

Caregiving
Across the
United
States

**Caregivers of
Persons with
Alzheimer's
Disease or
Dementia in 14
States**

Data from the 2011, 2012, and 2013 Behavioral Risk Factor Surveillance System

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Introduction

Caregivers for individuals with Alzheimer’s and other dementias face unique burdens in their caregiving experiences and represent a significant portion of the 34 million Americans who provide informal, unpaid care to individuals with disabilities and chronic conditions over the age of 50 in the United States.¹ In order to fully understand the impact of caregiving on the population level, the Centers for Disease Control and Prevention (CDC) developed a set of ten questions for the state-based Behavioral Risk Factor Surveillance System (BRFSS). The Caregiver Module collects information on adult caregivers who provide care for an individual with a disability or chronic condition; the type and amount of care they provide; and the difficulties they face in providing care.

This report contains an analysis of the data from the 2011, 2012, and 2013 BRFSS Caregiver Module, aggregated across all three years and across the 14 states that used the module in those years. It also compares caregivers of those with Alzheimer’s and other dementias with caregivers for those with all other conditions. Because 95 percent of care recipients with Alzheimer’s and other dementias were aged 65 and older, while just 58 percent of care recipients with all other conditions were, this report compares Alzheimer’s and dementia caregivers with both (a) all other caregivers; and (b) all other caregivers where the care recipient is aged 60 and older. The latter may be a more legitimate comparison with Alzheimer’s and dementia caregivers.

Year	States Using the Caregiver Module
2011	New Jersey, North Carolina
2012	California, Georgia, Indiana, Iowa, Maine, Mississippi, Missouri, Oregon,* West Virginia, Wisconsin
2013	Arkansas, Illinois, Oregon*

*To prevent overrepresentation of Oregon among the aggregated dataset, only the 2013 data were included for analysis. Data for Oregon in 2012 and 2013 were similar.

Among the highlights of the report:

- **Alzheimer’s caregiving is very time-intensive.** Nearly one in five Alzheimer’s and dementia caregivers has been providing care for longer than five years, and more than 60 percent have been providing care for more than one year.
- **Alzheimer’s caregiving creates problems for both the specific caregiver and the family as a whole.** Those who care for someone with Alzheimer’s or another dementia are 2.2 times more likely than caregivers of people with other conditions to say that caregiving negatively affects their family

¹ National Alliance for Caregiving and AARP. *Caregiving in the U.S.* Washington, DC: National Alliance for Caregiving and AARP; 2015. Available at: <http://www.caregiving.org/caregiving2015>.

relationships than non-Alzheimer’s caregivers. And, Alzheimer’s and dementia caregivers are nearly 40 percent more likely to say that the greatest difficulty associated with caregiving is that it creates stress.

- **Alzheimer’s and other dementias are responsible for a large portion of all unpaid care.** For 16 percent of people aged 60 and older who receive care, the major condition for which they are receiving care is Alzheimer’s or dementia. This is a larger percentage than for any other condition.
- **Many Alzheimer’s caregivers are also caring for minor children.** Nearly one-fourth of Alzheimer’s caregivers are part of the “sandwich generation” of individuals caring for both a minor child and aging adult simultaneously.

Data from the Caregiver Module were previously collected and analyzed in 2009 and 2010. Reports from each year and from an aggregated analysis across both years are available at the Alzheimer’s Association’s Public Health Resource Center (www.alz.org/publichealth).

Tables

Table 1	Page 3
Caregiving experience characteristics by Alzheimer’s disease or dementia presence among care recipients (weighted).	
Table 2	Page 6
Demographic and health behavior characteristics of caregivers by Alzheimer’s disease or dementia presence among care recipients (weighted).	
Table 3	Page 9
Major health problem, long-term illness, or disability among care recipients, as reported by caregivers (weighted).	
Appendix	Page 11
Behavioral Risk Factor Surveillance System State-Added Caregiver Module	

Table 1

Caregiving experience characteristics by Alzheimer’s disease or dementia presence among care recipients (weighted). Data from the Behavioral Risk Factor Surveillance System (BRFSS), 2011-2013.

Variable	Category	Caregivers of persons with Alzheimer’s disease or dementia (care recipients of all ages; n=1,615)	Caregivers of Persons without Alzheimer’s disease or dementia	
			Care recipients of all ages (n=10,920)	Care recipients age ≥60 only (n=7,713)
		Percent (95% CI)+	Percent (95% CI)+	Percent (95% CI)+
Care recipient gender	Female	70.8 (66.5-74.7)	60.5 (58.7-62.3)	65.0 (62.8-67.1)
Care recipient age* [§]	0-64	4.9 (2.8-8.5)	42.0 (40.0-44.1)	12.1 (10.7-13.7)
	65-74	15.1 (12.1-18.8)	17.2 (15.8-18.7)	26.1 (24.1-28.2)
	75-84	34.6 (30.5-38.9)	21.3 (19.8-22.8)	32.2 (30.2-34.3)
	85 or older	45.4 (41.1-49.7)	19.5 (18.1-21.0)	29.6 (27.6-31.6)
Care recipient’s relationship to caregiver	Parent or Parent-in-Law*	52.1 (47.7-56.4)	41.9 (40.0-43.7)	54.4 (52.2-56.6)
	Spouse	8.5 (6.6-11.0)	10.5 (9.6-11.5)	10.2 (9.1-11.3)
	Other relative [§]	30.2 (25.9-35.0)	31.6 (29.8-33.4)	22.2 (20.4-24.2)
	Non-relative* [§]	9.1 (7.2-11.5)	16.1 (14.7-17.5)	13.2 (11.9-14.6)
Care recipient’s major health problem as identified by the caregiver	Alzheimer’s disease or dementia	100.0	--	--
	Cancer	--	9.7 (8.7-10.8)	9.8 (8.6-11.1)
	Heart disease	--	7.8 (6.9-8.8)	10.0 (8.9-11.2)
	Diabetes	--	8.5 (7.4-9.7)	9.5 (8.1-11.0)
	Arthritis	--	5.8 (5.1-6.6)	6.7 (5.8-7.7)
	Stroke	--	5.8 (5.0-6.8)	7.2 (6.2-8.4)

Variable	Category	Caregivers of persons with Alzheimer's disease or dementia (care recipients of all ages; n=1,615)	Caregivers of Persons without Alzheimer's disease or dementia	
			Care recipients of all ages (n=10,920)	Care recipients age ≥60 only (n=7,713)
		Percent (95% CI)+	Percent (95% CI)+	Percent (95% CI)+
Cognitive status change* [§]	Care recipient experienced a change in thinking or remembering in the past year	91.9 (89.3-93.9)	49.0 (47.1-50.8)	56.3 (54.2-58.5)
Length of care* [§]	Mean months* [§] (Standard Error)	42.4 (2.21)	56.2 (1.64)	51.1 (1.85)
	0-3 months	13.5 (10.4-17.3)	22.6 (21.0-24.3)	20.0 (18.2-21.8)
	4-12 months	24.5 (20.3-29.4)	20.4 (19.0-22.0)	21.5 (19.7-23.4)
	13-24 months	18.4 (15.2-22.2)	12.6 (11.3-14.2)	14.2 (12.4-16.1)
	25-60 months	25.2 (21.7-29.0)	20.0 (18.6-21.5)	22.0 (20.2-23.9)
	More than 5 years	18.4 (15.1-22.1)	24.3 (22.7-26.0)	22.3 (20.5-24.4)
Hours of care provided per week [§] ¹	Mean* (Standard Error)	26.1 (2.0)	36.4 (3.6)	31.2 (3.9)
	0-8	48.6 (43.9-53.3)	52.8 (50.9-54.8)	55.3 (52.9-57.7)
	9-19	17.1 (14.2-20.6)	17.2 (15.7-18.8)	18.1 (16.3-20.0)
	20-39	13.8 (10.5-17.9)	14.5 (13.2-15.9)	14.3 (12.7-16.0)
	40 or more	20.5 (16.9-24.6)	15.5 (14.1-17.0)	12.3 (10.9-14.0)
Area in which care recipient needs most help ²	Self-care* [§]	27.6 (23.8-31.7)	17.6 (16.1-19.2)	16.6 (15.0-18.4)
	Household care	29.3 (25.1-34.0)	30.8 (28.9-32.7)	32.9 (30.6-35.2)
	Communicating with others	1.8 (1.2-2.6)	2.8 (2.0-3.7)	1.8 (1.2-2.5)
	Learning, remembering, confusion* [§]	11.4 (8.5-15.0)	2.1 (1.6-2.8)	1.9 (1.3-2.7)

Variable	Category	Caregivers of persons with Alzheimer's disease or dementia (care recipients of all ages; n=1,615)	Caregivers of Persons without Alzheimer's disease or dementia	
			Care recipients of all ages (n=10,920)	Care recipients age ≥60 only (n=7,713)
		Percent (95% CI)+	Percent (95% CI)+	Percent (95% CI)+
Area in which care recipient needs most help (continued)	Seeing or hearing	0.6 (0.3-1.4)	1.1 (0.8-1.4)	1.1 (0.9-1.5)
	Moving around* [§]	2.2 (1.4-3.6)	5.5 (4.7-6.3)	5.8 (4.9-6.8)
	Transportation outside the home* [§]	16.2 (13.0-20.1)	23.9 (22.2-25.6)	26.8 (24.8-29.0)
	Getting along with people* [§]	0.1 (0.1-0.3)	0.9 (0.6-1.4)	0.4 (0.2-0.6)
	Feeling anxious or depressed	3.0 (2.0-4.6)	4.6 (3.9-5.6)	3.2 (2.4-4.2)
	Something else*	7.7 (5.8-10.2)	10.8 (9.6-12.0)	9.6 (8.3-11.0)
	Financial burden*	4.3 (3.1-6.1)	7.0 (6.1-8.0)	5.0 (4.1-6.0)
Greatest difficulty faced by caregiver	Not enough time for him/herself	9.8 (7.4-12.9)	8.6 (7.5-9.9)	9.0 (7.6-10.6)
	Not enough time for family	6.5 (4.3-9.7)	4.5 (3.7-5.5)	4.9 (3.9-6.2)
	Interferes with work	3.8 (2.1-6.8)	4.1 (3.3-5.2)	4.2 (3.1-5.6)
	Creates or aggravates health problems* [§]	2.0 (1.2-3.3)	2.4 (2.0-3.0)	2.6 (2.0-3.3)
	Affects family relationships* [§]	8.4 (6.0-11.5)	3.7 (3.1-4.5)	3.8 (3.0-4.9)
	Creates stress* [§]	28.6 (24.5-33.0)	20.5 (19.0-22.1)	20.7 (18.9-22.6)
	Another difficulty* [§]	10.6 (7.7-14.6)	18.4 (16.2-20.8)	18.0 (15.7-20.7)
	No difficulty* [§]	25.9 (22.3-30.0)	30.7 (28.5-33.1)	31.8 (29.3-34.5)

+ 95 % confidence interval for the proportion

* Statistically significant difference (p<0.05) between the proportion of caregivers of persons with Alzheimer's disease or dementia reporting the variable compared to other caregivers of people of all ages (chi-square test). For ordered variables like age, the chi-square test is applied across categories while for nominal variables like relationship, the chi-square test is applied within each category.

§ Statistically significant difference (p<0.05) between the proportion of caregivers of persons with Alzheimer's disease or dementia reporting the variable compared to other caregivers among care recipients age 60 and older (chi-square test). For ordered variables like age, the chi-square test is applied across categories while for nominal variables like relationship, the chi-square test is applied within each category.

¹ Estimates exclude Wisconsin due to differences in response categorization.

² Estimates exclude North Carolina because only a partial response list was asked of participants.

Table 2

Demographic and health behavior characteristics of caregivers by Alzheimer's disease or dementia presence among care recipients (weighted). Data from the Behavioral Risk Factor Surveillance System (BRFSS), 2011-2013.

Variable	Category	Caregivers of persons with Alzheimer's disease or dementia (care recipients of all ages; n=1,615)	Caregivers of Persons without Alzheimer's disease or dementia	
			Care recipients of all ages (n=10,920)	Care recipients age ≥60 only (n=7,713)
		Percent (95% CI)+	Percent (95% CI)+	Percent (95% CI)+
Gender	Female	63.3 (59.1-67.4)	63.2 (61.2-65.1)	63.7 (61.5-65.8)
Age* [§]	18-34	15.8 (12.5-19.8)	21.9 (19.9-24.0)	14.5 (12.6-16.6)
	35-44	10.6 (8.0-13.8)	18.3 (16.7-20.0)	17.9 (15.9-20.0)
	45-54	26.0 (22.3-30.1)	23.8 (22.3-25.4)	25.7 (23.7-27.7)
	55-64	25.2 (21.8-28.9)	19.8 (18.5-21.1)	22.3 (20.7-23.9)
	65+	22.5 (19.2-26.1)	16.2 (15.1-17.5)	19.7 (18.3-21.2)
Education*	Less than high school	26.6 (22.5-31.3)	28.8 (26.5-31.2)	27.0 (24.6-29.5)
	High school degree or equivalent	24.4 (20.8-28.4)	29.1 (27.3-30.9)	27.8 (25.8-29.9)
	Some college or beyond	49.0 (43.8-54.1)	42.1 (39.1-45.2)	45.2 (42.0-48.5)
Employment status	Employed, student, or homemaker [§]	67.2 (62.8-71.3)	65.9 (64.1-67.6)	63.0 (60.9-65.1)
	Retired*	20.2 (17.2-23.4)	16.8 (15.6-18.1)	20.7 (19.2-22.3)
	Out of work or unable to work* [§]	12.7 (9.5-16.7)	17.3 (15.8-18.8)	16.3 (14.5-18.2)
Marital status	Married/Coupled	62.0 (57.4-66.5)	58.8 (56.8-60.8)	63.3 (61.0-65.5)
Children in household* [§]	At least one child under age 18 lives in household	24.7 (20.9-28.9)	36.4 (34.5-38.3)	31.8 (29.7-34.0)
Disability status	Respondent has a disability	25.9 (22.0-30.3)	28.4 (26.8-30.1)	24.5 (21.1-28.2)

Variable	Category	Caregivers of persons with Alzheimer's disease or dementia (care recipients of all ages; n=1,615)	Caregivers of Persons without Alzheimer's disease or dementia	
			Care recipients of all ages (n=10,920)	Care recipients age ≥60 only (n=7,713)
		Percent (95% CI)+	Percent (95% CI)+	Percent (95% CI)+
Race/ethnicity ¹	White only, non-Hispanic	73.5 (68.7-77.8)	75.7 (73.6-77.8)	79.7 (77.5-81.7)
	Black only, non-Hispanic	15.8 (12.4-20.0)	14.0 (12.4-15.7)	11.7 (10.2-13.4)
	Other race or multiracial, non-Hispanic	5.4 (3.4-8.4)	4.3 (3.7-5.0)	4.0 (3.3-4.9)
	Any race, Hispanic	4.5 (2.5-7.8)	5.4 (4.3-6.9)	4.0 (3.0-5.3)
	Not reported or missing	0.8 (0.4-1.7)	0.6 (0.4-0.8)	0.6 (0.4-0.8)
Household annual income* [§]	Less than \$15,000	6.6 (4.9-8.8)	11.8 (10.4-13.3)	10.4 (8.9-12.2)
	\$15,000-\$24,999	14.8 (11.7-18.5)	16.5 (15.1-17.9)	15.0 (13.5-16.5)
	\$25,000-\$34,999	23.3 (19.8-27.2)	24.4 (22.7-26.2)	23.0 (21.2-24.8)
	\$35,000-\$49,999	14.6 (11.8-17.9)	14.7 (13.5-16.0)	16.2 (14.7-17.8)
	\$50,000 or more	31.4 (27.2-35.9)	24.4 (22.8-26.2)	27.4 (25.3-29.6)
	Not reported or missing	9.3 (7.4-11.8)	8.2 (7.2-9.3)	8.1 (7.0-9.2)
General health* [§]	Excellent, very good, or good	86.0 (83.4-88.2)	80.7 (79.1-82.1)	81.7 (79.9-83.4)
Frequent mental distress	14 days or more of poor mental health in the past 30 days	14.6 (12.0-17.5)	16.6 (15.2-18.2)	14.9 (13.3-16.6)
Body Mass Index (BMI)	Neither overweight nor obese (<25.0)	36.2 (31.8-40.8)	34.2 (32.4-36.2)	32.9 (30.7-35.1)
	Overweight (25.0-29.9)	35.9 (31.6-40.4)	35.2 (33.3-37.0)	36.7 (34.6-38.9)
	Obese (≥30.0)	27.9 (24.1-32.0)	30.6 (28.9-32.3)	30.4 (28.5-32.5)

Variable	Category	Caregivers of persons with Alzheimer's disease or dementia (care recipients of all ages; n=1,615)	Caregivers of Persons without Alzheimer's disease or dementia	
			Care recipients of all ages (n=10,920)	Care recipients age ≥60 only (n=7,713)
		Percent (95% CI)+	Percent (95% CI)+	Percent (95% CI)+
Smoking status	Never Smoker* [§]	58.2 (53.7-62.6)	52.6 (50.7-54.5)	52.7 (50.4-54.9)
	Former Smoker	25.1 (21.4-29.1)	23.9 (22.4-25.5)	26.6 (24.7-28.5)
	Current Smoker* [§]	16.7 (13.7-20.3)	23.5 (21.8-25.2)	20.8 (19.0-22.7)
Physical activity	Engage in physical activity outside of work	81.8 (77.7-85.2)	78.5 (76.9-80.1)	79.9 (78.0-81.6)
Veteran status	Ever served on active duty	9.5 (7.6-11.9)	8.6 (7.7-9.5)	9.0 (8.0-10.1)
Health insurance plan*	Any coverage	86.2 (82.8-89.0)	80.8 (79.0-82.4)	83.7 (81.7-85.6)
Medical costs* [§]	Needed to see a doctor in the past year but could not because of cost	14.0 (11.4-17.1)	21.4 (19.7-23.2)	19.1 (17.2-21.2)

+ 95 % confidence interval for the proportion

* Statistically significant difference (p<0.05) between the proportion of caregivers of persons with Alzheimer's disease or dementia reporting the variable compared to other caregivers of people of all ages(chi-square test). For ordered variables like age, the chi-square test is applied across categories while for nominal variables like relationship, the chi-square test is applied within each category.

§ Statistically significant difference (p<0.05) between the proportion of caregivers of persons with Alzheimer's disease or dementia reporting the variable compared to other caregivers of people age 60 and older(chi-square test). For ordered variables like age, the chi-square test is applied across categories while for nominal variables like relationship, the chi-square test is applied within each category.

¹ Estimates exclude California due to response categories that were not mutually exclusive.

Table 3

Major health problem, long-term illness, or disability among care recipients, as reported by caregivers (weighted). Data from the Behavioral Risk Factor Surveillance System (BRFSS), 2011-2013.

Note: Percent is based on weighted data; therefore, some conditions in this table with a lower n value than other conditions will have a higher percentage than those conditions.

Health problem, illness, or disability	Care recipients of all ages (n=11,845)	Care recipients age ≥60 only (n=8,880)
	n (Weighted Percent)	n (Weighted Percent)
Attention deficit-hyperactivity disorder (ADHD) or learning disability	27 (0.3)	6 (0.05)
Alzheimer's disease or dementia	1,615 (11.5)	1,558 (16.0)
Anxiety or depression	199 (1.8)	79 (0.8)
Arthritis/rheumatism	722 (5.1)	590 (5.6)
Asthma	62 (1.0)	28 (0.5)
Cancer	1,103 (8.8)	764 (8.3)
Cerebral palsy (CP)	78 (0.9)	8 (0.1)
Diabetes	809 (7.7)	619 (8.1)
Down's syndrome	52 (0.5)	3 (0.02)
Heart disease	977 (7.1)	853 (8.6)
Hypertension	155 (1.8)	136 (2.4)
Lung disease/emphysema	370 (2.7)	297 (3.1)
Multiple sclerosis (MS)	123 (1.0)	54 (0.6)
Osteoporosis	104 (0.8)	89 (0.9)
Parkinson's disease	203 (1.5)	178 (2.0)

Health problem, illness, or disability	Care recipients of all ages (n=11,845)	Care recipients age ≥60 only (n=8,880)
	n (Weighted Percent)	n (Weighted Percent)
Sensory disability (eye/vision problems including blindness or hearing problems including deafness)	301 (3.1)	256 (3.6)
Spinal cord injury (SCI)	144 (1.6)	73 (0.8)
Stroke	611 (5.3)	519 (6.2)
Traumatic brain injury (TBI)	65 (0.8)	23 (0.4)
Other developmental disability (e.g., spinal bifida, muscular dystrophy, fragile X)	206 (2.0)	83 (1.1)
Other condition	3,874 (34.2)	2,658 (30.7)

Appendix
Behavioral Risk Factor Surveillance System
State-Added Caregiver Module, 2011-2013

People may provide regular care or assistance to a friend or family member who has a health problem or disability.

1. During the past month, did you provide any such care or assistance to a friend or family member?
(1) Yes
(2) No
2. What age is the person to whom you are giving care?

The remainder of these questions will be about the person to whom you are giving the most care.

3. What is the gender of the person you are caring for?
(1) Male
(2) Female
4. What is his/her relationship to you? For example, is he/she your (mother/daughter or father/son)?
(1) Parent
(2) Parent-in-law
(3) Child
(4) Spouse
(5) Sibling
(6) Grandparent
(7) Grandchild
(8) Other Relative
(9) Non-relative
5. For how long have you provided care for that person?

(1) __ Days
(2) __ Weeks
(3) __ Months
(4) __ Years
6. What has a doctor said is the major health problem, long-term illness, or disability that the person you care for has? [Interviewer checks only one health condition mentioned.]

7. In which of the following areas does the person you care for need the most help?
 - (1) Taking care of himself/herself, such as eating, dressing, or bathing
 - (2) Taking care of his/her resident or personal living spaces, such as cleaning, managing money, or preparing meals
 - (3) Communicating with others
 - (4) Learning or remembering
 - (5) Seeing or hearing
 - (6) Moving around within the home
 - (7) Transportation outside of the home
 - (8) Getting along with people
 - (9) Relieving/decreasing anxiety or depression
 - (10) Something else

8. In an average week, how many hours do you provide care for that person because of his/her health problem, long-term illness, or disability?
 - (1) __hours per week

9. I am going to read a list of difficulties you may have faced as a caregiver. Please indicate which one of the following is the greatest difficulty you have faced in your caregiving:
 - (1) Creates a financial burden
 - (2) Doesn't leave enough time for yourself
 - (3) Doesn't leave enough time for your family
 - (4) Interferes with your work
 - (5) Creates stress
 - (6) Creates or aggravates health problems
 - (7) Affects family relationships
 - (8) Other difficulty
 - (9) No difficulty

10. During the past year, has the person your care for experienced changes in thinking or remembering?
 - (1) Yes
 - (2) No