



# SUPPORTING CAREGIVERS

## *A HEALTHY BRAIN INITIATIVE ISSUE MAP*

The *Healthy Brain Initiative: State and Local Road Map for Public Health, 2023–2027* is a guidebook for state and local public health practitioners to address brain health and caregiving in their communities, advance health equity, and fully integrate cognitive health into public health practice.

Find the HBI Road Map and additional tools, resources and data at:  
[alz.org/HBIRoadMap](https://alz.org/HBIRoadMap) and [cdc.gov/aging](https://cdc.gov/aging)

# PUBLIC HEALTH AND CAREGIVING

Caregivers report positive feelings about caregiving, such as family togetherness and the satisfaction of helping others, yet they also frequently report higher levels of stress.<sup>1</sup> For some caregivers, the demands of caregiving may cause declines in their own health. Evidence suggests that the stress of providing dementia care increases caregivers' susceptibility to disease and health complications.<sup>2</sup>

Interventions to support dementia caregivers have been developed to improve their health and well-being by relieving the negative aspects of caregiving. Some also aim to delay nursing home admission of the person with dementia by providing caregivers with skills and resources (emotional, social, psychological and/or technological) to continue caring for their relatives, friends or neighbors at home. Specific approaches include providing education to caregivers, helping caregivers manage dementia-related symptoms, improving social support for caregivers and providing caregivers with respite from caregiving duties.

Further, primary care providers' awareness and understanding of their patients' caregiving responsibilities can help them manage the caregivers' stress and physical health effects of caregiving, link them to needed resources and improve their overall quality of life.

Public health can expand implementation and availability of these interventions using available awareness and messaging channels to focus on the overlapping needs and challenges related to cognitive decline, healthy aging and dementia caregiving. Efforts can educate the public using localized, culturally and linguistically tailored messages about care-related tasks, managing stress, social isolation and mental health; and connect people to resources, consumer-ready facts about symptoms, diagnosis, services and other resources.

**Caregivers provide care to people who need some degree of ongoing assistance with everyday tasks on a regular or daily basis. The recipients of care can live either in the community or institutional settings, range from children to older adults and have chronic illnesses or disabling conditions. Because of their partnership with people living with dementia in making joint decisions to enhance their care and quality of life, caregivers can also be referred to as "care partners" or "carers."**

## COMPELLING DATA

**Caregiving is common and its value is underrecognized.** Embedding support for dementia caregiving in policies, systems and environments is essential to protect caregivers' health and reduce the toll of their unpaid assistance — an estimated 18 billion hours in 2022, valued at \$339.5 billion.<sup>1</sup>

- » More than 11 million family and friends provide an estimated 18 billion hours of unpaid care annually to people living with Alzheimer's and other dementias. Approximately two-thirds of dementia caregivers are women.<sup>1</sup>
- » Nearly half (48%) of people who provide help to older adults do so for someone with Alzheimer's or another dementia.<sup>1</sup>

**Most caregivers are women, which can lead to disproportionate financial and health impacts.** Of all dementia caregivers who spend more than 40 hours per week providing care, 73% were women.<sup>1</sup> Of those providing care to someone with dementia for more than five years, 63% were women.<sup>1</sup>

- » Nearly 19% of women caring for a person with Alzheimer's had to quit work either to become a caregiver or because their caregiving duties became too difficult.<sup>3</sup>
- » Women who are Latina and African American who are caregivers contribute 47% and 34%, respectively, of their annual income to caregiving.<sup>4</sup>

**Caregivers of LGBTQ+ people may be older and face more barriers.** Caregivers of LGBTQ+ people are often chosen family members, friends and community members, since LGBTQ+ older adults are less likely to have children to assist them and are more likely to be single.<sup>5</sup>

- » As a result, caregivers of LGBTQ+ older adults may be the same age as the person for whom they are caring.<sup>5</sup>
- » Additionally, if they are not designated as the health care proxy, caregivers of LGBTQ+ who are not legal or biological family members have limited legal power to be involved in decision making, which may happen as cognitive decline worsens.<sup>6</sup>

### References

1. Alzheimer's Association. 2023 Alzheimer's Disease Facts and Figures. *Alzheimers Dement*. 2023;19(4):1109–1695. doi.org/10.1002/alz.13016
2. Fonareva I, Oken BS. Physiological and functional consequences of caregiving for relatives with dementia. *Int Psychogeriatr*. 2014;26(5):725–47. doi.org/10.1017/S1041610214000039
3. Alzheimer's Association. Women and Alzheimer's. 2022; Available from: <https://www.alz.org/alzheimers-dementia/what-is-alzheimers/women-and-alzheimer-s>
4. 2021 Caregiving Out-of-Pocket Costs Study; 2021. <https://aarp.org/caregivercosts>. doi.org/10.26419/res.00473.001
5. Fredriksen-Goldsen KI, Jen S, Bryan AEB, et al. Cognitive impairment, Alzheimer's disease, and other dementias in the lives of lesbian, gay, bisexual and transgender (LGBT) older adults and their caregivers: Needs and competencies. *J Appl Gerontol*. 2018;37(5):545–569. doi.org/10.1177/0733464816672047
6. Flatt JD, Johnson JK, Karpiak SE, et al. Correlates of subjective cognitive decline in lesbian, gay, bisexual, and transgender older adults. *J Alzheimers Dis*. 2018;64(1):91–102. doi.org/10.3233/JAD-171061



# CAREGIVING ACTION AGENDA

The framework of the Healthy Brain Initiative (HBI) Road Map, built on the 10 Essential Public Health Services (EPHS) and Public Health 3.0, consists of four domains that encompass one or more of the essential services. All four of those domains include actions to better support dementia caregivers. Pursuit of any action should include plans to collect and analyze pertinent data, evaluate implementation, and share findings with multi-sector partners to work toward shared goals and outcomes.

## STRENGTHEN PARTNERSHIPS AND POLICIES



**P-3** Partner across the community to promote **equitable access to services, supports and quality care** for people living with dementia and their caregivers.

**P-6** Equip **policymakers** with information on risk factors, the stigma associated with cognitive impairment and the impact of social determinants of health; and offer evidence-informed policy options across the life course.

**P-7** Join ongoing coalitions and partnerships to **prevent or remediate abuse, neglect and exploitation** of people living with dementia.

## MEASURE, EVALUATE AND UTILIZE DATA



**M-1** Support implementation of the Behavioral Risk Factor Surveillance System (BRFSS) optional modules for Cognitive Decline and Caregiving and use the data to shape programs and policies.



## BUILD A DIVERSE AND SKILLED WORKFORCE



**W-1** Provide evidence-informed training and informational resources for **primary health care providers** to facilitate culturally sensitive conversations about brain health with patients and caregivers across the life course.

**W-3** Promote inclusion of the life course approach to brain health in **licensing, certification and continuing education** requirements for health care and allied professionals.

**W-4** Strengthen training of **community health and direct service workers** about brain health across the life course to improve equitable care and quality of life for those living with cognitive impairment and to support caregivers.

**W-5** Partner with **public safety and emergency response agencies** to improve their ability to recognize and meet the needs of people living with cognitive decline and dementia.

## ENGAGE AND EDUCATE THE PUBLIC



**E-1** Engage diverse audiences to develop **culturally responsive messaging** about brain health, cognitive decline, healthy aging and caregiving.

**E-2** Disseminate culturally relevant messaging to **encourage conversations** about brain health, cognitive decline, healthy aging and caregiving.

**E-6** Enhance communication with **people living with dementia, their families and caregivers** about how to access services, care and social supports.

**E-7** Ensure **caregivers** have information, tools and resources about their vital role and ways to maintain their own **health and well-being**.

# PUBLIC HEALTH EXPERTISE TO SUPPORT CAREGIVERS

The [Healthy Brain Initiative \(HBI\) Collaborative](#) is a multi-component approach that aims to fully integrate cognitive health into public health practice, reducing the risk and impact of Alzheimer's and other dementias. Membership includes the Centers for Disease Control and Prevention and organizations funded to implement the national HBI strategy and BOLD Public Health Centers of Excellence. Each issue map features different HBI Collaborative members.

## BOLD Public Health Center of Excellence on Dementia Caregiving

The mission of the BOLD Public Health Center of Excellence on Dementia Caregiving (PHCOE-DC) is to assist state, local and tribal public health agencies to develop their existing programs and begin new initiatives to support family caregivers of people living with dementia in their jurisdictions. The Center seeks to increase access to and use of tools, best practices and effective public health strategies to support the work and well-being of family dementia caregivers across the United States.

The Center's three primary activities are to:

1. Identify and disseminate evidence-based programs and innovative approaches public health agencies can implement to support dementia caregivers.
2. Facilitate connections between public health agencies and a wide range of service organizations and partners who serve people living with dementia and their caregivers.
3. Provide free-of-charge assistance to public health agencies for selecting, sustaining and promoting effective public health interventions to support family dementia caregivers.

Connect with PHCOE-DC and discover ways to:

- » **Connect with experts.** Get advice and guidance from national organizations and leaders in the development and dissemination of tools, resources, and evidence-based programs to support dementia caregivers.
- » **Learn from peers.** Hear what other public health agencies are doing to support dementia caregivers, and get ideas and input for your own work.
- » **Get help with strategy.** Select dementia caregiving-related goals, get help with evaluation, build new partnerships and use data to inform the strategy.
- » **Find the right program.** Identify effective, culturally responsive programs to support diverse caregivers in your jurisdiction.

Website: [bolddementiacaregiving.org](http://bolddementiacaregiving.org)

Email: [phcoe-dc@umn.edu](mailto:phcoe-dc@umn.edu)



**Caregiving** for people with dementia is unpaid help provided by spouses, partners, adult children, other relatives and friends to people living with dementia. Caregivers for people with dementia often assist with activities of daily living such as personal care, household management, medication and health care management and coordination of financial matters.

**Chosen family** is a group of individuals who deliberately choose one another to play significant roles in each other's lives. It is a term often used in the LGBTQ+ (lesbian, gay, bisexual, transgender, queer and others) community.