Caregiving is a Public Health Issue

Lisa C. McGuire, PhD

Lead, Alzheimer’s Disease and Healthy Aging Program
Division of Population Health
National Center for Chronic Disease Prevention and Health Promotion
Centers for Disease Control and Prevention

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Population ≥65 and ≥85 Years Old
United States, 1900–2014 and Projected 2020–2060

https://agingstats.gov/data.html
Significance of Caregiving

85% of baby boomers desire to “age in place”*

- 4.6 years is the average length of time for caregiving in home settings, and for persons living with dementia may range from 4-20 years

25% of adults aged 18+ reported providing care or assistance to person with long-term illness or disabilities in past 30 days (2009 BRFSS)**

- People willingly provide support but caregiving activities put people at increased risk for injury, mental health problems, and economic insecurity


**Anderson et al. (2013). Adult Caregivers in the United States: Characteristics and Differences in Well-being, by Caregiver Age and Caregiving Status. Preventing Chronic Disease,10:130090. DOI: http://dx.doi.org/10.5888/pcd10.130090.
Population Dynamics Related to Caregiving

- Currently 7 caregivers per patient exist
- This will drop to 4 caregivers per patient
- Number of childless elderly is growing
“There are four kinds of people in the world:

Those who have been caregivers;

Those who currently are caregivers;

Those who will be caregivers; and

Those who will need caregivers.”

Rosalynn Carter
Former First Lady and Chair of the Rosalynn Carter Institute on Caregiving
Caregivers

- Play critical role
- Health care system could not sustain costs of care
- Caregiving can take a physical and financial toll
The longer a caregiver has been providing care, the more likely she or he is to report *fair* or *poor* health.

22 percent of caregivers feel their health has gotten worse as a result of caregiving.

19% caregivers reports a high level of physical strain resulting from caregiving and 38% consider their caregiving situation to be emotionally stressful.

*Physical Impact of Caregiving*
Caregivers were 28% more likely to eat less or go hungry while caring for someone with Alzheimer’s. About half cut back on their own expenses to afford dementia-related care for their family member or friend. 13% sold personal belongings, such as car, to help pay for costs related to dementia. Nearly half tapped into their retirement funds.
Impact on Work

Caregivers’ Work-Related Changes

- Lost job benefits: 3%
- Retired early: 4%
- Turned down promotion: 5%
- Had to quit work: 6%
- Warning about performance/attendance: 7%
- Reduce or less demanding: 14%
- Leave of absence: 12%
- Late/leave early/take time off: 49%

Caregiving in the U.S. 2015
Caregiving is a public health issue
Healthy People 2020

- OA-8(Developmental) Reduce the proportion of noninstitutionalized older adults with disabilities who have an unmet need for long-term services and supports
National Plans and Reports (2)

Assure the needs of caregivers are met and implement caregiver supports. Specific recommendations include:

- Assure that health systems funded to provide chronic disease management and related services for family caregivers
- Engage families in care planning and referrals to appropriate community resources to support this planning
- Expansion of evidence-based caregiver support programs
- Ensure caregivers of older adults are routinely identified and their needs assessed
- Support caregivers through respite care, pension credits, financial subsidies, training and home nursing services to reduce their burden

Sources: Road Map, 2016 NAPA, HP2020 Older Adults, 2015 IOM Cognitive Aging, & 2016 IOM Caregiving
Strengthen data collection and research. Specific recommendations include:

- Implementing the Behavioral Risk Factor Surveillance System’s cognitive impairment and caregiver modules and inclusion of questions on core rather than as optional module.
- Expanding data collection on caregivers and cognitive aging
- Launch a multi-agency research program to evaluate caregiver intervention in real world health care and community settings, across diverse conditions and populations, and with respect to a broad array of outcomes
- Identify family/unpaid caregivers in EHRs of individuals with AD/ADRD, as well as in the caregiver's own medical records.

Sources: 2016 NAPA, Road Map, & 2016 IOM Caregiving
The Healthy Brain Initiative

The Healthy Brain Initiative is designed to spread understanding of and support for healthy cognitive aging as a central part of public health practice.

- creates and supports partnerships,
- collects and reports data,
- increases awareness of cognitive aging, and
- promotes the use of the Roadmap.

www.cdc.gov/aging/healthybrain/index.htm
CDC’s Public Health Road Map

The Public Health Road Map for State and National Partnerships 2013-2018

35 action items for public health officials to:

• Promote cognitive functioning
• Address cognitive impairment and Alzheimer’s disease
• Meet the needs of caregivers

https://www.cdc.gov/aging/healthybrain/roadmap.htm
<table>
<thead>
<tr>
<th>Action Number</th>
<th>Description</th>
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<tbody>
<tr>
<td>M-01</td>
<td>Implement the Behavioral Risk Factor Surveillance System’s cognitive impairment and <strong>caregiver</strong> modules.</td>
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<tr>
<td>M-08</td>
<td>Define the needs of <strong>caregivers</strong> and persons with dementia, including Alzheimer’s disease and younger onset, as they relate to employment and employers.</td>
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<td>M-10</td>
<td>Conduct a national-level review of <strong>caregiver programs and policies</strong> consistent with The Guide to Community Preventive Services methodologies.</td>
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<td>M-13</td>
<td>Conduct a national-level literature review on the potential and optimal use of technology for delivering best practices in programs for <strong>caregivers</strong> and persons with dementia, including Alzheimer’s disease.</td>
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<td>E-03</td>
<td>Encourage public health entities to provide links on their Web sites to local, state, and national dementia resources, including those specific to Alzheimer’s disease and <strong>caregiving</strong>, such as <a href="http://www.alzheimers.gov">www.alzheimers.gov</a>.</td>
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Behavioral Risk Factor Surveillance System (BRFSS)

- BRFSS is a partnership between CDC and state health departments to produce data that benefits states, territories, localities and public health professionals.
- Includes 57 state/territorial level telephone surveys on health status, health risk behaviors and chronic conditions.
- The world’s largest continuously conducted telephone health surveillance system.
- The only source of public health behavior and risk factor data at state/territorial level for most states/territories.
- Non-institutionalized adults age 18+.
- Approximately 450,000 respondents in 2014.
- Data and more information: [http://www.cdc.gov/brfss/](http://www.cdc.gov/brfss/)
Prevalence of Caregiving, by State and Territory, BRFSS, 2009*

*BRFSS core question: “People may provide regular care or assistance to a friend or family member who has a health problem, long-term illness, or disability. During the past month, did you provide any such care or assistance to a friend or family member?”
Promoting the Health and Well-being of Caregivers for Older Adults

Caregiving Surveillance

- In 2009, a question about caregiver status was added to the BRFSS Core.
- 10-item caregiver module added to BRFSS in 2011-2013
- Revised 8-item caregiver module added to BRFSS in 2015 with 24 states administering it.

State-Level Caregiving Information

- A series of reports and fact sheets were developed with the BRFSS caregiving data from 2011-2013 and products for 2015 data are in development.
Optional BRFSS Caregiving Module

Caregiving

- Characteristics of caregivers
- Problems they face
- Greatest care needs
- 24 states in 2015
- $N = 141,191$

http://www.cdc.gov/brfss
Caregiving Screener

During the past 30 days, did you provide regular care or assistance to a friend or family member who has a health problem or disability?

Yes/No
Forecasting

If not a current caregiver:

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?
Relationship

What is his/her relationship to you? For example is he/she your (mother/daughter or father/son)?
Length of Care

For how long have you provided care for that person? Would you say…

- Less than 30 days
- 1 month to less than 6 months
- 6 months to less than 2 years
- 2 years to less than 5 years
- More than 5 years
In an average week, how many hours do you provide care or assistance? Would you say…

- Up to 8 hours per week
- 9 to 19 hours per week
- 20 to 39 hours per week
- 40 hours or more per week
Cause

What is the main health problem, long-term illness, or disability that the person you care for has?

Broader categories

Match co-occurring chronic conditions
Caregiving Needs

In the past 30 days, did you provide care for this person by...

...Managing personal care such as giving medications, feeding, dressing, or bathing?  
Yes/No

...Managing household tasks such as cleaning, managing money, or preparing meals?  
Yes/No
Support Services Needed

Of the following support services, which ONE you MOST need, that you are not currently getting?

- Classes about caregiving, such as giving medication
- Help in getting access to services
- Caregiver support groups
- Individual counseling to help cope with caregiving
- Respite care
- No caregiver support services needed
2015 Highlights

- 22% of respondents aged 18 and older provides regular care or assistance

Physical and Mental Health

- More likely to report Fair/poor physical health, depression, frequent mental and physical distress, and obesity
- No differences on coronary heart disease, stroke, CVD, diabetes, and routine check-up (2 years)

- 17.8% of non-caregivers expect to provide care to someone due to a health problem or disability within the next two years

- 53.7% provided help managing personal care and 79.8% provided help managing household tasks
Data for Action: 2015 BRFSS

Cognitive Data from the 2015 BRFSS

Subjective Cognitive Decline Among Those Aged 45 and Over by Education Level

1 in 9 Americans aged 45 and older are experiencing Subjective Cognitive Decline

SCD is self-reported MEMORY PROBLEMS that have been getting worse over the past year.

Many with SCD also have other chronic conditions

http://www.alz.org/publichealth/data-collection.asp#cognitive
Data for Action: Data Portal

http://www.cdc.gov/aging/agingdata/index.html
Planning and Programmatic Information

- Understand the state-level experience & needs of caregivers
  - Wide variation in prevalence of caregiving and impacts of caregiving across states
- Broad age range of caregivers and care recipients (not just older adults)
- Measure burden (time, tasks) for caregivers
- Link to caregiver outcomes, e.g., health, injury
Promoting the Health and Well-being of Caregivers for Older Adults

REACH OUT: Moving Programs into Practice
Developed a step-by-step guide to using REACH OUT, an evidence-based intervention for dementia caregivers, in communities of varying size and composition.

American Indian and Alaska Native (AI/AN) Caregiving
This Critical Issue Brief, Caregiving in Indian Country: Tribes Supporting Family Traditions[PDF-303K], looks at caregiving issues in Indian country and the support systems that can maintain this traditional family value, while there is outward migration of family caregivers.
A Public Health Approach to Alzheimer’s and Related Dementias

• Flexible curriculum linked to public health competencies
• Designed for faculty to use with undergraduate public health courses
• Developed & evaluated

http://www.cdc.gov/aging
http://www.cdc.gov/aging
For More Information

- Centers for Disease Control and Prevention:
  - [http://www.cdc.gov/aging](http://www.cdc.gov/aging)
  - [http://www.cdc.gov/aging/caregiving](http://www.cdc.gov/aging/caregiving)
  - [http://www.cdc.gov/brfss](http://www.cdc.gov/brfss)

- ClinicalTrials.gov, a service of NIH: [http://clinicaltrials.gov](http://clinicaltrials.gov)

- Community Programs:
  - Contact a local Area Agency on Aging (AAA)
  - Contact a local Aging & Disability Resource Center (ADRC)
  - Or, go to [http://eldercare.gov/](http://eldercare.gov/)


For more information, contact CDC
1-800-CDC-INFO (232-4636)

The findings and conclusions in this report are those of the authors and do not necessarily represent the official position of the Centers for Disease Control and Prevention.

Dr. Lisa McGuire
LMcGuire@cdc.gov

The Healthy Brain Initiative