

# A PUBLIC HEALTH APPROACH TO ALZHEIMER'S AND OTHER DEMENTIAS



alzheimer's   
association®

  
CENTERS FOR DISEASE™  
CONTROL AND PREVENTION



EMORY  
ROLLINS  
SCHOOL OF  
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HEALTH

Emory Centers  
for Training and  
Technical Assistance

REVISED 2019

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## ABOUT THE CURRICULUM

*A Public Health Approach to Alzheimer's and Other Dementias* is an introductory curriculum from the Alzheimer's Association that is intended to increase awareness of the impact of Alzheimer's and other dementias as well as the role of public health. Developed as part of a cooperative agreement with the Centers for Disease Control and Prevention's Alzheimer's Disease and Healthy Aging Program, and in partnership with Emory University's Rollins School of Public Health, this curriculum addresses cognitive health, cognitive impairment, and Alzheimer's disease and is for use by undergraduate faculty in schools and programs of public health. It can also be adapted for other purposes. This work supports *The Healthy Brain Initiative: The Public Health Road Map for State and National Partnerships* (Road Map) goal of developing a competent workforce. The curriculum has four modules that are designed to be used individually or as a whole.

The following materials are provided for each module:

- **Faculty Guide**, including:
  - Learning objectives
  - Competencies
  - Discussion questions
  - Learning activities
  - Slide guide with talking points
  - Sample test questions
  - Case studies
  - Video resources
  - References
- **PowerPoint slides**
- **Novel Approaches for Implementing the Curriculum**

## ABOUT EACH MODULE

### ALZHEIMER'S DISEASE – A PUBLIC HEALTH CRISIS (MODULE 1)

**Module 1: Alzheimer's Disease – A Public Health Crisis** frames Alzheimer's disease and dementia as a public health epidemic with a large and rapidly growing burden that has a significant impact on the nation. Alzheimer's disease is felt at a **national, state, and local** level through **financial burdens, resource needs, and professional requirements**.

Module 1 focuses primarily on the U.S. as it explores the current and projected scope of the epidemic, the financial burden on federal and state governments as well as individuals, and the care burden on caregivers and the health care system. Health disparities are highlighted, as rates of Alzheimer's disease are substantially higher for African-Americans and Hispanics.

### ***Learning Objectives:***

At the end of **Module 1: Alzheimer's and Dementia – A Public Health Crisis**, students will be able to:

- Provide a general description of dementia and Alzheimer's disease
- Explain the current and projected scope of the Alzheimer's disease epidemic
- Discuss the cost burden of Alzheimer's disease for federal/state governments and individuals/caregivers
- Describe the care burden of Alzheimer's disease, including caregivers and the health care system
- Identify health disparities related to Alzheimer's and dementia
- Explain why public health must play a role in addressing the Alzheimer's disease epidemic

## **ALZHEIMER'S AND OTHER DEMENTIAS – THE BASICS (MODULE 2)**

**Module 2: Alzheimer's and Other Dementias – The Basics** provides background information on Alzheimer's disease and other dementias. It lays a foundation for what cognitive health is and how changes within the brain may lead to cognitive aging, cognitive impairment, and Alzheimer's disease and other dementias.

The module then shifts to focus more specifically on Alzheimer's disease. Learners gain a general understanding about the stages of Alzheimer's disease, risk factors, and how the disease is diagnosed and treated. The module also addresses unique aspects of Alzheimer's disease (including financial hardship, stigma, and vulnerability to abuse) and the role of caregivers and caregiving impacts.

### ***Learning Objectives:***

At the end of **Module 2: Alzheimer's and Other Dementias – The Basics**, students will be able to:

- Define cognitive health
- Define and differentiate between dementia and Alzheimer's
- List at least five early signs of Alzheimer's
- Describe the changes that occur during the course of Alzheimer's disease
- Describe the role of caregivers in the care of someone with Alzheimer's

## WHAT IS THE ROLE OF PUBLIC HEALTH? (MODULE 3)

**Module 3: What is the Role of Public Health?** briefly describes the Alzheimer's disease epidemic in the U.S., followed by a discussion of four tools of public health that may play significant roles in mitigating the Alzheimer's disease crisis.

The four public health intervention tools discussed are:

1. Surveillance/monitoring
2. Primary prevention
3. Early detection and diagnosis
4. Ensuring safety and quality of care

Each tool is described and applied to the context of a public health response to Alzheimer's disease and dementia. Progress to date and challenges associated with each tool are addressed.

### **Learning Objectives:**

At the end of **Module 3: What is the Role of Public Health?** students will be able to:

- List four key tools public health can apply to the Alzheimer's epidemic
- Describe surveillance/monitoring and how public health practitioners can apply it in response to Alzheimer's disease
- Name the two Behavioral Risk Factor Surveillance System (BRFSS) modules that pertain to cognitive decline and caregiving
- Describe primary prevention and how public health practitioners may apply it in response to Alzheimer's disease
- Explain why it is important to promote early detection of Alzheimer's disease
- Summarize one workforce challenge that affects the safety and quality of care for people living with dementia

## DEMENTIA CAPABLE SYSTEMS AND DEMENTIA FRIENDLY COMMUNITIES (MODULE 4)

**Module 4: Dementia Capable Systems and Dementia Friendly Communities** addresses the public health response to the Alzheimer's disease epidemic at the state and community levels. The module describes the concepts of "dementia capable" systems and dementia friendly communities, both of which involve accommodating the needs of a population with memory loss, and a variety of related **physical, cognitive, and behavior** symptoms, as well as other **co-morbidities**.

Module 4 explores how public health may support the development of such systems at the state and local levels through support services and programs, workforce training, and the creation of dementia friendly communities.

### ***Learning Objectives:***

At the end of **Module 4: Dementia Capable Systems and Dementia Friendly Communities**, students will be able to:

- Define dementia capable systems and dementia friendly communities
- Explain how public health can contribute to the development of dementia capable systems by analyzing community-support needs, developing support services and programs, and establishing workforce training, and also to the creation of dementia friendly communities
- List at least two support services that may benefit a caregiver of someone with Alzheimer's or dementia
- Identify at least three professions that would benefit from workforce training related to Alzheimer's and dementia
- Describe at least two components of a dementia friendly community

## **HOW TO USE THE MATERIALS**

- ✓ The four modules were designed for use either as a set or as stand-alone modules.
- ✓ Users are free to make changes to the materials to fit their needs, including: adding, modifying or removing content, graphics, talking points, discussion questions, or learning activities.
- ✓ The Faculty Guide for each module includes a slide guide that contains the information as presented in the slide, talking points, space for presenter notes, and references.
- ✓ The talking points included in the Faculty Guide should not be read word for word; each presenter should review the materials before delivering the material to ensure familiarity and deliver the information in his/her own style.
- ✓ Delivery time will generally be 60-90 minutes per module, depending on class engagement, presenter style, and the addition or elimination of any content, discussion questions, or learning activities.
- ✓ Discussion questions are included in the slide deck of each module. These may be modified or removed at the discretion of the presenter. Questions may also be used for other activities such as small group discussion or individual writing assignments.
- ✓ Video resources, a list of articles, and case studies are also included to help in learning more about the topics presented in each module.
- ✓ Test questions are provided with each module as an additional resource for faculty.

- ✓ All materials are 508 compliant. (Note: if changes are made to the curriculum, 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/making-files-accessible/index.html>)

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This curriculum was initially developed in 2015 as the result of guidance and expertise from the following advisory committee members:

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## **ABOUT THE COVER**

The cover illustration created by **Sophie Banspach, BS**, depicts the growing prevalence of Alzheimer's in the United States, showing differences across age and race on a stylized linear plane.

## **DISCLAIMER**

This curriculum is supported by Cooperative Agreement #5 NU58DP006115, funded by the Centers for Disease Control and Prevention. The findings and conclusions in this curriculum are those of the Alzheimer's Association and do not necessarily represent the official views of the CDC, the U.S. Department of Health and Human Services, or the advisory committee members or their affiliated organizations.

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# FACULTY GUIDE

Module 1: Alzheimer's Disease – A Public Health Crisis

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Alzheimer's Association and the Centers for Disease Control and Prevention

## ABOUT MODULE 1

This module is part of the Alzheimer's Association curriculum, *A Public Health Approach to Alzheimer's and Other Dementias*. Developed as part of a cooperative agreement with CDC's Healthy Aging Program, and in partnership with Emory University's Rollins School of Public Health, this curriculum addresses cognitive health, cognitive impairment, and Alzheimer's disease and is for use by undergraduate faculty in schools and programs of public health and other related disciplines. It can also be adapted for other purposes.

**Module 1: Alzheimer's Disease – A Public Health Crisis.** This module frames Alzheimer's and dementia as a public health epidemic with a large and rapidly growing burden that has a significant impact on the nation. The impact of Alzheimer's disease is felt at a national, state, and local level – as well as on a family and personal level – through financial burdens, resource needs, and professional requirements.

Module 1 focuses primarily on the United States as it explores the current and projected scope of the epidemic, the financial burden on federal and state governments as well as individuals, and the care burden on caregivers and the health care system. Health disparities are highlighted, as rates of Alzheimer's disease are substantially higher for African-Americans and Hispanics.

**Module 1 covers the following topics:**

- Scope of the epidemic
- Financial burden
- Care burden
- Public health approach

## LEARNING OBJECTIVES

At the end of **Module 1: Alzheimer's Disease – A Public Health Crisis**, students will be able to:

- Provide a general description of dementia and Alzheimer's disease
- Explain the current and projected scope of the Alzheimer's disease epidemic
- Discuss the cost burden of Alzheimer's disease for federal/state governments and individuals/caregivers
- Describe the care burden of Alzheimer's disease, including caregivers and the health care system
- Identify health disparities related to Alzheimer's and dementia

- Explain why public health must play a role in addressing the Alzheimer’s disease epidemic

## **COMPETENCIES**

Module 1 promotes basic learning that supports the development of certain competencies:

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

- 1.3.3 Demonstrate knowledge of signs, symptoms, and impact of common cognitive and mental health problems in late life (e.g., dementia, depression, grief, anxiety)

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

- 2. Locate, use, evaluate, and synthesize public health information (bachelors level)
- 4. Interpret results of data analysis for public health research, policy, or practice (masters-level)

### **Council on Linkages Between Academia and Public Health Practice:**

- 2A5. Identifies current trends (e.g., health, fiscal, social, political, environmental) affecting the health of a community

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## LAYOUT OF MODULE 1 FACULTY GUIDE

This guide is laid out in the following sections:

1. Slide guide with talking points
2. Sample test questions
3. Case studies
4. Video resources

*Note: Some slides in this module duplicate content from other modules and may be removed as needed.*

### HOW TO USE THE MATERIALS

- ✓ This module is one of four modules in this curriculum that were designed for use either as a set or as stand-alone modules
- ✓ Users are free to make changes to the materials to fit their needs, including: adding, modifying, or removing content, graphics, talking points, discussion questions, or learning activities
- ✓ The Faculty Guide for each module includes a slide guide that contains the information as presented in the slide, talking points, space for presenter notes, and references
- ✓ The talking points included in the Faculty Guide should not be read word for word; each presenter should review the materials before delivering the material to ensure familiarity and deliver the information in his/her own style
- ✓ Delivery time will generally be 60-90 minutes per module, depending on class engagement, presenter style, and the addition or elimination of any content, discussion questions, or learning activities
- ✓ Discussion questions are included in the slide deck of each module. These may be modified or removed at the discretion of the presenter. Questions may also be used for other activities such as small group discussion or individual writing assignments
- ✓ Video resources, a list of articles, and case studies are also included to help in learning more about the topics presented in each module
- ✓ Test questions are provided with each module as an additional resource for faculty.
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## STUDENT ENGAGEMENT OPTIONS

In addition to the PowerPoint slide deck and guide, there are additional resources included in this guide. These resources are designed to increase student engagement and enhance understanding of the concepts covered in this module. Following the slide guide, there is a series of case studies and a list of video resources. It is recommended that the presenter review these resources to determine if these additional materials would be useful in illustrating the concepts covered in the module.

## DISCUSSION QUESTIONS

The following discussion questions are included in the slide deck:

- What are Medicare and Medicaid? (*Slide 15*)
- What might be the roles and responsibilities of a caregiver for someone with Alzheimer's disease? (*Slide 22*)

## LEARNING ACTIVITIES

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

- Washington University in St. Louis. (n.d). Alzheimer's Disease Knowledge Scale (ADKS). This scale contains 30 true or false items to assess knowledge about Alzheimer's disease. It takes approximately 5-10 minutes to complete. Questions address risk factors, assessment and diagnosis, symptoms, course, life impact, caregiving, and treatment management.  
<https://pages.wustl.edu/geropsychology/adks>
- Compare the Alzheimer's epidemic to at least one other chronic disease (e.g., cancer, HIV, heart disease, diabetes). How many people are affected? What are the costs associated with the disease? How does the epidemic compare to Alzheimer's disease?
- Research aging trends within the population. What is happening in the U.S. and internationally? In developing vs. developed countries? What challenges does an aging population present to public health?
- How does caregiving for Alzheimer's and dementia differ from other types of caregiving? What resources are available for caregivers in general? What resources are available for caregiving specific to Alzheimer's and other dementias?
- Review the Healthy Brain Initiative's 25 road map actions for addressing Alzheimer's and dementia. Select 1—2 road map actions and discuss what impact they could have on risk reduction, quality of care, disparities, workforce, or caregivers. <https://www.cdc.gov/aging/healthybrain/roadmap.htm>

## ADDITIONAL READING

- Alzheimer's Association. (2019). 2019 Alzheimer's Disease Facts and Figures. Chicago, IL: Alzheimer's Association. <http://www.alz.org/facts>
- Alzheimer's Association and Centers for Disease Control and Prevention. *Healthy Brain Initiative, State and Local Public Health Partnerships to Address Dementia: The 2018-2023 Road Map*. Chicago, IL: Alzheimer's Association; 2018
- Alzheimer's Association. (2019). 2019 Alzheimer's Disease Facts and Figures. Chicago, IL: Alzheimer's Association. <https://www.alz.org/alzheimers-dementia/facts-figures>
- Olivari BS, Baumgart M, Lock SL, et al. CDC Grand Rounds: Promoting Well-Being and Independence in Older Adults. *MMWR Morb Mortal Wkly Rep* 2018; 67:1036–1039. DOI: <http://dx.doi.org/10.15585/mmwr.mm6737a4>

## SLIDE GUIDE

This slide guide accompanies the PowerPoint presentation for this module. The right margin has been widened to allow the presenter to write notes.

### SLIDE 1:

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#### Module 1: Alzheimer's Disease – A Public Health Crisis

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#### TALKING POINTS:

This presentation entitled **Alzheimer's Disease – A Public Health Crisis**, is part of a curriculum for public health students entitled, *A Public Health Approach to Alzheimer's and Other Dementias*. It was developed by the Emory Centers for Training and Technical Assistance for the Alzheimer's Association with funding from the Centers for Disease Control and Prevention.

During this module, we will discuss the epidemic of Alzheimer's and other dementias, and why it is an important issue for public health to understand and act on.

## SLIDE 2:

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### Learning Objectives

- Provide a general description of dementia and Alzheimer's disease
- Explain the current and projected scope of the epidemic
- Discuss the cost burden of Alzheimer's for federal/state governments and individuals/caregivers
- Describe the care burden of Alzheimer's, including caregivers and the health care system
- Identify health disparities related to Alzheimer's and other dementias
- Explain why public health must play a role in addressing the Alzheimer's epidemic

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### TALKING POINTS:

By the end of the presentation, you will be able to:

- Provide a general description of dementia and Alzheimer's disease
- Explain the current and projected scope of the epidemic
- Discuss the cost burden of Alzheimer's for federal/state governments and individuals/caregivers
- Describe the care burden of Alzheimer's, including caregivers and the health care system
- Identify health disparities related to Alzheimer's and other dementias
- Explain why public health must play a role in addressing the Alzheimer's epidemic

## SLIDE 3:

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### Alzheimer's – Public Health Crisis<sup>1</sup>

- Historically viewed as aging or medical issue
  - Impact at national, state, and local levels
  - Multi-faceted approach needed
- 

#### TALKING POINTS:

For many years after its discovery in 1906, Alzheimer's disease was primarily viewed through the lenses of **medical care** and **aging**.

There are valid reasons for this. **Medical care** is an essential component of identifying and treating individuals with Alzheimer's disease, which primarily affects **older populations**. **Aging services**, such as nursing homes and programs aimed at assisting seniors, are often a vital source of support for people with Alzheimer's and other dementias.

Yet Alzheimer's disease affects more than just the individual and his or her medical and support team.

The impact of Alzheimer's is felt at **national, state, and local** levels, as well as on a family and personal level, through **financial burdens, resource needs, and professional requirements**. It is a growing epidemic that has profound social and economic implications, especially given the current trends of an aging population.

As more is learned about Alzheimer's disease and its impact, it becomes clear that a multi-faceted response by the health care sector, government, public health and within communities is vitally important to address the growing crisis within the U.S. and throughout the world.

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<sup>1</sup> Alzheimer's Association and Centers for Disease Control and Prevention. *Healthy Brain Initiative, State and Local Public Health Partnerships to Address Dementia: The 2018-2023 Road Map*. Chicago, IL: Alzheimer's Association; 2018

*Image source:* Pixabay.com

## SLIDE 4:

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### What is Dementia?<sup>2,3</sup>

- General term for decline in cognitive function severe enough to interfere with daily life
  - Affects memory, thinking ability, social ability
  - Many dementias are progressive
- 

### TALKING POINTS:

It is first important to understand what characterizes dementia.

**Dementia** is a general term for a decline in cognitive functioning—that is, thinking, remembering, and reasoning severe enough to interfere with daily life.

Dementia is not a specific disease. It is an **overall term** that describes a wide range of symptoms associated with a decline in memory or other thinking skills. Dementia is characterized by damage to the brain cells due to age, brain injury, other conditions or diseases, heredity, or a combination of factors.

Many dementias are **progressive**, meaning that symptoms start out slowly and gradually get worse. In the most severe stages of dementia, a person must depend on others for basic activities of daily life.

The causes of dementia can vary, depending on the types of brain changes that may be taking place. Alzheimer's disease is the most common cause of dementia in older adults. Other dementias include Lewy body dementia, frontotemporal disorders, and vascular dementia. It is common for people to have mixed dementia—a combination of two or more types of dementia.

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<sup>2</sup> Alzheimer's Association. (n.d.) *What is Dementia?* Retrieved from <https://www.alz.org/alzheimers-dementia/what-is-dementia#causes>

<sup>3</sup> National Institute on Aging. (2017) *What is Dementia?* Retrieved from <https://www.nia.nih.gov/health/what-dementia>

## SLIDE 5:

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### What is Alzheimer's Disease?<sup>4,5</sup>

- Irreversible, progressive brain disease
  - Slowly destroys memory, thinking skills, and ability to carry out basic functions
  - Brain changes can begin years prior to any noticeable symptoms
  - Most common cause of dementia (60-80% of cases)
- 

### TALKING POINTS:

Certain brain diseases and conditions cause dementia. Alzheimer's disease is an **irreversible, progressive** brain disease that slowly destroys **memory** and **thinking skills**, and eventually the ability to carry out the simplest tasks. The brain changes associated with Alzheimer's disease occur on a continuum and can begin up to 20 years before a person has any noticeable symptoms or impairment. Alzheimer's progressively damages and eventually destroys brain cells over the course of many years, even decades.

**Alzheimer's disease** is the most common cause of dementia. It accounts for an estimated 60% to 80% of cases.

The term **Alzheimer's dementia** is used to describe the stage of Alzheimer's disease when an individual has observable symptoms such as memory loss, mood/behavior changes, and difficulty with activities of daily living.

*\*Note: The image on the slide shows a healthy brain (left side) as compared to a severe Alzheimer's brain (right*

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<sup>4</sup>Alzheimer's Association. (n.d.) *What is Dementia?* Retrieved from <http://www.alz.org/what-is-dementia.asp#causes>

<sup>5</sup> National Institute on Aging. (2019) *Alzheimer's Disease Fact Sheet*. Retrieved from <https://www.nia.nih.gov/health/alzheimers-disease-fact-sheet>

*Image source:* National Institute on Aging

*side). The Alzheimer's brain is significantly smaller than the healthy brain.*

Media supplement: "Inside the Brain: A tour of how the mind works" Alzheimer's Association.

Link: [https://www.alz.org/alzheimers-dementia/what-is-alzheimers/brain\\_tour](https://www.alz.org/alzheimers-dementia/what-is-alzheimers/brain_tour)

## SLIDE 6:

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### SCOPE OF THE EPIDEMIC

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Now that you have a basic understanding of Alzheimer's and dementia, we will look at how widespread these conditions are.

## SLIDE 7:

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### Scope of the Epidemic (U.S.)<sup>6</sup>

- Over 5.8 million adults
- 1 in 10 adults age ≥65
- 1 in 3 adults age ≥85
- 2/3 are women

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### TALKING POINTS:

Alzheimer's disease must be considered a public health crisis. There are many reasons for this.

First, the **burden** is large and it is growing. Today, **over 5.8 million adults** in the U.S. are living with Alzheimer's disease, including an estimated 200,000 under the age of 65.

**One in ten** adults age 65 and older (10%) currently has Alzheimer's dementia meaning they are in the stage of Alzheimer's disease when their symptoms are noticeable and impacting daily living. Approximately **one in three** (32%) people age 85 and older has the disease.

**Women** make up almost **2/3** of seniors living with Alzheimer's dementia in the U.S. According to the Framingham Heart Study data, the estimated lifetime risk for Alzheimer's dementia at age 45 was approximately one in five (20%) for women and one in ten (10%) for men.

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<sup>6</sup> Alzheimer's Association. (2019) *2019 Alzheimer's Disease Facts and Figures*.

Image source: Pexels.com

## SLIDE 8:

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### Health Disparities<sup>7,8</sup>

- African—Americans and Hispanics have higher rates of dementia than whites:
  - African-Americans: 2 times more likely
  - Hispanics: 1.5 times more likely
- Less likely to receive a diagnosis
- Often diagnosed at later stages, requiring more medical care

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### TALKING POINTS:

The rates of Alzheimer's and other dementias also reveal certain health disparities.

Although whites make up the majority of people with Alzheimer's in the U.S., **African-Americans** and **Hispanics** have higher rates of Alzheimer's and other dementias than people of other races and ethnicities.

In the United States, older African-Americans are about **two times more** likely than older whites to have Alzheimer's and other dementias. It is estimated that the prevalence is 64% higher in African-Americans. Yet, African-Americans are less likely to receive a diagnosis of Alzheimer's or other dementias than whites.

Older Hispanics are about **one and one-half times** more likely than older whites to have these conditions.

When African-Americans and Hispanics are diagnosed, it is often in the later stages of the disease when cognitive and physical impairment are more severe and require more medical care. Thus, they incur much higher costs for care such as hospitals, doctors, home health or nursing home services.

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<sup>7</sup> Matthews, K.A. et al. (2019) *Racial and Ethnic Estimates of Alzheimer's Disease and Related Dementias in the United States (2015–2060) in Adults Aged ≥ 65 years*. Retrieved from [https://aandjournal.net/article/S1552-5260\(18\)33252-7/fulltext](https://aandjournal.net/article/S1552-5260(18)33252-7/fulltext)

<sup>8</sup> Alzheimer's Association. (2018) *Race, Ethnicity, and Alzheimer's Fact Sheet*.

*Image source:* Copyrighted image; used with permission from the Alzheimer's Association

Genetic factors do not appear to impact risk or prevalence. The greater prevalence in these groups may be caused by the increased incidence of other chronic conditions such as high blood pressure and diabetes —both suspected risk factors for Alzheimer’s and other dementias.

Socioeconomic factors may also play a role in risk, diagnosis, and care.

Large proportional increases are also expected in both African-American and Hispanic populations in the U.S., which will contribute significantly to the growth of the epidemic in these groups and overall.

Information is emerging about the prevalence of Alzheimer’s in other racial and ethnic groups, including Asian Americans and American Indians/Alaska Natives. It appears that the prevalence is lower in these groups.

## SLIDE 9:

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### Alzheimer's Deaths<sup>9</sup>

- 6<sup>th</sup> leading cause of death
- 5<sup>th</sup> leading cause among adults age ≥ 65
- Deaths increased 145% from 2000-2017

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### TALKING POINTS:

Alzheimer's disease is the **6<sup>th</sup> leading cause of death** in the United States and the **5<sup>th</sup> leading cause of death** for those aged 65 and older.

Deaths from Alzheimer's disease **increased 145%** from 2000 to 2017, while deaths from other **major diseases** (including stroke, prostate cancer, and HIV/AIDS) decreased.

The science related to Alzheimer's and other dementias is rapidly evolving. Current evidence indicates that opportunities may exist to lessen the burden of the disease while the search for a cure continues.

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<sup>9</sup> Alzheimer's Association. (2019) *2019 Alzheimer's Disease Facts and Figures*.

## SLIDE 10:

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### Changes in Causes of Death (2000-2017) (*bar chart*)<sup>10</sup>

- HIV (-60.6%)
- Stroke (-12.7%)
- Heart disease (-8.9%)
- Prostate cancer (-1.9%)
- Breast cancer (.5%)
- Alzheimer's disease (145%)

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### TALKING POINTS:

Compared to other **top causes of death** in the U.S., deaths from Alzheimer's have **increased significantly**, while deaths from other causes have **declined**.

From 2000 to 2017, the percentage changes in deaths are as follows:

- HIV: declined by 60.6%
- Stroke: declined by 12.7%
- Heart disease: declined by 8.9%
- Prostate cancer: declined by 1.9%
- Breast cancer: increased by .5%
- Alzheimer's disease: **increased** by 145%

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<sup>10</sup> Alzheimer's Association. (2019) *2019 Alzheimer's Disease Facts and Figures*.

## SLIDE 11:

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### Growing Epidemic<sup>11,12</sup>

- By 2050 U.S. population age  $\geq 65$  expected to be 88 million
- By 2050, 13.8 million with Alzheimer's
- Today, one new case every 65 seconds
- By 2050, every 33 seconds

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### TALKING POINTS:

The number of people living with Alzheimer's and other dementias will **continue to grow** each year, as the number and proportion of the U.S. population age 65 and older continues to increase rapidly.

The cause of the increase can be attributed to people living longer, the large increase in the number of people over age 65 (baby boomers), and the increasing population of racial and ethnic groups with higher prevalence of Alzheimer's and other dementias.

By 2050, the U.S. population aged 65 and over is expected to be 88 million.

By 2050, the number of Americans living with Alzheimer's disease is expected to total **13.8 million**.

Today, someone in the U.S. develops Alzheimer's **every 65 seconds**. By 2050, that rate is expected to increase to one person **every 33 seconds**.

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<sup>11</sup> Alzheimer's Association. (2019) *2019 Alzheimer's Disease Facts and Figures*.

<sup>12</sup> Matthews, K.A. et al. (2019) *Racial and Ethnic Estimates of Alzheimer's Disease and Related Dementias in the United States (2015–2060) in Adults Aged  $\geq 65$  years*. Retrieved from [https://aandjournal.net/article/S1552-5260\(18\)33252-7/fulltext](https://aandjournal.net/article/S1552-5260(18)33252-7/fulltext)

Image source: Pexels.com

## SLIDE 12:

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### Worldwide Epidemic<sup>13</sup>

- Estimated 50 million have dementia with 10 million new cases annually
- Projected to nearly double every 20 years:
  - 82 million in 2030
  - 152 million in 2050
- New case of dementia every 3 seconds

---

### TALKING POINTS:

Worldwide, the total number of people with dementia (including Alzheimer's disease) is estimated at **50 million**.

This number is projected to **nearly double every 20 years** to 82 million in 2030 and 152 million in 2050.

The total number of new cases of dementia each year worldwide is nearly 10 million, which equates to one new case **every three seconds**.

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<sup>13</sup> World Health Organization. (2017) *Key Facts*. Retrieved from <https://www.who.int/news-room/fact-sheets/detail/dementia>

## **SLIDE 13:**

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### **FINANCIAL BURDEN**

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#### **TALKING POINTS:**

The escalating Alzheimer's disease epidemic has profound implications for government budgets.

## SLIDE 14:

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### Financial Burden: U.S. & Worldwide<sup>14,15</sup>

- Alzheimer's is most expensive disease in U.S.
- Annual costs of direct care over \$290 billion
- Worldwide annual costs exceed \$818 billion (2015)

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### TALKING POINTS:

Alzheimer's disease is the **most expensive** disease to treat and provide care for in the U.S., costing more than heart disease and cancer.

In the U.S., the **annual costs** of direct care for people with Alzheimer's disease exceed **\$290 billion**. "Direct care" includes both paid health care, long-term care, and out of pocket costs. It does not include costs of caregiving provided by family members, which will be discussed later in the module.

Worldwide, the annual costs of Alzheimer's and other dementias are estimated to be **over \$818 billion**.

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<sup>14</sup> Alzheimer's Association. (2019) *2019 Alzheimer's Disease Facts and Figures*.

<sup>15</sup> Alzheimer's Disease International. (2015) *World Alzheimer Report 2015: 'The Global Impact of Dementia: An Analysis of Prevalence, Incidence, Cost and Trends*. Retrieved from <http://www.worldalzreport2015.org/>

*Image source:* Copyrighted image; used with permission from the Alzheimer's Association

## SLIDE 15:

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### Discussion Question

What are Medicare and Medicaid?

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First, we'll start by looking at the Alzheimer's disease burden on two federally-funded health care programs.

### **What are Medicare and Medicaid?**

**Open responses.**

## SLIDE 16:

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### Medicare & Medicaid<sup>16</sup>

- Medicare: federally-funded health insurance
  - U.S. citizen or legal permanent resident age ≥ 65
  - People under age 65 with certain disabilities or End-Stage Renal Disease
- Medicaid: funded by federal and state governments
  - Helps with medical costs and nursing home expenses for low-income individuals

---

### TALKING POINTS:

Alzheimer's disease imposes a significant cost on **federal and state budgets** through **Medicare** and **Medicaid**.

**Medicare** is **federally funded** health insurance for people **age 65 and older** who are U.S. citizens or legal permanent residents, or people under 65 with certain **disabilities** or with End-Stage Renal Disease (kidney failure that requires dialysis or a kidney transplant).

**Medicaid** is a program funded by both **federal** and **state** governments to help with medical costs for some people with **limited income** and resources.

Medicare does not cover the cost of long-term care for assisted living, nursing homes, or in-home care such as sitters or certified nursing assistants. Medicaid will cover the cost of nursing home care for low-income individuals or once an individual has limited personal assets and/or may require that the majority of the individual's monthly income be spent on nursing home care expenses.

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<sup>16</sup> Department of Health and Human Services. (2019) *What's Medicare?* Retrieved from <https://www.medicare.gov/pubs/pdf/11306-Medicare-Medicaid.pdf>

Image source: Pexels.com

## SLIDE 17:

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### Alzheimer's: Medicare & Medicaid<sup>17,18</sup>

- Pays 67% of health and long-term costs of Alzheimer's
- Nearly 1 in 5 Medicare dollars
- Per-person spending for those with Alzheimer's:
  - Medicare: 3 times higher than average
  - Medicaid: 23 times higher than average

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### TALKING POINTS:

These facts underscore the significant costs facing Medicare and Medicaid as a result of the Alzheimer's epidemic.

About **67%** of the health and long-term care costs of caring for those with Alzheimer's disease are paid for by Medicare and Medicaid.

In 2019, the Medicare and Medicaid government programs will spend an estimated **\$195 billion** caring for those with Alzheimer's and other dementias — **67% of total annual costs** of these conditions. Nearly **one in every five** Medicare dollars is spent on people with Alzheimer's and other dementias.

Average per-person Medicare spending for those with Alzheimer's and other dementias is **three times higher** than average per-person spending across all other seniors. Medicaid payments are **23 times higher**. People with Alzheimer's and other dementias also have high out-of-pocket costs. These costs are for Medicare and other health insurance premiums and for deductibles, copayments and services not covered by Medicare, Medicaid or additional sources of support.

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<sup>17</sup> Alzheimer's Association. (2019) *2019 Alzheimer's Disease Facts and Figures*.

<sup>18</sup> Alzheimer's Association. (2018) *Costs of Alzheimer's to Medicare and Medicaid*.

## SLIDE 18:

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### Alzheimer's: Projected Costs (2050)<sup>19,20</sup>

- Total annual costs over \$1.1 trillion
  - Annual costs to Medicare: \$559 billion (over 300% increase)
  - Out-of-pocket costs: \$198 billion
- 

### TALKING POINTS:

Just as the number of people with Alzheimer's disease is projected to dramatically increase, so will the costs associated with their care.

Currently, 1 in every 5 dollars spent by Medicare is spent on someone with Alzheimer's. By 2050, it will be 1 in every 3 dollars. If current conditions go unchanged, in 2050 the annual costs of treating Alzheimer's disease in the US will be over **\$1.1 trillion**. Annual costs to Medicare will increase over **300%** to **\$559 billion**.

It is estimated that Medicaid spending on people with Alzheimer's will reach \$191 billion in 2050. Combined costs for Medicare and Medicaid expenses will be \$750 billion (in today's dollars).

Out-of-pocket costs for individuals and families affected by Alzheimer's and other dementias will similarly see increases from \$63 billion in today's dollars to \$198 billion in 2050.

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<sup>19</sup> Alzheimer's Association. (2016) *2016 Alzheimer's Disease Facts and Figures*.

<sup>20</sup> Alzheimer's Association. (2018) *Costs of Alzheimer's to Medicare and Medicaid*.

Image source: Pexels.com

## **SLIDE 19:**

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### **CARE BURDEN**

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#### **TALKING POINTS:**

The care burden associated with the Alzheimer's disease epidemic is also a significant and growing challenge.

## SLIDE 20:

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### Care Workforce

- Caregivers (family or friends)
  - Health care providers
  - Paid care providers
- 

### TALKING POINTS:

People with Alzheimer's and other dementias are generally cared for by a network of family or friend **caregivers**, **health care providers**, and **paid care providers** (such as those who help with daily tasks and self-care).

Most individuals with Alzheimer's disease have a primary **caregiver**, often a family member, who is crucial to ensuring appropriate care.

The type and scope of the care needed by people with Alzheimer's disease changes throughout the course of the illness.

*Image source:* Copyrighted image; used with permission from the Alzheimer's Association

## SLIDE 21:

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### Alzheimer's & Dementia Caregivers<sup>21</sup>

- 83% of care provided to older adults is by family members, friends or other unpaid caregivers
- 70% of people with Alzheimer's live in the community
- Over 16 million caregivers (family and friends)
- 18.5 billion hours of unpaid care annually
- Unpaid care valued at \$233.9 billion (2018)

---

#### TALKING POINTS:

In the US, **83%** of the care provided to older adults is by family members, friends or other unpaid caregivers.

About **70%** of **people with Alzheimer's disease** live in the community in **home settings** where the vast majority of their care is provided by family and friends.

Currently in the U.S., it is estimated that over **16 million family and friends** provide nearly **18.5 billion** hours of unpaid care annually.

In 2018, this care was valued at **\$233.9 billion**. This is approximately **46%** of the net value of **Walmart** annual sales which was \$500.3 billion in 2018 and nearly **10 times** the total annual revenue of **McDonald's** which was **\$22.8 billion** in 2017.

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<sup>21</sup> Alzheimer's Association. (2019) *2019 Alzheimer's Disease Facts and Figures*.

## SLIDE 22:

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### Discussion Question

What might be the roles and responsibilities of a caregiver for someone with Alzheimer's?

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**Ask:** What might be the roles and responsibilities of a caregiver for someone with Alzheimer's?

**Open responses.**

## SLIDE 23:

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### Alzheimer's & Dementia Caregivers<sup>22,23</sup>

- Caregiver profile
  - 2/3 are women (typically daughter or wife)
  - Middle-aged
  - Over half currently employed
- Caregiving responsibilities
  - Help with activities of daily living
  - Medical and financial management
  - Provide increasing levels of care as disease progresses

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#### TALKING POINTS:

The term **caregiver** is used to describe a person who provides a level of care and support for another that exceeds typical responsibilities of daily life. This is usually a family member or friend. This does not include hired help, such as home health aides, which we'll discuss in a few slides.

According to caregiver data from the Behavioral Risk Factor Surveillance System (BRFSS), the typical caregiver for a person with Alzheimer's or another dementia is the middle-aged daughter/daughter-in-law who is also often still employed or self-employed.

Caregiving responsibilities, especially in the moderate and severe stages of Alzheimer's, often include:

- Help with activities of daily living such as dressing, bathing, toileting, and feeding
- Shopping, meal preparation, transportation

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<sup>22</sup> Alzheimer's Association. (2019) *2019 Alzheimer's Disease Facts and Figures*.

<sup>23</sup> Centers for Disease Control and Prevention. (2019) *Behavioral Risk Factor Surveillance System (BRFSS) Caregiver Module*. Retrieved from <https://www.cdc.gov/aging/healthybrain/brfss-faq-caregiver.htm>

Image source: Pixabay.com

- Medication management, financial management
- Providing emotional support

People with Alzheimer's require increasing levels of care as the disease progresses; more severe stages may require constant supervision and result in complete dependence on caregivers (paid and/or unpaid).

## SLIDE 24:

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### Caregivers: Challenges<sup>24</sup>

- Physical, psychological, social challenges
  - \$11.8 billion additional health care costs (2018)
  - 60% rate emotional stress as high or very high
  - 30-40% suffer from depression
  - Increased likelihood of new or worsening health problems

---

### TALKING POINTS:

Caregivers of people with Alzheimer's and other dementias often experience **physical, psychological, and social** challenges.

Several recent findings highlight these challenges:

- Due to the physical and emotional toll of caring for someone with Alzheimer's or other dementias, these caregivers had **\$11.8 billion in additional health care costs** in 2018.
- Nearly 60% of Alzheimer's and dementia caregivers rate the **emotional stress** of caregiving as high or very high.
- About 30-40% of Alzheimer's and dementia caregivers suffer from **depression**, as compared to 5-17% of non-caregivers of similar ages.
- Caring for a loved one with Alzheimer's can put caregivers at increased risk for new or worsening health conditions. Nearly 75% of caregivers express concern about the ability to maintain their own health since becoming a caregiver. Many caregivers delay attending to their own health care needs due to lack of time and/or resources.

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<sup>24</sup> Alzheimer's Association. (2018) *Alzheimer's Disease Caregivers*.

Image source: Pexels.com

## SLIDE 25:

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### Caregivers: Impact on Work<sup>25</sup>

- Went in late/ left early/ took time off (57%)
- Went from full-time to part-time work (18%)
- Took leave of absence (16%)
- Turned down a promotion (8%)
- 1 in 6 quit work entirely to be a caregiver

---

### TALKING POINTS:

In many cases, caring for an individual with Alzheimer's has a negative effect on employment, income, and financial security.

Among Alzheimer's and dementia caregivers 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
- 18% had to go from working full time to part time
- 16% took a leave of absence
- 8% turned down a promotion
- 1 in 6 had to quit work entirely either to become a caregiver or because their caregiving duties became too demanding.

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<sup>25</sup> Alzheimer's Association. (2018) *Alzheimer's Disease Caregivers*.

## SLIDE 26:

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### Caregivers: Length of Care<sup>26,27</sup>

- 86% at least one year
- 50% four or more years
- May range from 4-20 years
- Burden of care higher than for non-dementia caregiving

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### TALKING POINTS:

Caregivers of individuals with Alzheimer's and other dementias spend much more time providing care than caregivers of individuals with other conditions.

In 2017, of the unpaid Alzheimer's and dementia caregivers:

- 86% had been providing care for **at least a year**
- 50% had been providing care for **four or more years**

All rates for length of care are significantly higher for dementia caregivers than for non-dementia caregivers.

In addition to the overall length of time care is provided, the intensity and variety of care provided is greater among those caring for someone with dementia than among caregivers for individuals without dementia. According to a report by the National Alliance for Caregiving, the **burden of care index** for dementia caregivers is much higher than the burden for non-dementia caregivers. The burden of care index is based on the number of hours of care, types and number of care activities performed.

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<sup>26</sup> Alzheimer's Association. (2018) *Alzheimer's Disease Caregivers*.

<sup>27</sup> National Alliance for Caregiving & Alzheimer's Association. (2017) *Dementia Caregiving in the U.S.*

Image source: Pexels.com

## SLIDE 27:

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### Caregivers: Critical Role

- Health care system could not sustain costs of care without caregivers
  - Support for caregivers is a public health issue
- 

### TALKING POINTS:

The burden on caregivers is significant; yet they play a **critical role** in supporting individuals with Alzheimer's and dementia.

More broadly, without caregivers, the health care system could **not sustain the costs** of care for persons with Alzheimer's and other dementias.

Assuring caregivers receive needed support is a **public health issue**.

*Image source: Pexels.com*

*Image source: Pexels.com*

## SLIDE 28:

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### Health Professionals: Shortage<sup>28,29</sup>

- Shortage of health care professionals trained to work with older adults
  - Additional 3.5 million needed by 2030
  - Currently have half the number of certified geriatricians needed
  - Less than 1% of RNs, PAs, and pharmacists identify as geriatric
- Many not adequately trained for Alzheimer's and dementia

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### TALKING POINTS:

With the growing number of older adults in the U.S. population (both with and without Alzheimer's and other dementias), the country is facing a **workforce shortage** of health care professionals who are trained to meet the needs of older adults. Furthermore, many professionals already in the workforce are often **not adequately trained** on the needs of people with Alzheimer's and other dementias.

**Current estimations** of workforce shortages include:

- The U.S. will need an **additional 3.5 million health care professionals** by 2030 just to maintain the current ratio of health care professionals to older adults.
- The U.S. has **approximately half** the number of **certified geriatricians** than it needs. Currently, this equates to 1 geriatrician for every 1,924 adults age 65 or older.
- Less than **1%** of registered **nurses, physician assistants, and pharmacists** identify themselves as specializing in **geriatrics**.

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<sup>28</sup> Alzheimer's Association. (2019) *2019 Alzheimer's Disease Facts and Figures*.

<sup>29</sup> Institute of Medicine (US) Committee on the Future Health Care Workforce for Older Americans. (2008) *Retooling for an Aging America: Building the Health Care Workforce*. Washington (DC): National Academies Press (US).

## SLIDE 29:

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### Direct Care Workforce<sup>30</sup>

- Provide majority of care for Alzheimer's (after caregivers)
  - Includes nurse aides, home health aides, personal-care aides and home-care aides
  - Help with daily activities: bathing, dressing, eating
  - Costs range from \$48,000 to over \$90,000 a year
- 

### TALKING POINTS:

Many older adults, including those with Alzheimer's and other dementias, receive a large part of their care from **direct-care workers**, such as **nurse aides**, **home health aides**, **personal-care aides**, and **home-care aides**.

These workers help with **bathing**, **dressing**, **eating**, and numerous other **daily tasks**, both at home and within institutions.

It typically costs \$132 per day or \$48,000/year for a home care agency to provide care in the home.

For care provided in a long term care facility, the cost is about \$48,000 per year for assisted living and upwards of \$90,000 or more per year for nursing home care.

Given that Medicare and most private insurance (other than long term care insurance) do not cover these costs, most individuals and/or their families pay out of pocket for this care.

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<sup>30</sup> Alzheimer's Association. (2019) *2019 Alzheimer's Disease Facts and Figures*.

*Image source:* Copyrighted image; used with permission from the Alzheimer's Association

## SLIDE 30:

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### Direct Care Workforce: Challenges<sup>31</sup>

- Workforce shortage
  - Rapid increases in number of workers needed as population ages
  - High turnover
  - Recruitment and retention difficult
- Challenging job given nature of the work
- Limited training, especially on Alzheimer's and dementia

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### TALKING POINTS:

**Challenges** within the direct care workforce include shortages in the number of workers needed and insufficient training. As with family caregivers, the role of providing ongoing, extensive care for a person with Alzheimer's and other dementias is physically and emotionally taxing. This makes finding, hiring, and retaining the right person for the role difficult. Added to that is the challenge of finding the large amount of workers needed to care for the rapidly increasing population needing care services. These jobs typically pay slightly more than minimum wage, often have inconsistent work hours, and usually includes working weekends, holidays, overnight hours...whenever an individual needs care.

Subsequently, **turnover rates** are high among direct-care workers, and recruitment and retention are persistent challenges.

Many direct-care workers receive little training on Alzheimer's and dementia care although there is a growing awareness of the need for training related to the special care needs and considerations for people with Alzheimer's or other dementias. For most direct-care workers

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<sup>31</sup> Paraprofessional Healthcare Institute (PHI). (2018) *U.S. Home Care Workers Key Facts*.

currently, the average training is 75 hours, with little focus on Alzheimer's and dementia.

Many people wish to remain in their own home or a loved one's home as they age. Therefore, there is tremendous growth in the home care industry. The home care workforce more than doubled between 2007 and 2017, with the expectation that the field will need to add another one million jobs by 2026 to keep pace with the growing tide of older adults needing care.

## SLIDE 31:

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### PUBLIC HEALTH APPROACH

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#### TALKING POINTS:

Fortunately, there are ways to intervene using **public health tools and techniques**. The public health approach can be used to improve the quality of life for those living with the disease, their caregivers, and to reduce the costs associated with the disease.

## SLIDE 32:

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### Healthy People 2030<sup>32</sup>

- Proposed objectives for Alzheimer’s and other dementias:
    - Increasing diagnosis and awareness
    - Reducing preventable hospitalizations
    - Increasing number of older adults discussing their memory issues with a health care professional
- 

### TALKING POINTS:

Alzheimer’s and other dementias were included for the first time in *Healthy People 2020*.

*Healthy People*, released every ten years by the U.S. Department of Health and Human Services, is a framework of goals and objectives that is used to guide national health promotion and disease prevention efforts in the U.S.

The proposed objectives for Healthy People 2030 includes the topic area “Dementias, including Alzheimer’s” and contains **specific objectives** regarding **increasing diagnosis and awareness**, reducing **preventable hospitalizations**, and increasing the number of older adults who discuss their confusion or memory loss issues with a health care professional. Public health has a role to play in reaching those objectives.

Inclusion in *Healthy People* underscores the growing public health threat that Alzheimer’s and other dementias pose to the nation.

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<sup>32</sup> Department of Health and Human Services. (n.d.) *Healthy People Topics and Objectives*. Retrieved from <https://www.healthypeople.gov/>

Image source: Pexels.com

## SLIDE 33:

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### Role of Public Health<sup>33</sup>

- 4 key ways public health can have an impact:
  - Surveillance/monitoring
  - Risk reduction
  - Early detection and diagnosis
  - Safety and quality of care

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### TALKING POINTS: *(See module 3 for more information)*

According to the Healthy Brain Initiative's *State and Local Public Health Partnerships to Address Dementia*, public health has a vital role to play in promoting cognitive function and addressing the impact on the healthcare system, community and individuals.

Through its broad community-based approach, public health can provide the following:

- **Surveillance and monitoring** that allows public health to compile data and use it to:
  - Develop strategies and interventions
  - Inform public policy
  - Guide research
  - Evaluate programs and policies
  - Educate populations
- **Risk reduction strategies: Primary prevention** strategies can be used to promote **risk reduction** for cognitive decline and dementia, as well as **promote cognitive health** in general.

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<sup>33</sup> Alzheimer's Association and Centers for Disease Control and Prevention. *Healthy Brain Initiative, State and Local Public Health Partnerships to Address Dementia: The 2018-2023 Road Map*. Chicago, IL: Alzheimer's Association; 2018.

*Image source:* Unsplash.com

- **Early detection and diagnosis:** Public health plays an important role in efforts to increase **early detection and diagnosis** of Alzheimer's, including:
  - **Educating** the public about the warning signs of dementia, benefits of early detection, and training to health care providers and newly diagnosed individuals, families, and caregivers.
  - Identifying and promoting **strategies** designed to promote early detection
- **Safety and quality of care:** Caring for those with Alzheimer's and dementia requires specialized knowledge about the disease continuum and skill to effectively communicate and care for individuals and their family caregivers. Providing training for health care providers and caregivers can increase the quality of care and safety of the individual and the caregiver. Information sharing is also important for those in the community who may interact with individuals with Alzheimer's such as first responders, public transportation providers, pharmacies, faith communities, etc.

As mentioned earlier, dementia caregivers also face challenges such as emotional and physical stress, lack of time for self-care, financial issues, isolation, etc. Caregivers need support and access to resources that will enable them to maintain their health and well-being during the years of caregiving.

## SLIDE 34:

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### Dementia Capable Systems and Dementia Friendly Communities

- Dementia capable systems
    - Support services
    - Workforce training and education
  - Dementia friendly communities
    - Safe, supportive environments
- 

#### TALKING POINTS: *(See module 4 for more information.)*

Public health also has a role to play in supporting dementia capable systems and dementia friendly communities. At a larger level, states and communities can become dementia capable and accommodate the needs of a population with Alzheimer's and other dementias.

A **dementia capable system** is one that meets the needs of people with dementia and their caregivers by providing education, support, and services. Public health can contribute to a **dementia capable system** through:

- Ensuring access to **support services** for people with dementia and their caregivers
- Workforce **training** and **education**

Public health also can support the creation of **dementia friendly communities**. These are cross-sector, community-wide efforts to have support services, resources, and safe environments that allow people with dementia and their caregivers to stay connected to the community. Over time, these partnerships should:

- Enhance support services and resources
- Address accessibility and mobility barriers
- Provide dementia training for health care providers and first responders
- Provide a range of resources to support family caregivers such as respite care services.

*Image source:* Copyrighted image; used with permission from the Alzheimer's Association

## SLIDE 35:

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### For More Information

For more information, please visit:

Alzheimer's Association: <http://www.alz.org>

CDC's Alzheimer's Disease and Healthy Aging Program:  
<https://www.cdc.gov/aging/>

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### TALKING POINTS:

For more information on the topics covered in this presentation, please go to the Alzheimer's Association website at <http://www.alz.org> or the Centers for Disease Control and Prevention's Alzheimer's Disease and Healthy Aging Program at <https://www.cdc.gov/aging/>. There you can find resources, latest research and information.

## SLIDE 36:

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### Competencies

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

- 1.3.3 Demonstrate knowledge of signs, symptoms, and impact of common cognitive and mental health problems in late life (e.g., dementia, depression, grief, anxiety).

#### **Council on Education for Public Health (CEPH)**

##### **Foundational Competencies**

- 2. Locate, use, evaluate and synthesize public health information (bachelors-level)
- 4. Interpret results of data analysis for public health research, policy, or practice (masters-level)

#### **Council on Linkages Between Academia and Public Health**

##### **Practice:**

- 2A. Identifies current trends (e.g., health, fiscal, social, political, environmental) affecting the health of a community.

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**TALKING POINTS:** *(this slide can be edited as needed or removed)*

The content in this presentation supports the development of the following competencies:

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

- 1.3.3 Demonstrate knowledge of signs, symptoms, and impact of common cognitive and mental health problems in late life (e.g., dementia, depression, grief, anxiety).

#### **Council on Education for Public Health Foundational Competencies**

- 2. Locate, use, evaluate, and synthesize public health information (bachelors-level)

- 4. Interpret results of data analysis for public health research, policy, or practice (masters-level)

**Council on Linkages Between Academia and Public Health Practice:**

- 2A. Identifies current trends (e.g., health, fiscal, social, political, environmental) affecting the health of a community.

## SAMPLE TEST QUESTIONS

**1- What is dementia?**

- a. Severe confusion caused by dietary deficiencies
- b. Decline in mental ability that interferes with daily life
- c. Mental illness that can lead to insanity if untreated
- d. Reversible condition caused by severe iron deficiency

**Answer: B**

**2- Alzheimer's disease can include brain changes that begin many years before noticeable symptoms occur.**

- a. True
- b. False

**Answer: A**

**3- Alzheimer's disease is the\_\_ leading cause of death among adults over 65 years old.**

- a. 1<sup>st</sup>
- b. 2<sup>nd</sup>
- c. 5<sup>th</sup>
- d. 10<sup>th</sup>

**Answer: C**

**4- How many US adults have Alzheimer's disease?**

- a. Less than 500,000
- b. About 1,000,000
- c. Nearly 6,000,000
- d. More than 10,000,000

**Answer: C**

**5- Who provides most of the direct care for people with dementia?**

- a. Family members
- b. Home health aides
- c. Social workers
- d. Nurses

**Answer: A**

# FACULTY GUIDE

Module 2: Alzheimer's and Other Dementias – The Basics

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Alzheimer's Association and the Centers for Disease Control and Prevention

## ABOUT MODULE 2

This module is part of the Alzheimer’s Association curriculum, *A Public Health Approach to Alzheimer’s and Other Dementias*. Developed as part of a cooperative agreement with CDC’s Alzheimer’s Disease and Healthy Aging Program, and in partnership with Emory University’s Rollins School of Public Health, this curriculum addresses cognitive health, cognitive impairment, and Alzheimer’s disease and is for use by undergraduate faculty in schools and programs of public health and other related disciplines. It can also be adapted for other purposes.

**Module 2: Alzheimer’s and Other Dementias – The Basics** provides background information on Alzheimer’s and other dementias. It lays a foundation for what cognitive health is and how changes within the brain may lead to cognitive aging, cognitive impairment, and Alzheimer’s and other dementias.

The module then shifts to focus more specifically on Alzheimer’s disease. Learners gain a general understanding about the stages of Alzheimer’s disease, risk factors, and how the disease is diagnosed and treated. The module also addresses unique aspects of Alzheimer’s disease (including financial hardship, stigma, and vulnerability to abuse) and the role of caregivers and caregiving impacts.

### **Module 2 contains the following topics:**

- Cognitive health
- Dementia
- Alzheimer’s disease
- Risk factors
- Treatment and management
- Caregivers
- Unique aspects

## LEARNING OBJECTIVES

At the end of **Module 2: Alzheimer’s and Other Dementias – The Basics**, students will be able to:

- Define cognitive health
- Define and differentiate between dementia and Alzheimer’s
- List at least five early signs of Alzheimer’s
- Describe the changes that occur during the course of Alzheimer’s disease

- Describe the role of caregivers in the care of someone with Alzheimer's

## **COMPETENCIES**

Module 2 promotes basic learning that supports the development of certain competencies:

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

- 1.2.1 Distinguish normal biological aging changes from pathology including genetic factors
- 1.2.4 Recognize common late-life syndromes and diseases and their related bio-psychosocial risk and protective factors

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

- 2. Locate, use, evaluate, and synthesize public health information (bachelors level)
- 4. Interpret results of data analysis for public health research, policy, or practice (masters level)

### **Council on Linkages Between Academia and Public Health Practice:**

- 1A1. Describes factors affecting the health of a community (e.g., equity, income, education, environment)

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## LAYOUT OF MODULE 2 FACULTY GUIDE

This guide is laid out in the following sections:

- Slide guide with talking points
- Sample test questions
- Case studies
- Video resources

*Note: Some slides in this module duplicate content from other modules and may be removed as needed.*

## HOW TO USE THE MATERIALS

- ✓ This module is one of four modules in this curriculum that were designed for use either as a set or as stand-alone modules
- ✓ Users are free to make changes to the materials to fit their needs, including: adding, modifying or removing content, graphics, talking points, discussion questions, or learning activities
- ✓ The Faculty Guide for each module includes a slide guide that contains the information as presented in the slide, talking points, space for presenter notes, and references
- ✓ The talking points included in the Faculty Guide should not be read word for word; each presenter should review the materials before delivering the material to ensure familiarity and deliver the information in his/her own style
- ✓ Delivery time will generally be 60-90 minutes per module, depending on class engagement, presenter style, and the addition or elimination of any content, discussion questions, or learning activities
- ✓ Discussion questions are included in the slide deck of each module. These may be modified or removed at the discretion of the presenter. Questions may also be used for other activities such as small group discussion or individual writing assignments
- ✓ Video resources, a list of articles, and case studies are also included to help in learning more about the topics presented in each module
- ✓ Test questions are provided with each module as an additional resource for faculty
- ✓ All materials are 508 compliant. (Note: if changes are made to the curriculum, 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/making-files-accessible/index.html>)

## STUDENT ENGAGEMENT OPTIONS

In addition to the PowerPoint slide deck and guide, there are additional resources included in this guide. These resources are designed to increase student engagement and enhance understanding of the concepts covered in this module. Following the slide guide, there is a series of case studies and a list of video resources. It is recommended that the presenter review these resources to determine if these additional materials would be useful in illustrating the concepts covered in the module.

## DISCUSSION QUESTIONS

The following discussion questions are included in the slide deck:

- What is cognitive health? (*Slide 3*)
- What are the characteristics of Alzheimer's? (*Slide 14*)

## LEARNING ACTIVITIES

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

- Research personal perspectives on Alzheimer's and dementia. What happens to someone's mind, lifestyle, and relationships, in their own words?
- Describe the physiological changes to the brain that occur with Alzheimer's disease. What do scientists know about how the disease develops? What are current focus areas in research?
- Conduct a short interview with 4-5 adults over the age of 50. Develop and ask questions related to their concerns about their risk for Alzheimer's and barriers to getting diagnosed. Summarize their responses and describe implications for a campaign to promote early diagnosis.
- Research the other types of dementia to determine how they are similar in symptoms and if there is a known underlying cause.

## ADDITIONAL READING

- Alzheimer's Association. 2019. Alzheimer's Disease Facts and Figures. Chicago, IL: Alzheimer's Association. <http://www.alz.org/facts>
- The NIH Alzheimer's Disease Education and Referral Center: Information about symptoms at each stage of Alzheimer's and how the disease progresses. <https://www.nia.nih.gov/alzheimers>
- Alzheimer's Association. (n.d.) What is Alzheimer's? <https://www.alz.org/alzheimers-dementia/what-is-alzheimers>

## SLIDE GUIDE

This slide guide accompanies the PowerPoint presentation for this module. The right margin has been widened to allow the presenter to write notes.

### SLIDE 1:

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#### Module 2: Alzheimer's and Other Dementias – The Basics

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#### TALKING POINTS:

This presentation entitled, **Alzheimer's and Other Dementias – The Basics** is part of a curriculum for public health students entitled, *A Public Health Approach to Alzheimer's and Other Dementias*. It was developed by the Emory Centers for Training and Technical Assistance for the Alzheimer's Association with funding from the Centers for Disease Control and Prevention.

This module provides background information on cognitive health, cognitive impairment, dementia, and Alzheimer's disease. It provides essential information on Alzheimer's disease, including what is known about its causes, its progression, risk factors, and care.

## SLIDE 2:

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### Learning Objectives

- Define cognitive health
- Define and differentiate between dementia and Alzheimer's
- List at least 5 early signs of Alzheimer's
- Describe the changes that occur during the course of Alzheimer's
- Describe the role of caregivers

---

### TALKING POINTS:

By the end of the presentation, you will be able to:

- Define cognitive health
- Define and differentiate between dementia and Alzheimer's
- List at least 5 early signs of Alzheimer's
- Describe the changes that occur during the course of Alzheimer's
- Describe the role of caregivers

## **SLIDE 3:**

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### **Discussion Question**

What is cognitive health?

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**Ask:** What is cognitive health?

**Open responses.**

## SLIDE 4:

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### Cognitive Health<sup>1</sup>

- Cognition: the ability to think, learn, and remember
  - Cognitive health continuum: “optimal functioning” to severe disability
- 

### TALKING POINTS:

To understand what happens to a person when he or she develops Alzheimer’s or dementia, it is helpful to first consider **cognitive health**.

**Cognition** refers to the ability to think, learn, solve problems, and remember.

**Cognitive health** can be viewed along a continuum. At one end is “optimal functioning,” which refers to a healthy brain that can perform the following mental processes:

- Learning new things
- Intuition
- Judgment
- Language
- Remembering

At the other end of the spectrum are people with severe Alzheimer’s, dementia, and other brain injuries with limited cognitive functioning.

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<sup>1</sup> National Institute on Aging. (n.d.) *Cognitive Health and Older Adults*. Retrieved from <https://www.nia.nih.gov/health/cognitive-health-and-older-adults>

## SLIDE 5:

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### Cognitive Aging<sup>2,3,4</sup>

- The brain changes as it ages
  - Increase in wisdom and expertise
  - Speed of processing, making decisions, remembering may slow
  - Normal part of aging
- 

### TALKING POINTS:

Like other organs in the human body, the brain changes as it ages. Physical structures in the brain change, and its ability to carry out various functions tends to decline.

Wisdom and expertise can increase with age, while the speed of processing information, making decisions, and recall of information can slow down.

This process is known as **cognitive aging**, which refers to a decline in memory, decision-making, processing speed, and learning. For example, a person might need longer to learn a new skill, have more difficulty recalling certain words or finding common items such as glasses or keys. These changes are considered a normal part of aging and varies from person to person from day to day.

When changes in a person's cognitive ability affects their daily life, it may be an indication that it is due to something other than normal aging changes. **Subjective Cognitive Decline** is self-reported confusion or memory loss that is happening more often or is getting worse. A growing body of evidence suggests that Subjective Cognitive Decline is one of the earliest warning signs for Alzheimer's and other dementias. In the 2016 Behavioral Risk Factor Surveillance

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<sup>2</sup>Institute of Medicine. (2015) *Cognitive Aging: Progress in Understanding and Opportunities for Action*.

<sup>3</sup>National Institute on Aging. (n.d.) *Do Memory Problems Always Mean Alzheimer's Disease?*

<sup>4</sup>Taylor CA, Bouillon ED, McGuire LC. *Subjective Cognitive Decline Among Adults Aged ≥45 Years — United States, 2015–2016*. MMWR Morb Mortal Wkly Rep 2018; 67:753–757. DOI: <http://dx.doi.org/10.15585/mmwr.mm6727a1>

*Image source:* Copyrighted image; used with permission from the Alzheimer's Association

System (BRFSS) surveys conducted by state health departments, one in 9 adults age 45 or older reported experiencing subjective cognitive decline. Over half of those respondents reporting Subjective Cognitive Decline had not talked about their memory issues with a health care provider.

## SLIDE 6:

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### Mild Cognitive Impairment (MCI)<sup>5,6</sup>

- Difficulty with cognitive processes
- Not severe enough to interfere with daily life
- Increased risk of Alzheimer's or dementia
- May be caused by external factors (vitamin B12 deficiency, depression)

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### TALKING POINTS:

**Mild cognitive impairment (MCI)** is a condition in which people have memory or other thinking problems that are noticeable, but their symptoms are not severe enough to interfere with everyday activities.

Symptoms of MCI may include forgetting important information that he or she would have previously recalled easily (such as appointments, conversations, or recent events), or a decreased ability to make sound decisions, judge the time or sequence of steps needed to complete a complex task, or have trouble with visual perception.

A person with MCI is at an **increased risk** of developing Alzheimer's or other dementia.

In some cases, however, the condition may be caused by **external factors**, such as medication, vitamin B12 deficiency, and depression. In these cases, the condition may be reversed if the underlying cause is addressed, reverse on its own, or remain stable.

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<sup>5</sup> Alzheimer's Association. (2019) *2019 Alzheimer's Disease Facts and Figures*.

<sup>6</sup> National Institute on Aging. (n.d.) *What is Mild Cognitive Impairment?* Retrieved from <https://www.nia.nih.gov/alzheimers/topics/mild-cognitive-impairment>

*Image source:* National Cancer Institute, NCI Visuals Online

## SLIDE 7:

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### Cognitive Impairment<sup>7</sup>

- Difficulty with cognitive processes that affect everyday life
- Spans wide range of functioning
- Can occur as a result of Alzheimer's, dementia, stroke, traumatic brain injury

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### TALKING POINTS:

Further along the cognitive health continuum is **cognitive impairment**.

When a person has trouble with cognitive processes that begin to affect the things he or she does in everyday life, it is often referred to as **cognitive impairment**.

Cognitive impairment spans a **wide range of functioning**. It can occur as a result of Alzheimer's or other dementias, or with other conditions such as stroke and traumatic brain injury.

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<sup>7</sup> Alzheimer's Association and Centers for Disease Control and Prevention. *Healthy Brain Initiative, State and Local Public Health Partnerships to Address Dementia: The 2018-2023 Road Map*. Chicago, IL: Alzheimer's Association; 2018.

## SLIDE 8:

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### Dementia<sup>8</sup>

- Decline in mental ability severe enough to interfere with daily life
  - Not a specific disease
  - Not normal aging
  - Caused by damage to brain cells from disease or trauma
  - Many dementias are progressive
- 

### TALKING POINTS:

Dementia is a general term for a **decline in mental ability** severe enough to interfere with daily life.

Dementia is not a specific disease. Rather, it's an overall term that describes a **wide range of symptoms** associated with a decline in memory or other thinking skills.

Dementia is **NOT normal aging**.

It is caused by **damage** to **brain cells** from disease or trauma (such as a brain injury or stroke). This damage interferes with the ability of brain cells to communicate with each other. When brain cells cannot communicate normally, thinking, behavior, and feelings can be affected.

Many dementias are progressive, meaning symptoms start out slowly and gradually get worse.

There are several types of dementia. Alzheimer's is the most common cause of dementia, followed by vascular dementia.

Vascular dementia is a decline in thinking skills caused by conditions that block or reduce blood flow to the brain such as a stroke that deprives brain cells of vital oxygen and nutrients.

Other types of dementia include Lewy Body dementia, frontotemporal, Huntington's disease and others.

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<sup>8</sup> Alzheimer's Association. (n.d.) *What is Dementia?* Retrieved from <http://www.alz.org/what-is-dementia.asp#causes>

Researchers increasingly believe a large number of dementia cases are **mixed dementia** when a person has multiple types of dementia.

Sometimes dementia-like symptoms can be caused by other conditions, such as depression, vitamin deficiencies, thyroid problems, and some infections, that when treated will result in improvement of dementia-like symptoms. A key difference between these conditions and dementia is that the symptoms usually appear suddenly, whereas dementia develops slowly over time. This is one reason why it is important for someone with memory changes to be seen by a health professional to determine a possible cause of confusion or memory loss.

## **SLIDE 9:**

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### **ALZHEIMER'S DISEASE**

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#### **TALKING POINTS:**

The most common cause of dementia is Alzheimer's disease. We will focus our attention on understanding more about the stages of Alzheimer's as well as risk factors, treatment, and management of the disease.

## SLIDE 10:

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### Alzheimer's History<sup>9</sup>

- Identified in 1906 by Dr. Alois Alzheimer
  - Examined brain of woman who died after living with profound memory loss
  - Found abnormal clumps (plaques) and tangled fibers (tangles) in the brain
- 

### TALKING POINTS:

Alzheimer's disease was first **identified** in 1906 by Dr. Alois Alzheimer. He noticed certain changes in the brain tissue of a woman in her 50s who had died after several years of progressive cognitive impairment, hallucinations, disorientation, and unpredictable behavior.

Dr. Alzheimer examined her brain after death and found many **abnormal clumps** (now called amyloid plaques) and tangled bundles of fibers (now called neurofibrillary, or tau, tangles). These **plaques** and **tangles** in the brain are still considered some of the hallmarks of Alzheimer's disease, along with the loss of connections between **nerve cells** (neurons) in the brain.

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<sup>9</sup> National Institute on Aging. (n.d.) *Alzheimer's Disease Fact Sheet*. Retrieved from <https://www.nia.nih.gov/health/alzheimers-disease-fact-sheet>

*Image source:* National Library of Medicine, History of Medicine

## SLIDE 11:

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### Alzheimer's Overview<sup>10</sup>

- Most common cause of dementia
  - 60% - 80% of cases
  - Progressive – symptoms gradually worsen over number of years
- 

### TALKING POINTS:

**Alzheimer's disease** is the most common cause of dementia. It accounts for an estimated 60% to 80% of cases.

Alzheimer's is a progressive disease, in which brain changes may go unnoticed for years, but gradually worsen over time as the brain deteriorates due to the disease. The image on the slide shows a healthy brain (left side) as compared to a severe Alzheimer's brain (right side). The Alzheimer's brain is significantly smaller than the healthy brain.

Alzheimer's is viewed as a continuum where brain changes can begin a decade or more before symptoms begin to appear. Eventually the brain changes caused by Alzheimer's may result in the first symptoms of cognitive decline, and over time reach the mild cognitive impairment stage. The term **Alzheimer's dementia** refers to the stage of the disease when an individual has observable symptoms such as memory loss, mood/behavior changes, and difficulty with activities of daily living.

In mild (early) stages of dementia, people experience some memory loss, but with severe (late-stage) Alzheimer's, individuals lose the ability to carry on a conversation and respond to their environment. The degenerative nature of the disease means many in the severe stage have difficulty moving, often become bed-bound, and need round-the-clock care.

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<sup>10</sup> Alzheimer's Association. (n.d.) *What is Alzheimer's?* Retrieved from <https://www.alz.org/alzheimers-dementia/what-is-alzheimers>

*Image source:* National Institute on Aging

## SLIDE 12:

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### Alzheimer's Causes<sup>11</sup>

- Precise changes in brain largely unknown
  - Probably develops as a result of complex interactions among:
    - Age
    - Genetics
    - Environment
    - Lifestyle
    - Coexisting medical conditions
- 

### TALKING POINTS:

Although research has revealed a great deal about Alzheimer's, the precise **changes** that occur in the brain and trigger the development of the disease remain largely unknown.

Experts agree that in the vast majority of cases, Alzheimer's, like other common chronic conditions, probably develops as a result of complex interactions among multiple factors, including advancing age, genetics, environment, lifestyle, and coexisting medical conditions.

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<sup>11</sup> Alzheimer's Association. (n.d.) *Causes and Risk Factors*. Retrieved from <https://www.alz.org/alzheimers-dementia/what-is-alzheimers/causes-and-risk-factors>

## SLIDE 13:

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### Alzheimer's Physical Brain Changes<sup>12</sup>

- Brain shrinks dramatically
    - Nerve cell death
    - Tissue loss
  - Plaques: abnormal clusters of protein fragments
  - Tangles: twisted strands of another protein
- 

### TALKING POINTS:

Alzheimer's leads to **nerve cell death** and **tissue loss** throughout the brain. Over time, the brain **shrinks dramatically**, affecting nearly all its functions.

Scientists are not absolutely sure what causes cell death and tissue loss in the Alzheimer's brain, but **plaques** and **tangles** are prime suspects.

**Plaques**, abnormal clusters of protein fragments, build up between nerve cells in the brain. Plaques form when protein pieces called **beta-amyloid** clump together.

Dead and dying nerve cells contain **tangles**, which are made up of twisted strands of another protein.

Plaques and tangles tend to spread through the brain in a predictable pattern as Alzheimer's progresses.

*\*Note: The image on the slide shows a microscopic illustration of Alzheimer's tissue with plaques and tangles.*

**Video Supplement:** "How Alzheimer's Changes the Brain."

National Institutes of Health.

<https://www.nia.nih.gov/health/what-happens-brain-alzheimers-disease> or

"Inside the Brain: A tour of how the mind works"

Alzheimer's Association. [https://www.alz.org/alzheimers-dementia/what-is-alzheimers/brain\\_tour](https://www.alz.org/alzheimers-dementia/what-is-alzheimers/brain_tour)

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<sup>12</sup> Alzheimer's Association. (n.d.) *Inside the Brain- A Tour of How the Mind Works*. Retrieved from [https://www.alz.org/alzheimers-dementia/what-is-alzheimers/brain\\_tour](https://www.alz.org/alzheimers-dementia/what-is-alzheimers/brain_tour)

Image source: National Institute on Aging

## SLIDE 14:

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### Discussion Question

What are the characteristics of Alzheimer's?

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**Ask:** What are the characteristics of Alzheimer's?

**Open responses.**

## SLIDE 15:

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### 10 Early Signs of Alzheimer's<sup>13</sup>

1. Memory loss that disrupts daily life
  2. Challenges in planning or solving problems
  3. Difficulty completing familiar tasks
  4. Confusion with time or place
  5. Trouble understanding visual images and spatial relationships
- 

### TALKING POINTS:

In the last slide we looked at the physical changes that take place inside the brain as a result of Alzheimer's, but what most people associate with Alzheimer's is the cognitive and behavioral symptoms. These symptoms also change and become more severe as the disease progresses.

Alzheimer's affects people in different ways. The most common symptom begins with **gradually worsening ability to remember new information**. As damage spreads, individuals experience other difficulties.

The following are **ten early signs and symptoms of Alzheimer's**:

#### 1. Memory loss that **disrupts daily life**

One of the most common signs of Alzheimer's dementia, especially in the early stages, is forgetting recently learned information.

Others include: forgetting important dates or events; asking for the same information over and over; relying on family members for things they used to handle on their own.

#### 2. Challenges in **planning or solving problems**

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<sup>13</sup> Alzheimer's Association. (n.d.) *10 Early Signs and Symptoms of Alzheimer's*. Retrieved from [https://www.alz.org/alzheimers-dementia/10\\_signs](https://www.alz.org/alzheimers-dementia/10_signs)

*Image source:* National Cancer Institute, NCI Visuals Online

Some people may experience changes in their ability to develop and follow a plan or work with numbers.

They may have trouble following a familiar recipe or keeping track of monthly bills.

They may have difficulty concentrating and take much longer to do things than they did before.

**3. Difficulty completing familiar tasks** at home, at work or at leisure

People with Alzheimer's may have a hard time completing daily tasks. Sometimes, people may have trouble driving to a familiar location, managing a budget at work, or using a cell phone.

**4. Confusion with time or place**

People with Alzheimer's can lose track of dates, seasons, and the passage of time. They may have trouble understanding something if it is not happening immediately. Sometimes they may forget where they are or how they got there.

**5. Trouble understanding visual images and spatial relationships**

For some people, having vision problems is a sign of Alzheimer's. They may have difficulty with balance or judging distance, and trip over things at home, or spill or drop things more often. In terms of perception, they may pass a mirror and think someone else is in the room. They may not recognize their own reflection.

## SLIDE 16:

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### 10 Early Signs of Alzheimer's (continued)<sup>14</sup>

6. New problems with words in speaking or writing
  7. Misplacing things and losing the ability to retrace steps
  8. Decreased or poor judgment
  9. Withdrawal from work or social activities
  10. Changes in mood and personality
- 

### TALKING POINTS:

#### 6. New problems with words in **speaking** or **writing**

People with Alzheimer's may have trouble following or joining a conversation. They may stop in the middle of a conversation and have no idea how to continue, or they may repeat themselves. They may struggle with vocabulary or call things by the wrong name (e.g., calling a watch a "hand clock").

#### 7. **Misplacing** things and losing the ability to retrace steps

A person with Alzheimer's may put things in unusual places. They may lose things and be unable to go back over their steps to find them again. Sometimes, they may accuse others of stealing.

#### 8. Decreased or poor **judgment**

People with Alzheimer's may experience changes in judgment or decision-making. For example, they may use poor judgment when dealing with money, such as giving large amounts to telemarketers. They may pay less attention to grooming or keeping themselves clean.

#### 9. **Withdrawal** from work or social activities

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<sup>14</sup> Alzheimer's Association. (n.d.) *10 Early Signs and Symptoms of Alzheimer's*. Retrieved from [https://www.alz.org/alzheimers-dementia/10\\_signs](https://www.alz.org/alzheimers-dementia/10_signs)

*Image source:* pexels.com

A person with Alzheimer's may start to remove themselves from hobbies, social activities, work, or volunteer projects. They may have trouble keeping up with a favorite sports team or remembering how to complete a favorite hobby.

**10. Changes** in mood and personality

The mood and personalities of people with Alzheimer's can change. They can become confused, suspicious, depressed, fearful, or anxious. They may be easily upset at home, at work, with friends, or in places where they are out of their comfort zone.

## SLIDE 17:

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### Stages of Alzheimer's<sup>15</sup>

- Average lifespan 4-8 years after diagnosis; as long as 20 years
  - Progresses slowly in 3 stages:
    - Mild (early-stage)
    - Moderate (middle-stage)
    - Severe (late-stage)
- 

### TALKING POINTS:

On average, a person with Alzheimer's lives **four to eight years** after diagnosis, but can live as long as 20 years, depending on many factors (such as the progression of the disease, other co-occurring conditions, infections, and unintentional injuries). The symptoms of Alzheimer's worsen over time, although the **rate** at which the disease progresses **varies**.

Alzheimer's typically progresses slowly in **three general stages** –mild (early-stage), moderate (middle-stage), and severe (late-stage).

The beginning of Alzheimer's –or the presymptomatic stage– starts years before there are noticeable changes or symptoms. Eventually the brain changes caused by Alzheimer's may result in the first symptoms of cognitive decline, and over time reach the mild cognitive impairment stage. For many of these individuals, dementia will progress through early, mid, and late stages.

*\*Note: The image on the slide shows the progression of changes to the brain, from preclinical Alzheimer's (top), mild to moderate (middle), to severe (bottom).*

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<sup>15</sup> Alzheimer's Association. (n.d.) *Stages of Alzheimer's*. Retrieved from <https://www.alz.org/alzheimers-dementia/stages>

*Image source:* National Institute on Aging

## SLIDE 18:

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### Mild Alzheimer's (Early-Stage)<sup>16</sup>

- Able to function independently
  - Common difficulties:
    - Forgetting familiar words
    - Losing everyday objects
    - Trouble remembering names
    - Greater difficulty performing tasks
    - Forgetting material just read
    - Increasing trouble with planning, organizing
- 

### TALKING POINTS:

In the mild stages of Alzheimer's, a person may function **independently**. He or she may still **drive, work**, and be part of **social activities**.

Despite this, the person may feel as if he or she is having **memory lapses**, such as **forgetting familiar words** or the **location of everyday objects**.

Other common difficulties in the mild stage of Alzheimer's include:

- Trouble **remembering names** when introduced to new people
- Having greater difficulty **performing tasks** in social or work settings
- **Forgetting material** that one has just read
- Increasing trouble with **planning** or **organizing**

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<sup>16</sup> Alzheimer's Association. (n.d.) *Stages of Alzheimer's*. Retrieved from <https://www.alz.org/alzheimers-dementia/stages>

## SLIDE 19:

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### Moderate Alzheimer's (Middle-Stage)<sup>17</sup>

- Requires increasing care
  - Symptoms include:
    - Forgetfulness of personal history
    - Confusion about place or time
    - Need for help with bathing, toileting, dressing
    - Changes in sleep patterns
    - Increased risk of wandering
    - Personality and behavioral changes
- 

### TALKING POINTS:

As the disease progresses, a person with Alzheimer's will require a **greater level of care**.

In the moderate stage, **damage to nerve cells** in the brain can make it difficult to express thoughts and perform routine tasks.

During this stage, symptoms will be noticeable to others and may include:

- Forgetfulness of events or about one's own personal history
- Confusion about where they are or what day it is
- The need for help choosing proper clothing for the season or the occasion
- Trouble controlling bladder and bowels in some individuals
- Changes in sleep patterns, such as sleeping during the day and becoming restless at night
- An increased risk of wandering and becoming lost
- Personality and behavioral changes, including suspiciousness and delusions or compulsive, repetitive, behavior like hand-wringing or tissue shredding

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<sup>17</sup> Alzheimer's Association. (n.d.) *Stages of Alzheimer's*. Retrieved from <https://www.alz.org/alzheimers-dementia/stages>

## SLIDE 20:

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### Severe Alzheimer's (Late-Stage)<sup>18</sup>

- Typically longest stage
  - Requires full-time care
  - Loss of awareness of recent experiences and surroundings
  - Changes in physical abilities (walking, sitting, swallowing)
  - Vulnerable to infections
- 

### TALKING POINTS:

The severe stage of Alzheimer's is typically the **longest stage** and can last for many years. In the severe stage of Alzheimer's, individuals lose the ability to respond to their environment, to carry on a conversation, and, eventually, to control movement. They may still say words or phrases, but **communicating** becomes difficult.

As memory and **cognitive skills** continue to worsen, **personality** changes may take place, and individuals need **extensive help** with daily activities. At this stage, individuals may:

- Require full-time, round-the-clock **assistance** with daily personal care
- Lose **awareness** of recent experiences as well as of their surroundings
- Experience changes in **physical abilities**, including the ability to walk, sit, and eventually, swallow
- Become **vulnerable to infections**, especially pneumonia

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<sup>18</sup> Alzheimer's Association. (n.d.) *Stages of Alzheimer's*. Retrieved from <https://www.alz.org/alzheimers-dementia/stages>

*Image source:* Copyrighted image; used with permission from the Alzheimer's Association

## **SLIDE 21:**

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### **RISK FACTORS**

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#### **TALKING POINTS:**

Let's look at the risk factors for Alzheimer's disease.

## SLIDE 22:

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### Risk Factors: Age<sup>19,20 21</sup>

- #1 risk factor is advancing age
  - Risk doubles every 5 years after age 65
  - 1 in 3 people age ≥85
- 

### TALKING POINTS:

Currently, researchers don't fully understand what causes Alzheimer's disease in most people. As described earlier, in most cases it is likely a combination of **genetic**, **environmental**, and **lifestyle** factors that take place over a long period of time.

A number of risk factors have been identified that contribute to the development of Alzheimer's. Other risk factors are associated with dementia but need additional research.

The greatest risk factor for Alzheimer's dementia is **advancing age**. Most individuals with Alzheimer's diagnoses are age 65 or older. However, Alzheimer's and dementia are not normal parts of aging.

The risk of developing Alzheimer's increases with age. It approximately doubles every five years after age 65. In persons age 85 or older, about one in three have Alzheimer's.

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<sup>19</sup> Alzheimer's Association. (n.d.) *Causes and Risk Factors*. Retrieved from <https://www.alz.org/alzheimers-dementia/what-is-alzheimers/causes-and-risk-factors>

<sup>20</sup> Alzheimer's Association. (2019) *2019 Alzheimer's Disease Facts and Figures*.

<sup>21</sup> Alzheimer's Association. (n.d.) *Younger/Early Onset*. Retrieved from <https://www.alz.org/alzheimers-dementia/what-is-alzheimers/younger-early-onset>

*Image source:* pexels.com

## SLIDE 23:

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### Younger-Onset Alzheimer's Disease<sup>22</sup>

- Affects people younger than 65
  - Many are in their 40s and 50s
  - 200,000 have younger onset (in U.S.)
  - Up to 5% of population with Alzheimer's
- 

### TALKING POINTS:

While the vast majority of Alzheimer's occurs in older adults, Alzheimer's disease is not just a disease of old age. Younger-onset Alzheimer's (also known as early-onset) affects people beginning in their 40s and 50s. Although it is not known why younger-onset cases occur, scientists have identified rare genes that directly cause Alzheimer's in a few families.

In the U.S., it is estimated that approximately 200,000 people have younger-onset Alzheimer's disease- up to 5% of the population with Alzheimer's.

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<sup>22</sup> Alzheimer's Association. (n.d.). *Younger/Early Onset*. Retrieved from website: <https://www.alz.org/alzheimers-dementia/what-is-alzheimers/younger-early-onset>

*Image source:* National Cancer Institute, NCI Visuals Online, Rhoda Baer (Photographer)

## SLIDE 24:

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### Risk Factors: Family History, Education <sup>23</sup>

- Family history
  - Environmental factors
  - Years of formal education
- 

### TALKING POINTS:

In addition to advancing age, another strong risk factor is **family history**. People who have an immediate family member—a parent, brother, sister, or child—with Alzheimer’s are more likely to develop the disease. This risk increases if more than one family member has the disease.

When diseases tend to run in families, either **hereditary (genetics)** or environmental factors, or both, may play a role.

Scientists have identified a number of **hereditary genes** that either increase the likelihood or guarantee that people with the gene will develop Alzheimer’s.

Researchers are trying to determine the link between dementias and possible environmental factors such as exposure to pesticides, food additives, air pollution, and other problematic chemical compounds.

Several studies have demonstrated that fewer years of formal **education** and lower levels of **cognitive engagement may be** risk factors for dementia. People who have more years of formal education have lower rates of Alzheimer’s and other dementias than those with less education. Additional studies suggest that remaining socially and mentally active throughout life may support brain health and possibly reduce the risk of Alzheimer’s and other dementias.

Some researchers have proposed a “**cognitive reserve**” hypothesis to explain why some people maintain cognitive

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<sup>23</sup> Alzheimer’s Association. (n.d.) *Causes and Risk Factors*. Retrieved from <https://www.alz.org/alzheimers-dementia/what-is-alzheimers/causes-and-risk-factors>

*Image source:* Copyrighted image; used with permission from the Alzheimer’s Association

functioning even when damage to the brain from Alzheimer's is present. They posit that mental activity and stimulation over the life course (such as through education, mentally stimulating jobs, or leisure activities) enable some brains to flexibly and efficiently use cognitive networks (networks of neuron-to-neuron connections) in ways that may mask or delay appearance of symptoms.

## SLIDE 25:

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### Risk Factors: Race & Ethnicity<sup>24</sup>

- African-Americans: 2 times greater risk
  - Hispanics: 1.5 times greater risk
  - Cardiovascular risk factors more common
  - Lower levels of education, socioeconomic status
- 

### TALKING POINTS:

**Race and ethnicity** may also contribute to increased risk of developing Alzheimer's and other dementias. In the U.S., older **African-Americans** are about **two times more likely than** older whites to have Alzheimer's. Older **Hispanics** are about **one and one-half times more likely** than older whites to have Alzheimer's.

Variations in health, lifestyle, and socioeconomic circumstances across racial groups likely account for most of the differences in risk of Alzheimer's and other dementias by race. For example, African-American and Hispanic communities have higher incidence of certain Alzheimer's risk factors:

- Conditions such as **high blood pressure** and **diabetes** which are risk factors for Alzheimer's, are more common in African-Americans and Hispanic populations than in whites.
- Lower levels of **education** and other **socioeconomic** characteristics (such as lower income and access to quality care) among older racial and ethnic minorities may also contribute to increased risk.

Some studies suggest that differences based on race and ethnicity do not persist in rigorous analyses that account for such risk factors.

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<sup>24</sup> Alzheimer's Association. (2019) *2019 Alzheimer's Disease Facts and Figures*.

## SLIDE 26:

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### Risk Factors: Women<sup>25,26</sup>

- 2/3 of affected population
  - 16% of women age ≥ 71 (11% of men)
  - After age 65, have more than 1 in 5 chance (1 in 11 for men)
- 

### TALKING POINTS:

Almost 2/3 of U.S. adults with Alzheimer's are **women**.

Among those aged 71 and older, **16% of women have Alzheimer's** and other dementias, compared with 11% of men.

At age 65, women without Alzheimer's have more than a **one in five chance** of developing Alzheimer's during the remainder of their lives, compared with a one in 11 chance for men.

This may be partially explained by the fact that women live longer, on average, than men. Men who live longer may also be healthier and not have some of the chronic conditions such as cardiovascular disease that can heighten risk for Alzheimer's and other dementias.

However, researchers are questioning whether Alzheimer's risks for women could be higher at any age due to biological and/or genetic variations or differences in life experiences such as educational attainment.

Although rates of Alzheimer's are higher among women, the risk for some other types of dementia, such as vascular dementia, are greater in men.

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<sup>25</sup> Alzheimer's Association. (2019) *2019 Alzheimer's Facts & Figures*.

<sup>26</sup> Podcasy, J. & Epperson, C. (2016) Considering Sex and Gender in Alzheimer Disease and Other Dementias. *Dialogues in Clinical Neuroscience*, 18(4), 437–446.

*Image source:* National Cancer Institute, NCI Visuals Online, Daniel Sone (Photographer)

## SLIDE 27:

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### Modifiable Risk Factors: Head Trauma<sup>27</sup>

- Moderate and severe traumatic brain injury
    - Moderate injury: 2.3 times greater risk
    - Severe injury: 4.5 times greater risk
  - Risk remains for years after injury
- 

### TALKING POINTS:

There are some risk factors that may be changed or prevented to help reduce the risk of developing Alzheimer's.

Research has linked **moderate and severe traumatic brain injury** to a greater risk of developing Alzheimer's or another type of dementia years after the original head injury.

One of the key studies showing an increased risk found that older adults with a history of **moderate traumatic brain injury** (unconsciousness lasting more than 30 minutes) had a 2.3 times greater risk of developing Alzheimer's than their peers with no history of head injury.

Those with a history of **severe traumatic brain injury** (unconsciousness lasting more than 24 hours) had a 4.5 times greater risk of Alzheimer's. Also, people with repeated head injuries (such as boxers, football players, and combat veterans) are at an even higher risk of developing dementia.

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<sup>27</sup> Alzheimer's Association. (n.d.) *Traumatic Brain Injury*. Retrieved from [https://www.alz.org/alzheimers-dementia/what-is-dementia/related\\_conditions/traumatic-brain-injury](https://www.alz.org/alzheimers-dementia/what-is-dementia/related_conditions/traumatic-brain-injury)

## SLIDE 28:

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### Modifiable Risk Factors: Lifestyle<sup>28,29</sup>

- Increases risk
    - Current smoking
    - Midlife obesity
  - Decreases risk
    - Physical activity
    - Heart-healthy diets: DASH, Mediterranean diet
    - Mental and social activity
- 

### TALKING POINTS:

Certain **lifestyle factors** may help to lower the risk for developing Alzheimer's and other dementias.

There is fairly strong evidence that **current smoking** increases the risk of cognitive decline and possibly also dementia, and that quitting smoking may reduce the associated risk to levels comparable to those who have never smoked.

**Diet** and **physical activity** may help to prevent against obesity; **midlife obesity** has been shown to increase risk for Alzheimer's and other dementias.

**Exercise** may also directly benefit brain cells by increasing blood and oxygen flow in the brain.

Current evidence also suggests that eating a **heart-healthy diet** may also help protect the brain against cognitive decline.

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<sup>28</sup> Morris, MC, Tangney, CC, Wang, Y, Sacks, FM, Bennett, DA, and Aggarwal, NT. (2015) MIND Diet Associated with Reduced Incidence of Alzheimer's Disease. *Alzheimer's & Dementia*, 11(9), 1007–1014. doi:10.1016/j.jalz.2014.11.009

<sup>29</sup> Alzheimer's Association. (n.d.) *Prevention*. Retrieved from [https://www.alz.org/alzheimers-dementia/research\\_progress/prevention](https://www.alz.org/alzheimers-dementia/research_progress/prevention)

*Image source:* National Cancer Institute, NCI Visuals Online

Two diets that have been studied and may be beneficial are the **DASH (Dietary Approaches to Stop Hypertension) diet** and the **Mediterranean diet**.

- The **DASH diet** emphasizes vegetables, fruits, and fat-free or low-fat dairy products; includes whole grains, fish, poultry, beans, seeds, nuts, and vegetable oils, and limits sodium, sweets, sugary beverages, and red meats.
- The **Mediterranean diet** includes relatively little red meat and emphasizes whole grains, fruits and vegetables, fish and shellfish, and nuts, olive oil, and other healthy fats.

More recently, researchers have been studying a combined version of the DASH and Mediterranean diet called the **MIND diet**, which stands for Mediterranean-DASH Intervention for Neurodegenerative Delay. This diet has more emphasis on foods that support a healthy brain, such as those with omega-3 fatty acids.

Some studies have also indicated that staying **cognitively** and **socially active** may help reduce the risk of cognitive decline. This involves mentally stimulating activities and social connections.

## SLIDE 29:

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### Modifiable Risk Factors: Cardiovascular<sup>30,31</sup>

- Heart-head connection
  - Cardiovascular risk factors:
    - High blood pressure in midlife
    - Heart disease
    - Stroke
    - Diabetes
- 

### TALKING POINTS:

Growing evidence suggests that the health of the brain is closely linked to the overall health of the **heart** and **blood vessels**.

The brain is nourished by one of the body's richest networks of blood vessels. With every beat, the **heart pumps blood to the head**, where brain cells use the food and oxygen carried by the blood in order to function normally. As a result, many factors that damage the heart or blood vessels may also damage the brain and may increase the risk for developing Alzheimer's and other dementias.

Several conditions known to increase the risk of **cardiovascular disease**, including high blood pressure, heart disease, stroke, and diabetes, appear to increase the risk of developing dementia. Some autopsy studies show that as many as **80% of individuals** with Alzheimer's also have cardiovascular disease.

Controlling high blood pressure may reduce the combined risk of mild cognitive impairment and dementia. In addition to treating high blood pressure, reducing the risk for cardiovascular disease also includes not smoking, preventing or effectively managing diabetes, as well as avoiding obesity. This is especially important for people in their 40s-50s (midlife) when the early brain changes of Alzheimer's can begin.

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<sup>30</sup> Alzheimer's Association. (n.d.) *Prevention*. Retrieved from [https://www.alz.org/alzheimers-dementia/research\\_progress/prevention](https://www.alz.org/alzheimers-dementia/research_progress/prevention)

<sup>31</sup> Yaffe, K. (2019) Prevention of Cognitive Impairment with Intensive Systolic Blood Pressure Control. *JAMA*, 321(6), 548-549.

*Image source:* pixabay.com

## **SLIDE 30:**

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### **TREATMENT & MANAGEMENT**

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#### **TALKING POINTS:**

Next, we will discuss how Alzheimer's dementia is diagnosed, treated, and managed.

## SLIDE 31:

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### Diagnosing Alzheimer's Dementia<sup>32</sup>

- No single test
  - Medical evaluation
    - Medical history
    - Mental status testing
    - Information from family and friends
    - Physical and neurological exams
    - Rule out other causes
- 

#### TALKING POINTS:

Physicians can almost always determine if a person has **dementia**; however, it can be difficult to identify the exact cause.

Establishing a diagnosis for Alzheimer's can be more challenging. There is no single test that can show whether a person has Alzheimer's.

A careful medical evaluation is required, which includes:

- A thorough medical history
- Mental status testing
- Information from family and friends
- Physical and neurological exams
- Tests (such as blood tests and brain imaging) to rule out other causes of dementia-like symptoms

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<sup>32</sup> Alzheimer's Association. (n.d.) *Diagnosis*. Retrieved from <https://www.alz.org/alzheimers-dementia/diagnosis>

*Image source:* National Cancer Institute, NCI Visuals Online

## SLIDE 32:

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### Treating & Managing Alzheimer's<sup>33</sup>

- No cure
  - Drug and non-drug treatments
  - Goals of existing treatment
    - Maintain quality of life
    - Maximize functioning in daily activities
    - Foster safe environment
    - Promote social engagement
- 

### TALKING POINTS:

Currently, there is no cure for Alzheimer's and no treatment that slows the progression of the disease. Drug and non-drug treatments may help with both cognitive and behavioral *symptoms*, but don't affect the underlying disease.

**Medications** are used to treat symptoms and are more effective if administered after early diagnosis.

The chief goals of existing treatment are to:

- Maintain quality of life
- Maximize function in daily activities
- Enhance cognition, mood, and behavior
- Foster a safe environment
- Promote social engagement, as appropriate

Clinical trials are ongoing for a search for a cure and better treatment of the Alzheimer's and other dementias.

Researchers need people at-risk of or living with dementia, caregivers, and healthy individuals to participate in clinical trials to test potential treatments and methods of prevention.

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<sup>33</sup> Alzheimer's Association. (2019) *2019 Alzheimer's Disease Facts and Figures*.

## SLIDE 33:

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### Alzheimer's: Co-Morbidities<sup>34,35</sup>

- Additional chronic conditions (e.g., heart disease, diabetes, depression)
  - Difficult to manage
  - Higher rates of hospitalizations and costs
  - Preventable hospitalizations
- 

### TALKING POINTS:

Treating people with Alzheimer's often requires the management of **co-morbidities**. Co-morbidities refer to additional chronic conditions –such as heart disease, diabetes, depression, and arthritis– that are present in combination with a primary disease. People with Alzheimer's and other dementias are **more likely** to have co-morbidities than other older people without dementia. It is estimated that more than 95% of people with dementia have one or more chronic conditions.

The cognitive problems associated with Alzheimer's and dementia can lead to **poor self-management** of co-morbidities. On average, people with dementia have twice as many **hospital stays** and have significantly higher **Medicare costs** of other older people.

Most of the hospitalizations are not for Alzheimer's itself, but for these other conditions that are often complicated by, or result from, Alzheimer's, such as falls. Many of these hospitalizations are preventable (or potentially avoidable) with better quality care and management of co-morbidities and injury risks.

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<sup>34</sup> Alzheimer's Association and Centers for Disease Control and Prevention. *Healthy Brain Initiative, State and Local Public Health Partnerships to Address Dementia: The 2018-2023 Road Map*. Chicago, IL: Alzheimer's Association; 2018.

<sup>35</sup> Alzheimer's Association. (2019) *2019 Alzheimer's Disease Facts and Figures*.

*Image source:* pixabay.com

## SLIDE 34:

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### Alzheimer's: Unique Aspects<sup>36</sup>

- Financial hardship
    - May lose income and savings
    - Increased reliance on public programs
  - Stigma
  - Vulnerability to abuse
  - Caregiver burden
- 

### TALKING POINTS:

People with younger-onset dementia may **lose income and savings** when they become unable to work. Those with dementia at any age may need to pay for additional services, especially as the disease progresses.

As the need for care intensifies, many people with Alzheimer's and dementia may live in nursing homes for long periods of time. The financial burden of this care can result in turning to **Medicaid** and other **public programs** to help pay for their services and support.

People with dementia report being **afraid** of the reactions of others and a **lower perceived status** within society because of the diagnosis. The stigma associated with dementia may contribute to **social exclusion**, a reluctance to seek **help** or even a diagnosis, a sense of **shame** and **inadequacy**, and **low self-esteem**.

People with Alzheimer's and other dementias tend to be especially **vulnerable to abuse** because the disease may prevent them from reporting the abuse or recognizing it. Abuse can occur anywhere, including at home and in care settings. Abuse can take many forms: physical or emotional abuse, neglect, and/or financial misuse.

Another unique aspect of Alzheimer's is the level of care that must be provided as the disease progresses and the

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<sup>36</sup> Alzheimer's Association. (n.d.) *Abuse*. Retrieved from <https://www.alz.org/help-support/caregiving/safety/abuse>

stress this can put on the caregiver. An individual with Alzheimer's will need ever-increasing levels of care. Most people with Alzheimer's disease have a primary caregiver, often a family member, who is crucial to ensuring appropriate care. As the person with Alzheimer's declines, the primary caregiver often takes on an increasing role in advocating for and attending to all aspects of the person's health and well-being as well as all their financial affairs. Given the level, duration, and intensity of care needed, caregivers for people with dementia have a greater burden of care than non-dementia caregivers.

## SLIDE 35:

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### Alzheimer's: Caregivers<sup>37</sup>

- Types of care activities include daily living activities, medication management, financial management
  - Level of care needed increases and often results in complete dependence
  - Caregiving has significant physical and emotional stress
- 

### TALKING POINTS:

The term **caregiver** is used to describe a person who provides a level of care and support for another that exceeds typical responsibilities of daily life.

Caregiving responsibilities, especially in the moderate and severe stages, often include:

- Helping with **dressing, bathing, using the toilet, and eating**
- **Shopping, meal preparation, transportation, medication management, and financial management**
- Providing **emotional support**

People with Alzheimer's require **increasing levels of care** as the disease progresses; more severe stages may require constant supervision and result in complete dependence on caregivers (paid or unpaid).

Being a caregiver for someone with Alzheimer's can take a significant **physical** and **emotional** toll.

- Caregivers of someone with Alzheimer's or other dementias are at increased risk for negative health impacts
- Nearly 60% of Alzheimer's and dementia caregivers rate the emotional stress of caregiving as high or very high

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<sup>37</sup> Alzheimer's Association. (n.d.) *Caregiving*. Retrieved from <https://www.alz.org/help-support/caregiving>

## SLIDE 36:

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### Role of Public Health

- 4 key ways public health can have an impact :
    - Surveillance/monitoring
    - Risk reduction/primary prevention
    - Early detection and diagnosis
    - Safety and quality of care
- 

### TALKING POINTS: (see module 3 for more information)

Public health plays an important part in addressing Alzheimer's. Four key public health intervention tools that can reduce the burden of Alzheimer's disease are:

- **Surveillance/monitoring** that allows public health to compile data and use it to:
  - Develop interventions
  - Inform public policy
  - Guide research
  - Educate populations
- **Promoting primary prevention** can be used to promote **risk reduction** and **promote cognitive health**
- Public health may play an important role increasing **early detection and diagnosis** of Alzheimer's disease
- **Safety and quality of care:** Caring for those with Alzheimer's and dementia requires specialized knowledge about the disease continuum and skill to effectively communicate and care for individuals and their family caregivers. Providing training for health care providers and caregivers can increase the quality care for and safety of the individual, as well as help caregivers sustain their role. Information sharing is also important for those in the community who may interact with individuals with Alzheimer's such as first responders, public transportation providers, pharmacies, faith communities, etc.

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## SLIDE 37:

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### Dementia Capable Systems and Dementia Friendly Communities

- Dementia capable systems
    - Support services
    - Workforce training
  - Dementia friendly communities
- 

#### TALKING POINTS: (see module 4 for more information)

Public health also has a role to play in supporting dementia capable systems and dementia friendly communities. At a larger level, states, and communities can become dementia capable in accommodating the needs of a population with Alzheimer's and other dementias.

A **dementia capable system** is a system or infrastructure that works to meet the needs of a people with dementia and their caregivers through providing education, support, and services. Public health can contribute to a **dementia capable system** through:

- Ensuring access to **support services** for people with dementia and their caregivers
- Workforce **training** and **education**
- Public health can also support the creation of **dementia friendly communities**. These are cross-sector, community-wide efforts to have support services, resources, and safe environments that allow people with dementia and their caregivers to stay connected to the community. This can include enhancing support services and resources, addressing accessibility and mobility issues, providing dementia training for health care, police, EMS, and firefighters, and providing resources to support family caregivers such as respite care services.

*Image source:* Copyrighted image; used with permission from the Alzheimer's Association

## SLIDE 38:

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### For More Information

For more information, please visit:

Alzheimer's Association: <http://www.alz.org>

CDC's Alzheimer's Disease and Healthy Aging Program:

<https://www.cdc.gov/aging/>

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### TALKING POINTS:

For more information on the topics covered in this presentation, please go to the Alzheimer's Association website at <http://www.alz.org> or the Centers for Disease Control and Prevention's Alzheimer's Disease and Healthy Aging Program at <https://www.cdc.gov/aging/>. There you can find resources, latest research and information.

## SLIDE 39:

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### Competencies:

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

- 1.2.1 Distinguish normal biological aging changes from pathology including genetic factors.
- 1.2.4 Recognize common late-life syndromes and diseases and their related bio-psycho-social risk and protective factors.

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

- 2. Locate, use, evaluate, and synthesize public health information (bachelors level)
- 4. Interpret results of data analysis for public health research, policy, or practice (masters-level)

#### **Council on Linkages Between Academia and Public Health Practice:**

- 1A1. Describes factors affecting the health of a community (e.g., equity, income, education, environment)
- 

**TALKING POINTS:** *(this slide can be edited as needed or removed)*

The content in this presentation supports the development of the following competencies:

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

- 1.2.1 Distinguish normal biological aging changes from pathology including genetic factors.
- 1.2.4 Recognize common late-life syndromes and diseases and their related bio-psycho-social risk and protective factors.

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

- 2. Locate, use, evaluate and synthesize public health information (bachelor's level)
- 4. Interpret results of data analysis for public health research, policy or practice (master's-level)

**Council on Linkages Between Academia and Public Health Practice:**

- 1A1. Describes factors affecting the health of a community (e.g., equity, income, education, environment)

## SAMPLE TEST QUESTIONS

**1- Dementia is a decline in mental ability that is a normal part of aging.**

- a. True
- b. False

**Answer: B**

**2- The number one risk factor for Alzheimer's disease is:**

- a. Getting older
- b. High blood pressure
- c. High cholesterol
- d. Heredity/genetics
- e. Lack of mental stimulation

**Answer: A**

**3- The more years of education a person has may decrease his/her risk for getting Alzheimer's disease.**

- a. True
- b. False

**Answer: A**

**4- The lifespan for someone after being diagnosed with Alzheimer's can be up to 20 years.**

- a. True
- b. False

**Answer: A**

**5- Which of the following statements is true about Alzheimer's disease:**

- a. Can be diagnosed through a blood test
- b. Is a progressive disease
- c. Is reversible with proper medication
- d. All of the above
- e. None of the above

**Answer: B**

## **FACULTY GUIDE**

Module 3: Alzheimer's Disease – What is the Role of Public Health?

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Alzheimer's Association and the Centers for Disease Control and Prevention

## ABOUT MODULE 3

This module is part of the Alzheimer's Association curriculum, *A Public Health Approach to Alzheimer's and Other Dementias*. Developed as part of a cooperative agreement with CDC's Alzheimer's Disease and Healthy Aging Program, and in partnership with Emory University's Rollins School of Public Health, this curriculum addresses cognitive health, cognitive impairment, and Alzheimer's disease and is for use by undergraduate faculty in schools and programs of public health and other related disciplines. It can also be adapted for other purposes.

**Module 3: Alzheimer's Disease – What is the Role of Public Health?** briefly describes the Alzheimer's disease epidemic in the U.S., followed by a discussion of four tools of public health that may play significant roles in mitigating the Alzheimer's disease crisis.

The four public health intervention tools discussed are:

5. Surveillance/monitoring
6. Primary prevention
7. Early detection and diagnosis
8. Ensuring safety and quality of care

Each tool is described and applied to the context of a public health response to Alzheimer's disease and dementia. Progress to date and challenges associated with each tool are addressed.

## LEARNING OBJECTIVES

At the end of **Module 3: Alzheimer's Disease – What is the Role of Public Health?** students will be able to:

- List four key tools public health can apply to the Alzheimer's epidemic
- Describe surveillance/monitoring and how public health practitioners can apply it in response to Alzheimer's disease
- Name the two Behavioral Risk Factor Surveillance System (BRFSS) modules that pertain to cognitive decline and caregiving
- Describe primary prevention and how public health practitioners may apply it in response to Alzheimer's disease
- Explain why it is important to promote early detection of Alzheimer's disease
- Summarize one workforce challenge that affects the safety and quality of care for people living with dementia

## COMPETENCIES

Module 3 promotes basic learning that supports the development of certain competencies:

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

- 1.6.1 Identify and explain research methodologies, interpretations, and applications used by different disciplines to study aging

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

- 2. Locate, use, evaluate, and synthesize public health information (bachelors level)
- 4. Interpret results of data analysis for public health research, policy, or practice (masters-level)

### **Council on Linkages Between Academia and Public Health Practice:**

- 3A8. Describes the roles of governmental public health, health care, and other partners in improving the health of a community
- 8A3. Describes the ways public health, health care, and other organizations can work together or individually to impact the health of a community

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## LAYOUT OF MODULE 3 FACULTY GUIDE

This guide is laid out in the following sections:

- Slide Guide with talking points
- Sample test questions
- Case studies
- Video resources

*Note: Some slides in this module duplicate content from other modules and may be removed as needed.*

### HOW TO USE THE MATERIALS

- ✓ This module is one of four modules in this curriculum that were designed for use either as a set or as stand-alone modules
- ✓ Users are free to make changes to the materials to fit their needs, including adding, modifying or removing content, graphics, talking points, discussion questions, or learning activities
- ✓ The Faculty Guide for each module includes a slide guide that contains the information as presented in the slide, talking points, space for presenter notes, and references
- ✓ The talking points included in the Faculty Guide should not be read word for word; each presenter should review the materials before delivering the material to ensure familiarity and deliver the information in his/her own style
- ✓ Delivery time will generally be 60-90 minutes per module, depending on class engagement, presenter style, and the addition or elimination of any content, discussion questions, or learning activities
- ✓ Discussion questions are included in the slide deck of each module. These may be modified or removed at the discretion of the presenter. Questions may also be used for other activities such as small group discussion or individual writing assignments
- ✓ Video resources, a list of articles and case studies are also included to help in learning more about the topics presented in each module
- ✓ Test questions are provided with each module as an additional resource for faculty
- ✓ All materials are 508 compliant. (Note: if changes are made to the curriculum, 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/making-files-accessible/index.html>)

## STUDENT ENGAGEMENT OPTIONS

In addition to the PowerPoint slide deck and guide, there are additional resources included in this guide. These resources are designed to increase student engagement and enhance understanding of the concepts covered in this module. Following the slide guide, there is a series of case studies and a list of video resources. It is recommended that the presenter review these resources to determine if these additional materials would be useful in illustrating the concepts covered in the module.

## DISCUSSION QUESTIONS

The following discussion questions are included in the slide deck:

- How could the Cognitive Decline and Caregiver data be used by state and local public health entities? *(Slide 18)*
- What are risk factors for Alzheimer's disease that could be modified/reduced? *(Slide 22)*
- How could public health play a role in promoting risk reduction and cognitive health? *(Slide 27)*
- Would you want to know if you had Alzheimer's? Why or why not? *(Slide 31)*
- What can public health do to promote early detection of Alzheimer's? *(Slide 35)*

## LEARNING ACTIVITIES

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

- Envision and describe a health education campaign focused on early diagnosis of Alzheimer's using the "10 Early Signs." Describe what would take place during the campaign, including target audience, strategy, partners, and materials.
- Research health education campaigns that focus on cardiovascular health. Select one or more and describe how the campaign(s) could be adapted to include brain health.
- Your state health official asks you to select just one of the three key public health intervention tools to address the disproportional impact of Alzheimer's disease on a specific population. In a two-page memo, select a population and one of the three key interventions; justify the choice of that intervention to reduce health disparities.

## ADDITIONAL READING

Alzheimer's Association. (2019). 2019 Alzheimer's Disease Facts and Figures. Chicago, IL: Alzheimer's Association. <http://www.alz.org/facts>

Alzheimer's Association and Centers for Disease Control and Prevention. Healthy Brain Initiative, State and Local Public Health Partnerships to Address Dementia: The 2018-2023 Road Map. Chicago, IL: Alzheimer's Association; 2018.  
<https://www.alz.org/media/Documents/healthy-brain-initiative-road-map-2018-2023.pdf>

Alzheimer's Association. (n.d.). Data and Needs Assessment.  
<https://www.alz.org/professionals/public-health/issues/data-and-needs-assessment>

CDC, Behavioral Risk Factor Surveillance System (BRFSS) Modules:  
<http://www.cdc.gov/aging/healthybrain/brfss-faq.htm>

Hoffman, D. (2015, July 14). Looking at the future of Alzheimer's disease policy. [Blog post]. Retrieved from  
<https://www.healthaffairs.org/doi/10.1377/hblog20150714.049333/full/>  
[Olivari BS, Baumgart M, Lock SL, et al. CDC Grand Rounds: Promoting Well-Being and Independence in Older Adults. MMWR Morb Mortal Wkly Rep 2018;67:1036–1039. DOI: http://dx.doi.org/10.15585/mmwr.mm6737a4](https://doi.org/10.1186/s12916-018-1036-1)

*Learn About Careers in Aging*. Washington, DC: Association for Gerontology in Higher Education and The Gerontological Society of America.  
<https://www.pdx.edu/ioa/sites/www.pdx.edu.ioa/files/learnaboutcareersinaging.pdf>

Warshaw, G. A., & Bragg, E. J. (2014). Preparing the health care workforce to care for adults with Alzheimer's disease and related dementias. *Health Affairs*, 33(4), 633-641.  
<http://content.healthaffairs.org/content/33/4/633.abstract>

## SLIDE GUIDE

This slide guide accompanies the PowerPoint presentation for this module. The right margin has been widened to allow the presenter to write notes.

### SLIDE 1:

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#### Module 3: Alzheimer's Disease- What is the Role of Public Health?

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#### TALKING POINTS:

This presentation entitled, **Alzheimer's Disease – What is the Role of Public Health?**, is part of a curriculum for public health students entitled, *A Public Health Approach to Alzheimer's and Other Dementias*. It was developed by the Emory Centers for Training and Technical Assistance for the Alzheimer's Association with funding from the Centers for Disease Control and Prevention.

This presentation will cover specific tools of public health and how they may be used to address the Alzheimer's and dementia epidemic.

## SLIDE 2:

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### Learning Objectives

- List 4 key ways that public health can respond to the Alzheimer's disease epidemic
  - Describe surveillance/monitoring and how public health can apply it in response to Alzheimer's
  - Name the 2 BRFSS modules that pertain to cognitive decline and caregiving
  - Describe risk reduction and how public health can apply it to Alzheimer's
  - Explain why it is important to promote early detection of Alzheimer's
- 

### TALKING POINTS:

By the end of the presentation, you will be able to:

- List 4 key ways that public health can respond to the Alzheimer's disease epidemic
- Describe surveillance/monitoring and how public health can apply it in response to Alzheimer's
- Name the 2 BRFSS modules that pertain to cognitive decline and caregiving
- Describe risk reduction and how public health can apply it to Alzheimer's
- Explain why it is important to promote early detection of Alzheimer's

## SLIDE 3:

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### Introduction: Dementia & Alzheimer's Disease<sup>1</sup>

- Dementia is a decline in mental ability that interferes with daily life
  - Alzheimer's disease is the most common form of dementia
    - Progressive loss of memory and brain function
    - Requires increasing aid and assistance
    - No cure and limited treatment options
  - Huge financial and emotional burden
  - Public health plays important role in addressing Alzheimer's disease
- 

### TALKING POINTS:

Before we begin discussing the role of public health in addressing Alzheimer's disease, it may be helpful to know a little more about Alzheimer's and dementia.

The term **dementia** is a general term for a decline in mental abilities that is severe enough to interfere with daily life. Dementia, which is not a disease but a syndrome, is characterized by damage to brain cells due to age, brain injury, other conditions or diseases, heredity, or a combination of factors.

There are several types of dementia and most occur in those over 65; however, there are types of dementia that occur in those younger than 65.

The term **Alzheimer's dementia** is used to describe the stage of Alzheimer's disease when an individual has observable symptoms such as memory loss, mood/behavior changes, and difficulty with activities of daily living.

**Alzheimer's disease** is the most common cause of dementia. Alzheimer's is a disease that progressively

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<sup>1</sup> Alzheimer's Association. (2019) *2019 Alzheimer's Disease Facts and Figures*.

damages and eventually destroys brain cells over the course of many years, even decades.

There is **no cure** for Alzheimer's. While there are approved drug **treatments**, the goal of existing treatment is to delay or reduce symptoms, not to cure or reverse the course of the disease.

As the person with Alzheimer's loses memory and function, **caregivers**, who are most often family members, are needed to provide increasing amounts of assistance. This assistance can range from helping to manage finances and household tasks to hands-on care, such as bathing, dressing, feeding, and other activities of daily living.

Given the nature of the disease and its increasing prevalence, there is a **huge financial, emotional and physical impact** on people with Alzheimer's, their families, caregivers, and the health care system as a whole.

**Public health** plays an important role in addressing Alzheimer's disease through surveillance, prevention, detection, and support of dementia-capable systems.

In this presentation, we will be focusing on the role of public health.

## SLIDE 4:

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### Alzheimer's: A Public Health Crisis

- Historically viewed as a medical or aging issue
  - Growing recognition of public health crisis:
    - Large and growing epidemic
    - Significant impact
    - Ways to intervene
- 

### TALKING POINTS:

Historically, Alzheimer's and other dementias have been viewed primarily as **medical** or **aging** issues.

Yet as more is learned about these conditions and the impact they are having on society, there is a strong recognition of Alzheimer's and dementia as issues in which **public health** has an important role to play.

Alzheimer's disease is a public health crisis because:

- The **epidemic** is large and growing
- The **impact** on populations and communities is substantial
- There are ways to **intervene** using a public health approach to achieve meaningful improvements in health outcomes

## SLIDE 5:

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### Alzheimer's: Epidemic (U.S.)<sup>1</sup>

- Nearly 6 million adults
  - 1 in 10 adults age ≥65
  - 1 in 3 adults age ≥85
  - By 2050, expected to reach 13.8 million
- 

### TALKING POINTS:

Today, nearly **6 million adults** in the U.S. are living with Alzheimer's, including an estimated 200,000 under the age of 65.

**One in ten** adults age 65 and older (10%) currently has Alzheimer's disease; approximately **one in three** people age 85 and older have the disease.

By 2050, the number of Americans living with Alzheimer's disease is expected to total **13.8 million** and could be as high as **16 million**.

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<sup>1</sup> Alzheimer's Association. (2019) *2019 Alzheimer's Disease Facts and Figures*.

Image source: pixabay.com

## SLIDE 6:

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### Alzheimer's Impact: Costs<sup>2</sup>

- Significant costs to Medicare, Medicaid, individuals, caregivers
  - Annual costs of care nearly \$300 billion
  - Most expensive disease in the U.S.
- 

### TALKING POINTS:

Alzheimer's imposes **significant costs** on federal and state budgets through Medicare and Medicaid, as well as on individuals, families, and caregivers.

In the U.S. the **annual costs** of direct care for people with Alzheimer's disease is nearly **\$300 billion**. "Direct care" includes both paid health care and long-term care. It does not include caregiving (an essential part of Alzheimer's care).

Alzheimer's disease is the **most expensive disease** to treat and provide care for in America, costing more than heart disease and cancer.

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<sup>2</sup> Alzheimer's Association. (2019) *2019 Alzheimer's Disease Facts and Figures*.

Image source: cker.com

## SLIDE 7:

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### Alzheimer's: Disproportional Impact<sup>3</sup>

- Women: 2/3 of affected population
  - African-Americans: 2 times more likely
  - Hispanics: 1.5 times more likely
- 

### TALKING POINTS:

Alzheimer's dementia disproportionately impacts **women** and **minority** populations.

Women make up **2/3** of the population with Alzheimer's.

In the U.S., **African-Americans** and **Hispanics** have higher rates of Alzheimer's and other dementias than whites. Available data indicate that in the United States, older **African-Americans** are about **two times more** likely than older whites to have Alzheimer's and other dementias.

Older **Hispanics** are about **one and one-half times** more likely than older whites to have these conditions.

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<sup>3</sup> Alzheimer's Association. (2019) *2019 Alzheimer's Disease Facts and Figures*.

*Image source:* National Cancer Institute, NCI Visuals Online, Daniel Sone (Photographer)

## SLIDE 8:

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### Alzheimer's: Caregiving Burden<sup>4</sup>

- Requires increasing levels of caregiving (paid and unpaid)
  - Over 16 million caregivers
  - 18 billion hours of unpaid care annually
  - Hardships: health, emotional, financial
- 

### TALKING POINTS:

Living with Alzheimer's disease requires increasing levels of **caregiving** (paid and unpaid) as the disease progresses.

Later stages may require constant supervision and involve complete dependence on caregivers.

Currently, it is estimated that over **16 million** family members and friends provide **nearly 18 billion hours** of unpaid care annually. Financially, these contributions are valued at **over \$230 billion**.

As a result of their role in caring for someone with Alzheimer's, caregivers often face significant hardships related to their own health, emotional wellbeing, and financial stability.

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<sup>4</sup> Alzheimer's Association. (2019) *2019 Alzheimer's Disease Facts and Figures*.

*Image source:* Copyrighted image; used with permission from the Alzheimer's Association

## SLIDE 9:

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### Alzheimer's: Health Care Burden<sup>5</sup>

- Disproportionate use of health care resources
    - Hospitalized twice as often
    - 7 in 10 residents in assisted living have some form of cognitive impairment
  - Workforce shortage
  - Inadequate professional training
- 

### TALKING POINTS:

The burden of Alzheimer's and other dementias on the **health care system** is significant.

Individuals with Alzheimer's disease use a disproportionate amount of health care resources. For example, they have twice as many **hospitalizations** than older adults without the disease.

In addition, nearly 7 in 10 of residents in assisted living facilities have some sort of cognitive impairment. Many people with Alzheimer's and other dementias receive care in their home or a loved one's home as long as possible before entering an assisted living or nursing home. Care is most often provided by family members or paid home care workers.

With the growing number of older adults in the U.S. population (both with and without Alzheimer's and other dementias), the country is facing a **workforce shortage** of health care and home care professionals who are trained to meet the needs of older adults.

Many professionals already in the workforce are not adequately **trained** on the needs of people with Alzheimer's and other dementias.

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<sup>6</sup>U.S. Department of Health and Human Services. (2018) *National Plan to Address Alzheimer's Disease: 2018 Update*.

*Image source:* Copyrighted image; used with permission from the Alzheimer's Association

## SLIDE 10:

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### Public Health: Poised for Impact <sup>6</sup>

4 key ways public health can have an impact:

- Surveillance/monitoring
  - Risk reduction
  - Early detection and diagnosis
  - Safety and quality of care
- 

### TALKING POINTS:

According to the Healthy Brain Initiative's *State and Local Public Health Partnerships to Address Dementia*, public health has a vital role to play in promoting cognitive function and addressing the impact on healthcare system, community, and individuals.

Through its broad community-based approach, public health can provide the following:

- **Surveillance/monitoring**
- **Risk reduction**
- **Early detection and diagnosis**
- **Safety and quality of care**

We will discuss each of these in more detail.

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<sup>6</sup> Alzheimer's Association and Centers for Disease Control and Prevention. *Healthy Brain Initiative, State and Local Public Health Partnerships to Address Dementia: The 2018-2023 Road Map*. Chicago, IL: Alzheimer's Association; 2018.

*Image source:* Copyrighted image; used with permission from the Alzheimer's Association

## **SLIDE 11:**

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### **Public Health Impact: SURVEILLANCE & MONITORING**

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#### **TALKING POINTS:**

Public health surveillance and monitoring involve collecting, analyzing, and interpreting health-related data within a population.

## SLIDE 12:

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### Surveillance & Public Health<sup>7</sup>

- Compile data on a population level, including:
    - Prevalence of certain diseases
    - Health risk factors
    - Health behaviors
    - Burden of diseases
  - State-level data on Alzheimer's and dementia growing; yet data gaps remain
- 

### TALKING POINTS:

Public health surveillance is the collection, analysis, and interpretation of health data that informs planning, implementation, and evaluation of public health practice, policies, and programs. Surveillance activities are done at the federal, state, and local levels.

Surveillance is used to compile data on a population level, including:

- The **prevalence** of certain diseases to understand how common or widespread they are
- Health **risk factors** (such as tobacco use, high blood pressure, and overweight/obesity)
- Health **behaviors** (such as nutrition and physical activity)
- **Burden** of particular diseases and conditions (such as financial costs, mortality, and morbidity)

Developing effective responses to the Alzheimer's epidemic necessitates understanding how Alzheimer's and dementia impact states and communities. As it relates to Alzheimer's and other dementias, the availability of **state-level data** is growing, but gaps remain regarding prevalence and impact of cognitive decline as well as roles and impact on caregivers of those with dementia.

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<sup>7</sup> Alzheimer's Association. (2018) *Data Collection and Behavioral Risk Factor Surveillance System (BRFSS)*.

Image source: pexels.com

## SLIDE 13:

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### Behavioral Risk Factor Surveillance System (BRFSS)<sup>8</sup>

- Behavioral Risk Factor Surveillance System (BRFSS) – CDC
    - Health-related risk behaviors
    - Chronic health conditions
    - Use of preventive services
  - State-based data
  - Cognitive Decline module, Caregiver module
- 

#### TALKING POINTS:

In the U.S., state-based data on health-related risk behaviors, chronic health conditions, and use of preventive services is collected through the **Behavioral Risk Factor Surveillance System (BRFSS)**. The BRFSS is the nation's premier system for collecting data on health-related risk behaviors, chronic conditions and use of preventive services. The survey is conducted by telephone and is collected at the state level by all 50 states and U.S. territories. It is a partnership between the Centers for Disease Control and Prevention (CDC) and state health departments. The survey is conducted by state health departments and is comprised of core component questions, optional modules and state-based questions.

CDC has developed two BRFSS modules that allow states to collect data on the prevalence of and impact on those experiencing cognitive decline as well as provide insight into the role and challenges faced by caregivers. The two BRFSS modules are the **Cognitive Decline** module and the **Caregiver** module.

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<sup>8</sup> Centers for Disease Control and Prevention. (2014) *About BRFSS*. Retrieved from <https://www.cdc.gov/brfss/about/index.htm>

*Image source:* cker.com

## SLIDE 14:

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### BRFSS: Cognitive Decline Module<sup>9,10</sup>

- Comprised of questions about:
    - Confusion or memory loss
    - Impact on daily activities
    - Need for assistance and caregiving
    - Discussions about memory with health care professional
  - 52 states/territories have used at least once
- 

### TALKING POINTS:

The **Cognitive Decline** module contains questions for BRFSS respondents age 45 and older that ask about:

- Increased **confusion** or **memory loss** in the previous 12 months (known as **subjective cognitive decline** –the self-reported experience of these symptoms )
- If day-to-day activities have been affected by confusion or memory loss
- Whether individuals need assistance with day-to-day activities, and if so, were they able to get the help they needed
- Whether confusion or memory loss interfered with activities outside the home, such as work, volunteering, or social activities
- Whether individuals have discussed their memory problems with a **health care professional**

To date, all 50 states plus DC and Puerto Rico have used the Cognitive Decline module at least once.

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<sup>9</sup> Alzheimer's Association. (2018) *Nationwide Cognitive Data from the 2015-2016 BRFSS [Fact Sheet]*.

<sup>10</sup> Centers for Disease Control and Prevention. (2015) *Behavioral Risk Factor Surveillance System (BRFSS) 2015 Cognitive Decline Module*. Retrieved from website: <http://www.cdc.gov/aging/healthybrain/brfss-faq.htm>

## SLIDE 15:

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### BRFSS and Subjective Cognitive Decline<sup>11,12</sup>

- About 80% have at least one other chronic condition
  - More than 1/3 said cognitive issues interfered with ability to work, volunteer, engage socially
  - Over 50% have not talked to a health care provider about memory problems
- 

### TALKING POINTS:

**Subjective cognitive decline** is a person's self-reported memory issues or decline in thinking processes. The most recent survey results of the BRFSS Cognitive Decline module found that among those who report having memory problems:

- About 80 percent have at least one other chronic condition
- More than a third said cognitive decline interfered with their ability to work, volunteer, or engage socially
- Over half have not talked to a health care provider about their memory problems

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<sup>11</sup> Alzheimer's Association. (2018) *Nationwide Cognitive Data from the 2015-2016 BRFSS [Fact Sheet]*.

<sup>12</sup> Centers for Disease Control and Prevention. (2015) *Behavioral Risk Factor Surveillance System (BRFSS) 2015 Cognitive Decline Module*. Retrieved from website: <http://www.cdc.gov/aging/healthybrain/brfss-faq.htm>

Image source: pexels.com

## SLIDE 16:

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### BRFSS: Caregiver Module<sup>13</sup>

- Comprised of questions about:
    - Prevalence of caregiving and caregiving activities
    - Caregiver relationship to care recipient and health condition necessitating care
    - Scope of caregiving
    - Caregiver challenges
  - 49 states/territories have used at least once
- 

### TALKING POINTS:

The **Caregiver Module** asks questions to collect data about:

- Prevalence of caregiving and caregiving activities
- Who is a **caregiver** (age, gender, relationship with care recipient)
- **Scope** of caregiving, average hours, types of assistance provided
- **Challenges** associated with caregiving

To date, there are 49 states/territories that have used the Caregiver Module at least once.

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<sup>13</sup> Alzheimer's Association. (2018) *Caregiver Data from the 2016 BRFSS*.

## SLIDE 17:

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### BRFSS: Caregiver Module Findings<sup>14</sup>

- Typical dementia caregiver is a middle-aged woman, usually daughter/daughter-in-law, often still employed
  - Nearly 1/3 provide 20+ hours of care per week
  - Majority of care is personal care tasks
  - Caregivers' mental or physical health can be negatively impacted by strain of long-term caregiving
- 

### TALKING POINTS:

Recent survey findings from the BRFSS **Caregiver Module** include:

- The typical caregiver for a person with Alzheimer's or other dementia is a middle-aged woman, usually a daughter or daughter-in-law, who is often still employed while being a primary caregiver
- Nearly one-third provide 20+ hours of care per week, the majority of which is intimate personal care tasks such as bathing, dressing, and feeding in addition to managing household activities for the individual
- The strain of long-term caregiving for someone with Alzheimer's or other dementias can negatively impact the caregivers' mental or physical health

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<sup>14</sup> Alzheimer's Association. (2018) *Caregiver Data from the 2016 BRFSS*.

*Image source:* National Cancer Institute, NCI Visuals Online, Rhoda Baer (Photographer)

## SLIDE 18:

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### Discussion Question

How could the **Cognitive Decline** and **Caregiver** data be used by state and local public health?

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### TALKING POINTS:

**Ask:** How could the **Cognitive Decline** and **Caregiver BRFSS** data be used by state and local public health?

**Open responses.**

## SLIDE 19:

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### Use of Surveillance Data<sup>15</sup>

- Understand impact and burden of Alzheimer's on state level
  - Develop strategies to reduce risk
  - Design interventions to alleviate burden
  - Inform public policy and planning
  - Evaluate programs and policies
  - Educate the public and the health care community
  - Guide research
- 

### TALKING POINTS:

Public health and its partners can use surveillance data to:

- Understand the impact and burden of Alzheimer's disease and cognitive decline on a state level
- Develop strategies to reduce risk and devise effective interventions, such as increasing public awareness about Alzheimer's, supporting early detection, and promoting cognitive and brain health
- Design interventions to **alleviate burden**, such as providing caregiver support and access to services needed by people with Alzheimer's and dementia
- Make informed decisions about public policy and planning related to program funding, public awareness campaigns, promoting early detection
- **Evaluate** existing programs and policies at the state and local levels
- **Educate** the public and the health care community about cognitive impairment
- Guide **research** into the causes, treatment, and prevention of Alzheimer's and dementia

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<sup>15</sup> Alzheimer's Association. (2018) *Data Collection and Behavioral Risk Factor Surveillance System (BRFSS)*. Image source: cker.com

## **SLIDE 20:**

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### **Public Health Impact: RISK REDUCTION & PRIMARY PREVENTION**

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#### **TALKING POINTS:**

Now we turn to risk reduction and primary prevention as ways public health can impact Alzheimer's and other dementias.

## SLIDE 21:

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### Primary Prevention<sup>16</sup>

- Designed to prevent a disease or condition from developing in a population
  - Causes of Alzheimer's not fully understood
  - Primary prevention for Alzheimer's:
    - Risk reduction
    - Promotion of cognitive health
- 

### TALKING POINTS:

An important role of public health is promoting **primary prevention** which is intervening before health effects can occur. Common examples of primary prevention in public health include regular physical activity to reduce risk of cardiovascular disease, vaccination against infectious diseases, bike helmet laws, and anti-tobacco use campaigns.

**Secondary** and **tertiary prevention** refer to identifying and managing a disease or condition at its earliest stage, and minimizing or reducing complications of or disability resulting from a disease or injury, respectively.

Research hasn't yet revealed the exact causes of Alzheimer's in most people. However, a growing base of evidence suggests there are ways to **reduce risk** for cognitive decline and possibly dementia, as well as ways to **promote cognitive health** at the population level.

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<sup>16</sup> Centers for Disease Control and Prevention. (2017) *Picture of America- Prevention*. Retrieved from <https://www.cdc.gov/pictureofamerica/>

## SLIDE 22:

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### Discussion Question

What are risk factors for Alzheimer's and other dementias that could be modified or reduced?

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### TALKING POINTS:

**Ask:** What are risk factors for Alzheimer's and other dementias that could be modified or reduced?

**Open responses.**

## SLIDE 23:

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### Risk Reduction: Head Trauma<sup>17,18</sup>

- Traumatic brain injury
  - Risk remains for years after original injury
  - Prevention efforts include:
    - Seat belt use
    - Use of helmets
    - Falls prevention
- 

### TALKING POINTS:

Research has linked **traumatic brain injury (TBI)** to a greater risk of developing dementia, including Alzheimer's. The risk remains even years after the original head injury, and the risk of dementia increases with the number of TBIs sustained.

Prevention efforts for the general public may include:

- Promoting (through education and policy) the use of:
  - **Seat belts**
  - **Helmets** when bicycling and participating in certain sports
- **Falls prevention**, including:
  - Putting **safety measures** in place at home (such as reducing tripping hazards, adding grab bars, and improving lighting)
  - **Exercise** to improve balance and coordination
  - Reviewing **medicines** and **vision** with health care provider

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<sup>17</sup> Alzheimer's Association. (n.d.) *Traumatic Brain Injury*. Retrieved from [https://www.alz.org/alzheimers-dementia/what-is-dementia/related\\_conditions/traumatic-brain-injury](https://www.alz.org/alzheimers-dementia/what-is-dementia/related_conditions/traumatic-brain-injury)

<sup>18</sup> Centers for Disease Control and Prevention. (2017) *Important Facts about Falls*. Retrieved from <http://www.cdc.gov/HomeandRecreationalSafety/Falls/adultfalls.html>

Image source: pixabay.com

## SLIDE 24:

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### Risk Reduction: Heart Health<sup>19,20,21,22</sup>

- Close link between heart health and brain health
  - Modifying cardiovascular risk:
    - Quit smoking
    - Diet (DASH, Mediterranean, MIND)
    - Physical activity
- 

### TALKING POINTS:

Growing evidence suggests a close link between the health of the **heart** and the health of the **brain**.

Several conditions known to increase the risk of **cardiovascular disease**—including high blood pressure, heart disease, stroke, and diabetes— also appear to increase the risk of developing Alzheimer’s. Some autopsy studies show that up to 80% of individuals with Alzheimer’s also have cardiovascular disease.

Many cardiovascular disease risk factors are **modifiable**—that is, they can be changed to decrease the likelihood of developing cardiovascular disease. Many experts believe that controlling cardiovascular risk factors may be the most cost-effective and helpful approach to protecting brain health and reducing the risk of cognitive decline.

Risk factors that may be modified include:

- **Quitting smoking:** Smoking has a negative effect on cardiovascular health. There is evidence that

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<sup>19</sup> Alzheimer’s Association. (2019) *2019 Alzheimer’s Disease Facts and Figures*.

<sup>20</sup> Alzheimer’s Association. (n.d.) *Prevention*. Retrieved from [https://www.alz.org/alzheimers-dementia/research\\_progress/prevention](https://www.alz.org/alzheimers-dementia/research_progress/prevention)

<sup>21</sup> U.S. Department of Health and Human Services. (2018) *Physical Activity Guidelines for Americans, 2nd edition*. Washington, DC: U.S. Department of Health and Human Services.

<sup>22</sup> McKenzie J, Bhatti L, Tursan d’Espaignet E. (2014) *WHO Tobacco Knowledge Summaries: Tobacco and Dementia*. Retrieved from: [https://www.who.int/tobacco/publications/mental\\_health/dementia\\_tks\\_14\\_1/en/](https://www.who.int/tobacco/publications/mental_health/dementia_tks_14_1/en/)

Image source: unsplash.com

current smoking increases the risk of cognitive decline and possibly dementia and that quitting smoking may over time reduce the associated risk to levels comparable to those who never smoked.

- **Diet:** Current evidence also suggests that eating a **heart-healthy diet** may also help protect the brain. Two diets that have been studied and may be beneficial are the **DASH (Dietary Approaches to Stop Hypertension)** diet and the **Mediterranean diet**. A third dietary intervention is the **Mediterranean-DASH Intervention for Neurodegenerative Delay (MIND)** diet, which is a combination of the two diets and focuses on foods that support cognitive health.
- **Physical activity:** Regular **physical activity** is important for heart health and may help lower the risk of Alzheimer's and vascular dementia. Exercise may directly benefit brain cells by increasing blood and oxygen flow in the brain.

Adults should engage in **150 minutes of moderate aerobic activity** (such as brisk walking) a week and muscle-strengthening activities on 2 or more days a week that work all major muscle groups (legs, hips, back, abdomen, chest, shoulders, and arms).

## SLIDE 25:

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### Risk Reduction: Avoidance/Management<sup>23,24</sup>

- Prevent onset of or effectively manage conditions that can increase risk for Alzheimer's
    - High blood pressure (hypertension)
    - Diabetes
    - Midlife obesity
- 

### TALKING POINTS:

Growing evidence suggests that the avoidance and management of high blood pressure (**hypertension**), **diabetes**, and **midlife obesity** may reduce risk for **Alzheimer's** and other **dementias**. There is even stronger evidence that these factors may also help protect against **cognitive decline** in general.

A large-scale clinical trial showed that medical treatment to reduce blood pressure can significantly lower the occurrence of **mild cognitive impairment (MCI)** and combined outcome of MCI and dementia in older adults with hypertension. Controlling blood pressure is also important for reducing risk for stroke, another source of cognitive impairment.

Preventing and managing these and other chronic diseases and conditions have been priorities of public health practice for many years. The increasing evidence base about the impact of these conditions on **cognitive health** must also be taken into account and incorporated into public health practice going forward.

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<sup>23</sup> Alzheimer's Association. (2019) *2019 Alzheimer's Disease Facts and Figures*.

<sup>24</sup> Centers for Disease Control and Prevention. (2018) *Preventing Stroke: Control Medical Conditions*. Retrieved from [https://www.cdc.gov/stroke/medical\\_conditions.htm](https://www.cdc.gov/stroke/medical_conditions.htm)

*Image source:* National Cancer Institute, NCI Visuals Online

## SLIDE 26:

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### Risk Reduction: Active Brain<sup>25,26</sup>

- Mental activity:
    - Learning new information and skills
    - Volunteering
    - Reading
    - Playing challenging games
  - Social connections (friends, social groups, volunteering)
- 

### TALKING POINTS:

In addition to the findings that having a greater number of years of formal education may be a protective factor for Alzheimer's and other dementias, a number of studies indicate that **keeping the brain active** as one ages is also associated with a lower risk for developing Alzheimer's and other dementias.

**Mentally stimulating activities** may include:

- Learning new information and skills that challenges the brain in novel ways
- Volunteering
- Reading
- Playing challenging games (such as bridge, chess, Sudoku, etc.)

Other studies have also suggested a link between **social connections** and cognitive health. Keeping strong social connections with others through activities such as clubs, friends, social groups, volunteering may help reduce the risk of cognitive decline and possibly delay the onset of dementia.

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<sup>25</sup> National Institute on Aging. (2018) *Alzheimer's Disease: Unraveling the Mystery*.

<sup>26</sup> Alzheimer's Association. (2019) *2019 Alzheimer's Disease Facts and Figures*.

*Image source:* Copyrighted image; used with permission from the Alzheimer's Association

These activities are thought to build one's "cognitive reserve," which researchers say may explain why some people maintain cognitive functioning even when damage to the brain from Alzheimer's is present. Mentally stimulating activities over one's life may enable the brain to flexibly and efficiently use cognitive networks (networks of neuron-to-neuron connections) in ways that may mask or delay appearance of dementia symptoms.

## SLIDE 27:

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### Discussion Question

How could public health play a role in promoting risk reduction and cognitive health?

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### TALKING POINTS:

**Ask:** How could public health play a role in promoting risk reduction and cognitive health?

**Open responses.**

## SLIDE 28:

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### Risk Reduction: Public Health Interventions<sup>27,28</sup>

- Health education and promotion campaigns
    - Brain and cardiovascular health
    - Detection/treatment of diabetes and high blood pressure
    - Smoking cessation
  - Programs and policies
    - Injury prevention
    - Cardiovascular health
- 

### TALKING POINTS:

Public health may design and implement **health education and promotion campaigns** that directly promote brain health and risk reduction strategies, or incorporate **brain health** messages into **cardiovascular** health and injury prevention campaigns.

Similarly, reducing risk for cognitive decline and possibly dementia is in line with public health efforts to improve **detection** and **treatment** of **high blood pressure** and **diabetes** and promote **smoking cessation**.

Such campaigns should include in their target audience midlife and **older adults**. Specifically, evidence-based interventions are needed to increase physical activity, promote smoking cessation and heart-healthy diets, and control high blood pressure.

To achieve health equity goals, public health campaigns need **culturally appropriate** education and awareness campaigns for heart health and brain health. These are especially important for African-Americans and

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<sup>27</sup> Alzheimer's Association and Centers for Disease Control and Prevention. *Healthy Brain Initiative, State and Local Public Health Partnerships to Address Dementia: The 2018-2023 Road Map*. Chicago, IL: Alzheimer's Association; 2018.

[Image source: pixabay.com](https://pixabay.com)

[Image source: National Cancer Institute, NCI Visuals Online, Bill Branson \(Photographer\)](#)

Hispanics, who are at higher risk of Alzheimer's as well as for high blood pressure and diabetes.

Public health and its partners may also initiate or strengthen **programs and policies** aimed at risk reduction for dementia.

Programs and policies could help ensure access to:

- **Injury prevention** resources (e.g., helmets, falls prevention assets)
- Safe and accessible **public spaces**
- Options for healthy **eating**, physical **activity**, smoking cessation assistance, and **social** connections

## **SLIDE 29:**

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### **Public Health Impact: Early Detection & Diagnosis**

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#### **TALKING POINTS:**

Promoting early detection and diagnosis of Alzheimer's is another important role for public health.

## SLIDE 30:

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### Why Promote Early Detection?<sup>29,30,31,32</sup>

- Access to treatment and services
  - Planning
  - Potentially reversible causes
  - Clinical trials
- 

### TALKING POINTS:

Promoting and assuring **early detection** of disease and disability is a third key impact for public health and is vitally important for people with Alzheimer's and dementia. Although there are no pharmacological treatments that change the course of the disease, there are numerous reasons why early detection is important:

**Access to treatment and services:** A formal diagnosis allows individuals and their caregivers to have access to available **treatments**, build a **care team**, and identify **support services**.

It may help individuals:

- Begin **medication** to help manage symptoms
- Identify **health care professionals** to help with different aspects of the disease (such as primary care, neurologist, occupational therapist, etc.)
- Manage **co-morbidities** (such as high blood pressure, diabetes) and potentially minimize or avoid further complications

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<sup>29</sup> Alzheimer's Association and Centers for Disease Control and Prevention. *Healthy Brain Initiative, State and Local Public Health Partnerships to Address Dementia: The 2018-2023 Road Map*. Chicago, IL: Alzheimer's Association; 2018.

<sup>30</sup> Alzheimer's Association. (2019) *2019 Alzheimer's Disease Facts and Figures*.

<sup>31</sup> National Institutes on Aging. (2018) *Alzheimer's Disease: Unraveling the Mystery*.

<sup>32</sup> U.S. Department of Health and Human Services. (2018) *National Plan to Address Alzheimer's Disease: 2018 Update*.

Image source: pixabay.com

- Access **community-based** services, such as support groups and services to assist with daily life

All of these factors may help reduce the **burden** on people with Alzheimer's and their caregivers. **Health care costs** could be reduced if better care averts avoidable hospitalizations or delays admission to long-term care facilities.

**Planning:** Early detection of Alzheimer's and other dementias can also help individuals and their families make important **decisions** and **plans** surrounding care, treatment options, and finances.

Many people with Alzheimer's and their families may benefit from creating **advance directives** –legal documents that specify the type of medical and end-of-life care a person wants to receive once he or she can no longer make or communicate these decisions. Such a document allows the person's wishes to be carried out by their family.

**Reversible Causes:** In some cases, dementia-like symptoms are not actually dementia, but are due to reversible causes.

Common causes of dementia-like symptoms are depression, untreated sleep apnea, delirium, side effects of medications, thyroid problems, certain vitamin deficiencies and excessive alcohol consumption. Unlike Alzheimer's and other dementias, these conditions often may be reversed with treatment.

**Clinical Trials:** Having access to clinical trials provides individuals with the opportunity to **access the latest experimental approaches** available and provides them with care by clinical research staff.

It is important for **diverse populations** to participate in clinical studies. This is especially true for **African American** and **Hispanic** populations, both of which are at increased risk for Alzheimer's and are traditionally under-represented in research.

## **SLIDE 31:**

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### **Discussion Question**

Would you want to know if you had Alzheimer's?  
Why or why not?

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### **TALKING POINTS:**

**Ask:** Would you want to know if you had Alzheimer's?  
Why or why not?

**Open responses.**

## SLIDE 32:

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### Early Detection: Factors Influencing Diagnosis Rates<sup>33,34</sup>

- Many people with Alzheimer's and other dementias either:
    - Have not been diagnosed
    - Have a diagnosis but have not been made aware
  - Fear of Alzheimer's and/or lack of knowledge about cognitive decline by individuals
  - Only 35% aware of diagnosis, yet vast majority say they'd want to know
  - Health care disparities
- 

### TALKING POINTS:

Despite the many benefits of early detection and diagnosis, many people living with Alzheimer's and other dementias either:

- Have **not** been diagnosed, or
- Have **been diagnosed** but have not been made aware of the diagnosis

Individuals, their families, and health care providers have to overcome barriers to diagnosis in order for early detection to occur. Many people of all ages fear getting Alzheimer's more than any other disease, and others may lack basic knowledge about cognitive decline, including the early signs of Alzheimer's. These are two of many reasons why we saw, as with the BRFSS data on subjective cognitive decline, many people experiencing memory issues are not discussing the symptoms with their doctor. Yet, 90% or more of people would want to know if they themselves or a family member had Alzheimer's.

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<sup>33</sup> Alzheimer's Association. (2019) *2019 Alzheimer's Disease Facts and Figures*.

<sup>34</sup> Alzheimer's Association. (2018) *Race, Ethnicity, and Alzheimer's Fact Sheet*.

A key challenge with early detection and diagnosis of Alzheimer's is that many individuals and their caregivers are not being **told** of the diagnosis, even when their doctor has diagnosed it.

An analysis by the CDC found that among people with Alzheimer's or another dementia, they or their caregivers reported being **aware of the diagnosis** only in **35% of the cases**. *(For more information: <https://www.healthypeople.gov/2020/data-search/Search-the-Data#objid=4158>)*

These rates are far below diagnoses for other chronic diseases. Analyses have shown that **90% or more** of those diagnosed with cancer and cardiovascular disease, for example, were aware of their diagnosis.

There are also **health care disparities** surrounding diagnosis. Medicare data show that African-Americans are even less likely than whites to be diagnosed.

Furthermore, when they are diagnosed, African-Americans and Hispanics, possibly due to issues surrounding access to health care, are typically diagnosed in **later stages of the disease**, resulting in higher use of health care services and substantially higher costs.

In the next slide, we will look at possible reasons for the lower rate of diagnosis and disclosure.

## SLIDE 33:

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### Early Detection: Challenges<sup>35,36</sup>

- Diagnostic uncertainty
  - Time constraints, lack of support
  - Communication difficulties
  - Fear of causing emotional distress
  - Reluctance to discuss with health care provider
- 

### TALKING POINTS:

There are many reasons why Alzheimer's and other dementias go undiagnosed or diagnosed but not disclosed to the patient.

- **Diagnostic uncertainty:** Health care providers frequently cite the complexity and uncertainty of the diagnosis as barriers to disclosure.
- **Time constraints and lack of support:** Disclosing a diagnosis of Alzheimer's or another dementia to a patient usually requires discussion of treatment options and support services, as well as education about the disease and what to expect. In many health care settings, providers may perceive they have insufficient time to properly assess and effectively communicate with the patient. However, to address this barrier, Medicare created a billing code for conducting comprehensive assessments for patients diagnosed with cognitive impairment, developing a care plan, and referring the patient and caregivers to community resources.

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<sup>35</sup> Alzheimer's Association. (2019) *2019 Alzheimer's Disease Facts and Figures*.

<sup>36</sup> Taylor C.A., Bouldin E.D., McGuire L.C. (2018) Subjective Cognitive Decline Among Adults Aged ≥45 Years — United States, 2015–2016. *MMWR Morb Mortal Wkly Rep* 67, 753–757. DOI: <http://dx.doi.org/10.15585/mmwr.mm6727a1>

- **Communication difficulties:** Many providers report challenges in communication skills related to disclosing a diagnosis of Alzheimer's or other dementias. It is also important for providers to be culturally competent and aware in presenting information on Alzheimer's that is respectful of and responsive to the needs, concerns, and belief systems of diverse patient populations.
- **Fear of causing emotional distress:** One of the most common reasons family members and health care providers give for not disclosing an Alzheimer's diagnosis is fear of causing **emotional distress**. However, studies have found that few patients become depressed or have other long-term emotional problems because of the diagnosis.
- **Reluctance to discuss with health care provider:** Many people are reluctant to discuss memory or cognitive issues with their health care provider. The BRFSS (Behavioral Risk Factor Surveillance System) survey found that the majority of people who have experienced subjective cognitive decline have not talked to their health care provider about it.

*[Note to Presenters:* It was more common in the past for physicians to withhold a serious diagnosis from patients. For example, survey results published in 1961, indicated that 9 in 10 physicians said it was their usual policy to *not* tell patients that they had been diagnosed with cancer. Typical reasons included not causing patients unnecessary anxiety or depression, a perceived lack of effective treatments, and not wanting to take away hope.]

## SLIDE 34:

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### Early Detection: Most Want to Know<sup>37</sup>

- 89% of U.S. adults would want to know
  - Of those age 60 and older, 95% would want to know
  - 97% would want to know for family member
- 

### TALKING POINTS:

Despite the barriers to diagnosis, studies show that most U.S. adults would want to know if they had Alzheimer's disease.

- Nearly **89% of Americans** say that if they were exhibiting confusion and memory loss, they would want to know if the cause of the symptoms was Alzheimer's disease.
- Of those aged 60 and older, **95%** say they would want to know.
- Over **97%** say that if they had a **family member** exhibiting problems with memory loss, they would want them to see a doctor to determine if the cause was Alzheimer's disease.

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<sup>37</sup> Alzheimer's Association. (2017) *Early Diagnosis: The Value of Knowing [Fact Sheet]*. Retrieved from <https://www.alz.org/media/Documents/factsheet-2013-value-of-knowing.pdf>

Image source: pexels.com

## SLIDE 35:

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### Discussion Question

What can public health do to promote early detection and diagnosis of Alzheimer's?

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### TALKING POINTS:

**Ask:** What can public health do to promote early detection and diagnosis of Alzheimer's?

**Open responses.**

## SLIDE 36:

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### Public Health: Early Diagnosis<sup>38</sup>

- General education and awareness
    - “10 Early Signs” – Alzheimer’s Association
    - Benefits of early detection
  - Education and training for health care providers
  - Education/support for newly diagnosed and their family
- 

### TALKING POINTS:

**Public health** may play an important role in efforts to increase **early detection and diagnosis** of Alzheimer’s, including:

- **Educating** the public about the early signs of dementia (such as the “10 Early Signs”), the benefits of early detection, and the importance of talking to a health care provider about increasing memory problems
- Identifying and promoting **culturally appropriate strategies** designed to promote early detection

Public health may also play a role in providing **education to health care providers** about the importance of early detection and diagnosis.

Education provided to the medical community should include topics such as:

- The importance of discussing memory issues with older patients
- The availability and use of **tools** and **guidelines** to identify dementia, including validated cognitive assessment tools

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<sup>38</sup> Alzheimer’s Association. (2017) *Early Diagnosis: The Value of Knowing [Fact Sheet]*. Retrieved from <https://www.alz.org/media/Documents/factsheet-2013-value-of-knowing.pdf>

*Image source:* Copyrighted image; used with permission from the Alzheimer's Association

- Early **symptoms** and **signs** of dementia
- Ways to **counsel** to individuals and their care partners upon diagnosis
- **Caregiver** needs
- Managing dementia in the context of other **chronic diseases**
- Accessing **services** in the community
- Participating in **clinical trials**

A diagnosis of Alzheimer’s or other dementia should be followed by **continued education** and **support** for individuals, families, and caregivers.

The strengths and capacities of public health can also be used to:

- Promote **advance care planning** and **advance financial planning** to care partners, families, and individuals with Alzheimer’s and dementia in the early stages before function declines
- Inform and connect people to **private and public resources** that may help with treatment, support services, and information
- Promote awareness of **abuse** and **exploitation**, and support related prevention efforts as they pertain to a person with Alzheimer’s or other dementias

For information on the 10 early signs and symptoms of Alzheimer’s: [https://www.alz.org/alzheimers-dementia/10\\_signs](https://www.alz.org/alzheimers-dementia/10_signs)

## **SLIDE 37:**

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### **Public Health Impact: Safety and Quality of Care**

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#### **TALKING POINTS:**

Helping to ensure the safety and quality of care for those with Alzheimer's and their caregivers is a way public health can make a difference both at an individual and community level.

## SLIDE 38:

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### Safety and Quality of Care<sup>39</sup>

- Workforce supply and training/development
  - Safety of those with dementia and their caregivers
  - Caregiver support and resources
- 

### TALKING POINTS:

Given the epidemic of Alzheimer's and other dementias, it is vital that health systems and communities infrastructure are equipped to serve the growing number of individuals needing care and services.

A well-trained, adequate workforce is needed to enhance the safety of those with Alzheimer's and dementia and deliver high-quality care. The public health challenge is two-fold:

- Currently, in many communities, there is a shortage of care professionals (geriatricians, nurses, personal care attendants, home health aides, etc.) needed to provide care to people living with Alzheimer's and dementia. Workforce shortages are likely to worsen as the population with Alzheimer's increases
- At the same time, those who work with individuals with Alzheimer's and other dementias do not often have the specialized knowledge and training needed to best meet the needs of these individuals

Both of these issues will impact the quality of care and safety of those with Alzheimer's. At present, many health care and other care professionals have received little formal training in Alzheimer's and other dementias.

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<sup>39</sup> Alzheimer's Association and Centers for Disease Control and Prevention. *Healthy Brain Initiative, State and Local Public Health Partnerships to Address Dementia: The 2018-2023 Road Map*. Chicago, IL: Alzheimer's Association; 2018.

*Image source:* Copyrighted image; used with permission from the Alzheimer's Association

For example, in 2015, only 23 states required training in dementia for staff in nursing homes. A variety of stakeholders have created training opportunities in recent years, so the situation is slowly changing.

**Caregiver Support and Resources:** Currently about 70% of people with Alzheimer's and other dementias live in the community, not in a long-term care facility. Therefore, the care provided to these individuals is most often by family caregivers, followed by paid home-care staff. Both family and professional caregivers need to understand the unique nature of Alzheimer's and how to effectively communicate with and care for an individual with cognitive impairment.

Caring for a family member or friend with Alzheimer's, especially in the later stages, is a very challenging job. Caregivers need knowledge about the disease, changes to expect, and ways to care for a loved one over the course of the disease.

The health of caregivers can be negatively impacted by the physical and emotional stress experienced in providing a high level of care for multiple years. In addition to education and training, caregivers need community support, such as **respite care** (short-term care for the person with Alzheimer's), adult day services, financial/legal planning assistance, peer support groups, and resources that promote self-care.

(Module 4 covers more information on these topics.)

## SLIDE 39:

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### Conclusion: Public Health Impact

4 key ways public health can have an impact:

- Surveillance/monitoring
  - Risk reduction
  - Early detection and diagnosis
  - Safety and quality of care
- 

### TALKING POINTS:

Public health addresses Alzheimer's disease from a population perspective in four primary ways:

**1. Surveillance and monitoring** allows public health to compile data and use it to:

- Develop strategies and interventions
- Inform public policy
- Evaluate programs and policies
- Educate populations
- Guide research

**2. Risk reduction**

Primary prevention strategies can be used to promote **risk reduction** for Alzheimer's and dementia, as well as to **promote cognitive health** in general. Public health may design and implement **health education and promotion campaigns** to promote brain health and risk reduction strategies, reaching wide audiences and affecting change on the population level.

Public health and its partners may also initiate or strengthen programs and policies aimed at risk reduction for Alzheimer's disease.

**Programs and policies** could help ensure access to:

- Injury prevention resources (e.g., helmets, falls prevention assets)

- Safe and accessible public spaces
- Health care services that improve management of cardiovascular risk factors, diabetes, high blood pressure (hypertension), and midlife obesity
- Options for help with quitting smoking, healthy eating, physical activity, and social connections

### 3. Early detection and diagnosis

Public health may play an important role in efforts to increase **early detection and diagnosis** of Alzheimer’s disease, including:

- **Educating** the public about the warning signs of dementia (such as the “10 Warning Signs”), and the benefits of early detection
- Identifying and promoting **culturally appropriate strategies** designed to promote early detection
- Providing education and training to health care providers and newly diagnosed individuals, families, and caregivers

### 4. Safety and quality of care

Alzheimer’s affects individuals and their families who are often the primary caregivers throughout much of the disease progression. Public health can support individuals and their caregivers by ensuring safety and quality of care through workforce training and development and by providing information and support to caregivers.

- Providing specialized training on Alzheimer’s and other dementia to prepare a healthcare workforce that understands and adequately meets the needs of those with Alzheimer’s and other dementias and their families

- Provide caregivers with the training and support services needed to care for loved ones with Alzheimer's and dementia

*Image source:* Copyrighted image; used with permission from the Alzheimer's Association

## SLIDE 40:

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### Dementia Capable Systems and Dementia Friendly Communities

- Dementia capable systems
    - Public health research and translation
    - Support services
    - Workforce training
  - Dementia friendly communities
- 

#### TALKING POINTS: (See module 4 for more information)

Public health also has a role to play in supporting dementia capable systems and dementia friendly communities. At a larger level, states and communities can become dementia capable in accommodating the needs of a population with Alzheimer's and other dementias.

A **dementia capable system** is a system or infrastructure that works to meet the needs of a people with dementia and their caregivers through providing education, support, and services. Public health can contribute to a **dementia capable system** through:

- Public health **research** and **translation**
- Ensuring access to **support services** for people with dementia and their caregivers
- Workforce **training** and **education**

Public health can also support the creation of **dementia friendly communities**. These are cross-sector, community-wide efforts to have support services, resources, and safe environments that allow people with dementia and their caregivers to stay connected to the community. Over time, these partnerships should:

- Enhance support services and resources
- Address accessibility and mobility barriers
- Provide dementia training for health care providers and first responders
- Provide a range of resources to support family caregivers such as respite care services

*Image source:* Copyrighted image; used with permission from the Alzheimer's Association

## SLIDE 41:

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### For More Information

For more information, please visit the Alzheimer's Association: <http://www.alz.org>

CDC's Alzheimer's Disease and Healthy Aging Program: <https://www.cdc.gov/aging/>

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### TALKING POINTS:

For more information on the topics covered in this presentation, please go to the Alzheimer's Association website at <http://www.alz.org> or the Centers for Disease Control and Prevention's Alzheimer's Disease and Healthy Aging Program at <https://www.cdc.gov/aging/>. There you can find resources, latest research and information.

## SLIDE 42:

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### Competencies

#### Academy for Gerontology in Higher Education (AGHE):

- 1.6.1 Identify and explain research methodologies, interpretations, and applications used by different disciplines to study aging.

#### Council on Education for Public Health (CEPH)

##### Foundational Competencies:

- 2. Locate, use, evaluate, and synthesize public health information (bachelors level)
- 4. Interpret results of data analysis for public health research, policy, or practice (masters level)

#### Council on Linkages Between Academia and Public Health Practice:

- 3A8. Describes the roles of governmental public health, health care, and other partners in improving the health of a community.
- 8A3. Describes the ways public health, health care, and other organizations can work together or individually to impact the health of a community.

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**TALKING POINTS:** (this slide can be edited as needed or removed)

The content in this presentation supports the development of the following competencies:

#### Academy for Gerontology in Higher Education (AGHE):

- 1.6.1 Identify and explain research methodologies, interpretations, and applications used by different disciplines to study aging

#### Council on Education for Public Health (CEPH)

##### Foundational Competencies:

- 2. Locate, use, evaluate, and synthesize public health information (bachelors level)

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**Council on Linkages Between Academia and Public Health Practice:**

- 3A8. Describes the roles of governmental public health, health care, and other partners in improving the health of a community.
- 8A3. Describes the ways public health, health care, and other organizations can work together or individually to impact the health of a community.

# SAMPLE TEST QUESTIONS

**1- Alzheimer's impacts 1 in \_\_\_\_ adults over age 65.**

- a. 5
- b. 9
- c. 15
- d. 20

**Answer: B**

**2- Annual costs of care for Alzheimer's disease is over \$\_\_\_\_\_.**

- a. \$ 100 million
- b. \$ 500 million
- c. \$ 50 billion
- d. \$ 200 billion
- e. \$ 1 trillion

**Answer: D**

**3- Which of the following is true about Alzheimer's disease?**

- a. Diagnosis is difficult but easily treated
- b. Diagnosis is done through a blood test
- c. Alzheimer's is a progressive disease
- d. Alzheimer's only affects older adults

**Answer: C**

**4- Caregivers provide how many hours of unpaid care annually to people with Alzheimer's?**

- a. Nearly 1 billion hours
- b. Close to 10 billion hours
- c. Almost 20 billion hours
- d. Over 50 billion hours

**Answer: C**

**5- The role of public health in addressing Alzheimer's includes the following except:**

- a. Surveillance
- b. Early detection and diagnosis
- c. Risk reduction
- d. Curative therapies
- e. Safety and quality of care

**Answer: D**

# FACULTY GUIDE

Module 4: Dementia Capable Systems and Dementia Friendly Communities  
Alzheimer’s Association and the Centers for Disease Control and Prevention

## ABOUT MODULE 4

This module is part of the Alzheimer’s Association curriculum, *A Public Health Approach to Alzheimer’s and Other Dementias*. Developed as part of a cooperative agreement with CDC’s Alzheimer’s Disease and Healthy Aging Program, and in partnership with Emory University’s Rollins School of Public Health, this curriculum addresses cognitive health, cognitive impairment, and Alzheimer’s disease and is for use by undergraduate faculty in schools and programs of public health and other related disciplines. It can also be adapted for other purposes.

**Module 4: Dementia Capable Systems and Dementia Friendly Communities** addresses the public health response to the Alzheimer’s disease epidemic at the state and community levels. The module describes the concepts of “dementia capable” systems and dementia friendly communities, both of which involve accommodating the needs of a population with memory loss, and a variety of related **physical, cognitive, and behavior** symptoms, as well as other **co-morbidities**.

Module 4 explores how public health may support the development of such systems at the state and local levels through support services and programs, workforce training, and the creation of dementia friendly communities.

### **Module 4 contains the following topics:**

1. Community-support needs assessments
2. Support services & programs
3. Workforce training
4. Dementia friendly communities

## LEARNING OBJECTIVES

At the end of **Module 4: Dementia Capable Systems and Dementia Friendly Communities**, students will be able to:

- Define dementia capable systems and dementia friendly communities
- Explain how public health can contribute to the development of dementia capable systems by analyzing community-support needs, developing support services and programs, establishing workforce training, and the creation of dementia friendly communities.
- List at least two support services that may benefit a caregiver of someone with Alzheimer’s or dementia
- Identify at least three professions that would benefit from workforce training related to Alzheimer’s and dementia

- Describe at least two components of a dementia friendly community

## **COMPETENCIES**

Module 4 promotes basic learning that supports the development of certain competencies:

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

- 1.6.7 Promote and apply the use of appropriate forms of evidence-based interventions and technologies for older adults, their families, and caregivers
- II.4.5 Provide information and education to the following groups in order to build a collaborative aging network:
  - Key persons in the community (police officers, firefighters, mail carriers, locale service providers, and others)
  - Aging workforce professionals and personnel (paid and unpaid; full-and part-time) in the field of aging

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

- 2. Locate, use, evaluate, and synthesize public health information (bachelors level)
- 4. Interpret results of data analysis for public health research, policy, or practice (masters level)

### **Council on Linkages Between Academia and Public Health Practice:**

- 8A3. Describes the ways public health, health care, and other organizations can work together or individually to impact the health of a community
- 8A4. Contributes to development of a vision for a healthy community (e.g., emphasis on prevention, health equity for all, excellence, and innovation)

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## LAYOUT OF MODULE 4 FACULTY GUIDE

This guide is laid out in the following sections:

- Slide guide with talking points
- Sample test questions
- Case studies
- Video resources

*Note: Some slides in this module duplicate content from other modules and may be removed as needed.*

### HOW TO USE THE MATERIALS

- ✓ This module is one of four modules in this curriculum that were designed for use either as a set or as stand-alone modules
- ✓ Users are free to make changes to the materials to fit their needs, including: adding, modifying or removing content, graphics, talking points, discussion questions, or learning activities
- ✓ The Faculty Guide for each module includes a slide guide that contains the information as presented in the slide, talking points, space for presenter notes, and references
- ✓ The talking points included in the Faculty Guide should not be read word for word; each presenter should review the materials before delivering the material to ensure familiarity and deliver the information in his/her own style
- ✓ Delivery time will generally be 60-90 minutes per module, depending on class engagement, presenter style, and the addition or elimination of any content, discussion questions, or learning activities
- ✓ Discussion questions are included in the slide deck of each module. These may be modified or removed at the discretion of the presenter. Questions may also be used for other activities such as small group discussion or individual writing assignments
- ✓ Video resources, a list of articles, and case studies are also included to help in learning more about the topics presented in each module
- ✓ Test questions are provided with each module as an additional resource for faculty
- ✓ All materials are 508 compliant. (Note: if changes are made to the curriculum, 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/making-files-accessible/index.html>)

## STUDENT ENGAGEMENT OPTIONS

In addition to the PowerPoint slide deck and guide, there are additional resources included in this guide. These resources are designed to increase student engagement and enhance understanding of the concepts covered in this module. Following the slide guide, there is a series of case studies and a list of video resources. It is recommended that the presenter review these resources to determine if these additional materials would be useful in illustrating the concepts covered in the module.

## DISCUSSION QUESTIONS

The following discussion questions are included in the slide deck:

- Imagine you or someone you care about has Alzheimer's or dementia. What might be some of your concerns or fears about going out in your community? How could those be addressed at a community level? *(Slide 5)*
- What kinds of support services might people with Alzheimer's and their caregivers need? *(Slide 12)*
- What is the role of public health in connecting people to the services they need? *(Slide 15)*
- What training should health care and direct care professionals receive? *(Slide 20)*
- What training should public health professionals receive? *(Slide 22)*
- What training should first responders receive? *(Slide 24)*

## LEARNING ACTIVITIES

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

- Conduct a brief observational study of the community in which you live, work, or go to school. What characteristics could be considered dementia friendly? What changes would be needed? How could public health support the development or growth of a dementia friendly community where you live/work/study?
- Select a workforce (such as public health, health care, first responder, etc.) that would benefit from training on Alzheimer's and dementia. Create an outline of training topics- what information would you present? What educational techniques would you use during the training?
- View the following videos from two different cultures: Asian-American and American Indian. Compare and contrast how these communities address Alzheimer's and dementia.

- Asian American: <https://vimeo.com/268811803/6745380c62>
- American Indian: <https://vimeo.com/279478897/788d394e8f>

## ADDITIONAL READING

- Alzheimer’s Association. (2019). Alzheimer’s Disease Facts and Figures. Chicago, IL: Alzheimer’s Association. <http://www.alz.org/facts>
- Alzheimer’s Association and Centers for Disease Control and Prevention. *Healthy Brain Initiative, State and Local Public Health Partnerships to Address Dementia: The 2018-2023 Road Map*. Chicago, IL: Alzheimer’s Association; 2018. <https://www.alz.org/media/Documents/healthy-brain-initiative-road-map-2018-2023.pdf>
- Bynum, J. (2014). The long reach of Alzheimer’s disease: Patients, practice, and policy. *Health Affairs*, 33(4), 534-540. Retrieved from <http://content.healthaffairs.org/content/33/4/534.short>
- Hoffman, D. (2015, July 14). Looking at the future of Alzheimer’s disease policy. [Blog post]. Retrieved from <https://www.healthaffairs.org/doi/10.1377/hblog20150714.049333/full/>
- Lin, S. Y., & Lewis, F. M. (2015). Dementia friendly, dementia capable, and dementia positive: concepts to prepare for the future. *The Gerontologist*, 55(2), 237-244. <http://gerontologist.oxfordjournals.org/content/55/2/237.short>

## SLIDE GUIDE

This slide guide accompanies the PowerPoint presentation for this module. The right margin has been widened to allow the presenter to write notes.

### SLIDE 1:

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#### Module 4: Dementia Capable Systems and Dementia Friendly Communities

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##### TALKING POINTS:

This presentation entitled, ***Dementia Capable Systems and Dementia Friendly Communities***, is part of a curriculum for public health students entitled, *A Public Health Approach to Alzheimer's and Other Dementias*. It was developed by the Emory Centers for Training and Technical Assistance for the Alzheimer's Association with funding from the Centers for Disease Control and Prevention.

This presentation addresses the public health response to the Alzheimer's epidemic at the state and community levels and the importance of dementia capable systems and dementia friendly communities.

## SLIDE 2:

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### Learning Objectives

- Define dementia capable system and dementia friendly community
- Explain how public health can contribute to dementia capable systems through support services/programs, workforce training, and dementia friendly communities
- List at least two services that may benefit a caregiver
- Identify at least three professions that would benefit from workforce training
- Describe at least two components of a dementia friendly community

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### TALKING POINTS:

By the end of the presentation, you will be able to:

- Define dementia capable system” and “dementia friendly community”
- Explain how public health can contribute to dementia capable systems through support services/programs, workforce training, and dementia friendly communities
- List at least two services that may benefit a caregiver
- Identify at least three professions that would benefit from workforce training
- Describe at least two components of a dementia friendly community

## SLIDE 3:

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### Introduction: Dementia & Alzheimer's Disease<sup>1</sup>

- Dementia is a decline in mental ability that interferes with daily life
- Alzheimer's disease is the most common form of dementia
  - Progressive loss of memory and brain function
  - Requires increasing aid and assistance
  - No cure and limited treatment options
- Huge financial and emotional burden
- Public health plays important role in addressing Alzheimer's disease

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### TALKING POINTS:

Before we begin discussing dementia capable systems and dementia friendly communities in addressing Alzheimer's disease, it may be helpful to know a little more about Alzheimer's and dementia.

The term **dementia** is a general term for a decline in mental abilities that is severe enough to interfere with daily life. Dementia, which is not a disease but a syndrome, is characterized by damage to the brain cells due to age, brain injury, other conditions or diseases, heredity, or a combination of factors.

There are several types of dementia and most occur in those over 65; however, there are types of dementia that occur in those younger than 65.

**Alzheimer's disease** is the most common cause of dementia. Alzheimer's is a progressive disease that ranges from mild to severe cognitive impairment that occurs on a continuum over the course of many years, even decades. The term

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<sup>1</sup> Alzheimer's Association. (2019) *2019 Alzheimer's Disease Facts and Figures*.

**Alzheimer's dementia** is used to describe the stage of Alzheimer's disease when an individual has observable symptoms such as memory loss, mood/behavior changes, and difficulty with activities of daily living. There is **no cure** for Alzheimer's. While there are approved drug **treatments**, the goal of existing treatment is to delay or reduce symptoms, not to cure or reverse the course of the disease.

As the person with Alzheimer's loses memory and function, **caregivers**, who are most often family members, are needed to provide increasing amounts of assistance. This assistance can range from helping to manage finances and household tasks to hands-on care, such as bathing, dressing, feeding, and other activities of daily living. Given the nature of the disease and its increasing prevalence, there is a **huge financial, emotional, and physical impact** on people with Alzheimer's, their families, caregivers, and the health care system as a whole.

**Public health** plays an important role in addressing Alzheimer's disease through surveillance, prevention, detection, and support of **dementia-capable systems**.

In this presentation, we will be focusing on **dementia capable systems and dementia friendly communities**, both of which involve government and health care agencies, organizations, and communities accommodating the needs of people with dementia and their caregivers through education, services, and support within their community.

## SLIDE 4:

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### Alzheimer's: A Larger Context<sup>2</sup>

- States/communities play significant role
  - Assessing burden
  - Risk reduction
  - Care services: health care, support services, government agencies
  - Public and private resources: transportation, grocery stores, places of worship, financial institutions, law enforcement

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### TALKING POINTS:

Alzheimer's and other dementias affect not only the individual but also families and communities. **Communities** have many people living with Alzheimer's and other dementias and many others who are at risk for developing these conditions. As many as 70% of people living with Alzheimer's and other dementias live in the community, with 74% of those individuals living with a caregiver. Family caregivers also need support. Professionals who interact with both individuals with dementia and their caregivers need training on how best to provide services and support to both.

Individuals with dementia and their caregivers rely on many **care services**, including health care, support services (in-home, community, and long-term care), and government agencies to meet their ongoing and changing care needs.

People with Alzheimer's and other dementias also interact with and depend on community services and businesses such as transportation, grocery stores, places of worship, banks, and law enforcement.

Later in the module, you will learn how a **public health response** to the epidemic considers the unique needs of people with dementia and their caregivers on state and local levels, within institutions, and across communities.

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<sup>2</sup> Alzheimer's Association. (2019) *2019 Alzheimer's Disease Facts and Figures*.

Image source: pexels.com

## SLIDE 5:

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### Discussion Questions

Imagine you or someone you care about has Alzheimer's or dementia.

What might be some of your concerns or fears about going out in your community?

How could those be addressed at a community level?

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### TALKING POINTS:

**Ask:** Imagine you or someone you care about has Alzheimer's or dementia.

What might be some of your concerns or fears about going out in your community?

How could those be addressed at a community level?

**Open responses.**

**Video: Alzheimer's Society (UK)** (3:35 minutes)

[Brief video shows simulation of what it might be like for someone with dementia to navigate everyday life in her community.](https://www.youtube.com/watch?v=Fz8ACEu7Lho)

<https://www.youtube.com/watch?v=Fz8ACEu7Lho>

## SLIDE 6:

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### Two Frameworks: Dementia Capable System and Dementia Friendly Communities<sup>3</sup>

- Designed to meet the needs of older adults within a community
- Aim to help older adults remain independent and in the community as long as possible
- Bring together community members and key stakeholders to focus on accommodations, provide support, and improve quality of life for older adults

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#### TALKING POINTS:

Given that the population of adults over age 65 is rapidly increasing, there are efforts at the national and international level to put in place infrastructure, policies, and practices from the local level upward to support older adults and their families. The vast majority of older adults want to remain independent in their homes and in their communities for as long as possible. This means having communities prepared to meet the changing and increasing needs of older adults in terms of community resources and infrastructure, health care, and social services.

Many of the issues discussed in this presentation tie into the concept of **dementia friendly communities** and what it means to have **dementia capable systems** in place that help communities be more accommodating to people with dementia and dementia caregivers.

These two frameworks aim to help communities plan for and address the challenges associated with the growing impact of dementia. While also used in other countries, in the United States, the concept of **dementia friendly communities** is intended to involve multiple sectors by

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<sup>3</sup> Turner, N., Morken, L. (2016) *Better Together: A Comparative Analysis of Age-Friendly and Dementia Friendly Communities*. AARP International Affairs. Retrieved from <https://www.aarp.org/content/dam/aarp/livable-communities/livable-documents/documents-2016/Better-Together-Research-Report.pdf>

Image source: Dementia Friendly America

bringing together community members and key stakeholders to enhance support and improve quality of life for all affected by dementia. The federal Administration for Community Living has also championed the **dementia capable system** framework, which may focus on a single sector or organization.

Both frameworks are designed to meet the needs of the rapidly increasing population affected by dementia (including caregivers) by preparing communities, health systems, and governments.

Both aim to help people living with dementia remain independent and in the community as long as possible.

Each of these frameworks has the potential to help communities begin to address the overall needs of older adults and the unique needs of people with dementia and their caregivers.

## SLIDE 7:

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### Dementia Friendly Communities<sup>4,5</sup>

- Health care, community services, resources
- Safe and accessible
  - Transportation
  - Mobility
- Respectful and supportive
- Public education and workforce training
- Technology
  - GPS, GIS
  - Registry

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### TALKING POINTS:

In the **dementia friendly community** framework, people with dementia, their family, and caregivers are understood, respected, supported, and able to continue to engage with and contribute to their community. The effort to become **dementia friendly** is made at a community level and requires planning and participation from all sectors with involvement of those with dementia and dementia caregivers.

Although overlap exists between the concepts of dementia *capable* and dementia *friendly*, a dementia friendly community encompasses a broader goal of supporting a higher quality of life for people with dementia beyond simply meeting their physical and health needs.

In this framework, dementia friendly communities would have:

- Access to **quality health care and community services**. While encompassing the same aspects of

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<sup>4</sup> U.S. Administration for Community Living/Administration on Aging. (2014) *Dementia-Capable States and Communities: The Basics*.

<sup>5</sup> The Gerontological Society of America. (2015) *Dementia Friendly, Dementia Capable, and Dementia Positive: Concepts to Prepare for the Future*.

*Image source:* Copyrighted image; used with permission from the Alzheimer's Association

dementia capable systems, dementia friendly communities offer:

- Resources and supports that are **geographically, financially, and culturally available and accessible**
- **Support services and activities**, such as educational sessions regarding symptoms, disease processes, self-care, and providing care, as well as support groups and dementia friendly social events that are readily available throughout the community
- **Safety and accessibility:** People can live **safely**, with as much independence as possible

This concept includes **public transportation, walkability** for leisure and to complete daily tasks, minimizing confusion when moving from place to place, and ensuring **safety**

- **Mobility** considerations that may include:
  - Age-friendly pavements
  - Adequate signage
  - Safe pedestrian crossings
  - Trained safety personnel
  - Welcoming open spaces, including squares, parks, and playgrounds
- **Public education and workforce development:** In these communities, residents, agencies, businesses, health care facilities, places of worship, and general service providers are learning about dementia through education and awareness efforts, so they can better assist people with the condition and their caregivers as they go about their daily lives
- **Technology** may also play a role in the creation of dementia friendly communities:
  - **Geographic Information Systems (GIS) and Global Positioning Systems (GPS)** can help people navigate their community while still allowing family or caregivers to track their whereabouts

- **Community registry:** Law enforcement can also create or partner with a voluntary registry for individuals with dementia

These registries have the name, home address, and contact information for family members or care partners should the individual with dementia need help from or interact with law enforcement

Evaluations are needed to better understand the utility of the dementia-friendly community framework in helping communities develop these attributes.

**Additional reading:**

<https://alz.org/media/Documents/spotlight-dementia-friendly-communities.pdf>

## SLIDE 8:

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### Dementia Capable Systems<sup>6, 7</sup>

- Accommodate needs of population with:
  - Memory loss
  - Physical, cognitive, and/or behavioral symptoms
  - Co-morbidities
- Knowledgeable workforce/residents:
  - Identify people with dementia
  - Work effectively with them
  - Inform/refer to services

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### TALKING POINTS:

Part of creating a dementia friendly community is ensuring there are **support services and infrastructure** in place to meet the needs of individuals with Alzheimer's and dementia and their caregivers. Having this support in place within the community is referred to as having **dementia capable systems**.

**Dementia capable** means being able to help people with dementia and their caregivers. This definition applies both to dementia capable systems and dementia friendly communities. More specifically, being **dementia capable** means being skilled in **identifying people** with possible dementia and **working effectively** with them and their caregivers, being **knowledgeable** about the kinds of services needed, and being able to **inform** or **refer** to agencies and individuals that provide such services.

A **dementia capable system** is a system that accommodates the needs of a population that, in addition to memory loss, experiences a variety of **physical, cognitive, and behavioral**

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<sup>6</sup> Alzheimer's Association and Centers for Disease Control and Prevention. Healthy Brain Initiative, State and Local Public Health Partnerships to Address Dementia: The 2018-2023 Road Map. Chicago, IL: Alzheimer's Association; 2018.

<sup>7</sup> Tilly, J., Weiner, J., Gould, E., and O'Keefe, J. (2011) *Making the Long-Term Services and Supports System Work for People with Dementia and Their Caregivers*. Washington, DC: Administration for Community Living. Retrieved from <https://acl.gov/sites/default/files/triage/BH-Brief-Dementia-Capable-Basics.pdf>

*Image source:* Copyrighted image; used with permission from the Alzheimer's Association

symptoms resulting from dementia, in addition to other **co-morbidities**.

Dementia capable systems can be implemented at different levels, such as within a care system, a business or organization, or within a community or state. The focus of dementia capable systems is often on:

- Increasing knowledge and skills of those who will help care for or interact with people who have dementia and their family members
- Addressing service gaps and specialized assistance needs
- Providing long term services and support systems to fulfill the needs of people with dementia and their caregivers

**Public health** must take an active role in fostering dementia capable systems and helping to bridge the gap between the needs of individuals and caregivers and the larger establishments within states and communities that can best meet those needs.

## SLIDE 9:

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### Dementia Capable: Public Health<sup>8</sup>

- Analyzing community support needs
- Building connections to support services and programs
- Providing Workforce training
- Establishing Dementia friendly communities

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### TALKING POINTS:

Public health can play a role in developing and supporting dementia capable systems by:

- Analyzing the community support needs of people living with dementia and their caregivers
- Serving to provide, inform, and connect individuals and caregivers to **support services and programs**
- Designing, implementing and evaluating **workforce training** to ensure workers across a wide range of professions are able to identify and meet the needs of people with Alzheimer's and dementia
- Supporting the creation of **dementia friendly communities** that help people with Alzheimer's and dementia remain safe and as independent as possible within their community

Each of these will be discussed in more detail.

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<sup>8</sup>Alzheimer's Association and Centers for Disease Control and Prevention. Healthy Brain Initiative, State and Local Public Health Partnerships to Address Dementia: The 2018-2023 Road Map. Chicago, IL: Alzheimer's Association; 2018.

*Image source:* Copyrighted image; used with permission from the Alzheimer's Association

## SLIDE 10:

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### Dementia Capable: Public Health (continued)<sup>9,10</sup>

- Use data to inform the public health program and policy response to:
  - Cognitive health
  - Cognitive impairment
  - Caregiving
- Evaluate training and programs
- Estimate gap between workforce capacity and demand for services

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### TALKING POINTS:

Public health utilizes data from available surveillance strategies and sources (local, state, national, and even global) to guide programs, priorities, and policies.

Public health practice can actively incorporate evaluation into training and programs. Programs (such as support programs for caregivers) can evaluate how accessible, effective, and impactful the program is for participants. Evaluation is key to creating and sustaining an effective program.

The number of people with Alzheimer's is projected to triple in the next 35 years, with the number of caregivers also continuing to rise. As these populations grow, the workforce that provides support will also need to grow. This workforce includes professions such as:

- Adult day workers
- Community-based and long-term care services
- Social workers
- Occupational therapists
- Healthcare professionals

Public health can prepare the workforce to provide support to people with Alzheimer's and their caregivers by estimating demand for different types of professionals and identifying gaps in workforce readiness.

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<sup>9</sup> Alzheimer's Association. (2019) *2019 Alzheimer's Disease Facts and Figures*.

<sup>10</sup> Alzheimer's Association and Centers for Disease Control and Prevention. Healthy Brain Initiative, State and Local Public Health Partnerships to Address Dementia: The 2018-2023 Road Map. Chicago, IL: Alzheimer's Association; 2018.

## SLIDE 11:

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### SUPPORT SERVICES & PROGRAMS

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#### TALKING POINTS:

Public health can inform the design of **support services and programs** for people with Alzheimer's and other dementias.

## SLIDE 12:

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### Discussion Question

What kinds of support services might people with Alzheimer's and their caregivers need?

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### TALKING POINTS:

**Ask:** What kinds of support services might people with Alzheimer's and their caregivers need?

**Open responses.**

## SLIDE 13:

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### Support Services: Alzheimer's<sup>11,12</sup>

- Support groups
- Wellness programs
- Care services, including in-home care
- Legal and financial services
- Residential care
- Transportation
- Adult day care

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### TALKING POINTS:

Individuals with Alzheimer's and dementia may **require** varying levels of **care and support from numerous sources**, including:

- **Support groups and socialization programs:** aimed at persons with mild (early) stage Alzheimer's disease, these groups can provide social support and engagement, help with planning for future needs, and provide general guidance and support for individuals and caregivers
- **Wellness programs:** includes nutrition and physical activity programs, physical/occupational/speech therapy; may also include opportunities for cognitive stimulation, such as creative arts or intergenerational connections

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<sup>11</sup> US. Administration on Aging. (2011) *Dementia Capability Toolkit*. Retrieved from <https://www.aarp.org/content/dam/aarp/livable-communities/old-learn/health/Dementia-Capability-Toolkit-2011-AARP.pdf>

<sup>12</sup> Tilly, J., Wiener, J., & Gould, E. (2014) *Dementia-Capable States and Communities: The Basics*. Washington, DC: Administration for Community Living. Retrieved from: <https://acl.gov/sites/default/files/triage/BH-Brief-Dementia-Capable-Basics.pdf>

*Image source:* Copyrighted image; used with permission from the Alzheimer's Association  
*Image source:* Pexels.com

- **Care services:** includes care managers, chore services, home safety, personal care assistants, and respite
- **Legal or financial services:** financial, health care, and end-of-life planning
- **Residential care:** includes living options with varying levels of care, such as independent living communities, assisted living residences, and nursing homes tailored to people with dementia
- **Transportation:** includes safe driving supports and individual and group transportation options
- **Adult day care:** care for individuals who require regular supervision along with activities for socialization, cognitive stimulation, and physical activity; provides caregivers time to work or fulfill other responsibilities

## SLIDE 14:

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### Examples of Evidence-based Programs<sup>13,14</sup>

- Reducing Disability in Alzheimer’s Disease (RDAD) – University of Washington
  - Focus: teach family caregivers strategies
- Minds in Motion (MIM)
  - Focus: improve function in early stages with mild cognitive impairment
- Sharing History through Active Reminiscence and Photo-imagery (SHARP) - Oregon Health & Science University
  - Focus: neighborhood walking groups to trigger memories and increase social engagement
- Skills2Care – Thomas Jefferson University
  - Focus: occupational therapy-based strategies for caregivers

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### TALKING POINTS:

There are many examples of evidence-based programs for people with Alzheimer’s and dementia and their caregivers.

- **Reducing Disability in Alzheimer’s Disease (RDAD):**  
Developed by the University of Washington, the primary aims of the RDAD program are to teach family caregivers:
  - Strategies to decrease challenging behaviors related to Alzheimer’s and dementia, such as depression, anxiety, agitation, and aggression
  - Methods to engage in and encourage physical activity in order to reduce the physical disabilities that often result in a loss of independence

RDAD consists of 12 hourly sessions, conducted in participants’ homes over three months.

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<sup>13</sup> Alliance for Aging Research. (2012) *Translating Innovation to Impact: Evidence-based Interventions to Support People with Alzheimer’s Disease and their Caregivers at Home and in the Community.*

<sup>14</sup> Oregon Health & Sciences University. (2017) *Preserving Memories to Maintain Cognitive Health.*

- **Minds in Motion®:** Minds in Motion is designed to improve or sustain cognitive and physical functioning in persons with mild (early) stage dementia or mild cognitive impairment (MCI). From the Alzheimer Society of Manitoba, the group-based program, delivered in community settings, includes a variety of evidence-based components, including:
  - Cognitive training exercises
  - Physical exercises (Tai Chi and Qi Gong)
  - Creative/community involvement activities (writing, art, photography, etc.)
- **Sharing History through Active Reminiscence and Photo-imagery (SHARP):** Developed by Oregon Health & Science University. This program engages older African American adults in the Portland area to take group walks in familiar neighborhoods.
  - Using designated routes and a smart phone, the walkers are prompted with questions about landmarks to trigger memories of the location
  - The goal was to reduce barriers to activity and engagement within their changing neighborhoods and to increase social engagement
- **Skills2Care®:** This occupational therapy-based intervention for caregivers and individuals with dementia living at home was developed by Thomas Jefferson University. The intervention is designed to reduce caregiver burden, improve caregiver ability to manage daily care challenges, and reduce behavioral symptoms and functional dependence in individuals with dementia. Caregivers are trained in five types of strategies:
  - Communication techniques
  - Environmental modification
  - Task simplification
  - Use of activities to engage individuals with dementia
  - Self-care

A resource with additional evidence-based programs can be found on the National Alzheimer's and Dementia Resource Center site: <https://nadrc.acl.gov/node/140>

## SLIDE 15:

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### Discussion Question

What is the role of public health in connecting people to the services they need?

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### TALKING POINTS:

**Ask:** What is the role of public health in connecting people to the services they need?

**Open responses.**

## SLIDE 16:

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### Public Health: Support Services<sup>15</sup>

- Evidence-based programs and interventions
- Information and referrals
- Identify gaps in available support services
- Funding, space, expertise

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### TALKING POINTS:

Public health may serve to **provide, connect, and inform** individuals, families, and caregivers about support services within **clinical and community** settings.

Public health agencies and organizations can:

- **Develop and disseminate** evidence-based programs and interventions
- Offer **information and referrals** to specific support services, programs, and sources of information
- **Identify gaps** in available **support services** by reviewing current support services in a community as well as identify and address disparities in services available to underserved populations
- **Provide funding, space, expertise**, or other support for needed programs

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<sup>15</sup> Alzheimer's Association and Centers for Disease Control and Prevention. *Healthy Brain Initiative, State and Local Public Health Partnerships to Address Dementia: The 2018-2023 Road Map*. Chicago, IL: Alzheimer's Association; 2018.

*Image source:* National Cancer Institute, NCI Visuals Online, Bill Branson (Photographer)

## SLIDE 17:

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### Support Services: Partnerships<sup>16</sup>

- Offices on Aging / Aging and Disability Resource Centers / Area Agencies on Aging
  - Education
  - Caregiver and safety assessments
  - Support programs
  - Resources
- Non-profit organizations
- Residential care facilities

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### TALKING POINTS:

Public health is also in a unique position to strengthen **partnerships** within the community to build **dementia capable systems** and ensure that needed services and resources are available.

- **Offices on Aging/Aging and Disability Resource Centers/Area Agencies on Aging** can partner with local public health departments to **assess** community needs, **develop** programs and supports, and **provide** referrals.

Staff may be knowledgeable about Alzheimer's and dementia, offer **caregiver and safety assessments** and family **caregiver supports**, and have information about **resources** and **programs** available in the community for individuals with dementia and their families.

- **Non-profit organizations**, such as the **Alzheimer's Association**, have experts in the field of dementia care with a wide variety of information and educational materials and programs to support individuals, families, and caregivers.

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<sup>16</sup> ACT on Alzheimer's. (2014) *Alzheimer's Disease Curriculum, Module X: Caregiver Support*.

*Image source:* Centers for Disease Control and Prevention, Amanda Mills (Photographer)

Other non-profits, such as **faith-based organizations** and **civic groups**, can be partners that may co-sponsor educational events, distribute information, offer services, provide a place for caregiver support groups to meet, etc.

- **Residential care facilities** may be able to reach out to other health care and business partners in the community to promote awareness, support program development, and initiate dementia friendly policies.

## **SLIDE 18:**

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### **WORKFORCE TRAINING**

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#### **TALKING POINTS:**

Public health may also play a key role in training the workforce – professionals in health-related fields as well as others – to better understand, identify, and respond to individuals with Alzheimer’s and dementia and their caregivers.

## SLIDE 19:

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### Workforce Training

- Health care
  - Direct care
  - Public health
  - First responders
  - Other support services: transportation, customer service, faith-based organizations
- 

### TALKING POINTS:

Certain professions may provide service and support to people with Alzheimer's disease and their caregivers in a variety of ways. The workforces that would benefit from training and education include:

- **Health care workforce:** including primary care physicians, specialists (neurologists, geriatricians, psychiatrists), nurses, community health workers, social workers, psychologists, pharmacists, and dentists
- **Direct care professionals:** the workforce that provides the majority of the paid daily care (such as helping with bathing, dressing, housekeeping, food preparation, etc.) for people with Alzheimer's and dementia; includes nurse aides, home health aides, and personal and home-care aides
- **Public health** workforce including health educators, evaluators, biostatisticians, epidemiologists
- **First responders:** including law enforcement, fire, emergency response teams, emergency medical technicians (EMTs), and adult protective services
- **Other** professions: including **transportation**, **customer service**, and **faith-based** or spiritual organizations

Each of these will be discussed in more detail.

*Image source:* Copyrighted image; used with permission from the Alzheimer's Association

## SLIDE 20:

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### Discussion Question

What training should health care and direct care professionals receive?

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### TALKING POINTS:

**Ask:** What training should **health care and direct care professionals** receive?

**Open responses.**

## SLIDE 21:

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### Workforce Training: Health Care & Direct Care<sup>17</sup>

- Basics of dementia
- Benefits of early diagnosis
- How to address physical, cognitive, emotional, behavioral symptoms
- Assisting caregivers
- Managing co-morbidities
- Use of validated assessment tools (health care)

---

### TALKING POINTS:

The health care and direct-care workforce need **training and education** on identifying and caring for someone with Alzheimer's and dementia including:

- The basics of **dementia**, including recognizing early warning signs
- The benefits of **early diagnosis**
- How to address the physical, cognitive, emotional, and behavioral **symptoms** of the disease to provide person-centered care. **Person-centered care** is a philosophy of care built around the needs of the individual with dementia and depends on interpersonal relationships with caregivers. Caregivers get to know the complete person-likes/dislikes, values/beliefs, who they are- past and present and build a caring relationship that can enhance person's quality of life and wellbeing
- How to assist **caregivers** as they cope with the physical and emotional aspects of their caregiving responsibilities

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<sup>17</sup> Fazio, S., Pace, D., Flinner, J. & Kallmyer, B. (2018) The Fundamentals of Person-Centered Care for Individuals With Dementia. *The Gerontologist*, 58(1), S10–S19. <https://doi.org/10.1093/geront/gnx122>

*Image source:* Copyrighted image; used with permission from the Alzheimer's Association

- Management of **co-morbidities** (such as diabetes, hypertension, and heart disease)
- The availability and use of **tools** and **guidelines** to identify dementia, including validated cognitive assessment tools (health care providers)

## SLIDE 22:

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### Discussion Question

What training should public health professionals receive?

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### TALKING POINTS:

**Ask:** What training should **public health professionals** receive?

**Open responses.**

## SLIDE 23:

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### Workforce Training: Public Health

- Alzheimer's as a public health priority
- Importance of early detection
- Cognitive health and risk reduction
- Types and availability of resources and supports
- Caregiver burden and needs
- Surveillance
- Health disparities
- Unique issues (stigma, abuse, advance planning)

---

### TALKING POINTS:

Public health plays a key role in surveillance, education, and prevention related to Alzheimer's.

Training and education priorities for public health include:

- Understanding Alzheimer's as a **public health priority**
- The importance of **early detection**
- **Cognitive health** and **risk reduction** for Alzheimer's
- **Types and availability of resources and supports** for individuals with Alzheimer's and dementia
- Needs and burden of **caregivers**
- Tracking **surveillance data** on cognitive decline and caregiving
- **Health disparities** related to Alzheimer's and dementia
- Issues unique to Alzheimer's and dementia, including **stigma**, potential for **abuse**, and the need for **advance planning**

*Image source:* Copyrighted image; used with permission from the Alzheimer's Association

## SLIDE 24:

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### Discussion Question

What training should first responders receive?

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### TALKING POINTS:

**Ask:** What training should **first responders** receive?

**Open responses.**

## SLIDE 25:

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### Workforce Training: First Responders

- Situations involving stress or fear
- Training needs:
  - Identifying Alzheimer's and dementia
  - Effective interaction/communication
  - Resources
  - Registries, technologies

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### TALKING POINTS:

First responders such as police, emergency medical personnel, and fire fighters may have first-hand contact with individuals with Alzheimer's and other dementias during situations that involve stress or fear, such as:

- **Wandering**, being **lost**, or **disoriented**
- **Natural** or **other disasters** that may displace individuals with Alzheimer's and/or separate them from their usual caregivers
- Being subjected to physical, emotional, or financial **abuse** which is more likely to occur and can be harder to detect when an individual with dementia is no longer able to advocate for themselves or may be unable to recognize behaviors as abusive
- Being reported to law enforcement for **improper behavior**, such as leaving a place of business after forgetting to pay for purchase

First responders and law enforcement need **training** on:

- How to **identify** someone with Alzheimer's and dementia
- How to **interact** and **communicate** with people with Alzheimer's in various situations (especially ones that are stressful for the person)
- **Resources** to call upon for assistance or information

- Existence of **special needs registries** or other technologies that may assist in locating individuals, their places of residence, or their caregivers
- How to recognize the signs of abuse or neglect and notify **adult protective services** which investigates cases of abuse, neglect, or exploitation of older adults or disabled adults

**Supplemental reading:** Case study on EMS workers in CO

<https://alz.org/media/Documents/case-study-co-ems-training.pdf>

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## SLIDE 26:

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### Workforce Training: Other Professions

- Public transportation, customer service, faith/spiritual communities, etc.
  - Awareness
  - Recognizing need for help
  - Resources
  - Communication
  - Ways to assist and support

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### TALKING POINTS:

Many other professionals come into contact with people with Alzheimer's disease and require different levels of information:

- **Public transportation:** For individuals with dementia, navigating public transportation can be very challenging. Operators and drivers need to be aware of the special challenges faced by individuals with dementia, as well as how to recognize the signs that someone may need help
- **Customer service:** Those in service positions may be trained to recognize when they are dealing with someone with possible Alzheimer's and dementia and how to best communicate with them and meet their needs
- **Faith or spiritual communities:** These communities can be an important source of support and engagement for people with dementia, their families, and their caregivers. Church liaisons and volunteers may be trained to assist and support community members living with dementia

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## SLIDE 27:

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### CAREGIVER NEEDS AND SUPPORT

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#### TALKING POINTS:

Usually, the very first line of support and care for the person with dementia is a family caregiver. The family caregiver is part of the “workforce” in the sense that they have definite training needs. At the same time, they also need support themselves as they care for someone living with dementia.

Caregiving can be a rewarding experience, but also one that is high stress. As dementia progresses, caregivers often face a steep learning curve as well as the need for extra support as the person living with dementia needs more and more care. Part of making a dementia friendly community is putting in place supports and services for the caregiver. Let’s look at the needs of the dementia caregiver.

## SLIDE 28:

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### Support Services: Caregivers<sup>18,19</sup>

- Education/information/training
  - Alzheimer's/dementia
  - Behavioral management
  - Available resources
  - Self-care

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### TALKING POINTS:

When someone has Alzheimer's or dementia, family members and friends who are caregivers will face an ever-changing set of needs that increase as the disease progresses. The majority of people with Alzheimer's and dementia live in the community with many living independently until it becomes unsafe for them to continue living alone.

In 2017, **16 million** family members and friends provided **18.4 billion** hours of unpaid care to people with Alzheimer's and other dementias. It is usually a daughter or daughter-in-law who takes on the role of being the primary caregiver for the individual.

As the disease progresses, the individual becomes more reliant on others for all their care needs. Many family caregivers try to meet these care needs themselves as long as possible, often reducing work hours or quitting their jobs as the level of care increases. Many arrange for the help of paid caregivers to provide additional assistance in the home, until the individual's care needs exceed what can safely and continuously be provided in the home.

Most family caregivers are initially unprepared for the role. There is much to learn about the disease itself. At the same time, the caregiver is also taking on more of the individual's

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<sup>18</sup> ACT on Alzheimer's. (2014) *Alzheimer's Disease Curriculum, Module X: Caregiver Support*.

<sup>19</sup> Alzheimer's Association and Centers for Disease Control and Prevention. Healthy Brain Initiative, State and Local Public Health Partnerships to Address Dementia: The 2018-2023 Road Map. Chicago, IL: Alzheimer's Association; 2018.

*Image source:* Copyrighted image; used with permission from the Alzheimer's Association

life routines such as house maintenance, financial management, medication management, and eventually activities of daily living such as bathing, dressing, and eating.

These responsibilities typically add up to the caregiver needing support services for the person living with dementia and themselves, as well as training and ongoing education.

Support services and programs that have been found to be most effective for caregivers include multiple components to address different needs:

- **Education/information/training on:**
  - Alzheimer's and dementia and its effects on behavior throughout the continuum
  - **Training on working with dementia-related behaviors** designed to train caregivers to use specific techniques to manage behaviors that can be challenging (such as agitation, repetition, aggression, wandering)
  - Information on the availability of **resources**
  - **Self-care**, such as stress management, using respite services

## SLIDE 29:

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### Support Services: Caregivers (continued)<sup>20,21</sup>

- Counseling/support groups
  - Case management
  - Respite services
- 

### TALKING POINTS:

Support services for caregivers vary based on the individual need, but some of the most common forms of support include emotional support through individual counseling or support groups; care management to help manage the needs and coordinate care; and respite care which provides temporary time off.

- **Counseling/support groups:**
  - Individual and family **counseling**
  - **Support groups** that have been found to have the most positive outcomes focus on specific objectives, such as teaching certain skills or strategies
- **Care management:** helping to identify and manage care needs, and coordinate across care systems and providers. Professional care managers can help alleviate some of the tasks associated with caregiving, such as managing medical appointments, securing resources and services, and finding long term care if needed
- **Respite services:** provides care for a person with Alzheimer's disease on a temporary basis, providing much-needed time off for a family caregiver

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<sup>20</sup> ACT on Alzheimer's. (2014) *Alzheimer's Disease Curriculum, Module X: Caregiver Support*.

<sup>21</sup> Alzheimer's Association. (2019) *2019 Alzheimer's Disease Facts and Figures*.

*Image source:* Copyrighted image; used with permission from the Alzheimer's Association

## SLIDE 30:

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### Conclusion: Dementia Capable and Dementia Friendly

- States/communities play significant role
- Dementia capable systems and dementia friendly communities
  - Analyze community support needs
  - Support services and programs
  - Workforce training
  - Caregiver training and support

---

### TALKING POINTS:

In conclusion, states and communities can play an active role in reducing the burden of the Alzheimer's and dementia. Two approaches are creating **dementia capable systems** and **dementia friendly communities**. The concepts are similar and can overlap, but the focus of both is on accommodating those with dementia and their caregivers through providing support and services within their communities. **Public health** must take an active role in fostering dementia capable systems and dementia friendly communities through:

- Analyzing community support needs for those with dementia and their caregivers, and using those findings to design effective programs, policies, and best practices
- Serving to provide, inform, and connect individuals and caregivers to **support services and programs**
- Designing and implementing **workforce training** to ensure workers across a wide range of professions are able to identify and meet the needs of people with Alzheimer's and dementia
- Providing caregivers with the support and training they need to better care for the person living with dementia
- Supporting the creation of **dementia friendly communities** that help people with Alzheimer's and dementia remain safe and as independent as possible

## SLIDE 31:

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### For More Information

For more information, please visit:

Alzheimer's Association website at <http://www.alz.org>

CDC's Alzheimer's Disease and Healthy Aging Program at <https://www.cdc.gov/aging/>

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### TALKING POINTS:

For more information on the topics covered in this presentation, please go to the Alzheimer's Association website at <http://www.alz.org> or the Centers for Disease Control and Prevention's Alzheimer's Disease and Healthy Aging Program at <https://www.cdc.gov/aging/>. There you can find resources, latest research and information.

## SLIDE 32:

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### Competencies

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

- I.6.7 Promote and apply the use of appropriate forms of evidence-based interventions and technologies for older adults, their families, and caregivers
- II.4.5 Provide the following groups information and education in order to build a collaborative aging network:
  - Key persons in the community (police officers, firefighters, mail carriers, locale service providers, and others)
  - Aging workforce professionals and personnel (paid and unpaid; full-and part-time) in the field of aging

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

- 2. Locate, use, evaluate, and synthesize public health information (bachelors level)
- 4. Interpret results of data analysis for public health research, policy, or practice (masters level)

#### **Council on Linkages Between Academia and Public Health Practice:**

- 8A3. Describes the ways public health, health care, and other organizations can work together or individually to impact the health of a community
- 8A4. Contributes to development of a vision for a healthy community (e.g., emphasis on prevention, health equity for all, excellence, and innovation)

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**TALKING POINTS:** (this slide can be edited as needed or removed)

The content in this presentation supports the development of the following competencies:

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

- I.6.7 Promote and apply the use of appropriate forms of evidence-based interventions and technologies for older adults, their families, and caregivers
- II.4.5 Provide the following groups information and education in order to build a collaborative aging network:
  - Key persons in the community (police officers, firefighters, mail carriers, locale service providers, and others)
  - Aging workforce professionals and personnel (paid and unpaid; full-and part-time) in the field of aging

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

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**Council on Linkages Between Academia and Public Health Practice:**

- 8A3. Describes the ways public health, health care, and other organizations can work together or individually to impact the health of a community
- 8A4. Contributes to development of a vision for a healthy community (e.g., emphasis on prevention, health equity for all, excellence, and innovation)

# SAMPLE TEST QUESTIONS

**1- Which professions need to be knowledgeable about dementia?**

- a. Health care workers (nurses, direct care providers)
- b. Public sector workers (government- federal/local)
- c. Private sector workers (for profit/non-profit)
- d. A & B
- e. All of the above

**Answer: E**

**2- Training and education priorities for public health include:**

- a. The importance of early detection
- b. Needs and burden of caregivers
- c. Tracking surveillance data on cognitive decline and caregiving
- d. All of the above
- e. B & C

**Answer: D**

**3- What support services do people with Alzheimer's need?**

- a. Wellness programs
- b. Financial planning services
- c. Support groups
- d. A & C
- e. All of the above

**Answer: E**

**4- The term "dementia capable" means all of the following *except*:**

- a. A device able to be used by someone with dementia
- b. Accommodating the needs of those with dementia
- c. Able to identify people with dementia
- d. Support systems for people with dementia

**Answer: A**

**5- Some states have registries of people with Alzheimer's for surveillance, monitoring and research.**

- a. True
- b. False

**Answer: A**

## **CURRICULUM RESOURCES**

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Alzheimer's Association and the Centers for Disease Control and Prevention

## Case Studies

Based on faculty requests, a set of case studies have been developed for use with one or more of the curriculum modules. The case studies can be used in class or as an outside assignment.

The case studies are designed to be used in conjunction with the article or video listed. All case study videos come from the curriculum's video resource list, and there are several well done documentaries that cover various aspects of Alzheimer's and its impacts on individuals and families. For video-based case studies, the program title, run time, web link, keywords, relevance to modules, a program description and discussion questions are listed for each piece. However, if time and/or internet access is limited, each case study has a summary that provides enough information to generate discussion or conversation without needing to access the video/audio.

### 1. "Alzheimer's Disease Underdiagnosed in Indian Country," NPR (2015).

- **Audio/Transcript Link:**  
<http://www.npr.org/templates/transcript/transcript.php?storyId=458041798>
- **Run Time:** 3:46 minutes (audio)
- **Key Terms:** cultural context, Native Americans, diagnosis, community outreach, family relationships, tradition, stigma, caregiver burden, long term care
- **Modules:** 1, 3, 4

#### Description:

Mrs. Williams is an older woman who has been having severe memory problems for the past seven years. Mrs. Williams lived on a Native American reservation in Arizona before moving in with her daughter, Delma, in Los Angeles. In many tribal communities, obtaining an Alzheimer's diagnosis is a challenge; for example, tribal communities may not have a word for dementia. Native American cultures have historically considered aging and signs of Alzheimer's (memory issues, forgetfulness, getting lost) as part of the cycle of life: people begin life as children and leave as children. Mrs. Williams' daughter did not know what Alzheimer's disease is because no one ever talked about it.

Once in Los Angeles, Mrs. Williams' memory problems grew increasingly worse. Mrs. Williams began wandering and becoming lost. During moments of lucidity, Mrs. Williams begged her daughter to return her to her home on the reservation. Eventually Delma and her family moved back to the reservation. Mrs. Williams has 13 other children who live in that area, but Delma is the only one who cares for their mother. Delma is not sure why her siblings do not visit their mother

and their absence upsets her. Delma also feels guilty for doubting her mother when she first mentioned having memory issues.

### Discussion Questions:

- Why is cultural humility and respect important in public health?
- In this story, what are cultural barriers to diagnosing and understanding Alzheimer's disease?
- How can public health address Alzheimer's disease misinformation and stigma in a culturally competent and relevant way?
- What is the role of family and care in an Alzheimer's disease diagnosis?
- What components may be useful in creating a community outreach program for this particular community?

## 2. "When Mom Has Alzheimer's: A Stranger Comes for Christmas," NPR (2015).

- **Audio/Transcript Link:**  
<http://www.npr.org/templates/transcript/transcript.php?storyId=460042950>
- **Run Time:** 2:44 minutes (audio)
- **Key Terms:** caregiver burden, family, long term care, social stigma
- **Modules:** 1, 3, 4

### Description:

Helen was diagnosed with Alzheimer's disease seven years ago and now lives with her son, Terry, and his wife, Mary. Terry and Mary have created a structured routine for Helen that involves time at the adult day center that provides socialization with other older adults, engaging activities, and care. This routine has become an important part of maintaining Helen's health and wellness.

The winter holidays are coming up, and Terry and Mary must strategize about how to celebrate with family and friends without disrupting Helen's routine. The winter holidays are additionally stressful to families caring for members with Alzheimer's and can make caretakers feel overwhelmed. Terry and Mary must prepare visiting relatives for Helen's worsening condition. They also must mentally prepare themselves for the disappointment of fewer and fewer friends visiting to celebrate the holidays. Terry and Mary are exhausted all the time and say that they are just trying to get through Christmas now.

As Helen's Alzheimer's progresses, Terry and Mary have come to accept that their lives are very different than from seven years ago when Helen moved in, and they continue to make personal sacrifices in order to take the best possible care of Helen. For example, Terry and Mary can no longer go to all of their friends' and family's various holiday celebrations anymore, and often friends and family don't understand why. Terry and Mary have accepted they can no longer do everything

they once did during the holidays; however, they still feel the sense of missing out and being excluded.

#### Discussion Questions:

- What are ways that extended family and friends could be more inclusive and understanding of this couple's difficult situation?
- How can public health reduce social stigma surrounding Alzheimer's disease?
- What kinds of basic information about Alzheimer's should most people know?
- What kind of modifications can be made in the home to increase safety and independence for the individual with Alzheimer's disease?

### 3. "Inside Alzheimer's: What's It Like to Live with Early-Onset Alzheimer's Disease? Greg O'Brien Offers a Glimpse," NPR special series (2015).

- **Audio/Transcript Link:** <http://www.npr.org/series/389781574/inside-alzheimers>
- **Run Time:** 4-6 minutes per segment (audio)
- **Key Terms:** progression, younger-(early) onset, cancer, long term care, end of life decisions, caregiver burden, spouse/partner relationship, family relationship, loss of appetite, loss of smell, loss of taste, hallucinations, medications, GPS app, loss of identity
- **Modules:** 1, 2, 4

#### Description:

A nine part series of articles and audio clips that chronicle aspects of one man's journey with Alzheimer's disease; audio clips are 4-6 minutes each.

Writer Greg O'Brien was diagnosed with younger-onset Alzheimer's disease six years ago when he was 59 years old. Not only was he diagnosed with younger-onset Alzheimer's, but he was also diagnosed with stage-three prostate cancer a few years later. Greg is a journalist and writer living in Cape Cod with his wife, Mary Catherine, and their three children. Greg began demonstrating signs of Alzheimer's dementia, such as memory loss and getting lost, as his own mother was in the end stages of Alzheimer's.

Mary Catherine says that Alzheimer's changed Greg's personality in many ways. On one hand, Greg discusses certain topics with her more openly than he would have in the past, but she also has noticed that he gets angry now, something he never used to do before. In the past, Greg was a loud, outgoing man who was often at the center of discussion. Now he is quieter and more solitary, even disappearing into a different room when crowds of visitors become overwhelming for him. Greg also used to run upwards of six miles daily as a part of his daily routine; however, he began getting lost and switched to running in a gym.

Greg's personality is not the only thing that has changed since his younger-onset Alzheimer's diagnosis. Greg's appetite and sense of taste and smell have declined. Greg says that food now often tastes the same, like "rolled up newspaper." Greg does buy frozen fruit bars and states that although they have no taste, they do feel cold, which is a different and enjoyable sensation.

As Greg's Alzheimer's has progressed over the past six years, so have his hallucinations. Hallucinations are a rarely discussed aspect of Alzheimer's but can often accompany memory loss. According to Greg's doctors, these hallucinations are due to the changes in his brain as a result of the disease.

Mary Catherine's and Greg's outlook on life has also changed over time. For example, Mary Catherine says that she no longer can get impatient, which is difficult, but important. In the beginning of his diagnosis, Greg used to get very angry, but now he no longer does as he tries to focus on the moment instead of the past or future. Mary Catherine believes their marriage has gotten even stronger.

Because of Greg's Alzheimer's, Greg and Mary Catherine have had to make many difficult decisions, including deciding to sell their house that Greg built, where they raised their three children and planned to grow old together. Growing old in that house together is no longer a realistic possibility.

Greg, Mary Catherine, and his physician have discussed "exit strategies" for Greg while he is still aware and able to make these types of decisions. One of these exit strategies includes not treating his stage three prostate cancer. Greg's physician says that not treating the prostate cancer will most likely shorten his life, but Greg is okay with this because he would rather his life be shortened by the prostate cancer than by Alzheimer's. Greg states that he is most afraid of the "in-between." He loves living and he is not afraid to die, but he fears the middle portion, the loss of identity and independence, and dreads his family's suffering as they watch his slow decline.

### Discussion Questions:

- Why is it important that individuals with Alzheimer's disease are diagnosed early?
- In what ways can Greg maintain his independence as his Alzheimer's progresses?
- Discuss the importance of end of life planning and role of public health in encouraging people to make plans.
- Discuss the importance of a strong social network and family support.
- Discuss the advantages and disadvantages of deciding not to treat stage-three prostate cancer as Alzheimer's progresses.

## 4. “Can Technology Ease the Burden of Caring for People with Dementia?” NPR (2015).

- **Audio/Transcript Link:**  
<http://www.npr.org/templates/transcript/transcript.php?storyId=417205451>
- **Run Time:** 4:35 minutes (audio)
- **Key Terms:** care givers burden, financial burden, healthcare system, family support, technology, monitoring systems, long term care
- **Modules:** 2, 3, 4

### Description:

Aurora is 78 years old and lives with her husband, Arturo, in a small apartment in San Rafael. Aurora’s daughter, Maria, comes by their apartment almost daily to help her mother bathe, grocery shop, do laundry, provide medical care, and do many other tasks around the house to help her father and care for her mother.

Early in her Alzheimer’s disease diagnosis, Aurora began wandering at night. Afraid that she might wander into the street, Arturo, began sleeping on the floor in front of the bedroom door in order to keep Aurora from leaving the apartment. Maria had the idea of attaching wind chimes to the door so that Arturo can hear when the door is opened and closed.

Maria and Arturo are currently able to provide all the necessary care for Aurora to live safely in her own home. However, caring for people living with Alzheimer’s tends to be mentally and financially exhausting. As Aurora’s Alzheimer’s progresses, her safety in the apartment becomes an increasing concern.

The story discusses ways that technology, such as remote sensor monitoring systems, can help people with dementia stay independent longer while giving caregivers a way to monitor activity and safety.

### Discussion Questions:

- What are some technologies available to help monitor the health of people diagnosed with Alzheimer’s disease?
- What are ethical dilemmas about these kinds of technologies that may be considered invasive of an individual’s privacy and health?
- What are other ideas for technology that will allow for increased safety and prolonged independence of older adults with Alzheimer’s disease?
- What is the role of public health with assistive technologies?

## 5. “Dementia Village’ Inspires New Care,” CNN (2013).

- **Video Link and Article:** <https://edition.cnn.com/2013/07/11/world/europe/wus-holland-dementia-village/index.html>
- **Run Time:** 3:27 minutes (accompanying news article included in link)
- **Key Terms:** long term care, stigma, financial burden, caregiver burden, community, cultural context, increasing aging population, healthcare system, health policy
- **Modules:** 4

### Description:

Hogewey, or “Dementia Village” as it is known, is a facility created in 2009 in Weesp, Netherlands that is home to 152 residents with dementia. The village is comprised of dormitories uniquely decorated like patients’ homes, a grocery store, restaurants, theater, salon, courtyards, and gardens for residents to enjoy. There is only one exit at the facility, which allows the many skilled caretakers to come and go while the residents are free to wander safely inside the village. The creator of the nursing home, Yvonne van Amerongen, has taken considerable time to create a space unique to each resident that reminds of them of their early life.

While this facility seems ideal to many, some question the ethics of creating a “fake” reality or “duping” the residents. For example, residents can go to the supermarket and not worry about paying. The staff will take care of payment later, without including and potentially confusing the resident. Yvonne defends the model of care, explaining that the facility is the true reality of the residents and provides them peace of mind.

Additionally, this facility costs the same amount of money as any other nursing home in the Netherlands due to the state health care system that all residents pay into and covers expenses such as this as individuals’ age.

### Discussion Questions:

- What are the pros and cons of living in a community like this?
- Discuss the criticism that Hogewey is “duping” the residents.
- Could you see this model of care being implemented in the US? Why or why not?
- How can a community like Hogewey impact the family of residents?
- What would you change (or not change) about Hogewey?

## 6. “Alive inside: A Story of Music and Memory Featurette,” Movieclips Indie (2014).

- **Video Link:** <https://www.youtube.com/watch?v=8HLer-zP3fc>
- **Run Time:** 6:29 minutes
- **Key Terms:** cultural context, music, long term care, family relationships, healthcare system, increasing aging population, loss of identity, technology, community
- **Modules:** 3, 4

### Description:

This video clip demonstrates how music can be used as a form of therapy for individuals diagnosed with Alzheimer’s disease. Yvonne Russell, a recreation therapist discusses how music has positively impacted one of her patients, Henry. Henry has been in a nursing home for ten years after he began having seizures and his wife was no longer able to care for him at home. His daughter recalls how her father was always singing and dancing when she was a child. At the nursing home, Henry is typically unresponsive and spends most of the day looking down sitting in his chair, unable to carry on a conversation or speak more than a few words. After learning about his love of music, Yvonne had all of Henry’s favorite songs downloaded on to an iPod. When she puts the headphones on Henry and plays the music, he immediately sits up, eyes go wide and begins to sing along and dance in his chair. After listening to the music, Henry is asked a series of questions and is able to respond quicker and with more detail than usual. He recalls the name of his favorite singer and even sings his favorite song.

### Discussion Questions:

- How did music impact Henry?
- Discuss ways that caregivers and care facilities can better engage individuals with Alzheimer’s.
- What should public health professionals take away from this case study?

## 7. My Typical Day

- **Website Link:** <http://www.mytypicalday.org/>
- **Key Terms:** mild cognitive impairment, caregiving, photograph diary, identity
- **Module:** 2, 3, 4

### Description:

This photography project features seventeen older adults with mild cognitive impairment (MCI) as they share their world with researchers through images, rather than words. The project is a collaboration of Penn Memory Center, Penn Healthy

Brain Research Center, Penn Medicine CAREs grant, and Penn Neurosciences. Explore the stories of each individual.

### Discussion Questions:

- In what ways has life changed since their diagnoses?
- How have they reacted to their diagnoses? Positively? Negatively?
- How have they adapted their everyday routines?
- What support do they have?
- What changes have they noticed?
- What role do their families and friends play?

## 8. “Following a Couple from Diagnosis to the Final Stages of Alzheimer’s,” CBS News (2018).

- **Video Link:** [https://www.cbs.com/shows/60\\_minutes/video/NdL7R\\_Ds72aHh9tZg8nacFW\\_5ZB4wMC/following-a-couple-from-diagnosis-to-the-final-stages-of-alzheimer-s/](https://www.cbs.com/shows/60_minutes/video/NdL7R_Ds72aHh9tZg8nacFW_5ZB4wMC/following-a-couple-from-diagnosis-to-the-final-stages-of-alzheimer-s/)
- **Run Time:** 13:18 minutes
- **Key Terms:** caregiver’s burden, family relationships, financial burden, end of life planning
- **Module:** 1, 2

### Description:

This 60 Minutes segment follows Dr. Jon LaPook’s who has been checking in on Carol Daly, a woman diagnosed with Alzheimer’s, and her caregiver husband, Mike, each year for the last 10 years to see how the disease progresses. The segment illustrates the devastating impact the disease has on both of them over the decade.

### Discussion Questions:

- Describe some of the physiological changes that occur for Carol over the course of the video.
- In what ways is Mike impacted by the disease?
- What are some of the challenges, changes, and tough decisions Mike and Carol experienced?

## 9. “Tribal Outreach Video –A Project of the UW Alzheimer’s Disease Research Center and Partnerships for Native Health,” Vimeo (2019).

- **Video Link:** <https://vimeo.com/314071595>

- **Run Time:** 5:30 minutes
- **Key Terms:** American Indian, Native Alaskan, oral tradition, memory loss, research, diversity
- **Module:** 3, 4

### Description:

Becky Bendixon talks about her mother’s diagnosis of Alzheimer’s disease. Becky first noticed that her mother was experiencing some memory loss when she struggled to fill out a form with her basic information. She then realized that something was seriously wrong when her mother’s pharmacy called because her mother was having issues remembering to take her medications, putting her life in danger. Becky describes the importance of oral tradition in her culture and how memory loss due to Alzheimer’s prevents generations from passing down these oral traditions, resulting in a loss of culture and identity of the community. Researchers at the University of Washington Alzheimer’s Disease Research Center discuss their goal of increasing representation of American Indian and Alaska Native populations in their research.

### Discussion Questions:

- Why is cultural humility and respect important in public health?
- Why is diversity of participants important in Alzheimer’s disease research?
- How might Becky’s community and culture change if Alzheimer’s disease becomes more prevalent?

The following case studies (10-14) are pulled directly from the Health Brain Initiative 2018-2023 Road Map, which was developed by the Alzheimer’s Association and the Centers for Disease Control and Prevention (CDC) to advance cognitive health as an integral component of public health.

**Source:** Alzheimer’s Association and Centers for Disease Control and Prevention. *Healthy Brain Initiative, State and Local Public Health Partnerships to Address Dementia: The 2018-2023 Road Map*. Chicago, IL: Alzheimer’s Association; 2018.

## 10. “Educating African Americans, Asian Americans and Pacific Islanders about Dementia,” Healthy Brain Initiative Road Map: Washington

- **Key Terms:** cultural context, African American, Asian American, Pacific Islander, prevention, stigma, education, community outreach, healthcare, service provider
- **Modules:** 2, 3

- **Supplemental video:** start at 25:55 minutes and end at 37:12 minutes.  
<http://www.astho.org/generickey/GenericKeyDetails.aspx?contentid=20941&folderid=5162&catid=7254>
- **Supplemental materials:** Healthy Brain Initiative Roadmap
  - <https://www.alz.org/media/Documents/healthy-brain-initiative-road-map-2018-2023.pdf>
  - <https://www.alz.org/media/Documents/healthy-brain-initiative-executive-summary.pdf>

### Description:

As a partner in Washington State’s Dementia Action Collaborative, a voluntary statewide workgroup charged with implementing the state’s Alzheimer’s plan, the Washington Department of Health (DOH) began a two-part initiative to increase awareness of brain health among African Americans and encourage cognitive assessments among Asian Americans and Pacific Islanders (AAPIs). These efforts support implementation of the *Washington State Plan to Address Alzheimer’s Disease and Other Dementias* regarding culturally-appropriate strategies to educate the public about reducing risk for cognitive decline and possibly dementia.

DOH prioritized African American women as a main audience for cognitive health education based on national prevalence data. DOH then reviewed evidence-based, brain health messages developed by the Alzheimer’s Association for the Healthy Brain Initiative. After securing approval from Washington’s state health officer, DOH partnered with the Seattle based, nonprofit Center for MultiCultural Health (CMCH) to help tailor and disseminate brain health messages to African American audiences. CMCH identified African American churches as a promising venue to reach women and recommended creating hand fans printed with culturally-tailored messages.

Additionally, the National Asian Pacific Center on Aging (NAPCA) and the University of Washington Healthy Brain Research Network (UW-HBRN) partnered to conduct outreach and education for Seattle AAPIs. Through six focus groups, they solicited input from local Chinese and Japanese adults with at least one living relative age 65 or over. The focus groups assessed the acceptability of messages developed by the University of Pennsylvania HBRN Center to encourage non-Hispanic white or African American urban adults concerned about the cognitive health of an older relative to accompany that relative to an appointment with a healthcare provider. NAPCA and UW-HBRN released two briefs on their findings: *Connecting with AAPIs about Dementia: An Action Guide for Service Providers* and *Connecting with AAPIs about Dementia: An Action Guide for Policymakers*. Each offers dementia resources and information on treatment options. The importance of early detection of cognitive impairment is emphasized in the guide for service providers, as these professionals play a crucial role in facilitating older AAPIs’ and their caregivers’ access to cognitive assessment resources. The Dementia Action Collaborative provided guidance on the action briefs and also helped to disseminate

them. UW-HBRN received a 2017 Seattle Innovation Fund grant for its work on the AAPI action briefs.

If you would like to learn more about this case study, a supplemental video has been provided to illustrate public health in action.

### Discussion Questions:

- Why is cultural humility and respect important in public health?
- How did the Washington DOH address Alzheimer’s disease in a culturally competent and relevant way?
- What stakeholders did the Washington DOH involve in this two-part initiative?
- How do these efforts align with the Health Brain Initiative Road Map goals?

## 11. “Improving Early Detection during Medicare Annual Wellness Visits,” Healthy Brain Initiative Road Map: Utah

- **Key Terms:** early detection, cognitive impairment, screening, providers, assessment tools
- **Modules:** 3, 4
- **Supplemental Video:** start at 33:00 minutes and end at 47:20 minutes.  
[https://www.youtube.com/watch?v=O\\_sQ4arm8UU&index=19&t=0s&list=PLb15WDa0LdCYxu4ZX9pISVFCtNCxxrpnU](https://www.youtube.com/watch?v=O_sQ4arm8UU&index=19&t=0s&list=PLb15WDa0LdCYxu4ZX9pISVFCtNCxxrpnU)
- **Supplemental materials:** Healthy Brain Initiative Roadmap
  - <https://www.alz.org/media/Documents/healthy-brain-initiative-road-map-2018-2023.pdf>
  - <https://www.alz.org/media/Documents/healthy-brain-initiative-executive-summary.pdf>

### Description:

Utah is one of the most rural and fastest growing states in America. Currently, about 11% of the state’s three million residents is aged 65 or older, and the state has about 30,000 people with Alzheimer’s dementia, which is expected to rise 40% to 42,000 by 2025. Diagnoses of dementia in later stages may lead to higher levels of disability while receiving care, delays in accessing timely primary care, lack of care coordination, and duplication of services.

To improve early detection of cognitive impairment, a focus of *Utah’s State Plan for Alzheimer’s and Related Dementias*, the Utah Department of Health (UDOH) contracted with HealthInsight, a quality improvement organization. HealthInsight interviewed providers about their experiences and processes conducting cognitive assessments during the Medicare Annual Wellness Visit (AWV). While some providers reported performing routine cognitive assessments during the AWV, others reported screening only under certain conditions, such as when patients

request assessment or when patients have specific risk factors for cognitive decline, etc. Providers also expressed a need for better tools to detect early stage memory loss. The resulting report, *Cognitive Assessments during Medicare Annual Wellness Visits*, was a collaborative product from HealthInsight; UDOH; the Center for Alzheimer’s Care, Imaging and Research at the University of Utah; and Intermountain Medical Center.

Actions in the Healthy Brain Initiative Road Map include improving healthcare providers’ ability to recognize the early warning signs of dementia and knowledge of validated cognitive assessment tools. As a step in this process, UDOH sent the study report to all Utah primary care physicians, along with a list of resources for people with cognitive impairment and a recommendation from UDOH’s executive director for routine cognitive assessment during the AWV using the Mini-Cog as the primary assessment tool, followed by the Montreal Cognitive Assessment tool (MoCA).

The project deepened UDOH’s understanding of some challenges that physicians face in assessing cognition during the AWV, one of which is uncertainty about which validated tool to use. Receiving clear recommendations from UDOH’s executive director may begin increasing physician use of the tools during AWVs or other occasions in which a physician has concerns about potential cognitive impairment. Use of validated early detection tools helps physicians assess cognitive functioning and detect potential concerns early, the first step in increasing early diagnoses. With some legislative support, UDOH plans to continue collaborating with HealthInsight to develop:

- Cognitive assessment training for primary care physicians and their office staff that will include use of recommended tools and workflow improvement techniques to instill a reliable, repeatable process in clinics; and
- Cognitive health and wellness toolkit to help health professionals navigate the cognitive assessment process, including assessment, diagnosis, referrals, and community resources.

### Discussion Questions:

- What stakeholders did the Utah DOH involve in this initiative?
- Why is early detection of cognitive impairment important?
- Describe some of the barriers to early detection of cognitive impairment and the recommendations that came from this evaluation to overcome those barriers.
- Why is it important that public health professionals conduct evaluations like this?
- How does this study align with the Health Brain Initiative Road Map goals?

## 12. “Preparing First Responders for Interactions with People with Dementia,” Healthy Brain Initiative: Colorado

- **Key Terms:** EMS, healthcare system, stigma, first responders, increasing aging population, community outreach, training, education, cultural context
- **Modules:** 3, 4
- **Supplemental Materials:** <https://www.alz.org/media/Documents/case-study-co-ems-training.pdf>
- **Supplemental materials:** Healthy Brain Initiative Roadmap
  - <https://www.alz.org/media/Documents/healthy-brain-initiative-road-map-2018-2023.pdf>
  - <https://www.alz.org/media/Documents/healthy-brain-initiative-executive-summary.pdf>

### Description:

Emergency Medical Service (EMS) providers receive many calls to assist people with Alzheimer’s and other dementias. However, they often have little or no formal training to prepare them for the unique physical, behavioral, and communication challenges related to dementia.

To develop a dementia-competent workforce throughout Colorado, the Colorado Department of Public Health and the Environment (CDPHE) partnered with the Alzheimer’s Association Colorado Chapter to deliver its *Approaching Alzheimer’s: First Responder Training Program*. CDPHE marketed the availability of the free, in-person training through its internal networks and all 11 of Colorado’s Regional Emergency and Trauma Advisory Councils.

The training helps first responders serve people with Alzheimer’s in situations involving wandering, disasters or other emergency situations, abuse or neglect, “shoplifting” because they forgot to pay, and driving. At the completion of training, participants receive a poster—*Tips for EMS Working with People with Alzheimer’s*—to display and reinforce effective responses.

See the supplemental material link to learn more about this example of public health workforce education.

### Discussion Questions:

- Why is it important that EMS providers have formal training on assisting people with Alzheimer’s and other dementias?
- What other professionals or community members may benefit from this formal training?
- Discuss the ways that public health providers can expand upon or improve this program.

- Review the *Tips for EMS working with people with Alzheimer’s* listed in the supplemental material and discuss the “do’s” and “don’ts” of interacting with someone with Alzheimer’s disease.
- How does this example align with the Health Brain Initiative Road Map goals?

### 13. “Using Social Media to Promote Engagement,” Healthy Brain Initiative: Puerto Rico

- **Key Terms:** education, cultural context, stigma, community outreach, caregiver, prevention, family support, increasing aging population, progression, healthcare
- **Modules:** 2, 3

**Supplemental materials:** Healthy Brain Initiative Roadmap

- <https://www.alz.org/media/Documents/healthy-brain-initiative-road-map-2018-2023.pdf>
- <https://www.alz.org/media/Documents/healthy-brain-initiative-executive-summary.pdf>

#### Description:

The Puerto Rico Department of Health worked with the Prevention Research Center’s South Carolina Healthy Brain Research Network at the University of South Carolina to implement the *Puerto Rico Alzheimer’s Action Plan*, with a special focus on education and empowerment of individuals and families. One component was a collaborative educational initiative called *Un café por el Alzheimer*. With special attention toward decreasing stigma, this initiative used social media and in-person gatherings to support informal but structured conversations with experts about Alzheimer’s disease, risk factors, diagnosis, pharmacological and non-pharmacological treatments, management of behavioral changes, and healthy living. The Alzheimer’s cafés enabled participants to have informal conversations in coffee shops across the island. Participants could raise questions at any time and were encouraged to share testimonials and comments. At the end of the gatherings, the participants were invited to continue the conversation online by following the Facebook page. These social media efforts reinforced key messages and helped engage and educate the wider audience.

Pre/post surveys in four sessions with a total of 212 participants showed improved knowledge and high satisfaction ratings. All participants said they learned something new from the program, and 80% said most of the information presented was new to them. A total of 250 messages were posted on the *Un café por el Alzheimer* community Facebook page over a seven-month period. An average increase of nearly 65% in the number of people reached by the Facebook page offered evidence of the program’s success in helping participants remain actively engaged while fostering social support and reducing stigmas and myths surrounding the disease.

### Discussion Questions:

- How did public health professionals help to reduce social stigma surrounding Alzheimer’s disease?
- Why do you think this educational initiative was successful?
- How could this model be implemented in your community? What would you change or keep the same?
- How does this initiative align with the Health Brain Initiative Road Map goals?

## 14. “Encouraging Advance Care Planning for People with Dementia,” Healthy Brain Initiative: Maryland

- **Key Terms:** increasing prevalence, increasing aging population, family support, caregiver burden, policy, healthcare, advance directive, end of life decisions, education, community outreach, long term care
- **Modules:** 2, 3, 4
- **Supplemental materials:** Healthy Brain Initiative Roadmap
  - <https://www.alz.org/media/Documents/healthy-brain-initiative-road-map-2018-2023.pdf>
  - <https://www.alz.org/media/Documents/healthy-brain-initiative-executive-summary.pdf>

### Description:

Maryland’s population of people with Alzheimer’s dementia is projected to rise—from 110,000 people in 2018 to 130,000 in 2025, an 18% increase in eight years. As the number of people with dementia rises, so too does the need to assist families in planning for future care needs. The passage of Maryland House Bill 1385 in May 2016 aimed to increase advance care planning among families impacted by dementia. Among other mandates, the law directs the Maryland Department of Health (MDH) to encourage the use of electronic advance directives, develop an electronic platform to connect with healthcare providers at point-of-care using the state-designated health information exchange, and conduct outreach to increase public awareness of the Advance Directive Program. An early assessment found that advance care planning in Maryland is offered primarily through hospitals and hospice providers, with limited free care planning services available through Maryland Legal Aid and Maryland Volunteer Lawyers Service Pro Bono Resource Centers.

To increase advance care planning, MDH collaborated with the Maryland Faith Health Network to lead a year-long series of community engagement activities on electronic advance directives. More than 500 Marylanders learned about advance care planning through health fairs, faith-based events, and end-of-life seminars. In

addition, three local health improvement coalitions hosted seven advance-planning educational sessions, with a combined total of 144 participants. More than twice as many participants were able to identify core legal and financial advance planning documents post-session (25%) as pre-session (10%). Also, a greater number of participants (post-session compared with pre-session) reported understanding the importance of involving people with cognitive impairment in advance planning.

The medical director of the MDH Center for Chronic Disease Prevention and Control served as a co-chair (along with a representative from the Maryland Department of Aging) of the governor-appointed Virginia I. Jones Alzheimer's Disease and Related Disorders Council during this time. The Council monitors implementation of the *Maryland State Plan on Alzheimer's Disease and Related Disorders*. As a tenet of the Maryland State Plan, MDH used this unique opportunity to engage partners to discuss potential cognitive health education and establish interventions in Maryland's public health programming.

### Discussion Questions:

- Why is it important for an individual diagnosed with Alzheimer's disease to have an advance directive?
- What challenges may arise if an individual with Alzheimer's disease does not have an advanced directive? Consider the different perspectives of the individual, family, and medical providers.
- Discuss the different levels of action taken to promote the use of advance directives among persons with dementia. Who were the key players or stakeholders?
- How does this study align with the Health Brain Initiative Road Map goals?
- Test your knowledge! Do you know what information is included in an advanced directive? Find your states advanced directive to learn more.

# Video Resources

The following videos are listed as suggested accompaniments to the curriculum modules. These could be shown in class or as suggested viewing outside of class. Please note that some of the videos listed are only for purchase. Check with your specific institution to see if some videos may be available through your universities' library resources for free.

## 1. "6 Siblings Living in the Shadow of Alzheimer's," TODAY Show (2017).

- **Video Link:** <https://www.youtube.com/watch?v=dLiu07V4cUI>
- **Run Time:** 6:20 minutes
- **Keywords:** early onset, caregiver, genetic
- **Modules:** 1, 2, 3

### Description:

The DeMoe family are fighting a unique battle against Alzheimer's disease. Five of the six DeMoe siblings have tested positive for early onset Alzheimer's disease. Their father was diagnosed with Alzheimer's in his 40s. They share their story and how their own children have been impacted by the disease.

## 2. "14 Days with Alzheimer's: A Film By Lisa Cerasoli," Lisa Cerasoli (2012).

- **Video Link:** [http://www.amazon.com/14-Days-Alzheimers-Film-Cerasoli/dp/1589850998/ref=sr\\_1\\_1?s=movies-tv&ie=UTF8&qid=1427304005&sr=1-1&keywords=14+days+with+alzheimer%27s](http://www.amazon.com/14-Days-Alzheimers-Film-Cerasoli/dp/1589850998/ref=sr_1_1?s=movies-tv&ie=UTF8&qid=1427304005&sr=1-1&keywords=14+days+with+alzheimer%27s)
- **Run Time:** 29:00 minutes
- **Keywords:** caregiver burden, family relationship
- **Modules:** 1, 2, 3
- **Purchase Price:** \$18.22\*

### Description:

Winner of the Audience Choice Award at the Life and Death Matters Film Festival, Boulder, Colorado. Based on the memoir, *As Nora Jo Fades Away*, this short documentary examines 14 days in the life of the filmmaker's grandmother.

## 3. "Alive Inside: A Story of Music and Memory Featurette," Movieclips Indie (2014).

- **Video Link:** <https://www.youtube.com/watch?v=8HLEr-zP3fc>
- **Run Time:** 6:29 minutes
- **Key Terms:** Alzheimer's disease, music, therapy

- **Modules:** 4

**Description:**

This video clip demonstrates music as a therapy for individuals diagnosed with Alzheimer’s disease. Watch as a gentleman with dementia who is largely non-verbal begin singing once he hears his favorite music and becomes more responsive to questions after the music is played.

#### 4. “Alive Inside,” M. Rossato-Bennett (2014).

- **Video Link:** [http://www.theconnexion.com/aliveinside/aliveinside\\_index.cfm](http://www.theconnexion.com/aliveinside/aliveinside_index.cfm)

- **Run Time:** 78:00 minutes
- **Key Terms:** music, memory loss, healing
- **Modules:** 4
- **Purchase Price:** \$14.99

**Description:**

Depicts the power of music listening to revitalize and soothe the human spirit in persons with memory loss. Contains interviews with Oliver Sachs and Bobby McFerrin. Won the 2014 Audience Award at the Sundance Film Festival.

#### 5. “Alzheimer’s: An Emerging Public Health Issue,” Alzheimer’s Association (2017).

- **Video Link:** <https://www.youtube.com/watch?v=f0a8KuYlpy4&list=PLb15WDa0LdCYxu4ZX9pISVFCtNCxxrpnU&index=12&t=0s>
- **Run Time:** 9:30 minutes
- **Key Terms:** public health, prevention, intervention
- **Modules:** 1, 3

**Description:**

Historically, Alzheimer's disease has been seen as an aging issue, but more and more people are viewing Alzheimer's as a public health issue because the burden is large, the impact is major, and there are ways public health can intervene. This video provides an overview of Alzheimer’s disease as a public health issue and the ways that public health professionals can intervene.

#### 6. “Alzheimer’s Association 2019 Alzheimer’s Disease Facts and Figures,” (Alzheimer’s Association (2019).

- **Video Link:** <https://www.youtube.com/watch?v=vR-cwADz-V0>
- **Run Time:** 1:20 minutes
- **Key Terms:** public health, data
- **Modules:** 1

### Description:

Brief overview of the Alzheimer's Association's 2019 facts and figures on Alzheimer's disease that covers prevalence and impact figures.

## 7. "Caregivers," HBO (2009).

- **Video Link:** <http://www.hbo.com/alzheimers/caregivers.html>
- **Run Time:** 48:48 minutes (each segment is approximately 10 minutes)
- **Key Terms:** stigma, caregiver relationship, life after caregiving, duties and responsibility, assisted living facilities
- **Modules:** 2, 3, 4
- **Purchase Price:** HBO subscription required

### Description:

This documentary shares the stories of 5 caregivers and demonstrates the struggle and resilience of the caregiver when a family member is diagnosed with Alzheimer's disease. These caregivers struggle to balance their own lives and responsibilities with the daily duties and responsibilities of caring for a loved one with Alzheimer's disease. This documentary illustrates the many challenges and sacrifices of a caregiver, such as personal responsibilities and the social stigma of caring for a loved one whether in their family home or in professional medical facilities.

## 8. "Communicating with People with Dementia: New Educational Videos," Alzheimer's Association (2017).

- **Video Link:** See individual episode links below
- **Key Terms:** dementia, selfhood, communication, caregivers
- **Modules:** 1, 4

### Description:

This new educational resource can help the public and professionals communicate effectively and sensitively with people with dementia. In a series of three videos – *Communicating with People with Dementia: Understanding Their Selfhood*, Dr. Steven Sabat of Georgetown University speaks about the importance of language in communications with persons with Alzheimer's and other dementias. He describes how the words we choose can lessen the social stigmas associated with dementia. Stories illustrate different communications choices with regards to the selfhood of people with dementia.

### A. "The Effects of Labeling Relationships (part 1)"

- **Video Link:** <https://www.youtube.com/watch?v=kPppik-FtGE&index=13&list=PLb15WDa0LdCYxu4ZX9pISVFctNCxxrpnU&t=49s>
- **Run Time:** 15:52 minutes
- **Key Terms:** stigma, selfhood, communication, caregivers

- **Module:** 1, 4

### Description:

Dr. Steven Sabat of Georgetown University speaks about the importance of language when communicating with individuals who have been diagnosed with Alzheimer's disease and other dementias. In this video, Dr. Sabat explains how labels (such as doctor-patient) can affect the nature of the relationship and the importance of personal attributes.

## B. "The Value of Individuality (part 2)"

- **Video Link:**

<https://www.youtube.com/watch?v=7MC2dctNTzE&list=PLb15WDa0LdCYxu4ZX9pISVFCtNCxxrpnU&index=13>

- **Run Time:** 12:40 minutes
- **Key Terms:** dementia, selfhood, communication, caregivers
- **Module:** 1, 4

**Description:** Dr. Sabat speaks about the effects of the label "patient." Dr. Sabat offers advice on how to communicate with and describe individuals living with Alzheimer's disease and other dementias to better emphasize their individuality.

## C. "Normal Behaviors Post-Diagnosis (part 3)"

- **Video Link:** <https://www.youtube.com/watch?v=t27Z-lfCRzU&index=14&list=PLb15WDa0LdCYxu4ZX9pISVFCtNCxxrpnU>
- **Run Time:** 16:17 minutes
- **Key Terms:** dementia, selfhood, communication, caregivers
- **Module:** 1, 4

### Description:

In this video, Dr. Sabat discusses a case study that illustrates how normal behaviors are perceived differently after receiving an Alzheimer's or other dementia diagnosis and how important it is to remember to treat these behaviors as normal.

## 9. "'Dementia Village' Inspires New Care," CNN (2013).

- **Video Link and Article:** <https://edition.cnn.com/2013/07/11/world/europe/wus-holland-dementia-village/index.html>
- **Run Time:** 3:27 minutes (accompanying news article included in link)
- **Key Terms:** long term care, stigma, financial burden, caregiver burden, community, cultural context, increasing aging population, health care system, health policy
- **Modules:** 4

### Description:

Hogewey, or “Dementia Village” as it is known, is a facility created in 2009 in Weesp, Netherlands, that is home to 152 residents with dementia. The village is comprised of dormitories uniquely decorated like patient’s’ homes, a grocery store, restaurants, theater, salon, courtyards, and gardens for residents to enjoy. There is only one exit at the facility, which allows the many skilled caretakers to come and go while the residents are free to wander safely inside the village. The creator of the nursing home, Yvonne van Amerongen, has taken considerable time to create a space unique to each resident that reminds of them of their early life. While this facility seems ideal to many, some question the ethics of creating a “fake” reality or “duping” the residents. For example, residents can go to the supermarket and not worry about paying. The staff will take care of payment later, without including and potentially confusing the resident. Yvonne defends the model of care, explaining that the facility is the true reality of the residents and provides them peace of mind. Additionally, this facility costs the same amount of money as any other nursing home in the Netherlands due to the state health care system that all residents pay into and covers expenses such as this as individuals’ age.

## 10. “Diagnosing Alzheimer’s: The Case for Public Health Action” Alzheimer’s Association (2019).

- **Video Link:** [https://www.youtube.com/watch?v=O\\_sQ4arm8UU&index=19&t=0s&list=PLb15WDa0LdCYxu4ZX9pISVFctNCxxrpnU](https://www.youtube.com/watch?v=O_sQ4arm8UU&index=19&t=0s&list=PLb15WDa0LdCYxu4ZX9pISVFctNCxxrpnU)
- **Run Time:** 59:33 minutes
- **Key Terms:** early diagnosis, education, public health
- **Modules:** 2, 3

### Description:

This webinar explains why early diagnosis of Alzheimer's and other dementias is a public health priority. Lauren Seemeyer of the Alzheimer's Association provides best practices and resources that can aid public health agencies in promoting early diagnosis, and Lynn Meinor of the Utah Department of Health highlights Utah's successes in educating health care providers about the need for early diagnosis as well as increasing the general public's understanding of dementia warning signs and community resources.

## 11. “A Different Visit: Montessori-Based Activities for People with Alzheimer’s/Dementia,” Center for Applied Research in Dementia (2012).

- **Video Link:** <https://www.youtube.com/watch?v=FLDwzgRTbVA>
- **Run Time:** 8:07 minutes
- **Key Terms:** caregivers, emotional health, meaningful visits

- **Modules:** 1, 2, 3, 4

**Description:**

This clip gives suggestions about how to have a meaningful visit with someone who has been diagnosed with Alzheimer’s disease. The video emphasizes focusing on positive feelings. If conversation is not an option, do a simple, safe activity by focusing on the individual’s interests and abilities. The most important thing is for the individual to feel good about the visit at the end. The first half of the clip is applicable to Alzheimer’s disease, and the second half discusses the theory behind their suggestions (Montessori-based activities).

**12. “Family Caregiving: The Frontline of Dementia Care,” Alzheimer’s Association (2018).**

- **Video Link:** <https://www.youtube.com/watch?v=ecp7lgQS1v0&index=23&list=PLb15WDa0LdCYxu4ZX9pISVFCtNCxxrpnU>
- **Run Time:** 1:01:52 minutes
- **Key Terms:** caregiver, BRFSS, surveillance, public health, Healthy Brain Initiative Road Map
- **Module:** 1, 2, 3

**Description:**

Webinar presented by the Alzheimer’s Association discussing overview of 2016 BRFSS Caregiver Module in New York, and the origin and first year results of the Alzheimer’s Disease Caregiver Support Initiative (ADCSI) in New York. Featured speakers include Dr. Erin Bouldin, Dr. David Hoffman, and Dr. Mary Gallant.

**13. “First Cousin Once Removed,” Alan Berliner (2013).**

- **Video Link:** [https://www.amazon.com/First-Cousin-Once-Removed-Berliner/dp/B00J7JXMBE/ref=sr\\_1\\_1?keywords=first+cousin+once+removed&qid=1547758337&sr=8-1](https://www.amazon.com/First-Cousin-Once-Removed-Berliner/dp/B00J7JXMBE/ref=sr_1_1?keywords=first+cousin+once+removed&qid=1547758337&sr=8-1)
- **Run Time:** 27:00 minutes
- **Key Terms:** progression, caregiver, intervention
- **Modules:** 1, 2, 3, 4
- **Purchase Price:** Amazon
  - Buy \$11.99
  - Rent 3.99

**Description:**

Edwin Honig is a distinguished poet, translator, critic, teacher, honorary knight, and cousin and mentor to the filmmaker, Alan Berliner. Shot over five years for HBO, First Cousin Once Removed documents Honig's experience with Alzheimer's through

conversations with family and friends. Berliner captures Honig's literary skills, playfulness and poetic soul, obvious even through his cognitive impairment.

#### 14. “Following a Couple from Diagnosis to the Final Stages of Alzheimer’s,” CBS News (2018).

- **Video Link:**  
[https://www.cbs.com/shows/60\\_minutes/video/NdL7R\\_Ds72aHh9tZg8nacFW\\_5ZB4wMC/following-a-couple-from-diagnosis-to-the-final-stages-of-alzheimer-s/](https://www.cbs.com/shows/60_minutes/video/NdL7R_Ds72aHh9tZg8nacFW_5ZB4wMC/following-a-couple-from-diagnosis-to-the-final-stages-of-alzheimer-s/)
- **Run Time:** 13:18 minutes
- **Key Terms:** caregiver’s burden, family relationships, financial burden, end of life planning
- **Modules:** 1, 2, 3, 4

##### **Description:**

This 60 Minutes segment follows Dr. Jon LaPook’s who has been checking in on Carol Daly, a woman diagnosed with Alzheimer’s, and her caregiver husband, Mike, each year for the last 10 years to see how the disease progresses. The segment illustrates the devastating impact the disease has on both of them over the decade.

#### 15. “GAPS,” Peter Trinh (2018).

- **Video Link:** <https://vimeo.com/268811803/6745380c62>
- **Run Time:** 15:24 minutes
- **Key Terms:** stigma, Asian culture, community, awareness
- **Modules:** 1, 4

##### **Description:**

This documentary examines the cultural and epidemiological aspects of Alzheimer’s disease and other dementias among Asian American/Pacific Islanders (AAPI). Although dementias and related neurodegenerative diseases are major public health issues around the world, cultural stigmas and traditions play a role in how they are dealt with in Asian communities. This may be particularly true of Alzheimer’s disease. Alzheimer’s disease affects millions of Asians, yet in most Asian countries and cultures, a word does not exist to describe the disease. Trang Tu shares her emotional stories of being the full-time caregiver to her mom, who is living with Alzheimer’s. Trang has experienced the difficulties and pressures of caring for her mother as an Asian-American and dealt with a system that has not yet fully understood or addressed the need for culturally relevant resources. These same topics are also discussed in the documentary with professional health care experts from various organizations and universities, including the Alzheimer’s Association, University of Washington, and the University of California, San Francisco.

## 16. “Glen Campbell: I’ll Be Me,” PCH Films (2014).

- **Video Link:** <https://www.amazon.com/Glen-Campbell-III-Be-Me/dp/B00ZOGES3E>
- **Run Time:** 116:00 minutes
- **Key Terms:** progression, music therapy, family
- **Purchase Price:** \$3.99

### Description:

In 2011, music legend Glen Campbell set out on an unprecedented tour across America. He thought it would last 5 weeks; instead it went for 151 spectacular sold-out shows over a triumphant year and a half. What made this tour extraordinary was that Glen had recently been diagnosed with Alzheimer’s disease. He was told to hang up his guitar and prepare for the inevitable. Instead, Glen and his wife went public with his diagnosis and announced that he and his family would set out on a “Goodbye Tour.” The film documents this extraordinary journey as he and his family attempt to navigate the wildly unpredictable nature of Glen’s progressing disease using love, laughter, and music as their medicine of choice.

## 17. “Grandpa, Do you know who I am?” The Alzheimer’s Project on HBO (2016).

- **Video Link:** <https://www.hbo.com/documentaries/the-alzheimers-project-grandpa-do-you-know-who-i-am>
- **Run Time:** 30:48 minutes
- **Key Terms:** children, family, impact of disease on family
- **Modules:** 1, 4
- **Purchase Price:** HBO subscription required

### Description:

This film tells five stories of children, ages 6-15, who are coping as their grandfathers or grandmothers live with Alzheimer's disease. Maria Shriver provides commentary and delivers valuable "lessons" for the kids, urging them not to blame themselves for what their grandparents do or say. "We are all children of Alzheimer's," says Shriver, sympathetically making it clear that "if it's too painful to visit, you don't have to go." Maria's own father, Sargent Shriver, has the disease. Comparing his earlier vitality to his present condition is hard, but it is offset by good memories and an unexpected "gift": bonds between generations that may not have been made otherwise. Ultimately, the film shows how important it is to "go with the flow," offering up a variety of perspectives on how kids can handle a grandparent's loss of memory through kindness, patience, and compassion.

## 18. “Healthy Aging: Promoting Well-being in Older Adults,” CDC (2017).

- **Video Link:** <https://www.cdc.gov/grand-rounds/pp/2017/20170919-senior-aging.html>
- **Run Time:** 1:05:04 minutes
- **Key Terms:** prevention, health behaviors, intervention, aging, workforce, chronic disease
- **Modules:** 1, 2, 3, 4

### Description:

CDC’s Public Health Grand Rounds in September 2017 focuses on aging, chronic disease (including Alzheimer’s disease), role of caregivers, and the role of public health.

## 19. “How Alzheimer’s Changes the Brain,” National Institutes of Health, National Institute on Aging (2017).

- **Video Link:** [https://www.nia.nih.gov/health/video-how-alzheimers-changes-brain?utm\\_source=20180612\\_animation&utm\\_medium=email&utm\\_campaign=ealert](https://www.nia.nih.gov/health/video-how-alzheimers-changes-brain?utm_source=20180612_animation&utm_medium=email&utm_campaign=ealert)
- **Run Time:** 4:00 minutes
- **Key Terms:** neurobiology of Alzheimer’s disease, beta amyloid, tau
- **Modules:** 2, 3

### Description:

This video describes how Alzheimer’s disease biologically affects the brain.

## 20. “Inside the Brain: An Interactive Tour,” Alzheimer’s Association (2018).

- **Web Link:** [http://www.alz.org/alzheimers\\_disease\\_4719.asp](http://www.alz.org/alzheimers_disease_4719.asp)
- **Run Time:** interactive tour of brain
- **Key Terms:** Alzheimer’s disease, brain activity, neurotransmitters, amyloid plaques, tangles
- **Modules:** 2, 3

### Description:

This interactive tour helps explain the basic components of the brain and how Alzheimer’s disease affects the brain. The tour teaches the participant the different parts of the brain, how Alzheimer’s disease damages the brain and brain activity, and the different stages of the disease.

## 21. “Living with Memory Loss: In our own words,” The Gathering Place (n.d.)

- **Video Link:** <https://www.phinneycenter.org/memoryloss-film/>
- **Run time:** 5:00 minutes (short version); 16-min. full version also available
- **Key Terms:** community, coping with memory loss
- **Modules:** 4

### Description:

Brief video from the Phinney Center’s The Gathering Place program for people living with early stage memory loss. The video showcases several members of the program sharing their thoughts on living with early stage memory loss.

## 22. “A Marriage to Remember,” The New York Times (2014).

- **Video Link:** <https://www.youtube.com/watch?v=PZu51MngfF4>
- **Run Time:** 8:34 minutes
- **Key Terms:** progression, early onset, caregiver
- **Modules:** 2, 3

### Description:

Filmmaker Banker White filmed this documentary about his parents. His mother was diagnosed with Alzheimer’s disease and his father has become her caregiver. They share their thoughts as the disease progresses.

## 23. “ASTHOConnects Series on Brain Health,” ASTHO (2019).

- **Video Link:** See individual video links below
- **Run Time:** See individual video links below
- **Key Terms:** public health, programs, road map, caregiving, communication, Alzheimer’s disease, brain health
- **Modules:** 2, 3, 4

### Description:

This learning series brings experts in their field to the table to discuss brain health and aging.

### A. “Series on Brain Health: Virtual Open House” (part 1):

- **Video Link:**  
<http://www.astho.org/generickey/GenericKeyDetails.aspx?contentid=20481&folderid=5162&catid=7254>
- **Run Time:** 59:34 minutes
- **Key Terms:** public health, programs, road map, implementation
- **Modules:** 2, 3, 4

### Description:

This webinar highlights national partners at the CDC's Alzheimer's Disease and Healthy Aging Program, Alzheimer's Association, and International Association for Indigenous Aging about the HBI Road Map. Speakers present a national overview of the HBI Road Map, how it was developed, and current approaches for distribution and implementation.

## B. “Series on Brain Health: Conversation and Cup of Joe” (part 2):

- **Video Link:**  
<http://www.astho.org/generickey/GenericKeyDetails.aspx?contentid=20941&folderid=5162&catid=7254>
- **Run Time:** 58:39 minutes
- **Key Terms:** public health, programs, road map, caregiving, communication
- **Modules:** 2, 3

### Description:

In this video from the Association of State and Territorial Health Officials (ASTHO), learn from CDC and featured state public health experts about ongoing efforts to implement brain health and Alzheimer's disease programs, including approaches using the Healthy Brain Initiative (HBI) Road Map. The CDC's Alzheimer's disease and Healthy Aging Program presents data from the BRFSS optional modules on cognitive decline and caregiving. Speakers from health departments in Tennessee and Washington share their experiences using the HBI Road Map to incorporate brain health messages into state public health programs.

## C. “ASTHOConnects Series on Aging: Ask the Experts” (part 3):

- **Video link:**  
<http://www.astho.org/generickey/GenericKeyDetails.aspx?contentid=21412&folderid=5162&catid=7254>
- **Run Time:** 60:00 minutes
- **Key Terms:** caregiving, brain health, Alzheimer's disease
- **Modules:** 2, 3

### Description:

This webinar engages with experts from the national and state level about specific ways to incorporate brain health, Alzheimer's disease, and caregiving content into programs in your jurisdiction. Participants are provided tools, examples, and practical tips.

## 24. “Still Alice,” Sony Pictures Classics (2014).

- **Video Link:** <http://sonyclassics.com/stillalice/>
- **Run Time:** 101:00 minutes

- **Key Terms:** Alzheimer’s disease, academia, family relationships, end of life planning, early onset, caregiver
- **Modules:** 2, 3
- **Purchase Price:**
  - Digital Rent (Amazon): \$2.99
  - DVD (Amazon): \$8.64
  - Available on additional rental platforms

**Description:**

A blockbuster movie featuring Oscar-winning actress Julianne Moore, based on the book of the same title. Still Alice is the story of Alice Howland, a renowned linguistics professor, happily married with three grown children, who starts to forget words. When she receives a diagnosis of younger-onset Alzheimer's disease, Alice and her family find their bonds thoroughly tested. Her struggle to stay connected to who she once was is frightening, heartbreaking, and inspiring.

**25. “Still Here,” Wake Forrest (2018).**

- **Video Link:** <https://vimeo.com/279478897/788d394e8f>
- **Run Time:** 35:05 minutes
- **Key Terms:** American Indian communities, community, care taking
- **Modules:** 1, 2, 3, 4

**Description:**

This documentary examines caregiving and the impact of Alzheimer’s disease and other dementias in American Indian communities. The film focuses on American Indian families and tribal communities in North Carolina.

**26. “Take Brain Health to Heart: Evidence and Public Health Action Webinar,” Alzheimer’s Association (2018).**

- **Video Link:** <https://www.youtube.com/watch?v=LYG9QLjelzM&index=22&list=PLb15WDa0LdCYxu4ZX9pISVFctNCxxrpnU>
- **Run Time:** 50:43 minutes
- **Key Terms:** prevention, intervention, health behavior, risk factors
- **Modules:** 2, 3

**Description:**

Webinar presented by the Alzheimer’s Association discuss the results of the Lancet International Commission on Dementia Prevention, Intervention and Care, and modifiable risk factors backed by scientific evidence. The South Carolina Department of Health and Environmental control’s brain health campaign is featured.

## 27. “The Sum Total of Our Memory,” Barbara Klutnis (2014).

- **Video Link:**  
[https://www.amazon.com/gp/video/detail/0TEJTCLWDMU8OH4PTVS9DH0I7X/ref=imdbref\\_tt\\_wbr\\_piv](https://www.amazon.com/gp/video/detail/0TEJTCLWDMU8OH4PTVS9DH0I7X/ref=imdbref_tt_wbr_piv)
- **Run Time:** 57:00 minutes
- **Key Terms:** family relationship, recent diagnosis, stigma, clinical trials, health care
- **Purchase Price:**
  - Digital Rent (Amazon): \$4.99
  - DVD (Amazon): \$9.99
  - Available on additional rental platforms

### Description:

Couples affected by a partner's recent diagnosis of younger-onset Alzheimer's come to terms with their changing roles. Prominent Alzheimer's medical experts offer their perspectives on diagnosis, the nature of the disease, helpful attitudes in caring for loved ones, stigma, clinical trials, support for caregivers, and overall health care concerns.

## 28. Teepa Snow (2018).

- **Video Links:** <https://teepasnow.com/resources/about-dementia/>
- **Run Time:** 2- 6 minutes each
- **Key Terms:** dementia, caregivers, activities, behavior
- **Module:** 1, 2, 4

### Description:

Teepa Snow has been an occupational therapist, with 40 years of clinical practical experience. In 2005, she founded Positive Approach to Care (PAC) to provide dementia care training, services, and products to professionals and family caregivers to change the culture of dementia care and increase awareness. Videos include the following topics:

- **Activities:** Reviews four categories of activity that help individuals feel valued, productive, and purposeful. The categories are work, leisure, self-care, and rest and restoration.
- **Behaviors:** Discusses the ways providers can approach behavior change among individuals with dementia, in a productive and respectful manner.
- **Brain change:** A brief overview of how the brain is changed due to dementia.
- **Dementia 101:** Overview of early signs of dementia and what is and is not normal aspects of aging.
- **Teepa's GEMS®:** Teepa's model builds upon existing progression models that define changes in an individual due to dementia and focuses on ability, rather than skills lost.

- **Music:** Reviews the benefits of music therapy for individuals with dementia and providers.

## 29. “Tribal Outreach Video –A Project of the UW Alzheimer’s Disease Research Center and Partnerships for Native Health,” Vimeo (2019).

- **Video Link:** <https://vimeo.com/314071595>
- **Run Time:** 5:30 minutes
- **Key Terms:** American Indian, Native Alaskan, oral tradition, memory loss, research, diversity
- **Module:** 3, 4

### Description:

The University of Washington Alzheimer’s Disease Research Center seeks tribal participation to help understand the prevalence of Alzheimer’s among the many Native communities.

## 30. “Your Fantastic Mind,” Georgia Public Broadcasting (2019).

- **Video Link:** <http://www.gpb.org/television/shows/your-fantastic-mind/episode/893dced9-2604-4029-a41d-c7fbb0f2f22d>
- **Run Time:** 11:50 (stop video at 11:50 minutes)
- **Key Terms:** early onset, caregiver, prevention, risk reduction, Alzheimer’s research
- **Modules:** 1, 2, 3

### Description:

Cecile Bazaz was a high-level banking executive in her 40s when she was diagnosed with Alzheimer’s disease at 49 years old. This video discusses early onset Alzheimer’s disease and who it impacts. Leading researchers also discuss how you can lower your risk of developing Alzheimer’s disease.

## Additional Learning Activities

The following suggestions are additional learning activities that can be used to increase student interaction and engagement with the, *A Public Health Approach to Alzheimer's and Other Dementias* curriculum.

### Reverse Classroom Approach

The reverse classroom, also known as the flipped classroom, is an approach that provides students with instructional materials to review outside of the classroom and encourages assignments that mirror homework to be used during the designated instructional time. Examples of incorporating this approach are as follows:

- **Think, Pair, and Share.** Assign students to review the curriculum, video, case study, or related assignment and propose a question about the material at the start of the next class. Students will first think quietly for a minute or two to collect their thoughts and questions about the material. Next, students will pair up and discuss their thoughts with a partner or small group. Finally, each pair will briefly share their discussion with the class. This activity can be used at the start of class to help students review any assignments. Alternatively, this activity can also be used at the end of class to help students reflect on the day's teachings.
- **Mini Curriculum.** Divide the class into four groups and have each group present one module to the class. Ask students to create a "mini curriculum" to teach their peers about Alzheimer's disease and the role public health and related disciplines plays. This assignment is meant to be creative and allows students to use any platform they think would work best for their peers to learn the material by using video, lecture, handout, games, or discussion. This may also provide insight into your students' preferred learning style.
- **Reflection Paper.** Reflection papers allow students not only to reflect on the curriculum, but also on the larger effect Alzheimer's and other dementias have on society. Students will review a module, case study, or video as assigned and then write a reflection paper that will be used to guide discussion during the next class. These reflections should ask students to critically think about the topic at hand, but do not need to be a specific length. This activity may also be done during class time by setting a 5-minute timer and asking students to write down their reflections from the class that day.

## Learning Lab

A learning lab instructional approach is participatory and results-oriented with the sole objective of students working together to innovatively solve an issue or public health challenge. In each activity, students are tasked with thinking through various potential actions to solve the challenges raised using a public health lens.

Examples of incorporating this approach are as follows:

- **Assistive Technology.** Break the class into groups and ask them to come up with an innovative assistive technology or monitoring system to support individuals living with dementia and their caregivers. This is meant to be a creative project and students do not have to produce an actual product; however, students should demonstrate their knowledge of the behavioral and physical changes associated with Alzheimer's and other dementias.
- **Policy Brief.** Ask students to write a one-page policy brief and present it to the class. Using what they have learned from the curriculum, videos, and case studies, students should be able to identify a need of someone living with dementia or their caregiver that can affect policy change. The policy brief should include the following sections: title, summary, scope of problem, policy alternatives, policy recommendations, and sources. Students should also have a specific audience in mind for the policy brief, such as a Member of Congress. This activity can be done by an individual or group.
- **What's Happening in the News?** Ask students to find a recent scholarly article or news article related to Alzheimer's. Students may find articles related to prevention, clinical trials, interventions, or other related topics and be prepared to briefly explain them to the class. The purpose of this activity is to expose students to the current state of Alzheimer's research and to learn more about public health and related disciplines in action. Helpful resources may include the National Institutes of Health, Centers for Disease Control and Prevention, Alzheimer's Association, credible newspapers, scholarly articles, and research happening at your own university.
- **Case Study Stations:** This activity allows students to get up and move around the class as they visit different case studies placed around the room. It is suggested that you use the My Typical Day case studies (available at <http://www.mytypicalday.org/>) for this activity, but feel free to use any examples from the provided case studies in the curriculum. Print a copy of each case study you have selected (as many as appropriate for your class size) and place them around the classroom. Students will then break into small groups and rotate around the room to read and discuss each case study. Students should discuss each case both from the perspective of the individual, but also the caregiver and others involved if applicable. Prompts for the students are listed below.
  - In what ways has life changed since their diagnosis?

- How have they reacted to their diagnosis? Positively? Negatively?
- How have they adapted their everyday routine?
- What support do they have?
- What changes have they noticed?
- What role do their family and friends play?
- **Dementia Friendly Communities.** The sources below provide visual images and key takeaways on how communities can be dementia friendly. After reviewing the example images as a class, students will be asked to draw their own community and identify ways in which their community is dementia friendly and ways their community could improve. Students may choose the town or city where the university is located or even their own hometown if they would like to offer a different example to the class. If you would like to make this a group activity, project a map of your university on a chalkboard or whiteboard and have students draw directly on it during class time.
  - Fostering Dementia Friendliness: <https://www.dfamerica.org/communities-overview>
  - Building Dementia –Friendly Communities: A Priority for Everyone: <https://dementiapartnerships.com/resource/building-dementia-friendly-communities/>
  - Dementia Friendly Community Toolkit: <https://www.actonalz.org/dementia-friendly-toolkit>

## Guest Speakers

Pairing the curriculum with guest speakers is an instructional approach that allows students to learn from the experiences of people who have been affected by Alzheimer’s and other dementias or work in a related field.

Examples of guest speakers include:

- Caregivers of someone with dementia.
- An individual with early stage dementia.
- Local Alzheimer’s Association chapter.
- Nonprofit organization working on issues related to dementia.
- A local department of public health, another government agency, or a community-based group such as an Area Agency on Aging.
- Nurses, doctors, social workers, and other professionals who work with individuals with dementia.
- Faculty and staff at your university who are conducting related research.

### **Test Your Knowledge**

Quiz the class using the Alzheimer's Disease Knowledge Scale (ADKS). The ADKS contains 30 true or false items to assess their knowledge about Alzheimer's disease. The scale addresses topics such as risk factors, assessment and diagnosis, symptoms, course, life impact, caregiving, treatment, and management. This is a quick way to gauge what the students have learned, without creating a formal exam. Students can take the quiz independently (5 to 10 minutes) and then review the answers as a class. The ADKS and answers to each question can be found at the Resources for the Alzheimer's Disease Knowledge Scale website using this link: <https://pages.wustl.edu/geropsychology/adks>

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