



SUPPORTING CAREGIVERS

A HEALTHY BRAIN INITIATIVE ISSUE MAP



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SUPPORTING CAREGIVERS to Make Alzheimer's Our Next Public Health Success Story

The challenges of caring for persons with Alzheimer's and other dementias can become difficult and overwhelming, especially when intensive care is needed for long periods of time. For many, however, caregiving is also a rewarding experience, bringing family members closer together in time of great need.

In 2017, 16 million family members and friends provided 18.4 billion hours of unpaid care to people with Alzheimer's and other dementias, at an economic value of more than \$232 billion.¹

Public health can play a central role in offering information, guidance, and supportive resources to caregivers to help them provide effective dementia care and attend to their own well-being. Public health can also work with partners to facilitate access to affordable, evidence-informed services, programs, interventions, and supports to reduce stress and improve coping, self-efficacy, and overall health. Some of the many resources that public health can help expand, promote, or tailor to specific populations include:

- » Community-based programs for physical activity, chronic disease self-care, and caregiver education;
- » Peer support groups and social gatherings for people affected by dementia;
- » Online support and information resource centers;
- » Apps for caregivers and persons living with dementia and GPS tracking devices;
- » Home healthcare services and home modification programs;
- » Adult day and respite care;
- » Advanced care and advanced financial planning;
- » Transportation services; and
- » Information and referral services.

References

1. Alzheimer's Association. 2018 Alzheimer's Disease Facts and Figures. *Alzheimer's Dement* 2018;14(3):367-429. Available at: alz.org/facts
2. National Alliance for Caregiving in Partnership with the Alzheimer's Association. *Dementia Caregiving in the U.S. National Alliance for Caregiving*; 2017.
3. National Alliance for Caregiving and AARP. *Caregiving in the U.S. National Alliance for Caregiving*; 2015.

COMPELLING DATA

Nearly half of all caregivers (48%) who care for an older adult do so for someone with Alzheimer's or another dementia.¹

About one in three Alzheimer's caregivers report their health has gotten worse due to care responsibilities, compared with one out of five caregivers of other older adults.²

Among caregivers for people with Alzheimer's and other dementias:

- » Nearly one in four are "sandwich generation" caregivers — caring for both an older adult and a child.¹
- » Nearly 60% rate the emotional stress of caregiving as high or very high. As many as 40% report symptoms of depression.¹
- » Caring for people with Alzheimer's can have a negative effect on employment, income, and financial security. Among caregivers for people with Alzheimer's and other dementias who are employed full or part time, 57% said they had to go in late, leave early, or take time off because of their caregiving responsibilities. In addition, 18% had to go from full to part time, 16% took a leave of absence, and 8% turned down a promotion due to the burden of caregiving.¹
- » Only half of employers have policies that support caregivers: 53% offer flexible work hours/paid sick days, 32% offer paid family leave, 23% offer employee assistance programs, and 22% allow telecommuting.³



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State and Local Public Health
Partnerships to Address Dementia:
The 2018-2023 Road Map

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For the full HBI Road Map, data, ready-to-use resources, and case studies, visit:
alz.org/publichealth or cdc.gov/aging

THE CAREGIVING ACTION AGENDA

The Healthy Brain Initiative's (HBI) *State and Local Public Health Partnerships to Address Dementia, The 2018–2023 Road Map* charts a course for state and local public health agencies and their partners to act quickly and strategically to prepare all communities by stimulating changes in policies, systems, and environments. Many of the Road Map's 25 expert-developed actions would help meet the needs of dementia caregivers.



EDUCATE & EMPOWER

- E-3** Increase messaging that emphasizes both the important role of caregivers in supporting people with dementia and the importance of maintaining caregivers' health and well-being.
- E-4** Promote prevention of abuse, neglect, and exploitation of people with dementia.
- E-5** Provide information and tools to help people with dementia and caregivers anticipate, avert, and respond to challenges that typically arise during the course of dementia.
- E-6** Strengthen knowledge about, and greater use of, care planning and related tools for people in all stages of dementia.
- E-7** Improve access to and use of evidence-informed interventions, services, and supports for people with dementia and their caregivers to enhance their health, well-being, and independence.



DEVELOP POLICIES & MOBILIZE PARTNERSHIPS

- P-1** Promote the use of effective interventions and best practices to protect brain health, address cognitive impairment, and help meet the needs of caregivers for people with dementia.
- P-5** Engage public and private partners in ongoing planning efforts to establish services and policies that promote supportive communities and workplaces for people with dementia and their caregivers.
- P-6** Assure public health plans that guide emergency preparedness and emergency response address the special needs of people with dementia and their caregivers, support access to critical health information during crises, and prepare emergency professionals for situations involving people with dementia.



ASSURE A COMPETENT WORKFORCE

- W-2** Ensure that health promotion and chronic disease interventions include messaging for healthcare providers that underscores the essential role of caregivers and the importance of maintaining their health and well-being.
- W-3** Educate public health professionals about the best available evidence on dementia (including detection) and dementia caregiving, the role of public health, and sources of information, tools, and assistance to support public health action.
- W-4** Foster continuing education to improve healthcare professionals' ability and willingness to support early diagnoses and disclosure of dementia, provide effective care planning at all stages of dementia, offer counseling and referral, and engage caregivers, as appropriate, in care management.
- W-7** Educate healthcare professionals 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.



MONITOR & EVALUATE

- M-1** Implement the Behavioral Risk Factor Surveillance System (BRFSS) optional module for Cognitive Decline in 2019 or 2020, and the BRFSS optional module for Caregiving in 2021 or 2022.
- M-2** Support national data collection on dementia and caregiving.
- M-3** Use data gleaned through available surveillance strategies and other sources to inform the public health program and policy response to cognitive health, impairment, and caregiving.
- M-4** Embed evaluation into training and caregiving support programs to determine program accessibility, effectiveness, and impact.
- M-5** Estimate the gap between workforce capacity and anticipated demand for services to support people with dementia and their caregivers.

PUBLIC HEALTH STRATEGIES TO SUPPORT CAREGIVERS

The following are examples of how public health departments are supporting dementia caregivers.

NEW YORK

New York State Department of Health (NYSDOH) expanded caregiver and clinical supports across the state through its Alzheimer's Disease Caregiver Support Initiative (ADCSI).



Grounded in an effective model program developed by New York University (NYU) and others, ADCSI promotes early diagnosis and has a protocol for providing education, care consultation, and a plan for medical and social services to persons living with Alzheimer's and their caregivers — thereby helping facilitate clinical-community linkages.

To augment its \$2 million annual budget, NYSDOH prepared a funding proposal based on data documenting impact of evidenced-based support models and state surveillance data on caregiving and cognitive impairment. The proposal called for adapting the model for statewide implementation — with the ultimate outcome of keeping people living with Alzheimer's dementia in the community longer and reducing caregiver stress. After several years, the department's proposal was included in the governor's budget, and bipartisan legislative approval resulted in an annual \$25 million infusion to the NYSDOH budget for an expanded array of services. The scope of New York State's investment enabled extensive scale in both service availability and utilization. In the first year, community support services for people with dementia and their caregivers reached approximately 13,000 individuals and families; as the expanded capacity reaches maturity, it is expected to serve many more New Yorkers each year.

NEW MEXICO

New Mexico Department of Health partnered with the state's Aging and Long-Term Services Department to encourage caregivers of people with memory loss or dementia to participate in a free Savvy Caregiver course. Graduates learn how to handle the challenges of caring for a family member with Alzheimer's and other dementias and care for themselves. A second course, developed by Stanford University, educated persons with chronic conditions and their caregivers on topics such as: managing common chronic disease issues, participating in treatment decisions, problem-solving and adhering to treatment plans, making advance directives, and maintaining a healthy lifestyle.



The health department chose to co-market the courses because older adults living with dementia are more likely than their peers to have multiple chronic conditions, including hypertension, heart disease, or diabetes. As an additional way to support people affected by dementia, the health department posted information on cognitive decline and dementia on the New Mexico Department of Health website.

The full HBI Road Map, other examples of strategies used by state public health agencies, and additional resources are available at alz.org/publichealth and cdc.gov/aging.

Data to guide your efforts can be found on your state's portal at alz.org/publichealth and at the Centers for Disease Control and Prevention's Healthy Aging Data Portal at cdc.gov/aging.

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