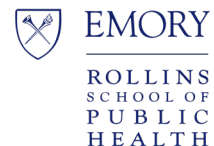
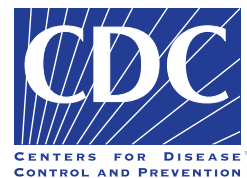




# Public Health and Dementia Caregiving

## INSTRUCTOR GUIDE



Emory Centers  
for Public Health  
Training and  
Technical Assistance

The Healthy Brain Initiative, the BOLD Public Health Center of Excellence on Dementia Caregiving and the development and dissemination of this module is supported by the Centers for Disease Control and Prevention and the U.S. Department of Health and Human Services (HHS) as part of a financial assistance award totaling \$13,708,792 with 100 percent funding by CDC/HHS. The contents are those of the Alzheimer's Association and Center of Excellence on Dementia Caregiving and do not necessarily represent the official views of, nor an endorsement, by CDC/HHS, or the U.S. Government.

## WHAT IS INCLUDED IN THE INSTRUCTOR'S GUIDE?

- **How to Use the Public Health and Dementia Caregiving Module Instructor Guide:** Provides guidance on how to use the Instructor Guide.
- **About the Public Health and Dementia Caregiving Module:** Provides a brief overview of the public health and dementia caregiving module and how it fits within the larger public health curriculum on dementia.
  - **Learning Objectives:** Lists 5 learning objectives for a participant completing this module.
- **Competencies:** Lists competencies met by this module from AGHE/GSA; CEPH; Council on Linkages; and PHAB.
- **Participant Engagement Options:** Includes supplementary resources that are designed to increase participant engagement and enhance understanding of the concepts covered.
  - **Discussion Questions:** Provides several questions to be used before participants complete the module and questions that can be used after participants complete the module.
  - **Learning Activities:** Provides several interactive, application-based activities participants can use to apply and integrate knowledge from the module into their life.
  - **Sample Test Questions:** Provides multiple choice and true/false questions that could be used to assess knowledge based on the content in the module.
  - **Case Studies:** Copy of the case studies and accompanying knowledge checks that are in the module. Additional discussion questions for each case study are provided.
  - **Video Resources:** Links to select videos that are used throughout the module. Additional discussion questions for each video are provided.
  - **Graphic Resources:** Copies of select graphics that are used in the module. Additional discussion questions and activities for each graphic are provided.
  - **Additional Readings and Resources:** The list of additional resources that is included in the module that could be used for supplementary activities or reading by participants.
- **Appendix A:** Copy of the sample test questions without correct answers included for ease of printing.

## HOW TO USE THE MATERIALS:

- This module is part of a larger curriculum where each module is designed for use either as part of a complete set or as a stand-alone module.
- Participants can use the module at their own independent pace, without any supplementary work or guidance from an instructor, presenter or trainer. The module can also be used as a base for training, assignments, group projects or class discussion. In addition to the module content, this guide has supplementary materials to support activities used in a class setting.
- This is meant as a flexible guide that instructors can adapt to fit their needs.
- The module itself will take approximately 60-90 minutes to complete. If including the supplementary materials, time will vary depending on participant engagement, instructor style and the activities included.
- Discussion questions, learning activities, sample test questions, case studies, video resources with questions, graphic resources and additional reading and resources are also included in this guide. These may be modified or removed at the discretion of the instructor. Questions may also be used for other activities such as small group discussion or individual writing assignments. Many of the questions will directly reference specific sections in the module, so participants may benefit from having discussion questions or learning activities prior to beginning the module.
- Module content can be downloaded from the module to be used as a reference.
- All materials are 508 compliant. (Note: if changes are made to the supplementary materials, it is recommended that changes continue to follow 508 compliance guidelines. For more information on 508 compliance, visit the Department of Health and Human Services website: <https://www.hhs.gov/web/section-508/index.html>)

## ABOUT THE PUBLIC HEALTH AND DEMENTIA CAREGIVING MODULE

This 90-minute course, *Public Health and Dementia Caregiving*, is designed for public health students, educators and professionals and is part of the larger Healthy Brain Initiative curriculum, *A Public Health Approach to Dementia*. This suite of training modules was developed for the Alzheimer's Association by the Emory Centers for Public Health Training and Technical Assistance with support from the Centers for Disease Control and Prevention (CDC). This course was also developed in partnership with the [BOLD Public Health Center of Excellence on Dementia Caregiving](#) located at the University of Minnesota.

*Public Health and Dementia Caregiving* approaches caregiving for people living with Alzheimer's disease and other dementias from a broad, population-based perspective. Participants can use this learning module format at their own independent pace, without any supplementary work or guidance from an instructor, presenter or trainer. The module can also be used as a base for training, assignments, group projects or class discussion. This guide contains supplementary materials to support any additional activities that might be done in addition to the module itself. The module contains the following 6 sections with 15 subsections and addresses five learning objectives.

### Topics:

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1. Module Introductions
  - a. Module Instructions
  - b. Introduction
  - c. Learning Objectives
2. Who are Dementia Caregivers
  - a. Dementia Caregivers Overview
  - b. Who are Dementia Caregivers?
  - c. Health Equity and Dementia Caregiving
3. Caregiver Roles
  - a. Caregiver Roles
  - b. Triadic Model of Caregiving
4. Dementia Caregiving and Public Health
  - a. Dementia Caregiving as a Public Health Priority
  - b. Health Implications for the Dementia Caregiver
5. Supporting Dementia Caregivers
  - a. Types of Evidence-Based Supports for Dementia Caregiving
  - b. What Can Public Health Organizations Do?
  - c. Public Health in Action on Dementia Caregiving
6. Conclusion
  - a. Conclusion
  - b. Next Steps
  - c. Resources
  - d. References

### Learning Objectives:

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1. Describe dementia caregiving and at least two groups that are disproportionately affected by dementia caregiving.
2. Describe the public health context of dementia caregiving.
3. Identify two or more health implications associated with dementia caregiving.
4. Identify two or more actions public health organizations can take to address the impacts of dementia caregiving.
5. Describe how a public health department can utilize essential public health services as a framework to address the needs of dementia caregivers.

## COMPETENCIES

The Public Health and Dementia Caregiving module promotes basic learning that supports the development of certain competencies and aligns with public health accreditation standards.

### **Academy for Gerontology in Higher Education (AGHE, through GSA):**

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- I.1.4: Interpret the gerontological frameworks in relationship to aspects and problems of aging persons, their families, their environment and communities.
- I.3.3: Demonstrate knowledge of signs, symptoms, and impact of common cognitive and mental health problems in late life (e.g., dementia, depression, grief, anxiety).
- I.4.3: Appraise the changing dynamics of contemporary multigenerational families and their impact on social solidarity and interdependence.
- I.6.2: Identify gaps in research regarding both aging-related problems and successes in order to promote continued knowledge building.
- II.1.3: Assess and reflect on one's work in order to continuously learn and improve outcomes for older persons.
- II.2.2: Respect interdependence of individuals of all ages and abilities.
- II.2.3: Respect cultural values and diversity.
- II.4.4: Involve the older person, their family and caregivers as members of the interprofessional care team in planning and service decisions.
- II.4.5: Provide the following groups information and education in order to build a collaborative aging network:
  - Key persons in the community (e.g., police officers, firefighters, mail carriers, local service providers and others)
  - Aging workforce professionals and personnel (e.g., paid and unpaid; full- and part-time) in the field of aging.
- III.7.2: Analyze policy to address key issues and methods to improve the quality of life of older persons and their caregivers/families.

### **Council on Education for Public Health (CEPH) Foundational Competencies:**

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- 4. Interpret results of data analysis for public health research, policy, or practice.
- 6. Discuss the means by which structural bias, social inequities and racism undermine health and create challenges to achieving health equity at organizational, community, and systemic levels.
- 8. Apply awareness of cultural values and practices to the design, implementation, or critique of public health policies or programs.
- 20. Describe the importance of cultural competence in communicating public health content.

### **Council on Linkages Between Academia and Public Health Practice (supported by ASPPH):**

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- 1.1: Describes factors that affect the health of a community.
- 4.1: Applies principles of ethics, diversity, equity, inclusion, and justice.
- 4.3.2: Describes how diversity influences policies, programs, services, and the health of a community.
- 4.6.4: Contributes to implementation of strategies for achieving and sustaining a diverse, inclusive, and competent public health workforce.
- 5.4.1: Explains the importance of collaborating with community members and organizations to identify and address community health and resilience needs.
- 8.1.4: Describes the ways public health, healthcare, and other organizations can work together or individually to impact the health of a community.

### **Public Health Re-accreditation Standards (PHAB):**

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- 3.2: Use health communication strategies to support prevention, health, and well-being.
- 8.2: Build a competent public health workforce and leadership that practices cultural humility.

## PARTICIPANT ENGAGEMENT OPTIONS

These supplementary resources are designed to increase participant engagement and enhance understanding of the concepts covered in this module. These include discussion questions, learning activities, a series of case studies, additional reading and a list of video resources. It is recommended that the instructor review these resources to determine which of these additional materials would be useful in illustrating the concepts covered in the module.

### DISCUSSION QUESTIONS

The following discussion questions may be useful for engaging learners before and after module completion:

#### Before completing the module:

- Think about those in your life who may need care now or in the future. What are some things to consider if someone is diagnosed with Alzheimer's or another dementia?
- How do you define caregiving? How do you think caregiving for someone with dementia might be different from other kinds of caregiving? What kinds of support and information would be helpful for you if you were supporting a dementia caregiver?
- How do you define health equity? What health inequities are you aware of among different communities? What health inequities might be present among dementia caregivers?
- Can you think of supports for caregivers? An example to start with may be support groups or meal trains. How could these supports be related to public health? How can these supports be leveraged for dementia caregivers across the community?
- What are the ten essential public health services? How could some of these be leveraged to support dementia caregivers?

#### After completing the module:

- Imagine someone you care about is diagnosed with Alzheimer's or another dementia. What are some tasks their care team may need to prepare for?
- Imagine someone tells you that health equity does not impact dementia caregivers. How would you respond?
- Imagine you are supporting a dementia caregiver. Who or what might be impacting their role? How can you use this information to better support them?
- Imagine you work at a local or state health department. Consider the ten essential public health services and their overlap with dementia caregiving. How can you use this model to best support dementia caregivers?
- Consider some of the paths to expand implementation discussed in the module. What communication strategies would you be interested in using to advance support for dementia caregivers?
- Think about the "Next Steps" listed in the module. Which of these feels actionable to you? What will your next step be?



## LEARNING ACTIVITIES

The following learning activities may be used or adapted to enhance learning:

- Observe the place in which you live, work or go to school. What are some components that might support dementia caregivers? What are ways they might not support dementia caregivers? What changes would need to be made to improve dementia caregiver support?
- Create a diagram, interactive tool or resource to explain the interactions between professional caregivers, family caregivers, care recipients, and external factors. Provide one example of how an external factor may impact the relationships in the caregiving team.
- Select a business or organization in your community that may benefit from training on dementia caregivers. Create an outline of training topics — What information would you present? What educational techniques would you use during the training?
- Watch the nine-minute video below about a dementia caregiver balancing care and work. Think about some of the health implications for dementia caregivers. Describe some ways you could incorporate dementia caregiving support into public health messaging and programming.
  - <https://www.youtube.com/watch?v=zPIRD9COUck>
- Draft potential next steps for one of the examples of “Public Health in Action on Dementia Caregiving”. Identify why you selected the example you did; what organizations are involved; and 3–5 possible next steps they could take to continue furthering support for dementia caregivers.
- Choose an underserved population listed under “Acknowledging health inequities and Alzheimer’s” on the Alzheimer’s Association’s [Diversity, Equity and Inclusion page](#). Create a fact sheet or infographic about the impact of dementia caregiving on that community. Include resources and successes.
- Read the article: [The Intersection of Social Determinants of Health and Family Care of People Living with Alzheimer’s Disease and Related Dementias: A Public Health Opportunity](#). Summarize and respond to the argument made by the authors about dementia caregiving and its relationship to social determinants of health.

## SAMPLE TEST QUESTIONS

The correct answer and explanation are included below each question.

Test questions without correct answers are included as Appendix A for ease of printing.

1. What is a “Sandwich” caregiver?

- A. A caregiver feeling pressure from working while providing care
- B. A caregiver caring for an aging parent as well as a child under 18
- C. A caregiver caring for multiple aging parents
- D. A caregiver struggling with their own health issues as well as caring for someone else

*The correct answer is B.* Approximately one-quarter of dementia caregivers are “sandwiched” between generations by caring for an aging parent as well as at least one child under 18.

2. True or False: Dementia caregivers often say that love and a sense of duty and obligation are what motivates them to take on care responsibilities for a relative or friend.

*The correct answer is True.* Dementia caregivers often indicate love and a sense of duty and obligation when describing what motivates them to assume care responsibilities for a relative or friend.

3. Dementia caregivers

- A. provide care for the health needs and well-being of a person living with Alzheimer’s disease or other dementias.
- B. are 2 million of the 48 million caregivers living in America.
- C. experience much lower emotional stress, health problems and financial challenges compared to other caregivers.

*The correct answer is A.* There are 11 million dementia caregivers living in America. Dementia caregivers, more so than other caregivers, experience increased emotional stress and depression, new or exacerbated health problems, and depleted income and finances due in part to disruptions in employment and paying for health care costs for themselves or the care recipient.

4. Which of the following groups are disproportionately affected by dementia caregiving?

- A. LGBTQ+
- B. Women
- C. Diverse racial or ethnic groups
- D. Parents and siblings of people with intellectual and developmental disabilities
- E. All of the above

*The correct answer is E.* Several sources have examined the demographic background of dementia caregivers and have found dementia caregivers who are LGBTQ+, women, from diverse racial or ethnic groups, or who are parents or siblings of people with intellectual and developmental disabilities are all disproportionately affected by dementia caregiving.

## SAMPLE TEST QUESTIONS [CONTINUED]

5. A dementia care team can include: (Select all that apply)
- A. Family members, living close by or far away
  - B. Friends, neighbors or others who may help with day-to-day tasks
  - C. Medical providers
  - D. Counselors, care managers or in-home care support
  - E. Policymakers

*The correct answers are A, B, C and D. Policymakers influence the external environment which impacts the dementia care team.*

6. Which of the following activities or tasks might a dementia caregiver be responsible for?
- A. Advocating for the care recipient
  - B. Supporting care recipients with activities of daily living
  - C. Planning for end-of-life care
  - D. Participating in medical appointments and navigating health care systems.
  - E. Finding and using support services like support groups or adult day services.
  - F. All of the above

*The correct answer is F. All of the above tasks are things a dementia caregiver may be responsible for during the journey of dementia caregiving.*

7. True or False: The three people in the triadic model of caregiving are the doctor, social worker and physical therapist.

*The correct answer is False. The Triadic model demonstrates the three-way relationship between the caregiver, the care recipient, and the professional provider.*

8. What is the best definition of the family care gap?
- A. The lack of resources existing for family caregivers
  - B. The communication breakdown that occurs between family members providing care
  - C. The growing gap between the number of caregivers available and the increasing number of care recipients
  - D. Counselors, care managers or in-home care support
  - E. Policymakers

*The correct answer is C. The family care gap refers to the decreasing number of caregivers and the increasing number of people needing care that will result in a care gap in the future.*

## SAMPLE TEST QUESTIONS [CONTINUED]

9. What is driving the family care gap?
- A. People are spending a longer time in the workforce
  - B. The incoming excess of people working in geriatric care
  - C. Men being more likely to participate in the workforce

*The correct answer is A.* A few of the many driving factors of the growing family care gap include longer time spent in the workforce, women being more likely to participate in the workforce, and the aging of and incoming shortage of people working in geriatric care.

10. All of the below illustrate why dementia caregiving should be a public health priority, except:
- A. Financial impact of and decreasing demand for dementia caregiving
  - B. Social and economic implications for dementia caregivers, including cost of care and impact on workplace productivity
  - C. Growing family care gap, where there will be fewer caregivers and more people

*The correct answer is A.* The financial impact of and increasing demand for dementia caregiving illustrate why dementia caregiving should be a public health priority.

11. True or False: Caregivers rarely report positive feelings about caregiving.

*The correct answer is False:* Caregivers often report positive feelings about caregiving, such as family togetherness and the satisfaction of helping others.

12. Possible health implications for dementia caregivers include:
- A. Too much stress leading to burnout
  - B. Increased likelihood of experiencing depression and anxiety
  - C. Increased risk of developing chronic conditions
  - D. Positive feelings about caregiving, such as family togetherness and the satisfaction of helping others
  - E. All of the above

*The correct answer is E.* Dementia caregivers frequently report high levels of stress and, for some dementia caregivers, the demands of caregiving may cause declines in their own health. Dementia caregivers also report positive feelings about caregiving, such as family togetherness and the satisfaction of helping others, which may have a positive impact on health.

13. True or False: Older adults with Alzheimer's disease and other types of dementia are more likely to be hospitalized than older adults without dementia.

*The correct answer is True.* Older adults with Alzheimer's disease and other types of dementia are more likely to be hospitalized than older adults without dementia.

## SAMPLE TEST QUESTIONS [CONTINUED]

14. Some acts of self-care for a dementia caregiver may include all of the following except:

- A. Being physically active
- B. Eating well
- C. Seeing the doctor
- D. Delaying respite care
- E. Finding strategies to cope with stress

*The correct answer is D.* It is important for dementia caregivers to consider respite care where someone else provides care short term so that the caregiver can have a break.

15. Use the words from the word bank to fill in the statements below regarding the types and focus of caregiver interventions.

### WORD BANK:

**Care management • Counseling • Multicomponent approaches • Respite • Support groups**

- A. **Respite** provides planned, temporary relief for the caregiver.
- B. **Counseling** aims to resolve pre-existing personal problems that complicate caregiving.
- C. **Support groups** provide caregivers the opportunity to share personal feelings, concerns and overcome feelings of isolation by connecting with peers.
- D. **Care management** provides assessment, information, planning, referral, care coordination and/or advocacy for the person living with dementia and support for caregivers.
- E. **Multicomponent approaches** combine several forms of interventions into a single, long-term service.

16. Public health actions that can be taken to support dementia caregivers include:

(Select all that apply)

- A. Measuring the number of dementia caregivers
- B. Educating dementia caregivers about health risks they might face
- C. Supporting community meetings and activities related to health advocacy
- D. Steering clear of partnerships to ensure clear public health delineation
- E. Providing input on public health policies that impact dementia caregivers

*The correct answers are A, B, C and E.* Partnering across the community to promote equitable access to services, supports and quality care for dementia caregivers is an important action that public health organizations can take.

17. What are possible next steps to learn more or get involved in supporting dementia caregivers?

- A. Sign up for CDC's Healthy Aging for Older Adults newsletter
- B. Volunteer with community partners in your area
- C. Find caregiver data in your state and share what you learn with others
- D. Learn more about policies that support caregivers
- E. All of the above

*The correct answer is E.* All of the above actions are next steps to take to learn more or get involved to support dementia caregivers.

## CASE STUDIES

These are the case studies that are used in the module. Additional discussion questions are included as supplementary resources to be used in your learning environment. Possible answers are provided in italics with the discussion questions, but answers are not necessarily exhaustive or comprehensive.

### Triadic Model Case Study: Moving Near Family

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Sherry (age 75) is caring for her husband, Steven, who was diagnosed with dementia five years ago. Steven was a professional musician, and music is an important part of maintaining his identity and memories for him as his dementia progresses. Many of their local friends have either passed away or have moved to be closer to their families. Sherry and Steven have decided to also move closer to one of their children so they can have greater ongoing physical support. Their child lives in a rural area with limited internet access. What are some ways their care relationships will be impacted by their move?

- Accessing professional providers may be more difficult given the increased distance to providers.
- Accessing online and in-person musical groups will be more difficult given the lack of internet or remoteness of the area.
- The caregiving team will be expanded by being closer to their child.

In this example, we can see the external variables of internet access, geographic location, health care systems, society and aging demographics have positive and negative impacts on the triadic care relationship.

The ongoing challenge for public health is to understand the care partnerships that may be particularly vulnerable to these external factors and how they can negatively or positively impact each person. It is vital that research continue to identify and broaden our understanding of who dementia caregivers are, the risks and strengths of dementia caregiving and care partnerships, and the evidence-based supports and improvements that benefit everyone on the dementia care team.

### Discussion Questions

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1. What are some other external factors that may impact the triadic care relationship of Sherry, Steven and the professional care providers?
  - A. *Consumer choice may be more limited in a rural community.*
  - B. *Scientific discoveries that may impact treatments for Steven.*
  - C. *Advocacy/Membership Organizations may be more or less active in their new location.*
  - D. *Media portrayals may make it easier or harder for Sherry and Steven to talk about their journey with people in their lives.*
  - E. *Insurance industry that may make it easier or harder for Sherry and Steven to access and afford providers in their new area.*

2. How might these external factors vary for different people with different demographics? For example, think about people who are LGBTQ+ or people from diverse racial or ethnic backgrounds. What if Steven was providing care for Sherry living with dementia, or if Steven was living with Down syndrome and dementia and was being cared for by his sister? Now consider the scenario if someone were experiencing the intersectionality of multiple factors of these demographics.
  - A. *LGBTQ+: If Sherry and Steven are part of the LGBTQ+ community, they may encounter societal barriers when moving to a new area. Alternatively, if Sherry and Steven's child is part of the LGBTQ+ community and they do not understand or accept their child's identity, relationships may be strained as care needs progress.*
  - B. *Diverse racial or ethnic backgrounds: If Sherry or Steven are Black, they may experience discrimination from their health care provider, which could impact their care relationships and quality of care. Research has shown that support from family may result in better self-rated health for Black dementia caregivers, so if Sherry is Black she may experience better health while living near her children.*
  - C. *Steven caring for Sherry: Steven may have a harder time finding social support or media portrayals that he can identify with than if roles were reversed. As a male caregiver, he may have slightly lower levels of burden, depression, impaired mood and impaired health than if Sherry were caring for Steven.*
  - D. *Sherry (age 63) caring for her younger brother Steven (age 60) who is living with Down syndrome and dementia: Sherry may also be caring for her aging parents, while she and her brother are also aging. Sherry may also not have anticipated having to care for Steven while he was living with dementia so early in their lives. She had not planned to retire yet, but providing care for her parents and Steven is causing her to rethink her decision. She needs health insurance for her own health conditions and does not qualify for age-based Medicare until she turns 65. If she chooses to retire without health insurance, her own health and finances may be impacted, but if she chooses to continue working, she may quickly experience caregiver burnout from high levels of stress.*
  - E. *Diverse racial or ethnic backgrounds and LGBTQ+: If Sherry is Black and part of the LGBTQ+ community, she may find that people in her new local LGBTQ+ community are mostly White. From an alternate perspective, few Black people in her new community may be part of the LGBTQ+ community. She may experience unique forms of discrimination because of the intersection of her identities as a Black LGBTQ+ person, and caregiving research applicable to this identity may be limited.*
  
3. Why is it important to understand the triadic care relationship model when thinking about public health and dementia caregiving?
  - A. *It is important to understand that the dementia caregiver, care recipient and professional providers all interact with one another to ensure quality care and support for the person living with dementia and their caregiver. From a public health perspective, it is important to recognize the external factors which may be interacting with one another and impacting the population of dementia caregivers. These include aging demographics, scientific discoveries, advocacy/membership organizations, global disease burden, political factors, media portrayals, health care systems, insurance industry, society, internet access and consumer choice. Public health organizations can engage with these factors in different ways to better support dementia caregivers.*

### CASE STUDY

The following case study illustrates an approach that public health professionals can take to better understand and address dementia caregiver needs.

#### Strategies for Supporting Dementia Caregivers

Jesse works for a local public health department in the chronic disease branch. Jesse's county has a large population of people aged 65 years and older. The health department leadership wants to increase support for aging adults in the community. Jesse sees a need to support not only the people living with dementia, but their caregivers as well.

Jesse's supervisor asks them to come up with a plan to provide public health support for dementia caregivers.

Using the following framework as a guide, Jesse makes a plan:



- **Mobilize individuals and organizations**

The first step is to find key partners and involve community members, both those to be served and those who have a role in helping to address needs. For example:

- ▶ Engage the dementia care community (dementia caregivers, people living with dementia, health care and community organizations).
- ▶ Talk with health department colleagues and with community organizations that provide older adult care services (adult day care, respite care, transportation, etc.).
- ▶ Join or form a coalition with members from these organizations and dementia caregivers.
- ▶ Establish a shared vision on priorities for supporting dementia caregivers.

- **Assess needs and available resources**

Next, gather information on dementia caregiver needs and identify resources that already exist or will be needed. For example:

- ▶ Confirm what resources (financial, people, infrastructure) are available.
- ▶ Identify specific needs by communicating directly with dementia caregivers, documenting their experiences and health status, and gathering testimonials.
- ▶ Review available data from the Behavioral Risk Factor Surveillance System's (BRFSS) Caregiver module. Identify gaps in services in the community.
- ▶ Consider how the social determinants of health impact dementia caregivers' ability to access services.



- **Plan the approach: Vision and strategies**

Once information is gathered on needs and resources, develop an action plan. Steps include:

- ▶ Prioritize areas of need and strengths for dementia caregivers and design solutions.
- ▶ Utilize the [BOLD Public Health Center of Excellence on Dementia Caregiving](#) for evidence-based best practice caregiving programs and national caregiving resources.
- ▶ Identify additional partners or service organizations to be included in the planning and implementation.
- ▶ Explore best practices of dementia friendly communities for initiatives that support people with dementia and their caregivers.

- **Implement the plan: Action steps**

The next step is to work with the coalition and partners to roll out initiatives in the community. Actions could include:

- ▶ Launch initiatives to address service gaps.
- ▶ Provide dementia caregivers with information and training on topics such as care planning, caregiving skills, stress reduction and financial planning.
- ▶ Provide input on public health ordinances, policies and laws that impact dementia caregivers.
- ▶ Develop health-related awareness campaigns on caregiver health and available resources.
- ▶ Develop messaging for the community, including dementia caregivers, healthcare professionals, employers, service providers and religious communities.

- **Track the progress: Evaluate**

Tracking and evaluation is important in measuring success of the efforts and to build momentum for continued support. Examples include:

- ▶ Consider how to measure the impact of the strategies or initiatives to be implemented.
- ▶ Collect data on measures such as people served by programs, participation in educational offerings, increase in the number of services available.
- ▶ Talk with dementia caregivers about their use of services and the benefits. Get feedback on what additional supports may be needed or strengths that may have been overlooked.
- ▶ Use data to build visual messages demonstrating impact and share success stories.

## VIDEO RESOURCES

These are some of the videos used throughout the Public Health and Dementia Caregiving module. Consider playing them in your learning environment and using them for discussion or reflection among the learners. Suggested discussion questions are included below each video title/link.

### 1. [Katie Connects Emotionally With Her Husband](#)

- a. What impacted you about this video?
- b. What can we learn from Katie's story about reading stories with her husband and child?
- c. This video shares the experience of Katie finding ways to connect emotionally with her husband. Why is that important when working to advance public health support for dementia caregivers?
- d. What are ways this video could be used to support dementia caregivers in public health?

### 2. [Family Profile of José and His Wife](#)

- a. What impacted you about this video?
- b. Why do you think this module includes this video near the beginning?
- c. This video centers the story of José and his wife, as well as showing their larger family. Why is that important when working to advance public health support for dementia caregivers?
- d. What are ways this video could be used to support dementia caregivers in public health?

### 3. [Katie Connects With Her Dad](#)

- a. What impacted you about this video?
- b. What can we learn from Katie's story about celebrating her birthday with her dad?
- c. This video shares the experience of Katie setting social expectations for herself when interacting with her dad. Why is that important when working to advance public health support for dementia caregivers?
- d. What are ways this video could be used to support dementia caregivers in public health?

### 4. [Judith Connects With Her Mom](#)

- a. What impacted you about this video?
- b. What can we learn from Judith and her story about caring for her mom?
- c. This video features a dementia caregiver describing ways to connect with her parent. Why is that important when working to advance public health support for dementia caregivers?
- d. What are ways this video could be used to support dementia caregivers in public health?

### 5. Jim Hires Support for His Wife

- a. What impacted you about this video?
- b. What can we learn from Jim and his story about caring for his wife?
- c. This video shares the experience of Jim hiring outside help to support his wife. Why is that important when working to advance public health support for dementia caregivers?
- d. What are ways this video could be used to support dementia caregivers in public health?

### 6. Judith Hires In-Home Support for Her Mother

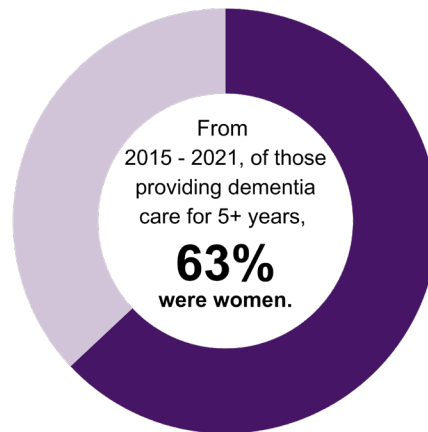
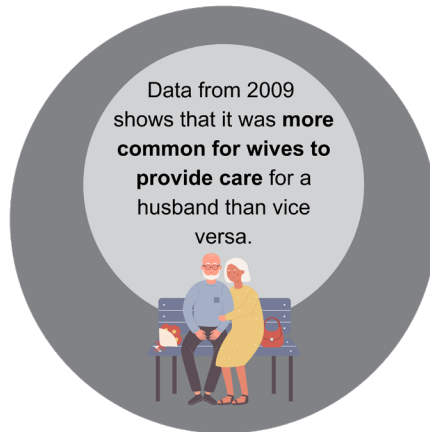
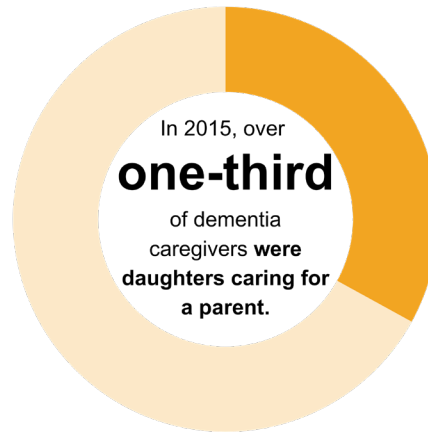
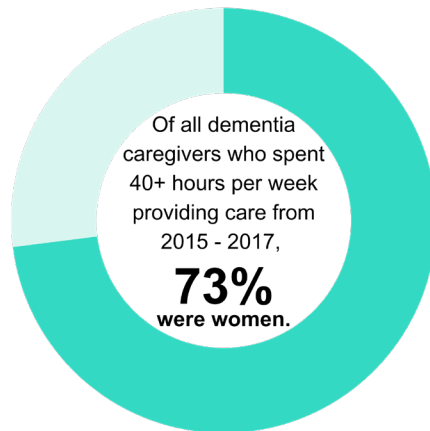
- a. What impacted you about this video?
- b. What can we learn from Judith's story about hiring in-home help for her mother?
- c. This video shares the experience of Judith and her sister deciding to hire additional in-home support for her mother. Why is that important when working to advance public health support for dementia caregivers?
- d. What are ways this video could be used to support dementia caregivers in public health?

### 7. Priscilla and Kaylin Talk About Their Mom's Gratitude

- a. What impacted you about this video?
- b. What can we learn from Priscilla and Kaylin's story about getting hugs from their mom?
- c. This video shares the experience of Priscilla and Kaylin and the positive interactions with their mom. Why is that important when working to advance public health support for dementia caregivers?
- d. What are ways this video could be used to support dementia caregivers in public health?

## GRAPHIC RESOURCES

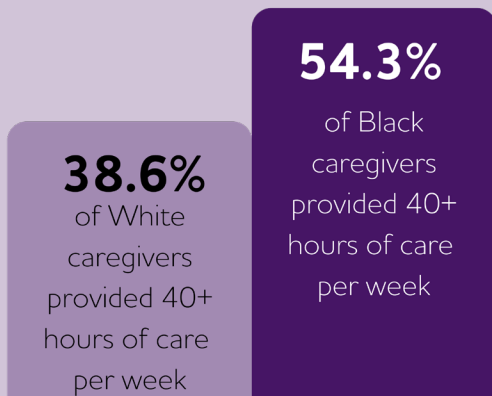
These are some of the graphics used in the module. They can be used as a basis for discussion or activities in your learning environment. Possible answers are shown in italics, where appropriate, but answers are not exhaustive or comprehensive. Graphics may be copied and inserted into a PowerPoint.



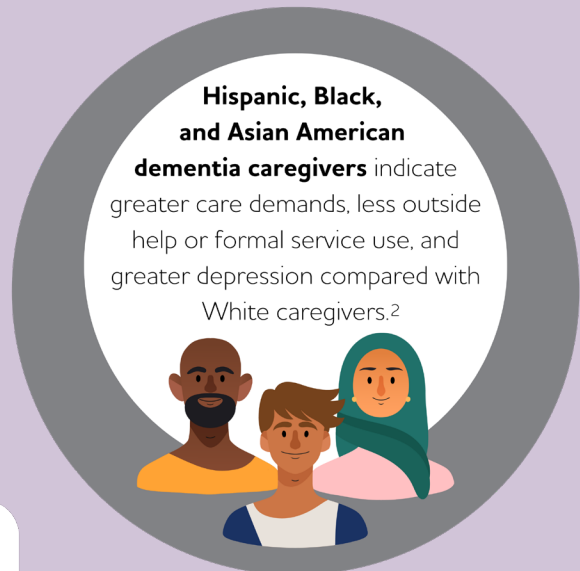
### Questions:

1. What is surprising to you about these graphics?
2. Summarize the meaning of these graphics in a few sentences.
  - a. *Women provide more full-time dementia care, for more years, and more often for their husbands than men provide for their wives. Daughters also provide a lot of dementia care for their parents and in-laws.*
3. Why are these graphics important for public health professionals addressing Alzheimer's disease and other dementias?
  - a. *Help illustrate the need for more support for women dementia caregivers. Women may experience slightly higher levels of burden, impaired mood, depression and impaired health than caregivers who are men.*

**Caregivers:** The graph below demonstrates the difference between Black caregivers and White caregivers who were providing full-time care in 2015.<sup>2</sup>



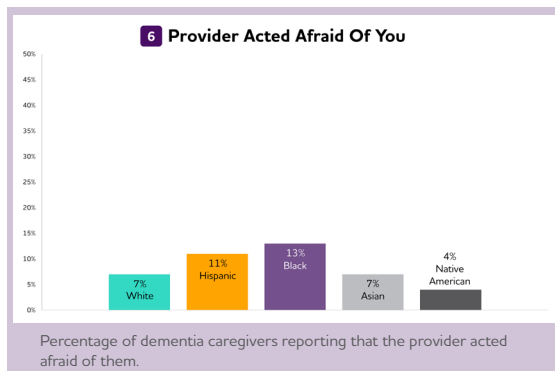
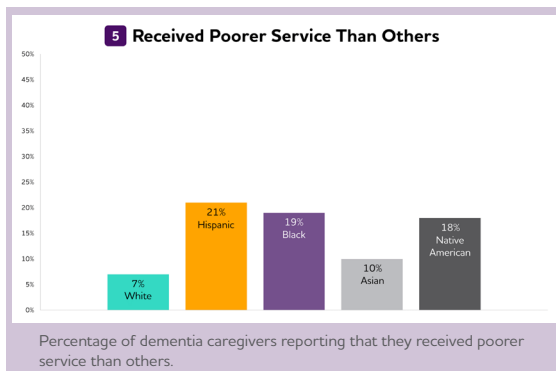
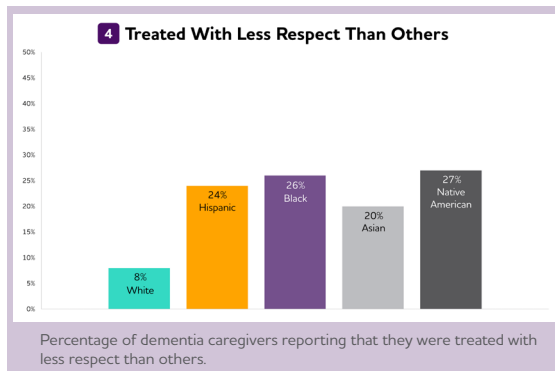
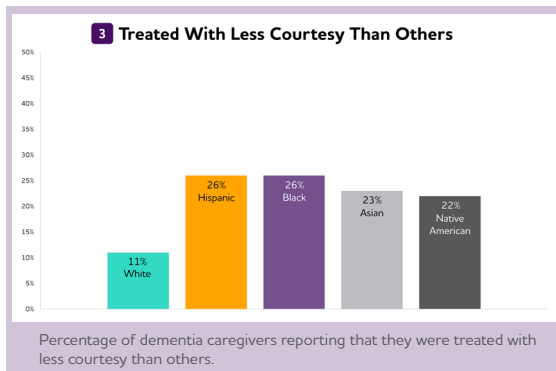
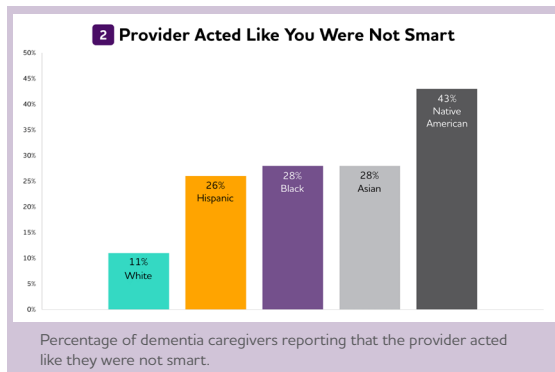
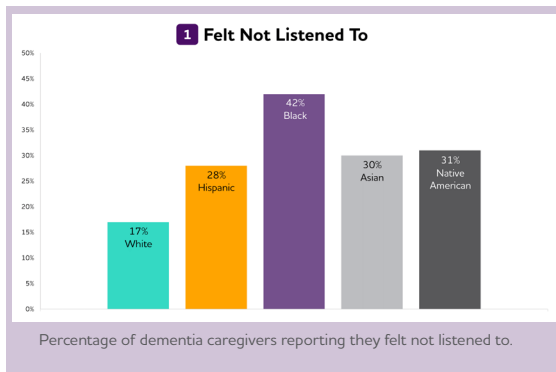
**Dementia Caregivers:** The figure below highlights the difference between Black caregivers and White caregivers who are caring for someone living with dementia.<sup>2</sup>



### Questions:

- What is surprising to you about these graphics?
- Summarize the meaning of these graphics in a few sentences.
  - There is a higher percentage of Black caregivers providing full time care than White caregivers.
  - Black caregivers are at least three times more likely to specifically provide dementia care compared to White caregivers.
  - Hispanic, Black and Asian American dementia caregivers report greater depression, less outside support, and greater care demands than White caregivers.
- Why are these graphics important for public health professionals addressing Alzheimer's disease and other dementias?
  - Illustrates the differences of dementia caregiving by racial and ethnic groups, indicating the need for increased and tailored resources and supports for diverse racial and ethnic groups.

## Types of Discrimination Based on Race or Ethnicity Among Alzheimer's and Dementia Caregivers



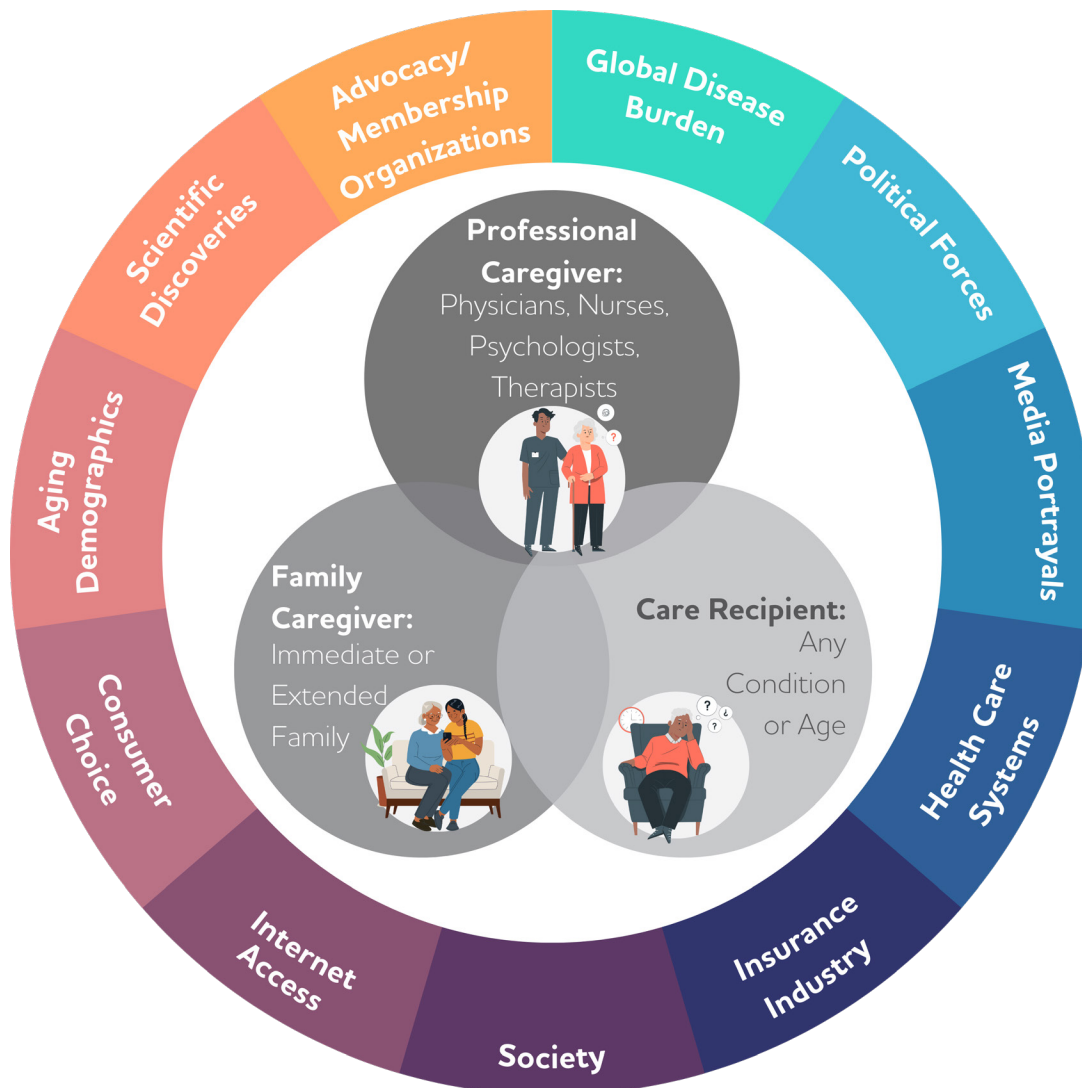
### Questions:

1. What is surprising to you about these graphics?
2. Summarize the meaning of these graphics in a few sentences.
  - a. Dementia caregivers who are Hispanic, Black, Asian, or Native American consistently report higher levels of discrimination in health care settings than dementia caregivers who are White.
3. Why are these graphs important for public health professionals addressing Alzheimer's disease and other dementias?
  - a. Discrimination in health care settings can deepen health inequities by resulting in poorer quality of care and more negative health outcomes for both the care recipient and dementia caregiver.



**Questions:**

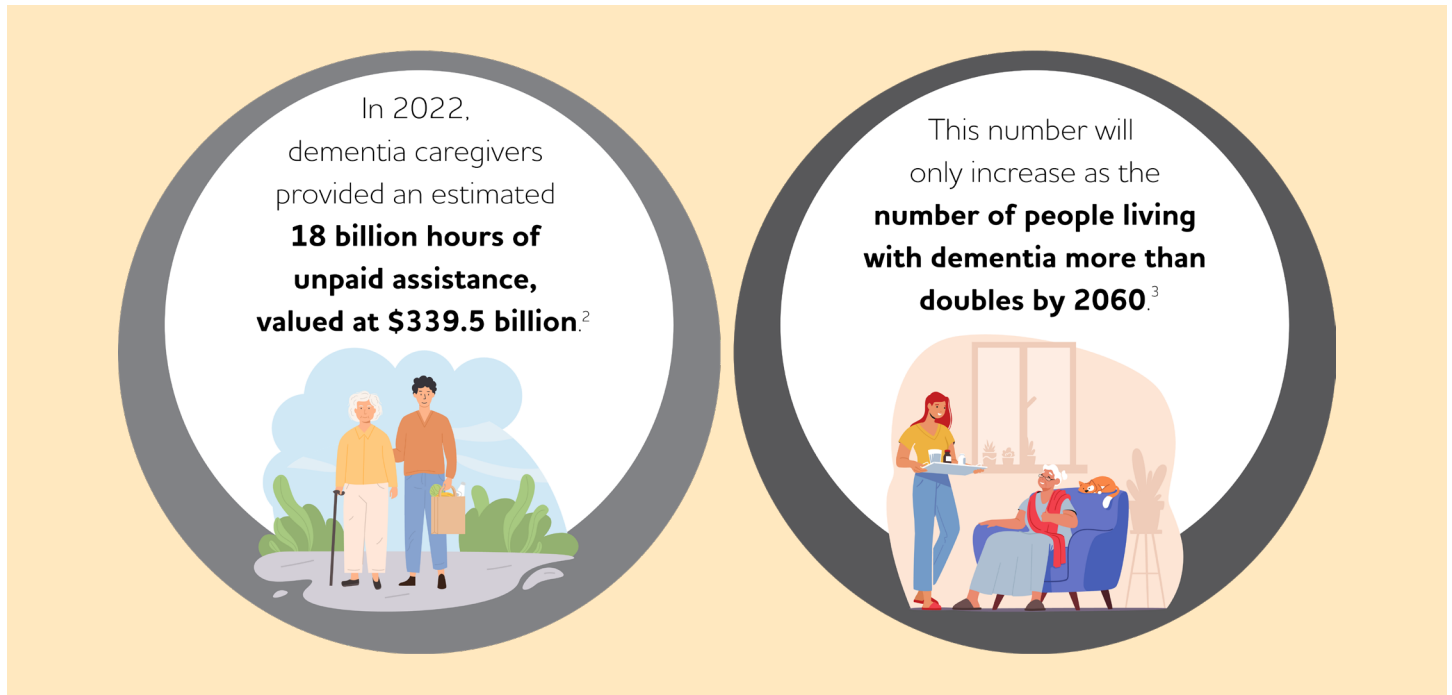
1. What is surprising to you about these graphics?
2. Summarize the meaning of these graphics in a few sentences.
  - a. *Dementia caregivers have a wide range of possible care roles.*
3. Why is this graphic important for public health professionals addressing Alzheimer’s disease and other dementias?
  - a. *Dementia caregivers provide care in many ways that go beyond just physical care.*
  - b. *All of these care roles require time, skill, and patience, and dementia caregivers often receive little formal training.*
  - c. *Many of these care roles exist in public spaces as well or require interaction and support from external resources.*
  - d. *Public health can positively impact many of the spaces in which dementia caregivers provide care to better support the dementia caregivers.*



**Questions:**

1. What is surprising to you about this graphic?
2. Summarize the meaning of this graphic in a few sentences.
  - a. *The triadic caregiving relationship includes the dementia caregiver, the care recipient, and the professional care provider. Their relationship is impacted by many external factors.*
3. Why is this graphic important for public health professionals addressing Alzheimer’s disease and other dementias?
  - a. *It is important to understand that the dementia caregiver, care recipient, and professional providers all interact with one another to ensure quality care and support for the person living with dementia and their caregiver. From a public health perspective, it is important to recognize the external factors which may be interacting with one another and impacting the population of dementia caregivers.*

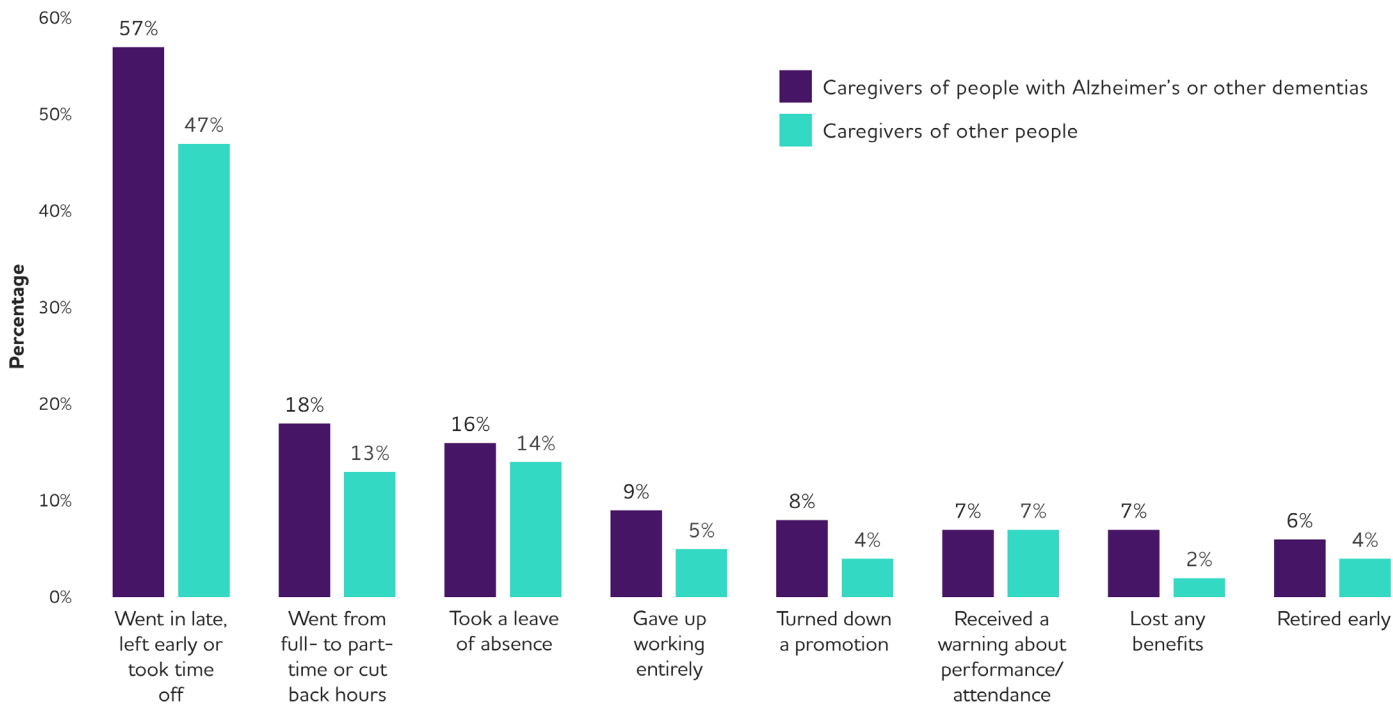




### Questions:

1. What is surprising to you about these graphics?
2. Summarize the meaning of these graphics in a few sentences.
  - a. *Dementia caregivers currently provide a large number of hours of care, and the need for care is only expected to increase.*
3. Why are these graphics important for public health professionals addressing Alzheimer's disease and other dementias?
  - a. *Dementia caregivers already make up a significant part of the population, and this number is only expected to grow. It is critical for public health to address and support the infrastructure and health needs of this growing portion of our population.*

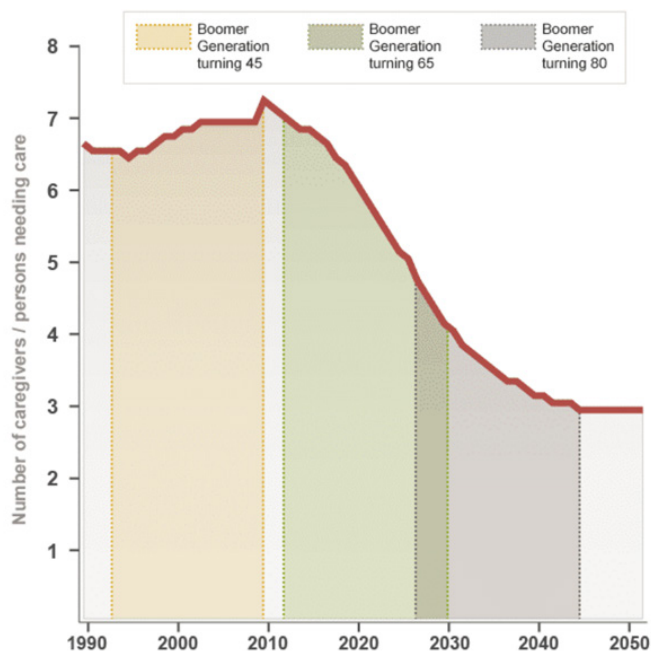
**Work-Related Changes Among Caregivers of People with Alzheimer’s or Other Dementias Who Had Been Employed at Any Time Since They Began Caregiving<sup>23</sup>**



**Questions:**

1. What is surprising to you about this graph?
2. Summarize the meaning of this graph in a few sentences.
  - a. Compared with non-dementia caregivers, dementia caregivers were more likely to go in late, leave early or take time off; reduce hours; take a leave of absence; give up working entirely; turn down a promotion; lose benefits; and retire early.
3. Why is this graph important for public health professionals addressing Alzheimer’s disease and other dementias?
  - a. This may have significant social and economic implications beyond just the financial stability of dementia caregivers.

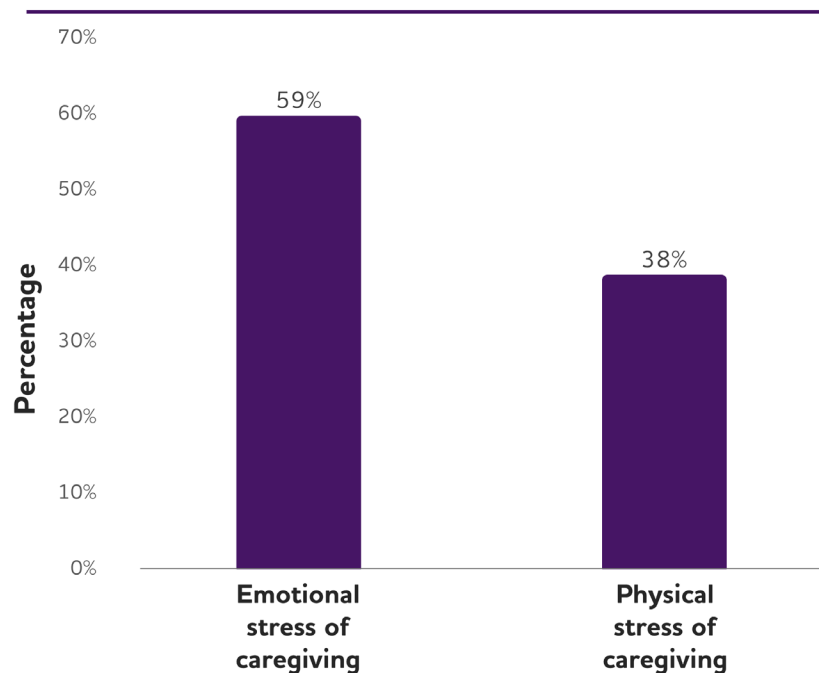
Caregiver Support Ratio



**Questions:**

1. What is surprising to you about this graph?
2. Summarize the meaning of this graph in a few sentences.
  - a. *At the same time that the need for dementia care and the support of a dementia care team continues to grow, there is expected to be a declining number of people available to provide care.*
3. Why is this graph important for public health professionals addressing Alzheimer’s disease and other dementias?
  - a. *The declining caregiver support ratio shown in the figure illustrates the growing need for public health interventions. This growing family care gap, as it is called, has many driving factors which public health professionals must understand as they work to support dementia caregivers.*

### Percentage of Caregivers Who Report High to Very High Stress Due to Caregiving<sup>2</sup>



#### Questions:

1. What is surprising to you about this graph?
2. Summarize the meaning of this graph in a few sentences.
  - a. Most caregivers report high levels of emotional stress due to caregiving and 38% also report high levels of physical stress due to caregiving.
3. Why is this graph important for public health professionals addressing Alzheimer’s disease and other dementias?
  - a. Too much stress can lead to burnout as well as other health impacts and increased use of health services for the care recipient. Stress in dementia caregivers must be addressed from a public health perspective to support the health and health systems of communities as a whole.

**Percentage of Dementia Caregivers Who Report Having a Chronic Health Condition Compared with Caregivers of People Without Dementia or Non-Caregivers**

Condition	Dementia Caregivers	Non-Dementia Caregivers	Non-Caregivers
Stroke	5.2	3.4	3.2
Coronary heart disease	8.3	7.2	6.6
Cardiovascular disease*	11.8	9.5	8.6
Diabetes	12.8	11.1	11.3
Cancer	14.3	13.3	11.5
Obesity	32.7	34.6	29.5

\* Combination of coronary heart disease and stroke.

Table includes caregivers age 18 and older.

Created from unpublished data from the 2015, 2016, 2017, 2020, and 2021 Behavioral Risk Factor Surveillance System survey, analyzed by and provided to the Alzheimer’s Association by the Alzheimer’s Disease and Healthy Aging Program (AD+HP), Centers for Disease Control and Prevention (CDC).

**Questions:**

1. What is surprising to you about this table?
2. Summarize the meaning of this table in a few sentences.
  - a. *There is a higher percentage of dementia caregivers reporting chronic health conditions, including stroke, coronary heart disease, cardiovascular disease, diabetes, cancer and obesity compared to non-dementia caregivers and non-caregivers.*
3. Why is this table important for public health professionals addressing Alzheimer’s disease and other dementias?
  - a. *Evidence suggests that the stress of providing dementia care increases caregivers’ susceptibility to disease and health complications. This table indicates the importance of providing support for health care and stress reduction for dementia caregivers, as providing care increases their risk of having chronic diseases.*

### Role of Public Health in Supporting Self-Care of Dementia Caregivers


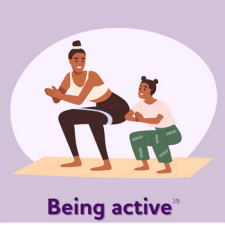


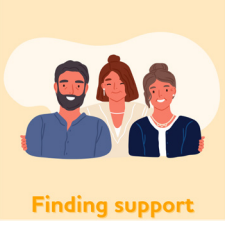
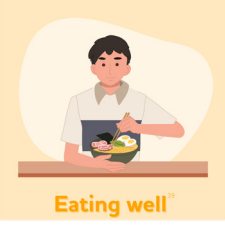
**Activity 1:** In groups, brainstorm as many actions as you can think of that may be important for dementia caregivers in maintaining their own self-care. As a class, go through the groups and share out brainstorm ideas. Record the ideas on the class whiteboard. Divide the ideas among the groups and have each group discuss ways public health can support those self-care actions. Have each group present back to the class.

**Activity 2:** Using the graphic organizer below, place the phrase from the Answer Bank with the corresponding image and description that identifies how public health can support dementia caregivers' self-care. (Note: This can also be done interactively as a class by using the flip cards in the module to name the role public health can play with each act of self-care and then discussing who public health organizations would need to work with in order to fulfill their role.)

#### Answer Bank

- Work with health care providers to identify caregivers and provide them with appropriate information and resources
- Improve the built environment by advocating for parks, sidewalks, bike paths or other amenities
- Ensure access to quality nutrition and nutrition education
- Support mental health resource access
- Support policies and resources for respite care
- Work with aging service providers to conduct outreach and coordinate with community partners

## GRAPHIC RESOURCES [CONTINUED]

Image	Self-Care Activity	Role of Public Health
 <p>Coping with stress™</p>	Coping with stress	<i>Support mental health resource access</i>
 <p>Being active™</p>	Being active	<i>Improve the built environment by advocating for parks, sidewalks, bike paths or other amenities</i>
 <p>Taking a break™</p>	Taking a break	<i>Support policies and resources for respite care</i>
 <p>Seeing their doctor™</p>	Seeing their doctor	<i>Work with health care providers to identify caregivers and provide them with appropriate information and resources</i>
 <p>Finding support™</p>	Finding support	<i>Work with aging service providers to conduct outreach and coordinate with community partners</i>
 <p>Eating well™</p>	Eating well	<i>Ensure access to quality nutrition and nutrition education</i>



### Questions:

1. What is surprising to you about this graph?
2. Summarize the meaning of this graph in a few sentences.
  - a. *There are many different kinds of evidence-based supports for dementia caregivers.*
3. Why is this graphic important for public health professionals addressing Alzheimer's disease and other dementias?
  - a. *It is important for public health organizations to recognize and utilize different kinds of evidence-based supports to implement successful interventions that support dementia caregivers.*



## ADDITIONAL READINGS AND RESOURCES

### Stay Informed

- [Sign up](#) for the Alzheimer's Association Public Health eNews
- [Sign up](#) for CDC's Healthy Aging for Older Adults Newsletter
- [Visit](#) the Public Health Center of Excellence on Dementia Caregiving's website

### Research your state

Find caregiver data and learn about public health actions and initiatives [in your state](#). Share what you learn with others.

- See if your [state has a dementia plan](#) and whether caregiver support is included as a focus

### Identify partnership and collaboration opportunities with community organizations

Consider a variety of organizations, such as:

- Volunteer organizations
- Faith communities
- Art organizations
- Educational organizations

### Learn more about policies and programs that support caregivers

Some examples include:

- [The RAISE Family Caregiving Advisory Council](#)
- [The Caregiver Advise Record and Enable \(CARE\) Act](#)
- [The Older Americans Act](#)
- [The GUIDE model](#)
- Paid family leave laws

### Monitor policy

Monitor policies and actions that will impact dementia caregivers, including the refinancing of long-term services and supports and changes to training and payment models.

- [National Association of Chronic Disease Directors Legislative Tracking](#)
- [AARP Public Policy Institute: Long-Term Services and Supports and Family Caregiving](#)
- [National Alliance for Caregiving Policy Initiatives](#)
- [Family Caregiving Alliance: Caregiving Policy Digest eNewsletter](#)
- [Leading Age: Advocacy Efforts](#)
- Locally:
  - Your local state legislative database
  - The branch of government that oversees Long-Term Care in your state
  - Your Long-Term Care Council

### **Learn about ways you can support people living with dementia and their caregivers**

Learn about ways to support them in [different everyday scenarios](#) developed by the International Association for Indigenous Aging using the [Dementia Friends](#) model. While this interaction is built for use by American Indian and Alaska Native communities, it is relevant to many communities.

### **Expand your learning by volunteering or getting involved with local organizations**

If you're not in a place to implement these strategies directly in your work, volunteering with community partners will continue your learning and give you a unique perspective to bring to your future work.

- Find [community partners](#) in your area, including your local Area Agency on Aging or state office of aging services
- Search for your [local chapter](#) of the Alzheimer's Association
- Volunteer or work with a community to build a [Dementia Friendly Community](#)
- Get involved in or help your university become an [Age Friendly University](#)
- Join a student organization of your university or college's center on aging, your state gerontology society or the national [Gerontological Society of America](#)

### RESOURCES

#### CDC Resources

- [CDC Caring for Yourself When Caring for Another](#)
- [CDC Care Planning Tool](#)

#### Alzheimer's Association Resources

- [Alzheimer's Association Be a Healthy Caregiver](#)
- [Alzheimer's Association Facts and Figures 2023](#)
- [Facts and Figures Special Report 2021: Race, Ethnicity, and Alzheimer's in America](#)
- [Health Equity in Dementia — Using a Public Health Lens to Advance Health Equity in Alzheimer's and Other Dementias](#)

#### Public Health Center of Excellence on Dementia Caregiving Resources

- [BOLD Public Health Center of Excellence on Dementia Caregiving Resource Library](#)
  - [Public Health Strategies in Dementia Caregiving: A Toolkit for Public Health Agencies](#)
- [I am a Caregiver](#)

#### Other

- [A Practical Guide: Communicating Brain Health Messages with Latino and African American Communities](#)
- [Alzheimer's Disease and Down Syndrome: A Practical Guidebook for Caregivers](#)
- [Alzheimer's Disease and Down Syndrome Overview](#)
- [Best Practice Caregiving](#)
- [Diverse Elders Training](#)
- International Association for Indigenous Aging (IA2)
  - [Dementia Friends](#) for American Indian and Alaska Native Communities
  - [Brain Health Resource Library](#)
- [National Alliance for Caregiving: Chronic Disease Caregiving Through a Public Health Lens](#)
- [National Task Group on Intellectual Disabilities and Dementia Practices](#)
- National Alzheimer's and Dementia Resource Center [Guide to Billing Codes for Dementia Services](#)
- [National Center on Elder Abuse](#)
- [Title VI](#) Serving Tribal Elders Across the United States

#### Funding Statement

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## APPENDIX A: SAMPLE TEST QUESTIONS

1. What is a “Sandwich” caregiver?
  - A. A caregiver feeling pressure from working while providing care
  - B. A caregiver caring for an aging parent as well as a child under 18
  - C. A caregiver caring for multiple aging parents
  - D. A caregiver struggling with their own health issues as well as caring for someone else
2. True or False: Dementia caregivers often say that love and a sense of duty and obligation are what motivates them to take on care responsibilities for a relative or friend.
3. Dementia caregivers
  - A. provide care for the health needs and well-being of a person living with Alzheimer’s disease or other dementias.
  - B. are 2 million of the 48 million caregivers living in America.
  - C. experience much lower emotional stress, health problems and financial challenges compared to other caregivers.
4. Which of the following groups are disproportionately affected by dementia caregiving?
  - A. LGBTQ+
  - B. Women
  - C. Diverse racial or ethnic groups
  - D. Parents and siblings of people with intellectual and developmental disabilities
  - E. All of the above
5. A dementia care team can include: (Select all that apply)
  - A. Family members, living close by or far away
  - B. Friends, neighbors or others who may help with day-to-day tasks
  - C. Medical providers
  - D. Counselors, care managers or in-home care support
  - E. Policymakers
6. Which of the following activities or tasks might a dementia caregiver be responsible for?
  - A. Advocating for the care recipient
  - B. Supporting care recipients with activities of daily living
  - C. Planning for end-of-life care
  - D. Participating in medical appointments and navigating health care systems.
  - E. Finding and using support services like support groups or adult day services.
  - F. All of the above

## APPENDIX A: SAMPLE TEST QUESTIONS [CONTINUED]

7. True or False: The three people in the triadic model of caregiving are the doctor, social worker and physical therapist.
8. What is the best definition of the family care gap?
  - A. The lack of resources existing for family caregivers
  - B. The communication breakdown that occurs between family members providing care
  - C. The growing gap between the number of caregivers available and the increasing number of care recipients
  - D. Counselors, care managers or in-home care support
  - E. Policymakers
9. What is driving the family care gap?
  - A. People are spending a longer time in the workforce
  - B. The incoming excess of people working in geriatric care
  - C. Men being more likely to participate in the workforce
10. All of the below illustrate why dementia caregiving should be a public health priority, except:
  - A. Financial impact of and decreasing demand for dementia caregiving
  - B. Social and economic implications for dementia caregivers, including cost of care and impact on workplace productivity
  - C. Growing family care gap, where there will be fewer caregivers and more people
11. True or False: Caregivers rarely report positive feelings about caregiving.
12. Possible health implications for dementia caregivers include:
  - A. Too much stress leading to burnout
  - B. Increased likelihood of experiencing depression and anxiety
  - C. Increased risk of developing chronic conditions
  - D. Positive feelings about caregiving, such as family togetherness and the satisfaction of helping others
  - E. All of the above
13. True or False: Older adults with Alzheimer's disease and other types of dementia are more likely to be hospitalized than older adults without dementia.

## APPENDIX A: SAMPLE TEST QUESTIONS [CONTINUED]

14. Some acts of self-care for a dementia caregiver may include all of the following except:

- A. Being physically active
- B. Eating well
- C. Seeing the doctor
- D. Delaying respite care
- E. Finding strategies to cope with stress

15. Use the words from the word bank to fill in the statements below regarding the types and focus of caregiver interventions.

### WORD BANK:

**Care management • Counseling • Multicomponent approaches • Respite • Support groups**

- A. \_\_\_\_\_ provides planned, temporary relief for the caregiver.
- B. \_\_\_\_\_ aims to resolve pre-existing personal problems that complicate caregiving.
- C. \_\_\_\_\_ provide caregivers the opportunity to share personal feelings, concerns, and overcome feelings of isolation by connecting with peers.
- D. \_\_\_\_\_ provides assessment, information, planning, referral, care coordination and/or advocacy for the person living with dementia and support for caregivers.
- E. \_\_\_\_\_ combine several forms of interventions into a single, long-term service.

16. Public health actions that can be taken to support dementia caregivers include:  
(Select all that apply)

- A. Measuring the number of dementia caregivers
- B. Educating dementia caregivers about health risks they might face
- C. Supporting community meetings and activities related to health advocacy
- D. Steering clear of partnerships to ensure clear public health delineation
- E. Providing input on public health policies that impact dementia caregivers

17. What are possible next steps to learn more or get involved in supporting dementia caregivers?

- A. Sign up for CDC's Healthy Aging for Older Adults newsletter
- B. Volunteer with community partners in your area
- C. Find caregiver data in your state and share what you learn with others
- D. Learn more about policies that support caregivers
- E. All of the above