

A PUBLIC HEALTH APPROACH TO ALZHEIMER'S AND OTHER DEMENTIAS

MODULE 3:

ALZHEIMER'S DISEASE — WHAT IS THE ROLE OF PUBLIC HEALTH?



alzheimer's 
association®


CENTERS FOR DISEASE™
CONTROL AND PREVENTION

 EMORY
ROLLINS
SCHOOL OF
PUBLIC
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Emory Centers
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Technical Assistance

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Table of Contents

About Module 3	3
Learning Objectives.....	3
Competencies	4
Layout of Module 3 Faculty Guide.....	5
How to Use the Materials	5
Student Engagement Options.....	6
Discussion Questions	6
Learning Activities.....	6
Additional Reading.....	7
Slide Guide	8
Sample Test Questions.....	62
Selected Case Studies-Module 3.....	63
Selected Video Resources-Module 3	76
Additional Learning Activities	85

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:

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: 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:

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

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:

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:

Introduction: Dementia & Alzheimer's Disease¹

- 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

¹ 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:

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:

Alzheimer's: Epidemic (U.S.)²

- 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**.

² Alzheimer's Association. (2019) *2019 Alzheimer's Disease Facts and Figures*.

Image source: pixabay.com

SLIDE 6:

Alzheimer's Impact: Costs³

- 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.

³ Alzheimer's Association. (2019) *2019 Alzheimer's Disease Facts and Figures*.

Image source: cker.com

SLIDE 7:

Alzheimer's: Disproportional Impact⁴

- 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.

⁴ Alzheimer's Association. (2019) *2019 Alzheimer's Disease Facts and Figures*.

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

SLIDE 8:

Alzheimer's: Caregiving Burden⁵

- 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.

⁵ 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:

Alzheimer's: Health Care Burden⁶

- 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.

⁶U.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:

Public Health: Poised for Impact ⁷

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.

⁷ 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:

Public Health Impact: SURVEILLANCE & MONITORING

TALKING POINTS:

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

SLIDE 12:

Surveillance & Public Health⁸

- 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.

⁸ Alzheimer's Association. (2018) *Data Collection and Behavioral Risk Factor Surveillance System (BRFSS)*.

Image source: pexels.com

SLIDE 13:

Behavioral Risk Factor Surveillance System (BRFSS)⁹

- 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.

⁹ 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:

BRFSS: Cognitive Decline Module^{10,11}

- 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.

¹⁰ Alzheimer's Association. (2018) *Nationwide Cognitive Data from the 2015-2016 BRFSS [Fact Sheet]*.

¹¹ 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:

BRFSS and Subjective Cognitive Decline^{12,13}

- 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

¹² Alzheimer's Association. (2018) *Nationwide Cognitive Data from the 2015-2016 BRFSS [Fact Sheet]*.

¹³ 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:

BRFSS: Caregiver Module¹⁴

- 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.

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

SLIDE 17:

BRFSS: Caregiver Module Findings¹⁵

- 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

¹⁵ Alzheimer's Association. (2018) *Caregiver Data from the 2016 BRFSS*.

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

SLIDE 18:

Discussion Question

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

TALKING POINTS:

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

Open responses.

SLIDE 19:

Use of Surveillance Data¹⁶

- 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

¹⁶ Alzheimer's Association. (2018) *Data Collection and Behavioral Risk Factor Surveillance System (BRFSS)*.

Image source: cker.com

SLIDE 20:

Public Health Impact: RISK REDUCTION & PRIMARY PREVENTION

TALKING POINTS:

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

SLIDE 21:

Primary Prevention¹⁷

- 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.

¹⁷ Centers for Disease Control and Prevention. (2017) *Picture of America- Prevention*. Retrieved from <https://www.cdc.gov/pictureofamerica/>

SLIDE 22:

Discussion Question

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

TALKING POINTS:

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

Open responses.

SLIDE 23:

Risk Reduction: Head Trauma^{18,19}

- 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

¹⁸ Alzheimer's Association. (n.d.) *Traumatic Brain Injury*. Retrieved from https://www.alz.org/alzheimers-dementia/what-is-dementia/related_conditions/traumatic-brain-injury

¹⁹ 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:

Risk Reduction: Heart Health^{20,21,22,23}

- 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

²⁰ Alzheimer's Association. (2019) *2019 Alzheimer's Disease Facts and Figures*.

²¹ Alzheimer's Association. (n.d.) *Prevention*. Retrieved from https://www.alz.org/alzheimers-dementia/research_progress/prevention

²² 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.

²³ 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/

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:

Risk Reduction: Avoidance/Management^{24,25}

- 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.

²⁴ Alzheimer's Association. (2019) *2019 Alzheimer's Disease Facts and Figures*.

²⁵ Centers for Disease Control and Prevention. (2018) *Preventing Stroke: Control Medical Conditions*. Retrieved from https://www.cdc.gov/stroke/medical_conditions.htm

Image source: National Cancer Institute, NCI Visuals Online

SLIDE 26:

Risk Reduction: Active Brain^{26,27}

- 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.

²⁶ National Institute on Aging. (2018) *Alzheimer's Disease: Unraveling the Mystery*.

²⁷ Alzheimer's Association. (2019) *2019 Alzheimer's Disease Facts and Figures*.

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

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

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:

Discussion Question

How could public health play a role in promoting risk reduction and cognitive health?

TALKING POINTS:

Ask: How could public health play a role in promoting risk reduction and cognitive health?

Open responses.

SLIDE 28:

Risk Reduction: Public Health Interventions^{28,29}

- 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

²⁸ 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

Image source: National Cancer Institute, NCI Visuals Online, Bill Branson (Photographer)

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

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:

Public Health Impact: Early Detection & Diagnosis

TALKING POINTS:

Promoting early detection and diagnosis of Alzheimer's is another important role for public health.

SLIDE 30:

Why Promote Early Detection?^{30,31,32,33}

- 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

³⁰ 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.

³¹ Alzheimer's Association. (2019) *2019 Alzheimer's Disease Facts and Figures*.

³² National Institutes on Aging. (2018) *Alzheimer's Disease: Unraveling the Mystery*.

³³ 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:

Discussion Question

Would you want to know if you had Alzheimer's?
Why or why not?

TALKING POINTS:

Ask: Would you want to know if you had Alzheimer's?
Why or why not?

Open responses.

SLIDE 32:

Early Detection: Factors Influencing Diagnosis Rates^{34,35}

- 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.

³⁴ Alzheimer's Association. (2019) *2019 Alzheimer's Disease Facts and Figures*.

³⁵ Alzheimer's Association. (2018) *Race, Ethnicity, and Alzheimer's Fact Sheet*.

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

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:

Early Detection: Challenges^{36,37}

- 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.

³⁶ Alzheimer's Association. (2019) *2019 Alzheimer's Disease Facts and Figures*.

³⁷ 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:

Early Detection: Most Want to Know³⁸

- 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.

³⁸ 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:

Discussion Question

What can public health do to promote early detection and diagnosis of Alzheimer's?

TALKING POINTS:

Ask: What can public health do to promote early detection and diagnosis of Alzheimer's?

Open responses.

SLIDE 36:

Public Health: Early Diagnosis³⁹

- 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

³⁹ 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

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

- 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

SLIDE 37:

Public Health Impact: Safety and Quality of Care

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:

Safety and Quality of Care⁴⁰

- 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.

⁴⁰ 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:

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

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

- 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:

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:

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/>

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:

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.
-

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)

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

- 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.

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

Selected Case Studies- Module 3

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. "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?

4. "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?

5. 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?

6. “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

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

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.

7. "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

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

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?

8. “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
- **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).

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

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?

9. “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

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

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?

10. “ 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?

11. "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

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

- <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?

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

- 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.

Selected Video Resources- Module 3

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
- **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. "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.

4. "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.

5. "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
- **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.

6. "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).

7. "Family Caregiving: The Frontline of Dementia Care," Alzheimer's Association (2018).

- **Video Link:** <https://www.youtube.com/watch?v=ecp7lgQS1v0&index=23&list=PLb15WDa0LdCYxu4ZX9pISVFCtNCxrpnU>
- **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.

8. "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
- **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.

9. “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/
- **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.

10. “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.

11. “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
- **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.

12. “Inside the Brain: An Interactive Tour,” Alzheimer’s Association (2018).

- **Web Link:** 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.

13. “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.

14. “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.

15. "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.

16. "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.

17. "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=PLb15WDa0LdCYxu4ZX9pISVFCtNCxrpnU>
- **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.

18. "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.

19. "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.

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

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?

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

- 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>