

PROMOTING CAREGIVING ACROSS THE FULL COMMUNITY:

A CALL TO ACTION FOR PUBLIC HEALTH PROFESSIONALS



Each day, more than 11 million* unpaid caregivers — often family and friends — provide invaluable assistance to people living with Alzheimer's and other dementias. Caregiving can be rewarding, but can also take a toll on caregivers' health, well-being, and productivity. Because dementia caregiving often entails multiple years of intense assistance, caregivers' own health may decline, making it difficult to sustain care. Social needs, such as food insecurity, housing instability, social isolation, loneliness, and employment can further exacerbate caregivers' strain.

By 2025, the need for dementia caregiving is expected to rise in tandem with the projected 16% increase in the number of people aged 65 and older living with Alzheimer's dementia. The imperative for immediate action is strong and compelling because when unpaid dementia caregiving cannot be sustained, expensive long-term care is often necessary. ***Embedding support for dementia caregiving in policies, systems, and environments is essential to protect both caregivers' health and the health of people living with dementia.***

Public health is uniquely positioned to convene stakeholders from multiple disciplines to take on the challenges of dementia caregiving. Today's public health leaders increasingly serve as their state's or region's chief health strategist and are charged with protecting residents from health threats and improving the health and well-being of populations in an equitable way. Chief health strategists can build a community infrastructure that promotes dementia caregiving throughout health care systems, workplaces, and communities. Leadership is also needed at the broad, macro level to make needed changes in policies, systems, and environments that address social risks contributing to caregiver strain.

The **Healthy Brain Initiative's Road Maps**

for state and local public health and for Indian Country call on public health agencies to assure that caregivers have information, guidance and support to provide effective dementia care. Using the HBI Road Map series and the chief health strategist framework, public health leaders can convene key partners across the full community, use data and evidence to diagnose problems at a systems level, and develop a plan to equitably promote caregiving in all sectors. Strategies can also be utilized to advance equity through better deployment of evidence-based support and the reduction of service fragmentation.



Strong public health leadership can drive structural changes that support effective, sustained caregiving for all people living with dementia. Learn how in the full action brief:

Promoting Caregiving Across the Full Community: The Role for Public Health Strategists

KEY FACTS:

- In 2020, more than 11 million family members and friends provided an estimated 15.3 billion hours of unpaid care to people with Alzheimer's and other dementias, at an economic value of more than \$257 billion. This represents an average of 26.3 hours of care per caregiver per week.
- More than 1 in 2 caregivers for people living with dementia are employed or self-employed. More than half (57%) report having to go to work late, leave early, or take time off because of their caregiving responsibilities.
- Over 40% of caregivers for people living with dementia reside in households with an annual income less than \$50,000.

*Note: Data presented here may differ from the full action brief. The full action brief uses estimates from the 2020 Alzheimer's Disease Facts and Figures report while estimates presented in this executive summary are from the 2021 report. Notably, caregiver prevalence is significantly lower in the 2021 report. This is due in part to a change in methodology: earlier reports used national data from 2009 to estimate caregiver prevalence, while the 2021 report uses more recent, state-specific data.

THE PROBLEM: Challenges to Effective Caregiving

For a variety of reasons, available services and supports are not fully utilized by all caregivers for people living with dementia.

- >> More than half of all **caregivers have little or no knowledge** of support services in their communities or how to access them.
- >> **Fragmentation of services** makes it difficult for caregivers to find the services they need and health care providers may not have been trained to support caregivers.
- >> **Gaps in equitable access** to interventions, services, and supports exist due to inadequate funding and/or program structure. Eligibility criteria, language, literacy, income, cultural variations, and geography can be significant access barriers.

The GOAL of public health action:

To embed support for dementia caregiving throughout policies, systems, and environments so that caregivers can continue providing vital, effective care in ways that protect both their health and the health of people living with dementia

THE SOLUTION: The Chief Health Strategist Role

Public health agencies can promote caregivers' health by using a "chief health strategist" approach. Public health leaders can **convene** key partners; **educate** them on caregiving; guide them in an **assessment** process to identify resources, gaps, and inequities; and **develop shared goals and action plans**.

Six high-level strategies to address the challenges faced by unpaid caregivers are:

1. Improve access to effective interventions, services, and supports for caregiving among underserved populations and increase use of these resources to promote caregivers' own health and well-being.
2. Embed systematic identification and assessment of caregivers in health and social systems and actively assist with obtaining caregiving resources based on individual needs and preferences.
3. Promote changes in policies, systems, and environments to improve the social and employment conditions that increase caregiver strain and respect the cultural context in which they live.
4. Track, analyze, report on, and promote caregivers' own health and well-being.
5. Assure pandemic response and emergency preparedness plans enable continuity in the essential assistance provided by caregivers to people living with dementia.
6. Shape cultural norms to respect and embrace caregiving.

TAKE ACTION: Resources and Tools

The **full action brief** explores the role of chief health strategist in more detail and provides state, local, and tribal public health leaders with a framework and resources including:

- >> Help in finding evidence-based interventions for caregiving.
- >> Assessment questions to examine ways to better support dementia caregiving through community supports and services and in health care and workplace sectors.
- >> A short case study of how the Arizona Department of Health Services has used its role as a chief health strategist to promote dementia caregiving.
- >> Links to an extensive list of tools and other resources to carry out four aspects of the chief health strategist role.

