

NOVEMBER 2017

ISSUE BRIEF

# Home Care Worker Training and People with Alzheimer's Disease and Related Dementias: Ideas for State Policymakers

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The number of people aged 65 and older with Alzheimer's disease and related dementias (ADRD) is expected to grow from 5.3 million to 7.1 million between 2017 and 2025.<sup>1</sup> However, successfully supporting people with dementia who live at home often requires the assistance of home care workers. Given this context, it is important to examine the training needs related to home care and dementia—and what states can do. This brief describes how dementia affects individuals, families, and home care workers. It explains why enhancing training for home care workers can better support clients, and where states are regarding dementia training requirements. Finally, it offers five general ways in which state policymakers can ensure home care workers are equipped to support this population.

## What is “Alzheimer’s Disease and Related Dementias?”

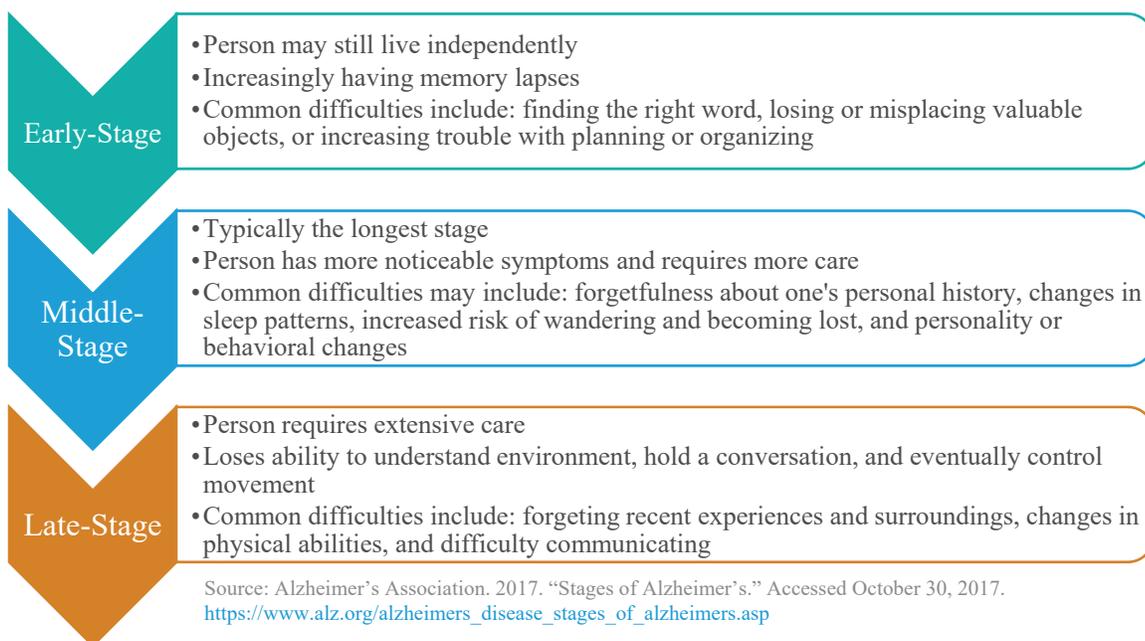
Alzheimer's disease and related dementias (ADRD) affect a person’s memory, thoughts, and actions. ADRD has no cure and people live an average of eight years once the symptoms become noticeable to others.<sup>2</sup> People with dementia might initially need help with tasks such as cooking, paying bills, and managing medications. As the disease progresses, they require additional assistance with daily tasks, such as bathing, dressing, walking, and eating, and they have increasing difficulty with decision making and judgement. They typically receive care from loved ones and, as the person’s needs increase, through the long-term care system. One in 10 people aged 65 and older has been diagnosed with ADRD, which has significant implications for the long-term care and aging fields.

## Why are home care workers important for people with dementia and their family caregivers?

Most people prefer to receive long-term care in their homes and communities,<sup>3</sup> and home care is a critical support for people with dementia who prefer to live at home. Home care workers help clients with activities of daily living – such as eating, walking, bathing, and dressing – and may also help with additional activities, such as meal preparation, transportation, and housekeeping. These supports allow people to stay in their homes as long as possible, avoiding the additional, psychological challenges of moving into assisted living or a nursing home.<sup>4,5</sup>

A majority of the paid, hands-on home care is provided by home care workers (including home health aides and personal care aides). As a home care worker creates a relationship with a client, they build trust and develop an understanding of the person’s needs and preferences, which improves the client’s care and quality of life.<sup>6</sup> They are a central part of the client’s life and critical to their health and well-being.

### Stages of Alzheimer's Disease



Home care workers are also a critical support for family caregivers. They allow many families to continue working, and to meet their numerous obligations, such as caring for children. Home care workers can also provide respite to family caregivers, helping them meet the demanding responsibilities of being a caregiver, and reducing the negative effects of stress and burnout.<sup>7,8,9</sup>

## Why is training on dementia important for home care workers?

Almost one in three home care agency clients have been diagnosed with ADRD,<sup>10</sup> which makes it essential that home care providers specialized training for their workers. Proper training can help workers spot ADRD symptoms in their clients, helping to ensure they receive early treatment. Additionally, a person with dementia will have unique needs at different stages of the disease, and a home care worker should be trained to address those needs. Research shows that proper care for people with dementia can improve their quality of life<sup>11</sup> and avoid or reduce the need for medications.<sup>12,13</sup> In contrast, research shows that a lack of proper training can lead to a more challenging situation for the worker, the client, and the family.<sup>14,15</sup>

## What dementia topics should be covered in home care training?

In addition to the common topics covered in home care training—providing personal hygiene, safe transfer techniques, and nutrition, as examples—workers can benefit from training specific to dementia. For example, curricula focused on dementia might describe the progression of the disease; its physical, emotional, and behavioral impact; how to maximize safety; and how to prevent falls.

Research shows that dementia training can also benefit from two additional areas: how to provide person-centered care and effective communication. Person-centered care helps a home care worker focus on the client's distinct personal needs and preferences, as well as their medical needs.<sup>16</sup> Person-centered care would ensure that the individual is recognized and respected for their uniqueness, not on the basis of their diagnosis. Knowing a client's biography and values enables the worker to provide autonomy, choice, and comfort based on the individual's emotional and physical needs.

Training home care workers on effective communication is especially important, since a person with dementia often communicates in ways that might not be intuitive, especially in mid- to late stages of the disease. They might not be able to verbally express their concerns (such as pain, constipation, hunger, or thirst) and instead communicate through behaviors such as anxiety, agitation, aggression, and depression.<sup>17,18</sup> Understanding these non-verbal cues requires training.



Building the home care worker’s awareness of emotional triggers when faced with challenging caregiving situations and developing self-management skills is also an essential aspect of training.

## Are home care workers required to be trained in supporting people with dementia?

Despite the prevalence of ADRD and the important role of home care workers in helping them live at home, there are few dementia-related training requirements for home care workers. Federal training standards do not require dementia training for home care workers,<sup>19</sup> and only 13 states (as of 2015)

have dementia-specific training requirements – with significant variation in requirements among those states.<sup>20</sup> Unfortunately, this means that most parts of the country lack dementia training requirements for home care workers, creating challenges for clients, their families, and workers alike.

Certain organizations, including PHI (See “Spotlight: PHI’s eLearning Training Model”), the Alzheimer’s Association,<sup>21</sup> and the Alzheimer’s Foundation of America<sup>22</sup> have developed enhanced dementia training programs, but they remain largely optional.

## What are some innovative areas to improve training for home care workers in dementia?

Two areas that hold promise for better supporting people with dementia are home care are technology and enhanced training models. Technology continues to shape the aging and long-term care fields, and can be used to

effectively support home care workers when caring for people with dementia. PHI’s eLearning model (see “Spotlight: PHI’s eLearning Training Model”) relies on technology to enhance and streamline training for home care workers, ensuring they can access dementia training that is useful

### Spotlight: PHI’s eLearning Training Model on Alzheimer’s and Related Dementias

PHI offers a suite of specialty eLearning training curricula for home care workers, which includes a module on Alzheimer’s Disease and Related Dementias. The eLearning format incorporates photography, video, animation, and audio instruction to engage learners and augment written content. PHI’s approach brings to life key concepts and case scenarios in ways that engage the typical home care worker, including those with low literacy and those with limited formal education. This eLearning approach reduces the hours of training needed to convey complex information, and leverages the existing training infrastructure of home care providers—providing a cost-effective solution to supporting clients with dementia. **Learn more at [PHInational.org](http://PHInational.org).**

and easy-to-understand. Technology can also provide new training opportunities. For example, home care workers might use smartphone apps to access “refresher” training modules on topics such as dementia when they are in the field. A worker newly assigned to a client with dementia would be able to quickly obtain the information they need to deliver tailored care in the home.

Enhanced training models augment a home care worker’s ability to support clients. One tested model is peer mentoring.<sup>23</sup> Peer mentors are home care workers who receive additional training on any number of topics, including dementia. This additional training provides them with enhanced skills to support a person with dementia, their family, and the home care worker. Peer mentors can support home care workers in several ways, including through additional training on dementia care, assistance in resolving specific challenges, and modelling best practices. Peer mentors can also interface with the client and family when issues arise, as well as with the care team, sharing information gathered from the worker. Another enhanced training model is specialized dementia workers. In this model, home care workers receive additional dementia training, which allows them to specialize in caring for clients with dementia. For any enhanced training model to be successful, there must be a shift in home care agency practice and infrastructure to support these new roles.

## What are some innovative areas to improve training for home care workers in dementia?

State policymakers can begin addressing the training needs of the home care workforce to properly care for people with dementia. Here are five recommendations:

- **Recommendation 1: Build public awareness about the growing need for home care for people with dementia and their families.** The first step in addressing these challenges is to create greater awareness of the need for home care worker training on dementia. State leaders can create workgroups and taskforces charged with understanding their state’s needs, hold legislative hearings and advocacy days, and commission reports and white papers. Building awareness creates momentum for solutions that support workers and people with dementia.
- **Recommendation 2: Invest in home care workers so they are better able to support people with dementia and their families.** Unfortunately, home care workers typically experience low compensation with limited opportunities for advancement. Policy fixes that strengthen and stabilize the home care workforce – such as increasing compensation, creating training opportunities and career ladders, and improving recruitment and retention – ultimately benefit their clients, including those with dementia, through improved quality of care.
- **Recommendation 3: Develop and implement training programs for home care workers to provide effective support and services for individuals with dementia.** States should invest in



building the infrastructure needed to train home care workers on dementia. As one example, states can fund innovative training approaches that successfully train home care workers on dementia.

- **Recommendation 4: Strengthen state training requirements to ensure home care workers can support people with dementia and their caregivers.** States should establish clear dementia training requirements for home care workers. These requirements should cover both entry-level training, which provides workers with the baseline knowledge on dementia, and ongoing training, which reinforces knowledge and builds new skills.
- **Recommendation 5: Fund and test innovations in the areas of technology and peer mentoring that can improve home care for people with dementia.** New innovations related to technology and peer mentoring would support both workers and people with dementia. Testing these innovations – which should build on existing, successful models – would ensure they work well for all parties involved.

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<sup>1</sup> Alzheimer’s Association. 2017. “2017 Alzheimer’s Disease Facts and Figures”. *Alzheimer’s & Dementia*. 2017(13):325-373. Doi: <http://dx.doi.org/10.1016/j.jalz.2017.02.001>

<sup>2</sup> Alzheimer’s Association. 2017. “What is Alzheimer’s?” Accessed November 7, 2017.

[https://www.alz.org/alzheimers\\_disease\\_what\\_is\\_alzheimers.asp](https://www.alz.org/alzheimers_disease_what_is_alzheimers.asp)

<sup>3</sup> Harrell, Rodney, Jana Lynott, Shannon Guzman, and Cheryl Lampkin. 2014. *What is Livable? Community Preferences of Older Adults*. Washington, DC: AARP Public Policy Institute.

[https://www.aarp.org/content/dam/aarp/research/public\\_policy\\_institute/liv\\_com/2014/what-is-livable-report-AARP-ppi-liv-com.pdf](https://www.aarp.org/content/dam/aarp/research/public_policy_institute/liv_com/2014/what-is-livable-report-AARP-ppi-liv-com.pdf)

<sup>4</sup> Robinson, Victoria. 2002. *A Brief Literature Review of the Effects of Relocation on the Elderly*. British Columbia: The Hospital Employees’ Union of British Columbia.

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<sup>5</sup> Spillman, Brenda. 2016. *Does Home Care Prevent or Defer Nursing Home Use?* Washington, DC: US Department of Health and Human Services. <https://aspe.hhs.gov/system/files/pdf/245701/preventNH.pdf>

<sup>6</sup> Alzheimer’s Association. 2009. *Dementia Care Practice Recommendations for Professionals Working in a Home Care Setting: Phase 4*. Washington, DC: Alzheimer’s Association Campaign for Quality Care.

[https://www.alz.org/national/documents/Phase\\_4\\_Home\\_Care\\_Recs.pdf](https://www.alz.org/national/documents/Phase_4_Home_Care_Recs.pdf)

<sup>7</sup> Kosloski, Karl, and Rhonda Montgomery. 1995. “The Impact of Respite Use on Nursing Home Placement.” *The Gerontologist*. 1995, 35(1): 67-74. <https://doi.org/10.1093/geront/35.1.67>

<sup>8</sup> Gaugler, Joseph, Anne Edwards, Elia Femia, Steven Zarit, Mary-Ann Parris Stephens, Aloen Townsend, and Rick Greene. 2000. “Predictors of Institutionalization of Cognitively Impaired Elders: Family Help and the Timing of Placement.” *The Journals of Gerontology: Series B*. 2000, 55(4): 247-255.

<https://doi.org/10.1093/geronb/55.4.P247>

<sup>9</sup> Padgett Coehlo, Deborah, Karen Hooker, and Sally Bowman. 2007. “Institutional Placement of Persons With Dementia: What Predicts Occurrence and Timing?” *Journal of Family Nursing*. 2007; 13(2): 253-277.

<https://doi.org/10.1177/1074840707300947>

<sup>10</sup> Harris-Kojetin, Lauren, Manisha Sengupta, Eunice Park-Lee, Roberto Valverde, Christine Caffrey, Vincent Rome, and Jessica Lendon. 2016. “Long-term care providers and services users in the United States: Data from the National Study of Long-Term Care Providers, 2013–2014.” Hyattsville, Maryland: National Center for Health Statistics. *Vital Health Statistics*. 3(38). 2016.

<sup>11</sup> Logsdon, Rebecca, Susan McCurry, and Linda Teri. 2007. “Evidence-Based Interventions to Improve Quality of Life for Individuals with Dementia.” *Alzheimer’s Care Today*. 2007; 8(4): 309-318.

<https://www.ncbi.nlm.nih.gov/pmc/articles/PMC2585781/>

<sup>12</sup> Martini de Oliveira, Alexandra, Marcia Radanovic, Patrícia Cotting Homem de Mello, Patrícia Cardoso Buchain, Adriana Dias Barbosa Vizzotto, Diego L. Celestino, Florindo Stella, Catherine Piersol, and Orestes Forlenza. 2015. “Nonpharmacological Interventions to Reduce Behavioral and Psychological Symptoms of Dementia: A Systematic Review.” *BioMed Research International*. 2015, 218980.

<http://doi.org/10.1155/2015/218980>

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<sup>13</sup> Brechin, Donald, Gemma Murphy, Ian James, and Jason Codner. 2013. *Alternatives to antipsychotic medication: Psychological approaches in managing psychological and behavioural distress in people with dementia*. Leicester, UK: The British Psychological Society. 2013.

<http://www.bps.org.uk/system/files/Public%20files/antipsychotic.pdf>

<sup>14</sup> Hoefler B, Talerico KA, Rasin J, et al., “Assisting Cognitively Impaired Nursing Home Residents with Bathing: Effects of Two Bathing Interventions on Caregiving,” *The Gerontologist*. 2006;46(4):524-532.

<sup>15</sup> Edvardsson D, Sandman PO, Nay R, Karlsson S. Predictors of job strain in residential dementia care nursing staff. *Journal of Nursing Management*. 2009;17(1):59-65. doi: 10.1111/j.1365-2834.2008.00891.x.

<sup>16</sup> Dawn Brooker. 2007. “Person-Centered Dementia Care: Making Services Better.” London, UK: Jessica Kingsley Publishers. 2007.

<sup>17</sup> McAuliffe L, Nay R, O'Donnell M, Fetherstonhaugh D, “Pain assessment in older people with dementia: Literature review,” *Journal of Advanced Nursing*. 2009;65(1):2-10. doi: 10.1111/j.1365-2648.2008.04861.x.

<sup>18</sup> Logsdon RG, McCurry SM, Teri L, “Evidence-based psychological treatments for disruptive behaviors in individuals with dementia,” *Psychology and Aging*. 2007;22(1):28-36.

<sup>19</sup> United States Code. “Condition of participation: Home health aide services.” 42 CFR 484.3

<sup>20</sup> Georgia Burke and Gwen Orlowki. 2015. *Training to Serve People with Dementia: Is our Health Care System Ready? – Paper 3: A Review of Dementia Training Standards Across Professional Licensure*. August 2015. Washington, DC: Justice in Aging. [http://www.justiceinaging.org/wp-content/uploads/2015/08/Training-to-serve-people-with-dementia-Alz3\\_FINAL.pdf](http://www.justiceinaging.org/wp-content/uploads/2015/08/Training-to-serve-people-with-dementia-Alz3_FINAL.pdf)

<sup>21</sup> Alzheimer’s Association. 2017. “Dementia Care Training and Certification.” Accessed November 13, 2017. [https://www.alz.org/professionals\\_and\\_researchers\\_11176.asp](https://www.alz.org/professionals_and_researchers_11176.asp)

<sup>22</sup> Alzheimer’s Foundation of America. 2017. “Professional Training and Education.” Accessed November 13, 2017. <https://alzfdn.org/professional-training-and-education/>

<sup>23</sup> PHI. 2003. *Workforce Strategies 2: Introducing Peer Mentoring in Long-Term Care Settings*. Bronx, NY: PHI. <https://www.phinational.org/sites/default/files/clearinghouse/WorkforceStrategies2.pdf>

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PHI works to transform eldercare and disability services. We foster dignity, respect, and independence for all who receive care, and all who provide it. As the nation’s leading authority on the direct care workforce, PHI promotes quality direct care jobs as the foundation for quality care. Drawing on 25 years of experience working side-by-side with direct care workers and their clients in cities, suburbs, and small towns across America, PHI offers all the tools necessary to create quality jobs and provide quality care. PHI’s trainers, researchers, and policy experts work together to:

- Learn what works and what doesn’t in meeting the needs of direct care workers and their clients, in a variety of long-term care settings;
- Implement best practices through hands-on coaching, training, and consulting, to help long-term care providers deliver high-quality care;
- Support policymakers and advocates in crafting evidence-based policies to advance quality care

For more information, visit our website at [www.PHInational.org](http://www.PHInational.org) and [www.60CaregiverIssues.org](http://www.60CaregiverIssues.org).