

# CAPITOL RESEARCH

## HEALTH

## Alzheimer's Disease and Caregiving

Alzheimer's disease—a progressive and fatal condition in which cells in certain parts of the brain are destroyed—creates severe problems in memory, judgment, ability to organize simple tasks and even speech. The most common form of irreversible dementia, Alzheimer's has no cure or even disease-modifying treatment.

Only 4 percent of the general population will be admitted to a nursing home by age 80; but for people with Alzheimer's, 75 percent will end up in a nursing home by age 80.<sup>1</sup> Among those nursing home residents with Alzheimer's and other dementias, 51 percent rely on Medicaid for payment of care.<sup>2</sup> Given the high cost of long-term care, this poses ongoing economic challenges to state Medicaid budgets—challenges that could be mitigated if an individual is able to delay entry into a long-term care facility. For this reason, states have a direct budgetary interest in policies that support family caregivers of individuals with Alzheimer's disease.

### The Stark Numbers

An estimated 5.4 million Americans are living with Alzheimer's disease—5.2 million age 65 and over; 200,000 with younger-onset Alzheimer's.<sup>3</sup> Nearly 30 percent of Americans now have a family member with the disease.<sup>4</sup> The number of Americans living with Alzheimer's disease will increase as the number of people over age 65 increases. Forecasted state increases in people living with the disease between 2010 and 2025 vary from none in Pennsylvania and Rhode Island to as much as 53 percent in Colorado and 56 percent in Utah.

Most people survive an average of four to eight years after an Alzheimer's diagnosis, but some live as long as 20 years.<sup>5</sup> This prolonged duration often places increasingly intensive demands on family members and friends who provide care, which can take a deep physical and financial toll.

Nearly 15 million caregivers provide an estimated 17 billion hours of care each year for individuals with Alzheimer's disease. The Alzheimer's Association estimates the economic value of that care in 2010 totaled more than \$202 billion.<sup>6</sup>



**Caregiver health can be compromised:** Many caregivers of people with Alzheimer's experience poor health, multiplying the overall cost of the disease. Stress is well-documented as a health risk for chronic disease, and 61 percent of caregivers for people with Alzheimer's or other dementia rate the emotional stress of caregiving as high or very high.<sup>7</sup> Public health data from the Behavioral Risk Factor Surveillance System show that caregivers of people with Alzheimer's and dementia are more than twice as likely as caregivers of people without these conditions to say the greatest difficulty associated with caregiving is that it creates or aggravates health problems.<sup>8</sup>

The physical and emotional toll on Alzheimer's and other dementia caregivers results in \$7.9 billion in higher health care costs for caregivers, according to 2011 Alzheimer's Disease Facts and Figures.<sup>9</sup> In addition, a 2006 study showed that spouse caregivers of people who were hospitalized for dementia were more likely than spouse caregivers of people who were hospitalized for other diseases to die in the following year, even after accounting for the age of the spouse caregiver.<sup>10</sup>

**Caregiving affects caregiver financial security:** Family and other unpaid caregivers often must reduce their hours of work—or even quit their jobs—resulting in a loss of job-related income and benefits, including retirement benefits. In a recent survey of Alzheimer's and dementia caregivers, 61 percent of women and 70 percent of men said they had to go in late, leave early

or take time off because of their caregiving responsibilities. About one in five had to take a leave of absence.<sup>11</sup> One in five female caregivers say they have been penalized at work because they needed to care for someone with Alzheimer's disease.<sup>12</sup>

While incomes tend to decrease, costs tend to increase. A 2004 Alzheimer's Association study found that 49 percent of unpaid, nonspousal Alzheimer's and dementia caregivers had caregiving-related out-of-pocket costs averaging \$219 per month.<sup>13</sup> The 2009 Evercare/National Alliance for Caregiving survey found that 65 percent of caregivers had difficulty paying for their own basic necessities and 63 percent found it difficult to save for their own retirement.<sup>14</sup>

**Most caregivers are women:** Women are at the epicenter of the Alzheimer's epidemic. Of the 5.2 million Americans 65 and over with the disease, 3.4 million are women. And among the 14.9 million Alzheimer's and dementia caregivers in the United States, 60 percent, or 8.9 million, are women.<sup>15</sup> Thus, more than 12 million American women either have Alzheimer's or are caring for someone with the disease. Given that 26 percent of family caregivers also have children under age 18 living with them,<sup>16</sup> the U.S. has become a nation of women raising the youngest generation while simultaneously caring for the oldest.

**High costs of institutional care:** The physical and financial toll of caring for someone with Alzheimer's or dementia makes it difficult to avoid eventually placing the individual with the disease in some form of institutionalized care. This has significant financial implications for state budgets. Average per person Medicaid payments for seniors with Alzheimer's and other dementias are nine times higher than Medicaid payments for seniors without the disease. The Alzheimer's Association estimates that Medicaid spending in 2011 on individuals with Alzheimer's and other dementias will total \$37 billion—and will increase nearly 400 percent, before inflation, by 2050.<sup>17</sup>



## Policy Options

State policymakers can provide relief to family caregivers and reduce state Medicaid expenses by providing both direct and indirect support to Alzheimer's caregivers. Several states have adopted programs that touch individuals and families directly. States also can become involved in planning and other activities that develop the infrastructure to support caregivers.

### Program options:

- **Help Alzheimer's caregivers locate and arrange care.** In 2009, the North Dakota legislature passed the Dementia Care Services Act ([House Bill 1043](#)) to provide resources, care planning assistance and support to caregivers across the state. The intent of the act was to create a mechanism to help families navigate between health and social services and to more effectively utilize community services, including from the private sector  
The law calls for a study of the impact on nursing home long-term care costs under Medicaid and health cost outcomes of the intervention. The Center for Rural Health is conducting the evaluation and recently published its first preliminary findings. (Available at <http://ruralhealth.und.edu/pdf/alzheimerspolicypolicybrief1210.pdf>.) Those findings indicate that families who participated in the Dementia Care Services Project had a “reduced intention for placement of persons with dementia in nursing homes.”<sup>18</sup> Additional results will be released later this year.
- **Participate in the federal Alzheimer's Disease Supportive Services Program.** This program provides federal funding to states to expand the availability of community-level supportive services for individuals with Alzheimer's disease and their caregivers. It funds both proven methods to deliver services as well as innovative ideas; it also supports efforts to translate evidence-based models into community-wide programs. Thirty-four states, the District of Columbia and Puerto Rico currently receive funds. More information on the Alzheimer's Disease Supportive Services Program is available at [http://www.aoa.gov/AoARoot/AoA\\_Programs/HCLTC/Alz\\_Grants/index.aspx](http://www.aoa.gov/AoARoot/AoA_Programs/HCLTC/Alz_Grants/index.aspx).
- **Promote use of evidence-based programs as part of home- and community-based services.** A number of demonstration projects have shown positive impacts on caregiver and care recipient health and on reducing health care costs. For example, when spouse caregivers of someone with Alzheimer's participated in a counseling program developed at New York University, the rate of nursing home placement dropped nearly 30 percent, with an average overall delay in placement of more than a year and a half.<sup>19</sup> Counseling programs can be easily translated to community settings, and states can integrate them into home- and community-based services funded by Medicaid and state aging programs. Examples of such programs—many of which were initially funded through the ADSSP—are available at [http://www.aoa.gov/AoARoot/AoA\\_Programs/HCLTC/Alz\\_Grants/compendium.aspx#evidence](http://www.aoa.gov/AoARoot/AoA_Programs/HCLTC/Alz_Grants/compendium.aspx#evidence).

- **Shift priorities under the National Family Caregiver Support Program, which is implemented by state units on aging.** This program offers a range of services to support family caregivers of older Americans. Under this program, states provide five types of services: (1) information to caregivers about available services; (2) assistance to caregivers in gaining access to the services; (3) individual counseling, organization of support groups and caregiver training; (4) respite care; and (5) supplemental services, on a limited basis. The most recent data available suggest that a majority of the funds are spent on information and assistance activities, with significantly less spent on individual counseling and caregiver training. Redirecting funds to place a greater emphasis on counseling, training and respite care would allow persons with Alzheimer’s disease to remain in community settings longer.

In addition, the National Family Caregiver Support Program specifically allows Alzheimer’s and dementia caregivers to qualify for services even if the individual with the disease is under age 60. Very little data exists, however, as to whether services are reaching this younger-onset population. Lawmakers could request data to ascertain the extent of participation by this group of Alzheimer’s caregivers.

- **Expand respite services and adult day care.** Almost all states offer some form of respite care and/or adult day services through a Medicaid waiver program. By tying these programs to Medicaid, however, states are reaching primarily the caregivers of the frailest and oldest individuals with Alzheimer’s disease—those whose nursing home placement may be imminent. This reduces any potential benefit that such services provide in delaying institutionalized care and thus saving Medicaid dollars. States could expand eligibility for respite services and adult day care to include individuals who are not Medicaid-eligible but with such services may be able to significantly delay placement in long-term care facilities. The Affordable Care Act provides states new options to expand respite services and adult day care.

- **Improve Medicaid home- and community-based services by providing assessment of caregiver health and needs.** As states—for both budgetary and quality-of-life reasons—move more Medicaid-supported care to home and community settings, the needs of caregivers cannot be forgotten. Without willing and able family caregivers, many Medicaid home- and community-based care plans simply cannot be implemented.

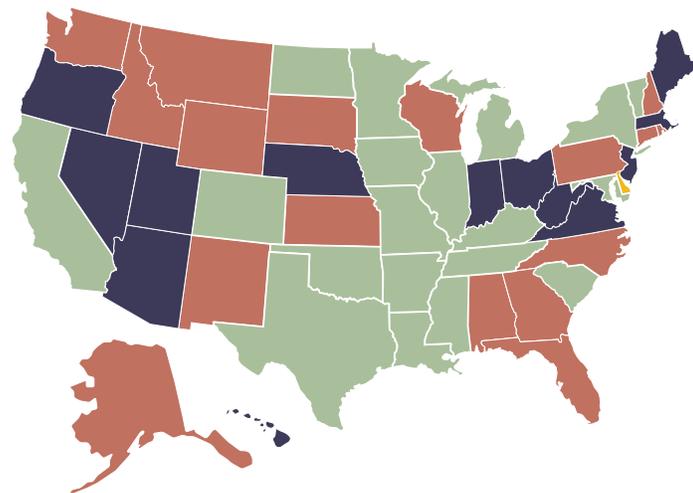
A family caregiver assessment can help identify a caregiver’s support needs and connect them with needed supports. Some programs focus assessment solely on the person with care needs, but assessing the caregiver’s health, willingness to provide care, and training and support needs would identify strategies and resources to enable caregivers to better care for themselves and the person for whom they are caring.

- **Support transportation services for caregivers and individuals with Alzheimer’s disease, and eliminate barriers for those with younger-onset Alzheimer’s—those under age 65—to utilize these services.** Mobility is essential for caregivers and care recipients to access health care services and daily essentials such as grocery shopping. While many local transportation systems are accessible to seniors and the disabled in general, they often are not fully capable of meeting the particular needs of those with dementia. Furthermore, access can be especially difficult for individuals under age 60 with younger-onset Alzheimer’s disease because of statutory or regulatory restrictions that make only older individuals eligible for alternative transportation services.

**Planning and Other Policy Activities:**

- **Create a state Alzheimer’s disease plan:** More than 30 states have published or are in the process of writing a state Alzheimer’s disease plan—a comprehensive blueprint to deal with the growing numbers of citizens with Alzheimer’s disease. State Alzheimer’s disease plans include strategies for improved caregiver support. Published state plans can be found at [http://www.alz.org/join\\_the\\_cause\\_state\\_plans.asp](http://www.alz.org/join_the_cause_state_plans.asp).

## States with Alzheimer’s Disease Plans



- Published a State Alzheimer’s Plan. (19)
- Task Force established to develop a State Alzheimer’s Plan. (13)
- Legislation pending or working on Executive Branch to establish a State Alzheimer’s Plan Task Force. (1 plus the District of Columbia)
- No Legislation filed or Executive Branch activity pending. (17)

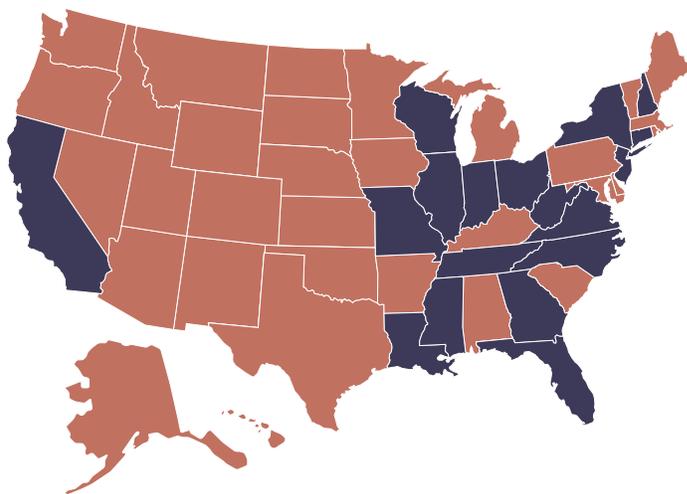
Source: Alzheimer’s Association, [http://alz.org/documents\\_custom/StatePlanMap.pdf](http://alz.org/documents_custom/StatePlanMap.pdf)

- **Conduct caregiving surveillance through the Behavioral Risk Factor Surveillance System.** Surveillance is a proven public health technique to develop data that can pinpoint problems, identify where resources are needed most and evaluate long-term results of interventions. Each state and territory public health department conducts an annual surveillance survey, known as the BRFSS. The Centers for Disease Control and Prevention has developed a series of 10 questions on caregiving to more fully assess the needs and health of caregivers that can be added to the annual survey. Since 2009, 16 states have added these questions to their BRFSS surveys, providing important planning data for service providers.
- **Encourage existing caregiver support programs to add health promotion and wellness activities.** Ex-

PLICIT messaging and outreach to caregivers regarding healthy lifestyles and wellness (e.g. maintaining a healthy body weight, regular physical activity, and tobacco cessation) can be a little- or no-cost initiative that improves the health and well-being of caregivers and reduces overall health care spending.

- **Engage caregivers to provide direct feedback in shaping programs.** Pennsylvania and New York have considered developing family Caregiving Councils as a way of recognizing the vital role played by family caregivers and to give them a voice in policymaking. Many states also are developing coalitions to explore and plan respite programs, such as the Lifespan respite approach funded by the federal Administration on Aging (see <http://archrespite.org/lifespan-programs>), which could be a model for increasing participation.

## 2009- 2012 Caregiver Module Included in State Public Health Survey



- State conducted module once (18 states plus Washington, D.C.)
- No Activity

Source: Alzheimer's Association.

## Conclusion

Medicaid is the largest single item in many state budgets, and caring for people with Alzheimer's is a significant driver of those costs, particularly because of the high numbers of people with the disease who end up in nursing homes. Studies have demonstrated that delaying entry into a long-term care facility reduces Medicaid spending, but it does not reduce an individual's need for care—care that falls overwhelmingly on family and friends when provided in the home. Thus, to be successful in keeping those with Alzheimer's and other dementias in the community and reducing overall Medicaid costs, states must find ways to support unpaid family caregivers.

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# Persons with Alzheimer's Disease and the Burden of Caregivers

State	Estimated Number of Individuals with Alzheimer's		Increase in Individuals with Alzheimer's	Number of Alzheimer's / Dementia Caregivers	Hours of Unpaid Care per Year	Value of Unpaid Care
	2010	2025	2010 to 2025	2010	2010	2010
Alabama	91,000	110,000	21%	287,605	327,524,195	\$3,907,363,643
Alaska	5,000	7,700	54%	30,927	35,219,116	\$420,164,054
Arizona	97,000	130,000	34%	298,440	339,863,759	\$4,054,574,648
Arkansas	60,000	76,000	27%	167,733	191,014,266	\$2,278,800,194
California	480,000	660,000	38%	1,459,978	1,662,623,044	\$19,835,092,909
Colorado	72,000	110,000	53%	222,124	252,954,381	\$3,017,745,769
Connecticut	70,000	76,000	9%	169,828	193,399,655	\$2,307,257,883
Delaware	14,000	16,000	14%	48,486	55,216,111	\$658,728,208
District of Columbia	9,100	10,000	10%	24,368	27,750,804	\$331,067,095
Florida	450,000	590,000	31%	960,037	1,093,290,130	\$13,042,951,247
Georgia	120,000	160,000	33%	482,255	549,192,095	\$6,551,861,693
Hawaii	27,000	34,000	26%	58,782	66,940,708	\$798,602,641
Idaho	26,000	38,000	46%	73,230	83,393,999	\$994,890,413
Illinois	210,000	240,000	14%	579,505	659,939,981	\$7,873,083,975
Indiana	120,000	130,000	8%	320,477	364,959,768	\$4,353,970,036
Iowa	69,000	77,000	12%	131,854	150,154,788	\$1,791,346,620
Kansas	53,000	62,000	17%	146,190	166,481,322	\$1,986,122,167
Kentucky	80,000	97,000	21%	260,815	297,016,579	\$3,543,407,792
Louisiana	83,000	100,000	20%	218,965	249,357,171	\$2,974,831,052
Maine	25,000	28,000	12%	66,702	75,960,081	\$906,203,767
Maryland	86,000	100,000	16%	270,156	307,654,020	\$3,670,312,453
Massachusetts	120,000	140,000	17%	319,337	363,660,975	\$4,338,475,436
Michigan	180,000	190,000	6%	507,176	577,572,277	\$6,890,437,260
Minnesota	94,000	110,000	17%	237,441	270,397,947	\$3,225,847,510
Mississippi	53,000	65,000	23%	198,199	225,709,258	\$2,692,711,448
Missouri	110,000	130,000	18%	304,448	346,705,485	\$4,136,196,441
Montana	21,000	29,000	38%	45,551	51,873,834	\$618,854,834
Nebraska	37,000	44,000	19%	77,632	88,407,470	\$1,054,701,115
Nevada	29,000	42,000	45%	126,003	143,492,193	\$1,711,861,862
New Hampshire	22,000	26,000	18%	63,808	72,664,273	\$866,884,778
New Jersey	150,000	170,000	13%	427,827	487,208,978	\$5,812,403,103
New Mexico	31,000	43,000	39%	100,582	114,542,742	\$1,366,494,918
New York	320,000	350,000	9%	990,490	1,127,970,106	\$13,456,683,363
North Carolina	170,000	210,000	24%	415,521	473,194,910	\$5,645,215,276
North Dakota	18,000	20,000	11%	26,280	29,927,827	\$357,038,974
Ohio	230,000	250,000	9%	585,317	666,558,493	\$7,952,042,822
Oklahoma	74,000	96,000	30%	205,843	234,414,494	\$2,796,564,913
Oregon	76,000	110,000	45%	162,761	185,352,080	\$2,211,250,320
Pennsylvania	280,000	280,000	0%	654,261	745,071,864	\$8,888,707,335
Rhode Island	24,000	24,000	0%	52,641	59,947,185	\$715,169,911
South Carolina	80,000	100,000	25%	274,195	312,252,785	\$3,725,175,727
South Dakota	19,000	21,000	11%	35,369	40,278,116	\$480,517,925
Tennessee	120,000	140,000	17%	400,859	456,497,713	\$5,446,017,719
Texas	340,000	470,000	38%	1,213,767	1,382,237,356	\$16,490,091,652
Utah	32,000	50,000	56%	132,991	151,450,408	\$1,806,803,372
Vermont	11,000	13,000	18%	29,244	33,302,526	\$397,299,134
Virginia	130,000	160,000	23%	422,116	480,706,197	\$5,734,824,927
Washington	110,000	150,000	36%	309,956	352,977,490	\$4,211,021,459
West Virginia	44,000	50,000	14%	105,464	120,102,716	\$1,432,825,396
Wisconsin	110,000	130,000	18%	186,380	212,249,635	\$2,532,138,141
Wyoming	10,000	15,000	50%	25,617	29,172,531	\$348,028,290

Source: Alzheimer's Association. "2011 Alzheimer's Disease Facts and Figures." Alzheimer's & Dementia Vol. 7, Issue 2. Accessed at [http://www.alz.org/downloads/Facts\\_Figures\\_2011.pdf](http://www.alz.org/downloads/Facts_Figures_2011.pdf), September 9, 2011.