

## PROMOTING CAREGIVING ACROSS THE FULL COMMUNITY: THE ROLE FOR PUBLIC HEALTH STRATEGISTS

***Strong public health leadership is essential to engage community partners in driving structural changes that support effective, sustained caregiving for all people living with dementia.***

### OVERVIEW

Caregiving is a crucial, and often overlooked, aspect of community life. Each day, unpaid caregivers — often family and friends — provide invaluable assistance to people living with functional limitations and other healthcare needs. Caregiving generates numerous benefits:

- >> People needing assistance receive support and care for better health and well-being, which can help them stay engaged in work, volunteer, and family roles as long as possible.
- >> Unpaid caregivers have the satisfaction and joy of helping a family member or friend.
- >> Unpaid caregiving can reduce the need for paid services from health, social service, and transit systems.
- >> Continued care from family and friends may enable people living with dementia to remain at home or delay moving to nursing homes or residential care.

As the population of people living with Alzheimer's and other dementia grows, so will the need for unpaid caregiving. Yet, caregiving can take a toll on caregivers' health, well-being, and productivity. This is particularly true for dementia caregiving, which often entails prolonged and intensive assistance. Sometimes caregivers' own physical and mental health deteriorates, requiring them to reduce the support they provide to the individual, scale back or leave paid employment, or both. Also, many caregivers drain their own personal finances to help a loved one living with dementia obtain needed care.<sup>1</sup> Social determinants of health that affect daily life — economic and social conditions such as income, living conditions, employment, social protections, and access to healthcare and other community services — may compound the toll of dementia caregiving.<sup>2</sup>

Public health agencies recognize dementia caregiving as a challenging and unique public health issue. It is highly prevalent and affects increasing numbers of individuals and families across all races, ethnicities, and cultures. The cost to society is high when unpaid dementia caregiving cannot be sustained and must be replaced with paid or formal care, such as residential or long-term care. Through their mandated responsibility to protect the public's health, governmental public health agencies can advance proven strategies to support and maintain the health, well-being, and productivity of caregivers. This “chief health strategist” leadership begins with convening key partners, using data and science to recognize and diagnose problems, and developing shared goals and action plans to ensure effective, sustained dementia caregiving in an equitable way.

This action brief offers an overview of the challenges of caregiving for people living with dementia, then provides state, local, and tribal public health leaders with a framework and resources for action. It calls for public health to employ its chief health strategist role



by bringing key stakeholders from multiple sectors to the table — alongside caregivers for adults living with dementia — to develop a broad, 360-degree, macro-level approach to promoting caregiving. This process would identify community assets, uncover inequities in access and use, and develop a plan that applies the best available evidence.

The 360-degree plans would set priority goals and strategies to address not only services, but also policies, systems, and environments in multiple sectors that need re-evaluation and reform. After all, opportunities to support caregivers of people living with dementia exist within all sectors, including businesses, community-based organizations, housing, libraries, and public safety and transportation agencies. Enhanced support from these sectors would help caregivers for people living with dementia to remain productive at work, healthy, and socially engaged through the months or years that they are needed. Thus, the public health focus is creating “a systemic approach to address the health of vulnerable members of society who require care and the integral informal caregivers who attempt to address these needs in every community across the country.”<sup>3</sup> Implementation of these plans would ideally result in widespread availability and use of caregiver supports, improved service coordination, and a firm commitment to caregiving throughout healthcare systems, workplaces, and communities.

## WHAT IS A “CHIEF HEALTH STRATEGIST”?

Public health leaders increasingly serve as **chief health strategists** for their state or region. In this role, they use data, the best available evidence, and community engagement to address the most pressing health threats and improve the well-being of their residents in an equitable way. Health strategists are committed to identifying and eliminating health inequities by concentrating resources on priority populations who experience a disproportionate burden of disease and/or disparities in health outcomes.

# CAREGIVING FOR PEOPLE LIVING WITH DEMENTIA

More than 1 in every 5 adults in the United States are unpaid caregivers who provide substantial services through in-home, unpaid assistance to their family members and friends.<sup>4</sup> In this population, as many as 16 million adults provide care to an older adult with Alzheimer’s or another dementia.<sup>1</sup> These caregivers are spouses, partners, adult children, other relatives, and friends providing unpaid help to people living in the community with dementia who have at least one limitation in their activities of daily living. Caregivers often assist with diverse tasks such as personal care, transportation, shopping, household management, medication and healthcare management, and coordination of financial matters. Studies have shown that having an informal caregiver can improve health and quality of life for people living with dementia,<sup>5,6</sup> improve chronic disease self-management,<sup>7,8</sup> and reduce depressive symptoms.<sup>9,10</sup> The ultimate impact can be prevention of or delays in institutionalization.<sup>6,11,12</sup> Conversely, the burden on caregivers and changes in their own health status have been related to earlier institutionalization for their loved ones.<sup>5</sup>

The term “dementia” describes symptoms characterized by the loss of cognitive function severe enough to interfere with a person’s daily life and activities. Dementia is usually caused by disorders that progressively damage and eventually destroy brain cells. Alzheimer’s is the most common cause of dementia, while vascular dementia is the second most common cause. Increasingly, many dementia cases are recognized as “mixed-cause” — such as a combination of Alzheimer’s-vascular dementia or frontotemporal-vascular dementia.<sup>1</sup>

Like other chronic conditions, Alzheimer’s and other dementias develop along a continuum, as depicted in Figure 1.<sup>13</sup> Although most older adults have healthy cognitive functioning, some will experience pre-symptomatic changes in the brain that may eventually lead to cognitive impairment or dementia. In dementia, symptoms become noticeable and the disruption to cognition and everyday life can range from mild to severe.

The progressive nature of most dementia means people living with the condition need more and more support as they lose the ability to care for themselves. People living with Alzheimer’s in the severe stage eventually need round-the-clock care for months or even years. Caregiving for people living with dementia typically lasts longer than caregiving for other older adults, as depicted in Figure 2 (see page 4), with almost 1 in 3 assisting an individual living with dementia for five or more years.<sup>14</sup>

Caregiving can be rewarding, but also may be demanding on a daily basis and sometimes challenging to sustain. The tasks required of caregivers for people living with dementia can be particularly personal and intrusive. Compared with caregiving for people with non-dementia conditions, dementia caregiving is much more likely to involve assisting with bathing or showering and dealing with incontinence.<sup>14</sup> Dementia caregiving often extends to directly administering medications, helping someone walk and get dressed, and managing bedsores. Other challenging symptoms that caregivers may encounter include agitation, anxiety, hallucinations, repetitive activities, paranoia, combativeness, and sleep disturbances.<sup>1</sup>

**FIGURE 1: LIFE COURSE PERSPECTIVE ON ALZHEIMER’S AND OTHER DEMENTIAS**



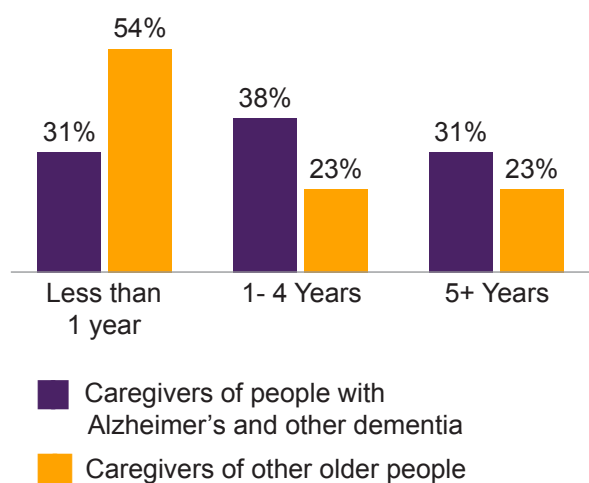
Dementia occurs along a continuum. Although most older adults have healthy cognitive functioning, some will experience pre-symptomatic changes in the brain that may eventually lead to cognitive impairment or dementia. In dementia, symptoms become noticeable and the disruption to cognition and everyday life can range from mild to severe.



The demands of dementia caregiving profoundly impact families, employers, healthcare providers, social and civic organizations, and other aspects of community life. Nearly 1 in 4 caregivers for people living with dementia are “sandwich generation” caregivers — caring for an older adult and also raising a child or grandchild.<sup>1</sup> About 1 in 2 caregivers for people living with dementia are employed or self-employed.<sup>15</sup> Other caregivers are retirees, spouses/partners, and even adolescents helping parents with younger-onset Alzheimer’s. Neighbors and friends also may be looking after or “helping out” someone in their community.

Public health analyses of available data can help identify caregiving populations who may be underserved or experience social risks related to housing, nutrition, transportation, employment, or immigration. Nearly half (46%) of caregivers for people living with dementia reside in households with an annual income less than \$50,000, and 1 in 3 do not have any formal education after high school. About 14% of caregivers assisting someone living with dementia are Black (non-Hispanic) and 13% are Hispanic (any race).<sup>15</sup> About 1 in 3 American Indian/Alaskan Native (AI/AN) adults are caregivers for any type of condition, and nearly half of these caregivers provide care for at least 20 hours per week.<sup>16</sup> These and other data offer insights into the social determinants of health that require attention when designing effective systems to support caregiving.

**FIGURE 2: DURATION OF CAREGIVING FOR PERSONS LIVING WITH DEMENTIA COMPARED TO OTHER OLDER ADULTS**



## A SERIOUS PUBLIC HEALTH ISSUE: THE DATA ON DEMENTIA CAREGIVING

Dementia caregiving poses many challenges as a complex, growing public health problem.

- >> In 2019, as many as 16 million family members and friends provided 18.6 billion hours of unpaid care to people with Alzheimer’s and other dementias, at an economic value of more than \$244 billion.<sup>1</sup>
- >> The need for dementia caregiving is expected to rise in tandem with the projected 22% increase in the number of people aged 65 and older living with Alzheimer’s dementia between 2020 and 2025.<sup>17</sup>

Because dementia caregiving often entails long and intense assistance, caregivers’ own health, well-being, and productivity may decline. Among caregivers for people with dementia:

- >> More than 1 in 8 report frequent physical distress — spending at least 14 of the previous 30 days in poor physical health — and 16.5% report that their overall health is fair or poor.
- >> About 1 in 3 report that their health has gotten worse due to care responsibilities, compared with 1 out of 5 caregivers of other older adults.<sup>14</sup>
- >> Nearly 60% rate the emotional stress of caregiving as high or very high, and as many as 40% report symptoms of depression.<sup>1</sup>

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. Further, 18% had to go from full to part-time work, and 16% took a leave of absence.<sup>14</sup> Just over half of employers have policies that support caregiving: 58% offer paid sick days, 56% offer flexible work hours, 39% offer paid family leave, 26% offer employee assistance programs, and 25% allow telecommuting.<sup>18</sup> These challenges are some of the reasons why supporting caregiving must extend to how communities are structured, not just what services they provide.

# SERVICES TO INDIVIDUAL CAREGIVERS

Supporting this growing population of caregivers requires an organized, coordinated array of well-designed individual services throughout the caregiving journey.<sup>19</sup> These supportive services may be provided for caregivers only or for both the caregiver and the person living with dementia. Examples include:

- >> Caregiver education and skills training.
- >> Advanced care and advanced financial planning.
- >> Home health or personal care services, as well as home modification programs.
- >> Adult day care and respite care.
- >> Community-based programs for physical activity and chronic disease self-care.
- >> Peer support groups and opportunities to learn and socialize.
- >> Transportation services.
- >> Apps for caregivers and people living with dementia and GPS tracking devices.
- >> Online support, information and referral centers.<sup>20,21</sup>

Through the Administration for Community Living (ACL), direct individual support and services are available to adults living with dementia and their caregivers. The ACL aging and disability networks and federal programs enable the delivery of dementia-capable information, education, counseling, respite care, peer support, transportation, and other services to individuals.\* Despite the availability of these supports and services, caregivers often are unaware of the range of support services in their communities, or they may have trouble taking advantage of them because of fragmentation or gaps in equitable access. Many of these services are available from or supported by the national aging network which includes Area Agencies on Aging (AAAs), Aging and Disability Resource Centers, state units on aging, and their partners.<sup>23</sup>

Services that enhance caregivers' health or their ability to provide care also may benefit adults living with dementia and facilitate stronger, healthier relationships between the two. For caregivers of someone living with dementia, telephone counseling by social workers and individual/family counseling sessions are among the enhanced support services that have been shown to improve caregivers' capabilities and well-being.

For example, the New York University (NYU) Caregiver Intervention reduced nursing home placement of people with Alzheimer's disease (by 28%) and delayed institutionalization (by 557 days).<sup>11</sup> Also, the North Dakota Dementia Care Services Program (based on the NYU model) reduced both inpatient admissions and emergency department visits while empowering caregivers to achieve their care goals and improve their ability to provide care.<sup>12</sup> Another type of support, called respite care, provides family caregivers with much needed relief and support by giving them a break from caregiving duties. While the cost of respite care can be expensive, it is a much less expensive alternative for state Medicaid programs than the cost of institutional care.<sup>24</sup> Some states have adopted an alternative service delivery model, the Program of All-Inclusive Care for the Elderly (PACE), sometimes called Living Independently for the Elderly (LIFE), which embeds supports for caregivers in the delivery of medical care and long-term services and supports.<sup>25</sup>

Supportive resources that are designed for both caregivers and people living with dementia are particularly effective when they take into account the unique social determinants of health and cultural attributes of the communities they serve.<sup>26</sup> However, when demand for services exceeds supply, caregivers may experience frustration, unmet needs, and poor outcomes.<sup>27</sup>

\* According to ACL, "[d]ementia capability means being skilled in identifying people with possible dementia, working effectively with individuals and caregivers, knowing what kinds of services are needed, and referring to agencies and individuals able to provide such services."<sup>22</sup>

# CHALLENGES TO SERVICE DELIVERY

For a variety of reasons, available services and supports are not fully utilized by all caregivers for people living with dementia. **First, more than half of these caregivers have little or no knowledge of formal support services in the community.**<sup>28</sup> Studies suggest that caregivers are not accessing available supports because of a lack of awareness of the resources, lack of knowledge about how to access them, concern about cost, fear of deportation and/or institutionalization, or the perception that the offerings do not correspond with their needs.<sup>19,29,30</sup> Also, people may not consider themselves to be “caregivers” if they view the assistance as integral to family living or being a friend or neighbor.<sup>31</sup>

**Second, fragmentation of services makes it difficult for caregivers to find the services they need.**<sup>18,32,33</sup> Many interventions, services, and supports exist for people living with dementia and their caregivers, but the patchwork is hard to navigate. Some communities simply don’t have enough healthcare providers who are trained to support caregivers and people living with dementia. Too often, healthcare providers are not informed about community-based services and supports available for their patients. Or, they may hesitate to make referrals because they distrust the quality or timeliness of the services.

**Third, gaps exist in equitable access to interventions, services, and supports.** Inadequate funding, program structure, or both can limit the type of support provided or hinder the support from having

the scale to serve all caregivers. Eligibility criteria, language, literacy, income, and cultural variations can be significant access barriers. Sometimes geography restricts access. Compared with urban residents, people living in rural areas often have fewer supportive services, and limited broadband connectivity can hinder searches for local services and participation in virtual programs. Even in more urban areas, logistics may be cumbersome if supports are not convenient to caregivers’ homes or offices. In other cases, materials and services may not be easily accessible to the diverse populations in need. For example, support staff may only speak English, making it difficult for them to serve Spanish-speaking caregivers.<sup>19</sup> Also, information and materials about eligibility criteria for long-term care services often use language that is not culturally sensitive.<sup>34</sup>

Communities face a growing challenge to improve knowledge and awareness among caregivers, ensure universal availability and access to needed services and supports, minimize fragmentation and inadequate coordination, and fill gaps that preclude equity in caregiving. Current aging and disability network efforts serve as a foundation to which public health can bring its unique capabilities: expertise in data collection and assessment, partnership and coalition building, and planning to mobilize change in policies, systems, and environments. These public health capabilities would extend to maintaining stakeholder engagement in plan implementation so that cultural and systems-change initiatives that promote caregiving may attain a scale that makes a difference in health outcomes.

## FINDING EVIDENCE-BASED INTERVENTIONS FOR CAREGIVING

**Best Practice Caregiving** is a free online resource with proven dementia programs for family caregivers, created by the Benjamin Rose Institute on Aging, Family Caregiver Alliance, and the Gerontological Society of America. It offers a searchable, interactive, national database of vetted, effective program models for providing caregivers with information and support. The database is an invaluable tool for healthcare and community-based organizations, as well as funders and policy makers, to discover and share high quality programs for caregivers.

# APPLYING A SYSTEMS APPROACH:

## THE CHIEF HEALTH STRATEGIST ROLE

Today's public health leaders increasingly serve as their state's or region's chief health strategist, charged with protecting residents from health threats and improving the health and well-being of populations in an equitable way.<sup>35,36</sup> With health equity as the foremost pursuit, strategists use data, the best available evidence, and community engagement to identify and address the most pressing health challenges.

A primary tenet of public health is that health inequities can and must be eliminated.<sup>37,38</sup> Resources should be concentrated on priority populations that face disparities in health outcomes and/or a disproportionate burden of disease. This commitment is reflected in recent state Alzheimer's disease plans, in which strategic recommendations seek to reduce barriers to care and services as a way to advance health equity.

Achieving health equity for caregiving requires inclusion and engagement of caregivers from diverse communities across ethnicities, cultures, disabilities, immigration statuses, and languages.<sup>39</sup> Together with stakeholders from multiple perspectives — such as business, healthcare, transportation, housing, libraries and other public services, and the aging network — public health would map a strategic course of macro-level changes to policies, systems, and environments. These types of cross-sector partnerships enable public and private resources to be leveraged for health and well-being.<sup>40,41</sup> Their focus on structures would improve the equitable distribution of resources, strengthen utilization of effective interventions by diverse populations, enable coordination of supports by reducing fragmentation, and complement the delivery of services to individuals by the aging network and other organizations.<sup>19,31</sup>

The Healthy Brain Initiative (HBI) Road Map series calls on public health to engage public and private partners in building supportive environments for people affected by the extensive health, caregiving, and financial impacts of dementia. Using the original Essential Public Health Services framework,<sup>42,43</sup> the Road Map series identifies caregiving as one of three interrelated public health priority issues (the other two are promoting cognitive health and improving early diagnosis and quality of care). The current Road Map for state and local public health practitioners provides 17 expert-developed actions that agencies can take to expand, promote, and tailor resources to support caregivers for people living with dementia. A comparable set of eight public health strategies is offered in the Road Map for Indian Country for AI/AN leaders.

To guide chief health strategists in navigating the Road Maps from a systems perspective, the Alzheimer's Association and the Centers for Disease Control and Prevention offer the overarching framework in this brief.

***The ultimate goal is 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 framework for achieving this goal is rooted in the Road Map actions, informed by the Arizona Department of Health Services' model initiative (Appendix A), and aligned with the 2020 update to Essential Public Health Services and the newly released Healthy People 2030. It is also consistent with the *National Plan to Address Alzheimer's Disease: 2020 Update*.<sup>44</sup>

### FROM THE HEALTHY BRAIN INITIATIVE

Designed for state and local public health practitioners, the *State and Local Public Health Partnerships to Address Dementia: The 2018-2023 Road Map* has 25 actions that help promote cognitive health, address cognitive impairment, and support the needs of caregivers.

Designed for American Indian/Alaska Native (AI/AN) communities, the *Road Map for Indian Country* is a guide for AI/AN leaders to learn about Alzheimer's and begin planning their response to dementia.

Learn more at [alz.org/publichealth](https://alz.org/publichealth) and at [cdc.gov/aging](https://cdc.gov/aging)



**HEALTHYBRAIN  
INITIATIVE**



# A FRAMEWORK FOR ACTION

Applying a broad, systems approach to caregiving entails envisioning communities and states in which:

- >> **All** caregivers have the training and knowledge to provide needed care.
- >> Healthcare providers **always** involve caregivers on the care team and refer them to supports and services to help maintain their own health.
- >> Employers institute supportive policies and practices to accommodate **all** caregivers' needs.
- >> **All** caregivers and people living with dementia readily participate in community life and find support wherever they live, work, and play.

To pursue this vision, public health leaders should begin by **convening caregivers, people living with dementia, and stakeholders** from the major community systems that affect caregivers. Involvement from caregivers and people living with dementia from diverse communities enables plans to respond to their priorities. Stakeholders — community-based organizations connected with groups experiencing disadvantages, employers, policy makers and others — also should be at the table to help craft a framework for sustained investment in caregiving. Depending on prior involvement in aging and dementia activities, public health strategists may need to first become more familiar with the current literature and relevant issues.

Chief health strategists can then **guide the partners in an assessment process** to inform how existing community resources can be woven together to reduce inequities in access and use. Comprehensive needs assessments are an essential tool for generating useful and reliable information for planning effective strategies. The process begins by estimating the number of caregivers and documenting their experiences and health status in a way that uncovers disparities.<sup>45</sup> Data from the Behavioral Risk Factor Surveillance System (BRFSS), other public health sources, and aging and healthcare systems can help provide a multi-dimensional understanding of caregiver diversity and potential needs.<sup>45</sup>

After describing caregiving populations, the assessment can then examine the community infrastructure to determine how well it promotes and sustains caregiving. From the perspective of caregivers and other stakeholders, what are current assets, gaps, and unmet needs? What are the foremost barriers in policies, systems, and environments that impede effective caregiving and self-care? How well is care coordinated across agencies and sectors? To answer these questions, chief health strategists should draw upon related needs assessments and plans. These include assessments that inform state and community health improvement plans, state Alzheimer's and dementia plans, AAA multi-year plans for services funded through the Older Americans Act, and state plans on aging.





Using all available evidence and community input, chief health strategists would build consensus among partners and stakeholders to **prioritize needs, set goals, develop strategies, and map out implementation** roles and monitoring.

Six strategies to reduce fragmentation, improve equitable access for populations experiencing disadvantages, and close gaps are:

1. Improve underserved populations' (i.e., linguistic, cultural, literacy, disability, socio-economic status) access to effective interventions, services, and supports for caregiving 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 caregivers' strain and to respond to the cultural contexts 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.

The resulting plan should identify changes in policy, systems, and environments for equitable access to caregiving support across the full community. The first priority should be caregivers most at risk of experiencing physical, emotional, or financial challenges. In addition to healthcare and long-term services and supports, attention is needed to mitigate social risks that can exacerbate caregivers' strain, including food insecurity, housing instability, social isolation, loneliness, and low educational attainment.<sup>19,46</sup> Strategies may include, among others, expanding and connecting services; reallocating resources; changing policies affecting employment: social services, transportation, and housing; investing in data infrastructure and workforces; and integrating caregivers and diverse populations into decision-making processes. Comprehensive hubs of coordinated service delivery like PACE may also be considered.<sup>47</sup>

Lastly, it is important to **measure progress and evaluate effectiveness** of policies, programs, and other strategies so that needed adjustments can be made. As plans are implemented, chief health strategists may need to cultivate additional partnerships to solve problems, coordinate resource utilization, and work toward common goals. Universities can be good partners for evaluation and training.

To illustrate these concepts, Appendix A provides a short case study of how the Arizona Department of Health Services has used its role as a chief health strategist to promote caregiving. Appendix B suggests tools and other resources to help public health professionals carry out the chief health strategist role.

## PARTNERING FOR DEMENTIA-FRIENDLY COMMUNITIES

A variety of initiatives encourage the development of dementia- and age-friendly communities in the United States, such as [Dementia Friendly Communities](#), [AARP Network of Age-Friendly States and Communities](#), [Age-Friendly Health Systems](#), and [Age-Friendly Public Health Systems](#). All of these movements encourage governments, businesses, and civic groups to form coalitions and pledge to actively make changes to support people living with dementia and their caregivers. Involving them as partners is essential for a broad, systems approach. Diverse stakeholders have called for evaluating the effectiveness and scaling of dementia-friendly community efforts.<sup>48</sup>

## ASSESSING THE CAREGIVING INFRASTRUCTURE

As public health agencies and partners examine ways to better support dementia caregiving, some pertinent questions to address in various sectors include:

### Community Supports and Services for Caregiving

- >> What is the anticipated increase in adults with dementia, and how may that affect communities and employers?
- >> What types of dementia-capable supportive services (see page 5) are readily accessible?  
Which populations lack equitable access?
- >> How do we address the special needs of groups who experience these disadvantages?
- >> To what extent is public transportation available and dementia-capable? What other social needs do caregivers for people living with dementia have, such as affordable, safe housing or supportive neighbors and friends?
- >> Are sectors of the community engaged and educated about dementia, caregiving, and ways that communities can systemically support caregivers and people living with dementia?
- >> Are resources adequately and equitably allocated to support caregiving needs?

### Healthcare Sector

- >> Do healthcare providers' policies and procedures support caregivers by:
  - > Identifying caregivers in health records?
  - > Including caregivers in assessing the person living with dementia and developing comprehensive care plans?
  - > Assessing the caregivers' own health and well-being as part of the dementia care process?
  - > Linking caregivers with dementia education and supportive services, especially as dementia progresses and during care transitions?
  - > Managing the complex care needs of people living with dementia (e.g., ready access to their electronic health records and proactive referrals to palliative care and adult day centers)?
  - > Encouraging families to do advanced care planning, including situations in which the caregiver is unable to continue providing assistance?
- >> How easy is it for healthcare providers to link caregivers to community services and supports?  
To provide effective case management services?
- >> How easily can caregivers find and obtain relevant healthcare and supportive services on their own?  
Does this vary by geography, literacy, income, race/ethnicity, sex, type of disability, or health insurance status?
- >> Are linguistically and culturally appropriate services available, taking into account the changing demographics of the community?
- >> What quality indicators could be adopted by health systems to improve caregiver identification, assessment, and referral?
- >> Are assessments being done to examine costs and benefits associated with changes in Medicaid and other coverage policies?

### Workplace Sector

- >> Do employers' policies and practices support flexible work hours, part-time status, living wages, employee assistance programs, and telecommuting for caregivers?
- >> Do employers uniformly provide paid time off for wellness appointments, poor health, and family leave?
- >> Do employee assistance programs, when offered, include information about caregiving issues and resources to help?
- >> Do workplaces offer support groups and onsite adult day care?

# CONCLUSION

By embracing the chief health strategist role, state, local, and tribal public health leaders can support and promote healthy caregiving for **all** people living with dementia and other serious health conditions. This entails convening caregivers, people living with dementia, and stakeholders in cross-sector partnerships to improve deployment of available resources, minimize fragmentation, and increase utilization in ways that reduce inequities. Attention 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. With strong public health leadership, partners can be guided in an assessment process that examines gaps and community infrastructure, prioritizes needs, sets

goals, develops strategies, maps out implementation, measures progress, and evaluates effectiveness.

To truly support dementia caregiving, **all** sectors of a community — businesses, community-based organizations, housing, libraries, and public safety and transportation agencies — must embrace changes that enable caregivers to carry out their vital role for as long as possible. Support for dementia caregiving must be embedded in the structural underpinnings of the community's culture through informed policies, systems, and environments. Only then can caregivers continue providing vital, effective care in ways that protect both their health and the health of people living with dementia.



# APPENDIX A: CASE STUDY OF A CHIEF HEALTH STRATEGIST IN ACTION:

## ARIZONA DEPARTMENT OF HEALTH SERVICES

Expanding the state's caregiver workforce (both paid and unpaid) is a priority for the Arizona Department of Health Services (ADHS).<sup>49</sup> In 2016, ADHS was part of a public-private statewide task force that developed the [Arizona Alzheimer's State Plan: A Framework for Action](#). Implementation began with a public-private partnership in Maricopa County, the state's most populous county, with collaboration from the Maricopa County Department of Public Health and other local partners.

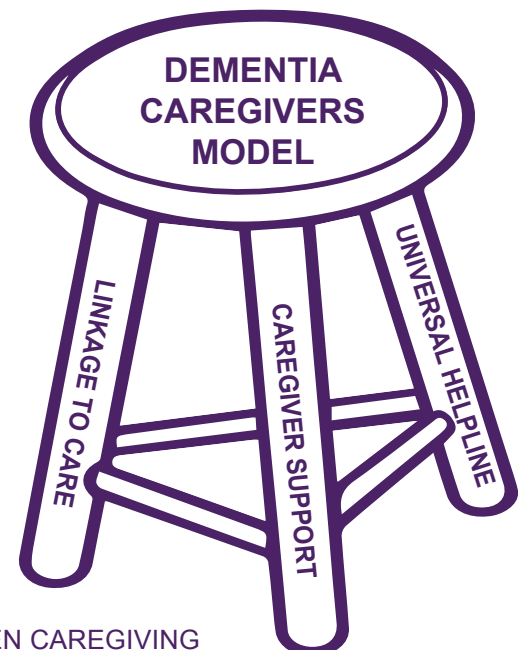
The initial step was to compile and analyze available data to better understand the needs of people living with dementia and their caregivers. With the help of a professional facilitator, ADHS and its partners then convened service providers, funders, and stakeholders to review the data and discuss implications. Together they brainstormed how organizations could be brought together to reduce silos and encourage coordination of services. ADHS built consensus for a single coordinating alliance through which individual service providers would have to work to obtain financing for services. Launched in 2018, the Arizona Dementia Caregivers Alliance (DCA) initially had 15 Arizona provider organizations working together to improve access to comprehensive services for caregivers of people living with dementia.

ADHS and its partners also adopted a three-component strategy: caregiver support (primarily education and training), a universal helpline, and linkages to care (depicted as a stool in Figure 3). These areas were felt to have the best potential to improve the lives of people living with dementia and their caregivers and could also be scaled to reach into the state's rural and frontier areas. Each area had early accomplishments:

Caregiver Support: ADHS is collaborating with Duet Partners in Aging, a DCA member, to use a train-the-trainer model for expanding a curriculum-based, peer-led online training for caregivers called "Finding Meaning and Hope."

Universal Hotline: ADHS envisioned a universal hotline (telephone and online) for DCA to better support caregivers through improved coordination and navigation of services across Maricopa County. This concept seeks to augment the currently available Community Resource Finder, an online hub for information about programs and services made available by the Alzheimer's Association and AARP, and the Alzheimer's Association's 24/7 Helpline (800.272.3900), a free service that provides confidential support and information.

Linkage to Care: To advance the "continuum of care" and "care team" guiding principles in the state Alzheimer's plan, ADHS and its partners adapted a rapid referral model that is used to quickly connect people with new diagnoses of HIV to treatment and support. Their goal is to identify caregivers more quickly than is happening under current diagnosis and care management practices, so that the care team begins receiving support early in the process. Plans call for establishing protocols for and training health and human service providers to rapidly detect potential cognitive impairment, identify caregivers, and refer both the person living with dementia and caregivers to diagnostic services and community supportive resources.



**FIGURE 3:** ADHS STRATEGY TO STRENGTHEN CAREGIVING

Source: Used with permission from Dr. Babak Nayeri with ADHS

## APPENDIX B: RESOURCES FOR THE CHIEF HEALTH STRATEGIST

The resources and tools in this appendix have been curated for public health practitioners in their chief health strategist role to develop partnerships and plans to drive structural changes to improve support for caregiving for people living with dementia. The recommended items are organized into four categories:

- >> Information/Education for the Public Health Approach to Dementia Caregiving
- >> Convening Partners
- >> Assessing Caregivers and Community Infrastructure
- >> Developing the Plan

**Although some resources serve multiple categories, each is listed only once.**

INFORMATION/EDUCATION FOR THE PUBLIC HEALTH APPROACH TO DEMENTIA CAREGIVING	
<i>Healthy Brain Initiative (HBI) Road Map Series</i>	
<a href="#"><u>HBI State and Local Public Health Partnerships to Address Dementia: The 2018-2023 Road Map</u></a> (Road Map)	Read the Road Map for state and local public health for practical actions and background information on dementia caregiving and case studies.
<a href="#"><u>Better Support Caregivers</u></a> (issue map)	Find dementia caregiving highlights from the state/local Road Map, including highlights of salient data, the case for action, and related HBI Road Map actions.
<a href="#"><u>HBI Road Map for Indian Country</u></a> (Road Map)	Read the Road Map for tribal leaders and tribal health and aging professionals to learn about dementia, ways to start discussions with American Indian/Alaska Native (AI/AN) communities, and actions to support the well-being of people living with dementia and their caregivers.
<i>Alzheimer's Association Public Health</i>	
<a href="#"><u>Alzheimer's Disease Facts and Figures</u></a> (report)	Learn more about dementia caregiving in this annual report that examines the burden of Alzheimer's and dementia on individuals, caregivers, government, and the nation's healthcare system.
<a href="#"><u>State Overview of Alzheimer's and All Other Dementia</u></a> (portal to state information)	Access individual state landscapes on dementia and caregiving, including Behavioral Risk Factor Surveillance System data and state Alzheimer's plans.
<a href="#"><u>Supporting the Front Line: A Public Health Approach to Dementia Caregiving</u></a> (webinar)	Learn from experts how public health can use a chief health strategist approach to better meet the needs of caregivers for people living with dementia in their communities.
<a href="#"><u>Family Caregiving: The Frontline of Dementia Care</u></a> (webinar)	Obtain an overview of the results from the 2016 Behavioral Risk Factor Surveillance System (BRFSS) Caregiver Module in New York and the origin, design, and results of the state's Alzheimer's Disease Caregiver Support Initiative.

<a href="#">Alzheimer's Association 2018 Dementia Care Practice Recommendations</a> (care guidelines)	Develop an understanding of person-centered care principles and evidence-based practice guidelines, especially in the “Person-Centered Assessment and Care” and “Meeting the Informational, Educational, and Psychosocial Support Needs of Persons Living with Dementia and Their Family Caregivers” sections.
<b>Centers for Disease Control and Prevention (CDC)</b>	
<a href="#">Caregiving for a Person with Alzheimer's Disease or a Related Dementia</a> (website)	Go to CDC's main portal for information on dementia and dementia caregiving, data, educational materials, and resources to support Road Map implementation.
Additional public health resources about caregiving for any individual needing assistance	Explore CDC's general caregiving resources, including <a href="#">podcasts and videos</a> for both consumers and professionals and a data brief called <a href="#">Caregiving for Family and Friends – A Public Health Issue</a> .
<b>Other Sources</b>	
State/local/tribal government agencies on aging (experts and state plan on aging)	Schedule a time with colleagues in your sister agencies to learn about supports and services for dementia caregiving and relevant plans and data. Discuss a partnership.
<a href="#">Healthy Brain Initiative (HBI) Road Map Module</a> (self-paced online course)	Learn by progressing through modules in this Association of State and Territorial Health Officials (ASTHO) e-Learning Center module.
<a href="#">Caregiving in the U.S. 2020</a> (report)	Find more data on dementia caregiving in this report from AARP and the National Alliance for Caregiving.
<b>CONVENING PARTNERS</b>	
<a href="#">Planning for Action: Initial Steps for Implementing the Healthy Brain Initiative Road Map</a> (planning tool)	Use the list of potential partners in this Road Map planning tool for state and local public health professionals.
<a href="#">Alzheimer's Association local chapters</a> (chapter locator)	Partner with your local chapter to learn about the state landscape on dementia and caregiving and to involve caregivers for people living with dementia in all phases of planning.
<b>ASSESSING CAREGIVERS AND COMMUNITY INFRASTRUCTURE</b>	
<a href="#">Alzheimer's Disease and Healthy Aging Data Portal</a> (interactive data portal)	Access national and state level CDC data on various indicators of health and well-being for older adults including caregiving (both general and dementia-specific) and subjective cognitive decline.
<a href="#">Needs Assessment Toolkit: Guidance and Resources for State Public Health Agencies on Comprehensive Needs Assessments Related to Alzheimer's and Other Dementias</a> (toolkit)	Use the guidance and tools in this Alzheimer's Association toolkit to plan and conduct needs assessments to inform priorities and strategies.
<a href="#">BRFSS Data on Caregivers for People Living with Dementia</a> (state and national fact sheets)	Access state-specific BRFSS data from the BRFSS Caregiver Module that is specific to dementia caregiving on this Alzheimer's Association portal.



<a href="#"><i>BRFSS Statistical Brief: Caregiver Optional Module 2015-2018</i></a> (technical brief)	Learn about how to conduct analyses of the data collected through the 2015–2018 BRFSS Caregiver Optional Module in this CDC brief.
<b>DEVELOPING THE PLAN</b>	
<i>Planning Tools</i>	
<a href="#"><i>Planning for Action: Initial Steps for Implementing the Healthy Brain Initiative Road Map</i></a> (planning tool)	Use the planning toolkit's worksheets and resources to help prioritize, plan, and promote Road Map actions.
<a href="#"><i>A Planning Guide for a Public Health Approach to Dementia in Indian Country</i></a> (planning tool)	Use this planning tool from the National Council on Urban Indian Health to select HBI Road Map for Indian Country actions and get started with implementation.
<a href="#"><i>Performance Measures Matrix</i></a> (planning tool, automatic download)	Find existing performance measures related to dementia caregiving in this planning tool from the Alzheimer's Association.
<a href="#"><i>Evaluating Dementia Services and Supports: Instrument Resource List</i></a> (tool)	Identify appropriate and well-researched measures for evaluation plans in this resources list from the National Alzheimer's and Dementia Resource Center.
<i>Sources of Macro Level Strategies to Policies, Systems and Environments</i>	
In addition to the macro strategies summarized on page 9 of this action brief:	
<a href="#"><i>HBI Road Maps</i></a>	Find actions, some at the macro level, to support dementia caregiving.
<a href="#"><i>State Alzheimer's plans</i></a> (portal to states' plans)	Get ideas for dementia caregiving strategies from other states' Alzheimer's plans.
<a href="#"><i>Caregiving for People Living with Dementia and How Health Departments Can Make an Impact</i></a> (brief)	Learn how some states have implemented the caregiving actions in the HBI Road Maps in this ASTHO brief.
<a href="#"><i>Reducing the Cost and Risk of Dementia</i></a> (report)	Obtain ideas for policy and systems changes from the Milken Institute's Alliance to Improve Dementia Care.
<a href="#"><i>Families Caring for an Aging America</i></a> (report)	Find expert recommendations to strengthen caregiving, including for people living with dementia, from a National Academies of Science, Engineering, and Medicine committee.

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