have other co-occurring chronic medical conditions.
- 3. Explore opportunities to engage private sector financial support from corporate philanthropy, foundations, and employers to help fund educational outreach initiatives and community services.**
- 4. Encourage employers to participate in programs such as the Alzheimer's Early Detection Alliance (AEDA),** a group of organizations dedicated to raising awareness of Alzheimer's among their employees and the public, as well as to include in Employee Assistance Programs care coordination counseling, advocacy and referral services, for example: Legal Services for the Elderly, and Maine Long-Term Care Ombudsman Program, that help with the challenges of Alzheimer's caregiving.
- 5. Support and appropriately reimburse the "health care home" model of care,** which provides a team approach to care coordination to support the individual and family, more successfully manages patient care, and results in decreased medical and long-term care costs and lower hospital admission and readmission rates. Ensure Alzheimer's disease and related dementias are identified as one of the chronic conditions in the Affordable Care Act and other funding sources' criteria that are used to identify people eligible for services, including home health services. Develop guidelines for medical homes and community health teams in the assessment, diagnosis, and support of people with dementia and their families.



6. Support reimbursement models that would enable a greater role for advanced nurse practitioners.

7. Fund state policies and programs that would expand or create new benefits and subsidies to family caregivers, which promote active involvement of families in dementia care. These incentives could be in the form of monetary incentives, tax incentives, health care coverage or deferred income incentives (retirement) as well as non-monetary incentives such as eligibility to obtain counseling and support for family caregivers through state or locally sponsored programs.

8. Adequately fund existing and new state policies and programs regarding subsidies for adult day programs (for example, Partners in Caring) similar to those for child care settings, which support, enable and supplement active caregiving by families and friends in order to encourage the ability to sustain home-based care. Diverse funding stream sources should be considered and evaluated to reflect the needs of a growing population, with emphasis on early intervention strategies and offering families options and choices appropriate to the unique care needs of individuals living with the disease.

9. Work with state partners and other stakeholders to preserve the elements of Medicaid essential to those living with Alzheimer's disease and their families and evaluate the use of Medicaid and Medicare waivers that would strengthen care coordination and management so as to reduce the use of more expensive facility-based long-term care services when cost efficient home- and community-based services are appropriate.

10. Research models that would expand the use of provider fees for community-based programs, such as Community First rebalancing provisions, and in coordination with the Affordable Care Act, in an effort to maximize available federal funding.

11. Evaluate demonstration projects that are available or become available under federal programs to expand adult day services for those with Alzheimer's and home health care for the purpose of preserving the abilities and independence of persons with dementia as long as possible. One possible example: The new Independence at Home Demonstration project (made possible through the Patient Protection and Affordable Care Act Section 3024 in late December 2011) that will test a payment incentive and service delivery model that uses primary care teams led by a physicians or nurse practitioners to deliver timely, in-home primary care to Medicare beneficiaries with multiple chronic illnesses and functional impairments. Other examples include: The Care Transition Model, Coleman model of care navigation. In instances where Alzheimer's disease or related dementias are not currently listed among eligible conditions of various programs, advocate that they be named eligible.

12. Support and fund care transitioning programs which help patients move from one health care setting to another (for example, from the hospital to home or to a long-term care facility). Care transitioning programs offer patients support to manage their own care and avoid costly, avoidable readmissions. Under the Affordable Care Act, HHS will work with the Centers for Medicare & Medicaid Services to implement the Community-Based Care Transition Program, a pilot program that aims to reduce hospital readmissions by educating patients to manage their own health and health care.



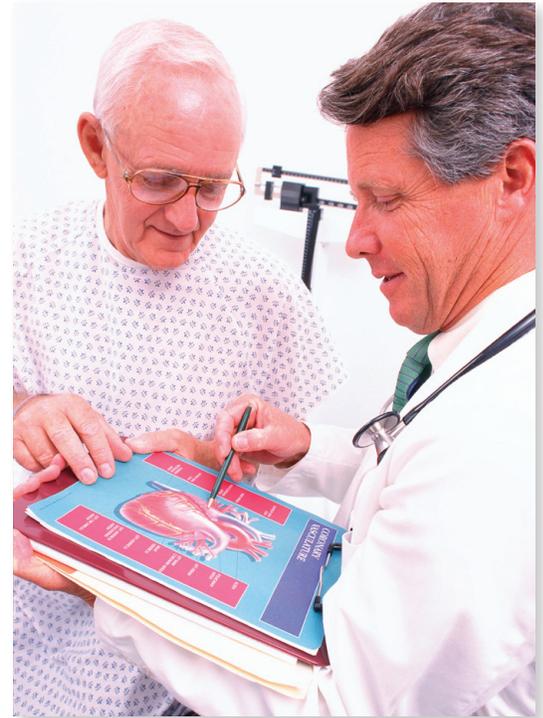
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13. **DHHS, with stakeholder input, should continue to explore all possible ways to support individuals living with dementia who reside in residential facilities**, ensuring access to housing that provides necessary personal care and medication management services. In addition to meeting needs that the short-term challenge presents, solutions should also be mindful of the necessity to increase capacity of a sustainable long-term care infrastructure in the mid- and long-term. This should also include funding for more home and community-based options that will be needed in the future as the population of those living with Alzheimer's or related dementias in Maine grows significantly over coming years.
 14. **Encourage and support the development of new cost and quality effective Medicaid/Medicare-eligible programs** such as the Program of All-Inclusive Care (PACE) for the Elderly in Maine that would offer Adult Day programming, multidisciplinary care coordination capabilities, expand capacity and access to community or home-based care services.
 15. **Work with industry and other stakeholders to identify strategies that would provide appropriate reimbursement and/or other incentives to sustain long-term care facilities and expand the number of dementia care units and adult day care options as needed across the state.** This should include consideration of acuity of facility populations in order to ensure high quality, person-centered care is maintained.

VIII. EDUCATION AND TRAINING

A. Geriatric education

There is a significant need to enhance the training that physicians, nurses and allied health professionals receive on dementia and its management.

The detection and diagnosis process can be a difficult and challenging experience for individuals and families affected by the disease. Diagnosing Alzheimer's takes more time than physician visits generally allot for an appointment and system issues such as provider time, costs and reimbursements can contribute to poor experiences. Families can feel rushed out the door because doctors have to move on to their next appointment. The lack of meaningful dialogue between physicians and those seeking assistance raises communication concerns about the ability to obtain a diagnosis. It also raises questions about physicians' ability or desire to diagnose Alzheimer's. They may not be trained in detection of the disease, or they may feel a diagnosis is of no value because no disease-modifying treatments exist. Some mistakenly presume Alzheimer's or other dementias are a normal part of aging. Health care providers who are properly trained in assessing dementia may also be reluctant to give a formal diagnosis because of implications attributed to a diagnosis, or before fully exhausting other possible causes. Identifying Alzheimer's in its early stages, however, is vital, as it allows affected individuals to participate in their own care process, including treatment options, clinical trials, long-term needs and financial and legal issues.



In the United States, an estimated 200,000 people have younger-onset Alzheimer's disease (Source: *Alzheimer's Association, 2012 Alzheimer's Disease Facts and Figures*). Alzheimer's disease is considered younger-onset if individuals are under the age of 65 years when symptoms first appear. Because of the individual's younger age and healthy appearance, clinicians often don't consider Alzheimer's as a possible diagnosis. Often times, doctors diagnose a younger individual with depression or attribute Alzheimer's like symptoms to stress. It is not unusual for individuals in their 30s, 40s and 50s with the disease to receive conflicting diagnoses from different health care professionals and to wait longer for a diagnosis than older individuals. Those affected by younger-onset Alzheimer's describe recognition of the disease in a younger population as a challenge often resulting in a delayed diagnosis.

Educating geriatric professionals on the stages of Alzheimer's (with special attention to early stage) and providing them with tools and information to share with individuals and family members about improving disease knowledge and management, promoting overall physical and cognitive health and enhancing quality of life would be beneficial.



Information on Alzheimer's and other dementias should be a compulsory component of formal training curriculums and continuing education requirements of physicians, nurses and allied health professionals who serve older persons. These should include early detection and diagnosis of cognitive impairment, dementia care interventions and management of the disease. Dementia care management competencies should be developed and taught in medical schools, academic health centers and allied

health professional education. Protocols and best practice standards for care of persons with Alzheimer's should be used in the training of geriatric professionals.

The National Alzheimer's Plan, currently being finalized under the oversight of the U.S. Department of Health & Human Services, indicates that HHS intends to "...undertake a comprehensive provider education effort targeting healthcare providers such as physicians, nurses, direct care workers and other professionals. The effort will be carried out through HRSA's Geriatric Education Centers and will focus on educating providers about Alzheimer's disease. It will include the latest clinical guidelines and information on how to work with people with the disease and their families. Healthcare providers will learn how to manage the disease in the context of other health conditions, and how to link people to support services in the community. Training will also discuss signs of caregiver burden and depression that providers should recognize and address. Healthcare providers will also be trained on the tools available to detect cognitive impairment and appropriate assessment processes for diagnosis of AD. These are being developed through a CMS, NIA, and CDC collaboration to help providers detect cognitive impairment detection in the Medicare Annual Wellness Visit." (Source: <http://aspe.hhs.gov/daltcp/napa/NatlPlan.shtml>).

(See also, *Diagnosis and Treatments section of plan, as well as Public Awareness, Public Health and Safety section of plan*).

B. Family caregiver education

Education and support, as mentioned previously throughout this plan, is paramount to enable family members to care for loved ones and manage the challenges they face, while helping to prevent premature more costly acute and long-term care facility admission.

Building a strong public awareness, public health and safety campaign will be necessary to serve as a foundation for education of the general public (See *related plan section*). It will help individuals and family members learn about the basics of the disease, its warning signs, of the importance of early detection of cognitive decline, and of the benefit of early intervention to prepare for future needs.



There are programs and services currently available in Maine and online that offer family members training on dementia-specific caregiving strategies as well as education about financial and legal planning and other relevant topics (See *Appendix A – Resource Guide*). As mentioned previously in this plan, however, Maine people would benefit from those services being expanded statewide, and new channels should be penetrated to reach those who would otherwise find it difficult to access opportunities (due to transportation, work responsibilities, or other barriers).

There is a great need for community support of caregivers, who often first look to trusted friends and neighbors for help. Best estimates indicate that at least one out of seven individuals who have Alzheimer's disease and other dementias live alone in the community (Source: *2012 Alzheimer's Disease Facts and Figures*). As Maine's population continues to age, so to will the growing number of persons with Alzheimer's who live alone, as there will be fewer family members available to provide needed care. The "community as caregiver" model will become a practical necessity.

Meeting the infrastructure capacity shortfall challenge in a way that successfully expands home- and community-based services and support, family caregiver and community education, and a system that is easier to navigate to access quality, person-centered services, will be critical (See *Home- and Community- Based Services: Quality service delivery in dementia-capable communities plan section*).

C. Direct care worker dementia-specific training

There are programs and services currently available in Maine and online that offer direct care worker dementia-specific training (*See Appendix A – Resource Guide*).

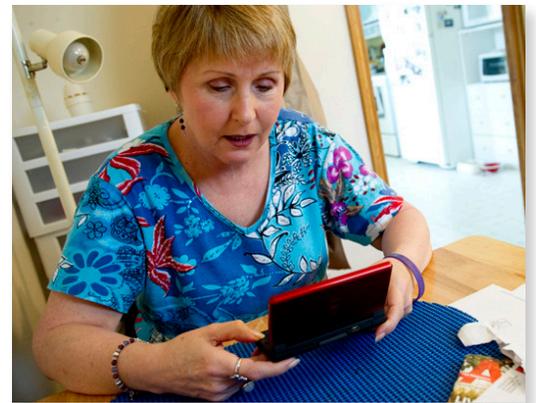
As mentioned previously in this plan, however, there are fewer standards specific to dementia care (*See Home- and Community-Based Services section, as well as Facility-Based Long-Term Care Services section of plan*). Competency-based trainings and performance evaluation criteria, in Maine and nationwide, need to be developed and implemented across settings based on evidence-based, best practices in quality dementia care.

The National Alzheimer’s Plan that is currently being finalized under the oversight of the U.S. Department of Health & Human Services indicates that HHS intends to work with a diverse group of stakeholders to identify best dementia care practices and evidence-based guidelines. The plan indicates that guidelines to be developed “...should be tailored to the stages of the disease and cover the myriad care settings in which care is delivered, such as in the home, physician’s office, and long-term care facility... and should also take into account how care might be modified for diverse populations and in the context of co-occurring chronic conditions in people with AD. Quality measures should be based on such guidelines and track whether recommended care is being provided.” This work can serve as a resource to guide Maine in the identification and development of metrics that promote high-quality dementia care in all settings upon which competency based trainings and requirements should be based. According to the national plan, “HHS will strengthen the nursing home direct-care workforce through new training focused on high-quality, person-centered care for people with AD... and will be available to all nursing homes to share with their staff. This training will be available for both new and established aides.” (*Source: <http://aspe.hhs.gov/daltcp/napa/NatiPlan.shtm>*).

Also noteworthy: In November of 2011, Maine DHSS Office of Elder Services published the Final Report of the LD 65 Taskforce on the Review of the Current and Future Dementia Training Needs of Long-Term Care Providers, which can be referenced at: <http://www.maine.gov/dhhs/reports/Training-Needs-of-Long-term-Care-Providers.pdf>.

EDUCATION AND TRAINING RECOMMENDATIONS

1. To form a basic awareness and educational foundation, implement the recommended strategies in the Public Awareness, Public Health & Safety section of this plan.
2. Dementia care management competencies should be taught in medical schools, academic health centers and allied health professional education and also to the full range of helping professionals; such as personal support specialists (PSS), family care partners and community agency partners. Improve access to dementia care specialists by working with educational institutions to encourage dementia training in post-graduate programs for nursing, medicine, psychiatry, neurology, psychology, social work professionals, and other interested disciplines.
3. Advocate that those living with Alzheimer’s disease or related dementias in Maine be recognized as a “Medically Underserved Population” for purposes of state (e.g. Finance Authority of Maine) and federal (Health Resources and Service Administration of the U.S. Dept. of Health and Human Services) specialty and geriatric physician educational loan forgiveness programs.



4. **Require the inclusion of education about Alzheimer's and other dementias in the training curriculum and continuing education requirements** of physicians, nurses, health, social service and allied health professionals who serve this population. (See also, *National Alzheimer's Plan*: <http://aspe.hhs.gov/daltcp/napa/NatlPlan.shtml>).
5. **Provide education, training and technical support to practicing primary care practitioners, specialists and other professionals** to facilitate adoption of best-practice dementia screening, treatment and management in their practices, including early detection and diagnosis of cognitive impairment, dementia care interventions and management of the disease. (See *Diagnosis & Treatment section of plan*, see also *National Alzheimer's Plan*: <http://aspe.hhs.gov/daltcp/napa/NatlPlan.shtml>).
6. **Promote strategies to grow, and to improve, the quality of the dementia care workforce.**
7. **Ensure that training and technical assistance includes a focus on assisting the practice of integrating activities that are appropriate for those with dementia into the practice system of care.** This should also include training of best practices in dementia care as it relates to primary care, hospital care, palliative care, hospice and other end-of-life care services.
8. **Work with state partners and other stakeholders to collaborate on creation of measurable criteria for defining systems of care for those with dementia.** These definitions should be tailored toward specific care settings (primary care practitioners, nursing homes, residential care homes, adult day centers, and other related settings).
9. **Enhance and expand the reach of dementia-specific family caregiving trainings.** In addition to information about the disease and caregiving strategies, trainings should include guidance on available resources and support and navigating systems of care (See also, *recommendations from Home- and Community-Based Services section of plan*, as well as *Appendix X: Resources Directory*).
10. **Educate family caregivers and individuals with dementia to recognize and choose quality dementia care.** Examples of educational tools include the Alzheimer's Association CareFinder™ online at <http://www.alz.org/carefinder>
11. **Work with state partners and other stakeholders to collaborate on the creation of employer-supported dementia awareness and caregiver training.**
12. **Identify and implement existing or emerging competency based trainings and evaluations to measure competency of professional caregivers based on quality dementia care best practice models.** Ensure that providers and consumers are informed of training that is required and available. (See also, *Quality Service Delivery in Dementia-Capable Communities of Home- and Community-Based Services plan section*, *Quality of Care: Facility-Based Long-term Care Services section of plan*, the *National Alzheimer's Plan* at <http://aspe.hhs.gov/daltcp/napa/NatlPlan.shtml> and the *Alzheimer's Association Quality of Care Campaign* at http://www.alz.org/professionals_and_researchers_dementia_care_practice_recommendations.asp).
13. **Ensure that any related educational and training materials or support are implemented in Maine that result from the federal Partnerships for Patients initiative, a public-private partnership that helps improve the quality of care and safety in hospitals.** Through this initiative, hospitals will identify best practices for reducing injuries, complications, and improving care transitions. Practices will be identified that benefit people with complex needs including people with Alzheimer's disease and CMS intends to share these findings broadly. Similarly disseminate in Maine the AD-specific educational toolkit on high-risk care transitions between settings that HHS intends to develop (according to the National Alzheimer's Plan).

APPENDIX A
RESOURCE DIRECTORY



Aging and Disability Services

*An Office of the
Department of Health and Human Services*

Paul R. LePage, Governor

Mary C. Mayhew, Commissioner