

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

## MODULE 3:

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



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## 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 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.

**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 three tools of public health that may play significant roles in mitigating the Alzheimer's disease crisis.

The three public health intervention tools discussed are:

1. Surveillance/monitoring
2. Primary prevention
3. Early detection and diagnosis

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 three 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.

## COMPETENCIES

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

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

- 1.2.4 Recognize common late-life syndromes and diseases and their related bio-psycho-social risk and protective factors.

### **Association of Schools and Programs of Public Health (ASPPH):**

- Domain 2: Describe how the methods of epidemiology and surveillance are used to safeguard the population's health.
- Domain 3: Endorse lifestyle behaviors that promote individual and population health and well-being.

### **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.
- 8A4. Contributes to development of a vision for a healthy community (e.g., emphasis on prevention, health equity for all, excellence and innovation).

### **National Association of Chronic Disease Directors (NACDD):**

- Domain 7: Identify relevant and appropriate data and information sources for chronic disease.
- Domain 7: Articulate evidence-based approaches to chronic disease prevention and control.

### **National Commission for Health Education Credentialing, Inc. (NCHEC):**

- 1.7.4 Identify emerging health education needs.
- 7.1.1 Identify current and emerging issues that may influence health and health education.

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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: <http://www.hhs.gov/web/section-508/making-files-accessible/checklist/>)

## 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? *(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 disease? Why or why not? *(Slide 30)*
- What can public health do to promote early detection of Alzheimer's disease? *(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 disease using the "10 Warning 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

101+ Careers in Aging. A list with links to many different occupations related to aging  
[http://businessandaging.blogs.com/ecg/101\\_careers\\_in\\_aging/](http://businessandaging.blogs.com/ecg/101_careers_in_aging/)

Alzheimer's Association. (2015). Special Report on Disclosing a Diagnosis of Alzheimer's Disease. In *2015 Alzheimer's Disease Facts and Figures*  
[https://www.alz.org/facts/downloads/facts\\_figures\\_2015.pdf](https://www.alz.org/facts/downloads/facts_figures_2015.pdf)

Alzheimer's Association and Centers for Disease Control and Prevention. *The Healthy Brain Initiative: The Public Health Road Map for State and National Partnerships, 2013–2018*: Chicago, IL: Alzheimer's Association; 2013.  
<http://www.cdc.gov/aging/healthybrain/roadmap.htm>

Alzheimer's Public Health Resource Center, Data Collection:  
<http://www.alz.org/publichealth/datacollection.asp>

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

CDC, About BRFSS: <http://www.cdc.gov/brfss/about/index.htm>

HP2020: <https://www.healthypeople.gov/2020/data-search/Search-the-Data#objid=4158>;

*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>

World Health Organization. Dementia. Report by the Secretariat. EB 139/3. April 2016. Geneva [http://apps.who.int/gb/ebwha/pdf\\_files/EB139/B139\\_3-en.pdf](http://apps.who.int/gb/ebwha/pdf_files/EB139/B139_3-en.pdf)

# SLIDE GUIDE

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

## SLIDE 1:

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

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### TALKING POINTS:

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

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

## SLIDE 2:

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### Learning Objectives

- List 3 key tools public health can apply to the Alzheimer's disease epidemic
  - Describe surveillance/monitoring and how public health can apply it in response to Alzheimer's disease
  - Name the 2 BRFSS modules that pertain to cognitive decline and caregiving
  - Describe primary prevention and how public health can apply it to Alzheimer's disease
  - Explain why it is important to promote early detection of Alzheimer's disease
- 

### TALKING POINTS:

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

- List 3 key tools public health can apply to the Alzheimer's disease epidemic
- Describe surveillance/monitoring and how public health can apply it in response to Alzheimer's disease
- Name the 2 BRFSS modules that pertain to cognitive decline and caregiving
- Describe primary prevention and how public health can apply it to Alzheimer's disease
- Explain why it is important to promote early detection of Alzheimer's disease

## SLIDE 3:

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### Competencies

#### Association for Gerontology in Higher Education (AGHE):

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#### Association of Schools and Programs of Public Health (ASPPH):

- Domain 2: Describe how the methods of epidemiology and surveillance are used to safeguard the population's health.
- Domain 3: Endorse lifestyle behaviors that promote individual and population health and well-being.

#### 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.
  - 8A4. Contributes to development of a vision for a healthy community (e.g., emphasis on prevention, health equity for all, excellence and innovation).
- 

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

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

#### Association for Gerontology in Higher Education (AGHE):

- 1.2.4 Recognize common late-life syndromes and diseases and their related bio-psycho-social risk and protective factors.

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

### **Association of Schools and Programs of Public Health (ASPPH):**

- Domain 2: Describe how the methods of epidemiology and surveillance are used to safeguard the population's health.
- Domain 3: Endorse lifestyle behaviors that promote individual and population health and well-being.

### **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.
- 8A4. Contributes to development of a vision for a healthy community (e.g., emphasis on prevention, health equity for all, excellence and innovation).

## SLIDE 4:

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### Competencies Cont.

#### National Association of Chronic Disease Directors (NACDD):

- Domain 7: Identify relevant and appropriate data and information sources for chronic disease.
- Domain 7: Articulate evidence-based approaches to chronic disease prevention and control.

#### National Commission for Health Education Credentialing, Inc. (NCHEC):

- 1.7.4 Identify emerging health education needs.
- 7.1.1 Identify current and emerging issues that may influence health and health education.

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

#### National Association of Chronic Disease Directors (NACDD):

- Domain 7: Identify relevant and appropriate data and information sources for chronic disease.
- Domain 7: Articulate evidence-based approaches to chronic disease prevention and control.

#### National Commission for Health Education Credentialing, Inc. (NCHEC):

- 1.7.4 Identify emerging health education needs.
- 7.1.1 Identify current and emerging issues that may influence health and health education.

## SLIDE 5:

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

- Dementia is a decline in mental ability severe enough to interfere with daily life
    - Caused by damage to brain cells, primarily affects older adults
  - Alzheimer's disease is the most common form of dementia
    - Progressive loss of memory and brain function, behavior and personality changes
    - As disease progresses, caregivers provide increasing aid and assistance
    - No cure and limited treatment options
  - Huge financial and emotional burden on people with Alzheimer's, their families, caregivers, and the health care system
  - Public health plays important role in addressing Alzheimer's disease through surveillance, prevention, detection, and support of dementia-capable systems
- 

### 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 the brain cells due to age, brain injury, other conditions or diseases or heredity.

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

**Alzheimer's disease** is the most common type of dementia. Alzheimer's is a progressive disease that ranges from mild to

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<sup>1</sup> Alzheimer's Association. *2015 Alzheimer's Disease Facts and Figures*.

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

severe cognitive impairment that occurs over the course of several years.

There is **no cure** for Alzheimer's. While there are approved drug **treatments**, the goal of 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.

Video supplements: "What is Alzheimer's disease?" TedEd.  
(run time: 3:49 mins)

Link: <https://www.youtube.com/watch?v=yJXTXN4xrI8>

Or:

"Inside the Brain: Unraveling the Mystery of Alzheimer Disease". National Institutes of Health, NIH Senior Health.  
(run time: 4 mins.)

[http://nihseniorhealth.gov/alzheimersdisease/whatisalzheimersdisease/video/a2\\_na.html?intro=yes](http://nihseniorhealth.gov/alzheimersdisease/whatisalzheimersdisease/video/a2_na.html?intro=yes)

## SLIDE 6:

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### Alzheimer's: A Public Health Crisis

- Historically viewed as an aging or medical 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 growing 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

*Image source:* U.S. federal government, Wikimedia Commons

## SLIDE 7:

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### Alzheimer's: Epidemic (U.S.)<sup>2</sup>

- Over 5 million adults
  - 1 in 9 adults age ≥65
  - 1 in 3 adults age ≥85
  - By 2050, expected to reach 13.8 million
- 

### TALKING POINTS:

- Today, over **5 million adults** in the U.S. are living with Alzheimer's disease, including an estimated 200,000 under the age of 65.
- **One in nine** adults age 65 and older (11%) currently has Alzheimer's disease; approximately **one in three** people age 85 and older have the disease.
- By 2050, the number of Americans living with Alzheimer's disease is expected to total **13.8 million** and could be as high as **16 million**.

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<sup>2</sup> Alzheimer's Association. *2016 Alzheimer's Disease Facts and Figures*.

## SLIDE 8:

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

- Significant costs to Medicare, Medicaid, individuals, caregivers
  - Annual costs of care over \$200 billion
  - Most expensive disease in the U.S.
- 

### TALKING POINTS:

Alzheimer's disease 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 exceeds **\$200 billion**. "Direct care" includes both paid health care and long-term care. It does not include caregiving (an essential part of Alzheimer's care).

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

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<sup>3</sup> Alzheimer's Association. *2016 Alzheimer's Disease Facts and Figures*.

Image source: ctker.com

## SLIDE 9:

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### Alzheimer's: Disproportional Impact<sup>4</sup>

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

### TALKING POINTS:

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

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

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

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

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<sup>4</sup> Alzheimer's Association. *2016 Alzheimer's Disease Facts and Figures*.

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

## SLIDE 10:

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### Alzheimer's: Caregiving Burden<sup>5</sup>

- Requires increasing levels of caregiving (paid and unpaid)
  - Over 15 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 **15 million** family members and friends provide **nearly 18 billion hours** of unpaid care annually. Financially, these contributions are valued at **over \$215 billion**.

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

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<sup>5</sup> Alzheimer's Association. *2016 Alzheimer's Disease Facts and Figures*.

## SLIDE 11:

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### Alzheimer's: Health Care Burden<sup>6,7,8</sup>

- Disproportionate use of health care resources
    - Hospitalized 2-3 times more often
    - Represents 64% of Medicare beneficiaries living in nursing homes
  - Workforce shortage
  - Inadequate 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 are **hospitalized** 2 to 3 times more than older adults without the disease.

In addition, of all Medicare beneficiaries residing in a **nursing home**, 64% have Alzheimer's and other dementias.

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

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

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<sup>6</sup> Alzheimer's Association. (2013) *Combating Alzheimer's Disease: A Public Health Agenda*.

<sup>7</sup> Alzheimer's Association. *2016 Alzheimer's Disease Facts and Figures*.

<sup>8</sup> U.S. Department of Health and Human Services. *National Plan to Address Alzheimer's Disease: 2013 Update*.

## SLIDE 12:

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### Public Health: Tools & Techniques<sup>9</sup>

3 key public health intervention tools:

- Surveillance/monitoring
  - Primary prevention
  - Early detection & diagnosis
- 

### TALKING POINTS:

Within public health, there are numerous tools and techniques that may be used to intervene on the Alzheimer's disease epidemic.

Three key public health intervention tools are:

- **Surveillance/monitoring**
- Promoting **primary prevention**
- Assuring **early detection** and **diagnosis**

We will discuss each of these in more detail.

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<sup>9</sup> Alzheimer's Association. (2013) *Combating Alzheimer's Disease: A Public Health Agenda*.

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

**SLIDE 13:**

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**TOOL #1: SURVEILLANCE**

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**TALKING POINTS:**

Public health surveillance involves collecting, analyzing, and interpreting health related data within a population.

## SLIDE 14:

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### Surveillance & Public Health<sup>10</sup>

- Compile data on a population level, including:
    - Prevalence of certain diseases
    - Health risk factors
    - Health behaviors
    - Burden of diseases
  - Little state-level data on Alzheimer's and dementia
- 

### TALKING POINTS:

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

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

To date, **very little state-level data** exists on cognitive decline, Alzheimer's disease, dementia, and caregivers of those with these conditions.

Many public health efforts that address detection, risk reduction, and alleviating disease burden, are implemented at **state and local levels**. Developing effective responses to the Alzheimer's epidemic necessitates understanding how Alzheimer's and dementia impact states and communities.

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<sup>10</sup> Alzheimer's Association. (2014) *Data Collection and Behavioral Risk Factor Surveillance System (BRFSS)*.

## SLIDE 15:

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### Behavioral Risk Factor Surveillance System (BRFSS)<sup>11</sup>

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

#### TALKING POINTS:

In the U.S., state-based data on health-related risk behaviors, chronic health conditions, and use of preventive services is collected through the **Behavioral Risk Factor Surveillance System (BRFSS)**. The BRFSS is the nation's premier system for collecting data on health-related risk behaviors, chronic conditions and use of preventive services. The survey is conducted by telephone and is collected at the state level by all 50 states and US 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.

In recent years, the CDC developed two BRFSS modules that enable states to collect data on the impact of **cognitive decline** and **caregiving**.

The two BRFSS modules are the **Cognitive Decline** module and the **Caregiver** module.

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<sup>11</sup> Alzheimer's Association. (2014) *Data Collection and Behavioral Risk Factor Surveillance System (BRFSS)*.

*Image source:* ctker.com

## SLIDE 16:

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### BRFSS: Cognitive Decline Module<sup>12,13</sup>

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

### TALKING POINTS:

The **Cognitive Decline** module contains questions that ask about:

- Increased **confusion** or **memory loss** in the previous 12 months
- If household activities or chores have been affected by confusion or memory loss
- Whether individuals need assistance with day-to-day activities, and if so, were they able to get the help they needed
- Whether confusion or memory loss interfered with activities outside the home, such as work, volunteering, or social activities
- Whether individuals have discussed their memory problems with a **health care professional**
- To date, all 50 states plus DC and Puerto Rico have used the Cognitive Decline module at least once.

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<sup>12</sup> Alzheimer's Association. (2014) *Data Collection and Behavioral Risk Factor Surveillance System (BRFSS)*.

<sup>13</sup> Centers for Disease Control and Prevention. *Behavioral Risk Factor Surveillance System (BRFSS) 2015 Cognitive Decline Module*. Accessed June 10, 2015 from website:

<http://www.cdc.gov/aging/healthybrain/brfss-faq.htm>

## SLIDE 17:

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

- Comprised of questions about:
    - Prevalence of caregiving and caregiving activities
    - Caregiver age, gender, relationship to care recipient
    - Scope of caregiving
    - Caregiver challenges
  - 40 states/territories have used at least once
- 

### TALKING POINTS:

The **Caregiver Module** asks questions 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

There are 40 states/territories that have used the Caregiver Module at least once.

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<sup>14</sup> Alzheimer's Association. (2014) *Data Collection and Behavioral Risk Factor Surveillance System (BRFSS)*.

## SLIDE 18:

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### Discussion Question

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

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### TALKING POINTS:

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

**Open responses.**

## SLIDE 19:

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### Public Health: Surveillance Data<sup>15,16</sup>

- Develop strategies to reduce risk
  - Design interventions to alleviate burden
  - Inform public policy
  - Guide research
  - Evaluate programs and policies
  - Educate the public and the health care community
- 

### TALKING POINTS:

Public health and its partners can use surveillance data to:

- Develop **strategies to reduce risk**, such as increasing public awareness about Alzheimer's disease, 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
- Inform **public policy decisions** related to program funding, health care, infrastructure, etc.
- Guide **research** into the causes, treatment, and prevention of Alzheimer's and dementia
- **Evaluate** existing programs and policies at the state and local levels
- **Educate** the public and the health care community about cognitive impairment

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<sup>15</sup> Alzheimer's Association. (2014) *Data Collection and Behavioral Risk Factor Surveillance System (BRFSS)*.

<sup>16</sup> Centers for Disease Control and Prevention. *The CDC Healthy Brain Initiative: Progress 2006 – 2011*.

Image source: clker.com

**SLIDE 20:**

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**TOOL #2: PRIMARY PREVENTION & RISK REDUCTION**

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**TALKING POINTS:**

Now we turn to tool #2 – primary prevention and risk reduction.

## SLIDE 21:

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### Primary Prevention<sup>17</sup>

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

### TALKING POINTS:

**Primary prevention** is an important tool of public health that is designed to keep a disease or condition (such as cancer) from developing in a population. Common examples of primary prevention in public health include: regular physical activity to reduce risk of cardiovascular disease; vaccination against infectious diseases; and anti-tobacco use campaigns and quit-lines.

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

Research hasn't yet revealed the exact causes of Alzheimer's in most people, but findings suggest there are ways to **reduce risk** for the disease, as well as ways to **promote cognitive health** at the population level.

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<sup>17</sup> Centers for Disease Control and Prevention. *The Concept of Prevention*. Accessed August 14, 2015 from: <http://www.cdc.gov/arthritis/temp/pilots-201208/pilot1/online/arthritis-challenge/03-Prevention/concept.htm>

*Image source:* National Institute on Aging

## SLIDE 22:

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### Discussion Question

What are risk factors for Alzheimer's disease that could be modified/reduced?

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### TALKING POINTS:

**Ask:** What are risk factors for Alzheimer's disease that could be modified/reduced?

**Open responses.**

## SLIDE 23:

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### Risk Reduction: Head Trauma<sup>18,19</sup>

- Moderate or severe 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 **moderate and severe traumatic brain injury** to a greater risk of developing Alzheimer's disease. The risk remains even years after the original head injury.

Prevention efforts for the general public may include:

- Promoting **seat belt use** (through education and policy)
- Promoting the use of **helmets** when bicycling and participating in certain sports (through education and policy)
- **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
  - Getting enough **sleep**

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<sup>18</sup> Alzheimer's Association. (2015) *Traumatic Brain Injury*.

<sup>19</sup> Centers for Disease Control and Prevention. *Older Adults Falls: Get the Facts*. Accessed June 10, 2015 from website: <http://www.cdc.gov/HomeandRecreationalSafety/Falls/adultfalls.html>

## SLIDE 24:

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

- Close link between heart health and brain health
  - Modifying cardiovascular risk:
    - Quitting smoking
    - Diet (DASH, Mediterranean)
    - 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 – appear to increase the risk of developing Alzheimer's 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.

Risk factors that may be modified include:

- **Quitting smoking:** Smoking has a negative effect on
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<sup>20</sup> Alzheimer's Association. (2014) *Alzheimer's and Public Health Spotlight: Heart Health and Brain Health*.

<sup>21</sup> Alzheimer's Association. *Prevention and Risk of Alzheimer's and Dementia*. Accessed July 16, 2015 from website: [http://www.alz.org/research/science/alzheimers\\_prevention\\_and\\_risk.asp](http://www.alz.org/research/science/alzheimers_prevention_and_risk.asp)

<sup>22</sup> Centers for Disease Control and Prevention, Division of Nutrition, Physical Activity, and Obesity. *Physical Activity is Essential to Healthy Aging*. Accessed September 1, 2015 from website: [http://www.cdc.gov/physicalactivity/basics/older\\_adults/](http://www.cdc.gov/physicalactivity/basics/older_adults/)

Image source: clker.com

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

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

- **Diet:** 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**.
- **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 who are 65 or older and generally fit (with no limiting health conditions) should engage in **150** minutes of **moderate aerobic activity** (such as brisk walking) a week and muscle-strengthening activities on 2 or more days a week that work all major muscle groups (legs, hips, back, abdomen, chest, shoulders, and arms).

## SLIDE 25:

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

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

### TALKING POINTS:

Growing evidence suggests that the avoidance and management of **diabetes, high blood pressure** (hypertension), 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.

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

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<sup>23</sup> Baumgart, M., Snyder, H., Carrillo, M., Fazio, S., et.al, *Summary of the evidence on modifiable risk factors for cognitive decline and dementia: A population-based perspective*. *Alzheimer's & Dementia* 11 (2015) 718-726.

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

## SLIDE 26:

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### Risk Factors: Active Brain<sup>24</sup>

- Mental stimulation:
    - Learning new information and skills
    - Volunteering
    - Reading
    - Playing challenging games
  - Social connections
- 

### TALKING POINTS:

In addition to the findings that years of formal education may be a preventative factor for Alzheimer's disease, a number of studies indicate that **keeping the brain active** is associated with lower risk for developing Alzheimer's disease.

**Mentally stimulating activities** may include:

- Learning new information and skills
- 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 may help reduce the risk of cognitive decline.

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<sup>24</sup> National Institute on Aging. (2015) *Alzheimer's Disease: Unraveling the Mystery*.

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

## SLIDE 27:

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### Discussion Question

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

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### TALKING POINTS:

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

**Open responses.**

## SLIDE 28:

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### Risk Reduction: Public Health<sup>25,26</sup>

- Health education and promotion campaigns
    - Brain and cardiovascular health
    - Detection/treatment of diabetes and high blood pressure
    - Smoking cessation
  - Programs and policies
    - Injury prevention
    - Cardiovascular health
- 

### TALKING POINTS:

Public health may design and implement **health education and promotion campaigns** that directly promote brain health and risk reduction strategies, or incorporate **brain health** messages into **cardiovascular** health campaigns.

Similarly, reducing risk for Alzheimer's disease is in line with public health efforts to improve **detection** and **treatment** of **diabetes** and **high blood pressure**, and promote **smoking cessation**.

Such campaigns should include in their target audience **older adults**, which is a population that has rarely been specifically targeted in prevention programs. Evidence-based interventions are also needed to increase physical activity and promote heart-healthy diets among older people.

To achieve health equity goals, public health campaigns

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<sup>25</sup> Alzheimer's Disease International. *World Alzheimer Report 2014: Dementia and Risk Reduction, An Analysis of Protective and Modifiable Factors, Summary Sheet*.

<sup>26</sup> Alzheimer's Association and Centers for Disease Control and Prevention. (2013) *The Public Health Road Map for State and National Partnerships, 2013-2018*.

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

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

need **culturally appropriate** education and awareness campaigns for heart health and brain health. These are especially important for African-Americans and Hispanics, who are at higher risk of Alzheimer's disease 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 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**
- Options for healthy **eating**, physical **activity**, and **social** connections

**SLIDE 29:**

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**Tool #3: Early Detection & Diagnosis**

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**TALKING POINTS:**

Promoting early detection and diagnosis of Alzheimer's disease is another important tool of public health.

## SLIDE 30:

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### Discussion Question

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

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### TALKING POINTS:

**Ask:** Would you want to know if you had Alzheimer's disease?

Why or why not?

**Open responses.**

## SLIDE 31:

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### Why Promote Early Detection?<sup>27,28,29,30</sup>

- Access to treatment and services
  - Planning
  - Potentially reversible causes
  - Clinical trials
- 

### TALKING POINTS:

Promoting and assuring **early detection** of disease and disability is a third tool of 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, psychiatrist, etc.)
- 

<sup>27</sup> Alzheimer's Association. (2013) *Combating Alzheimer's Disease: A Public Health Agenda*.

<sup>28</sup> Alzheimer's Association. *Early Detection*. Accessed June 8, 2015 from website: <http://www.alz.org/publichealth/early-detection.asp>

<sup>29</sup> National Institutes on Aging. (2015) *Alzheimer's Disease: Unraveling the Mystery*.

<sup>30</sup> U.S. Health and Human Services. *National Plan to Address Alzheimer's Disease: 2015 Update*

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

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

- Manage **co-morbidities** and potentially minimize or avoid further complications
- Identify **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 disease and their caregivers, and may also reduce **health care costs** by delaying placement in long-term 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 disease 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.

**Reversible Causes:** In some cases, dementia-like symptoms are not actually dementia, but are due to reversible causes.

Research suggests that the cognitive impairment in 9% of individuals experiencing dementia-like symptoms is due to a potentially reversible cause, such as depression or a vitamin B12 deficiency.

**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.

Clinical trials and clinical studies on Alzheimer's and other dementias focus on numerous aspects of these conditions:

- Helping people with Alzheimer's disease maintain their **mental functioning** and manage **symptoms**
- **Slowing, delaying, or preventing** Alzheimer's disease

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 disease.

## SLIDE 32:

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### Early Detection: Diagnosis Rates<sup>31,32</sup>

- Most people with Alzheimer's disease have either:
    - Not been diagnosed
    - Been diagnosed but are not aware of diagnosis
  - Only 35% aware of diagnosis
  - Health disparities
- 

### TALKING POINTS:

Despite the many benefits of early detection and diagnosis, most people living with Alzheimer's disease either:

- Have **not** been diagnosed, or
- Have **been diagnosed** but neither they nor their caregiver is aware of the diagnosis.

A key challenge facing the early detection and diagnosis of Alzheimer's disease is that many individuals and their caregivers are not being **told** of the diagnosis, even when their doctor has diagnosed it.

A recent analysis by the CDC that 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.

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<sup>31</sup> Alzheimer's Association. *2015 Alzheimer's Disease Facts and Figures*

<sup>32</sup> Alzheimer's Association. (2013) *Alzheimer's and Public Health Spotlight: Race, Ethnicity & Alzheimer's Disease*.

Image source: clker.com

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

There are also **health 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.

[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 33:

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### Early Detection: Challenges<sup>33,34</sup>

- Diagnostic uncertainty
  - Time constraints, lack of support
  - Communication difficulties
  - Fear of causing emotional distress
  - Reluctance to discuss with health care provider
- 

### TALKING POINTS:

There are many reasons why Alzheimer's and other dementias go undiagnosed or diagnosed but not disclosed to the patient.

- **Diagnostic uncertainty:** Health care providers frequently cite the complexity and uncertainty of the diagnosis as barriers to disclosure.
- **Time constraints and lack of support:** Disclosing a diagnosis of Alzheimer's or another dementia to a patient usually requires discussion of treatment options and support services, as well as education about the disease and what to expect. In many health care settings, providers have insufficient time to properly assess the patient. Physicians and other health care providers have also noted that there are insufficient resources and services to provide patients and caregivers with the support needed at the time of diagnosis and afterward. A new Medicare billing code to support care planning aims to address this barrier.
- **Communication difficulties:** Many providers report challenges in communication skills related to

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<sup>33</sup> Alzheimer's Association. *2016 Alzheimer's Disease Facts and Figures*.

<sup>34</sup> Alzheimer's Association. (2015) *Cognitive Data from the 2012 BRFSS*.

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

disclosing a diagnosis of Alzheimer's or other dementias.

- **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 2012 BRFSS (Behavioral Risk Factor Surveillance System) survey in 21 states found that 77% of people who have experienced subjective cognitive decline have not talked to their health care provider about it.

## SLIDE 34:

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### Early Detection: Most Want to Know<sup>35</sup>

- 89% of U.S. adults would want to know
  - Of those age 60 and older, 95% would want to know
  - 97% would want to know for family member
- 

### TALKING POINTS:

Despite the barriers to diagnosis, studies show that most U.S. adults would want to know if they had Alzheimer's disease.

- Nearly **89% of Americans** say that if they were exhibiting confusion and memory loss, they would want to know if the cause of the symptoms was Alzheimer's disease.
- Of those aged 60 and older, **95%** say they would want to know.
- Over **97%** say that if they had a **family member** exhibiting problems with memory loss, they would want them to see a doctor to determine if the cause was Alzheimer's disease.

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<sup>35</sup> Alzheimer's Association. (2013) *Early Diagnosis: The Value of Knowing*.

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

## SLIDE 35:

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### Discussion Question

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

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### TALKING POINTS:

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

**Open responses.**

## SLIDE 36:

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### Public Health: Early Diagnosis<sup>36</sup>

- General education and awareness
    - “10 Warning Signs” – Alzheimer’s Association
    - Benefits of early detection
  - Education and training for health care providers
  - Education for newly diagnosed
- 

### TALKING POINTS:

**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”), the benefits of early detection, and the importance of talking to a health care provider about increasing memory problems.
- Identifying and promoting **culturally appropriate strategies** designed to promote early detection.

Public health may also play a role in providing **education to health care providers** about the importance of early detection and diagnosis.

Education provided to the medical community should include topics such as:

- The importance of discussing memory issues with older patients
- The availability and use of **tools** and **guidelines** to identify dementia, including validated cognitive assessment tools

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<sup>36</sup> Alzheimer’s Association. (2013) *Early Diagnosis: The Value of Knowing*.

*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 warning signs: <http://alz.org/10-signs-symptoms-alzheimers-dementia.asp>

## SLIDE 37:

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### Conclusion: Public Health Response<sup>37</sup>

3 key public health intervention tools:

- Surveillance/monitoring
  - Primary prevention
  - Early detection and diagnosis
- 

### TALKING POINTS:

Public health addresses Alzheimer's disease from a population perspective in three primary ways:

#### 1. Conduct **surveillance and monitoring**

Surveillance allows public health to compile data on a population level and use it to:

- Develop strategies and interventions
- Inform public policy
- Guide research
- Evaluate programs and policies
- Educate populations

#### 2. Promote **primary prevention**

Primary prevention can be used to promote **risk reduction** for Alzheimer's disease, as well as **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:

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<sup>37</sup> *Image source:* Copyrighted image; used with permission from the Alzheimer's Association

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

- 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. Promote **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.

## SLIDE 38:

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### Dementia Capable Systems and Dementia Friendly Communities<sup>38</sup>

- 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**
- Supporting the creation of **dementia friendly communities** which describes communities that have taken steps to make their community safe for and accessible to people with Alzheimer's and dementia as well as support and empower people with Alzheimer's and dementia to continue living high-quality lives with as much independence as possible.

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<sup>38</sup> *Image source:* Copyrighted image; used with permission from the Alzheimer's Association

## SLIDE 39:

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### For More Information

For more information, please visit the Alzheimer's Association website at: <http://www.alz.org>

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### TALKING POINTS:

For more information on the topics covered in this presentation, please go to the Alzheimer's Association website at <http://www.alz.org>. There you can find resources, latest research and information.

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

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



## LEARNING OBJECTIVES

- List 3 key tools public health can apply to the Alzheimer's disease epidemic
- Describe surveillance/monitoring and how public health can apply it in response to Alzheimer's disease
- Name the 2 BRFSS modules that pertain to cognitive decline and caregiving
- Describe primary prevention and how public health can apply it to Alzheimer's disease
- Explain why it is important to promote early detection of Alzheimer's disease

## COMPETENCIES

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

- 1.2.4 Recognize common late-life syndromes and diseases and their related bio-psycho-social risk and protective factors.

### **Association of Schools and Programs of Public Health (ASPPH):**

- Domain 2: Describe how the methods of epidemiology and surveillance are used to safeguard the population's health.
- Domain 3: Endorse lifestyle behaviors that promote individual and population health and well-being.

### **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.
- 8A4. Contributes to development of a vision for a healthy community (e.g., emphasis on prevention, health equity for all, excellence and innovation).

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## COMPETENCIES CONT.

### **National Association of Chronic Disease Directors (NACDD):**

- Domain 7: Identify relevant and appropriate data and information sources for chronic disease.
- Domain 7: Articulate evidence-based approaches to chronic disease prevention and control.

### **National Commission for Health Education Credentialing, Inc. (NCHEC):**

- 1.7.4 Identify emerging health education needs.
- 7.1.1 Identify current and emerging issues that may influence health and health education.

4

## INTRODUCTION: DEMENTIA & ALZHEIMER’S DISEASE

- Dementia is a decline in mental ability severe enough to interfere with daily life
  - Caused by damage to brain cells, primarily affects older adults
- Alzheimer’s disease is the most common type of dementia
  - Progressive loss of memory and brain function, behavior and personality changes
  - No cure and limited treatment options
  - Caregivers provide increasing assistance
- Huge impact on individuals, families, caregivers, and the health care system
- Public health plays important role in addressing Alzheimer’s disease through surveillance, prevention, detection, and support of dementia capable systems

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<sup>1</sup> Alzheimer’s Association. 2015 Alzheimer’s Disease Facts and Figures.

## ALZHEIMER’S: A PUBLIC HEALTH CRISIS

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



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## ALZHEIMER'S: EPIDEMIC (U.S.)

- Over 5 million adults
- 1 in 9 adults age  $\geq 65$
- 1 in 3 adults age  $\geq 85$
- By 2050, expected to reach 13.8 million



<sup>2</sup> Alzheimer's Association. 2016 Alzheimer's Disease Facts and Figures.

## ALZHEIMER'S IMPACT: COSTS

- Significant costs to Medicare, Medicaid, individuals, caregivers
- Annual costs of care over \$200 billion
- Most expensive disease in the U.S.



<sup>3</sup> Alzheimer's Association. 2016 Alzheimer's Disease Facts and Figures.

## ALZHEIMER'S: DISPROPORTIONAL IMPACT

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



<sup>4</sup> Alzheimer's Association. 2016 Alzheimer's Disease Facts and Figures.

## ALZHEIMER'S: CAREGIVING BURDEN

- Requires increasing levels of caregiving (paid or unpaid)
- Over 15 million caregivers
- 18 billion hours of unpaid care annually
- Hardships: health, emotional, financial

<sup>5</sup> Alzheimer's Association. 2016 Alzheimer's Disease Facts and Figures.

## ALZHEIMER'S: HEALTH CARE BURDEN

- Disproportionate use of health care resources
  - Hospitalized 2-3 times more often
  - Represents 64% of Medicare beneficiaries living in nursing homes
- Workforce shortage
- Inadequate training



<sup>6</sup> Alzheimer's Association. (2013) *Combating Alzheimer's Disease: A Public Health Agenda*.  
<sup>7</sup> Alzheimer's Association. 2016 *Alzheimer's Disease Facts and Figures*.  
<sup>8</sup> U.S. Department of Health and Human Services. *National Plan to Address Alzheimer's Disease: 2013 Update*.

## PUBLIC HEALTH: TOOLS & TECHNIQUES

3 key public health intervention tools:

- Surveillance/monitoring
- Primary prevention
- Early detection and diagnosis



<sup>9</sup> Alzheimer's Association. (2013) *Combating Alzheimer's Disease: A Public Health Agenda*.



## TOOL #1: SURVEILLANCE

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



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## SURVEILLANCE & PUBLIC HEALTH

- Compile data on a population level including:
  - Prevalence of certain diseases
  - Health risk factors
  - Health behaviors
  - Burden of diseases
- Little state-level data on Alzheimer's and dementia

<sup>10</sup> Alzheimer's Association, (2014) *Data Collection and Behavioral Risk Factor Surveillance System (BRFSS)*.

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## BEHAVIORAL RISK FACTOR SURVEILLANCE SYSTEM (BRFSS)

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



<sup>11</sup> Alzheimer's Association. (2014) *Data Collection and Behavioral Risk Factor Surveillance System (BRFSS)*.

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## BRFSS: COGNITIVE DECLINE MODULE

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

<sup>12</sup> Alzheimer's Association. (2014) *Data Collection and Behavioral Risk Factor Surveillance System (BRFSS)*.

<sup>13</sup> Centers for Disease Control and Prevention. *Behavioral Risk Factor Surveillance System (BRFSS) 2015 Cognitive Decline Module*. Accessed June 10, 2015 from website: <http://www.cdc.gov/aging/healthybrain/brfss-faq.htm>

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## BRFSS: CAREGIVER MODULE

- Comprised of questions about:
  - Prevalence of caregiving and caregiving activities
  - Caregiver age, gender, relationship to care recipient
  - Scope of caregiving
  - Caregiver challenges
- 40 states/territories have used at least once

<sup>14</sup> Alzheimer's Association. (2014) *Data Collection and Behavioral Risk Factor Surveillance System (BRFSS)*.

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## DISCUSSION QUESTION



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

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## PUBLIC HEALTH: SURVEILLANCE DATA

- Develop strategies to reduce risk
- Design interventions to alleviate burden
- Inform public policy
- Guide research
- Evaluate programs and policies
- Educate public and health care community



<sup>15</sup> Alzheimer’s Association. (2014) Data Collection and Behavioral Risk Factor Surveillance System (BRFSS).  
<sup>16</sup> Centers for Disease Control and Prevention. The CDC Healthy Brain Initiative: Progress 2006 – 2011.



## TOOL #2: PRIMARY PREVENTION & RISK REDUCTION

ALZHEIMER’S DISEASE – WHAT IS THE ROLE OF PUBLIC HEALTH?



## PRIMARY PREVENTION

- 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



<sup>17</sup> Centers for Disease Control and Prevention. *The Concept of Prevention*. Accessed August 14, 2015 from: <http://www.cdc.gov/arthritis/temp/pilots-201208/pilot1/online/arthritis-challenge/03-Prevention/concept.htm>

## DISCUSSION QUESTION



What are risk factors for Alzheimer's disease that could be modified/reduced?

## RISK REDUCTION: HEAD TRAUMA

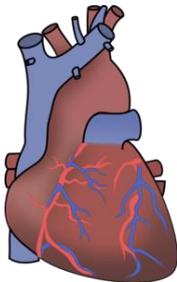
- Moderate or severe traumatic brain injury
- Risk remains for years after original injury
- Prevention efforts include:
  - Seat belt use
  - Use of helmets
  - Falls prevention



<sup>18</sup> Alzheimer’s Association. (2015) *Traumatic Brain Injury*.  
<sup>19</sup> Centers for Disease Control and Prevention. *Older Adults Falls: Get the Facts*. Accessed June 10, 2015 from website: <http://www.cdc.gov/HomeandRecreationalSafety/Falls/adultfalls.html>

## RISK REDUCTION: HEART HEALTH

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



<sup>20</sup> Alzheimer’s Association. (2014) *Alzheimer’s and Public Health Spotlight: Heart Health and Brain Health*.  
<sup>21</sup> Alzheimer’s Association. *Prevention and Risk of Alzheimer’s and Dementia*. Accessed July 16, 2015 from website: [http://www.alz.org/research/science/alzheimers\\_prevention\\_and\\_risk.asp](http://www.alz.org/research/science/alzheimers_prevention_and_risk.asp)  
<sup>22</sup> Centers for Disease Control and Prevention, Division of Nutrition, Physical Activity, and Obesity. *Physical Activity is Essential to Healthy Aging*. Accessed September 1, 2015 from website: [http://www.cdc.gov/physicalactivity/basics/older\\_adults/](http://www.cdc.gov/physicalactivity/basics/older_adults/)

## RISK REDUCTION: AVOIDANCE/MANAGEMENT

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



<sup>23</sup> Baumgart, M., Snyder, H., Carrillo, M., Fazio, S., et al, *Summary of the evidence on modifiable risk factors for cognitive decline and dementia: A population-based perspective. Alzheimer's & Dementia* 11 (2015) 718-726.

## RISK REDUCTION: ACTIVE BRAIN<sup>24</sup>

- Mental stimulation:
  - Learning new information and skills
  - Volunteering
  - Reading
  - Playing challenging games
- Social connections



<sup>24</sup> National Institute on Aging. (2015) *Alzheimer's Disease: Unraveling the Mystery.*

## DISCUSSION QUESTION



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

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## PUBLIC HEALTH: RISK REDUCTION

- 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



<sup>25</sup> Alzheimer's Disease International. *World Alzheimer Report 2014: Dementia and Risk Reduction, An Analysis of Protective and Modifiable Factors, Summary Sheet.*

<sup>26</sup> Alzheimer's Association and Centers for Disease Control and Prevention. (2013) *The Public Health Road Map for State and National Partnerships, 2013-2018.* 28

TOOL #3: EARLY DETECTION & DIAGNOSIS

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

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DISCUSSION QUESTION



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

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## WHY PROMOTE EARLY DETECTION?

- Access to treatment and services
- Planning
- Potentially reversible causes
- Clinical trials



<sup>27</sup> Alzheimer’s Association. (2013) *Combating Alzheimer’s Disease: A Public Health Agenda*.  
<sup>28</sup> Alzheimer’s Association. *Early Detection*. Accessed June 8, 2015 from website: <http://www.alz.org/publichealth/early-detection.asp> 31  
<sup>29</sup> National Institutes on Aging. (2015) *Alzheimer’s Disease: Unraveling the Mystery*.  
<sup>30</sup> U.S. Health and Human Services. *National Plan to Address Alzheimer’s Disease: 2015 Update*

## EARLY DETECTION: DIAGNOSIS RATES

- Most people with Alzheimer’s disease have either:
  - Not been diagnosed
  - Been diagnosed but are not aware of diagnosis
- Only 35% aware of diagnosis
- Health disparities



<sup>31</sup> Alzheimer’s Association. *2015 Alzheimer’s Disease Facts and Figures*.  
<sup>32</sup> Alzheimer’s Association. (2013) *Alzheimer’s and Public Health Spotlight: Race, Ethnicity & Alzheimer’s Disease*. 32

## EARLY DETECTION: CHALLENGES

- Diagnostic uncertainty
- Time constraints, lack of support
- Communication difficulties
- Fear of causing emotional distress
- Reluctance to discuss with health care provider

<sup>33</sup> Alzheimer's Association. 2016 Alzheimer's Disease Facts and Figures.

<sup>34</sup> Alzheimer's Association. (2015) Cognitive Data from the 2012 BRFSS.

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## EARLY DETECTION: MOST WANT TO KNOW

- 89% of Americans would want to know
- Of those age 60 and older, 95% would want to know
- 97% would want to know about a family member



<sup>35</sup> Alzheimer's Association. (2013) Early Diagnosis: The Value of Knowing.

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# DISCUSSION QUESTION



What can public health do to promote early detection of Alzheimer’s disease?

# PUBLIC HEALTH: EARLY DIAGNOSIS

- General education and awareness
  - “10 Warning Signs” – Alzheimer’s Association
  - Benefits of early detection
- Education and training for health care providers
- Education for newly diagnosed



<sup>36</sup> Alzheimer’s Association. (2013) *Early Diagnosis: The Value of Knowing*.

## CONCLUSION: PUBLIC HEALTH RESPONSE

- 3 key public health intervention tools:
  - Surveillance/monitoring
  - Primary prevention
  - Early detection and diagnosis



## DEMENTIA CAPABLE SYSTEMS AND DEMENTIA FRIENDLY COMMUNITIES

- Dementia capable systems
  - Public health research and translation
  - Support services
  - Workforce training
- Dementia friendly communities



FOR MORE INFORMATION

For more information, please visit the Alzheimer's Association website at: <http://www.alz.org>



# 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:

- a. Surveillance
- b. Early detection and diagnosis
- c. Primary prevention
- d. All of the above
- e. None of the above

**Answer: D**

## Selected Case Studies-Module 3

On the suggested video resources list, there are several well done documentaries that cover various aspects of Alzheimer's and its impacts on individuals and families. Several of the suggested videos are used as case studies with discussion questions that 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. The program title, run time, web link, keywords, relevance to modules, a program description and discussion questions are listed for each piece.

It is recommended that the audio/video be used in conjunction with the discussion questions. 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 having to view the video.

### 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, an Alzheimer's diagnosis is rare; in fact, many tribal communities do not even have a word for dementia. Native American cultures typically consider 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 even 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 thirteen other children who lived 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 respect important in public health?
- In this story, what are cultural barriers to diagnosing and understanding Alzheimer's disease?
  - Lack of word for dementia
  - Seen as a part of the lifecycle and natural
  - Stigma- no one talks about it and Mrs. Williams' other children do not visit
- How can public health address Alzheimer's disease misinformation and stigma in a culturally sensitive and relevant way?
- What is the role of family and care in an Alzheimer's disease diagnosis?
- What would components may be useful in creating a community outreach program for this 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

**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 care center that provides socialization with other older adults, engaging activities, and day 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 disease 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 disease 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 couples' difficult situation?
  - Be open with family about the situation and Helen's health
  - Emailing/calling relatives ahead of time to brief them on
    - What to expect from Helen
    - How best to support Helen
  - Smaller gatherings can make things easier for caregivers as well as Helen
    - Noisy events and big groups can be overwhelming
    - Prepare Helen by discussing the holidays ahead of time and looking at photos of family members
  - Having a quiet room when Helen can rest during the event
- 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?
  - Open shelves so it's easier to find things
  - Take the knobs off the stove to prevent accidents

**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:** 1, 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 things 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.

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

Maria and Arturo are currently able to provide all the necessary care for Aurora to live safely in her own home. However, caring for patients with Alzheimer's disease is mentally and financially exhausting. As Aurora's Alzheimer's disease 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?
  - Temperature sensor on stoves, Bluetooth blood sugar meters, sensor monitoring systems
- What are ethical dilemmas about these kinds of technologies that may be considered invasive of an individual's privacy and health?
  - These types of technologies could perhaps prolong independence and delay entering care facilities by allowing for close, consistent, and constant health and safety monitoring
  - Allows for peace of mind for family members who may not be able to visit daily
  - Sensor Monitoring Systems-  
<http://www.cnn.com/2014/08/25/tech/innovation/alzheimers-smart-home/> allows caregivers to keep a close watch on their loved ones with Alzheimer's disease through monitoring systems in the house that send notifications to the caregiver's smartphone
  - Some people with Alzheimer's disease say they feel better and safer knowing their family members are able to interact with them and monitor their safety even though they may live far away
- 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?
  - Possible roles: safety reviews and regulation, consumer education, policy development on ways to help make technology affordable for low-income families, addressing ethical challenges

#### 4- "Alzheimer's Long and Costly Goodbye-Heartache and Hope: America's Alzheimer's Epidemic (Episode 1)," University of California Television (2012).

- **Video Link:**  
<http://myuctv.tv/2012/09/18/alzheimers-the-long-and-costly-goodbye/>
- **Run Time:** 12:30 minutes

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

- **Key Terms:** stigma, loss of identity, increasing prevalence, increasing aging population, caregiver's burden, family relationships, financial burden
- **Modules:** 1, 2, 3, 4

#### **Description:**

This documentary discusses how Alzheimer's disease affects the lives of individuals and families, touching on concepts from daily tasks becoming difficult or impossible, to the loss of self-identity that occurs. Often receiving an Alzheimer's diagnosis creates an emotional, physical, and financial impact on not only the individual diagnosed, but also family members and friends. This documentary also describes the economic impact of Alzheimer's in the US and on the health care system, as well as its increasing prevalence as the aging population continues to increase around the globe. This documentary provides multiple real-life Alzheimer's examples, such as President Reagan's diagnosis and decline through an interview with his daughter, and Leeza Gibbon's struggle with caring for her mother who lived with Alzheimer's disease for 10 years. Experts also discuss Alzheimer's financial burden on individuals, families, and the US economy, as well as other countries. This documentary briefly mentions the National Plan to Address Alzheimer's Disease.

#### **Case Study: Patti**

Patti graduated as the valedictorian of her high school and a few years later, she graduated magna cum laude from Syracuse University. Patti was a successful professor at a university for many decades. A few years ago, Patti began having difficulty remembering how to do simple daily tasks, such as making coffee, and she was constantly losing her glasses, her phone, or other items. Patti never told anyone about her memory issues because she thought it was embarrassing to admit that she was getting older. However, recently, Patti was diagnosed with Alzheimer's disease. Now, Patti describes the difficulty of doing simple tasks as if a voice in her head is constantly challenging her, saying, "How do you do that?" Now, daily activities leave Patti lost and confused. Patti often finds herself turning around in circles as she tries to remember or figure out how to do.

Patti planned on leaving an inheritance for her son when she passed away. Patti has a reverse mortgage, which is a special type of home loan for older adults that allows them to convert a portion of the equity of the home into cash. Older adults often use the cash payments to supplement income from Social Security, for unexpected medical expenses, home improvements, and many other uses. Alzheimer's disease is a costly disease. Patti now worries that she will no longer be able to leave an inheritance for her son because she could be drained of all her finances to cover her care needs.

#### **Discussion Questions:**

- Consider the costs that are associated with medical care and long-term services for people with dementia. What kinds of financial protections are in place to protect older adults' finances who live on a fixed income?

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

- What are other countries doing to provide quality and affordable medical care to their older adults?
- How does financial planning play a role in preparing for aging, potential onset of illnesses or disability, and the associated costs of care?

#### 5- "Caregivers," HBO (n.d.).

- **Video Link:** <http://www.hbo.com/alzheimers/caregivers.html>
- **Run Time:** 48:48 minutes (each segment is approximately 10 mins)
- **Key Terms:** stigma, caregiver relationship, life after caregiving, duties and responsibility, assisted living facilities
- **Modules:** 1, 3, 4

#### **Description:**

This documentary shares the stories of five 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, such as personal responsibilities as well as social stigma that caregivers go through in order to care for their loved ones in the family home as well as in nursing care facilities.

**Case Studies:** (stories presented in progressing order of Alzheimer's disease stages)

#### **Chuck (and Marianne) (Minute: 2:40-13:10) - Social support network**

Chuck was diagnosed with younger-onset Alzheimer's disease in 2004. Chuck's mother was diagnosed with Alzheimer's disease the fall he began high school. Younger-onset Alzheimer's disease is caused by a rare genetic mutation (it accounts for less than 3% of Alzheimer's disease cases) and is passed down through families. 12 out of 14 of Chuck's older relatives have died from Alzheimer's disease.

Marianne is Chuck's ex-wife. After Chuck's diagnosis, Marianne invited Chuck back and became his primary caregiver. As the caregiver, it is important for Marianne to maintain some time and space for herself. That space allows for her to relax and gives her a break from caregiving for a short amount of time. Chuck takes many different kinds of medications in order to control the progression of his Alzheimer's disease. Chuck and Marianne have made new friends with a couple where one partner also has Alzheimer's disease. Chuck and Marianne really enjoy the support and understanding that comes from this other couple in a similar situation. Chuck stays in the moment. He must make an effort to be positive and accept the changes as they come.

#### **Discussion Question:**

- Discuss the importance of a supportive social network. What are the challenges in finding support such as social isolation and stigma?

**Daphne (and Jude) (minute: 13:10-21:25) - Caregiver support**

Daphne is 65 years old and lives with her partner, Jude; they have been together for 24 years and Jude has been Daphne's caregiver for the past six years. Daphne used to be an astrophysicist, but she has lost her ability to remember, compute, and use simple and complicated numbers. She also used to love cooking, but since her Alzheimer's diagnosis, she struggles with measuring ingredients. Instead, Daphne turned to art, using painting as an outlet for her expressions. Painting has become Daphne's second language, and she hopes that her artwork will speak for her once she loses her ability to speak.

Jude regularly attends an Alzheimer's Association support group for caregivers of people diagnosed with Alzheimer's disease. This group provides Jude and other caregivers like her with unconditional emotional support; this group also discusses the importance of taking a little time to oneself. Jude attends this support group as well as a singing group at her church. Jude reflects on how she still gets something from her time with Daphne, despite what the disease has taken.

**Discussion Questions:**

- Caring for a loved one with Alzheimer's disease can put tremendous stress and burden on the caregiver. What are ways to ease this burden?
- How can communities provide resources and safe spaces for people with Alzheimer's disease and their caregivers?

**Nacho (and Mike) (minute: 21:25-30:40) - Full-time care**

Mike has six brothers and sisters and runs his own business; he is also the primary caregiver for his father, Nacho, who has Alzheimer's disease. Mike is the primary caregiver for his father because he had extra space in his house. A year and half into Nacho living with Mike, Mike's girlfriend moved out due to the enormous amount of stress that caring for Nacho put on their relationship. Mike feels similar stress in his other relationships with family and friends. There are many ups and downs that come with taking care of Nacho. Mike and the adult day center where Nacho spends days adjust games in small ways that allow Nacho to win. It is important to help Nacho retain self-worth as his Alzheimer's becomes increasingly degenerative. Without self-worth, depression overtakes Nacho. Sometimes Mike feels as if he can provide in-home primary care for his father for months, years, even decades, but then his father has another Alzheimer's disease-related issue bringing back the reality of Alzheimer's disease.

At first, Mike took his father everywhere he went. As Nacho's Alzheimer's progressed, outings became more than Mike and Nacho could handle. Now, Nacho does not like crowds or noise. Mike declines outings now to stay home and care for Nacho. Since beginning to stay home more with Nacho two years ago, Mike has gained thirty pounds and now has high blood pressure.

Recently, Mike moved Nacho to a facility that provides 24-hour care. Moving was very hard on Nacho, especially the first few months as his Alzheimer's disease worsened. At the facility, Nacho often wakes up in the middle of the night and does not know where the bathroom is, so he urinates in the kitchen or living room because he does not know his surroundings. Because Nacho no longer sleeps through the night, Mike has had to hire someone to provide nighttime care for Nacho and make sure he is safe and does not disrupt the other residents; a nighttime caregiver is expensive. Even though Mike no longer sees Nacho every day, he still takes each day one at a time.

#### Discussion Questions:

- With Mike's caregiving responsibility, what were some of the impacts this role had on Mike's life and health?
- The transition to a full-time nursing facility is often difficult on both the person with Alzheimer's disease and their family. This move can be even more difficult depending on the stage of Alzheimer's disease. What are some ways to make this transition easier for the person and their family?
- What are some safety measures that nursing facilities need to provide care and a safe space for Nacho and others with Alzheimer's?

#### **Marvine (and Jackie) (minute: 30:40-39:10) – Full-time care**

When they were first married, Marvine and Jackie vowed to never put each other in nursing homes. Eventually, Marvine was diagnosed with Alzheimer's disease and Jackie began having health issues. Jackie felt like she did not have a choice about moving Marvine to a nursing home and this was a very difficult decision for her. Marvine has been living in the nursing home for a few years now and Jackie visits him often. Jackie tends to dress very nicely and carefully when she visits her husband because on the days he does remember her, this makes him very happy. While visiting her husband, she feeds him because this is one of the few ways that she can provide care for him.

Marvine is in the severe stages of Alzheimer's disease. His ability to communicate verbally has been severely limited and often does not recognize people who speak to him. It is emotionally very difficult for Marvine's children, family, and friends to visit him in the nursing home. Marvine is no longer the full-of-life man whom everyone remembers. Jackie makes it a point to never say goodbye while at the nursing home.

#### Discussion Questions:

- What types of information or professional services could help families know when it is time to move someone with Alzheimer's disease into a full-time care facility?
- The severe stages of Alzheimer's disease are incredibly difficult for friends and family members. What resources are available to help them through this difficult time?
- What impact does Alzheimer's disease have on relationships?

**Pat (and Terry and Suzanne) (minute: 39:10- 45:55) - Life after Alzheimer's**

Pat and Terry were married for 34 years. Seventeen years into their marriage, Pat and Terry began having problems. One evening, Pat said that she felt something was wrong with her and began to cry. Pat never cried. As it turned out, Pat had Alzheimer's disease. Terry cared for Pat for the rest of her life.

Terry remembers that taking care of Pat was lonely and difficult, but he took care of her for as long as he could because he loved her. While caring for Pat, Terry struggled with the increasing social isolation that comes from caring for a loved one with Alzheimer's disease. After nine years of caring for her at home, Terry moved Pat into a full-time care center. This was very emotional and difficult for Terry. At first, he continued to take as much care of Pat as he could, but as her Alzheimer's disease progressed, he realized he could not provide enough care for her anymore. Once Pat passed away, Terry realized he did not want to go back to the life he had before caregiving. He was not sure what to do with his life going forward.

When Terry met Suzanne on a cruise in Alaska, he realized there is a life after caregiving. They eventually married and began volunteering at a family center for people with Alzheimer's disease. They enjoy giving back to the community, and this work has given Terry a renewed sense of purpose. The center and Suzanne have given Terry a second chance at a fulfilling life.

**Discussion Questions:**

- What are some of the social impacts that Alzheimer's caregivers can experience?
- What are ways communities can help people transition from caregiving to life after caregiving?

**6- "The Memory Loss Tapes," HBO (n.d.).**

- **Video Link:** <http://www.hbo.com/alzheimers/memory-loss-tapes.html>
- **Discussion Guide:** [http://www.hbo.com/alzheimers/downloads/Memory\\_Loss.com.pdf](http://www.hbo.com/alzheimers/downloads/Memory_Loss.com.pdf)
- **Run Time:** 85 minutes (each segment is approximately 8-12 minutes)
- **Key Terms:** family relationship, caregiver relationship, Alzheimer's medications, individual acceptance, family acceptance, assisted living facilities, end of life planning
- **Modules:** 1, 3, 4

**Description:**

"The Memory Loss Tapes" are part of a four-part HBO documentary series entitled *The Alzheimer's Project*. This documentary gives a short glimpse into the lives of seven individuals in varying stages of Alzheimer's disease. Each of the profiles gives insight into the lives of those living with the diagnosis, their surrounding family members and

caregivers, and their reactions to the diagnosis. Central themes in this documentary include loss of independence, confusion, fear and anxiety, and the importance of support and community resources.

#### **Case Studies:**

##### **Bessie (0:00-12:08)- Living independently for as long as possible**

Bessie is an 87 year old woman who was diagnosed with Alzheimer's disease two months ago. Bessie is in the mild (early) stages of Alzheimer's disease, and she is still very independent, able to drive and live alone. Bessie is active in her community. Everyone in town knows Bessie and she is well loved. Bessie volunteers with other women to sing in nursing homes. When Bessie can't remember who people are, they remind her, but a few minutes later, she forgets who they are again. Bessie's friends have noticed her Alzheimer's disease and they worry about her. Bessie's daughter and son-in-law want her to take medications that may slow the progression of her Alzheimer's disease. Bessie has a positive perspective on life and does not believe in giving up. Her daughter attributes this positive attitude towards how well Bessie is doing. Bessie is still very intelligent and alert, but she knows she has Alzheimer's disease which is causing her memory issues. Bessie's children worry about how they will care for her as her Alzheimer's disease progresses, when she begins forgetting she has Alzheimer's disease or no longer understands what Alzheimer's disease means.

#### **Discussion Questions:**

- What are ways that Bessie's family prolong her independence?
- Discuss the importance of a supportive social network.

##### **Frannie (12:09- 19:34)- Driving issues**

Frannie is an 82 year old woman who was diagnosed with Alzheimer's disease three months ago. Two months ago, Frannie's doctor told her she should stop driving. Frannie feels inadequate and dislikes depending on other people when she has been taking care of herself. Frannie's daughter took her to have a driving assessment test to see if Frannie is able to drive. Even though she is in the mild (early) stages of Alzheimer's disease, her judgment may already be affected and is causing driving safety issues.

This driving assessment is comprised of three parts: one part is a self-assessment of driving skills, one part is identifying road signs, and the third part is the driving test. Frannie struggled with identifying road signs as well as remembering traffic laws; she had a lot of difficulty during the driving portion with reading the road signs, staying in her lane, and following verbal directions. The test assessment results support the doctor's recommendations that Frannie should no longer drive. Frannie's daughter tells her that she and her siblings are happy to drive Frannie anywhere she wants to go. They already pick her up every Sunday on the way to church. While Frannie admits that she does not need to drive every day, losing the ability to drive is more about losing her independence and freedom. Frannie is very disappointed in this decision.

**Discussion Questions:**

- What are barriers to independence when diagnosed with Alzheimer's disease?
- How can we, as a society and community, promote older adult independence and feelings of adequacy and self-worth while maintaining safety?
- Consider how difficult it would be to live without a car or to use buses and subways while dealing with Alzheimer's disease. What changes in city design or what types of services would help support independence for all older adults? For older adults with Alzheimer's disease?

**Joe (19:38-31:13)- End of life planning**

Joe is 63 years old and was diagnosed with Alzheimer's disease two years ago. Joe found his passion in the 1980s working in the technology industry. He helped develop CDs and DVDs. Now, Joe writes a blog about his Alzheimer's disease diagnosis and living with the disease. Joe chronicles the struggles of his progressing Alzheimer's disease, such as getting locked out of his house, forgetting how to get back in his house, and being afraid to leave home in case he gets lost and cannot get back. For example, one day Joe took his granddaughter to play at the park. He forgot how to get home and could not remember where he was. Fortunately, his granddaughter knew how to get home, and they returned safely. This is just one example of Joe getting lost and endangering his and others' safety. Joe struggles with his Alzheimer's diagnosis emotionally and physically. Sometimes, Joe is so overwhelmed with forgetting peoples' faces that he no longer wants to interact with anyone. Joe also knows that he is getting worse over time and worries about "stepping over the line" and becoming a completely different person. He attends counseling to help with this anxiety and the emotional toll of Alzheimer's disease. Joe has begun end-of-life planning and is determined not to lose himself in the disease. Joe tries to reconcile his existence and meaning within the context of the universe, but finds it very difficult. It upsets his family when he talks about dying.

**Discussion Questions:**

- What are benefits of end-of-life planning?
- What are barriers to end-of-life planning?
- In what ways can end-of-life planning be promoted?

**Yolanda (31:14- 39:24)- Hallucinations**

Yolanda is 75 years old and lives in a nursing home. She was diagnosed with Alzheimer's disease six years ago. Yolanda is in the later stages of Alzheimer's disease and cannot do anything for herself anymore. Yolanda often has hallucinations. Yolanda believes that her good friend Ruth lives in her mirror, and she sees animals such as spiders and snakes in her room. Her nursing home has many daily activities that residents can engage in to promote socialization, including arts and crafts and a beauty salon. Yolanda no longer remembers her son when he comes to visit. It is emotionally difficult to not be recognized by his own mother.

**Discussion Question:**

- What measures are in place for peoples' wellbeing in nursing homes?

*(Next segment picks up at min 39:43, starts at 00:00 min)*

**Woody (00:00-14:21) – Music and Memory**

Woody is an 81 year old man who was diagnosed with Alzheimer's disease 14 years ago. Woody has always loved singing, and this passion has remained with him throughout his Alzheimer's progression. Woody now lives in a nursing home, but his family takes him to sing with his old singing group often. During the trip out, Woody asks the same questions over and over and does not know what is happening. However, while performing, Woody can still sing all the words. Woody, who has been married for many years, does not remember that he is married but recognizes his wife and daughter when they come to visit. In the nursing home, he has female admirers. The film shows Woody spending time with a female resident who is very affectionate; they hold hands, kiss and take a nap with one another.

**Discussion Questions:**

- Woody enjoyed singing and still remembers the words to many songs despite his Alzheimer's disease progression. How can using a person's talents enhance quality of life?
- How does Alzheimer's change the nature of marital relationships, especially when the person with dementia does not remember their spouse?

**Josephine (12:21- 23:26)- The Fence**

Josephine is a 77 year old woman who was diagnosed with Alzheimer's disease five years ago. After Josephine's diagnosis, her daughter moved from her job and life in the city to a farm where Josephine lives with her. Josephine's daughter locks the farm gates and constantly worries about Josephine getting lost on the farm. Fortunately, Josephine's daughter was able to put up a fence around the farm, which has helped her to keep track of Josephine. Josephine's daughter must constantly watch on her mother for her safety and make sure she does not get into trouble. For example, Josephine often puts things in her mouth that must be removed despite Josephine's protests. Josephine's daughter does not know how much longer she will be able to care for her mother at home on the farm. Josephine no longer speaks, but does communicate a little through sounds such as humming. Josephine also leaves small art arrangements using small objects around the house that her daughter documents with photographs. These vignettes tell her daughter that Josephine is still there beneath her progressing Alzheimer's disease. Josephine also paints on both canvases and rocks. Unfortunately, Josephine paints white over many of her canvas paintings and these no longer exist.

**Discussion Questions:**

- What could be some special challenges for people in rural areas who are living with or caring for someone affected by Alzheimer's?

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

- How can we improve the home to ensure the safety and health of older adults with Alzheimer's disease?
- What resources are available to caregivers?

#### **Cliff (23:27-41:21)- Final Stages**

Cliff is 79 years old and used to perform as a magician on a children's television show. He was diagnosed with Alzheimer's disease six years ago. Cliff spends a lot of his time resting in bed or sitting down and cannot get out of bed by himself. Cliff believes he needs to get out of bed and go somewhere, often to his television show, and often continually tries to get out of the bed. Cliff lives with his wife and also has a homecare nurse who assists with caregiving. Cliff is in the severe stages of Alzheimer's disease. Cliff's wife cooks his favorite foods, which are not healthy, but if it gets him to eat, she will still make anything for him. Earlier in his diagnosis, Cliff planned with his wife not to prolong his life with artificial measures.

Cliff has tried medications to ease the symptoms of Alzheimer's. However, Cliff's disease has progressed enough that these medications no longer help. Cliff's doctor asked his wife about her wishes for Cliff. Cliff's wife wishes to prolong his life, but since he is no longer himself, she does not think it is fair to continue his life with medications, especially because this is not the life he wanted for himself.

#### **Discussion Questions:**

- Why is end-of-life planning uncommon? What are barriers to end-of-life planning?
- How can we support caregivers after caregiving?

## Alzheimer's Disease Video Resources

The following videos are listed as suggested accompaniments to the curriculum modules. These could be shown in class or as suggested viewing outside of class.

### 1- "Inside the Brain: An Interactive Tour," Alzheimer's Association (n.d.).

- **Tour Link:** [http://www.alz.org/alzheimers\\_disease\\_4719.asp](http://www.alz.org/alzheimers_disease_4719.asp)
- **Run Time:** N/A
- **Key Terms:** Alzheimer's disease, brain activity, neurotransmitters, amyloid plaques, tangles
- **Modules:** 1, 2

#### **Description:**

This interactive tour helps explain the basic components of the brain and how Alzheimer's disease affects it. 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.

### 2- "What is Alzheimer's disease?," TedEd (n.d.).

- **Video Link:** <https://www.youtube.com/watch?v=yJTXN4xrl8>
- **Run Time:** 3:49 minutes
- **Key Terms:** stages of Alzheimer's, pathology of Alzheimer's
- **Modules:** 1, 2

#### **Description:**

Alzheimer's disease is the most common cause of dementia, affecting over 40 million people worldwide. Though it was discovered over a century ago, scientists are still searching for a cure. Ivan Seah Yu Jun describes how Alzheimer's affects the brain, shedding light on the different phases of this complicated, destructive disease.

### 3- "Heartache and Hope: America's Alzheimer's Epidemic," University of California Television (2012).

- **Video Link:** <http://www.uctv.tv/alzheimers/>
- **Run Time:** approximately 12 minutes each
- **Key Terms:** stigma, increasing prevalence, clinical trials, research, caregiver's burden, family relationships, financial burden
- **Modules:** 1, 2, 3, 4

#### **Description:**

This three-part series reveals the heartache for those suffering from and coping with Alzheimer's disease and the hope offered by UCLA researchers leading the charge to slow its progress and, eventually, find a cure. The series also profiles a growing network of caregiver support groups established by Patti Davis, daughter of President Ronald Reagan, and television personality Leeza Gibbons, who lost her mother to the disease.

a) **Alzheimer's Long and Costly Goodbye – Heartache & Hope: America's Alzheimer's Epidemic (Ep. 1)**

- **Video link:** <http://myuctv.tv/2012/09/18/alzheimers-the-long-and-costly-goodbye/>
- **Run time:** 12:30 minutes
- **Key terms:** dementia, diagnosis, cost
- **Description:** As Baby Boomers become senior citizens, Alzheimer's Disease and other forms of dementia are on track to reach epidemic proportions, with a new case every 68 seconds and an annual cost of \$1.2 trillion projected by 2050. The disease also takes its toll on family members struggling to care for their loved ones, while watching them slowly slip away in what some describe as "the long goodbye." The first in a series of three programs from UCLA offers an overview of the looming epidemic and illustrates the fear and grief experienced by patients and their loved ones, including Patti Davis, daughter of Ronald Reagan, and TV personality Leeza Gibbons, who lost her mother to Alzheimer's.

b) **Alzheimer's Diagnosis and Clinical Trials - Heartache & Hope: America's Alzheimer's Epidemic (Ep. 2)**

- **Video link:** <http://www.uctv.tv/shows/Alzheimers-Diagnosis-and-Clinical-Trials-Heartache-Hope-Americas-Alzheimers-Epidemic-Ep-2-23979>
- **Run time:** 12:26 minutes
- **Key terms:** research, clinical trials
- **Description:** The projections for Alzheimer's disease and other forms of dementia are alarming, but not all the news is bad. The second installment in this series from UCLA assesses the progress researchers have made in understanding the disease and highlights some promising clinical trials and diagnosis techniques that could slow its progression, possibly the first step towards prevention and cure.

c) **Alzheimer's Patient and Caregiver Support - Heartache & Hope: America's Alzheimer's Epidemic (Ep. 3);**

- **Video link:** <http://www.uctv.tv/shows/Alzheimers-Patient-and-Caregiver-Support-Heartache-Hope-Americas-Alzheimers-Epidemic-Ep-3-23981>
- **Run Time:** 12:26 minutes
- **Key Terms:** caregiver support, patient support, resources
- **Description:** It's often said, "If you've seen one person with Alzheimer's, then you've seen one person with Alzheimer's." The disease affects everyone differently, but all patients and their families experience some form of grief and fear, not to mention the stress put on the caregivers. The third and final installment in this series from UCLA offers up new models for healthcare and caregiver support that emphasize early diagnosis and support networks for everyone touched by the disease, including Patti

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

Davis, daughter of Ronald Reagan, and TV personality Leeza Gibbons, who lost her mother to Alzheimer's.

#### 4- "Caregivers," HBO (n.d.).

- **Video Link:** <http://www.hbo.com/alzheimers/caregivers.html>
- **Run Time:** 48:48 minutes (each segment is approximately 10 mins)
- **Key Terms:** stigma, caregiver relationship, life after caregiving, duties and responsibility, assisted living facilities
- **Modules:** 1,3,4

##### **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- "Inside the Brain: Unraveling the Mystery of Alzheimer Disease," National Institutes of Health, NIH Senior Health (n.d.).

- **Video Link:** [http://nihseniorhealth.gov/alzheimersdisease/whatisalzheimersdisease/video/a2\\_n\\_a.html?intro=yes](http://nihseniorhealth.gov/alzheimersdisease/whatisalzheimersdisease/video/a2_n_a.html?intro=yes)
- **Run Time:** 4:21 minutes
- **Key Terms:** neurobiology of Alzheimer's disease, the brain, cellular circuitry, cellular communication, neurotransmission, beta amyloid plaque formation, neurofibrillary tangle formation
- **Modules:** 1, 2

##### **Description:**

This short video compares healthy, functioning cellular brain communication with the biological mechanism of plaque and neurofibrillary tangle formation in a brain of someone that has Alzheimer's disease.

#### 6- "Understanding the Selfhood of People with a Dementia: Context Is Key, "

Dr. Steven Sabat and Dementia Alliance International (2015).

- **Video Link:** <https://www.youtube.com/watch?v=3XxY7kMRSvk>
- **Run Time:** 68 minutes
- **Key Terms:** dementia, selfhood, communication, caregivers
- **Module:** 2

##### **Description:**

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

Professor Steven R. Sabat of Georgetown University has studied the intact cognitive and social abilities (including aspects of selfhood) of people with Alzheimer's disease in the moderate to severe stages of the disease, the subjective experience of having the disease, and the ways in which communication between those diagnosed and their caregivers may be enhanced. In this presentation for the Dementia Alliance International, A Meeting of the Minds Webinar, Dr. Sabat discusses three lenses -- biomedical, existential-phenomenological, and bio-psychosocial -- for understanding and interacting with a person with dementia, including Alzheimer's. Each lens can provide insights into the effects of dementia on a person and how the individual reacts to those effects. The video emphasizes the importance of personal history and respect for selfhood. Dr. Sabat suggests ways to help people living with dementia cope with their experiences.

#### 7- "The Memory Loss Tapes," HBO (n.d.).

- **Video Link:** <http://www.hbo.com/alzheimers/memory-loss-tapes.html>
- **Run Time:** 85 minutes (divided into 10-12 minute segments)
- **Key Terms:** family relationship, caregiver relationship, Alzheimer's medications, individual acceptance, family acceptance, assisted living facilities, end of life planning
- **Modules:** 1, 3, 4

##### **Description:**

This documentary gives a short glimpse into the lives of seven individuals in varying stages of Alzheimer's disease. While each diagnosis is different, all of the diagnosed individuals and surrounding family members and caregivers in this documentary are affected by the diagnosis. Central themes in this documentary include, loss of independence, confusion, fear and anxiety, and the importance of support and community resources.

#### 8- "What is Alzheimer's Disease?" National Institutes of Health, NIH Senior Health (n.d.).

- **Video Link:** [http://nihseniorhealth.gov/alzheimersdisease/whatisalzheimersdisease/video/a6\\_n\\_a\\_intro.html](http://nihseniorhealth.gov/alzheimersdisease/whatisalzheimersdisease/video/a6_n_a_intro.html)
- **Run Time:** 2:29 minutes
- **Key Terms:** biology and behavioral changes of Alzheimer's disease
- **Modules:** 1, 2

##### **Description:**

This short clip discusses some background information about Alzheimer's disease and explains some of the behavioral changes that occur in diagnosed individuals as the disease degenerately progresses.

**9- "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

**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).

**10- "Grandpa, Do you know who I am?" The Alzheimer's Project on HBO** (2016).

- **Video Link:** <http://www.hbo.com/alzheimers/grandpa-do-you-know-who-i-am.html>
- **Run Time:** 30:48 minutes
- **Key Terms:** children, family, impact of disease on family
- **Modules:** 1, 4

**Description:**

This film tells five stories of children, ages 6-15, who are coping with grandfathers or grandmothers suffering from Alzheimer's disease. Maria Shriver provides commentary and delivers valuable "lessons" for the kids, urging them not to blame themselves for what their grandparents do or say. "We are all children of Alzheimer's," says Shriver, sympathetically making it clear that "if it's too painful to visit, you don't have to go." Maria's own father, Sargent Shriver, suffers from the disease; comparing his earlier vitality to his present condition is hard, but it is offset by good memories and an unexpected "gift": bonds between generations that may not have been made otherwise. Ultimately, the film shows how important it is to "go with the flow," offering up a variety of perspectives on how kids can handle a grandparent's loss of memory through kindness, patience, and compassion.

**11- "The Supplemental Series," The Alzheimer's Project on HBO** (2016).

- **Video Link:** <http://www.hbo.com/alzheimers/the-supplementary-series.html>
- **Key Terms:** Research, genetics, biology, treatment, disease progression, risk factors
- **Modules:** 1, 2, 3

**Description:**

The Supplemental Series is a list of 15 videos highlighting a various aspect of Alzheimer's disease:

a) **“Understanding and Attacking Alzheimer’s”**

- **Run Time:** 12:26 minutes
- **Key Terms:** biology, beta-amyloid protein, plaque, treatments
- **Description:** This clip takes a close look at beta-amyloid protein which causes plaque and leads to Alzheimer’s disease. This clip focuses on beta-amyloid protein research and potential treatments to slow down Alzheimer’s progression or even create a vaccine.

b) **“How Far We Have Come in Alzheimer’s Research”**

- **Run Time:** 15:18 minutes
- **Key Terms:** treatment, research
- **Description:** This clip discusses the rapid progress in Alzheimer’s development and treatment research.

c) **“Identifying Mild Cognitive Impairment”**

- **Run Time:** 20:41 minutes
- **Key Terms:** research, disease progression, mild cognitive impairment, genetic/family inheritance, cognitive impairment tests, types of cognitive impairment, amnesic form, non-amnesic form, cognitive profile
- **Description:** This researcher studies people with mild cognitive impairment and how this progresses over time, as well as how to distinguish between the various different types of cognitive impairment diseases from early signs.

d) **“The Role of Genetics in Alzheimer’s”**

- **Run Time:** 14:18 minutes
- **Key Terms:** disease causation, genetics, genetic mutation/alteration, younger-onset, late onset, beta-amyloid plaque, inherited genes, susceptibility gene, sequencing, genetic predisposition
- **Description:** These two researchers discuss primarily the genetic mutation in the beta-amyloid gene that can lead to younger-onset Alzheimer’s disease.

e) **“Advances in Brain Imaging”**

- **Run Time:** 13:13 minutes
- **Key Terms:** brain imaging (MRI, fMRI), brain shrinking, hippocampus, precuneus, hyperactivity, treatment, vaccines
- **Description:** This scientist studies how the brain fails during Alzheimer’s disease using brain imaging to look at the function, structure, and pathology of the brain.

f) **“Looking into the Future of Alzheimer’s”**

- **Run Time:** 10:07 minutes
- **Key Terms:** increasing aging population, age profile
- **Description:** This expert discusses the risk factors for Alzheimer’s disease, its prevalence, and its increasing presence in public health around the world.

g) **“The Connection Between Insulin and Alzheimer’s”**

- **Run Time:** 21:50 minutes

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

- **Key Terms:** insulin resistance, insulin resistance as a risk factor, research, treatment, fat, diet, beta amyloid plaque accumulation and high saturated fat intake, insulin and memory, hippocampus, frontal lobe, intranasal insulin treatment
  - **Description:** This researcher discusses the evidence that insulin resistance (diabetes) may contribute to developing Alzheimer's disease through diet and insulin levels in the brain.
- h) "Inflammation, the Immune System, and Alzheimer's"**
- **Run Time:** 29:23 minutes
  - **Key Terms:** inflammation in the brain, brain samples, brain cells as living targets, vaccines, mouse models, microglia
  - **Description:** This scientist explains how inflammation affects the brain and can destroy parts of the brain and the nerve fibers over time, leading to Alzheimer's disease. These scientists also describe research that focuses on destroying the beta-amyloid plaque that builds up in the brain that causes Alzheimer's disease to create an effective vaccine using immunotherapy.
- i) "The Benefit of Diet and Exercise in Alzheimer's"**
- **Run Time:** 16:46 minutes
  - **Key Terms:** lifestyle modifications, oxidative damage, antioxidant rich diet, dog model, exercise, BDNF protein, mouse models
  - **Description:** This scientist examines how lifestyle modifications, primarily an antioxidant rich diet and exercise, can affect and even reduce the risk of Alzheimer's disease by studying oxidative damage in the brain.
- j) "Cognitive Reserve: What Religious Orders Study is Revealing about Alzheimer's"**
- **Run Time:** 22:14 minutes
  - **Key Terms:** memory tasks, brain activity, brain imaging, brain regions, brain reserve, Religious Orders Study, brain shrinkage, cognitive reserve
  - **Description:** This clips shows the difference in brain MRIs between the brains of an aging adult with no signs of Alzheimer's disease, an older adult with the brain pathology of Alzheimer's disease that is not yet cognitively impaired, and the brain of an older adult with progressive Alzheimer's disease. This clips also details the work of the Religious Orders Study that studies the progression of Alzheimer's disease as it affects the brain with a goal of how to age without memory loss, including the importance of a supportive social network.
- k) "Searching for an Alzheimer's Cure: The Story of Flurizan"**
- **Run Time:** 31:20 minutes
  - **Key Terms:** drugs, treatment, Flurizan, non-steroidal anti-inflammatory drugs (NSAIDs), beta-amyloid 42, pharmaceutical industry, statistical significance, ethics

- **Description:** This clip discusses how current Alzheimer's medications only treat symptoms without changing the progression of the disease, but new drugs, specifically Flurizan, are being researched that aim to modify the progress of the disease by reducing the amount of amyloid plaque built up in the brain. This is currently the largest Alzheimer's drug trial which studies the drug's ability to effectively slow down the biological progression of Alzheimer's disease.
- l) "The Pulse of Drug Development"**
- **Run Time:** 15:55 minutes
  - **Key Terms:** drugs, pathology, drug development, cleavage beta-amyloid plaque, detection, biomarkers, ethics, clinical trials, natural remedies, lifestyle changes
  - **Description:** This clip discusses how advanced technology is improving the process to develop specific, early use treatment drugs for Alzheimer's disease.
- m) "The DeMoe Family: Early-Onset Alzheimer's Genetics"**
- **Run Time:** 25:43 minutes
  - **Key Terms:** younger- (early) onset, genetics, family and intergenerational, predisposition, research, long term preparation, caregiver, family relationships, early diagnosis
  - **Description:** This short documentary examines the DeMoe family which has the dominant gene for younger- (early) onset Alzheimer's disease. Doctors and researchers are studying the DeMoe family in order to learn more about this genetically inherited form of Alzheimer's disease.
- n) "The Nanney/Felts Family: Late-Onset Alzheimer's Genetics"**
- **Run Time:** 22:71 minutes
  - **Key Terms:** late onset, research, genes, family, predisposition, early diagnosis, genetic mutation, gene sequencing, genetic background based risk, intergenerational
  - **Description:** This short documentary studies the Nanney/Felts family that has the late onset form of Alzheimer's due to a genetic predisposition from a mutated gene that affects the beta-amyloid protein.
- o) "The Quest for Biomarkers"**
- **Run Time:** 17:06 minutes
  - **Key Terms:** biomarkers, research, clinical trials, Pittsburgh Compound B (PIB) amyloid plaques, PET brain scanning, hereditary, spinal fluid, biofluids
  - **Description:** This video details the search for biological indicators that can be used to identify individuals who are at a higher risk for developing Alzheimer's disease. Earlier detection of Alzheimer's disease could potentially lead to more effective Alzheimer's treatment and cures as well as allow for treatment prior to the occurrence of becoming symptomatic. The

search for an indicative biological marker of Alzheimer's disease includes using brain imaging techniques and analysis of proteins in spinal fluid.

## 12-“Charlie Rose Brain Series 2: Generalized Defects in Cognition: Alzheimer's Disease,” Charlie Rose (2012).

- **Video Link:** <http://www.hulu.com/watch/333114>
- **Run Time:** 54:00 minutes
- **Key Terms:** Alzheimer's disease, frontotemporal dementia, Alzheimer's progression, biology, genetics, mutations, small animal laboratory model, diagnosis, healthcare, philanthropy, government funding and resources, early diagnosis, treatment, prevention
- **Modules:** 1, 3, 4

### **Description:**

This Charlie Rose segment features a panel of experts in fields including aging, neurobiology, and medicine. These experts discuss and compare dementia, Alzheimer's disease, and frontotemporal dementia. Dementia and Alzheimer's disease are differentiated and explained in great detail. This video also explains the difference between normal age-related memory loss and Alzheimer's disease, which is not a natural part of aging. The underlying biological mechanism of Alzheimer's disease is explained as well as the genetics behind younger-onset Alzheimer's disease are also explained in the context of family inheritance and risk factors. The experts discuss the advantages and disadvantages of current Alzheimer's drugs and when to administer these drugs. These experts stress the need for drugs that will address the underlying mechanism of Alzheimer's disease, not just treat the symptoms. These experts discuss the impact on the US economy and society, calling for more governmental support and resources for addressing Alzheimer's disease in addition to privately funded resources. These experts unanimously agree that a significant amount of research and progress has been made within the past 25 years surrounding Alzheimer's disease, however a lot more time, money, and research needs to occur to discover and distribute an effective Alzheimer's drug.

### **Programs Available for Purchase**

(Listed in order of most recent production date)

#### **1) “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, younger-onset
- **Purchase Price:**
  - Digital Download (Amazon): \$12.99
  - DVD (Amazon): \$12.59

### **Description:**

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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.

#### 2) "Glen Campbell: I'll Be Me," PCH Films (2014).

- **Video Link:** <http://virgil-films.myshopify.com/products/glen-campbell-ill-be-me>
- **Run Time:** 116:00 minutes
- **Key Terms:** progression, music therapy, family
- **Purchase Price:**
  - Digital Download \$14.99
  - DVD \$11.99

##### **Description:**

In 2011, music legend Glen Campbell set out on an unprecedented tour across America. He thought it would last 5 weeks; instead it went for 151 spectacular sold out shows over a triumphant year and a half. What made this tour extraordinary was that Glen had recently been diagnosed with Alzheimer's disease. He was told to hang up his guitar and prepare for the inevitable. Instead, Glen and his wife went public with his diagnosis and announced that he and his family would set out on a "Goodbye Tour." The film documents this extraordinary journey as he and his family attempt to navigate the wildly unpredictable nature of Glen's progressing disease using love, laughter and music as their medicine of choice. Special appearances include Bruce Springsteen, The Edge, Paul McCartney, Blake Shelton, Keith Urban, Brad Paisley, Taylor Swift, Steve Martin and Chad Smith among many others.

#### 3) "The Sum Total of Our Memory," Barbara Klutnis (2014).

- **Video Link:** <http://thesumtotalmovie.com/>
- **Run Time:** 57:00 minutes
- **Key Terms:** family relationship, recent diagnosis, stigma, clinical trials, healthcare
- **Purchase Price:** \$31.00

##### **Description:**

Couples affected by a partner's recent diagnosis of younger-onset Alzheimer's come to terms with their changing roles. Prominent Alzheimer's medical experts offer their perspectives on diagnosis, the nature of the disease, helpful attitudes in caring for loved ones, stigma, clinical trials, support for caregivers, and overall healthcare concerns.

#### 4) "Alive Inside," M. Rossato-Bennett (2014).

- **Video Link:** [http://www.theconnection.com/aliveinside/aliveinside\\_index.cfm](http://www.theconnection.com/aliveinside/aliveinside_index.cfm)
- **Run Time:** 78:00 minutes
- **Key Terms:** music, memory loss, healing

- **Purchase Price:** \$14.99

**Description:**

Depicts the power of music listening to revitalize and soothe the human spirit in persons with memory loss. Contains interviews with Oliver Sachs and Bobby McFerrin. Won the 2014 Audience Award at the Sundance Film Festival.

**5) "First Cousin Once Removed," Alan Berliner (2013).**

- **Video Link:** <http://www.hbo.com/documentaries/first-cousin-once-removed>
- **Run Time:** 27:00 minutes
- **Key Terms:** progression
- **Purchase Price:** HBO subscription

**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.

**6) "Forgetting (the): A Portrait of Alzheimer's: Stories of Love, Courage, and Hope," Twin Cities Public Television, Inc. (2013).**

- **Video Link:** <http://www.shoppbs.org/product/index.jsp?productId=1450826>
- **Run Time:** 90:00 minutes
- **Key Terms:** family, symptoms, treatment options, research, coping, community resources
- **Purchase Price:** \$19.99

**Description:**

A PBS documentary with experts Steven DeKosky and Rudolph Tanzi that follows several research studies and the lives of families affected by the disease. Includes a panel discussion of nationally recognized experts led by David Hyde Pierce. This discussion covers symptoms, treatment options, research, coping, community resources, and more.

**7) "14 Days with Alzheimer's: A Film By Lisa Cerasoli," Lisa Cerasoli (2012).**

- **Video Link:** [http://www.amazon.com/14-Days-Alzheimers-Film-Cerasoli/dp/1589850998/ref=sr\\_1\\_1?s=movies-tv&ie=UTF8&qid=1427304005&sr=1-1&keywords=14+days+with+alzheimer%27s](http://www.amazon.com/14-Days-Alzheimers-Film-Cerasoli/dp/1589850998/ref=sr_1_1?s=movies-tv&ie=UTF8&qid=1427304005&sr=1-1&keywords=14+days+with+alzheimer%27s)
- **Run Time:** 29:00 minutes
- **Keywords:** caregiver burden, family relationship
- **Purchase Price:** \$9.99

**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.

**8) "Bob and Nancy: Inside the Emotions of Alzheimer's,"** Video Press (2012).

- **Video Link:** <http://www.amazon.com/Bob-Nancy-Inside-Emotions-Alzheimers/dp/B009WSBKGO>
- **Run Time:** 20:00 minutes
- **Key Terms:** progression, family, partner
- **Purchase Price:** \$50.00

**Description:**

The progression of Alzheimer's is documented in *Bob and Nancy* through interviews by Peter Rabins who probes the emotions and responses that impact Nancy's life.

**9) "Caregiver Wellness,"** Medifecta (2012).

- **Video Link:** <http://www.medifecta.com/dvd-training-programs/caregiver-wellness/>
- **Run Time:** 60:00 minutes
- **Key Terms:** caregiver burden
- **Purchase Price:** \$158.99

**Description:**

Covers the factors of caregiver stress and offers realistic solutions for minimizing stress and nurturing wellness in caregivers. Topics include the importance of maintaining wellness, acknowledging and defusing difficult emotions, using simple and effective exercises for relaxation and renewal, performing activities that foster self-esteem and well-being, and the role of respite.

**10) "You're Looking at Me Like I Live Here and I Don't,"** Scott Krischenbaum & Shane Boris (2012).

- **Video Link:** <http://yourelookingatme.com/>
- **Run Time:** 54:00 minutes
- **Key Terms:** identity
- **Purchase Price:** \$18.00 (individual license) – 250.00 (colleges/university license)

**Description:**

Uniquely filmed in an Alzheimer's unit and told from the perspective of an Alzheimer's patient, Lee Gorewitz looks for evidence of her past, her identity, and struggles to remember who she is.

**11) "Dining with Friends: an Innovative Approach to Dining for People with Dementia,"** Alzheimer's Resource Center of Connecticut, Inc & Terra Nova Films (2012).

- **Video Link:** <http://terranova.org/film-catalog/dining-with-friends-an-innovative-approach-to-dining-for-people-with-dementia/>
- **Run Time:** 20:00 minutes
- **Key Terms:** caregiver burden, dining, connections, communication, independence, modified food choices
- **Purchase Price:** \$99.00

**Description:**

*Dining with Friends* emphasizes how to optimize the dining environment for a dignified experience including the importance of establishing connections between staff and people with dementia, understanding the stages of Alzheimer's disease, how caregivers may develop effective ways to communicate and support independence, and how to easily prepare modified food choices that appetizing and nutritious.

**12) "Whose Death Is It Anyways?"** Christopher Lukas (2011).

- **Video Link:** [https://www.amazon.com/Whose-Death-Anyway-Nancy-Snyderman/dp/B004TH7BZW?ie=UTF8&keywords=Whose%20death%20is%20it%20anyway%20DVD&qid=1429010157&ref= sr\\_1\\_2&sr=8-2](https://www.amazon.com/Whose-Death-Anyway-Nancy-Snyderman/dp/B004TH7BZW?ie=UTF8&keywords=Whose%20death%20is%20it%20anyway%20DVD&qid=1429010157&ref= sr_1_2&sr=8-2)
- **Run Time:** 56:00 minutes
- **Key Terms:** end of life care, legal rights, family conflicts, advance directives, palliative comfort care, hospice care, death
- **Purchase Price:**
  - Amazon Video \$19.95
  - Purchase DVD \$39.95-69.95

**Description:**

A studio audience hosted by Nancy Snyderman, physician and Chief Medical Editor for NBC News, with a live audience including people who have had to make end-of-life decisions. The program examines patients' legal rights, family conflicts about end-of-life care, advance directives, palliative care, and dying at home, in the hospital, or with hospice care.

**13) "More than Words: A New Culture of Care and Communication with Persons Who Have Dementia,"** Terra Nova Films (2011).

- **Video Link:** <http://terranova.org/film-catalog/more-than-words/>
- **Run Time:** 25:00 minutes
- **Key Terms:** person centered care, communication
- **Purchase Price:**
  - Watch On-Demand 24 hours \$19.95
  - Watch On-Demand 2 weeks \$45.00

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

- Rent DVD \$59.00
- Purchase DVD \$179.00

**Description:**

*More Than Words* demonstrates how person-centered care and knowledge of residents can reduce dementia related symptoms, such as sundowning, aggressive reactions when bathing, and wanting to leave. Shows valuable tips to redirect and lessen anxieties for persons with dementia while preserving their personal autonomy and dignity. Topics covered include building and maintaining a relationship, dealing with difficult situations, communicating to show respect, accepting their realities, respecting the person's preferences, and encouraging use of remaining abilities.