

CAREGIVING FOR PEOPLE LIVING WITH DEMENTIA AND HOW HEALTH DEPARTMENTS CAN MAKE AN IMPACT

Over 16 million family members and friends contributed 18.5 billion unpaid hours of care in 2018, valued at [\\$234 billion](#). The number of caregivers is expected to increase as the number of people living with Alzheimer's and other dementias more than doubles from nearly 6 million to 14 million by 2050. Almost [a third of caregivers](#) provided care for at least 20 hours a week and nearly half provided care for at least two years. This brief describes the caregiving landscape, the role of state and territorial health agencies (S/THAs), and opportunities for systems-level changes to support unpaid family caregivers.

Caregivers are people who provide direct care and support to people living with dementia for activities of daily living, which can either be paid or unpaid. The majority of caregivers assist with [household tasks and personal care](#) while providing loving support, and most agree that caring for a family member or friend is an overwhelming challenge and emotionally tolling. Unpaid family caregivers have a variety of responsibilities for their families and communities, such as meeting work demands and caring for multiple generations. [One in three caregivers](#) are caring for a parent or parent-in-law and over half of caregivers are women. [One in four caregivers](#) are from the millennial generation, many of whom are caring for an older adult and children simultaneously. These responsibilities lead to elevated stress and barriers to caring for themselves, which cause [higher rates of hypertension and depression](#).

A National Plan: Healthy Brain Initiative (HBI) Road Map for State and Local Partners

CDC and Alzheimer's Association released the third iteration of the [HBI Road Map](#) for 2018-2023, which includes 25 actions for state and local public health agencies. Thirteen actions offer evidence-informed changes to public health programs and infrastructure to support access to care and services for caregivers and/or caregiving for people living with dementia. Systems-level change in the HBI Road Map requires a multi-pronged approach and may involve community health workers, social workers, case managers/patient navigators, health educators, pharmacists, clinicians, and/or respite care in their efforts to support the health of caregivers. Similar to other public health efforts, S/THAs are encouraged to begin with data and education, then policy and systems change to sustain high quality impact. State examples from ASTHO and Alzheimer's Association Brain Health Learning Communities include:

- Leveraging HBI action M-5, the **Minnesota** Department of Health used local-level data to identify naturally occurring retirement communities – or NORCs. By overlaying the NORC data within county lines in ArcGIS, the team identified priority counties for funding allocation and resources based on need to expand services as adults age.
- Promoting HBI action W-2, the **Missouri** Department of Health and Senior Services launched a social media campaign for caregiver appreciation month, where advertisements directed caregivers to support offered by the local Alzheimer's Association chapter. Their goal was to connect family caregivers with healthcare and supportive services.
- Supporting HBI action W-7, the **Tennessee** Department of Health developed an [online resource hub](#) for S/THA staff and community members alike with a healthy brain toolkit and briefs about a variety of topics, including caregiving. The goals of the materials were to be graphically inviting and contain important information for S/THA staff to infuse brain health and support for caregivers into their existing activities.

Caregiving Policies

There is national and state movement to address the increasing needs of people living with dementia and their unpaid caregivers. Congress passed the [Recognize, Assist, Include, Support, and Engage \(RAISE\) Family Caregivers Act](#) of 2017 to develop an advisory council and national strategies for caregivers. There are several ways state health departments can educate and support caregivers, including leveraging existing relationships and building new partnerships to provide appropriate resources and services for caregivers.

Recommendations for Applying Public Health Strategies to Caregiver Policies

Where S/THAs Have Direct Influence	
Clinicians & Clinic Staff	S/THA protocols or workflows for screening caregivers for depression and anxiety, monitoring blood pressure, and referring them to support groups can connect caregivers with services.
Pharmacists	Pharmacy-based services, such as hypertension clinics, have been effective for improving health outcomes for other chronic conditions. S/THAs may work with pharmacists to promote medication management for both people living with dementia and their caregivers and make referrals to services in the community (i.e., respite care, support groups).
Where S/THAs Have Indirect Influence	
Transportation Authority	Transportation authorities can address the time it takes a person living with dementia and their caregiver to get to and from activities and appointments. Public transportation systems with accessibility routes can help alleviate some of the stress. S/THAs can work with the transportation authority in their jurisdiction to encourage comprehensive planning and design.
Financial Institutions	Financial institutions – especially community development financial institutions – can help families and caregivers explore their options for navigating the rising costs of care and supportive services. For caregivers who are self-employed or operating in the gig economy, AARP developed the Self-Saver tool for bookkeeping and tax preparation. S/THAs can refer caregivers to these and other resources to promote their economic well-being.
S/THA Human Resources & Employers	State legislatures, S/THA human resources offices, and employers can improve the conditions for people living in the jurisdiction and working for the state by updating workplace policies to include long-term care and flexible work hours. These interventions are shown to be effective for caregivers and employers. ASTHO’s issue brief, Policies and Interventions to Support Working Caregivers , details other state policies affecting working caregivers, including family medical leave, paid family medical leave, and paid time off.

Conclusion

Caregivers of people living with dementia provide billions of hours of care, the cost of which would otherwise be shouldered by states, territories, and other payers. As a result, caregivers face financial and health challenges during the years they provide care. The public health system has helped increase life expectancy and life quality, and now it’s time to reinvent and expand to support the caregivers of people living with dementia.

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