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# Caring for People with Alzheimer's Disease or Dementia in Maine

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# Research & Policy Brief

## Caring for People with Alzheimer’s Disease or Dementia in Maine

### A Matter of Public Health

Alzheimer’s disease is a devastating disorder of the brain’s nerve cells that impairs memory, thinking and behavior and leads, ultimately, to death. The impact of Alzheimer’s on individuals, families and our health care system makes the disease one of our nation’s greatest medical, social and economic challenges.<sup>1</sup>

The impact of caring for people with dementia extends to family members and friends, as well as the health and long term care system. More than 7 out of 10 people with Alzheimer’s disease live at home, where almost 75% of their care is provided by family and friends.<sup>1</sup>

Increasing age is the greatest risk factor for Alzheimer’s disease. Maine ranks sixth in the percent of people over 65 and 14th in the percent of people over 85. The U.S. Census Bureau estimates that there were 26,196 people in Maine over 85 in 2005 and projects that the number will grow by 52% by 2020.<sup>2</sup>

The impact of Alzheimer’s disease on the health and social service system will become an increasingly critical public health issue. Caring for people with the disease impacts family members and friends, the direct care workforce, employers, the home care system and the long term care system. As the major payor of long term care, MaineCare will continue to play a critical role in shaping policy, assuring access, and financing services and supports for people with Alzheimer’s and dementia.

### Maine leads the way in programs, services and training

Maine has been a leader in providing services and supports for people with Alzheimer’s and dementia and their caregivers. In 1993, Maine received its first grant to start the Maine Alzheimer’s Project and develop services and programs to serve the needs of people with Alzheimer’s or dementia and their families. Grant funds have continued through 2007. Grant funds, combined with state funds, have been used to:

- Develop new programs and services for the diagnosis and assessment of dementia
- Create an innovative caregiver companion program
- Develop and expand respite services
- Provide information and referral to people not eligible for publicly funded services
- Fund counseling services for families
- Provide information on use of hospice services for people with dementia
- Provide extensive training for direct care workers on the Best Friends™ approach to caregiving
- Provide start-up funding to develop and support programs at the Maine Alzheimer’s Association including an education and helpline staff person

It is time to take stock of the impact that caring for people with dementia has on Maine’s long term care system and the families and friends who are caring for people with dementia.

### Fast Facts

- Increasing age is the greatest risk factor for Alzheimer’s disease or dementia.<sup>1</sup>
- Nationally, one out of 8 people over 65 have Alzheimer’s disease. Almost half of those over 85 are affected by the disease.<sup>3</sup>
- 25,000 people in Maine are estimated to have Alzheimer’s disease.<sup>3</sup>
- 2% of people in Maine are over 85 and the number of people over 85 is projected to grow by 52% by 2020.<sup>2</sup>

**The Maine Alzheimer’s Project** is a demonstration program funded by the US Department of Health and Human Services’ Administration on Aging through the Maine Department of Health and Human Services’ Office of Elder Services.

The goal of the program is to increase access to services for caregivers of people with Alzheimer’s disease in rural Maine through a collaborative approach involving many providers and other partners in the aging community.

The USM Muskie School of Public Service provides evaluation and data analytic support for the Maine Alzheimer’s Project.

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## Characteristics of People with Dementia

Most people prefer to receive services at home and most families of people with Alzheimer's or dementia prefer to take care of their loved ones at home. There often comes a time when caring for someone at home is no longer possible or feasible.

Lack of a spouse or living alone are major factors that contribute to the decision to seek nursing or residential facility care. The burden on caregivers is great when people wander frequently or are incontinent.

Some of the characteristics of people with dementia who use long term care services are shown below.

### People with Dementia In Maine

	<b>Nursing Facilities</b> N=3,586	<b>Residential Care Facilities</b> N=1,675	<b>Home Care</b> N=605
<b>Percent with no spouse</b>	78%	88%	76%
<b>Percent who lived/ live alone</b>	14%	33%	30%
<b>Percent who wander at least one time a week</b>	27%	23%	16%
<b>Percent who are frequently incontinent</b>	76%	33%	55%
<b>Average age</b>	84	83	82
<b>Average length of stay</b>	1.8 years	1.9 years	

## MaineCare as a Major Payor

MaineCare (the Maine Medicaid program) is a major payor of long term care. In nursing facilities, 76% of people with dementia are MaineCare participants; in residential care 72% of people with dementia are on MaineCare. All of the home care participants reported in this paper receive services through MaineCare or state-funded programs. (Data on services paid privately or through other sources is not available).

## Maine's long term care system provides extensive services to people with dementia

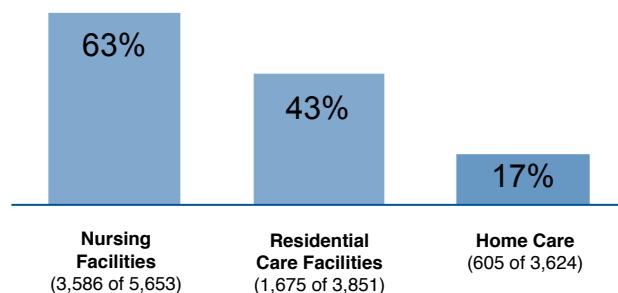
Maine's formal long term care system is a major provider of services for people with Alzheimer's and/or dementia. Using data from the Minimum Data Set for nursing homes and residential care facilities, and similar assessment items from Maine's MECARE data for home care participants, allows us to compare the characteristics and use patterns of people with Alzheimer's disease or dementia across long term care settings.

The data used in this report is from a roster of people in nursing facilities and residential care facilities as of September 15, 2005.\* The data from the MECARE assessment system represents home care users during fiscal year 2006.\*\* For purposes of this report, we use the term dementia to refer to people with Alzheimer's disease or other forms of dementia.

Maine's formal long term care system provides services to over 5,800 people with dementia. Almost two-thirds (63%) of the people in Maine nursing facilities have dementia. Residential care facilities also play a major role in caring for people with dementia. Close to half of the people (43%) in residential care facilities have dementia. Maine is #1 in the nation in the percent of people in nursing homes with dementia.<sup>2</sup>

In the publicly funded home care programs, 17% of the participants have dementia. This includes Maine's home based care program (which is funded by state funds), private duty nursing/ personal care services and services provided to people who are eligible to receive nursing level services but prefer to remain at home through the Elderly and Adults with Disabilities Waiver.

### Percent of People with Dementia by Service Setting



The percent of people with dementia receiving services at home varies by program. Almost one-third of the people receiving services in the Elderly and Adults with Disabilities Waiver have some form of dementia; 24% of people on home based care have the disease, while only 12% of people receiving private duty nursing/ personal care services have dementia.

\*Certain assessments conducted as part of the Medicare program were not included because they do not include items related to dementia.

\*\*This does not include consumer-directed waiver participants.

## The Stages of Alzheimer's Disease<sup>4</sup>

Alzheimer's disease is a complex disease that can last anywhere from 8 to 20 years or more from onset of symptoms.

Early stages of the disease are characterized by mild cognitive impairment that may include problems with memory or concentration. Families, friends and co-workers may begin to notice problems but the disease can be diagnosed in some but not all people.

In moderate to mid-stage Alzheimer's disease, major laps and deficits in cognitive function emerge. Some assistance with day-to-day activities becomes essential.

Later stages of the disease are accompanied by severe cognitive decline where a person may need extensive help with customary daily activities. Disruption in sleep patterns, wandering, personality changes and episodes of incontinence become more common.

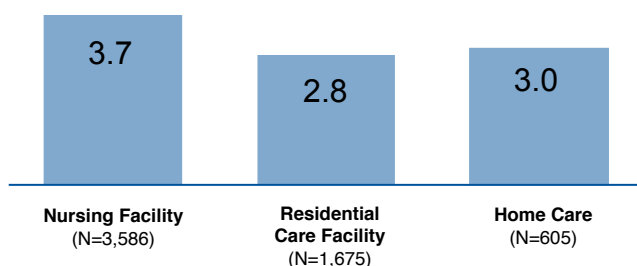
At the final stage of the disease people lose their ability to respond to the environment, the ability to speak, and ultimately to control movement.

## Cognitive Impairment Levels

Alzheimer's disease and other dementia are characterized by various stages of cognitive impairment. One way to measure the degree of cognitive impairment is a scale called the Cognitive Performance Scale (CPS). The Cognitive Performance Scale combines information on memory impairment, level of consciousness, and decision making, with scores ranging from 0 (intact) to 6 (very severe impairment).

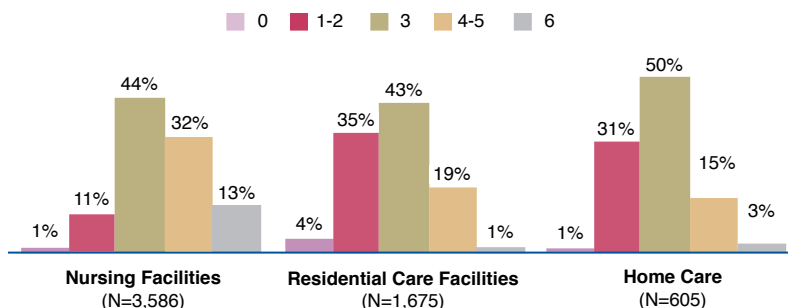
The average CPS for people with dementia in Maine nursing homes is 3.7, compared to 2.8 in residential care facilities and 3.0 in home care.

### Average Cognitive Performance Score (CPS) for People with Dementia by Service Setting



The distribution of people with dementia and the various levels of cognitive impairment is displayed below. Nursing facilities provide services to people with higher levels of cognitive impairment (13% of people with dementia in nursing facilities have a CPS of 6, compared to 1% in residential care or 3% at home); residential care services and home care services are provided primarily to people with early to mid stages of the disease.

### Cognitive Performance Scores (CPS) for People with Dementia by Service Setting



## Activities of Daily Living

Activities of daily living (ADLs) provide a way to measure the amount of assistance people need with bed mobility, transfer, locomotion, eating, toilet use, bathing and dressing.

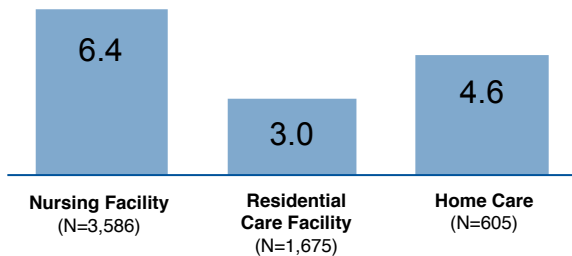
Counting the number of activities that require some level of supervision, assistance and/or physical help is one way to measure the level of care that people need.

Not surprisingly, people with dementia in nursing facilities have a high number of ADLs with which they need assistance. On average, people with dementia in nursing facilities need assistance or physical help with 6.4 out of 7 ADLs.

People in residential care facilities with dementia are much more independent. They need assistance with an average of only 3.0 of 7 ADLs.

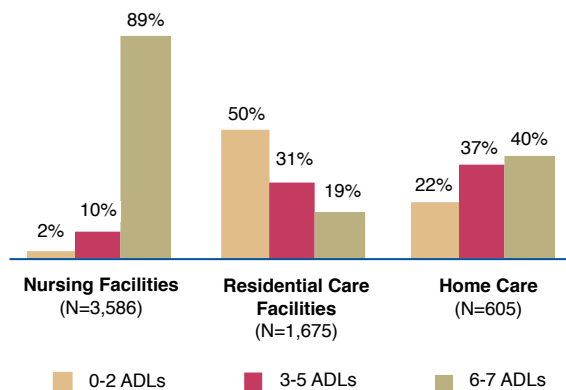
People receiving services at home need help with an average of 4.6 of 7 ADLs.

**Average ADL Count Among People with Dementia, by Service Setting**



The following table shows the distribution of the number of ADLs with which people with dementia need assistance by setting.

**Number of ADLs Requiring Assistance by People with Dementia, by Service Setting**



## Dementia and Other Chronic Conditions

People with Alzheimer's or dementia often have other chronic conditions that may need monitoring, supervision, or medical treatment.

Some of the more common conditions that people have include depression, arthritis, osteoporosis, diabetes, anxiety, congestive heart failure, emphysema and cancer. From a care perspective, it is important to consider the multiple conditions that may be affecting a person with dementia.

**Co-Existing Conditions People with Dementia**

Condition	Nursing Facilities N=3,586	Residential Care Facilities N=1,675	Home Care N=605
Depression	56%	42%	44%
Arthritis	38%	26%	55%
Osteoporosis	32%	23%	25%
Diabetes	24%	23%	34%
Anxiety	21%	16%	25%
Congestive Heart Failure	20%	13%	21%
Emphysema	18%	15%	15%
Cancer	9%	9%	12%

## Prevalence of Falls

People with dementia are at risk of falling. The following table shows the prevalence of falls among people with dementia by setting.

**Prevalence of Falls People with Dementia**

	Nursing Facilities N=3,586	Residential Care N=1,675	Home Care N=605
Fell in past 30 days	20%	16%	28%
Fell in past 31-180 days	41%	30%	46%

## Use of Hospice

Use of hospice services by people with dementia is still very low.

- 2.4% of people with dementia in nursing homes use hospice.
- 1.1% of people with dementia in residential care use hospice.
- The low utilization of hospice by people with dementia is consistent with the overall use of hospice in nursing homes and residential care facilities.

## Caregiver Characteristics

The Maine Alzheimer's Project provides support to caregivers and their families. Upon intake into the program, each caregiver is asked a number of questions about themselves and the person for whom they are caring. The following results are based on 442 interviews conducted with caregivers through the intake process at Maine's Area Agencies on Aging (AAAs) or with Elder Independence of Maine (EIM). This data represents all intake interviews completed as of March 2007.

The following are some of the characteristics of the clients for whom caregivers are caring. Caregivers were excluded from the denominator for questions where they did not provide an answer.

### Client Characteristics:

- 64% are female
- 47% are single or widowed
- 22% live alone

### Sons and daughters are major caregivers:

- 43% of caregivers were the child of the person with dementia
- 6% of caregivers were the son-in-law (1%) or daughter-in-law (5%) of the person with dementia

### Caregivers provide care during the week:

Caregivers provide an average of **17** hours per week of assistance with meal preparation, laundry and light housework

Caregivers provide an average of **11** hours per week of assistance with eating, bathing, dressing and toileting

### Caregivers provide care at home for as long as 2 to 5 years and more:

- 34% of caregivers had been providing assistance for 2 to 4 years
- 31% of caregivers had been providing assistance for 5 or more years

## Caregiver Burden

Caregiving is stressful for family members and friends. In a national study, 40% of caregivers reported high levels of emotional stress.<sup>1</sup> Results from intake interviews with caregivers in Maine illustrate the challenges that caregivers face.

### Caregiving has an impact on employment and health status:

- 14% of caregivers said they reduced their work hours
- 33% of caregivers reported that their health was fair or poor
- 25% of caregivers reported that their health was very good or excellent

### Caregivers help with all types of activities of daily living and instrumental activities of daily living. Some of the more common activities are:

- 79% of caregivers helped the client with meal preparation
- 76% of caregivers helped the client with laundry/light housework; banking and money matters
- 74% of caregivers helped the client with transportation for appointments or shopping
- 66% of caregivers helped the client with taking medications
- 58% of caregivers helped the client with bathing
- 53% of caregivers helped the client with dressing
- 40% of caregivers helped the client with toileting

### Caregivers are coping with many challenging behaviors. Some of the more common behaviors and situations that caregivers cope with are as follows:

- 76% of clients repeated questions/stories
- 55% of clients had a bowel or bladder accident at least one day in the past week
- 52% of caregivers had to deal with their relative clinging or following them around at least one day in the past week
- 38% of clients became restless or agitated
- 28% of clients kept the caregiver up at night
- 26% acted depressed or downhearted
- 15% became suspicious or believed someone was going to harm him/her
- 12% swore or used foul language
- 11% wandered
- 3% threatened people
- 1% showed sexual behavior or interest at wrong time or place

## Summary

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It is clear that caring for people with Alzheimer's disease and dementia is a growing public health issue. Alzheimer's is a progressively deteriorating disease that can last anywhere from 1 to 15 years. Families are the primary caregivers and will continue to need support to manage the care of their loved ones, to coordinate services within the long term care system and to maintain their own health and well-being. The impact of the increase in the age of the population and the number of people with Alzheimer's disease will extend to:

**Family members and friends** – Most care is provided at home by family members and friends. Finding creative ways to support families and friends who provide care will be an ongoing challenge. Technology, in the form of websites that connect caregivers, and other technological advances, may provide promise in extending the reach of a person's natural support system.

**Employers** – Many caregivers are employed and need to take time off or reduce hours to care for their family members. The stress of caring for a person with Alzheimer's has an impact on the caregiver's health and productivity when working.

**Direct Care Workers** – Maine has invested in the training of direct care workers throughout the long term care system using the model practice of Best Friends™ Training. Direct care workers will continue to be a backbone of the long

term care system that provides formal care to people with Alzheimer's. Maintaining and training direct care workers will be a critical component of plans to meet the needs of people with Alzheimer's.

**Long term care system** – Nursing homes and residential care facilities are major providers of care for people with Alzheimer's or dementia. Much of this care is paid for through the MaineCare program or state funds. The long term care system will need to be able to adopt and respond to promising practices and new models for caring for people with dementia. Payment strategies that can be sustained to support services will need to be examined.

**Medical and Research Community** – New advances in treatments, medications, and diagnostic techniques will undoubtedly reshape the way people are cared for and the progression of the disease. Emerging research on the relationship between Alzheimer's and other diseases (such as diabetes); the impact of exercise on the progression of the disease; and advances in understanding the genetics of Alzheimer's—will continue to provide hope for the millions of people who are living with or caring for someone with the disease.

## Endnotes

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- 1 *Fact Sheet: Alzheimer's Disease Statistics*. Chicago: Alzheimer's Association; 2006.
- 2 Houser, Ari, et. al. *Across the States: Profiles of Long-Term Care and Independent Living—Maine*. Washington, DC: AARP Public Policy Institute; 2006.
- 3 *Alzheimer's Disease Facts and Figures 2007*. Chicago: Alzheimer's Association; 2007.
- 4 Alzheimer's Association. Stages of Alzheimer's. Available at: [http://www.alz.org/alzheimers\\_disease\\_stages\\_of\\_alzheimers.asp](http://www.alz.org/alzheimers_disease_stages_of_alzheimers.asp). Accessed March 21, 2007.

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## Maine Alzheimer's Project is a collaboration among many providers and community-based aging agencies. The Maine Alzheimer's Project partners with:

- Elder Independence of Maine's Caregiver Companion Program to support caregivers.
- Maine's 5 Area Agencies on Aging to provide information, assistance, counseling, respite care and referral to mental health and hospice services.
- Maine Alzheimer's Association to provide caregiver and provider training.
- Maine Hospice Council to provide end-of-life training.
- Physician consultants to provide consultation on dementia and end-of-life care to families and professionals.
- The Office of Elder Services to provide funds for additional project support, Partners in Caring Respite Program and the Best Friends™ Training Program.

- The Office of Licensure and Regulatory Services to provide support for the Best Friends™ Training offered throughout the state.
- USM Muskie School of Public Service to provide evaluation, data analytic support and staff support.

**For more information on the Maine Alzheimer's Project, contact Romaine Turyn at 287-9214 or at [Romaine.Turyn@maine.gov](mailto:Romaine.Turyn@maine.gov).**

## Acknowledgements

This brief was prepared by a team from the USM Muskie School of Public Service in consultation with staff from the Maine Alzheimer's Project at the Maine Department of Health and Human Services.

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