



Caregiving for Family and Friends — A Public Health Issue



NATIONAL ASSOCIATION OF
CHRONIC DISEASE DIRECTORS
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CENTERS FOR DISEASE
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Caregiving is an important public health issue that affects the quality of life for millions of individuals. Caregivers provide assistance with another person's social or health needs. Caregiving may include help with one or more activities important for daily living such as bathing and dressing, paying bills, shopping and providing transportation. It also may involve emotional support and help with managing a chronic disease or disability. Caregiving responsibilities can increase and change as the recipient's needs increase, which may result in additional strain on the caregiver.^{1,2,3}

Caregivers can be unpaid family members or friends or paid caregivers.^{1,2} Informal or unpaid caregivers are the backbone of long-term care provided in people's homes. In particular, middle-aged and older adults provide a substantial portion of this care in the US, as they care for children, parents or spouses.^{2,3} These informal caregivers are the focus of this brief.^{2,3}

Caregiving can affect the caregiver's life in a myriad of ways including his/her ability to work, engage in social interactions and relationships, and maintain good physical and mental health.¹

Caregiving also can bring great satisfaction and strengthen relationships, thus enhancing the caregivers' quality of life. As the population ages and disability worsens, it is critical to understand the physical and mental health burden on caregivers, the range of tasks caregivers may perform, and the societal and economic impacts of long-term chronic diseases or disability.² Gathering information on these topics enables us to plan for public health approaches to assist individuals as well as their communities and maintain the health of caregivers and care recipients.¹

The Caregiving for Family and Friends brief is the second of a series of topic-specific documents focusing on public health issues related to older adults. The briefs provide public health professionals with the most recent data available on health and age-related conditions, including the importance of brain health, the management of chronic conditions, the burdens of caregiving, to help identify needs and lessen the future effects of a growing older population.

Informal caregivers provide regular care or assistance to a friend or family member who has a health problem or disability.^{2,4}

Data for Public Health Action

With an increasing older adult population and people with disabilities living longer, the need for caregiving is growing. By acting strategically, public health professionals can stimulate needed changes to systems that improve the health of both caregivers and care recipients, provide training to healthcare providers about the importance of family caregivers, and ensure that caregivers have the information and support they need to minimize the stress of caregiving.

This brief examines the following questions:

- What are the characteristics of caregivers and the caregiving situation?
 - What percentage of middle-aged and older adults provide care to someone else?
 - What percentage of caregivers provide care to a family member or friend with dementia or other cognitive impairment disorders?
- What is the health status of caregivers?
 - What percentage of caregivers have health care coverage and get annual check-ups?
 - What percentage of caregivers experience unhealthy days and insufficient sleep?
 - What percentage of caregivers have two or more chronic diseases or disability?
 - What percentage of caregivers reported having coronary heart disease (including angina and/or myocardial infarction) and/or stroke?
- What percentage of adults not currently caregivers think they will be caregivers in the future?

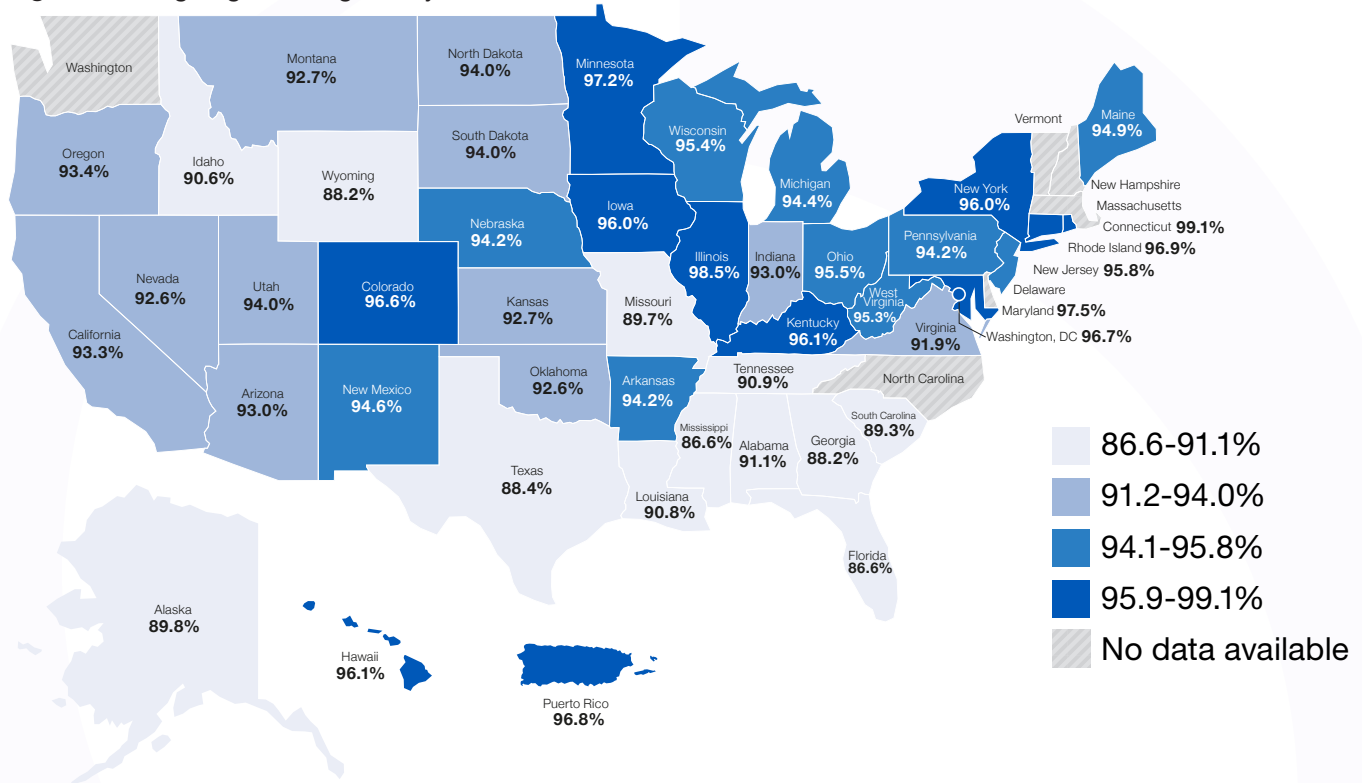
The caregiving data presented in this brief were collected from community-dwelling adults 45 years of age and older in 2015-2017 through the Behavioral Risk Factor Surveillance System (BRFSS).⁴ Questions related to caregiving were administered as part of the Caregiver Optional Module in 44 states, the District of Columbia and Puerto Rico. For states administering the module during multiple years, the most recent data were used. Additional data reports can be generated and viewed through the CDC Healthy Aging Data Portal (<https://www.cdc.gov/aging/agingdata/index.html>).

These data were examined in two age groups, adults 45-64 years and aged 65 years and older, as well as by sex, race and Hispanic ethnicity, chronic disease status, and other demographic characteristics.



Health Status of Caregivers: Caregiver Health Care Coverage and Annual Check-ups

Figure 2: Caregiving adults aged 45 years or older who had health insurance



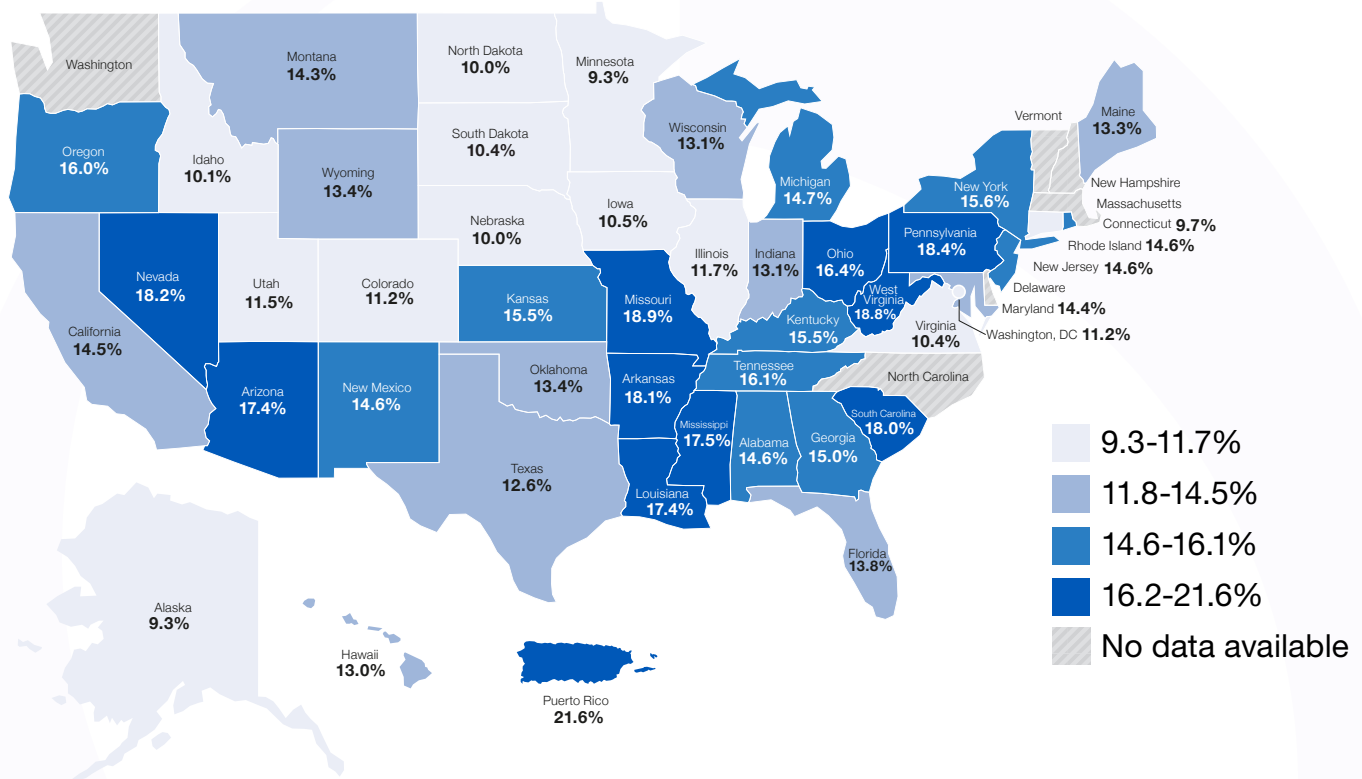
Do you have any kind of health care coverage, including health insurance, prepaid plans such as HMOs or government plans such as Medicare, or Indian Health Service?

Caregivers often neglect their own health needs.³ Having health care coverage and routine check-ups can impact their health status positively.³

- 92.9% of caregivers aged 45 years and older reported that they have some form of health care coverage.
 - 98.9% of caregivers aged 65 years and older have health care coverage in comparison to 90.1% of caregivers aged 45 to 64 years.
 - 94.3% of White caregivers reported having health care coverage compared to 89.1% of Black/African American caregivers, 85.2% of Hispanic caregivers, and 94.1% of Asian or Pacific Islander caregivers.
- 79.3% of caregivers aged 45 years and older reported having had a routine checkup in the past year.
 - 80.9% of women caregivers compared to 76.8% of men reported having a routine checkup.
 - 78.2% of White caregivers reported having a routine check-up, compared to 85.0% of Black/African American caregivers, 78.6% of Hispanic caregivers and 90.4% of Asian/Pacific Islander caregivers.

Health Status of Caregivers: Unhealthy Days and Insufficient Sleep

Figure 3: Caregivers aged 45 years or older who reported frequent mental distress



Caregiving can be emotionally and physically demanding. Over half (53%) of caregivers indicated that a decline in their health compromises their ability to provide care.³

Now thinking about your mental health, which includes stress, depression and problems with emotions, for how many days during the past 30 days was your mental health not good?

- 14.5% of caregivers reported experiencing 14 or more mentally unhealthy days in the past month.

Now thinking about your physical health, which includes physical illness and injury, for how many days during the past 30 days was your physical health not good?

- 17.6% of caregivers reported experiencing 14 or more physically unhealthy days in the past month.

On average, how many hours of sleep do you get in a 24 hour period?

Frequent mentally or physically unhealthy days can effect caregiver’s sleep. Insufficient sleep (defined as fewer than 7 hours in a 24 hour period) may negatively impact a caregiver’s health and also interfere with their ability to provide care.⁵

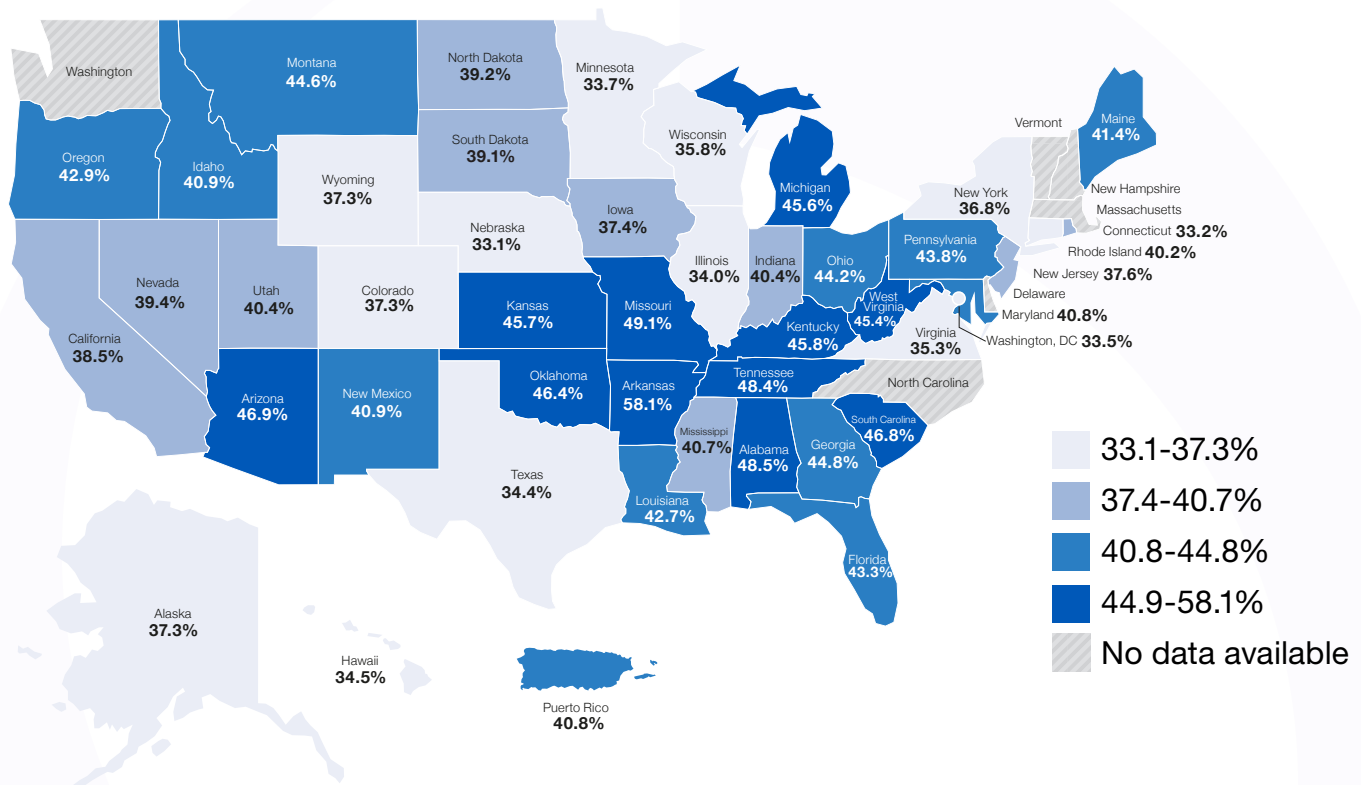
- 36.7% of caregivers reported getting insufficient sleep.

3. <https://www.cdc.gov/aging/caregiving/index.htm>, accessed August 2018

5. Seeking That Elusive Good Night Sleep, <https://www.caregiver.org/seeking-elusive-good-night-sleep>, accessed August 2018

Health Status of Adult Caregivers: Prevalence of Chronic Diseases and Disability Status

Figure 4: Caregivers aged 45 years or older who reported having 2 or more chronic diseases



Has a doctor, nurse or other health professional ever told you that you had one of the following: Coronary heart disease (including angina and/or myocardial infarction), stroke, asthma (still have), cancer (skin, other types of cancer), COPD, arthritis, depressive disorder, kidney disease, diabetes?

Caregivers are at increased risk for having multiple chronic diseases as they may neglect their own personal health needs while providing care to others.³

- 40.7% of caregivers report having two or more chronic diseases.
 - 53.4% of caregivers aged 65 years and older have two or more chronic diseases compared to 34.8% caregivers aged 45 to 64 years.

Are you limited in any way in any activities because of physical, mental, or emotional problems? OR Do you now have any health problem that requires you to use special equipment such as a cane, a wheelchair, a special bed or a special telephone?)

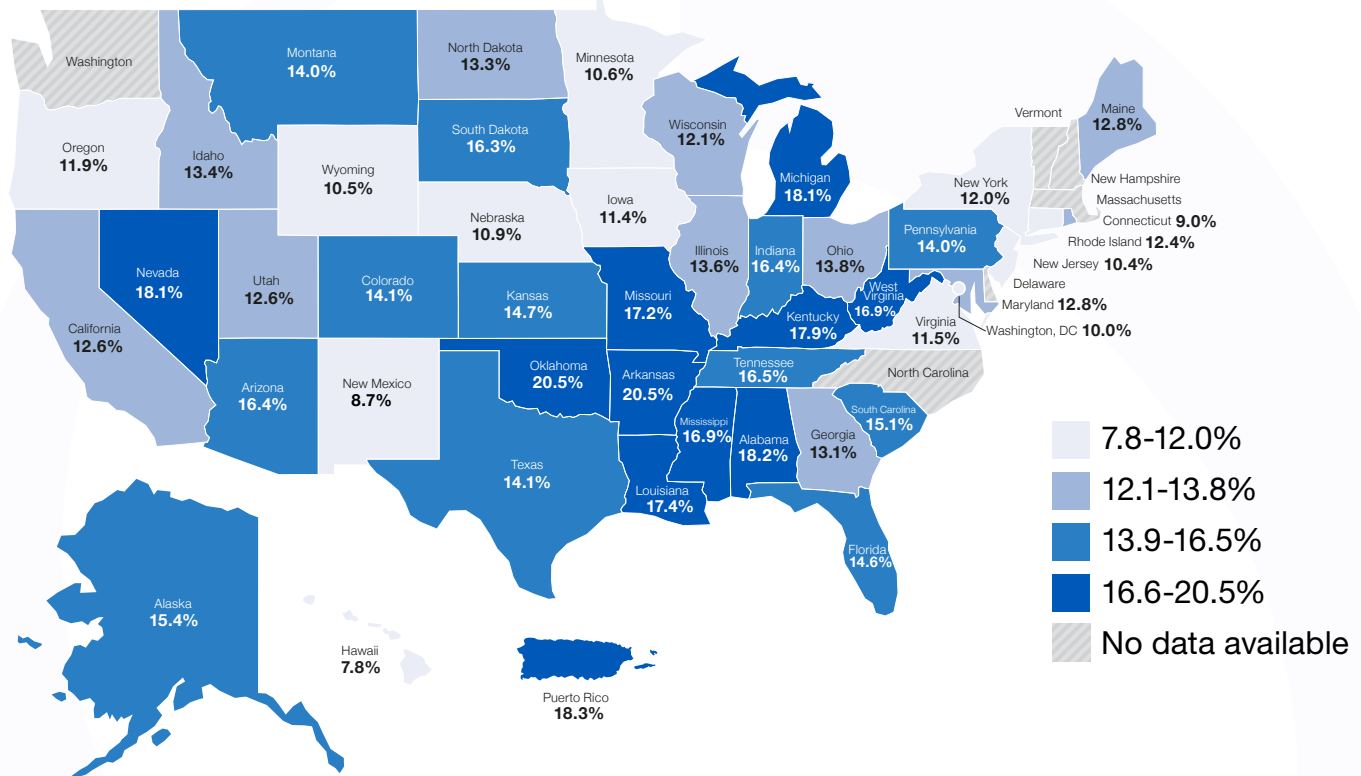
Disability status is defined as any degree of activity limitations because of physical, mental, or emotional problems or having any health problem that requires using special equipment such as a cane, a wheelchair, a special bed or a special telephone.

- 33.0% of caregivers reported having a disability.
 - 35.5% of caregivers aged 65 years and older reported having a disability compared to 31.9% of adult caregivers aged 45 to 64 years.

3. <https://www.cdc.gov/aging/caregiving/index.htm>, accessed August 2018

Health Status of Caregivers: Prevalence of Coronary Heart Disease and/or Stroke

Figure 5: Caregivers aged 45 years or older who reported having Coronary Heart Disease and/or Stroke



Has a doctor, nurse or other health care professional ever told you had angina or coronary heart disease (Yes, No), or Ever told you had a heart attack, also called a myocardial infarction? (Yes, No) or Ever told you had a stroke (Yes, No)?

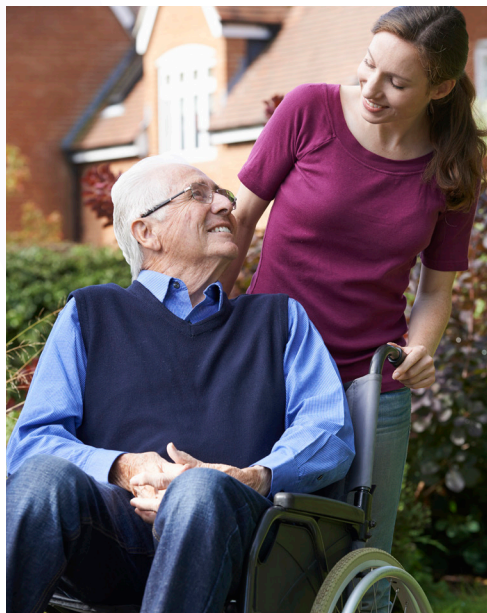
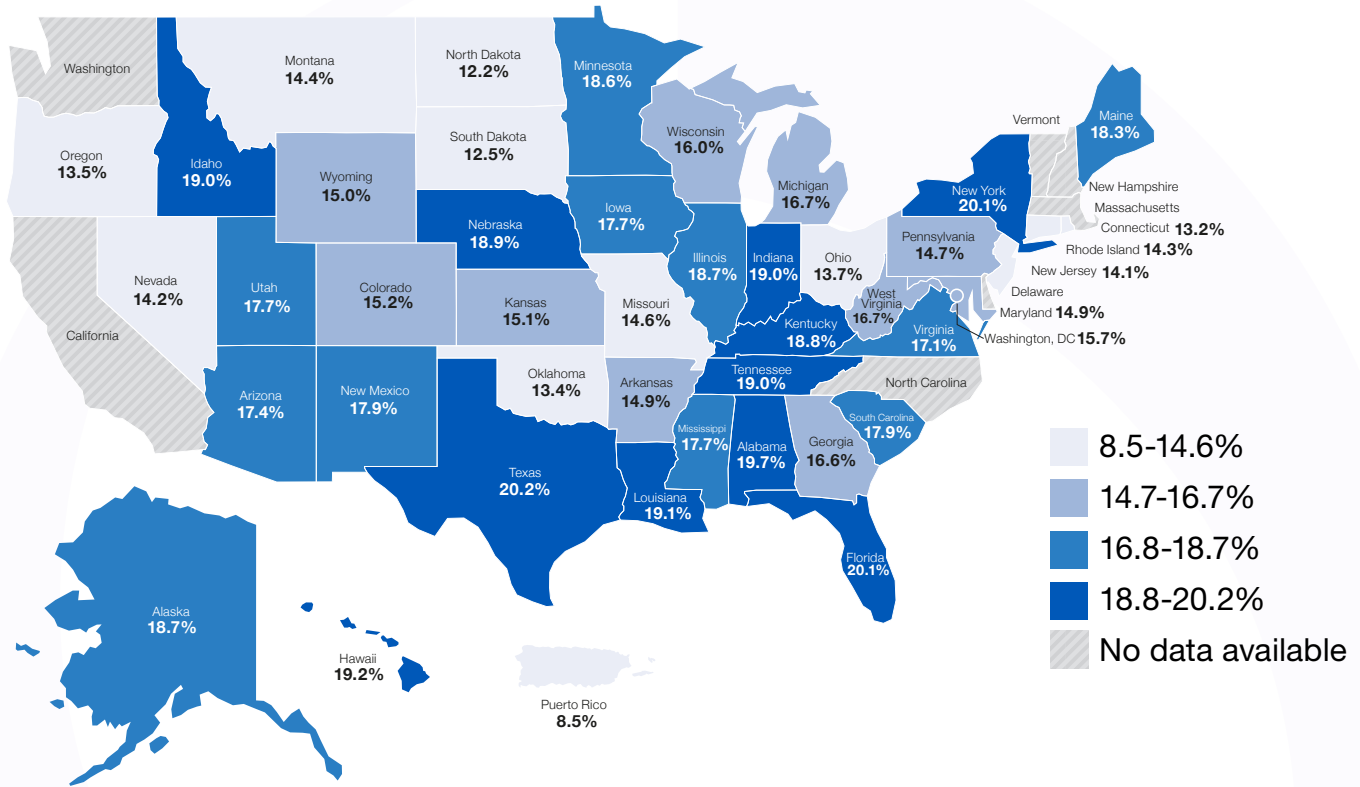
Persons who have experienced a heart attack or stroke and/or who have current coronary heart disease (including angina) may experience limitations caused by their chronic disease. Because these conditions may require substantial self-care, providing care to someone else may become more challenging.⁶

- 14.1% of caregivers reported coronary heart disease and/or stroke.
 - 22.2% of caregivers aged 65 years and older reported coronary heart disease and/or stroke compared to 10.3% of caregivers aged 45 to 64 years.
 - 17.6% of men caregivers 45 years of age and older reported coronary heart disease and/or stroke compared to 11.8% of women.
 - The prevalence of these conditions varied by racial/ethnic groups: 14.4% of white caregivers, 13.3% of Black/African American caregivers, 12.3% of Hispanic caregivers and 7.6% of Asians/Pacific Islanders caregivers reported coronary heart disease and/or stroke.

**Respondents were classified as having coronary heart disease (CHD) if they reported having been told by a provider they had CHD. Respondents were also classified as having CHD if they reported having been told they had a heart attack (i.e., myocardial infarction) or angina.

Estimating Future Caregiving

Figure 6: Non-caregivers aged 45 years or older who expect to be caregivers within the next two years



In the next 2 years, do you expect to provide care or assistance to a friend or family member who has a health problem or disability?

The need for caregivers is expected to continue to grow with increases in the US older adult population. Currently, there are 7 potential family caregivers per older adult. By 2030, it is estimated there will be only 4 potential family caregivers per older adult.²

- 17.2% of middle-aged and older adults who are not currently caregivers expect to provide care or assistance in the next two years to a friend or family members with a health problem or a disability.
- 20.0% of adults aged 45-64 years who do not currently provide care to someone expect to do so in the future compared to 12.8% of adults aged 65 years and older.

2. Hoffman D, Zucker H. A Call to Preventive Action by Health Care Providers and Policy Makers to Support Caregivers. Prev Chronic Dis 2016;13:160233

Call to Action

Caregiving is an increasingly common experience in middle and older adults that cuts across demographic groups. The need for caregivers is expected to grow due to the continued increases in the older adult population. Many middle-aged and older adults who are not currently caregivers do expect to provide care in the future. People are caregivers for various amounts of time, but most people provide care for six months or more and for many it is equivalent to a part-time job. These caregivers may have a substantial burden of disability and chronic disease as they care for others.

By acting strategically, public health professionals can stimulate needed changes to systems that promote the health and well-being of both caregivers and their care recipients. Below are some of the actions that you and your community can take to make changes that positively impact caregivers.

1. Increase messaging that emphasizes both the important role of caregivers and the importance of maintaining caregivers' health and well-being.
2. Educate the public about the importance of caregiving before they begin and the resources and supports available to them.
3. Educate healthcare providers to be mindful of the health risks for caregivers, encourage caregivers' use of available information and tools, and make referrals to supportive programs and services.
4. Evaluate caregiver training and support programs to determine program accessibility, effectiveness, and impact.
5. Estimate the gap between workforce capacity and anticipated demand for services to support people with dementia and disability and their caregivers.
6. Increase awareness of and access to evidence-based programs and services that can help caregivers and care recipients and increase access to these programs and services.
7. Encourage caregivers to get regular check-ups, use preventive services and engage in self-care to maintain health.
8. Ensure that caregivers with a disability and/or chronic diseases have access to self-management programs to maintain their health.

For additional actions refer to *The Healthy Brain Initiative: State and Local Public Health Partnerships to Address Dementias, The 2018-2023 Road Map*⁷

Technical Information

The Behavioral Risk Factor Surveillance System (BRFSS) is the nation's premier system of health-related telephone surveys that collect state data about U.S. residents regarding their health-related risk behaviors, chronic health conditions, and use of preventive services. Established in 1984 with 15 states, BRFSS now collects data in all 50 states as well as the District of Columbia and three U.S. territories.

BRFSS completes more than 450,000 adult interviews each year, making it the largest and longest continuously conducted health survey system in the world.

CDC's Behavioral Risk Factor Surveillance System (BRFSS) helps states survey U.S. adults regarding a wide range of health issues and behaviors that affect their health. The crucial information gathered through this state-based telephone surveillance system is used by national, state, and local public health agencies to identify populations that might be most at risk and to monitor the need for and the effectiveness of various public health interventions.

Although the BRFSS is a useful tool for assessing caregiving in middle-aged and older adult populations, it has some limitations: it excludes people who do not have telephones or are in institutions such as nursing homes; it may underrepresent people who are severely impaired because of the functional capacity required to participate in the survey; and responses to BRFSS are self-reported and therefore have not been confirmed by a healthcare provider. Despite these limitations, the BRFSS is a uniquely powerful tool to provide the prevalence of caregiving and related issues among older community-dwelling U.S. adults, due to its large sample size and proven reliability and validity.

The BRFSS is administered and supported by the Division of Population Health, National Center for Chronic Disease Prevention and Health Promotion, CDC. For more information, please visit <http://www.cdc.gov/brfss>.

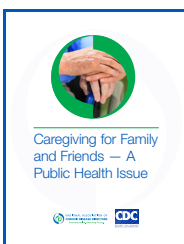
State of Aging and Health in America: Data Brief Series

The National Association of Chronic Disease Directors (NACDD) and the Centers for Disease Control and Prevention (CDC) developed a series of topic-specific data briefs on public health issues related to the aging population. The series is composed of four (4) briefs. Each brief provides data by state, age, gender, race, and ethnicity from the Behavioral Risk Factor Surveillance System. Topics include brain health, caregiving, heart disease, and other chronic diseases. Public health can use the data to make informed decisions and develop effective policies. Action steps provide direction on how to improve the health and well-being of aging Americans.



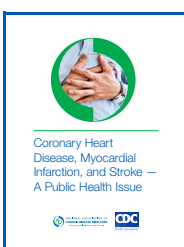
Subjective Cognitive Decline (SCD) is the self-reported experience of worsening or more frequent confusion or memory loss. It is a form of cognitive impairment and can be one of the earliest noticeable symptoms of Alzheimer's disease and related dementias.

The SCD Brief has recent data on age-related conditions, brain health, and chronic disease management.



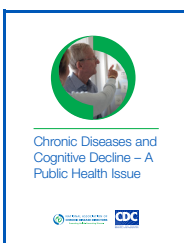
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The Caregiving Brief has recent data on age-related conditions, brain health, chronic disease management among caregivers, and burdens of caregiving.



Coronary heart disease, myocardial infarction, and stroke increase as the older adult population lives longer. Coronary heart disease can lead to decreased cognitive function. Promotion of chronic disease self-management through high blood pressure control and maintaining physical activity is critical.

The Heart Disease and Stroke Brief has recent data on age-related conditions, chronic disease management, blood pressure medication use, and the importance of physical activities.



Older adults are more likely to experience multiple chronic diseases, also known as co-morbidities, and greater functional limitations. Memory loss can complicate the management of these diseases.

The Chronic Diseases and Cognitive Decline Brief has recent data on multiple chronic diseases, brain health, and chronic disease management.

View all briefs at www.cdc.gov/aging/publications/briefs.htm
or at www.chronicdisease.org/page/HealthyAging