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Dementia in Maine: Characteristics, Care and Cost Across Settings. 2013

Maine Office of Aging and Disability Services

Maine Department of Health and Human Services

2013

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Characteristics, Care, and Cost Across Settings

- Nursing Facilities
- Residential Care Facilities
- At Home

PREPARED BY:
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Office of Aging and Disability Services
Maine Department of Health and Human Services

UNIVERSITY OF SOUTHERN MAINE
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Contents

INTRODUCTION

Dementia can no longer be neglected but should be considered a part of the public health agenda in all countries.

The World Health Organization and Alzheimer's Disease International have recommended that dementia be considered a public health priority for all nations[1]. The increased number of people with dementia combined with the cost of care and economic burden on families and social systems will place dementia in the forefront of policy and planning decisions for the future. In the U.S, state policy makers and Medicaid agencies, in particular, will be the focal point for these discussions and funding decisions.

Dementia is a disabling disease for the people who have it and is devastating for the family members and friends who know and care for those with the disease. As the disease progresses, so does the need for greater supervision, more help with activities of daily living, and eventually help with palliative and end of life care. People with dementia live with the disease on average four to eight years with some living as long as 20 years[2]. The duration and degenerative nature of the disease place significant strain on family members, caregivers and friends.

The risk of Alzheimer's and dementia increases with age. It is estimated that 18% of people between ages 75 to 84 have Alzheimer's disease; and 32% of people over 85. Overall, approximately 12% of people over 65 and 4% of people under 65 have Alzheimer's disease.[3] As the number of people over age 65 continues to grow, the number with dementia will increase significantly.

As the primary payer of long term care services, state Medicaid programs will bear much of the impact of the increasing number of people with dementia. National estimates suggest that much of this time will be spent in a nursing home where nursing home admission by age 80 is expected for 75 percent of people with Alzheimer's disease compared with only 4 percent of the general population. Furthermore, "an estimated two-thirds of those dying with dementia do so in nursing homes compared with 20 percent of cancer patients and 28 percent of people dying from other conditions."[4] The cost of caring for people with dementia has the potential to drain the savings and retirement funds of those with private resources.

What will this mean for Maine? The number of people with Alzheimer's disease in Maine is expected to nearly double from about 26,000 persons in 2010 to nearly 50,000 by 2030.

The number of people with dementia in Maine is expected to almost double between 2010 and 2030.

As the oldest state in the nation, Maine faces the impending impact of this disease on its social systems, community resources and its health and long term care systems. While remaining at home is the overwhelming preference for people needing long term services and supports, the increasing need for supervision and

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1 World Health Organization and Alzheimer's Disease International. Dementia: A Public Health Priority. Geneva: World Health Organization: 2012.

2 Alzheimer's Association, 2012 Alzheimer's Disease Facts and Figures, Alzheimer's & Dementia, Volume 8, Issue 2; p. 25.

3 Hebert, Liesi E., Weuve, Jennifer, Scherr, Paul A., et. al.,"Alzheimer disease in the United States (2010-2050) estimated using the 2010 census, *Neurology*, published online Feb. 6, 2013 at www.neurology.org

4 Alzheimer's Association, p. 25.

support with incontinence care, transfer, locomotion and eating makes living at home increasingly difficult particularly for those with dementia who live alone and/or who don't have a family caregiver.

In looking at the service and use patterns in this report, it is clear that Maine's long term care system is increasingly becoming a system of care for people with dementia. Across all long term care settings combined, almost half of the people served have some form of Alzheimer's or dementia. The proportion of people with dementia increases with each higher level of care. Two-thirds of the people in nursing homes have a diagnosis of dementia. If those with impaired decision making skills are also included, 8 out of 10 people in nursing homes either have dementia or impaired decision-making. This trend is expected to continue and will place pressure on policy makers, providers, practitioners and others to examine the impact and implications for Maine's public health, health care and long term care systems.

Policy makers nationally are calling for development of "dementia capable systems of care".[5] The Office of Aging and Disability Services of the Department of Health and Human Services has recently received grant funding to further this work in Maine. A dementia capable system of care has been defined as one that can provide the broad range of services required at the very earliest onset, through years of caregiving, to the final stages of the disease. This includes:

- the provision of information and assistance and options counseling for people with dementia and their families;
- the development of eligibility criteria that take into account the impact of dementia on the need for services;
- the ability of the service system to address the unique needs of people with dementia;
- the availability of self-directed services for people with dementia and their families;
- appropriate training for all levels of direct care workers and professionals; and
- quality assurance systems that measure the effectiveness of the service systems for serving people with dementia.

This report provides a baseline picture of the current use of services by people with and without dementia in Maine. While this provides a comprehensive view of those accessing services through state funded home care programs or other MaineCare funded long term care services, it does not include the costs of informal care by caregivers, friends and family members. Nor does it include the out-of-pocket costs that many incur with private resources to care for a family member. We hope, however, that this information will be useful to those who are planning for the future of Maine's long term care system and the needs of people with dementia and their families and caregivers.

[5] Tilley, Jane; Wiener, J.; Gould, E.; O'Keeffe, J.; Making the Long-Term Services and Supports System Work for People with Dementia and Their Caregivers, November 2011.

ABOUT THIS REPORT: DATA AND FORMAT

DEFINITION OF ALZHEIMER'S OR DEMENTIA: The data provided in this report provides a unique look at the cost and use of services across Maine's long term care system. This report looks at the current impact of dementia on services provided at home, in residential care settings and in nursing facilities. For purposes of this report, we compare people with and without dementia. We define those with dementia to include people who have a diagnosis of Alzheimer's Disease or a diagnosis of dementia other than Alzheimer's Disease in the diagnosis section of each assessment tool used across Maine's LTSS System.

USE OF COMMON ASSESSMENT DATA ACROSS SETTINGS: Maine is fortunate in that a common set of data elements are used as part of the assessment process for people receiving state funded or MaineCare funded services at home; and for all residents of residential care and nursing facilities. This makes it possible to examine the characteristics of people with Alzheimer's or dementia across settings using common terms and coding conventions. For purposes of this report, we examine the characteristics of people with and without Alzheimer's or dementia based on assessment data from the three sources; the MED assessment (Maine's in-home assessment instrument), the MDS-RCA (the assessment instrument for residential care) and the MDS for nursing homes. The MED assessment included people using MaineCare and state-funded home care services any time during 2010. MDS-RCA assessment data included all residential care residents listed on facility roster as of March 15, 2010. The MDS 2.0 assessments included nursing facility residents listed on facility rosters as of March 15, 2010, except for 831 residents, most of whom were on a Medicare short stay, and whose most recent assessment was a partial assessment that does not record information on dementia. The report does not include people in adult family care homes. We also examine selected other characteristics of people with and without dementia based on items from the three assessment instruments.

USE OF JEN ASSOCIATES iMMRS SYSTEM AND LINKAGE OF DATA: JEN Associates linked the MaineCare data and the Medicare data for SFY 2010. The Department of Health and Human Services provided JEN Associates with the IDs of people with and without dementia, as identified from the core assessment data described above. Additional data items from the assessment data, relevant to the analysis, were also included in the data set provided to JEN Associates (e.g. falls, challenging behaviors, chronic conditions). Once the full data set including the linked Medicare and MaineCare data and the assessment data was created by JEN Associates, we used the JEN data analytics tool called iMMRS to conduct our analysis, using a de-identified data set. Thus, we were able to examine the MaineCare and Medicare cost and use of services for people with and without dementia across long term care settings. Because we did not have to rely on a claims-based diagnosis of dementia, but could use the diagnosis from the assessment instruments, we believe we were able to create a more accurate profile of the use of services by people with dementia in Maine's long term care system.

POPULATIONS OF ANALYSIS: In reviewing this report, the reader should take note that the data reported in Sections 1 through 3, includes **all people who receive any state funded or MaineCare funded home care services; and includes all residents (regardless of payer source**) in residential care and all people in nursing facilities, except short-stay Medicare residents. In Sections 4 and 5, the data covers those who are **eligible and receiving MaineCare** services including those who are dually eligible for both MaineCare and Medicare services. For this reason the number of people in each setting in Sections 1-3 will not match the number of MaineCare people reported in Sections 4 and 5.

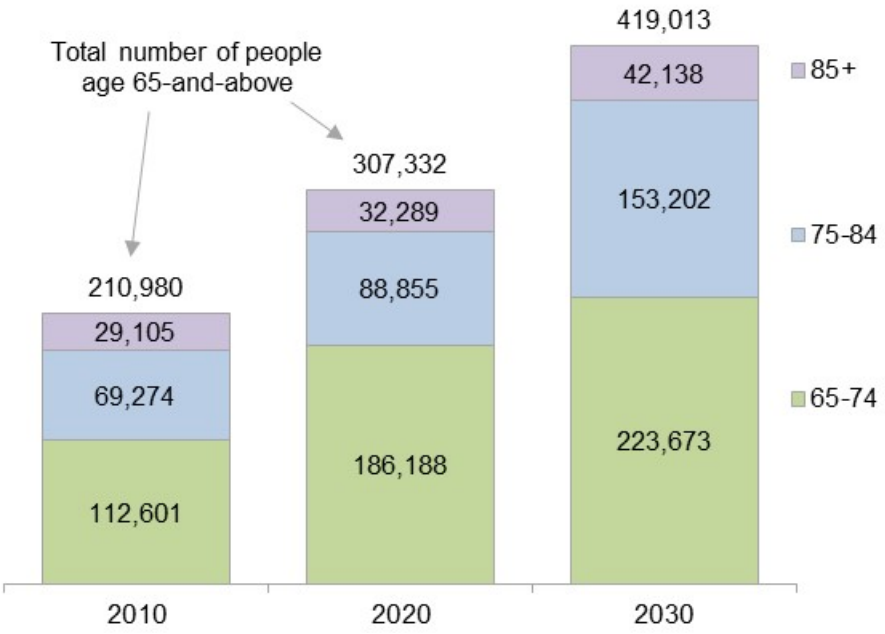
MaineCare Claims Data for Residential Care and Nursing Facilities. In 2010, MaineCare paid for residents in nursing facilities based on a facility-specific case mix payment method. This method identifies a case

mix group for each resident (based on a combination of diagnosis, condition, behavior needs and ADL needs). Each case mix group has an associated case mix index. Based on the MaineCare residents in the facility, an overall average case mix index is created for each facility at a point in time. The facility is paid an average cost per day adjusted for the overall case mix of MaineCare residents in the facility. For this reason, the nursing facility costs in this report will reflect the case mix adjusted costs for each facility, on average, but a claim for an individual person will not reflect the case mix adjusted cost for that individual. A similar method is used in residential care. In 2010, the method of payment to nursing homes changed such that payment to a nursing facility for an individual resident reflects the case mix group for that resident. For this reason, the nursing facility and residential care costs reflected in this report reflect case mix adjusted costs for each facility on average, but a claim for an individual person will not reflect the case mix adjusted costs for that individual.

OVERVIEW OF REPORT SECTIONS: **Section 1** of the report provides population projections for those age 65 and over from 2010 to 2030 and projects the use of long term services and supports for people with dementia in 2020 and 2030. **Section 2** examines the characteristics of people with and without dementia across the three long term care settings**. Section 3** takes a closer look at the characteristics of people with dementia in a home care setting. **Section 4** reports on the MaineCare and Medicare costs for people with and without dementia; and **Section 5** examines the chronic conditions and service use of people with dementia.

Section 1: Maine population trends signal more people with dementia

Figure 1-1: Maine's population over age 65 is projected to double between 2010 and 2030, with the greatest growth in the age 65-74 age group.

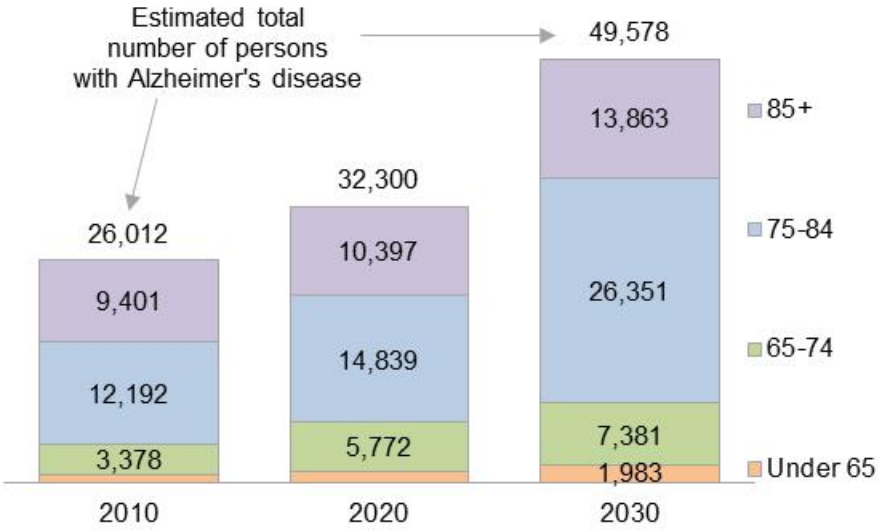


In 2012, Maine ranked 2nd among states in the percent of people age 65 and over. In 2012, 16.8% of Maine's population was over 65 compared with 13.6% for the U.S[6]. Between 2010 and 2030, the number of people 65-and-over is expected to double.[7] The age group with the greatest increase in number of people is the 65-74 group where the number of people is expected by grow by over 111,000. The age cohort of people 75-84 shows the greatest percent growth and will increase by almost 84,000 people or over 121%. The age cohorts with the greatest prevalence of dementia (between ages 75-84 and over age 85) will begin to see the greatest increases in 2030 and beyond.

[6] AARP, Across the States, Profiles of Long Term Services and Supports: Executive Summary, State Date, and Rankings, 2012.

[7] © 2011 Woods and Poole Economics, Inc., "2012 New England State Profile: State and County Projections to 2040", Woods & Poole does not guarantee the accuracy of this data. The use of this data and the conclusions drawn from it are solely the responsibility of the Muskie School at USM.

Figure 1-2: The size of Maine's Alzheimer's population is expected to nearly double in the twenty years between 2010 and 2030. *[NOTE: This forecast does not include other dementias.]*



Using national estimates of the prevalence of Alzheimer's Disease by age group, we project that the number of people with Alzheimer's Disease in Maine will nearly double from 26,012 to 49,578. Our estimates are based on the population projections and prevalence estimates displayed in Table 1-1.

Table 1-1: Estimate and forecasts of Maine's Alzheimer's population from 2010 to 2030

Age Group	Maine Population[8]			Nat'l. Alz Prevalence Rates[9]			Maine Persons with Alz.		
	2010	2020	2030	2010	2020	2030	2010	2020	2030
Under 65	*= 4% of total for all ages*						1,040	1,292	1,983
Age 65+	210,980	307,332	419,013	11.9%			24,971	31,008	47,595
65-74	112,601	186,188	223,673	3.0%	3.1%	3.3%	3,378	5,772	7,381
75-84	69,274	88,855	153,202	17.6%	16.7%	17.2%	12,192	14,839	26,351
85+	29,105	32,289	42,138	32.3%	32.2%	32.9%	9,401	10,397	13,863
All Ages							**26,012**	**32,300**	**49,578**
Increase in number of persons with Alzheimer's disease since 2010								24%	91%

Table 1-1 displays the population forecasts and Alzheimer's age-specific Alzheimer's disease prevalence rates that led to the Maine Alzheimer's estimates and forecasts illustrated by the chart in Figure 1-2 on the previous page.

METHOD: The national Alzheimer's prevalence rates are based on the same 2013 study that the Alzheimer's Association uses for their estimates and forecasts of the size of the U.S. Alzheimer's population. These studies used existing data from the Chicago Health and Aging Project (CHAP), a longitudinal study of a random sample of Chicago-area residents over age 65. CHAP participants had been measured by various characteristics and given a multi-year series of clinical evaluations for Alzheimer's.

This data from CHAP was used to estimate the prevalence and future incidence of Alzheimer's disease by year of age, gender, race, and education level. The calculated rates were then applied to the same variables in Census 2010 and the Census Bureau's American Community Survey to estimate and forecast the overall National Alzheimer's rates by 10-year age groups, for 2010 and future years.[9]

We then took those national rates and applied them to age-specific population forecasts for Maine, supplied by Woods & Poole Economics.[9]

RESULTS: Given the projected increase in Maine's older population, especially within the 75-to-84 age group, we expect to see a near doubling of Maine's Alzheimer's population within the twenty years between 2010 and 2030. We should note that while our estimate of Maine's Alzheimer's population in 2010 is close to the Maine estimate published by the Alzheimer's Association, our growth projections differ considerably. The Association forecasts that Maine will have only 28,000 persons with Alzheimer's by 2025,[10] the mid-point between our 2020 and 2030 projections. This difference is likely due to several factors. The Association's state-specific estimates are still based on a 2004 study using Census 2000 data, earlier CHAP data and older population forecasts. Woods and Poole use different forecasting methods and combine a greater variety of population data and growth indicators.

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[8] © 2011 Woods and Poole Economics, Inc., "2012 New England State Profile: State and County Projections to 2040", Woods & Poole does not guarantee the accuracy of this data. The use of this data and the conclusions drawn from it are solely the responsibility of the Muskie School at USM.

[9] Hebert, Liesi E., Weuve, Jennifer, Scherr, Paul A., et. al.,"Alzheimer's disease in the United States (2010-2050) estimated using the 2010 census, *Neurology*, published online Feb. 6, 2013 at www.neurology.org

[10] Alzheimer's Association, 2013 Alzheimer's Disease Facts and Figures, Alzheimer's & Dementia, Volume 9, Issue 2.

Figure 1-3: Among those 65 and above, persons with dementia were much more likely to use MaineCare and State-funded long term services and supports than persons without dementia in SFY 2010.

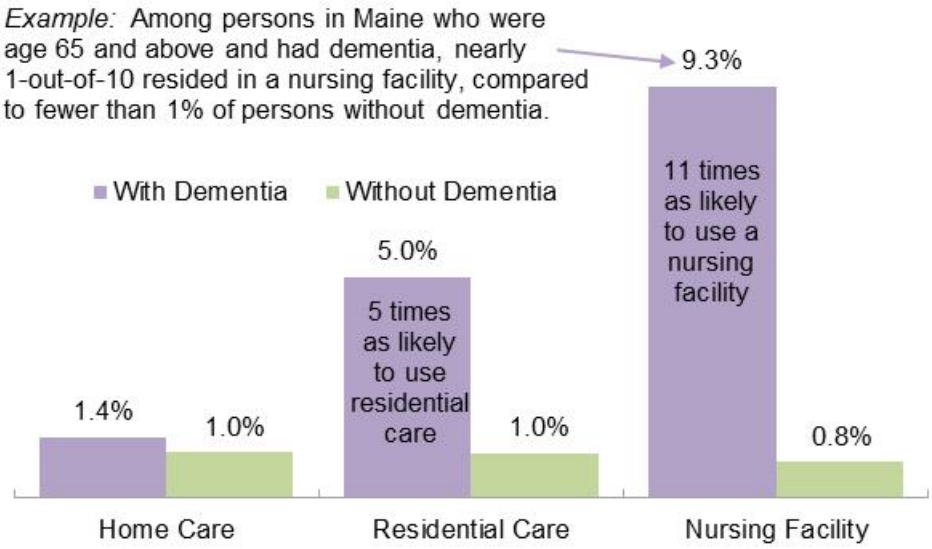


Table 1-2: Number of persons in Maine, age 65 and above, receiving long term services and supports (LTSS), as a percentage of the estimated number of persons, age 65 and above, who had or did not have dementia in SFY 2010.

Age 65 and above	Number of persons	MaineCare members using LTSS, by setting:					
		Number of members			As a percent of population		
Population 65+[11]	210,980	Home Care	Residential Care	Nursing Facility	Home Care	Residential Care	Nursing Facility
with Alzheimer's[12]	24,971						
with any dementia[13]	35,732	488	1,789	3,328	1.4%	5.0%	9.3%
without dementia	175,248	1,791	1,746	1,423	1.0%	1.0%	0.8%

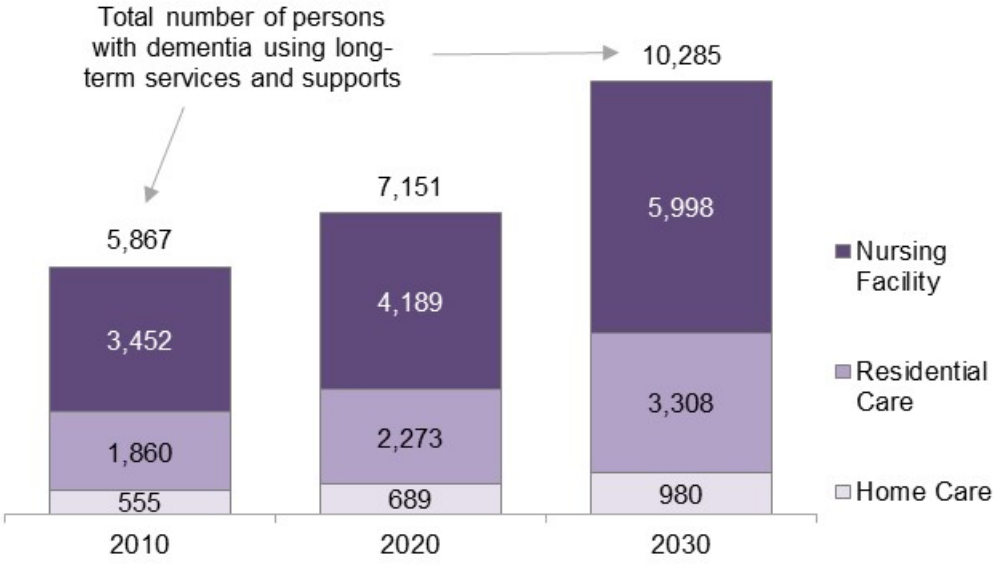
In Table 1-2, the estimate of 24,971 persons age 65 and above with Alzheimer's comes from Table 1-1 on the preceding page. We arrived at the number of persons in that age group with any type of dementia by applying the Aging, Demographics and Memory Study (ADAMS) national estimate that the number of persons, age 71 and above, with Alzheimer's disease was 70% of the total number of persons with all dementias. The estimated number of persons without dementia is the population total, minus the estimated number of persons with dementia. We arrived at the percentages by dividing the number of persons with (or without) dementia in each setting by the number of all persons with (or without) dementia.

[11] © 2011 Woods and Poole Economics, Inc., "2012 New England State Profile: State and County Projections to 2040", Woods & Poole does not guarantee the accuracy of this data. The use of this data and the conclusions drawn from it are solely the responsibility of the Muskie School at USM.

12 Op.cit., Hebert, Liesi, et.al.

13 B.L. Plassman, K.M. Langa, G.G. Fisher, S.G. Heeringa, D.R. Weir, M.B. Ofstedal, J.R. Burke, M.D. Hurd, G.G. Potter, W.L. Rodgers, D.C. Steffens, R.J. Willis, and R.B. Wallace, *Prevalence of Dementia in the United States: The Aging, Demographics, and Memory Study*, Neuroepidemiology 2007, vol. 29, pp. 125–132

Figure 1-4: Projected use of long term services and supports for persons of all ages with dementia, from 2010 to 2030[14]



An aging population will lead to increasing numbers of persons with dementia, and increasing demand for long term services and supports (LTSS) across all settings. Assuming current use rates, no change in current programs, and that age-specific prevalence rates remain unchanged, the overall demand for LTSS for persons with dementia is likely to grow by 75% between 2010 and 2030.

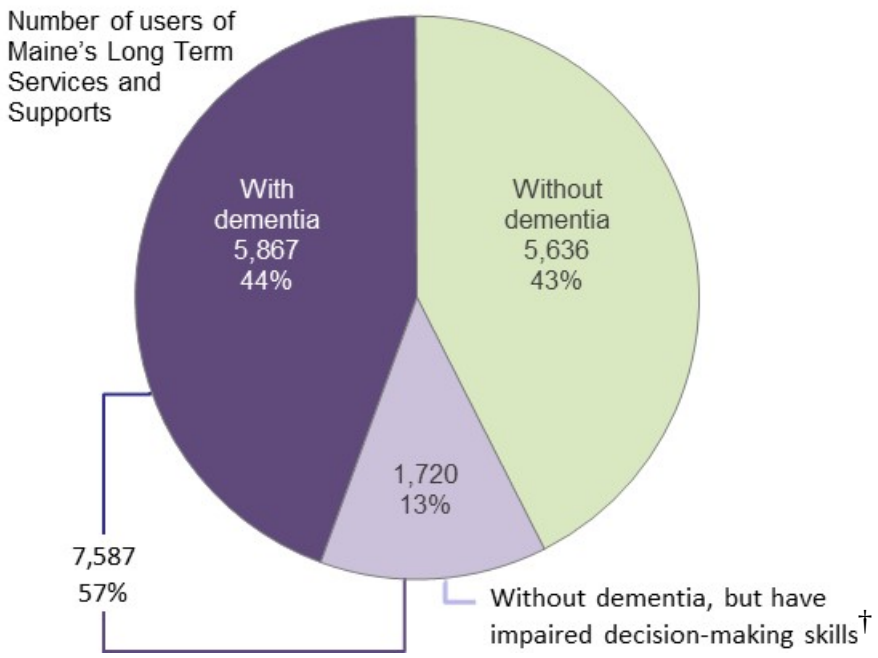
In just the ten years between 2010 and 2020, demand by persons with dementia in the home care setting is forecast to grow from 555 to 689, an increase of 24%. The number of people in residential and nursing facility care is expected to increase as well. The number of people with dementia in residential care is expected to grow from 1,860 to 2,273, an increase of 22%; and the number of people in nursing facilities is expected to grow from 3,452 to 4189, an increase of 21%.

These projections were made by calculating the percentage of the total 2010 population within four age groups (under 65, 65 to 74, 75 to 84, and 85 and above) who were service users with dementia in each of the three LTSS settings. We then applied those percentages to the population forecast, to project the future number of service users with dementia in each age group, and then summed the results across all four age groups.

[14] © 2011 Woods and Poole Economics, Inc., "2012 New England State Profile: State and County Projections to 2040", Woods & Poole does not guarantee the accuracy of this data. The use of this data and the conclusions drawn from it are solely the responsibility of the Muskie School at USM.

Section 2: Characteristics of people with dementia

Figure 2-1: In SFY 2010, 44% of Maine's 13,223 users of long term services and supports (LTSS), had Alzheimer's disease or dementia.*



Across all settings of long term services and supports (LTSS), including nursing facilities, residential care facilities and at home, almost half (44%) of long term service users in Maine had some form of Alzheimer's disease or dementia in State Fiscal Year 2010. When individuals who do not have dementia, but who have moderately or severely impaired skills for daily decision making are included, the percent of people with cognitive impairment across all settings increases to 57%.

The high percentage of people in the long term care system with dementia highlights the impact of dementia on Maine's long term care system.

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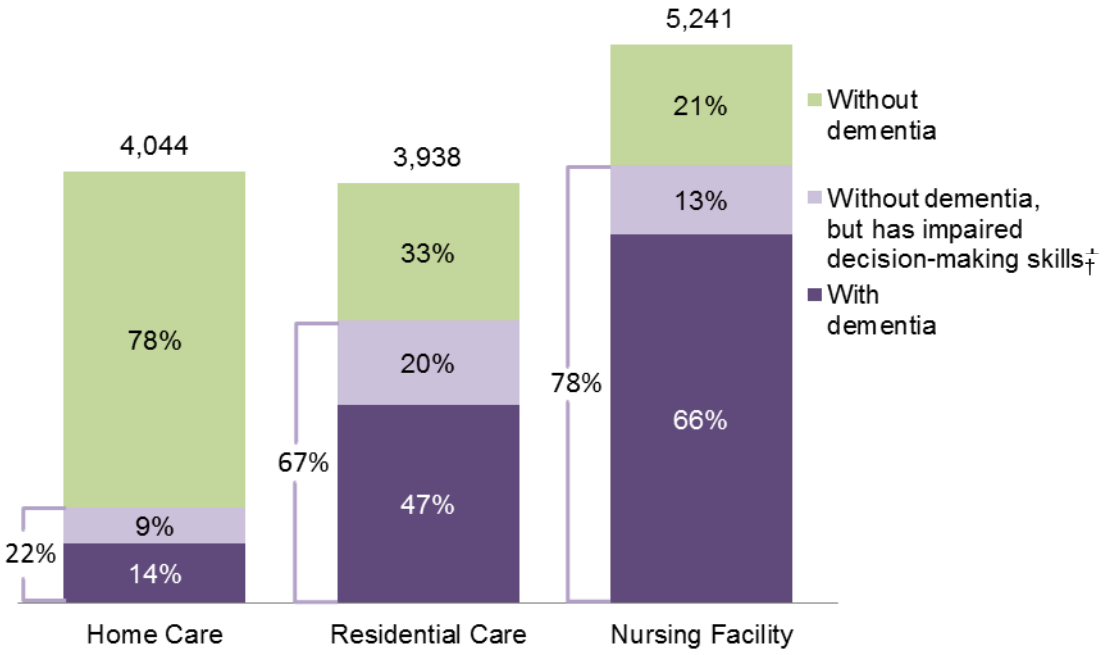
* For purposes of this report, people with Alzheimer's or dementia include people who have a diagnosis of Alzheimer's Disease or a diagnosis of Dementia other than Alzheimer's indicated in the Diagnosis Section of each assessment tool.

† Persons assessed with having moderately or severely impaired Cognitive Skills for Daily Decision Making

Sources: MED assessment data for persons using MaineCare or state-funded home care services at any time during SFY 2010. MDS-RCA assessment data for all residential care residents listed on facility roster as of March 15, 2010. MDS 2.0 assessments for all nursing facility residents listed on facility rosters as of March 15, 2010 except for 831 residents, most of whom were on a Medicare short stay, and whose most recent assessment was a partial assessment that does not record information on dementia.

Figure 2-2: In SFY 2010, nursing facilities served the highest proportion of people with dementia with more than two-thirds of nursing facility residents having dementia.



The proportion of people with dementia increases with each higher level of care. In residential care settings, almost half of the residents have dementia and in nursing facilities two thirds of the residents have dementia. If individuals who do not have an explicit diagnosis of dementia, but who have some impaired decision making skills are included, these percentages increase further – with almost two-thirds of people in residential care and three quarters of people in nursing facilities having either a diagnosis of dementia or impaired decision- making skills. According to national data, Maine ranks number 1 in the percent of people in nursing homes with dementia. [15]

Within the category of home care, the proportion of people with dementia varies greatly. Approximately one out of five people (21%) receiving Home Based Care or Elder and Adults Waiver services have dementia; whereas 9% of people receiving private duty nursing services; and less than 3% of people using consumer directed services or Physically Disabled Waiver services have dementia. People receiving care at home also may attend adult day programs. Of the 555 people receiving care at home, 170 had adult day in their service plan. Of these, 94 or 55% had dementia.

† Persons assessed with having moderately or severely impaired Cognitive Skills for Daily Decision Making

Sources: MED assessment data for persons using MaineCare or state-funded home care services at any time during SFY 2010. MDS-RCA assessment data for all residential care residents listed on facility roster as of March 15, 2010. MDS 2.0 assessments for all nursing facility residents listed on facility rosters as of March 15, 2010 except for 831 residents, most of whom were on a Medicare short stay, and whose most recent assessment was a partial assessment that does not record information on dementia. This does not include people in adult family care homes.

[15] AARP, Across the States, Profiles of Long Term Services and Supports: Executive Summary, State Date, and Rankings, 2012.

Figure 2-3: Across all LTSS settings, the percentage of persons age 65-and-above was higher among persons with dementia than persons without dementia.

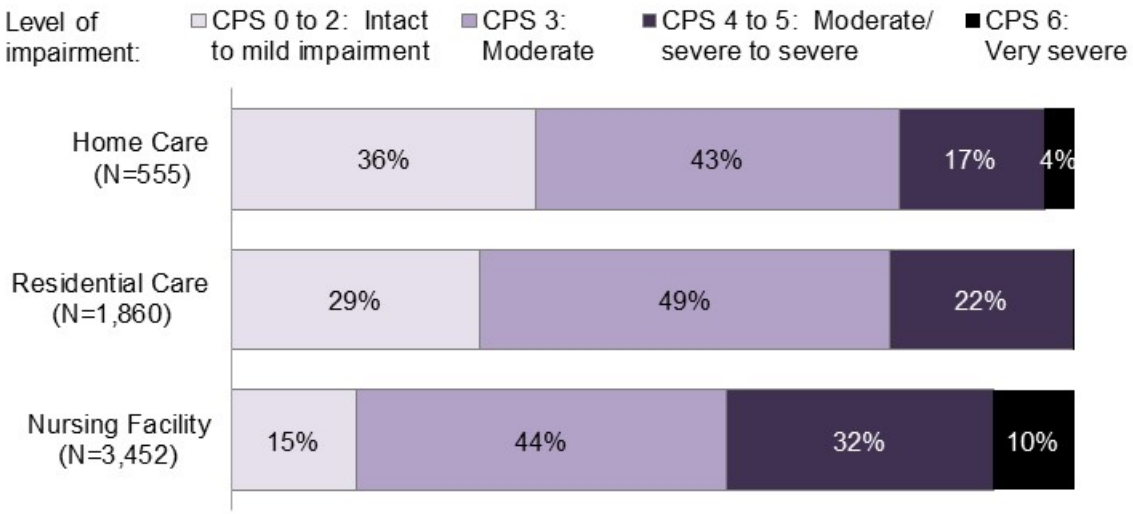
In the home care setting, 12% of people with dementia are under age 65; and 49% of people without dementia are under the age of 65. In the residential and nursing facility, less than 5% of people with dementia are under age 65.

Table 2-1: Distribution of LTSS service users by setting and by age group, SFY 2010

Age	All settings		Home Care		Residential Care		Nursing Facility	
	Dementia:		Dementia:		Dementia:		Dementia:	
	with	without	with	without	with	without	with	without
Under 65	279	2,400	67	1,710	74	332	138	358
65 and over	5,588	4,956	488	1,779	1,786	1,746	3,314	1,431
Total	5,867	7,356	555	3,489	1,860	2,078	3,452	1,789

Sources: MED assessment data for persons using MaineCare or state-funded home care services at any time during SFY 2010. MDS-RCA assessment data for all residential care residents listed on facility roster as of March 15, 2010. MDS 2.0 assessments for all nursing facility residents listed on facility rosters as of March 15, 2010 except for 831 residents, most of whom were on a Medicare short stay, and whose most recent assessment was a partial assessment that does not record information on dementia.

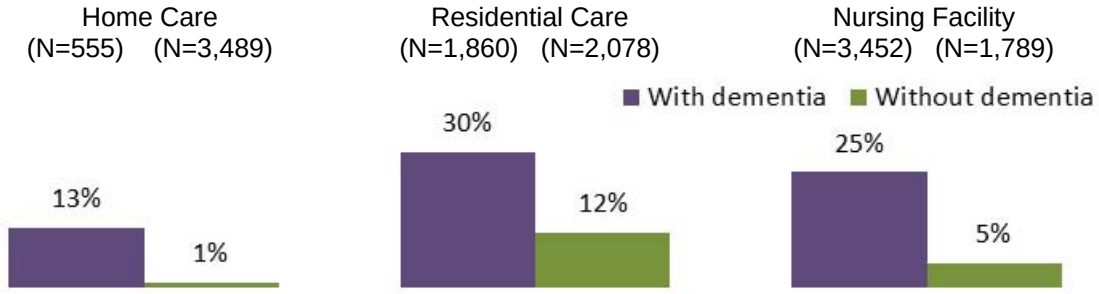
Figure 2-4: In SFY 2010, nursing facility residents with dementia were nearly twice as likely to have a cognitive performance score in the moderate-severe impairment category or higher, as LTSS service users in home care or residential care.



People living at home with dementia are more likely to have mild levels of cognitive impairment compared with people in residential care or nursing facilities.

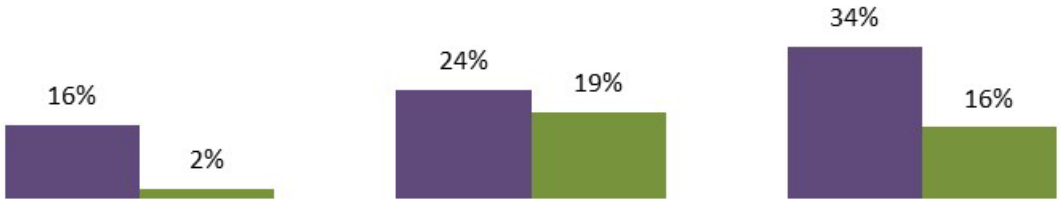
Sources: MED assessment data for persons using MaineCare or state-funded home care services at any time during SFY 2010. MDS-RCA assessment data for all residential care residents listed on facility roster as of March 15, 2010. MDS 2.0 assessments for all nursing facility residents listed on facility rosters as of March 15, 2010 except for 831 residents, most of whom were on a Medicare short stay, and whose most recent assessment was a partial assessment that does not record information on dementia.

Figure 2-5: Across all three LTSS settings, persons with dementia were usually more likely to display challenging behaviors, SFY 2010.



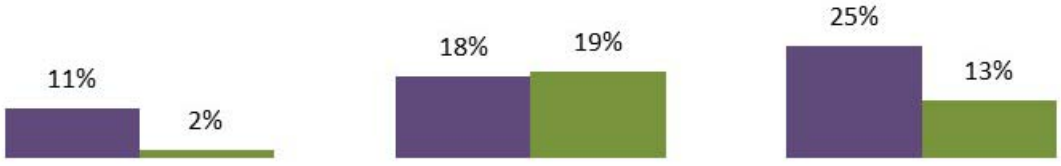
Wandered in the 7 days prior to assessment

Persons with dementia were far more likely than others to have wandered during one-or-more of the seven days leading up to their LTSS assessment. The residential care setting presented the highest risk of wandering for persons with and without dementia.



Resisted care in the 7 days prior to assessment

Persons with dementia who resided in a nursing facility were more likely to resist care than those in the residential and home care settings. In each setting, persons with dementia were more likely to resist care than those without dementia.

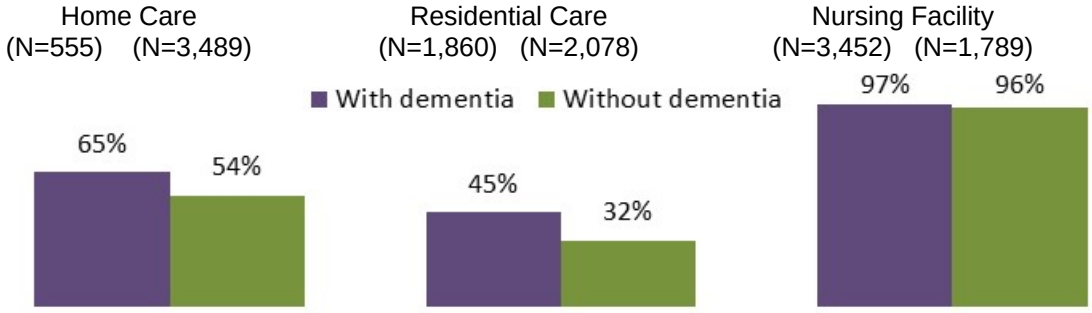


Displayed socially inappropriate or disruptive behavior in the 7 days prior to assessment

Persons with dementia receiving LTSS services in a home care setting were more likely than those without dementia to have displayed socially inappropriate or disruptive behavior. In residential care facilities, the percent of residents with socially inappropriate or disruptive behavior was similar for those with dementia (18%) compared with those without dementia (19%). One quarter (25%) of nursing facility residents with dementia displayed socially inappropriate or disruptive behavior compared with 13% of those without dementia.

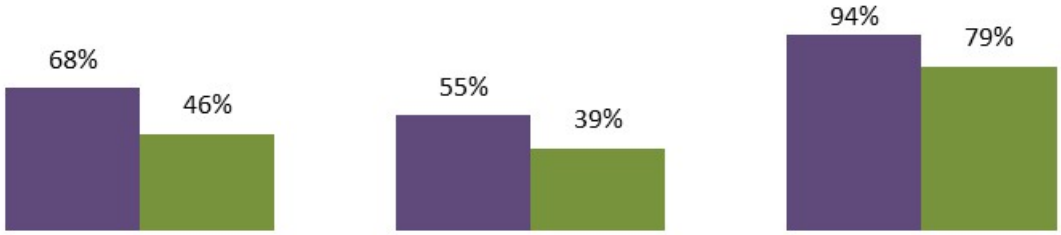
Sources: MED assessment data for persons using MaineCare or state-funded home care services at any time during SFY 2010. MDS-RCA assessment data for all residential care residents listed on facility roster as of March 15, 2010. MDS 2.0 assessments for all nursing facility residents listed on facility rosters as of March 15, 2010 except for 831 residents, most of whom were on a Medicare short stay, and whose most recent assessment was a partial assessment that does not record information on dementia.

Figure 2-6: Across all LTSS settings, persons with dementia were less likely to be independent in transferring and locomotion and more likely to have had falls, SFY 2010.



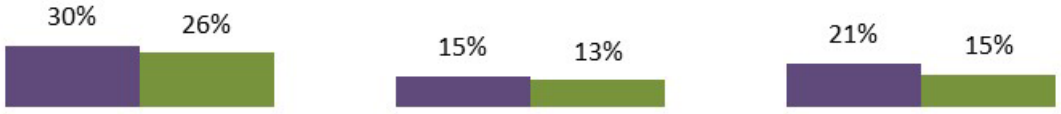
Percent of persons who were not independent (needed supervision, assistance or were totally dependent) in transferring in the 7 days prior to assessment

Two-thirds of people with dementia at home needed supervision or assistance with transferring compared with slightly more than half of the people without dementia. People in residential care settings had less need for supervision or assistance with transferring than those at home; although almost half of the people with dementia needed some kind of help with transferring.



Percent of persons who were not independent (needed supervision, assistance or were totally dependent) in locomotion in the 7 days prior to assessment

People with dementia at home were more likely to need supervision or help with locomotion (68%) compared with people with dementia in residential care settings (55%). Almost all people with dementia in nursing facilities needed supervision or assistance with locomotion.

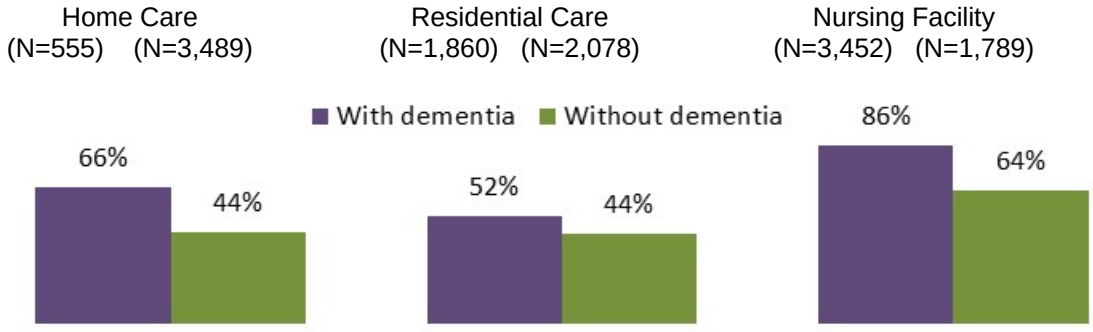


Percent of persons who had fallen in the 30 days prior to assessment

People at home (both with and without dementia) were more likely to have fallen in the last 30 days compared with people in residential care or nursing facility settings. Across all settings, people with dementia were more likely to have fallen than people without dementia.

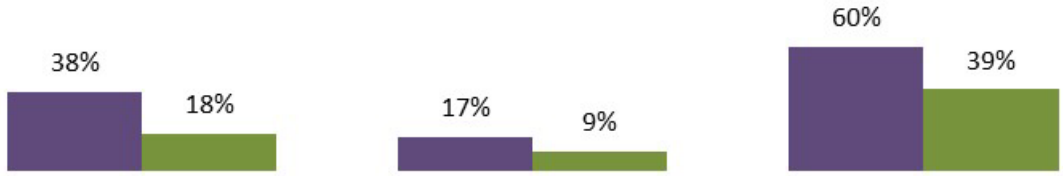
Sources: MED assessment data for persons using MaineCare or state-funded home care services at any time during SFY 2010. MDS-RCA assessment data for all residential care residents listed on facility roster as of March 15, 2010. MDS 2.0 assessments for all nursing facility residents listed on facility rosters as of March 15, 2010 except for 831 residents, most of whom were on a Medicare short stay, and whose most recent assessment was a partial assessment that does not record information on dementia.

Figure 2-7: Across all long term services and supports settings, persons with dementia were more likely to have incontinence in SFY 2010.



Percent of persons who had occasional or more frequent bladder incontinence

People with dementia at home were more likely to have bladder incontinence compared with people without dementia. People at home with dementia were also more likely than people with dementia in residential care facilities to have bladder incontinence.



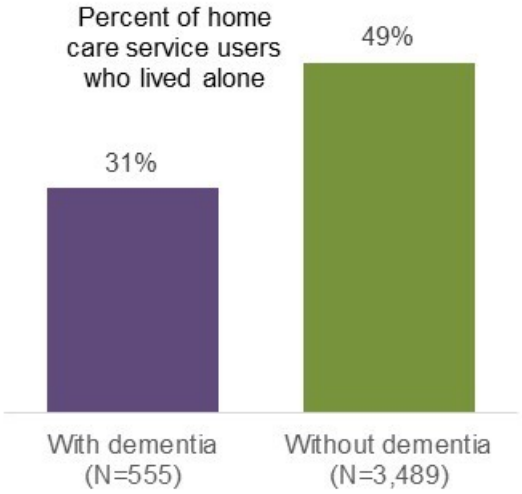
Percent of persons who had occasional or more frequent bowel incontinence

Similarly, people with dementia at home were more likely to have bowel incontinence compared with people without dementia. People with dementia in residential settings were more likely to have bowel incontinence than people without dementia in residential care; but they were also less likely than people with dementia at home.

Sources: MED assessment data for persons using MaineCare or state-funded home care services at any time during SFY 2010. MDS-RCA assessment data for all residential care residents listed on facility roster as of March 15, 2010. MDS 2.0 assessments for all nursing facility residents listed on facility rosters as of March 15, 2010 except for 831 residents, most of whom were on a Medicare short stay, and whose most recent assessment was a partial assessment that does not record information on dementia.

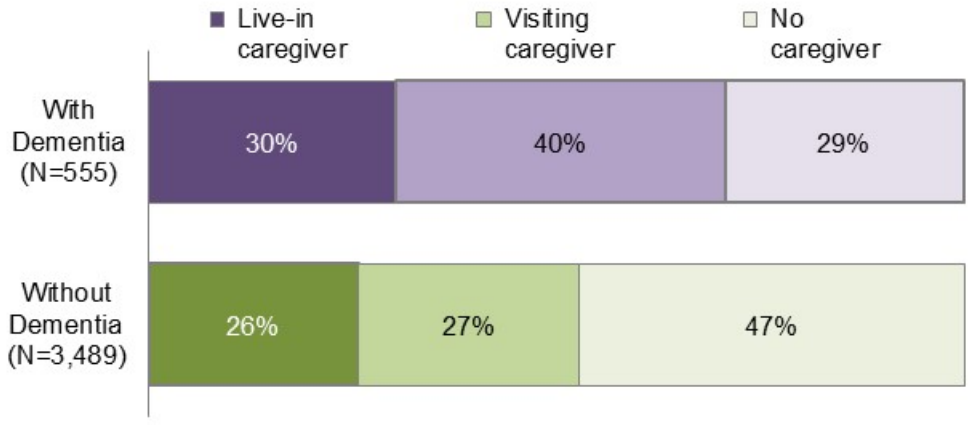
Section 3: People with dementia in a home care setting

Figure 3-1: In SFY 2010, almost half of the people without dementia who received services in a home care setting lived alone, while only 3-out-of-10 people with dementia did so.



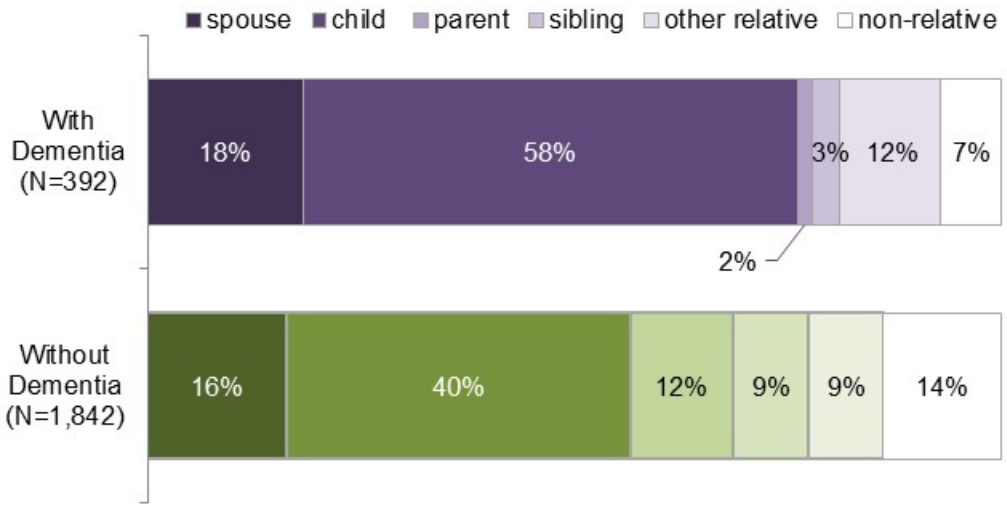
People with dementia who lived at home were less likely to live alone (31%) than those without dementia (49%). Of the 555 people with dementia at home, 173 lived alone. Of those 173 people living alone, 108 people (64%) had an identified informal caregiver and 65 did not. People at home include those receiving state funded Home Based Care; and people receiving MaineCare funded Elder and Adult Waiver Services, Private Duty Nursing services; and Waiver Services for those with physical disabilities.

Figure 3-2: Persons with dementia receiving services in their home were more likely than others to have unpaid live-in or unpaid visiting caregiver support, SFY 2010.



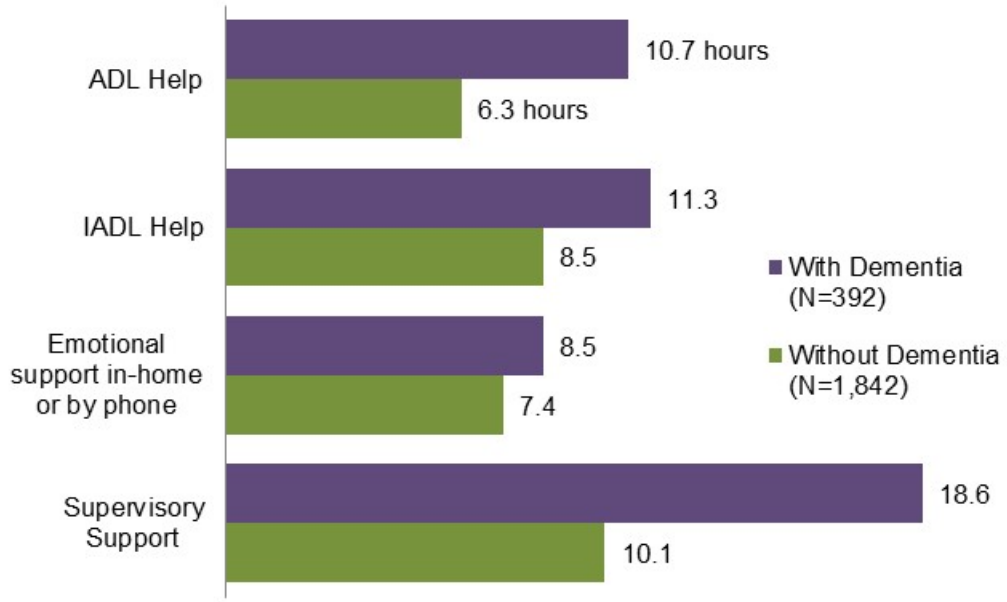
Source: MeCare assessment data for persons using MaineCare or state-funded home care services at any time during SFY 2010.

Figure 3-3: For persons receiving long term services and supports in a home setting and who also received informal support, those who had dementia were more likely than others to have received informal support from a child, and less likely to receive it from a parent, sibling or non-relative.



Most informal support for people with dementia at home was provided by either a spouse (18%) or a child (58%). People without dementia also rely heavily on a spouse (16%) or a child (40%). They also often have support from a parent or sibling. This is likely due to the fact that people without dementia receiving services in the home are more often younger (under age 65) than those with dementia.

Figure 3-4: Among persons who received unpaid caregiver support in the home, those with dementia received, on average, more hours of unpaid caregiver support per week than persons without dementia.

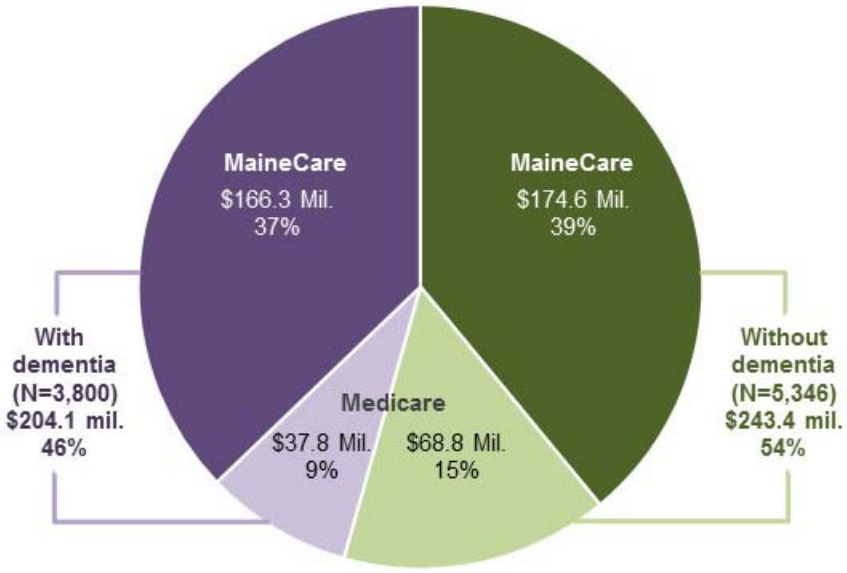


People with dementia needed the greatest number of hours of supervisory support (18.6 hours); followed by help with instrumental activities of daily living (IADLs) including laundry, housework, grocery shopping and meal preparation (1.3 hours) and Activities of Daily Living (ADLs) such as personal care help (10.7 hours). People with dementia received almost twice as many hours of supervisory support on average in a week, compared with those without dementia.

Sources: MeCare assessment data for persons using MaineCare or state-funded home care services at any time during SFY 2010.

Section 4: Annual expenditures for persons with dementia

Figure 4-1: Annual MaineCare and Medicare expenditures for MaineCare members using Long Term Services and Supports across all settings



MaineCare members with dementia represented approximately 42% (3,800 out of 9,146) of the people using long term services and 46% of the total MaineCare and Medicare expenditures in SFY 2010.

Table 4-1: Total MaineCare and Medicare Payments for MaineCare Members, SFY 2010

Payer	With Dementia (N=3,800)		Without Dementia (N=5,346)	
MaineCare	$166,322,439	(81%)	$174,617,397	(72%)
Medicare A-B	$37,814,175	(19%)	$68,759,155	(28%)
Total	$204,136,614	(100%)	$243,376,552	(100%)

MaineCare is the primary source of payment for people with and without dementia who use long term services and supports in Maine. MaineCare spent $166.3 million dollars for the support of people with dementia in SFY 2010. In contrast, Medicare expenditures for people with dementia were only $37.8 million. MaineCare expenditures for people with dementia using long term services and supports represented slightly more than 80% (81%) of total health and long term care spending.

Sources: MED assessment data for persons using MaineCare or state-funded home care services at any time during SFY 2010. MDS-RCA assessment data for all residential care residents listed on facility roster as of March 15, 2010. MDS 2.0 assessments for all nursing facility residents listed on facility rosters as of March 15, 2010 except for 831 residents, most of whom were on a Medicare short stay, and whose most recent assessment was a partial assessment that does not record information on dementia. We then used JEN Associates' Integrated Medical Management Research System (iMMRS®) to link members to MaineCare and Medicare claims data for SFY 2010.

Figure 4-2: Annual MaineCare expenditures for MaineCare members using Long Term Services and Supports (LTSS) by each setting, in SFY 2010

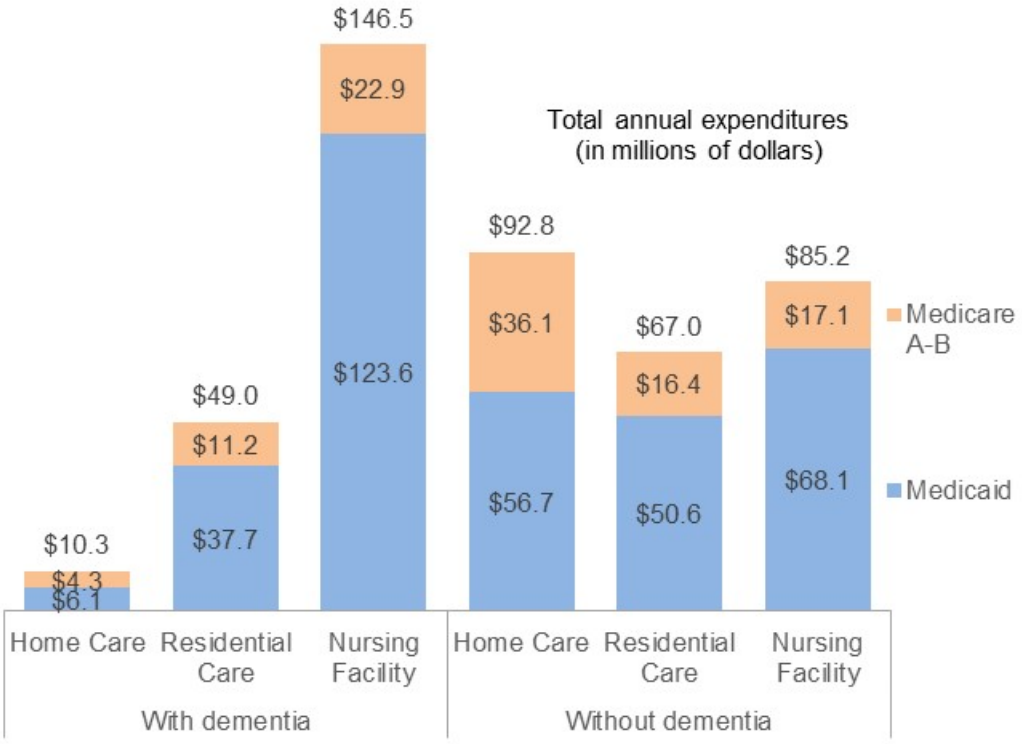
Three quarters of MaineCare's spending for people with dementia using LTSS is expended in nursing homes. MaineCare spent $123.6 million on care for people with dementia in nursing facilities in SFY 2010. LTSS spending for people without dementia is more evenly divided between home care, residential care and nursing facility care.

Table 4-2: Total annual MaineCare expenditures (in millions) for MaineCare members using LTSS, by setting, SFY 2010

	Home Care	Residential Care	Nursing Facility	Total
With dementia	$6.1 mil. (4%)	$37.7 mil. (23%)	$123.6 mil. (74%)	$167.4 mil. (100%)
Without dementia	$56.7 mil. (32%)	$50.6 mil. (29%)	$68.1 mil.(39%)	$175.5 mil. (100%)
Total	$62.8 mil. (18%)	$88.4 mil. (26%)	$191.7 mil. (56%)	$342.9 mil. (100%)

Sources: MED assessment data for persons using MaineCare or state-funded home care services at any time during SFY 2010. MDS-RCA assessment data for all residential care residents listed on facility roster as of March 15, 2010. MDS 2.0 assessments for all nursing facility residents listed on facility rosters as of March 15, 2010 except for 831 residents, most of whom were on a Medicare short stay, and whose most recent assessment was a partial assessment that does not record information on dementia. We then used JEN Associates' Integrated Medical Management Research System (iMMRS®) to link members to MaineCare and Medicare claims data for SFY 2010.

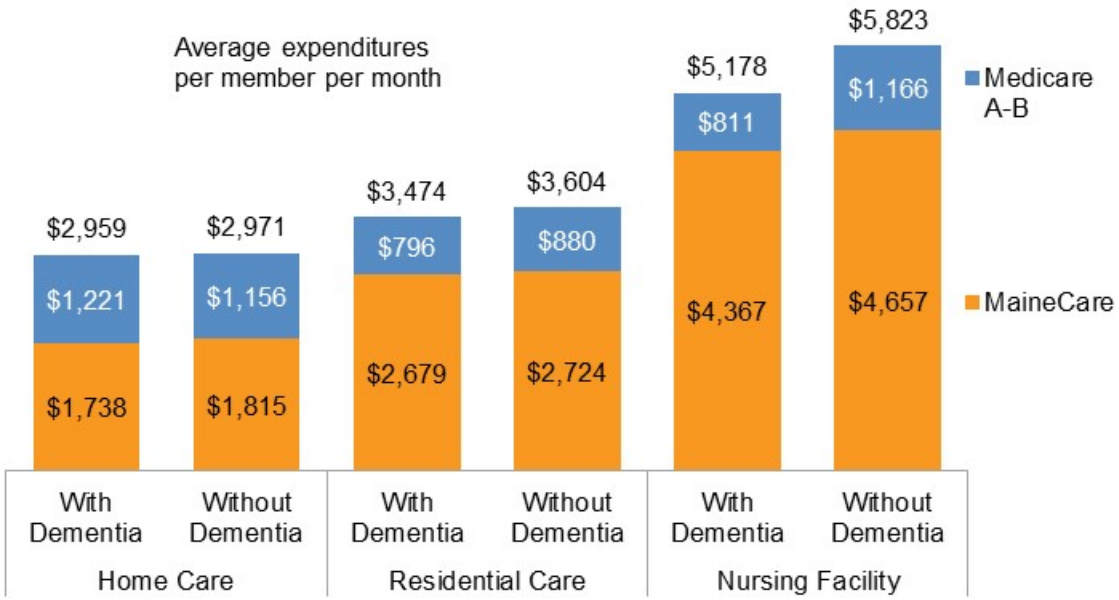
Figure 4-3: Annual MaineCare and Medicare A-B expenditures for MaineCare members using Long Term Services and Supports (LTSS), by each setting in SFY 2010



The inclusion of Medicare Part A and B expenditures increases the total cost of caring for people with and without dementia. For home care users, Medicare pays approximately 40% of the total cost of medical and LTSS care. In residential care settings, Medicare pays for approximately 20% of the combined cost of medical and LTSS care. In nursing homes, Medicare pays for approximately 15% of the total Medicare and MaineCare expenditures.

Sources: MED assessment data for persons using MaineCare or state-funded home care services at any time during SFY 2010. MDS-RCA assessment data for all residential care residents listed on facility roster as of March 15, 2010. MDS 2.0 assessments for all nursing facility residents listed on facility rosters as of March 15, 2010 except for 831 residents, most of whom were on a Medicare short stay, and whose most recent assessment was a partial assessment that does not record information on dementia. We then used JEN Associates' Integrated Medical Management Research System (iMMRS®) to link members to MaineCare and Medicare claims data for SFY 2010.

Figure 4-4: Average per member per month MaineCare and Medicare A-B expenditures for MaineCare LTSS, by each setting, SFY 2010



The average per member per month MaineCare and Medicare A-B combined expenditures for MaineCare LTSS members was lower across all settings for people with dementia compared with those without dementia. MaineCare per member per month expenditures were lower for people with dementia across all settings. Medicare per member per month expenditures for people with dementia were lower in residential care and nursing facilities but higher in the home care setting. As is discussed later in this report, the percent of people using the emergency room and the percent with an inpatient admission declines as the level of care increases.

Sources: MED assessment data for persons using MaineCare or state-funded home care services at any time during SFY 2010. MDS-RCA assessment data for all residential care residents listed on facility roster as of March 15, 2010. MDS 2.0 assessments for all nursing facility residents listed on facility rosters as of March 15, 2010 except for 831 residents, most of whom were on a Medicare short stay, and whose most recent assessment was a partial assessment that does not record information on dementia. We then used JEN Associates' Integrated Medical Management Research System (iMMRS®) to link members to MaineCare and Medicare claims data for SFY 2010.

Table 4-3: Average per person payments per month for MaineCare **nursing facility residents** with dementia (N=2,363) and without dementia (N-=1,220), by diagnosis, in SFY 2010

The following tables compare the average MaineCare and Medicare per person payment per month for MaineCare nursing facility residents for those with and without certain other chronic conditions. In all instances, MaineCare and Medicare expenditures per person were less for people with dementia than for people without dementia.

Nursing Facility	Medicaid	Medicare A-B	Total
All Members in Nursing Facilities			
With dementia (N=2,363)	$4,367	$811	$5,178
Without dementia (N=1,220)	$4,657	$1,166	$5,823
Coronary Heart Disease			
With dementia (N=720)	$4,306	$1,088	$5,394
Without dementia (N=387)	$4,377	$1,636	$6,012
Diabetes			
With dementia (N=630)	$4,474	$900	$5,374
Without dementia (N=432)	$4,606	$1,521	$6,127
Congestive Heart Disease			
With dementia (N=373)	$4,318	$1,258	$5,576
Without dementia (N=291)	$4,284	$1,757	$6,041
Asthma/COPD			
With dementia (N=292)	$4,365	$1,216	$5,580
Without dementia (N=249)	$4,563	$1,653	$6,216

Sources: MED assessment data for persons using MaineCare or state-funded home care services at any time during SFY 2010. MDS-RCA assessment data for all residential care residents listed on facility roster as of March 15, 2010. MDS 2.0 assessments for all nursing facility residents listed on facility rosters as of March 15, 2010 except for 831 residents, most of whom were on a Medicare short stay, and whose most recent assessment was a partial assessment that does not record information on dementia.

We then used JEN Associates' Integrated Medical Management Research System (iMMRS®) to link members to MaineCare and Medicare claims data. Member having a chronic disease were identified by using the JEN Chronic Disease annual marker, but limiting the diagnoses to those appearing on inpatient, outpatient, physician, nursing facility or home health claims.

Table 4-4: Average per person payments per month for MaineCare **residential care residents** with dementia (N=1,176) and without dementia (N=1,550), by diagnosis, in SFY 2010

Residential Care	Medicaid	Medicare A-B	Total
All Members in Residential Care			
With dementia (N=1,176)	$2,679	$796	$3,474
Without dementia (N=1,550)	$2,724	$880	$3,604
Coronary Heart Disease			
With dementia (N=380)	$2,606	$1,214	$3,820
Without dementia (N=501)	$2,578	$1,424	$4,002
Diabetes			
With dementia (N=283)	$2,640	$1,015	$3,655
Without dementia (N=525)	$2,790	$1,092	$3,882
Congestive Heart Disease			
With dementia (N=172)	$2,565	$1,732	$4,297
Without dementia (N=283)	$2,513	$1,695	$4,208
Asthma/COPD			
With dementia (N=187)	$2,570	$1,466	$4,036
Without dementia (N=330)	$2,716	$1,505	$4,220

Sources: MED assessment data for persons using MaineCare or state-funded home care services at any time during SFY 2010. MDS-RCA assessment data for all residential care residents listed on facility roster as of March 15, 2010. MDS 2.0 assessments for all nursing facility residents listed on facility rosters as of March 15, 2010 except for 831 residents, most of whom were on a Medicare short stay, and whose most recent assessment was a partial assessment that does not record information on dementia.

We then used JEN Associates' Integrated Medical Management Research System (iMMRS®) to link members to MaineCare and Medicare claims data. Member having a chronic disease were identified by using the JEN Chronic Disease annual marker, but limiting the diagnoses to those appearing on inpatient, outpatient, physician, nursing facility or home health claims.

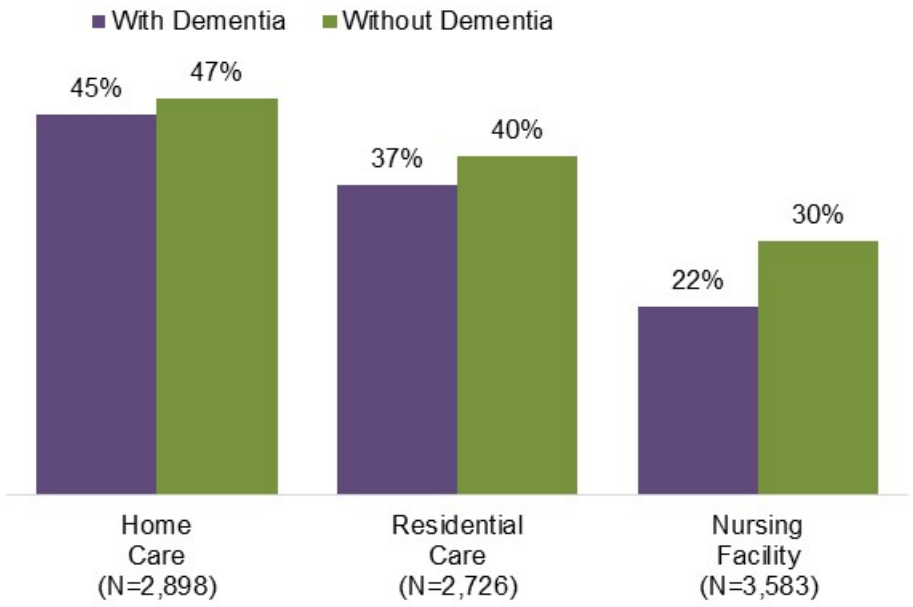
Table 4-5: Average per person payments per month for MaineCare **home care service users** with dementia (N=292) and without dementia (N=2,606), by diagnosis, in SFY 2010.

Home Setting	Medicaid	Medicare A-B	Total
All Members in Home Setting			
With dementia (N=292)	$1,738	$1,221	$2,959
Without dementia (N=2,606)	$1,815	$1,156	$2,971
Coronary Heart Disease			
With dementia (N=91)	$918	$1,450	$2,368
Without dementia (N=637)	$1,517	$2,096	$3,613
Diabetes			
With dementia (N=77)	$1,266	$1,775	$3,042
Without dementia (N=861)	$1,669	$1,606	$3,275
Congestive Heart Disease			
With dementia (N=41)	$1,359	$2,769	$4,128
Without dementia (N=351)	$1,416	$2,790	$4,205
Asthma/COPD			
With dementia (N=60)	$1,590	$1,871	$3,461
Without dementia (N=616)	$1,680	$1,752	$3,432

Sources: MED assessment data for persons using MaineCare or state-funded home care services at any time during SFY 2010. MDS-RCA assessment data for all residential care residents listed on facility roster as of March 15, 2010. MDS 2.0 assessments for all nursing facility residents listed on facility rosters as of March 15, 2010 except for 831 residents, most of whom were on a Medicare short stay, and whose most recent assessment was a partial assessment that does not record information on dementia.

We then used JEN Associates' Integrated Medical Management Research System (iMMRS®) to link members to MaineCare and Medicare claims data. Member having a chronic disease were identified by using the JEN Chronic Disease annual marker, but limiting the diagnoses to those appearing on inpatient, outpatient, physician, nursing facility or home health claims.

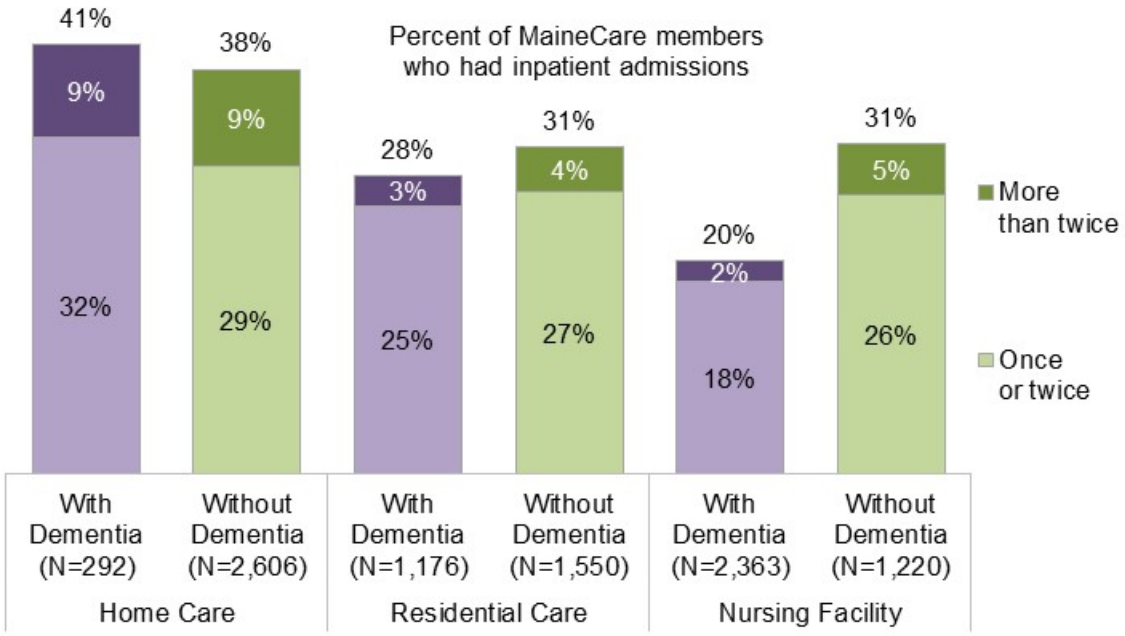
Figure 5-1: Within all three LTSS settings, MaineCare members with dementia were less likely to have had one-or-more emergency room visits in SFY 2010, than members without dementia.



The percent of people who have had one or more emergency room visits decreases as the level of care setting increases. People with dementia in nursing facilities are half as likely (22%) to have had an ER visit compared to those with dementia at home where almost half of the home care users had an ER visit. Across each setting, MaineCare members with dementia were less likely to have had an ER visit than those without dementia.

Sources: MED assessment data for persons using MaineCare or state-funded home care services at any time during SFY 2010. MDS-RCA assessment data for all residential care residents listed on facility roster as of March 15, 2010. MDS 2.0 assessments for all nursing facility residents listed on facility rosters as of March 15, 2010 except for 831 residents, most of whom were on a Medicare short stay, and whose most recent assessment was a partial assessment that does not record information on dementia.
We then used JEN Associates' Integrated Medical Management Research System (iMMRS®) to link members to MaineCare and Medicare claims data.

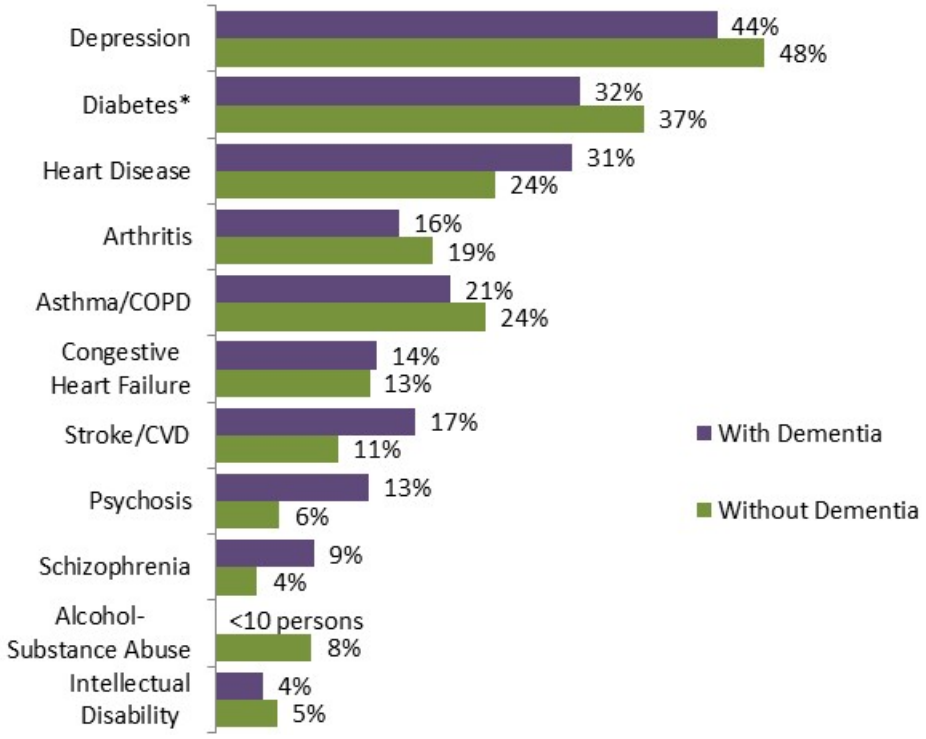
Figure 5-2: Among MaineCare members who used Long Term Services and Supports (LTSS), those with dementia were less likely than others to be admitted to a hospital if they lived in a residential care or nursing facility setting, but more likely than members without dementia if they received services at home in SFY 2010.



Among MaineCare members who used LTSS in SFY 2010, people with dementia who lived at home were at greatest risk of having an inpatient admission. Those without dementia who lived at home were at second highest risk (38%). Those with dementia in residential care or nursing facilities were less likely than those without dementia to have an inpatient admission.

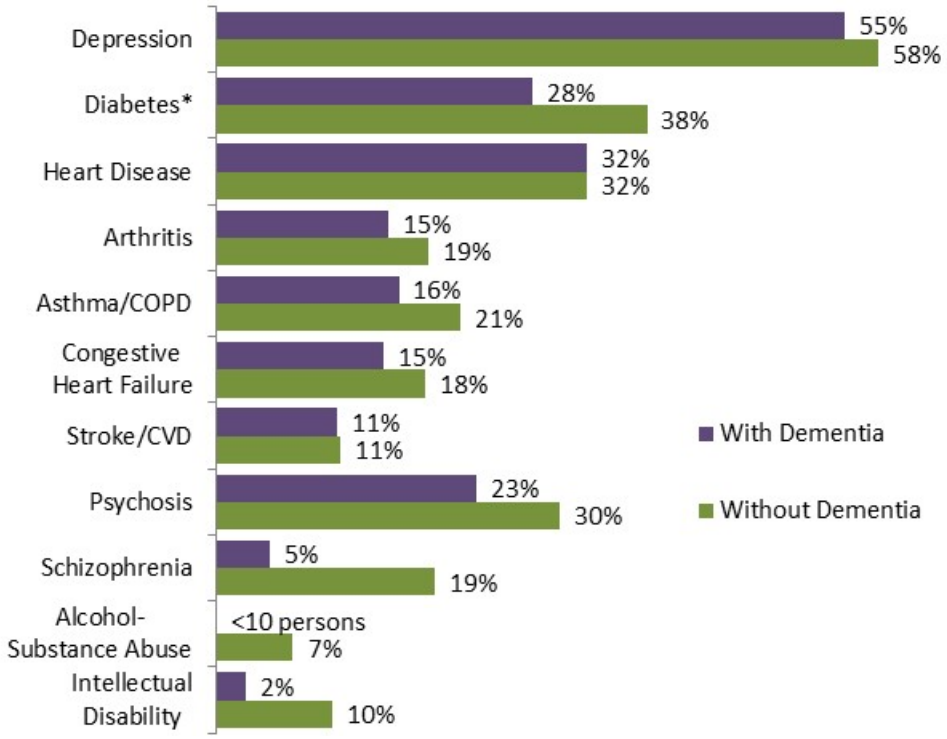
Sources: MED assessment data for persons using MaineCare or state-funded home care services at any time during SFY 2010. MDS-RCA assessment data for all residential care residents listed on facility roster as of March 15, 2010. MDS 2.0 assessments for all nursing facility residents listed on facility rosters as of March 15, 2010 except for 831 residents, most of whom were on a Medicare short stay, and whose most recent assessment was a partial assessment that does not record information on dementia.
We then used JEN Associates' Integrated Medical Management Research System (iMMRS®) to link members to MaineCare and Medicare claims data.

Figure 5-3: In SFY 2010, of those MaineCare members who used Long Term Services and Supports (LTSS) **at home**, members with dementia were less likely to have been diagnosed with depression, diabetes, arthritis, asthma or COPD, but more likely to have been diagnosed with heart disease, stroke and psychosis.



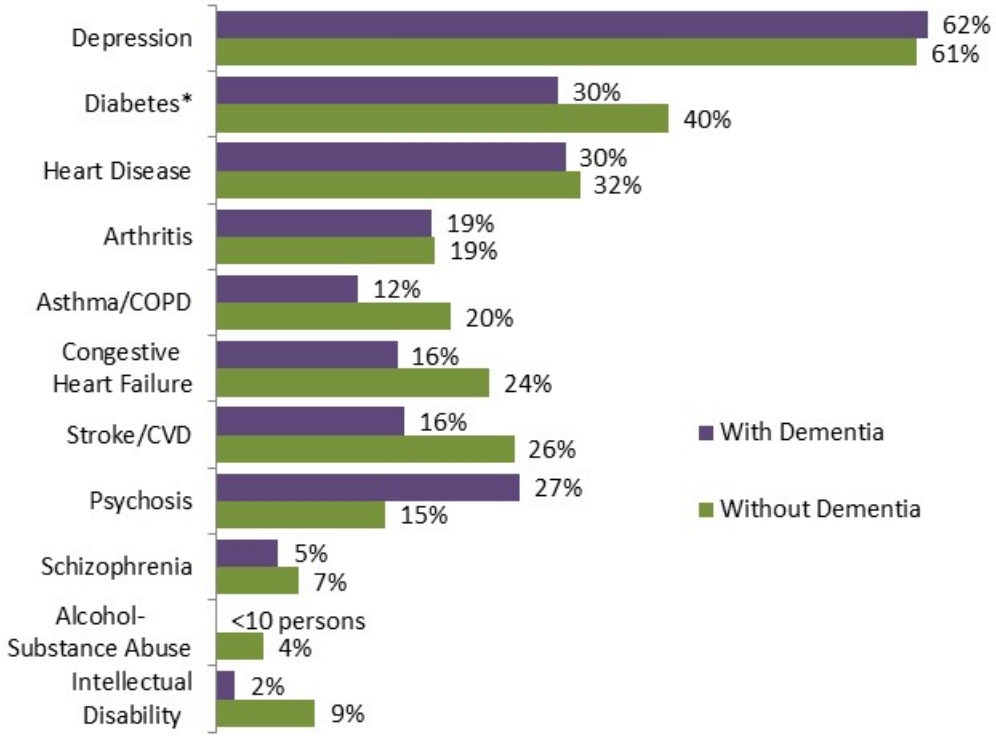
Sources: MED assessment data for persons using MaineCare or state-funded home care services at any time during SFY 2010. MDS-RCA assessment data for all residential care residents listed on facility roster as of March 15, 2010. MDS 2.0 assessments for all nursing facility residents listed on facility rosters as of March 15, 2010 except for 831 residents, most of whom were on a Medicare short stay, and whose most recent assessment was a partial assessment that does not record information on dementia.
We then used JEN Associates' Integrated Medical Management Research System (iMMRS®) to link members to MaineCare and Medicare claims data. Persons were counted as members of a chronic disease group if they had at least one diagnosis for the condition within the year. For medical conditions, we only counted primary diagnoses submitted on physician, inpatient, outpatient, home health or nursing facility claims.

Figure 5-4: In SFY 2010, of those MaineCare members who received services in **residential care,** members with dementia were less likely or equally likely to have been diagnosed with a range of chronic conditions as were members without dementia.



Sources: MED assessment data for persons using MaineCare or state-funded home care services at any time during SFY 2010. MDS-RCA assessment data for all residential care residents listed on facility roster as of March 15, 2010. MDS 2.0 assessments for all nursing facility residents listed on facility rosters as of March 15, 2010 except for 831 residents, most of whom were on a Medicare short stay, and whose most recent assessment was a partial assessment that does not record information on dementia.
We then used JEN Associates' Integrated Medical Management Research System (iMMRS®) to link members to MaineCare and Medicare claims data. Persons were counted as members of a chronic disease group if they had at least one diagnosis for the condition within the year. For medical conditions, we only counted primary diagnoses submitted on physician, inpatient, outpatient, home health or nursing facility claims.

Figure 5-5: In SFY 2010, of those MaineCare members who received services in **nursing facilities,** members with dementia were less likely to have been diagnosed with nine of the eleven chronic conditions displayed below, psychosis having been the large exception.



Sources: MED assessment data for persons using MaineCare or state-funded home care services at any time during SFY 2010. MDS-RCA assessment data for all residential care residents listed on facility roster as of March 15, 2010. MDS 2.0 assessments for all nursing facility residents listed on facility rosters as of March 15, 2010 except for 831 residents, most of whom were on a Medicare short stay, and whose most recent assessment was a partial assessment that does not record information on dementia.
We then used JEN Associates' Integrated Medical Management Research System (iMMRS®) to link members to MaineCare and Medicare claims data. Persons were counted as members of a chronic disease group if they had at least one diagnosis for the condition within the year. For medical conditions, we only counted primary diagnoses submitted on physician, inpatient, outpatient, home health or nursing facility claims.