

A PUBLIC HEALTH APPROACH TO ALZHEIMER'S AND OTHER DEMENTIAS



alzheimer's 
association®


CENTERS FOR DISEASE™
CONTROL AND PREVENTION

 EMORY
ROLLINS
SCHOOL OF
PUBLIC
HEALTH

Emory Centers
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Technical Assistance

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ABOUT THE CURRICULUM

The Alzheimer’s Association, as part of a cooperative agreement with CDC’s Healthy Aging Program, and in partnership with Emory University’s Rollins School of Public Health, developed these curricular materials on cognitive health, cognitive impairment, and Alzheimer’s disease for use by undergraduate faculty in schools and programs of public health. This work supports *The Healthy Brain Initiative: The Public Health Road Map for State and National Partnerships* (Road Map) in terms of developing a competent workforce.

The curriculum consists of four modules:

Module 1: Alzheimer’s Disease – A Public Health Crisis frames Alzheimer’s and other dementias as a public health epidemic with a large and rapidly growing burden that bears significant impact on the nation.

Module 2: Alzheimer’s and Other Dementias – The Basics describes Alzheimer’s and other dementias including symptoms, stages, risk factors, diagnosis, and management.

Module 3: Alzheimer’s Disease – What is the Role of Public Health? discusses three tools of public health that may play a significant role in mitigating the Alzheimer’s disease epidemic: surveillance/monitoring, primary prevention, and early detection and diagnosis.

Module 4: Dementia Capable Systems and Dementia Friendly Communities addresses the public health response to the Alzheimer’s disease epidemic on a state and community level. The module describes the concept of a “dementia capable” system and explores how public health may support the development of such systems through public health research and translation, support services and programs, workforce training, and the creation of dementia-friendly communities.

The following materials are provided for each module:

- **Faculty Guide**, including:
 - Learning objectives
 - Competencies
 - Discussion questions
 - Learning activities
 - Slide guide with talking points
 - Sample test questions
 - Case studies
 - Video Resources

- References
- **PowerPoint slides**

HOW TO USE THE MATERIALS

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

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COVER ILLUSTRATOR

The cover illustration by **Sophie Banspach** depicts the growing prevalence of Alzheimer's in the United States, showing differences across age and race on a stylized linear plane. As an undergraduate student at the University of Georgia, Sophie studies scientific illustration and global health and aims to increase health literacy through visual representations of scientific and health-related concepts. Sophie's future plans are to pursue a master of public health, gain international health experience, and grow her artist portfolio.

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FACULTY GUIDE

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

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

ABOUT MODULE 1

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

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

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

Module 1 covers the following topics:

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

LEARNING OBJECTIVES

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

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

- Identify health disparities related to Alzheimer’s and dementia.
- Explain why public health must play a role in addressing the Alzheimer’s disease epidemic.

COMPETENCIES

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

Association for Gerontology in Higher Education (AGHE):

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

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

- Domain 1: Discuss major local, national, and global health challenges.

Council on Linkages Between Academia and Public Health Practice:

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

National Association of Chronic Disease Directors (NACDD):

- Domain 7: Articulate key chronic disease issues.

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

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

Disclaimer: This publication was supported by Cooperative Agreement Number 5U58DP002945-05, funded by the Centers for Disease Control and Prevention. Its contents are solely the responsibility of the authors and do not necessarily represent the official views of the Centers for Disease Control and Prevention or the Department of Health and Human Services.

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STUDENT ENGAGEMENT OPTIONS

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

DISCUSSION QUESTIONS

The following discussion questions are included in the slide deck:

- What are Medicare and Medicaid? (*Slide 16*)
- What might be the roles and responsibilities of a caregiver for someone with Alzheimer's disease? (*Slide 23*)

LEARNING ACTIVITIES

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

- Compare the Alzheimer's epidemic to at least one other chronic disease (e.g., cancer, HIV, heart disease, diabetes). How many people are affected? What are the costs associated with the disease? How does the epidemic compare to Alzheimer's disease?
- Research aging trends within the population. What is happening in the U.S. and internationally? In developing vs. developed countries? What challenges does an aging population present to public health?
- How does caregiving for Alzheimer's and dementia differ from other types of caregiving? What resources are available for caregivers in general? What resources are available for caregiving specific to Alzheimer's and other dementias?

ADDITIONAL READING

- Alzheimer's Association. 2015. *Changing the Trajectory of Alzheimer's Disease: How a Treatment by 2025 Saves Lives and Dollars*. Chicago, IL: Alzheimer's Association. https://www.alz.org/documents_custom/trajectory.pdf
- Alzheimer's Association. 2016. *Alzheimer's Disease Facts and Figures*. Chicago, IL: Alzheimer's Association. <http://www.alz.org/facts>

SLIDE GUIDE

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

SLIDE 1:

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

TALKING POINTS:

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

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

SLIDE 2:

Learning Objectives

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

TALKING POINTS:

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

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

SLIDE 3:

Competencies

Association for Gerontology in Higher Education (AGHE):

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

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

- Domain 1: Discuss major local, national, and global health challenges.

Council on Linkages Between Academia and Public Health Practice:

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

National Association of Chronic Disease Directors (NACDD):

- Domain 7: Articulate key chronic disease issues.

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

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

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):

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

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

- Domain 1: Discuss major local, national, and global health challenges.

Council on Linkages Between Academia and Public Health Practice:

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

National Association of Chronic Disease Directors (NACDD):

- Domain 7: Articulate key chronic disease issues.

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

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

SLIDE 4:

Alzheimer's – Public Health Crisis¹

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

TALKING POINTS:

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

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

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

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

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

¹ Alzheimer's Association and Centers for Disease Control and Prevention. (2011) *The CDC Healthy Brain Initiative: Progress 2006–2011*.

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

SLIDE 5:

What is Dementia?^{2,3}

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

TALKING POINTS:

It is first important to understand what characterizes dementia.

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

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

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

² Alzheimer's Association. *What is Dementia?* Accessed June 8, 2015 from website: <http://www.alz.org/what-is-dementia.asp#causes>

³ National Institute on Aging. (2015) *Alzheimer's Disease Fact Sheet*.

SLIDE 6:

What is Alzheimer's Disease?^{4,5}

- Most common type of dementia
- Accounts for 60% – 80% of cases
- Irreversible, progressive brain disorder
- Slowly destroys memory, thinking skills, and ability to carry out basic functions

TALKING POINTS:

Certain brain diseases and conditions cause dementia.

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

Alzheimer's disease is an **irreversible, progressive** brain disorder that slowly destroys **memory** and **thinking skills**, and eventually the ability to carry out **basic functions**.

There are currently no known ways to **prevent, cure, or slow** the progression of Alzheimer's disease.

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

Video supplement: "What is Alzheimer's disease?" TedEd.

Link: <https://www.youtube.com/watch?v=yJTXN4xrI8>

⁴Alzheimer's Association. *What is Dementia?* Accessed June 8, 2015 from website: <http://www.alz.org/what-is-dementia.asp#causes>

⁵ National Institute on Aging. (2015) *Alzheimer's Disease Fact Sheet*.

Image source: National Institute on Aging

SLIDE 7:

SCOPE OF THE EPIDEMIC

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

SLIDE 8:

Scope of the Epidemic (U.S.)⁶

- Over 5 million adults
- 1 in 9 adults age ≥65
- 1 in 3 adults age ≥85
- 2/3 are women

TALKING POINTS:

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

First, the **burden** is large - and it is growing. Today, **over 5 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** (32%) people age 85 and older has the disease.

Women make up almost **2/3** of seniors living with Alzheimer's disease in the U.S.

⁶ Alzheimer's Association. *2016 Alzheimer's Disease Facts and Figures*.

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

SLIDE 9:

Health Disparities⁷

- African-Americans and Hispanics have higher rates:
 - African-Americans: 2 times more likely
 - Hispanics: 1.5 times more likely

TALKING POINTS:

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

In the U.S., **African-Americans** and **Hispanics** have higher rates of Alzheimer's and other dementias than people of other races and ethnicities.

In the United States, older African-Americans are about **two times more** likely than older whites to have Alzheimer's and other dementias.

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

Large proportional increases are also expected in both of these populations in the U.S., which will contribute significantly to the growth of the epidemic.

Limited data exists about the prevalence of Alzheimer's disease in other racial and ethnic groups, including Asian Americans and American Indians.

⁷ Alzheimer's Association. (2013) *Alzheimer's and Public Health Spotlight: Race, Ethnicity & Alzheimer's Disease*.

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

SLIDE 10:

Alzheimer's Deaths⁸

- 6th leading cause of death
- 5th leading cause among adults age ≥ 65
- Deaths increased 71% from 2000-2013
- Only cause of death among top 10 that cannot be prevented, cured, or slowed

TALKING POINTS:

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

Deaths from Alzheimer's disease **increased 71%** from 2000 to 2013, while deaths from other **major diseases** (including stroke, breast and prostate cancer, and HIV/AIDS) decreased.

Alzheimer's disease is the only cause of death among the top 10 in America that cannot currently be prevented, cured, or even slowed.

⁸ Alzheimer's Association. *2016 Alzheimer's Disease Facts and Figures*.

SLIDE 11:

Changes in Causes of Death (2000-2013) (*bar chart*)⁹

- HIV (-52%)
- Stroke (-23%)
- Heart disease (-14%)
- Influenza/Pneumonia (-13%)
- Prostate cancer (-11%)
- Breast cancer (-2%)
- Alzheimer's disease (71%)

TALKING POINTS:

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

From 2000 to 2013, the percentage changes in deaths are as follows:

- HIV: declined by 52%
- Stroke: declined by 23%
- Heart disease: declined by 14%
- Influenza/pneumonia: declined by 13%
- Prostate cancer: declined by 11%
- Breast cancer: declined by 2%
- Alzheimer's disease: **increased** by 71%

⁹ Alzheimer's Association. *2016 Alzheimer's Disease Facts and Figures*.

SLIDE 12:

Growing Epidemic^{10,11}

- By 2030 U.S. population age ≥ 65 expected to double
- By 2050, 13.8 million with Alzheimer's
- Today, one new case every 67 seconds
- By 2050, every 33 seconds

TALKING POINTS:

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

The cause of the increase can be attributed to people living longer and the large increase in the number of people over age 65 (baby boomers).

By 2030, the U.S. population aged 65 and over is expected to double.

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**.

Today, someone in the U.S. develops Alzheimer's **every 67 seconds**. By 2050, that rate is expected to increase to one person **every 33 seconds**.

¹⁰ Alzheimer's Association. *2016 Alzheimer's Disease Facts and Figures*.

¹¹ Alzheimer's Association. (2011). *Generation Alzheimer's: The Defining Disease of the Baby Boomers*.

Image source: clker.com

SLIDE 13:

Worldwide Epidemic¹²

- Over 47 million with dementia (including Alzheimer's)
- Projected to double every 20 years:
 - 76 million in 2030
 - 145 million in 2050
- New case of dementia every 4 seconds

TALKING POINTS:

Worldwide, the total number of people with dementia (including Alzheimer's disease) is estimated at **over 47 million**.

This number is projected to **nearly double every 20 years** to 76 million in 2030 and 145 million in 2050.

The total number of new cases of dementia each year worldwide is nearly 7.7 million, which equates to one new case **every four seconds**.

¹² World Health Organization. (2016) *Report by the Secretariat. EB139/3*

SLIDE 14:

FINANCIAL BURDEN

TALKING POINTS:

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

SLIDE 15:

Financial Burden: U.S. & Worldwide^{13,14}

- Alzheimer's is most expensive disease in U.S.
- Annual costs of direct care over \$200 billion
- Worldwide annual costs exceed \$818 billion (2015)

TALKING POINTS:

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

In the U.S. the **annual costs** of direct care for people with Alzheimer's disease exceed **\$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), which will be discussed later in the module.

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

¹³ Alzheimer's Association. *2016 Alzheimer's Disease Facts and Figures*.

¹⁴ Alzheimer's Disease International. *World Alzheimer Report 2015: 'The Global Impact of Dementia: An analysis of prevalence, incidence, cost and trends*.

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

SLIDE 16:

Discussion Question

What are Medicare and Medicaid?

First, we'll start by looking at the Alzheimer's disease burden on two federally-funded health care programs. **What are Medicare and Medicaid?**

Open responses.

SLIDE 17:

Medicare & Medicaid¹⁵

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

TALKING POINTS:

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

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

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

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

¹⁵ Department of Health and Human Services. (2015) *What's Medicare? What's Medicaid?*

Image source: clker.com

SLIDE 18:

Alzheimer's: Medicare & Medicaid^{16,17}

- Pay 70% of health and long-term costs of Alzheimer's
- Nearly 1 in 5 Medicare dollars
- Per-person spending for those with Alzheimer's:
 - Medicare: 3 times higher than average
 - Medicaid: 19 times higher than average

TALKING POINTS:

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

About **70%** of the health and long-term care costs of caring for those with **Alzheimer's disease** are paid for by Medicare and Medicaid.

In 2016, the Medicare and Medicaid government programs will spend an estimated **\$160 billion** caring for those with Alzheimer's and other dementias – **68% of total annual costs** of these conditions. Nearly **one in every five** Medicare dollars is spent on people with Alzheimer's and other dementias.

Average per-person Medicare spending for those with Alzheimer's and other dementias is **three times higher** than average per-person spending across all other seniors. Medicaid payments are **19 times higher**. People with Alzheimer's and other dementias have high out-of-pocket costs. These costs are for Medicare and other health insurance premiums and for deductibles, copayments and services not covered by Medicare, Medicaid or additional sources of support.

¹⁶ Alzheimer's Association. *2016 Alzheimer's Disease Facts and Figures*.

¹⁷ Alzheimer's Association. (2015) *Costs of Alzheimer's to Medicare and Medicaid*.

Image source: clker.com

SLIDE 19:

Alzheimer's: Projected Costs (2050)¹⁸

- Total annual costs over \$1.1 trillion
- Medicare: \$589 billion (over 400% increase)
- Out-of-pocket costs: \$198 billion (350% increase)
- Cumulative costs (2015 – 2050): \$20.8 trillion

TALKING POINTS:

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

If current conditions go unchanged, in 2050 the annual costs of treating Alzheimer's disease in the US will be over **\$1.1 trillion** (in 2016 dollars). Annual costs to Medicare will increase over **400%** to **\$589 billion**. This would represent nearly one in three Medicare dollars.

Out-of-pocket costs for individuals and families affected by Alzheimer's and other dementias will increase about 350% from \$44 billion in 2015 to \$198 billion in 2050.

Cumulatively between now and 2050, total costs of caring for people with Alzheimer's and other dementias will be **\$20.8 trillion**. Nearly 70% of those costs will be paid by federal and state governments.

¹⁸ Alzheimer's Association. *2016 Alzheimer's Disease Facts and Figures*.

SLIDE 20:

CARE BURDEN

TALKING POINTS:

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

SLIDE 21:

Care Workforce¹⁹

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

TALKING POINTS:

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

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

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

¹⁹ *Image source:* Copyrighted image; used with permission from the Alzheimer's Association

SLIDE 22:

Alzheimer's & Dementia Caregivers²⁰

- 83% of the care provided to older adults come from family members, friends or other unpaid caregivers
- 60% of people with Alzheimer's live in home settings
- Over 15 million caregivers (family and friends)
- 18 billion hours of unpaid care annually
- Unpaid care valued at \$221 billion (2015)

TALKING POINTS:

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

About **60%** of **people with Alzheimer's disease** live in **home settings** with the vast majority of their care provided by family and friends.

Currently in the U.S., it is estimated that over **15 million family and friends** provide nearly **18 billion** hours of unpaid care annually.

In 2015, this care was valued at **\$221 billion**. This is approximately **46%** of the net value of **Walmart** annual sales which was \$473.1 billion in 2014 and nearly **eight times** the total annual revenue of **McDonald's** which was **\$27.4 billion** in 2014.

²⁰ Alzheimer's Association. *2016 Alzheimer's Disease Facts and Figures*.

SLIDE 23:

Discussion Question

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

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

Open responses.

SLIDE 24:

Alzheimer's & Dementia Caregivers²¹

- Caregiving responsibilities
 - Help with dressing, bathing, toileting, feeding
 - Shopping, meal preparation, transportation
 - Medication management, financial management
 - Emotional support
- Requires increasing levels of care
- Results in complete dependence

TALKING POINTS:

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

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

- Help with dressing, bathing, toileting, and feeding
- Shopping, meal preparation, transportation
- Medication management, financial management
- Providing emotional support

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

²¹ Alzheimer's Association. (2016) *Alzheimer's Disease Facts and Figures*.

SLIDE 25:

Caregivers: Challenges²²

- Physical, psychological, social challenges
 - \$10.2 billion additional health care costs (2015)
 - 60% rate emotional stress as high or very high
 - 40% suffer from depression

TALKING POINTS:

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

Several recent findings highlight these challenges:

- Due to the physical and emotional toll of caring for someone with Alzheimer's or other dementias, these caregivers had **\$10.2 billion** in **additional health care costs** in 2015.
- Nearly 60% of Alzheimer's and dementia caregivers rate the **emotional stress** of caregiving as high or very high.
- About 40% of Alzheimer's and dementia caregivers suffer from **depression**.

²² Alzheimer's Association. (2016) *Alzheimer's Disease Caregivers*.

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

SLIDE 26:

Caregivers: Impact on Work (*bar chart*)²³

- Went in late/ left early/ took time off (54%)
 - Took leave of absence (15%)
 - Went from full-time to part-time work (13%)
 - Took a less demanding job (13%)
 - Quit work (9%)
 - Lost job benefits (8%)
-

TALKING POINTS:

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

Among Alzheimer's and dementia caregivers who are employed full or part time:

- 54% said they had to go in late, leave early, or take time off because of their caregiving responsibilities
- 15% had to take a leave of absence
- 13% had to go from working full time to part time
- 13% had to take a less demanding job
- 9% had to **quit work entirely** either to become a caregiver or because their caregiving duties became too burdensome
- 8% lost job benefits

²³ Alzheimer's Association. (2016) *Alzheimer's Disease Caregivers*.

SLIDE 27:

Caregivers: Length of Care^{24,25}

- 75% at least one year
- 33% five or more years
- Average length of time: 4.6 years
- May range from 4 – 20 years

TALKING POINTS:

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

In 2014, of the unpaid Alzheimer's and dementia caregivers:

- 75% had been providing care for **at least a year**
- 33% had been providing care for **five or more years**

The average length of time caregivers in general report providing care is 4.6 years, but in the cases involving dementia, caregiving may range from **4 to 20 years**.

²⁴ Alzheimer's Association. (2015) *Alzheimer's Disease Caregivers*.

²⁵ National Alliance for Caregiving & AARP (2009). *Caregiving in the U.S.*

SLIDE 28:

Caregivers: Critical Role

- Health care system could not sustain costs of care
 - Support for caregivers is public health issue
-

TALKING POINTS:

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

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

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

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

SLIDE 29:

Health Professionals: Shortage²⁶

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

TALKING POINTS:

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

Current estimations of workforce shortages include:

- The U.S. will need an **additional 3.5 million health care professionals** by 2030 just to maintain the current ratio of health care professionals to the older population
- The U.S. has **approximately half** the number of **certified geriatricians** than it currently needs
 - Less than **1%** of registered **nurses, physician assistants, and pharmacists** identify themselves as specializing in **geriatrics**

²⁶ Alzheimer's Association. *2015 Alzheimer's Disease Facts and Figures*.

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

SLIDE 30:

Direct Care Workforce^{27,28}

- Majority of care for Alzheimer's (after caregivers)
- Include nurse aides, home health aides, personal-care aides and home-care aides
- Help with daily activities: bathing, dressing, eating
- Typically earn \$20/hour or \$160/day

TALKING POINTS:

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

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

Paid caregivers typically cost \$20 per hour (or \$160 per day), an expense that most families pay out of pocket.

²⁷ Alzheimer's Association, *2015 Alzheimer's Disease Facts and Figures*

²⁸ American Elder Care Research Organization. (2015) *Home Care Financial Assistance and Payment Options*.

SLIDE 31:

Direct Care Workforce: Challenges²⁹

- Workforce shortage
 - Over 1 million additional needed by 2018
 - High turnover
 - Recruitment difficult
- Limited training on Alzheimer's and dementia

TALKING POINTS:

Challenges within the direct care workforce include workforce shortage and insufficient training.

According to one estimate, more than one million additional direct-care workers will be needed by 2018.

Turnover rates are high among direct-care workers, and recruitment and retention are persistent challenges.

Many direct-care workers receive little training on Alzheimer's and dementia care. Average training is 75 hours, with little focus on Alzheimer's and dementia.

²⁹ Paraprofessional Healthcare Institute (PHI). (2013). Fact Sheet: *America's Direct-Care Workforce*.

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

SLIDE 32:

PUBLIC HEALTH APPROACH

TALKING POINTS:

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

SLIDE 33:

Healthy People 2020³⁰

- Alzheimer's and other dementias included in *Healthy People 2020*
 - Increasing diagnosis and awareness
 - Reducing preventable hospitalizations

TALKING POINTS:

For the first time, Alzheimer's and other dementias are included in ***Healthy People 2020***.

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

The new topic area – “Dementias, including Alzheimer's” – contains **specific objectives** regarding **increasing diagnosis and awareness** and reducing **preventable hospitalizations**. Public health has a role to play in reaching those objectives.

Inclusion in *Healthy People 2020* underscores the growing public health threat that Alzheimer's and other dementias pose to the nation.

³⁰ Department of Health and Human Services. (2010) *Healthy People 2020*.

SLIDE 34:

Role of Public Health

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

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

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

- **Surveillance/monitoring** that allows public health to compile data and use it to:
 - Develop strategies and interventions
 - Inform public policy
 - Guide research
 - Evaluate programs and policies
 - Educate populations
- **Promoting primary prevention** can be used to promote **risk reduction** for cognitive decline and dementia, as well as **promote cognitive health** in general.
- 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, benefits of early detection and training to health care providers and newly diagnosed individuals, families, and caregivers.
 - Identifying and promoting **strategies** designed to promote early detection

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

SLIDE 35:

Dementia Capable Systems and Dementia Friendly Communities

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

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

Public health also has a role to play in supporting dementia capable systems and dementia friendly communities. At a larger level, states and communities can become dementia capable and accommodate 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 other dementias as well as support and empower people with Alzheimer's and dementia to continue living high-quality lives with as much independence as possible.

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

SLIDE 36:

For More Information

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

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 – A PUBLIC HEALTH CRISIS



LEARNING OBJECTIVES

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

COMPETENCIES

- **Association for Gerontology in Higher Education (AGHE):**
 - 1.3.3 Demonstrate knowledge of signs, symptoms, and impact of common cognitive and mental health problems in late life (e.g., dementia, depression, grief, anxiety).
- **Association of Schools and Programs of Public Health (ASPPH):**
 - Domain 1: Discuss major local, national, and global health challenges.
- **Council on Linkages Between Academia and Public Health Practice:**
 - 2A. Identifies current trends (e.g., health, fiscal, social, political, environmental) affecting the health of a community.
- **National Association of Chronic Disease Directors (NACDD):**
 - Domain 7: Articulate key chronic disease issues.
- **National Commission for Health Education Credentialing, Inc. (NCHEC):**
 - 7.1.1 Identify current and emerging issues that may influence health and health education.

ALZHEIMER'S – PUBLIC HEALTH CRISIS¹

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



¹Alzheimer's Association and Centers for Disease Control and Prevention. (2011) *The CDC Healthy Brain Initiative: Progress 2006–2011*.

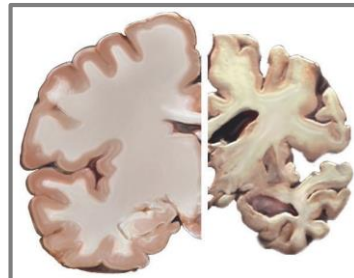
WHAT IS DEMENTIA?^{2,3}

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

²Alzheimer's Association. *What is Dementia?* Accessed June 8, 2015 from website: <http://www.alz.org/what-is-dementia.asp#causes>
³National Institute on Aging. (2015) *Alzheimer's Disease Fact Sheet*.

WHAT IS ALZHEIMER'S DISEASE?^{4,5}

- Most common type of dementia
- Accounts for 60%-80% of cases
- Irreversible, progressive brain disorder
- Slowly destroys memory, thinking skills, and ability to carry out basic functions



⁴Alzheimer's Association. *What is Dementia?* Accessed June 8, 2015 from website: <http://www.alz.org/what-is-dementia.asp#causes>
⁵National Institute on Aging. (2015) *Alzheimer's Disease Fact Sheet*.

SCOPE OF THE EPIDEMIC

ALZHEIMER'S DISEASE – A PUBLIC HEALTH CRISIS

SCOPE OF THE EPIDEMIC (U.S.)⁶

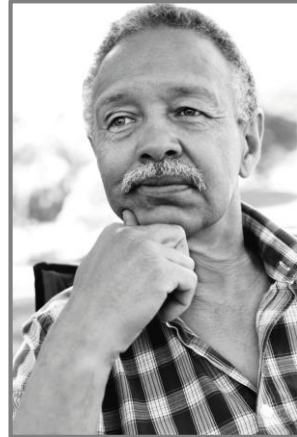
- Over 5 million adults
- 1 in 9 adults age ≥ 65
- 1 in 3 adults age ≥ 85
- 2/3 are women



⁶Alzheimer's Association. 2016 Alzheimer's Disease Facts and Figures.

HEALTH DISPARITIES⁵

- African-Americans and Hispanics have higher rates:
 - African-Americans 2 times more likely
 - Hispanics 1.5 times more likely



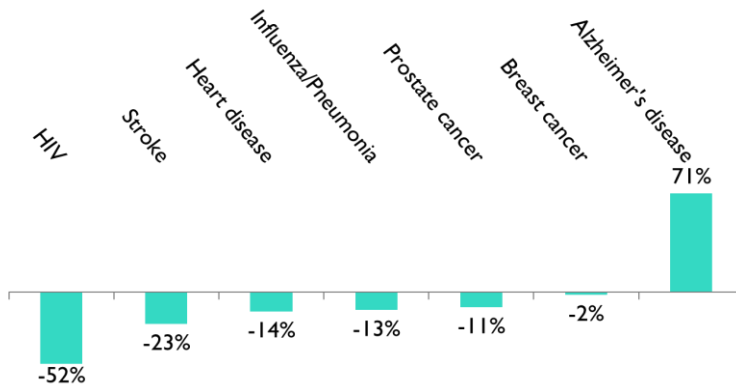
⁵Alzheimer's Association. (2013) Alzheimer's and Public Health Spotlight: Race, Ethnicity & Alzheimer's Disease.

ALZHEIMER'S DEATHS⁷

- 6th leading cause of death
- 5th leading cause among adults age ≥ 65
- Deaths increased 71% from 2000-2013
- Only cause of death among top 10 that cannot be prevented, cured, or slowed

⁷Alzheimer's Association. 2016 Alzheimer's Disease Facts and Figures.

CHANGES IN SELECTED CAUSES OF DEATH (ALL AGES) BETWEEN 2000-2013⁸



⁸ Alzheimer's Association. 2016 Alzheimer's Disease Facts and Figures.

GROWING EPIDEMIC^{10,11}

- By 2030, population age ≥ 65 expected to double
- By 2050, 13.8 million with Alzheimer's
- Today, one new case every 67 seconds
- By 2050, every 33 seconds



¹⁰Alzheimer's Association. 2016 Alzheimer's Disease Facts and Figures.

¹¹Alzheimer's Association. (2011). *Generation Alzheimer's: The Defining Disease of the Baby Boomers*.



WORLDWIDE EPIDEMIC¹²

- Over 47 million with dementia (including Alzheimer's) in 2015
- Projected to double every 20 years:
 - 76 million in 2030
 - 145 million in 2050
- New case of dementia every 4 seconds

¹²World Health Organization. (2016). Report by the Secretariat. EB139/3



FINANCIAL BURDEN

ALZHEIMER'S DISEASE – A PUBLIC HEALTH CRISIS



FINANCIAL BURDEN: U.S. & WORLDWIDE^{13,14}

- Alzheimer's is the most expensive disease in US
- Annual cost of direct care over \$200 billion
- Worldwide annual costs exceed \$818 billion (2015)



¹³ Alzheimer's Association. 2016 Alzheimer's Disease Facts and Figures.

¹⁴ Alzheimer's Disease International. World Alzheimer Report 2015: The Global Impact of Dementia: An analysis of prevalence, incidence, cost and trends

DISCUSSION QUESTION



What are Medicare and Medicaid?

MEDICARE & MEDICAID¹⁵

- Medicare: federally-funded health insurance
 - Any U.S. citizen or legal permanent resident age ≥65
 - People under age 65 with certain disabilities or End-Stage Renal Disease
- Medicaid: funded by federal and state governments
 - Helps with medical costs for some people with limited income and resources



¹⁵Department of Health and Human Services. (2015) *What's Medicare? What's Medicaid?*

ALZHEIMER'S: MEDICARE & MEDICAID^{16,17}

- Programs pay 70% of health and long-term costs of Alzheimer's disease
- Nearly 1 in 5 Medicare dollars
- Per-person spending for those with Alzheimer's:
 - Medicare: 3 times higher than average
 - Medicaid: 19 times higher than average



¹⁶Alzheimer's Association. 2016 *Alzheimer's Disease Facts and Figures*.

¹⁷Alzheimer's Association. (2015) *Costs of Alzheimer's to Medicare and Medicaid*.



ALZHEIMER'S: PROJECTED COSTS (2050)¹⁸

- Annual costs (US): over \$1.1 trillion
- Annual costs to Medicare: \$589 billion (over 400% increase)
- Out-of-pocket costs: \$198 billion (350% increase)
- Cumulative costs between 2015 and 2050: \$20.8 trillion

¹⁴Alzheimer's Association. 2016 *Alzheimer's Disease Facts and Figures*.



CARE BURDEN

ALZHEIMER'S DISEASE – A PUBLIC HEALTH CRISIS



CARE WORKFORCE

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



ALZHEIMER'S & DEMENTIA CAREGIVERS²⁰

- 83% of the care provided to older adults come from family members, friends or other unpaid caregivers
- 60% of people with Alzheimer's live in home settings
- Over 15 million caregivers (family and friends)
- 18 billion hours of unpaid care annually
- Unpaid care valued at \$221 billion (2015)

²⁰Alzheimer's Association. 2016 Alzheimer's Disease Facts and Figures

DISCUSSION QUESTION



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

ALZHEIMER'S & DEMENTIA CAREGIVERS²¹

- Caregiving responsibilities:
 - Help with dressing, bathing, toileting, feeding
 - Shopping, meal preparation, transportation
 - Medication management, financial management
 - Emotional support
- Requires increasing levels of care
- Results in complete dependence

²¹Alzheimer's Association. 2016 Alzheimer's Disease Facts and Figures.

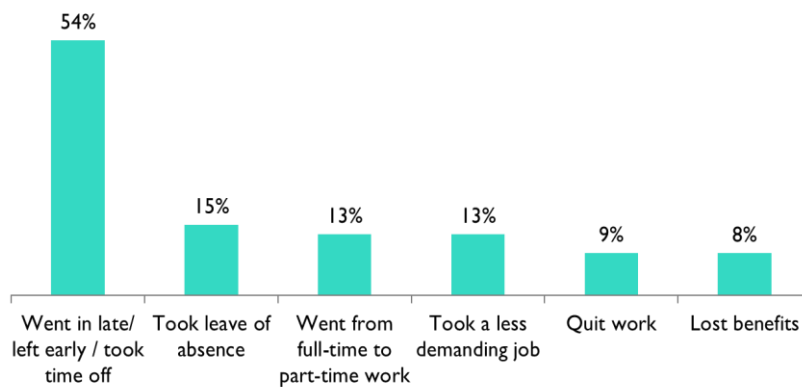
CAREGIVERS: CHALLENGES²²

- Physical, psychological, social challenges
 - \$10.2 billion additional health care costs (2015)
 - 60% rate emotional stress as high or very high
 - 40% suffer from depression



²²Alzheimer's Association. (2016) *Alzheimer's Disease Caregivers*.

CAREGIVERS: IMPACT ON WORK²³



²³Alzheimer's Association. (2016) *Alzheimer's Disease Caregivers*.

CAREGIVERS: LENGTH OF CARE^{24,25}

- 75% had provided care at least one year
- 33% had provided care for five or more years
- Average length of time: 4.6 years
- May range from 4 - 20 years

²⁴Alzheimer's Association. (2015) *Alzheimer's Disease Caregivers*.

²⁵National Alliance for Caregiving & AARP (2009). *Caregiving in the U.S.*

CAREGIVERS: CRITICAL ROLE

- Health care system could not sustain costs of care
- Support for caregivers is a public health issue



HEALTH PROFESSIONALS: SHORTAGE²⁶

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

²⁶Alzheimer's Association. 2015 *Alzheimer's Disease Facts and Figures*.

DIRECT CARE WORKFORCE^{27,28}

- Provide majority of care for Alzheimer's (after caregivers)
- Include nurse aides, home health aides, personal-care aides and home-care aides
- Help with daily activities: bathing, dressing, eating
- Typically cost \$20/hour or \$160/day



²⁷Alzheimer's Association. 2015 *Alzheimer's Disease Facts and Figures*.

²⁸American Elder Care Research Organization. (2015) *Home Care Financial Assistance and Payment Options*.



DIRECT CARE WORKFORCE: CHALLENGES²⁹

- Workforce shortage
 - Over 1 million additional needed by 2018
 - High turnover
 - Recruitment difficult
- Limited training on Alzheimer's and dementia

²⁹Paraprofessional Healthcare Institute (PHI). (2013). Fact Sheet: *America's Direct-Care Workforce*.



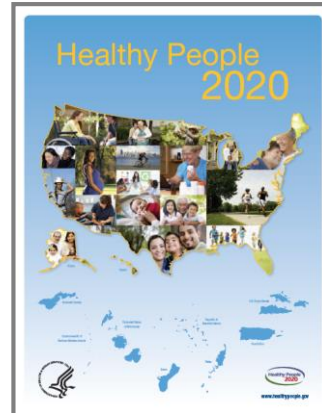
PUBLIC HEALTH APPROACH

ALZHEIMER'S DISEASE – A PUBLIC HEALTH CRISIS



HEALTHY PEOPLE 2020³⁰

- Alzheimer's and other dementias included in *Healthy People 2020*
 - Increasing diagnosis and awareness
 - Reducing preventable hospitalizations



³⁰Department of Health and Human Services. (2010) *Healthy People 2020*.

ROLE OF PUBLIC HEALTH

- 3 key public health intervention tools:
 - Surveillance/monitoring
 - Primary prevention (risk reduction)
 - 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- What is dementia?

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

Answer: B

2- Alzheimer's disease is the__ leading cause of death among adults over 65 years old.

- a. 1st
- b. 2nd
- c. 5th
- d. 10th

Answer: C

3- How many US adults have Alzheimer's disease?

- a. 500,000
- b. 1,000,000
- c. 5,000,000
- d. 10,000,000

Answer: C

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

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

Answer: A

5- What is the average length of time a person with dementia needs care?

- a. Less than 6 months
- b. About 1 year
- c. 3 years
- d. Almost 5 years
- e. About 10 years

Answer: D

FACULTY GUIDE

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

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

ABOUT MODULE 2

This module is part of the Alzheimer’s Association curriculum, *A Public Health Approach to Alzheimer’s and Other Dementias*. Developed as part of a cooperative agreement with CDC’s 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 2: Alzheimer’s and Other Dementias – The Basics provides background information on Alzheimer’s and other dementias. It lays a foundation for what cognitive health is and how changes within the brain may lead to cognitive aging, cognitive impairment, and Alzheimer’s and other dementias.

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

Module 2 contains the following topics:

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

LEARNING OBJECTIVES

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

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

- Identify at least three risk factors associated with Alzheimer’s disease.
- Describe the role of caregivers in the care of someone with Alzheimer’s disease.

COMPETENCIES

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

Association for Gerontology in Higher Education (AGHE):

- 1.2.1 Distinguish normal biological aging changes from pathology including genetic factors.
- 1.3.3 Demonstrate knowledge of signs, symptoms, and impact of common cognitive and mental health problems in late life (e.g., dementia, depression, grief, anxiety).
- 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 1: Describe risk factors and modes of transmission for infectious and chronic diseases and how these diseases affect both personal and population health.

National Association of Chronic Disease Directors (NACDD):

- Domain 7: Discuss the underlying causes and management of chronic diseases, including behavioral, medical, genetic, environmental and social factors.
- Domain 7: Articulate key chronic disease issues.
- Domain 7: Describe socioeconomic and behavioral determinants of health disparities.

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

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

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STUDENT ENGAGEMENT OPTIONS

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

DISCUSSION QUESTIONS

The following discussion questions are included in the slide deck:

- What is cognitive health? (*Slide 5*)
- What are the characteristics of Alzheimer's disease? (*Slide 20*)

LEARNING ACTIVITIES

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

- Research personal perspectives on Alzheimer's and dementia. What happens to someone's mind, lifestyle, and relationships, in their own words?
- Describe the physiological changes to the brain that occur with Alzheimer's disease. What do scientists know about how the disease develops? What are current areas of focus in research?
- Conduct a short interview with 4-5 adults over the age of 50. Develop and ask questions related to interest and concerns about participating in clinical trials related to Alzheimer's disease. Summarize their responses and describe implications for a campaign to promote clinical trials participation.

ADDITIONAL READING

- Alzheimer's Association. 2016. Overview of Alzheimer's Disease (pp. 5-14) In *Alzheimer's Disease Facts and Figures*. Chicago, IL: Alzheimer's Association. <http://www.alz.org/facts>
- The NIH Alzheimer's Disease Education and Referral Center: Information about symptoms at each stage of Alzheimer's and how the disease progresses. <https://www.nia.nih.gov/alzheimers>
- National Institute on Aging. 2008. *Alzheimer's Disease: Unraveling the Mystery*. NIH Publication No. 08-3782. Washington, DC: US Department of Health and Human Services. https://www.nia.nih.gov/sites/default/files/alzheimers_disease_unraveling_the_mystery_2.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:

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

TALKING POINTS:

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

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

SLIDE 2:

Learning Objectives

- Define cognitive health
- Define and differentiate between dementia and Alzheimer's
- List at least 5 common symptoms of Alzheimer's
- Describe the changes that occur during the course of Alzheimer's
- Identify at least 3 risk factors associated with Alzheimer's
- Describe the role of caregivers

TALKING POINTS:

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

- Define cognitive health
- Define and differentiate between dementia and Alzheimer's
- List at least 5 common symptoms of Alzheimer's
- Describe the changes that occur during the course of Alzheimer's
- Identify at least 3 risk factors associated with Alzheimer's
- Describe the role of caregivers

SLIDE 3:

Competencies:

Association for Gerontology in Higher Education (AGHE):

- 1.2.1 Distinguish normal biological aging changes from pathology including genetic factors.
- 1.3.3 Demonstrate knowledge of signs, symptoms, and impact of common cognitive and mental health problems in late life (e.g., dementia, depression, grief, anxiety).
- 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 1: Describe risk factors and modes of transmission for infectious and chronic diseases and how these diseases affect both personal and population health.

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):

- 1.2.1 Distinguish normal biological aging changes from pathology including genetic factors.
- 1.3.3 Demonstrate knowledge of signs, symptoms, and impact of common cognitive and mental health problems in late life (e.g., dementia, depression, grief, anxiety).
- 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 1: Describe risk factors and modes of transmission for infectious and chronic diseases and how these diseases affect both personal and population health.

SLIDE 4:

Competencies cont.:

National Association of Chronic Disease Directors (NACDD):

- Domain 7: Discuss the underlying causes and management of chronic diseases, including behavioral, medical, genetic, environmental and social factors.
- Domain 7: Articulate key chronic disease issues.
- Domain 7: Describe socioeconomic and behavioral determinants of health disparities.

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

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

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

National Association of Chronic Disease Directors (NACDD):

- Domain 7: Discuss the underlying causes and management of chronic diseases, including behavioral, medical, genetic, environmental and social factors.
- Domain 7: Articulate key chronic disease issues.
- Domain 7: Describe socioeconomic and behavioral determinants of health disparities.

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

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

SLIDE 5:

Discussion Question

What is cognitive health?

Ask: What is cognitive health?

Open responses.

SLIDE 6:

Cognitive Health¹

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

TALKING POINTS:

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

Cognition refers to the ability to think, learn, and remember.

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

- Ability to learn new things
- Intuition
- Judgment
- Language
- Remembering

At the other end of the spectrum are people with severe Alzheimer’s, dementia, and other brain injuries that render that person unable to function cognitively. Cognitive health is linked to brain **health** in terms of the physiologic health of the brain and overall functioning.

¹ Centers for Disease Control and Prevention, Division of Healthy Aging. *What is a Healthy Brain? New Research Explores Perceptions of Cognitive Health Among Diverse Older Adults*.

Image source: National Institute on Aging

SLIDE 7:

Cognitive Aging^{2,3}

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

TALKING POINTS:

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

Wisdom and expertise can increase with age, while the speed of processing information, making decisions, and remembering certain things can decline.

This process is known as **cognitive aging** – a decline in memory, decision-making, processing speed, and learning. For example, a person might have trouble following a recipe, remembering certain words, or finding common items such as glasses or keys.

These changes are considered a **normal part of aging**, are different for different people, and may vary from day to day.

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

³ National Institute on Aging. (2013) *Understanding Memory Loss: What To Do When you Have Trouble Remembering*.

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

SLIDE 8:

Mild Cognitive Impairment (MCI)^{4,5}

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

TALKING POINTS:

Mild cognitive impairment (MCI) is a condition in which people have more memory or other thinking problems than normal for their age, but their symptoms are **not severe enough to interfere with daily life** or their ability to function independently.

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

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

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

⁴ Alzheimer's Association. (2012) *Mild Cognitive Impairment*.

⁵ National Institute on Aging, *About Alzheimer's Disease: Mild Cognitive Impairment*. Accessed June 10, 2015 from website:

<https://www.nia.nih.gov/alzheimers/topics/mild-cognitive-impairment>.

SLIDE 9:

Cognitive Impairment⁶

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

TALKING POINTS:

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

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

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

⁶ Alzheimer's Association and Centers for Disease Control and Prevention. (2013) *The CDC Healthy Brain Initiative: Public Health Road Map for State and National Partnerships, 2013-2018*.

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

SLIDE 10:

DEMENTIA

TALKING POINTS:

Next we turn to **dementia**.

SLIDE 11:

Dementia⁷

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

TALKING POINTS:

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

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

Dementia is **NOT normal aging**.

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

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

⁷ Alzheimer's Association. *What is Dementia?* Accessed June 8, 2015 from website: <http://www.alz.org/what-is-dementia.asp#causes>

SLIDE 12:

Types of Dementia⁸

- Alzheimer's disease
- Vascular dementia
- Dementia with Lewy Bodies (DLB)
- Mixed dementia
- Parkinson's disease
- Frontotemporal dementia
- Creutzfeldt-Jakob disease
- Normal pressure hydrocephalus
- Huntington's disease
- Wernicke-Korsakoff Syndrome

TALKING POINTS:

(Provide descriptions as needed):

There are numerous types of dementia:

- **Alzheimer's disease:** *description begins on slide #12*
- **Vascular dementia:** *description on slide #11*
- **Dementia with Lewy bodies (DLB):** memory loss and thinking problems common in Alzheimer's disease; more likely to have initial or early symptoms such as sleep disturbances, well-formed visual hallucinations, and muscle rigidity or other parkinsonian movement features
- **Mixed dementia:** abnormalities linked to more than one type of dementia occur simultaneously in the brain; researchers increasingly believe a large number of dementia cases are of mixed pathology

⁸ Alzheimer's Association. *Types of Dementia*. Accessed June 8, 2015 from website: <http://www.alz.org/dementia/types-of-dementia.asp>.

National Institute on Aging. (2015) *Alzheimer's Disease Fact Sheet*.

Image source: clker.com

- **Parkinson's disease:** brain changes begin in a region that plays a key role in movement; as changes gradually spread, they often begin to affect mental functions, including memory and the ability to pay attention, make sound judgments and plan the steps needed to complete a task
- **Frontotemporal dementia:** typical symptoms include changes in personality and behavior and difficulty with language; nerve cells in the front and side regions of the brain are especially affected
- **Creutzfeldt-Jakob disease:** rapidly fatal disorder that impairs memory and coordination and causes behavior changes; variant CJD ("mad cow disease") occurs in cattle and has been transmitted to people under certain circumstances
- **Normal pressure hydrocephalus:** symptoms include difficulty walking, memory loss, and inability to control urination; caused by the buildup of fluid in the brain
- **Huntington's disease:** progressive brain disorder caused by a single defective gene on chromosome 4; symptoms include abnormal involuntary movements, a severe decline in thinking and reasoning skills, irritability, depression, and other mood changes
- **Wernicke-Korsakoff Syndrome:** a chronic memory disorder caused by severe deficiency of thiamine (vitamin B-1); most common cause is alcohol misuse; memory problems may be strikingly severe while other thinking and social skills seem relatively unaffected

Alzheimer's disease and **vascular dementia** are the most **common** types of dementia.

SLIDE 13:

Vascular Dementia⁹

- 2nd most common cause of dementia
 - 20% - 30% of cases
 - Caused by conditions that block or reduce blood flow to the brain
 - Symptoms may occur suddenly following strokes, or slowly as a result of cumulative damage
-

TALKING POINTS:

Vascular dementia is widely considered as the second most common cause of dementia after Alzheimer's disease, accounting for **20% to 30%** of cases.

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

In vascular dementia, changes in thinking sometimes **occur suddenly** following strokes that block major brain blood vessels. Thinking problems may also begin as mild changes that worsen gradually as a result of multiple minor strokes or other conditions that affect smaller blood vessels, leading to cumulative damage.

Researchers increasingly believe that many people have mixed vascular dementia and Alzheimer's.

⁹ Alzheimer's Association. (2015) *Vascular Dementia*.

SLIDE 14:

ALZHEIMER'S DISEASE

TALKING POINTS:

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

SLIDE 15:

Alzheimer's Disease: Overview¹⁰

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

TALKING POINTS:

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

Alzheimer's disease is a progressive disease, in which dementia symptoms gradually worsen over a number of years.

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

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

¹⁰ Alzheimer's Association. *What is Alzheimer's?* Accessed June 8, 2015 from website:

http://www.alz.org/alzheimers_disease_what_is_alzheimers.asp

Image source: National Institute on Aging

SLIDE 16:

Alzheimer's Disease: History¹¹

- Identified in 1906 by Dr. Alois Alzheimer
 - Examined brain of woman who died after mental illness
 - Found abnormal clumps (plaques) and tangled fibers (tangles)
-

TALKING POINTS:

Alzheimer's disease was first **identified** in 1906 by Dr. Alois Alzheimer. He noticed certain changes in the brain tissue of a woman who had died after a mental illness that included symptoms of memory loss, language problems, and unpredictable behavior.

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

¹¹ National Institute on Aging. (2015) *Alzheimer's Disease Fact Sheet*.

Image source: National Library of Medicine, History of Medicine

SLIDE 17:

Alzheimer's Disease: Physical Changes¹²

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

TALKING POINTS:

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

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

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

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

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

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

Video Supplement: 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

¹² Alzheimer's Association. *Brain Tour*. Accessed July 1, 2015 from website: http://www.alz.org/braintour/3_main_parts.asp

Image source: National Institute on Aging

SLIDE 18:

Alzheimer's Disease: Causes¹³

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

TALKING POINTS:

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

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

It is likely that damage to the brain starts a decade or more before symptoms begin to appear.

¹³ Alzheimer's Association. Risk Factors. Accessed June 8, 2015 from website: http://www.alz.org/alzheimers_disease_causes_risk_factors.asp

SLIDE 19:

Younger-Onset Alzheimer's Disease¹⁴

- Affects people younger than 65
 - Many are in their 40s and 50s
 - 200,000 have younger onset (in U.S.)
 - 4% of population with Alzheimer's
-

TALKING POINTS:

Alzheimer's disease is not just a disease of old age.

Younger-onset (also known as early-onset) Alzheimer's disease affects people younger than 65. Many people with early onset Alzheimer's disease are in their 40s and 50s.

In the U.S., it is estimated that approximately 200,000 people have younger onset Alzheimer's disease – up to 4% of the population with Alzheimer's disease.

¹⁴ Alzheimer's Association. *Younger/Early Onset Alzheimer's & Dementia*. Accessed June 8, 2015 from website: http://www.alz.org/alzheimers_disease_early_onset.asp

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

SLIDE 20:

Discussion Question

What are the characteristics of Alzheimer's disease?

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

Open responses.

SLIDE 21:

10 Warning Signs of Alzheimer's¹⁵

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

TALKING POINTS:

Alzheimer's disease affects people in different ways. Symptoms also change and become more severe as the disease progresses.

The most common symptom begins with **gradually worsening ability to remember new information**. As damage spreads, individuals experience other difficulties.

The following are **ten warning signs of Alzheimer's disease**:

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

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

Others include: forgetting important dates or events; asking for the same information over and over; relying on memory aids (e.g., reminder notes or electronic devices) or family members for things they used to handle on their own.

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

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

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

¹⁵ Alzheimer's Association. (2009) *Know the 10 Signs*.

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

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

People with Alzheimer's disease may have a hard time completing daily tasks. Sometimes, people may have trouble driving to a familiar location, managing a budget at work, or remembering the rules of a favorite game.

4. Confusion with time or place

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

5. Trouble understanding visual images and spatial relationships

For some people, having vision problems is a sign of Alzheimer's disease. They may have difficulty reading, judging distance and determining color or contrast. In terms of perception, they may pass a mirror and think someone else is in the room. They may not recognize their own reflection.

SLIDE 22:

Ten Warning Signs of Alzheimer's (continued)¹⁶

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

TALKING POINTS:

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

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

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

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

8. Decreased or poor *judgment*

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

9. *Withdrawal* from work or social activities

¹⁶ Alzheimer's Association. (2009) *Know the 10 Signs*.

A person with Alzheimer's disease may start to remove themselves from hobbies, social activities, work projects or sports. They may have trouble keeping up with a favorite sports team or remembering how to complete a favorite hobby. They may also avoid being social because of the changes they have experienced.

10. Changes in mood and personality

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

SLIDE 23:

Stages of Alzheimer's Disease¹⁷

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

TALKING POINTS:

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

The symptoms of Alzheimer's disease worsen over time, although the **rate** at which the disease progresses **varies**.

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

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

¹⁷ Alzheimer's Association. *Stages of Alzheimer's*. Accessed June 8, 2015 from website:

http://www.alz.org/alzheimers_disease_stages_of_alzheimers.asp

Image source: National Institute on Aging

SLIDE 24:

Mild Alzheimer's (Early-Stage)¹⁸

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

TALKING POINTS:

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

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

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

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

¹⁸ Alzheimer's Association. *Stages of Alzheimer's*. Accessed June 8, 2015 from website:

http://www.alz.org/alzheimers_disease_stages_of_alzheimers.asp

SLIDE 25:

Moderate Alzheimer's (Middle-Stage)¹⁹

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

TALKING POINTS:

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

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

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

- Forgetfulness of events or about one's own personal history
- Confusion about where they are or what day it is
- The need for help choosing proper clothing for the season or the occasion
- Trouble controlling bladder and bowels in some individuals
- Changes in sleep patterns, such as sleeping during the day and becoming restless at night
- An increased risk of wandering and becoming lost

¹⁹ Alzheimer's Association. *Stages of Alzheimer's*. Accessed June 8, 2015 from website:

http://www.alz.org/alzheimers_disease_stages_of_alzheimers.asp

- Personality and behavioral changes, including suspiciousness and delusions or compulsive, repetitive behavior like hand-wringing or tissue shredding

SLIDE 26:

Severe Alzheimer's (Late-Stage)²⁰

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

TALKING POINTS:

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

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

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

²⁰ Alzheimer's Association. *Stages of Alzheimer's*. Accessed June 8, 2015 from website:

http://www.alz.org/alzheimers_disease_stages_of_alzheimers.asp

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

SLIDE 27:

RISK FACTORS

TALKING POINTS:

Next we turn to risk factors for Alzheimer's disease.

SLIDE 28:

Risk Factors: Age^{21,22}

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

TALKING POINTS:

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

A number of risk factors have been identified that contribute to the development of Alzheimer's disease. Other risk factors show evidence of decreased risk pending further research.

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

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

²¹ Alzheimer's Association. *Risk Factors*. Accessed June 8, 2015 from website: http://www.alz.org/alzheimers_disease_causes_risk_factors.asp

²² Alzheimer's Association, *2015 Alzheimer's Disease Facts and Figures*, March 2015

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

SLIDE 29:

Risk Factors: Family History, Education ²³

- Family history
 - Hereditary (genetics)
 - Risk genes
 - Deterministic genes
 - Environmental factors
 - Years of formal education
-

TALKING POINTS:

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

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

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

- **Risk genes:** increase the likelihood of developing a disease, but **do not guarantee** it will happen. Scientists have identified several risk genes, including APOE-e4, tied to Alzheimer’s disease.
- **Deterministic genes:** directly cause a disease, **guaranteeing** that anyone who inherits them will develop the disorder. Scientists have discovered variations that directly cause Alzheimer’s disease in the genes of three proteins. This is very rare, representing perhaps 1% of Alzheimer’s cases. Onset for Alzheimer’s disease related to these genes tends to

²³ Alzheimer’s Association. *Risk Factors*. Accessed June 8, 2015 from website: http://www.alz.org/alzheimers_disease_causes_risk_factors.asp

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

occur at a very young age, including people in their 30s.

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

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

Some researchers have proposed a "**cognitive reserve**" hypothesis, in which ongoing mental activity and stimulation, such as through education, occupation, leisure activity, mental and physical activity, may help protect the brain against damage and decline.

SLIDE 30:

Risk Factors: Race & Ethnicity²⁴

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

TALKING POINTS:

Race and ethnicity may also contribute to increased risk of developing Alzheimer's and other dementias. In the U.S., older **African-Americans** are about **two times more likely than** older whites to have Alzheimer's disease. First-degree relatives of African-Americans with Alzheimer's disease have a 43% chance of developing dementia.

Older **Hispanics** are about **one and one-half times more likely** than older whites to have Alzheimer's disease. Variations in health, lifestyle and socioeconomic circumstances across racial groups likely account for most of the differences in risk of Alzheimer's and other dementias by race. For example, African-American and Hispanic communities have higher incidence of certain Alzheimer's risk factors:

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

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

²⁴ Alzheimer's Association. *2016 Alzheimer's Disease Facts and Figures*.

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

SLIDE 31:

Risk Factors: Women^{25,26}

- 2/3 of affected population
 - 16% of women age ≥ 71 (11% of men)
 - After age 65, have more than 1 in 6 chance (1 in 11 for men)
 - Age ≥ 60, twice as likely to develop Alzheimer's than breast cancer
-

TALKING POINTS:

- Almost 2/3 of U.S. adults with Alzheimer's disease are **women**.
- Among those aged 71 and older, **16% of women have Alzheimer's** and other dementias, compared with 11% of men.
- At age 65, women without Alzheimer's disease have more than a **one in six chance** of developing Alzheimer's disease during the remainder of their lives, compared with a one in 11 chance for men.
- Women in their 60s are about **twice as likely** to develop Alzheimer's disease over the rest of their lives as they are to develop breast cancer.

This may be primarily explained by the fact that women live longer, on average, than men.

However, researchers are increasingly questioning whether there may be other reasons for the difference in the number of women and men who develop the disease.

²⁵ Alzheimer's Association, *AAIC Press Release*, July 21, 2015

²⁶ Alzheimer's Association, *Public Health E-News*, July 22, 2015

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

SLIDE 32:

Modifiable Risk Factors: Head Trauma²⁷

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

TALKING POINTS:

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

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

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

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

²⁷ Alzheimer's Association. (2015) *Traumatic Brain Injury*.

Image source: ctker.com

SLIDE 33:

Modifiable Risk Factors: Lifestyle^{28,29}

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

TALKING POINTS:

Certain **lifestyle factors** may help to protect against developing Alzheimer's and other dementias.

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

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

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

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

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

²⁸ Alzheimer's Association. (2014) *Alzheimer's and Public Health Spotlight: Heart Health and Brain Health*.

²⁹ Alzheimer's Association. *Prevention and Risk of Alzheimer's & Dementia*. Accessed July 16, 2015 from website: http://www.alz.org/research/science/alzheimers_prevention_and_risk.asp

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

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

SLIDE 34:

Modifiable Risk Factors: Cardiovascular³⁰

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

TALKING POINTS:

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

The brain is nourished by one of the body's richest networks of blood vessels. With every beat, the **heart pumps about 20% to 25% of the blood to the head**, where brain cells use at least 20% of the food and oxygen carried by the blood in order to function normally.

As a result, many factors that damage the heart or blood vessels may also damage the brain – and may increase the risk for developing Alzheimer's and other dementias.

Several conditions known to increase the risk of **cardiovascular disease** – including high blood pressure, heart disease, stroke, and diabetes– appear to increase the risk of developing Alzheimer's disease.

Some autopsy studies show that as many as **80% of individuals** with Alzheimer's disease also have cardiovascular disease.

³⁰ Alzheimer's Association. *Prevention and Risk of Alzheimer's & Dementia*. Accessed July 16, 2015 from website: http://www.alz.org/research/science/alzheimers_prevention_and_risk.asp

Image source: clker.com

SLIDE 35:

TREATMENT & MANAGEMENT

TALKING POINTS:

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

SLIDE 36:

Diagnosing Alzheimer's Disease³¹

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

TALKING POINTS:

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

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

A careful medical evaluation is required, which includes:

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

³¹ Alzheimer's Association. *Diagnosis of Alzheimer's Disease and Dementia*. Accessed June 8, 2015 from website: http://www.alz.org/alzheimers_disease_diagnosis.asp

Image source: National Cancer Institute, NCI Visuals Online

SLIDE 37:

Treating & Managing Alzheimer's³²

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

TALKING POINTS:

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

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

The chief goals of treatment are to:

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

³² Alzheimer's Association. *Health Care Professionals and Alzheimer's*. Accessed June 8, 2015 from website: <http://www.alz.org/health-care-professionals/medical-management-patient-care.asp>

Image source: clker.com

SLIDE 38:

Alzheimer's: Co-Morbidities³³

- Additional chronic conditions (e.g., heart disease, diabetes, depression)
 - Difficult to manage
 - Higher rates of hospitalizations and costs
 - 3 times as many hospital stays
 - 3 times average Medicare costs
 - Preventable hospitalizations
-

TALKING POINTS:

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

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

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

³³ 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 39:

UNIQUE ASPECTS

TALKING POINTS:

There are various unique aspects and hardships that may accompany Alzheimer's and other dementias.

SLIDE 40:

Alzheimer's: Unique Aspects³⁴

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

TALKING POINTS:

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

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

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

People with Alzheimer's and other dementias tend to be especially **vulnerable to abuse** because the disease may prevent them from reporting the abuse or recognizing it. Abuse can occur anywhere, including at home and in care settings.

Abuse can take many forms:

- **Physical:** physical pain or injury

³⁴ Alzheimer's Association. *Abuse*. Accessed July 16, 2015 from website: <https://www.alz.org/care/alzheimers-dementia-elder-abuse.asp>

- **Emotional:** verbal assaults, threats of abuse, harassment and intimidation
- **Neglect:** failure to provide necessities, including food, clothing, shelter, medical care or a safe environment
- **Financial:** the misuse or withholding of the person's financial resources (money, property) to his or her disadvantage or the advantage of someone else

SLIDE 41:

CAREGIVERS

TALKING POINTS:

Most people with Alzheimer's disease have a primary **caregiver** – often a family member – who is crucial to ensuring appropriate care. As the person with Alzheimer's declines, the primary caregiver(s) often takes on an increasing role in advocating for and attending to all aspects of the person's health and well-being as well as all their financial affairs.

SLIDE 42:

Alzheimer's: Caregivers³⁵

- Responsibilities:
 - Dressing, bathing, toileting, feeding
 - Shopping, meal preparation, transportation
 - Medication
 - Financial management
 - Emotional support
 - Increasing levels of care
 - Results in complete dependence
-

TALKING POINTS:

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

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

- Helping with **dressing, bathing, toileting, and feeding**
- **Shopping, meal preparation, transportation, medication management, and financial management**
- Providing **emotional support**

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

³⁵ Alzheimer's Association. (2015) *Alzheimer's Disease Caregivers*.

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

SLIDE 43:

Caregivers: Challenges³⁶

- Physical, financial, psychological challenges
 - \$10.2 billion additional annual health care costs (2015)
 - 60% rate emotional stress as high or very high
 - 40% report depression
-

TALKING POINTS:

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

- Due to the physical and emotional toll of caring for someone with Alzheimer's or other dementias, these caregivers had **\$10.2 billion** in additional health care costs in 2014.
- Nearly 60% of Alzheimer's and dementia caregivers rate the emotional stress of caregiving as high or very high.
- About 40% of Alzheimer's and dementia caregivers suffer from depression.

³⁶ Alzheimer's Association. *2016 Alzheimer's Disease Facts and Figures*.

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

SLIDE 44:

Conclusion: Key Points

- Likely develops as a result of multiple factors
 - Symptoms worsen over time, average lifespan 4-8 years (up to 20)
 - Risk factors include: age, family history, head trauma, education, cardiovascular conditions
 - African-Americans, Hispanics, women more likely to develop
 - Risk reduction may include: physical activity, diet, mental stimulation, social connections
-

TALKING POINTS:

In conclusion, a review of key points from Module 2:

- Experts agree that in the vast majority of cases, Alzheimer's disease, like other common chronic conditions, probably develops as a result of **complex interactions** among **multiple factors**, including age, genetics, environment, lifestyle, and coexisting medical conditions.
- The symptoms of Alzheimer's disease worsen over time, although the **rate** at which the disease progresses **varies**.
- On average, a person with Alzheimer's disease lives **four to eight years** after diagnosis, but can live as long as 20 years, depending on other factors.
- Risk factors for Alzheimer's disease include:
 - Age
 - Years of formal education
 - Family history
 - Head trauma
 - Education
 - Lifestyle (current smoking, physical activity, diet, mental and social activity)

- Cardiovascular conditions (including high blood pressure, heart disease, stroke, and diabetes)
- African-Americans, Hispanics, and women are more likely to develop Alzheimer's disease.
 - In the U.S., older **African-Americans** are about **two times more likely than** older whites to have Alzheimer's disease. First-degree relatives of African-Americans with Alzheimer's disease have a 43% chance of developing dementia.
 - Older **Hispanics** are about **one and one-half times more likely** than older whites to have Alzheimer's disease.
 - Almost 2/3 of U.S. adults with Alzheimer's disease are **women**.

SLIDE 45:

Role of Public Health

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

TALKING POINTS: (see module 3 for more information)

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

- **Surveillance/monitoring** that allows public health to compile data and use it to:
 - Develop interventions
 - Inform public policy
 - Guide research
 - Educate populations
- **Promoting primary prevention** can be used to promote **risk reduction** and **promote cognitive health**.
- Public health may play an important role increasing **early detection and diagnosis** of Alzheimer's disease

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

SLIDE 46:

Dementia Capable Systems and Dementia Friendly Communities

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

TALKING POINTS: (see module 4 for more information)

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 other dementias as well as support and empower people with Alzheimer's and dementia to continue living high-quality lives with as much independence as possible.

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

SLIDE 47:

For More Information

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

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 & OTHER DEMENTIAS – THE BASICS



Emory Centers
for Training and
Technical Assistance

LEARNING OBJECTIVES

- Define cognitive health
- Define and differentiate between dementia and Alzheimer's
- List at least 5 common symptoms of Alzheimer's
- Describe the changes that occur during the course of Alzheimer's
- Identify at least 3 risk factors associated with Alzheimer's
- Describe the role of caregivers

COMPETENCIES

Association for Gerontology in Higher Education (AGHE):

- 1.2.1 Distinguish normal biological aging changes from pathology including genetic factors.
- 1.3.3 Demonstrate knowledge of signs, symptoms, and impact of common cognitive and mental health problems in late life (e.g., dementia, depression, grief, anxiety).
- 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 1: Describe risk factors and modes of transmission for infectious and chronic diseases and how these diseases affect both personal and population health.

COMPETENCIES CONT.

National Association of Chronic Disease Directors (NACDD):

Domain 7: Discuss the underlying causes and management of chronic diseases, including behavioral, medical, genetic, environmental and social factors.

Domain 7: Articulate key chronic disease issues.

Domain 7: Describe socioeconomic and behavioral determinants of health disparities.

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

7.1.1 Identify current and emerging issues that may influence health and health education

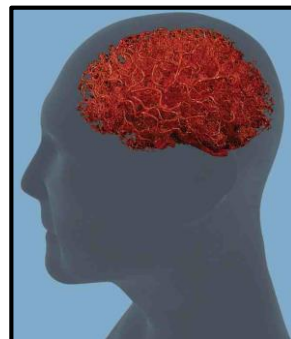
DISCUSSION QUESTION



What is cognitive health?

COGNITIVE HEALTH¹

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



¹ Centers for Disease Control and Prevention, Division of Healthy Aging. *What is a Healthy Brain? New Research Explores Perceptions of Cognitive Health Among Diverse Older Adults.*

COGNITIVE AGING^{2,3}

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



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

³ National Institute on Aging. (2013) *Understanding Memory Loss: What To Do When you Have Trouble Remembering*.

MILD COGNITIVE IMPAIRMENT (MCI)^{4,5}

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

⁴ Alzheimer's Association. (2012) *Mild Cognitive Impairment*.

⁵ National Institute on Aging. About Alzheimer's Disease: Mild Cognitive Impairment. Accessed June 10, 2015 from website: <https://www.nia.nih.gov/alzheimers/topics/mild-cognitive-impairment>.

COGNITIVE IMPAIRMENT⁶

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



⁶ Alzheimer's Association and Centers for Disease Control and Prevention. (2013) *The CDC Healthy Brain Initiative: Public Health Road Map for State and National Partnerships, 2013-2018*.

DEMENTIA

ALZHEIMER'S AND OTHER DEMENTIAS – THE BASICS

DEMENTIA⁷

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

⁷ Alzheimer's Association. *What is Dementia?* Accessed June 8, 2015 from website: <http://www.alz.org/what-is-dementia.asp#causes>

TYPES OF DEMENTIA⁸

- Alzheimer's disease
- Vascular dementia
- Dementia with Lewy Bodies (DLB)
- Mixed dementia
- Parkinson's disease
- Frontotemporal dementia
- Creutzfeldt-Jakob disease
- Normal pressure hydrocephalus
- Huntington's disease
- Wernicke-Korsakoff Syndrome



⁸ Alzheimer's Association. *Types of Dementia.* Accessed June 8, 2015 from website: <http://www.alz.org/dementia/types-of-dementia.asp>. National Institute on Aging. (2015) *Alzheimer's Disease Fact Sheet.*



VASCULAR DEMENTIA⁹

- 2nd most common cause of dementia
- 20% - 30% of cases
- Caused by conditions that block or reduce blood flow to the brain
- Symptoms may occur suddenly following strokes or slowly as a result of cumulative damage

⁹ Alzheimer's Association. (2015) *Vascular Dementia*.



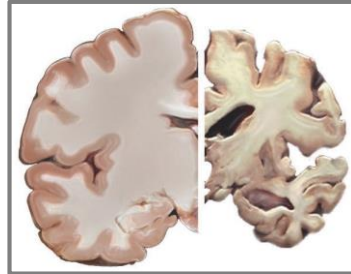
ALZHEIMER'S DISEASE

ALZHEIMER'S AND OTHER DEMENTIAS – THE BASICS



ALZHEIMER'S DISEASE: OVERVIEW¹⁰

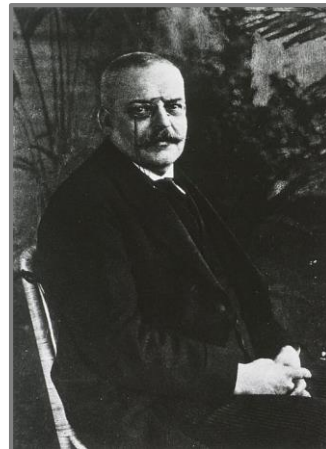
- Most common type of dementia
- 60% - 80% of cases
- Progressive – symptoms gradually worsen over number of years



¹⁰ Alzheimer's Association. *What is Alzheimer's?* Accessed June 8, 2015 from website: http://www.alz.org/alzheimers_disease_what_is_alzheimers.asp

ALZHEIMER'S DISEASE: HISTORY¹¹

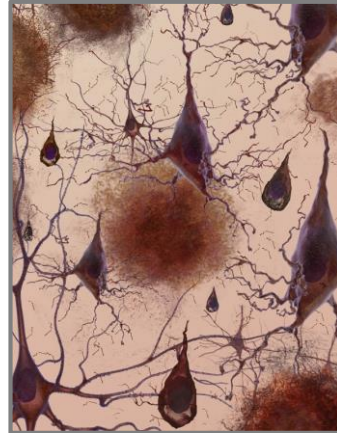
- Identified in 1906 by Dr. Alois Alzheimer
- Examined brain of woman who died after mental illness
- Found abnormal clumps (plaques) and tangled fibers (tangles)



¹¹ National Institute on Aging. (2015) *Alzheimer's Disease Fact Sheet*.

ALZHEIMER'S DISEASE: PHYSICAL CHANGES¹²

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



¹² Alzheimer's Association. *Brain Tour*. Accessed July 1, 2015 from website:
http://www.alz.org/braintour/3_main_parts.asp

ALZHEIMER'S DISEASE: CAUSES¹³

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

¹³ Alzheimer's Association. *Risk Factors*. Accessed June 8, 2015 from website:
http://www.alz.org/alzheimers_disease_causes_risk_factors.asp

YOUNGER-ONSET ALZHEIMER'S DISEASE¹⁴

- Affects people younger than 65
- Many are in their 40s and 50s
- 200,000 have younger onset (in U.S.)
- 4% of population with Alzheimer's



¹⁴ Alzheimer's Association. *Younger/Early Onset Alzheimer's & Dementia*. Accessed June 8, 2015 from website: http://www.alz.org/alzheimers_disease_early_onset.asp

DISCUSSION QUESTION



What are the characteristics of Alzheimer's disease?

10 WARNING SIGNS OF ALZHEIMER'S¹⁵

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

¹⁵ Alzheimer's Association. (2009) *Know the 10 Signs*.

10 WARNING SIGNS OF ALZHEIMER'S (CONTINUED)¹⁶

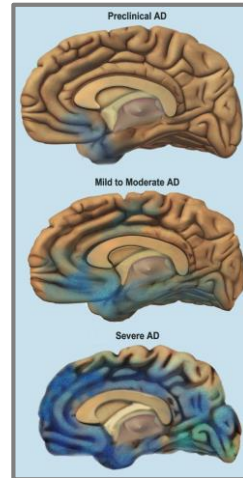
6. New problems with words in speaking or writing
7. Misplacing things and losing the ability to retrace steps
8. Decreased or poor judgment
9. Withdrawal from work or social activities
10. Changes in mood and personality

¹⁶ Alzheimer's Association. (2009) *Know the 10 Signs*.

STAGES OF ALZHEIMER'S DISEASE¹⁷

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

¹⁷ Alzheimer's Association. *Stages of Alzheimer's*. Accessed June 8, 2015 from website: http://www.alz.org/alzheimers_disease_stages_of_alzheimers.asp



MILD ALZHEIMER'S (EARLY-STAGE)¹⁸

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

¹⁸ Alzheimer's Association. *Stages of Alzheimer's*. Accessed June 8, 2015 from website: http://www.alz.org/alzheimers_disease_stages_of_alzheimers.asp

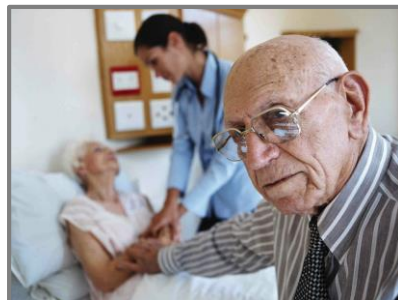
MODERATE ALZHEIMER'S (MIDDLE-STAGE)¹⁹

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

¹⁹ Alzheimer's Association. *Stages of Alzheimer's*. Accessed June 8, 2015 from website: http://www.alz.org/alzheimers_disease_stages_of_alzheimers.asp

SEVERE ALZHEIMER'S (LATE-STAGE)²⁰

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



²⁰ Alzheimer's Association. *Stages of Alzheimer's*. Accessed June 8, 2015 from website: http://www.alz.org/alzheimers_disease_stages_of_alzheimers.asp

RISK FACTORS

ALZHEIMER'S AND OTHER DEMENTIAS – THE BASICS

RISK FACTORS: AGE^{21,22}

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



21 Alzheimer's Association. *Risk Factors*. Accessed June 8, 2015 from website: http://www.alz.org/alzheimers_disease_causes_risk_factors.asp

22 Alzheimer's Association, *2015 Alzheimer's Disease Facts and Figures*, March 2015

RISK FACTORS: FAMILY HISTORY, EDUCATION

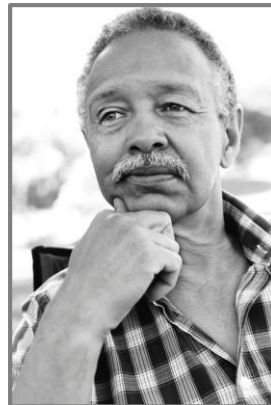
- Family history
- Hereditary/Genetics
- Education, cognitive engagement



²³ Alzheimer's Association. Risk Factors. Accessed from website: http://www.alz.org/alzheimers_disease_causes_risk_factors.asp

RISK FACTORS: RACE & ETHNICITY²⁴

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



²⁴ Alzheimer's Association (2016) *Alzheimer's Disease Facts and Figures*

RISK FACTORS: WOMEN^{25,26}

- 2/3 of affected population
- 16% of women age ≥ 71 (11% of men)
- At age 65 have more than 1 in 6 chance (1 in 11 for men)
- Age ≥ 60, are twice as likely to develop Alzheimer's than breast cancer



²⁵ Alzheimer's Association, *AAIC Press Release*, July 21, 2015
²⁶ Alzheimer's Association, *Public Health E-News*, July 22, 2015

MODIFIABLE RISK FACTORS: HEAD TRAUMA²⁷

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



²⁷ Alzheimer's Association. (2015) *Traumatic Brain Injury*.

MODIFIABLE RISK FACTORS: LIFESTYLE^{28,29}

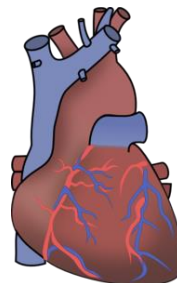
- Increases risk
 - Current smoking
 - Midlife obesity
- Decreases risk
 - Physical activity
 - Heart-healthy diets: DASH, Mediterranean diet
 - Mental and social activity

²⁸ Alzheimer's Association. (2014) *Alzheimer's and Public Health Spotlight: Heart Health and Brain Health*.

²⁹ Alzheimer's Association. *Prevention and Risk of Alzheimer's & Dementia*. Accessed July 16, 2015 from website: http://www.alz.org/research/science/alzheimers_prevention_and_risk.asp

MODIFIABLE RISK FACTORS: CARDIOVASCULAR³⁰

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



³⁰ Alzheimer's Association. *Prevention and Risk of Alzheimer's & Dementia*. Accessed July 16, 2015 from website: http://www.alz.org/research/science/alzheimers_prevention_and_risk.asp

TREATMENT & MANAGEMENT

ALZHEIMER'S AND OTHER DEMENTIAS – THE BASICS

DIAGNOSING ALZHEIMER'S DISEASE³¹

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



31 Alzheimer's Association. *Diagnosis of Alzheimer's Disease and Dementia*. Accessed June 8, 2015 from website: http://www.alz.org/alzheimers_disease_diagnosis.asp

TREATING & MANAGING ALZHEIMER'S³²

- No cure
- Drug and non-drug treatments
- Primary goals of treatment:
 - Maintain quality of life
 - Maximize function in daily activities
 - Enhance cognition, mood, behavior
 - Foster safe environment
 - Promote social engagement



³² Alzheimer's Association. *Health Care Professionals and Alzheimer's*. Accessed June 8, 2015 from website: <http://www.alz.org/health-care-professionals/medical-management-patient-care.asp>

ALZHEIMER'S: CO-MORBIDITIES³³

- Additional chronic conditions (e.g., heart disease, diabetes, depression)
- Difficult to manage
- Higher rates of hospitalizations and costs
 - 3 times as many hospital stays
 - 3 times average Medicare costs
- Preventable hospitalizations



³³ Alzheimer's Association. (2013) *Combating Alzheimer's Disease: A Public Health Agenda*.



UNIQUE ASPECTS

ALZHEIMER'S AND OTHER DEMENTIAS – THE BASICS



ALZHEIMER'S: UNIQUE ASPECTS³⁴

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

³⁴ Alzheimer's Association. Abuse. Accessed July 16, 2015 from website: <https://www.alz.org/care/alzheimers-dementia-elder-abuse.asp>

CAREGIVERS

ALZHEIMER'S AND OTHER DEMENTIAS – THE BASICS

ALZHEIMER'S: CAREGIVERS³⁵

- Responsibilities:
 - Dressing, bathing, toileting, feeding
 - Shopping, meal preparation, transportation
 - Medication
 - Financial management
 - Emotional support
- Increasing levels of care
- Results in complete dependence



³⁵ Alzheimer's Association. (2015) *Alzheimer's Disease Caregivers*.

CAREGIVERS: CHALLENGES³⁶

- Physical, financial, psychological challenges
 - \$10.2 billion additional annual health care costs (2015)
 - 60% rate emotional stress as high or very high
 - 40% suffer from depression



³⁶ Alzheimer's Association. 2016 Alzheimer's Disease Facts and Figures.

CONCLUSION: KEY POINTS

- Disease likely develops as result of multiple factors
- Symptoms worsen over time; average lifespan 4-8 years (up to 20)
- Risk factors include: age, family history, head trauma, education, lifestyle, cardiovascular conditions
- African-Americans, Hispanics, women more likely to develop

ROLE OF PUBLIC HEALTH

- 3 key public health intervention tools:
 - Surveillance/monitoring
 - Primary prevention (risk reduction)
 - 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- Dementia is a decline in mental ability that is a normal part of aging.
- a. True
 - b. False

Answer: B

- 2- The number one risk factor for Alzheimer's disease is:
- a. Getting older
 - b. High blood pressure
 - c. High cholesterol
 - d. Heredity/genetics
 - e. Lack of mental stimulation

Answer: A

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

Answer: A

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

Answer: A

- 5- Which of the following statements is true about Alzheimer's disease:
- a. Can be diagnosed through a blood test
 - b. Is a progressive disease
 - c. Is reversible with proper medication
 - d. All of the above
 - e. None of the above

Answer: B

FACULTY GUIDE

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

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

ABOUT MODULE 3

This module is part of the Alzheimer’s Association curriculum, *A Public Health Approach to Alzheimer’s and Other Dementias*. Developed as part of a cooperative agreement with CDC’s 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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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/

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

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

SLIDE GUIDE

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

SLIDE 1:

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

TALKING POINTS:

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

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

SLIDE 2:

Learning Objectives

- List 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:

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).

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.

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:

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.

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:

Introduction: Dementia & Alzheimer's Disease¹

- 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

¹ Alzheimer's Association. *2015 Alzheimer's Disease Facts and Figures*.

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

SLIDE 6:

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:

Alzheimer's: Epidemic (U.S.)²

- 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**.

² Alzheimer's Association. *2016 Alzheimer's Disease Facts and Figures*.

SLIDE 8:

Alzheimer's Impact: Costs³

- 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.

³ Alzheimer's Association. *2016 Alzheimer's Disease Facts and Figures*.

Image source: ctker.com

SLIDE 9:

Alzheimer's: Disproportional Impact⁴

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

TALKING POINTS:

Alzheimer's 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.

⁴ Alzheimer's Association. *2016 Alzheimer's Disease Facts and Figures*.

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

SLIDE 10:

Alzheimer's: Caregiving Burden⁵

- 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.

⁵ Alzheimer's Association. *2016 Alzheimer's Disease Facts and Figures*.

SLIDE 11:

Alzheimer's: Health Care Burden^{6,7,8}

- 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.

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

⁷ Alzheimer's Association. *2016 Alzheimer's Disease Facts and Figures*.

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

SLIDE 12:

Public Health: Tools & Techniques⁹

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.

⁹ 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:

TOOL #1: SURVEILLANCE

TALKING POINTS:

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

SLIDE 14:

Surveillance & Public Health¹⁰

- 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.

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

SLIDE 15:

Behavioral Risk Factor Surveillance System (BRFSS)¹¹

- 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.

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

Image source: ctker.com

SLIDE 16:

BRFSS: Cognitive Decline Module^{12,13}

- 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.

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

¹³ 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:

BRFSS: Caregiver Module¹⁴

- 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.

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

SLIDE 18:

Discussion Question

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

TALKING POINTS:

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

Open responses.

SLIDE 19:

Public Health: Surveillance Data^{15,16}

- 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

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

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

Image source: clker.com

SLIDE 20:

TOOL #2: PRIMARY PREVENTION & RISK REDUCTION

TALKING POINTS:

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

SLIDE 21:

Primary Prevention¹⁷

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

TALKING POINTS:

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.

¹⁷ 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:

Discussion Question

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

TALKING POINTS:

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

Open responses.

SLIDE 23:

Risk Reduction: Head Trauma^{18,19}

- 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**

¹⁸ Alzheimer's Association. (2015) *Traumatic Brain Injury*.

¹⁹ 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:

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

- 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

²⁰ Alzheimer’s Association. (2014) *Alzheimer’s and Public Health Spotlight: Heart Health and Brain Health*.

²¹ 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

²² 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/

Image source: clker.com

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:

Risk Reduction: Avoidance/Management²³

- 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.

²³ 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:

Risk Factors: Active Brain²⁴

- 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.

²⁴ 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:

Discussion Question

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

TALKING POINTS:

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

Open responses.

SLIDE 28:

Risk Reduction: Public Health^{25,26}

- 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

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

²⁶ 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)

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:

Tool #3: Early Detection & Diagnosis

TALKING POINTS:

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

SLIDE 30:

Discussion Question

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

Why or why not?

TALKING POINTS:

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

Why or why not?

Open responses.

SLIDE 31:

Why Promote Early Detection?^{27,28,29,30}

- 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.)

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

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

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

³⁰ 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

- 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:

Early Detection: Diagnosis Rates^{31,32}

- 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.

³¹ Alzheimer's Association. *2015 Alzheimer's Disease Facts and Figures*

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

Image source: clker.com

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:

Early Detection: Challenges^{33,34}

- 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

³³ Alzheimer's Association. *2016 Alzheimer's Disease Facts and Figures*.

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

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:

Early Detection: Most Want to Know³⁵

- 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.

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

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

SLIDE 35:

Discussion Question

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

TALKING POINTS:

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

Open responses.

SLIDE 36:

Public Health: Early Diagnosis³⁶

- 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

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

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

- Early **symptoms** and **signs** of dementia
- Ways to **counsel** to individuals and their care partners upon diagnosis
- **Caregiver** needs
- Managing dementia in the context of other **chronic diseases**
- Accessing **services** in the community
- Participating in **clinical trials**

A diagnosis of Alzheimer’s or other dementia should be followed by **continued education** and **support** for individuals, families, and caregivers.

The strengths and capacities of public health can also be used to:

- Promote **advance care planning** and **advance financial planning** to care partners, families, and individuals with Alzheimer’s and dementia in the early stages before function declines.
- Inform and connect people to **private and public resources** that may help with treatment, support services, and information
- Promote awareness of **abuse** and **exploitation**, and support related prevention efforts as they pertain to a person with Alzheimer’s or other dementias.

For information on the 10 warning signs: <http://alz.org/10-signs-symptoms-alzheimers-dementia.asp>

SLIDE 37:

Conclusion: Public Health Response³⁷

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:

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

- 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:

Dementia Capable Systems and Dementia Friendly Communities³⁸

- 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.

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

SLIDE 39:

For More Information

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

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).

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.

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

5

¹ 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



ALZHEIMER'S: EPIDEMIC (U.S.)

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



² Alzheimer's Association. 2016 Alzheimer's Disease Facts and Figures.

ALZHEIMER'S IMPACT: COSTS

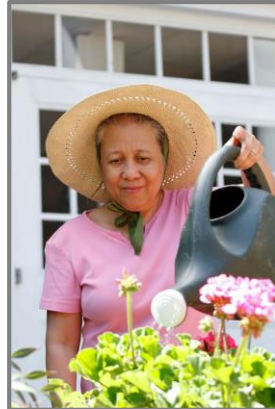
- Significant costs to Medicare, Medicaid, individuals, caregivers
- Annual costs of care over \$200 billion
- Most expensive disease in the U.S.



³ 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



⁴ 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

⁵ 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



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

⁷ Alzheimer's Association. 2016 *Alzheimer's Disease Facts and Figures*.

⁸ 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



⁹ 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?



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

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

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



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

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

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

¹³ 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>

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

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

DISCUSSION QUESTION



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

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



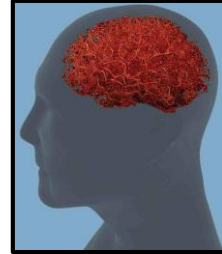
¹⁵ Alzheimer's Association. (2014) *Data Collection and Behavioral Risk Factor Surveillance System (BRFSS)*.
¹⁶ Centers for Disease Control and Prevention. *The CDC Healthy Brain Initiative: Progress 2006 – 2011*.

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



¹⁷ Centers for Disease Control and Prevention. *The Concept of Prevention*. Accessed August 14, 2015 from: <http://www.cdc.gov/arthritis/temp/pilots-201208/pilot/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

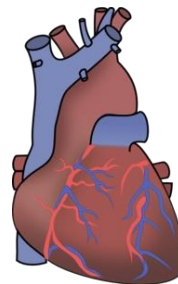


¹⁸ Alzheimer's Association. (2015) *Traumatic Brain Injury*.

¹⁹ 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



²⁰ Alzheimer's Association. (2014) *Alzheimer's and Public Health Spotlight: Heart Health and Brain Health*.

²¹ 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

²² 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/

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



²³ 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 BRAIN²⁴

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



²⁴ 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?

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



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

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

TOOL #3: EARLY DETECTION & DIAGNOSIS

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



DISCUSSION QUESTION



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

WHY PROMOTE EARLY DETECTION?

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



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

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

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

³⁰ 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



³¹ Alzheimer's Association. *2015 Alzheimer's Disease Facts and Figures*.

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

EARLY DETECTION: CHALLENGES

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

³³ Alzheimer's Association. 2016 *Alzheimer's Disease Facts and Figures*.

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

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



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

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



³⁶ 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

FACULTY GUIDE

Module 4: Dementia Capable Systems and Dementia Friendly Communities

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

ABOUT MODULE 4

This module is part of the Alzheimer’s Association curriculum, *A Public Health Approach to Alzheimer’s and Other Dementias*. Developed as part of a cooperative agreement with CDC’s 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 4: Dementia Capable Systems and Dementia Friendly Communities addresses the public health response to the Alzheimer’s disease epidemic at the state and community levels. The module describes the concept of a “dementia capable” system, which involves accommodating the needs of a population that experiences memory loss, a variety of **physical, cognitive, and behavior** symptoms, and other **co-morbidities**.

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

Module 4 contains the following topics:

- Public health research
- Support services & programs
- Workforce training
- Dementia friendly communities

LEARNING OBJECTIVES

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

- Define “dementia capable.”
- Explain how public health can contribute to the development of dementia capable systems through: public health research and translation, support services and programs, workforce training, and the creation of dementia-friendly communities.
- List at least 2 support services that may benefit a caregiver of someone with Alzheimer’s or dementia.
- Identify at least 3 professions that would benefit from receiving workforce training related to Alzheimer’s and dementia.
- Describe at least 2 components of a dementia friendly community.

COMPETENCIES

Module 4 promotes basic learning that supports the development of certain competencies:

Association of Schools and Programs of Public Health:

- Domain 1: Appreciate the role of community collaborations in promoting population health.
- Domain 2: Discuss the interconnectedness among the physical, social, and environmental aspects of community health.

Council on Linkages Between Academia and Public Health Practice:

- 1A1. Describes factors affecting the health of a community (e.g., equity, income, education, environment)
- 1A11. Describes assets and resources that can be used for improving the health of a community (e.g., Boys & Girls Clubs, public libraries, hospitals, faith-based organizations, academic institutions, federal grants, fellowship programs)
- 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)
- 8A6. Describes needs for professional development (e.g., training, mentoring, peer advising, coaching)

National Association of Chronic Disease Directors (NACDD):

- 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.
- 3.3.2 Identify training needs.

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STUDENT ENGAGEMENT OPTIONS

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

DISCUSSION QUESTIONS

The following discussion questions are included in the slide deck:

- What is public health research? What does it mean to translate findings? *(Slide 10)*
- How can public health research and translation be used to reduce the burden of Alzheimer's disease? *(Slide 12)*
- What kinds of support services might people with Alzheimer's and their caregivers need? *(Slide 15)*
- What is the role of public health in connecting people to the services they need? *(Slide 19)*
- What training should health care and direct care professionals receive? *(Slide 24)*
- What training should public health professionals receive? *(Slide 26)*
- What training should first responders receive? *(Slide 28)*
- Imagine you or someone you care about has Alzheimer's or dementia. What might be some of your concerns or fears about going out in your community? How could those be addressed at a community level? *(Slide 32)*

LEARNING ACTIVITIES

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

- Conduct a brief observational study of the community in which you live, work, or go to school. What characteristics could be considered dementia-friendly? What changes would be needed? How could public health support the development or growth of a dementia friendly community where you live/work/study?
- Select one of the interventions described in the report, *Translating Innovation to Impact: Evidence-based interventions to support people with Alzheimer's disease*

and their caregivers at home and in the community. Provide a brief description of the program, including any challenges or gaps (that are identified or that you recognize). How could public health support the expansion or improvement of this program? Document may be accessed from website:

<http://www.agingresearch.org/publications/view/18#.VgFoUuvL6M4>

- Select a workforce (such as public health, health care, first responder, etc.) that would benefit from training on Alzheimer's and dementia. Create an outline of training topics – what information would you present? What educational techniques would you use during the training?

ADDITIONAL READING

- Bynum, Julie PW. "The long reach of Alzheimer's disease: Patients, practice, and policy." *Health Affairs* 33.4 (2014): 534-540.
<http://content.healthaffairs.org/content/33/4/534.short>
- Lin, S. Y., & Lewis, F. M. (2015). Dementia friendly, dementia capable, and dementia positive: concepts to prepare for the future. *The Gerontologist*, 55(2), 237-244. <http://gerontologist.oxfordjournals.org/content/55/2/237.short>

SLIDE GUIDE

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

SLIDE 1:

Module 4: Dementia Capable Systems and Dementia Friendly Communities

TALKING POINTS:

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

This presentation addresses the public health response to the Alzheimer's epidemic at the state and community levels and the importance of dementia capable systems and dementia friendly communities.

SLIDE 2:

Learning Objectives

- Define “dementia capable”
- Explain how public health can contribute to dementia capable systems through: research and translation, support services/programs, workforce training, and dementia friendly communities
- List at least 2 services that may benefit a caregiver
- Identify at least 3 professions that would benefit from workforce training
- Describe at least 2 components of a dementia friendly community

TALKING POINTS:

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

- Define “dementia capable”
- Explain how public health can contribute to dementia capable systems through: research and translation, support services/programs, workforce training, and dementia-friendly communities
- List at least 2 services that may benefit a caregiver
- Identify at least 3 professions that would benefit from workforce training
- Describe at least 2 components of a dementia-friendly community

SLIDE 3:

Competencies

Association of Schools and Programs of Public Health:

- Domain 1: Appreciate the role of community collaborations in promoting population health.
- Domain 2: Discuss the interconnectedness among the physical, social, and environmental aspects of community health.

Council on Linkages Between Academia and Public Health

Practice:

- 1A1. Describes factors affecting the health of a community (e.g., equity, income, education, environment)
- 1A11. Describes assets and resources that can be used for improving the health of a community (e.g., Boys & Girls Clubs, public libraries, hospitals, faith-based organizations, academic institutions, federal grants, fellowship programs)
- 8A3. Describes the ways public health, health care, and other organizations can work together or individually to impact the health of a community

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

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

Association of Schools and Programs of Public Health:

- Domain 1: Appreciate the role of community collaborations in promoting population health
- Domain 2: Discuss the interconnectedness among the physical, social, and environmental aspects of community health

Council on Linkages Between Academia and Public Health

Practice:

- 1A1. Describes factors affecting the health of a community (e.g., equity, income, education, environment)
- 1A11. Describes assets and resources that can be used for improving the health of a community (e.g., Boys & Girls Clubs, public libraries, hospitals, faith-based organizations, academic institutions, federal grants, fellowship programs)
- 8A3. Describes the ways public health, health care, and other organizations can work together or individually to impact the health of a community

SLIDE 4:

Competencies Cont.

Council on Linkages Between Academia and Public Health Practice (cont.):

- 8A4. Contributes to development of a vision for a healthy community (e.g., emphasis on prevention, health equity for all, excellence and innovation)
- 8A6. Describes needs for professional development (e.g., training, mentoring, peer advising, coaching)

National Association of Chronic Disease Directors (NACDD):

- 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.
 - 3.3.2 Identify training needs
-

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

Council on Linkages Between Academia and Public Health Practice (cont.):

- 8A4. Contributes to development of a vision for a healthy community (e.g., emphasis on prevention, health equity for all, excellence and innovation)
- 8A6. Describes needs for professional development (e.g., training, mentoring, peer advising, coaching)

National Association of Chronic Disease Directors (NACDD):

- 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
- 3.3.2 Identify training needs

SLIDE 5:

Introduction: Dementia & Alzheimer's Disease¹

- 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 dementia capable systems and dementia friendly communities in addressing Alzheimer's disease, it may be helpful to know a little more about Alzheimer's and dementia.

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

¹ Alzheimer's Association. *2016 Alzheimer's Disease Facts and Figures*.

Alzheimer's disease is the most common type of dementia. Alzheimer's is a progressive disease that ranges from mild to 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 **dementia capable systems and dementia friendly communities**, both of which involve government and health care agencies, organizations and communities accommodating the needs of people with dementia and their caregivers through providing education, services and support within their community.

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

Link: <https://www.youtube.com/watch?v=yJTXN4xrI8>

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

SLIDE 6:

Alzheimer's: A Larger Context²

- States/communities play significant role
 - Assessing burden
 - Risk reduction
 - Care services: health care, support services government agencies
 - Public and private resources: transportation, grocery stores, places of worship, financial institutions, law enforcement

TALKING POINTS:

Alzheimer's and dementia are often considered in terms of the toll these conditions take on **individuals, families, and caregivers**.

As an **epidemic**, Alzheimer's and dementia also need to be addressed within a larger context. **States and communities** have many people living with Alzheimer's and other dementias, as well as many others who are at risk for developing these conditions.

States must assess the **burden** of Alzheimer's and dementia and take steps to **reduce risk** and **provide support** to affected populations.

At a community level, individuals with Alzheimer's and dementia and their caregivers rely on many **care services**, including health care, support services (in-home, community, and long-term care), and government agencies for their daily care needs.

They also interact with and depend on **public and private resources** such as transportation, grocery stores, places of worship, financial institutions, and law enforcement.

² Image source: *clker.com*

A **public health response** to the epidemic must therefore take into consideration the unique needs of people with Alzheimer's and dementia on state and local levels, within institutions, and across communities.

SLIDE 7:

Dementia Capable Systems^{3,4,5}

- Accommodate needs of population with:
 - Memory loss
 - Physical, cognitive, behavioral symptoms
 - Co-morbidities
- Knowledgeable workforce/residents:
 - Identify people with dementia
 - Work effectively with them
 - Inform/refer to services

TALKING POINTS:

During this presentation, we will discuss both **dementia capable systems and dementia friendly communities**. Each has an important part to play in helping people with dementia and their loved ones navigate the journey with dementia. First, we will discuss **dementia capable systems**.

Dementia capable means being able to help people with dementia and their caregivers. This definition applies both to dementia capable systems and dementia friendly communities. More specifically, being **dementia capable** means being skilled in **identifying people** with possible dementia and **working effectively** with them and their caregivers, being **knowledgeable** about the kinds of services needed, and being able to **inform** or **refer** to agencies and individuals that provide such services.

A **dementia capable system** is a system that accommodates the needs of a population that, in addition to memory loss, experiences a variety of **physical, cognitive, and behavioral**

³ Alzheimer's Association and Centers for Disease Control and Prevention. (2013) *The Healthy Brain Initiative: The Public Health Road Map for State and National Partnerships, 2013-2018*.

⁴ U.S. Administration on Aging. (2011) *Dementia Capability Toolkit*.

⁵ Tilly, J, Weiner, J, Gould, E, and O'Keefe, J. (2011) *Making the Long-Term Services and Supports System Work for People with Dementia and Their Caregivers*.

symptoms resulting from dementia, in addition to other **co-morbidities**.

Dementia capable systems can be implemented at different levels, such as within a care system, a business or organization, or within a community or state. The focus of dementia capable systems is often on:

- Increasing knowledge and skills of those who will help care for or interact with people who have dementia and their loved ones
- Addressing service gaps and specialized assistance needs
- Providing long term services and support systems to fulfill the needs of people with dementia and their caregivers

Public health must take an active role in fostering dementia capable systems and helping to bridge the gap between the needs of individuals and caregivers and the larger establishments within states and communities that can best meet those needs.

SLIDE 8:

Dementia Capable: Public Health⁶

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

TALKING POINTS:

Public health may play a role in developing and supporting dementia capable systems by:

- Conducting **public health research** and **translating** the findings through policy, programs, and best practices
- Serving to provide, inform and connect individuals and caregivers to **support services and programs**
- Designing and implementing **workforce training** to ensure workers across a wide range of professions are able to identify and meet the needs of people with Alzheimer's and dementia
- Supporting the creation of **dementia friendly communities** that help people with Alzheimer's and dementia remain safe and as independent as possible within their community

Each of these will be discussed in more detail.

⁶ *Image source:* Copyrighted image; used with permission from the Alzheimer's Association

SLIDE 9:

PUBLIC HEALTH RESEARCH

TALKING POINTS:

We will start with public health research.

Public health plays an important role in both **conducting** research and **translating** the findings from such research into practice.

SLIDE 10:

Discussion Questions

What is public health research?

What does it mean to translate findings?

TALKING POINTS:

Ask: What is public health research?

What does it mean to translate findings?

Open responses.

SLIDE 11:

Public Health Research & Translation⁷

- Public health research: generalizable knowledge to improve practice
- Translation: evidence-based practice
- Sources:
 - Published, peer-reviewed articles
 - Authoritative guidelines, recommendations
 - Surveillance systems

TALKING POINTS:

Public health research is conducted with the goal of developing or contributing to **generalizable knowledge** to improve public health practice. “Generalizable” means that the information or knowledge that is gained may be widely applied to populations.

Translating the information or knowledge gained through public health research means applying it in practice – such as through **policy**, the development of **programs** or **interventions**, or the development of **best practices**. When programs and policies are built on a framework of research findings they are referred to as being **evidence-based**.

Sources for public health research and translation include:

- Published peer-reviewed articles
- Established **best practices or guidelines** from **authoritative sources** including government agencies (such as NIH, CDC, state health departments, state department of aging services), and nongovernmental organizations (such as the Alzheimer’s Association)
- **Surveillance systems** such as the Behavioral Risk Factor Surveillance System (BRFSS)

⁷ Image source: cker.com

SLIDE 12:

Discussion Question

How can public health research and translation be used to reduce the burden of Alzheimer's disease?

TALKING POINTS:

Ask: How can public health research and translation be used to reduce the burden of Alzheimer's disease?

Open responses.

SLIDE 13:

Public Health Research & Translation^{8,9}

- Measure burden
 - Create policies
 - Identify/design practices and interventions
 - Promote risk reduction and cognitive health
-

TALKING POINTS:

For Alzheimer's and dementia, public health research may be applied to:

- Measuring the **burden** of cognitive impairment on populations
- Creating state and local **policies** that benefit and support people with Alzheimer's disease and their caregivers
- Identifying and designing effective **practices** and **interventions** to support the needs of individuals and their caregivers
- Promoting **risk reduction** and **cognitive health**

⁸ Centers for Disease Control and Prevention. (2010) *Distinguishing Public Health Research and Public Health Nonresearch*.

⁹ CDC & Alzheimer's Association. (2013) *The Healthy Brain Initiative: The Public Health Road Map for State and National Partnerships, 2013-2018*.

Image source: clker.com

SLIDE 14:

SUPPORT SERVICES & PROGRAMS

TALKING POINTS:

Public health research may be used to inform the design of **support services and programs** for people with Alzheimer's and other dementias.

SLIDE 15:

Discussion Question

What kinds of support services might people with Alzheimer's and their caregivers need?

TALKING POINTS:

Ask: What kinds of support services might people with Alzheimer's and their caregivers need?

Open responses.

SLIDE 16:

Support Services: Alzheimer's^{10,11}

- Support groups
- Wellness programs
- Care services
- Legal, financial services
- Residential care
- Transportation
- Adult day care

TALKING POINTS:

Individuals with Alzheimer's and dementia may **require** varying levels of **care and support from numerous sources**, including:

- **Support groups and socialization programs:** aimed at persons with mild (early) stage Alzheimer's disease, these groups can help with planning for future needs and provide general guidance and support for individuals and caregivers
- **Wellness programs:** includes nutrition and physical activity programs, physical/occupational/speech therapy; may also include opportunities for cognitive activity, such as creative arts or intergenerational connections

¹⁰ U.S. Administration on Aging. (2011) *Dementia Capability Toolkit*.

¹¹ ACT on Alzheimer's. *Dementia Capable Community: Key Elements & Resources*. Accessed August 4, 2015 from website: <http://www.actonalz.org/elements-and-resources>

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

- **Care services:** includes care managers, chore services, home safety, personal care assistant
- **Legal or financial services:** financial, health care, and end-of-life planning
- **Residential care:** includes living options with varying levels of care, such as independent living communities, assisted living residences, and nursing homes tailored to people with dementia
- **Transportation:** includes safe driving supports and individual and group transportation options
- **Adult day care:** care for individuals who require regular supervision: allowing people to socialize, participate in activities, and provide opportunities for caregivers to work or fulfill other responsibilities

SLIDE 17:

Support Services: Caregivers¹²

- Education/information/training
 - Alzheimer's/dementia
 - Behavioral management
 - Available resources
 - Self-care
- Counseling/support groups
- Case management
- Respite services

TALKING POINTS:

Support services and programs that have been found to be most effective for caregivers include **multiple components** to address different needs:

- **Education/information/training:**
 - Alzheimer's and dementia and its effects on behavior
 - **Behavioral management/problem solving training:** designed to train caregivers to use specific techniques to manage behaviors that can be challenging (such as agitation, repetition, aggression, wandering)
 - Information on the availability of **resources**
 - Self-care, such as stress management, using respite services
- **Counseling/support groups:**
 - Individual and family **counseling**

¹² ACT on Alzheimer's. (2014). *Alzheimer's Disease Curriculum, Module X: Caregiver Support*.

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

- **Support groups** that have been found to have the most positive outcomes focus on specific objectives, such as teaching certain skills or strategies
- **Care management:** helping to identify and manage care needs, coordinate across care systems and providers
- **Respite services:** provides care for a person with Alzheimer's disease on a temporary basis, providing time off for a family caregiver

SLIDE 18:

Examples of Evidence-based Programs¹³

- Reducing Disability in Alzheimer's Disease (RDAD) – University of Washington
 - Focus on teaching family caregivers strategies
- Minds in Motion (MIM)
 - Focus on improving function in early stages with mild cognitive impairment
- Skills2Care – Thomas Jefferson University
 - Focus on occupational therapy based strategies for caregivers

TALKING POINTS:

There are many examples of evidence-based programs for people with Alzheimer's and dementia and their caregivers.

- **Reducing Disability in Alzheimer's Disease (RDAD):** The primary aims of the RDAD program are to teach family caregivers:
 - Strategies to decrease challenging behaviors related to Alzheimer's and dementia, such as depression, anxiety, agitation, and aggression
 - Methods to engage in and encourage physical activity in order to reduce the physical disabilities that often result in a loss of independence

RDAD consists of 12 hourly sessions, conducted in participants' homes over three months.

- **Minds in Motion (MIM):** MIM is designed to improve or sustain cognitive and physical functioning in persons with mild (early) stage dementia or mild cognitive impairment (MCI). The group-based program,

¹³ Alliance for Aging Research. (2012) *Translating Innovation to Impact: Evidence-based Interventions to Support People with Alzheimer's Disease and their Caregivers at Home and in the Community.*

delivered in community settings, includes a variety of evidence-based components, including:

- Cognitive training exercises
 - Physical exercises (Tai Chi and Qi Gong)
 - Creative/community involvement activities (writing, art, photography, etc.)
- **Skills2Care:** An occupational therapy based intervention for caregivers and individuals with dementia living at home. The intervention is designed to reduce caregiver burden, improve caregiver ability to manage daily care challenges, and reduce behavioral symptoms and functional dependence in individuals with dementia. Caregivers are trained in five types of strategies:
 - Communication techniques
 - Environmental modification
 - Task simplification
 - Use of activities to engage individuals with dementia
 - Self-care

SLIDE 19:

Discussion Question

What is the role of public health in connecting people to the services they need?

TALKING POINTS:

Ask: What is the role of public health in connecting people to the services they need?

Open responses.

SLIDE 20:

Public Health: Support Services¹⁴

- Evidence-based programs and interventions
 - Information and referrals
 - Identifying service needs
 - Funding, space, expertise
-

TALKING POINTS:

Public health may serve to **provide, connect, and inform** individuals, families, and caregivers about support services within **clinical** and **community** settings.

Public health agencies and organizations can:

- **Develop** and **disseminate** evidence-based programs and interventions
- Offer **Information** and **referrals** to specific support services, programs, and sources of information
- Assist in **identifying service needs**, helping people understand what is available and how they may use different services throughout the course of the disease
- **Provide funding, space, expertise**, or other support for needed programs

¹⁴ *Image source:* National Cancer Institute, NCI Visuals Online, Bill Branson (Photographer)

SLIDE 21:

Support Services: Partnerships¹⁵

- Offices on Aging / Aging and Disability Resource Centers / Area Agencies on Aging
 - Education
 - Cognitive assessments
 - Support programs
 - Resources
- Non-profit organizations
- Residential care facilities

TALKING POINTS:

Public health is also in a unique position to strengthen **partnerships** within the community to build **dementia capable systems** and ensure that needed services and resources are available.

- **Offices on Aging/Aging and Disability Resource Centers/Area Agencies on Aging** can partner with local public health departments to **assess** community needs, **develop** programs and supports, and **provide** referrals.
Staff may be knowledgeable about Alzheimer's and dementia, offer **cognitive assessments** and family **caregiver supports**, and have information about **resources** and **programs** available in the community for individuals with dementia and their families.
- **Non-profit organizations** such as the **Alzheimer's Association** have experts in the field of dementia care with a wide variety of information and educational

¹⁵ ACT on Alzheimer's. (2014). *Alzheimer's Disease Curriculum, Module X: Caregiver Support*.

Image source: Centers for Disease Control and Prevention, Amanda Mills (Photographer)

materials and programs to support individuals, families and caregivers.

Other non-profits, such as **faith-based organizations** and **civic groups**, can be partners that may co-sponsor educational events, distribute information, offer services, provide a place for caregiver support groups to meet, etc.

- **Residential care facilities** may be able to reach out to other health care and business partners in the community to promote awareness, support program development, and initiate dementia friendly policies.

SLIDE 22:

WORKFORCE TRAINING

TALKING POINTS:

Public health may also play a key role in training the workforce – professionals in health related fields as well as others – to better understand, identify, and respond to individuals with Alzheimer’s and dementia and their caregivers.

SLIDE 23:

Workforce Training¹⁶

- Health care
- Direct care
- Public health
- First responders
- Other support services: transportation, customer service, faith-based organizations

TALKING POINTS:

Certain professions may provide service and support to people with Alzheimer's disease and their caregivers in a variety of ways. The workforces that would benefit from training and education include:

- **Health care workforce:** including primary care physicians, specialists (neurologists, geriatricians, psychiatrists), nurses, community health workers, social workers, psychologists, pharmacists, dentists.
- **Direct care professionals:** the workforce that provides the majority of the paid daily care (such as helping with bathing, dressing, housekeeping, food preparation, etc.) for people with Alzheimer's and dementia; includes nurse aides, home health aides, and personal and home-care aides
- **Public health workforce**
- **First responders:** including law enforcement, fire, emergency response teams, emergency medical technicians (EMTs), and adult protective services
- **Other professions:** including **transportation, customer service, and faith-based** or spiritual communities

Each of these will be discussed in more detail.

¹⁶ *Image source:* Centers for Disease Control and Prevention, Debora Cartagena (Photographer)

SLIDE 24:

Discussion Question

What training should health care and direct care professionals receive?

TALKING POINTS:

Ask: What training should **health care and direct care professionals** receive?

Open responses.

SLIDE 25:

Workforce Training: Health Care & Direct Care¹⁷

- Basics of dementia
- Benefits of early diagnosis
- How to address physical, cognitive, emotional, behavioral symptoms
- Assisting caregivers
- Managing co-morbidities
- Use of validated assessment tools (health care)

TALKING POINTS:

The health care and direct-care workforces need **training and education** on identifying and caring for someone with Alzheimer's and dementia including:

- The basics of **dementia**, including recognizing early warning signs
- The benefits of **early diagnosis**
- How to address the physical, cognitive, emotional, and behavioral **symptoms** of the disease
- How to assist **caregivers** as they cope with the physical and emotional aspects of their caregiving responsibilities
- Management of **co-morbidities** (such as arthritis, diabetes, and heart disease)
- The availability and use of **tools** and **guidelines** to identify dementia, including validated cognitive assessment tools (health care providers)

¹⁷ *Image source:* Copyrighted image; used with permission from the Alzheimer's Association

SLIDE 26:

Discussion Question

What training should public health professionals receive?

TALKING POINTS:

Ask: What training should **public health professionals** receive?

Open responses.

SLIDE 27:

Workforce Training: Public Health¹⁸

- Alzheimer's as a public health priority
- Importance of early detection
- Cognitive health and risk reduction
- Types and availability of resources and supports
- Caregivers
- Surveillance
- Health disparities
- Unique issues (stigma, abuse, advance planning)

TALKING POINTS:

Public health plays a key role in surveillance, education, and prevention related to Alzheimer's disease.

Training and education priorities for public health include:

- Understanding Alzheimer's disease as a **public health priority**
- The importance of **early detection**
- **Cognitive health** and **risk reduction** for Alzheimer's
- **Types and availability of resources and supports** for individuals with Alzheimer's and dementia
- Needs and burden of **caregivers**
- Tracking **surveillance data** on cognitive decline and caregiving
- **Health disparities** related to Alzheimer's and dementia
- Issues unique to Alzheimer's and dementia, including **stigma**, potential for **abuse**, and the need for **advance planning**

¹⁸ *Image source:* Copyrighted image; used with permission from the Alzheimer's Association

SLIDE 28:

Discussion Question

What training should first responders receive?

TALKING POINTS:

Ask: What training should **first responders** receive?

Open responses.

SLIDE 29:

Workforce Training: First Responders¹⁹

- Situations involving stress or fear
- Training needs:
 - Identifying Alzheimer's and dementia
 - Effective interaction/communication
 - Resources
 - Registries, technologies

TALKING POINTS:

First responders such as police, emergency medical personnel, and fire fighters may have first-hand contact with individuals with Alzheimer's and other dementias during situations that involve stress or fear, such as:

- **Wandering**, being **lost** or **disoriented**
- **Natural** or **other disasters** that may displace individuals with Alzheimer's and/or separate them from their usual caregivers
- Being subjected to physical or financial **abuse**
- Being reported to law enforcement for **improper behavior**, such as leaving a place of business after forgetting to pay for purchase

First responders and law enforcement need **training** on:

- How to **identify** someone with Alzheimer's and dementia
- How to **interact** and **communicate** with people with Alzheimer's in various situations (especially ones that are stressful for the person)
- **Resources** to call upon for assistance or information

¹⁹ Image source: Wikimedia commons, Jeshua Nace (photographer)

- Existence of **special needs registries** or other technologies that may assist in locating individuals or their places of residence

SLIDE 30:

Workforce Training: Other Professions²⁰

- Public transportation, customer service, faith/spiritual communities, etc.
 - Awareness
 - Recognizing need for help
 - Resources
 - Communication
 - Ways to assist and support

TALKING POINTS:

Many other professions come into contact with people with Alzheimer's disease and require different levels of information:

- **Public transportation:** For individuals with dementia, navigating public transportation can be very challenging.

Operators and drivers need to be aware of the special challenges faced by individuals with dementia, as well as how to recognize the signs that someone may need help.
- **Customer service:** Those in service positions may be trained to recognize when they are dealing with someone with possible Alzheimer's and dementia and how to best communicate with them and meet their needs.
- **Faith or spiritual communities:** These communities can be an important source of support and engagement for people with dementia, their families, and their caregivers. Church liaisons and volunteers may be trained to assist and support community members living with dementia.

²⁰ *Image source:* Pedestrian and Bicycle Information Center, Dan Burden (Photographer)

SLIDE 31:

DEMENTIA FRIENDLY COMMUNITIES

TALKING POINTS:

Many of the issues discussed in this module tie into the concept of **dementia friendly communities**.

This is growing movement in which communities in the U.S. and around the world are intentionally making changes to ensure that their communities are not only safe for and accessible to people with Alzheimer's and dementia, but also that they can support and empower people with Alzheimer's and dementia to continue living high-quality lives with as much independence as possible.

SLIDE 32:

Discussion Questions

Imagine you or someone you care about has Alzheimer's or dementia.

What might be some of your concerns or fears about going out in your community?

How could those be addressed at a community level?

TALKING POINTS:

Ask: Imagine you or someone you care about has Alzheimer's or dementia.

What might be some of your concerns or fears about going out in your community?

How could those be addressed at a community level?

Open responses.

Video supplement: Alzheimer's Society (UK) (3:35 minutes)

<https://www.youtube.com/watch?v=Fz8ACEu7Lho>

SLIDE 33:

Dementia Friendly Communities^{21,22}

- Health care, community services, resources
- Safety and accessibility
 - Transportation
 - Mobility
- Respectful and supportive
- Public education and workforce training
- Technology
 - GPS, GIS
 - Registry

TALKING POINTS:

In **dementia friendly** communities, people with dementia and their family and caregivers are understood, respected and supported, and able to continue to engage with and contribute to their community. The effort to become **dementia friendly** is made on a community-wide basis and requires planning and participation from all sectors as well as the general public.

While overlap exists between the concepts of dementia capable (discussed previously) and dementia friendly, a dementia-friendly community encompasses a broader goal of supporting a higher quality of life for people with dementia beyond simply meeting their physical and health needs.

²¹ U.S. Administration for Community Living/Administration on Aging. (2014) *Dementia-Capable States and Communities: The Basics*.

²² The Gerontological Society of America. (2015) *Dementia Friendly, Dementia Capable, and Dementia Positive: Concepts to Prepare for the Future*.

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

Elements of a dementia friendly community include:

- Access to **quality health care** and **community services**. While encompassing the same aspects of dementia capable systems, dementia friendly communities offer:
 - Resources and supports that are **geographically, financially, and culturally available** and **accessible**.
 - **Support services and activities**, such as educational sessions regarding symptoms, disease processes, self-care, and providing care, as well as support groups and dementia friendly social events that are readily available throughout the community.

- **Ensure safety and accessibility:** People can live **safely**, with as much independence as possible.

This concept includes **public transportation, walkability** for leisure and to complete daily tasks, minimizing confusion when moving from place to place, and ensuring **safety**.

Mobility considerations may include:

- Age-friendly pavements
 - Adequate signage
 - Safe pedestrian crossings
 - Trained safety personnel
 - Welcoming open spaces, including squares, parks, and playgrounds
- **Public education and workforce development:** In these communities, residents, agencies, businesses, health care facilities, places of worship, and general service providers are learning about dementia through education and awareness efforts, and providing assistance to people with the condition and their caregivers as they go about their daily lives.
 - **Technology** may also play a role in the creation of dementia-friendly communities:
 - **Geographic Information Systems (GIS) and Global Positioning Systems (GPS)** can help

people navigate their community while still allowing family or caregivers to track their whereabouts.

- **Community registry:** Law enforcement can also create a voluntary registry for individuals with dementia.

The registry provides the name, home address, and contact information for family members or care partners should the individual with dementia need help or become involved with law enforcement.

International community models differ slightly from those in the U.S. in that internationally, a more holistic approach is often taken, while in the U.S., communities lean more on a practical and structural approach, gradually ensuring all systems and services within the community are designed to support members living with dementia and their care partners. In the following slides, we will look at some examples of communities and organizations working to become dementia friendly.

SLIDE 34:

Dementia Friendly Communities²³

- Infographic of dementia friendly communities
-

TALKING POINTS:

ACT on Alzheimer's is a state-wide collaboration in Minnesota. We will learn more about the organization a few slides later. Here is an infographic that illustrates ACT on Alzheimer's view on what a dementia-friendly community involves:

- Raising awareness about Alzheimer's, transforming attitudes, and moving people to action
- Supporting family and friend caregivers by providing accessible information, resources, and in-person support
- Promoting meaningful participation in community life for everyone
- Including communities that experience inequities because of race, ethnicity, culture, language, sexual orientation, gender identity, mental illness, hearing/sensory differences, intellectual or physical abilities, and economic status

²³ *Image source:* ACT on Alzheimer's® developed tools and resources.
<http://actonalz.org/>

SLIDE 35:

Dementia Friendly: Middleton, WI^{24,25}

- Business trainings
 - Business promotions
 - Memory trail/park
 - Evaluation criteria
-

TALKING POINTS:

The **Alzheimer's & Dementia Alliance of Wisconsin (ADAW)** started a pilot dementia friendly program in Middleton, Wisconsin, in January 2014.

They brought together a group of citizens, business members, and city staff to launch the program, where they developed guidelines for businesses and organization to meet in order to be designated “dementia friendly”:

- Complete DFC training for management and 50% of their front-line employees
- Designate a team leader to be liaison between their organization and the DFC task force
- Be open to discussions regarding environment changes (e.g. lighting, signage, layout, etc.)
- Be willing to share DFC training materials with any new hires and all employees that did not attend training
- Undergo an on-site visit/follow-up training on an annual basis to recertify its dementia friendly status

²⁴ Wisconsin Department of Health Services. *Wisconsin Healthy Brain Initiative, A Tool Kit for Developing Dementia-Friendly Communities*.

²⁵ Alzheimer's and Dementia Alliance of Wisconsin. Dementia Friendly Community. <http://www.alzwisc.org/Dementia%20Friendly.html>.

Image source: ADAW

Dementia friendly organizations are given a window decal depicting a purple angel to display, allowing residents to easily identify participating locations. All city management departments are involved in the effort, including first responders. Middleton's local library, one establishment that has taken the steps to become designated dementia friendly, offers dementia-focused community programs such as a Music and Memory class. The local Walgreens also earned the dementia-friendly label and has improved signage throughout their stores as well as trained their employees on how to interact successfully with their customers with dementia. Banks, restaurants, local shops, and groceries are also trained.

ADAW is looking forward to expanding their dementia friendly training to personal service providers, such as beauticians and barbers, and even dentists. They are now working with other communities in Wisconsin to support them as they become dementia friendly.

Visit: <http://www.alzwisc.org/Dementia%20Friendly.html> for more information

SLIDE 36:

Dementia Friendly: ACT on Alzheimer's²⁶

- Minnesota's statewide, volunteer-driven collaboration
 - Community toolkit
 - Form action team
 - Assess community strengths and gaps
 - Analyze needs and develop action plan
 - Pursue priority goals
-

TALKING POINTS:

ACT on Alzheimer's is a statewide, volunteer-driven collaboration in Minnesota focused on preparing communities to respond to the growth of their populations with Alzheimer's and dementia. The goal is to create a community that raises awareness about Alzheimer's, transforms attitudes, and moves people to action; supports family and friend caregivers by providing accessible information, resources, and in-person support; promotes meaningful participation in community life for everyone; and includes communities that experience inequities because of race, ethnicity, culture, language, sexual orientation, gender identity, mental illness, hearing/sensory differences, intellectual or physical abilities, and economic status. Currently, 35 communities across the state participate in the initiative.

The process follows four action phases:

Convene key community leaders and members to form an **action team**

Assess **strengths** and **gaps** within the community related to dementia-friendly aspects

Analyze community needs and develop **action plans** to respond

1. **Launch** action plans

²⁶ ACT on Alzheimer's. (2013). *Is Your Community Prepared?*

Image source: ACT on Alzheimer's

ACT on Alzheimer's released a **toolkit** that is available for use by communities to create dementia-friendly environments. The toolkit includes sector specific training guides, such as those targeted toward businesses, finance, legal, and local government entities. Additionally, ACT offers a "Dementia Friendly @ Work" in-person training session to teach businesses and organizations about dementia and how they can take action to create an environment that is safe, respectful and welcoming for those with dementia. Those who complete the training are given posters, media materials and window stickers recognizing them as "dementia friendly."

Visit: <http://actonalz.org/> for more information

SLIDE 37:

Dementia Friendly America (DFA)²⁷

- Raising awareness about dementia
 - Having supportive options that foster quality of life
 - Supporting caregivers and families
 - Meaningful participation in community life
 - Reaching the underserved
-

TALKING POINTS:

The **Dementia Friendly America (DFA)** initiative is a national effort to equip all sectors of the community to support people with dementia and their caregivers and family.

The focus of DFA includes:

- Raising awareness about dementia and transforming attitudes and understanding of the conditions
- Having supportive options that foster quality of life on a community level
- Supporting caregivers and families
- Promoting meaningful participation in the community by people with dementia and their caregivers
- Reaching those in the community who are underserved

DFA is modeled after the community process developed by Minnesota's ACT on Alzheimer's. They provide a "Dementia Friendly Toolkit", sector specific guides, healthcare provider practice tools, and training videos for their partner communities to utilize as those communities work to become dementia-friendly. In 2015, 7 communities launched DFA's

²⁷ Dementia Friendly America press release, *Dementia Friendly America Initiative Launches in Communities Across the U.S., from Maryland to California*, July 13, 2015.

Image source: Dementia Friendly America

initiative, and another 80 communities across 30 states are looking to join them in 2016.

Visit: <http://www.dfamerica.org> for more information

SLIDE 38:

Dementia Friendly Tempe²⁸

- Arizona's first dementia friendly city
- Formed Action Team led by Chamber of Commerce
- Weekly Memory Café at library where people with dementia and caregivers can meet others
- "Dementia Friends" training to educate community on how to support dementia friendly efforts

Dementia Friendly Tempe (DFT), an initiative utilizing the Dementia Friendly America framework, is Arizona's first dementia-friendly city. The effort was initiated in 2015 by Tempe's mayor, Mark Mitchell, after his mother was diagnosed with Alzheimer's, and has since gained community-wide and legislative support. While still in the planning stages, Tempe has made significant progress:

- Held a successful kickoff summit in the community (see YouTube video below)
- Held Action Team meetings led by the Chamber of Commerce, where they are reviewing results of a survey given to sectors across the community to assess needs. Once the data review is completed, the Action Team will develop a strategic plan. Additionally, the Action Team is expecting to conduct environmental assessments of public spaces.

²⁸ Dementia Friendly America press release, *Dementia Friendly America Initiative Launches in Communities Across the U.S., from Maryland to California*, July 13, 2015.

Image source: dementiafriendlytempe.org

- Hired a coordinator for the DFT initiative to be housed in City Hall to more closely align with the Mayor’s office.
- Launching a weekly Memory Café at the Tempe Library, where people with dementia and their care partners can meet others in the community in like situations. The Café will be staffed by a professional who can answer questions, provide/direct access to resources and learn what participants hope to get from attending. Additionally, a monthly arts engagement program will be offered within the Café setting. The City of Tempe is handling the promotion of the event.
- Holding monthly community lectures at the Tempe Library that will include a variety of topics regarding dementia.
- Planning to launch “Dementia Friends” training to educate community members on how they can contribute to the dementia friendly efforts.

Visit <http://www.dementiafriendlytempe.org> for more information

Video supplement: Video highlighting Tempe’s Initiative

(5:06 minutes)

<https://www.youtube.com/watch?v=3zJOFQaUBAY>

SLIDE 39:

Conclusion: Dementia Capable and Dementia Friendly²⁹

- States/communities play significant role
- Dementia capable systems
 - Public health research and translation
 - Support services and programs
 - Workforce training
- Dementia friendly communities

TALKING POINTS:

In conclusion, let's review the key points from this presentation. States and communities play an active role in reducing the burden of the Alzheimer's and dementia epidemic. Two approaches are by creating **dementia capable systems** and **dementia friendly communities**. The concepts are similar and can overlap, but the focus of both is on accommodating those with dementia and their caregivers through providing support and services within their communities.

Public health must take an active role in fostering dementia capable systems and dementia friendly communities through:

- Conducting **public health research** on the burden of Alzheimer's and dementia, and use findings to design effective programs, policies, and best practices
- Serving to provide, inform and connect individuals and caregivers to **support services and programs**
- Designing and implementing **workforce training** to ensure workers across a wide range of professions are able to identify and meet the needs of people with Alzheimer's and dementia

²⁹ *Image source:* Copyrighted image; used with permission from the Alzheimer's Association

- Supporting the creation of **dementia friendly communities** that help people with Alzheimer's and dementia remain safe and as independent as possible

SLIDE 40:

For More Information

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

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

DEMENTIA CAPABLE SYSTEMS AND DEMENTIA FRIENDLY COMMUNITIES



Emory Centers
for Training and
Technical Assistance

LEARNING OBJECTIVES

- Define “dementia capable”
- Explain how public health can contribute to dementia capable systems through: research and translation, support services/programs, workforce training, and dementia-friendly communities
- List at least 3 services that may benefit someone with Alzheimer's/dementia
- List at least 2 services that may benefit a caregiver
- Identify at least 3 professions that would benefit from workforce training
- Describe at least 2 components of a dementia friendly community

COMPETENCIES

Association of Schools and Programs of Public Health:

- Domain 1: Appreciate the role of community collaborations in promoting population health.
- Domain 2: Discuss the interconnectedness among the physical, social, and environmental aspects of community health.

Council on Linkages Between Academia and Public Health Practice:

- IA1. Describes factors affecting the health of a community (e.g., equity, income, education, environment)
- IA1.1. Describes assets and resources that can be used for improving the health of a community (e.g., Boys & Girls Clubs, public libraries, hospitals, faith-based organizations, academic institutions, federal grants, fellowship programs)
- 8A3. Describes the ways public health, health care, and other organizations can work together or individually to impact the health of a community

COMPETENCIES CONT.

Council on Linkages Between Academia and Public Health Practice (cont.):

- 8A4. Contributes to development of a vision for a healthy community (e.g., emphasis on prevention, health equity for all, excellence and innovation)
- 8A6. Describes needs for professional development (e.g., training, mentoring, peer advising, coaching)

National Association of Chronic Disease Directors (NACDD):

- 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.
- 3.3.2 Identify training needs.

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

¹ Alzheimer's Association. 2016 Alzheimer's Disease Facts and Figures.

ALZHEIMER'S: A LARGER CONTEXT

- States/communities play significant role
 - Assessing burden
 - Risk reduction
 - Care services: health care, support services, government agencies
 - Public and private resources: transportation, grocery stores, places of worship, financial institutions, law enforcement



DEMENTIA CAPABLE SYSTEMS

- Accommodate needs of population with:
 - Memory loss
 - Physical, cognitive, behavioral symptoms
 - Co-morbidities
- Knowledgeable workforce/residents:
 - Identify people with dementia
 - Work effectively with them
 - Inform/refer to services

³ Alzheimer's Association and Centers for Disease Control and Prevention. (2013) The Healthy Brain Initiative: The Public Health Road Map for State and National Partnerships, 2013-2018.

⁴ U.S. Administration on Aging. (2011) Dementia Capability Toolkit.

⁵ Tilly, J, Weiner, J, Gould, E, and O'Keefe, J. (2011) Making the Long-Term Services and Supports System Work for People with Dementia and Their Caregivers.

DEMENTIA CAPABLE: PUBLIC HEALTH

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





PUBLIC HEALTH RESEARCH

DEMENTIA CAPABLE SYSTEMS AND DEMENTIA FRIENDLY COMMUNITIES



DISCUSSION QUESTION



What is public health research?
What does it mean to translate findings?

PUBLIC HEALTH RESEARCH & TRANSLATION

- Public health research: generalizable knowledge to improve practice
- Translation: evidence-based practice
- Sources:
 - Published peer-reviewed articles
 - Authoritative guidelines, recommendations
 - Surveillance systems



DISCUSSION QUESTION



How can public health research and translation be used to reduce the burden of Alzheimer's disease?

PUBLIC HEALTH RESEARCH & TRANSLATION

- Measure burden
- Create policies
- Identify/design practices and interventions
- Promote risk reduction and cognitive health



⁸ Centers for Disease Control and Prevention. (2010) *Distinguishing Public Health Research and Public Health Nonresearch*.
⁹ CDC & Alzheimer's Association. (2013) *The Healthy Brain Initiative: The Public Health Road Map for State and National Partnerships, 2013-2018*.

SUPPORT SERVICES & PROGRAMS

DEMENTIA CAPABLE SYSTEMS AND DEMENTIA FRIENDLY COMMUNITIES

DISCUSSION QUESTION



What kinds of support services might people with Alzheimer's and their caregivers need?

SUPPORT SERVICES: ALZHEIMER'S

- Support groups
- Wellness programs
- Care services
- Legal, financial services
- Residential care
- Transportation
- Adult day care



¹⁰ U.S. Administration on Aging. (2011) *Dementia Capability Toolkit*.

¹¹ ACT on Alzheimer's. *Dementia Capable Community: Key Elements & Resources*. Accessed August 4, 2015 from website: <http://www.actonalz.org/elements-and-resources>

SUPPORT SERVICES: CAREGIVERS

- Education/information/training
 - Alzheimer's/dementia
 - Behavioral management
 - Available resources
 - Self-care
- Counseling/support groups
- Care management
- Respite services



¹² ACT on Alzheimer's. (2014). *Alzheimer's Disease Curriculum, Module X: Caregiver Support*.

EVIDENCE-BASED PRACTICE

- Reducing Disability in Alzheimer's Disease (RDAD) – University of Washington
 - Focus on teaching family caregivers strategies
- Minds in Motion (MIM)
 - Focus on improving function in early stages with mild cognitive impairment
- Skills2Care – Thomas Jefferson University
 - Focus on occupational therapy based strategies for caregivers

¹³ Alliance for Aging Research. (2012) *Translating Innovation to Impact: Evidence-based Interventions to Support People with Alzheimer's Disease and their Caregivers at Home and in the Community*.

DISCUSSION QUESTION



What is the role of public health in connecting people to the services they need?

SUPPORT SERVICES: PUBLIC HEALTH

- Evidence-based programs and interventions
- Information and referrals
- Identifying service needs
- Funding, space, expertise



SUPPORT SERVICES: PARTNERSHIPS

- Offices on Aging / Aging and Disability Resource Centers
Agencies on Aging
 - Education
 - Cognitive assessments
 - Support programs
 - Resources
- Non-profit organizations
- Residential care facilities



¹⁵ ACT on Alzheimer's. (2014). *Alzheimer's Disease Curriculum, Module X: Caregiver Support*.

WORKFORCE TRAINING

DEMENTIA CAPABLE SYSTEMS AND DEMENTIA FRIENDLY COMMUNITIES

WORKFORCE TRAINING

- Health care
- Direct care
- Public health
- First responders
- Other support services: transportation, customer service, faith-based organizations



DISCUSSION QUESTION



What training should **health care and direct care professionals** receive?

WORKFORCE TRAINING: HEALTH CARE & DIRECT CARE

- Basics of dementia
- Benefits of early diagnosis
- How to address physical, cognitive, emotional, behavioral symptoms
- Assisting caregivers
- Managing co-morbidities
- Use of validated assessment tools (health care)



DISCUSSION QUESTION



What training should **public health professionals** receive?

WORKFORCE TRAINING: PUBLIC HEALTH

- Alzheimer's as a public health priority
- Importance of early detection
- Cognitive health and risk reduction
- Caregiver needs and burden
- Surveillance
- Health disparities
- Unique issues (stigma, abuse, advance planning)



DISCUSSION QUESTION



What training should **first responders** receive?

WORKFORCE TRAINING: FIRST RESPONDERS

- Situations involving stress or fear
- Training needs:
 - Identifying Alzheimer's and dementia
 - Interaction/communication
 - Resources
 - Registries, technologies



WORKFORCE TRAINING: OTHER PROFESSIONS

- Public transportation, customer service, faith or spiritual communities, etc.
 - Awareness
 - Recognizing need for help
 - Resources
 - Communication
 - Ways to assist and support



DEMENTIA FRIENDLY COMMUNITIES

DEMENTIA CAPABLE SYSTEMS AND DEMENTIA FRIENDLY COMMUNITIES



DISCUSSION QUESTIONS



Imagine you or someone you care about has Alzheimer's or dementia.

What might be some of your concerns or fears about going out in your community?

How could those be addressed at a community level?

DEMENTIA FRIENDLY COMMUNITIES

- Health care, community services, resources
- Safety and accessibility
 - Transportation
 - Mobility
- Respectful and supportive
- Public education and workforce training
- Technology
 - GPS, GIS
 - Registry



²¹ U.S. Administration for Community Living/Administration on Aging. (2014) *Dementia-Capable States and Communities: The Basics*.

²² The Gerontological Society of America. (2015) *Dementia Friendly, Dementia Capable, and Dementia Positive: Concepts to Prepare for the Future*.

DEMENTIA FRIENDLY COMMUNITIES



Reproduced from ACT on Alzheimer's® developed tools and resources.

DEMENTIA FRIENDLY: MIDDLETON, WI

- Business trainings
- Business promotions
- Memory trail/park
- Evaluation criteria



²⁴ Wisconsin Healthy Brain Initiative. *A Tool Kit for Building Dementia-Friendly Communities*
²⁵ Alzheimer's and Dementia Alliance of Wisconsin. Dementia Friendly Community.
<http://www.alzwisc.org/Dementia%20Friendly.html>

DEMENTIA FRIENDLY: ACT ON ALZHEIMER'S

- Minnesota's statewide, volunteer-driven collaboration
- Community toolkit
 - Form action team
 - Assess community strengths and gaps
 - Analyze needs and develop action plan
 - Pursue priority goals



²⁶ ACT on Alzheimer's. (2013). *Is Your Community Prepared?*

DEMENTIA FRIENDLY AMERICA (DFA)

- Raising awareness about dementia
- Supportive options that foster quality of life
- Supporting caregivers and families
- Meaningful participation in community life
- Reaching the underserved



²⁷ Dementia Friendly America press release, *Dementia Friendly America Initiative Launches in Communities Across the U.S., from Maryland to California*, July 13, 2015.

DEMENTIA FRIENDLY TEMPE

- Arizona's first dementia friendly city
- Formed Action Team led by Chamber of Commerce
- Weekly Memory Café at library where people with dementia and caregivers can meet others
- "Dementia Friends" training to educate community on how to support dementia friendly efforts



²⁸ Dementia Friendly America press release, *Dementia Friendly America Initiative Launches in Communities Across the U.S., from Maryland to California*, July 13, 2015.

CONCLUSION: DEMENTIA CAPABLE AND DEMENTIA FRIENDLY

- States/communities play significant role
- Dementia capable systems
 - Public health research and translation
 - Support services and programs
 - 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- Which professions need to be knowledgeable about dementia?

- a. Health care workers (nurses, direct care providers)
- b. Public sector workers (government- federal/local)
- c. Private sector workers (for profit/non-profit)
- d. A & B
- e. All of the above

Answer: E

2- Research translation is best described as:

- a. Making research available in different languages
- b. Putting research findings into practice
- c. Developing new methods for conducting research
- d. Using plain language to explain research findings

Answer: B

3- What support services do people with Alzheimer's need?

- a. Wellness programs
- b. Financial planning services
- c. Support groups
- d. A & C
- e. All of the above

Answer: E

4- The term "dementia capable" means all of the following *except*:

- a. A device able to be used by someone with dementia
- b. Accommodating the needs of those with dementia
- c. Able to identify people with dementia
- d. Support systems for people with dementia

Answer: A

5- Some states have registries of people with Alzheimer's for surveillance, monitoring and research.

- a. True
- b. False

Answer: A

CURRICULUM RESOURCES

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

Case Studies

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 needing to access the video/audio.

1. "Alzheimer's Disease Underdiagnosed in Indian Country," NPR (2015).

- **Audio/Transcript Link:**

- <http://www.npr.org/templates/transcript/transcript.php?storyId=458041798>

- **Run Time:** 3:46 minutes (audio)

- **Key Terms:** cultural context, Native Americans, diagnosis, community outreach, family relationships, tradition, stigma, caregiver burden, long term care

- **Modules:** 1, 3, 4

Description:

Mrs. Williams is an older woman who has been having severe memory problems for the past seven years. Mrs. Williams lived on a Native American reservation in Arizona before moving in with her daughter, Delma, in Los Angeles. In many tribal communities, 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- "Inside Alzheimer's: What's it like to live with early-onset Alzheimer's disease? Greg O'Brien offers a glimpse," NPR special series (2015).

- **Audio/Transcript Link:** <http://www.npr.org/series/389781574/inside-alzheimers>
- **Run Time:**4-6 minutes per segment (audio)
- **Key Terms:** progression, younger-(early) onset, cancer, long term care, end of life decisions, caregiver burden, spouse/partner relationship, family relationship, loss of appetite, loss of smell, loss of taste, hallucinations, medications, GPS app, loss of identity
- **Modules:** 1, 2, 4

Description:

A nine part series of articles and audio clips that chronicle aspects of one man's journey with Alzheimer's disease; audio clips are 4-6 minutes each.

Writer Greg O'Brien was diagnosed with younger-onset Alzheimer's disease six years ago when he was 59 years old. Not only was he diagnosed with younger- onset Alzheimer's disease, but he was also diagnosed with stage-three prostate cancer a few years later. Greg is a journalist and writer living in Cape Cod with his wife, Mary Catherine, and their three children. Greg began demonstrating signs of Alzheimer's disease, such as memory loss and getting lost as his own mother was in the end stages of Alzheimer's.

Mary Catherine says that Alzheimer's disease changed Greg's personality in many ways. On one hand, Greg discusses certain topics with her more openly than he would have in the past, but

she also has noticed that he gets angry now, something he never used to do before. In the past, Greg was a loud, outgoing man who was often was at the center of discussion. Now he is quieter and more solitary, even disappearing into a different room when crowds of visitors become overwhelming for him. Greg also used to run upwards of six miles daily as a part of his daily routine; however, he began getting lost and switched to running in a gym.

Greg's personality is not the only thing that has changed since his younger-onset Alzheimer's diagnosis. Greg's appetite and sense of taste and smell have declined. Greg says that food now often tastes the same, like "rolled up newspaper." Greg does buy fruit bars and states that although they have no taste, they do feel cold, which is a different and enjoyable sensation.

As Greg's Alzheimer's disease has progressed over the past six years, so have his hallucinations. Hallucinations are a rarely discussed aspect of Alzheimer's disease but can often accompany memory loss. According to Greg's doctors, these hallucinations are due to the changes in his brain as a result of the disease. .

Mary Catherine and Greg's outlook on life has also changed over time. For example, Mary Catherine says that she no longer can get impatient, which is difficult, but important. In the beginning of his diagnosis, Greg used to get very angry, but now he no longer does as he tries to focus in the moment instead of the past or future. Mary Catherine believes their marriage has gotten even stronger as they navigate Greg's Alzheimer's disease.

Because of Greg's Alzheimer's, Greg and Mary Catherine have had to make many difficult decisions, including deciding to sell their house that Greg built, where they raised their three children and planned to grow old together. Growing old in that house together is no longer a realistic possibility, due to Greg's Alzheimer's disease.

Greg, Mary Catherine, and his physician have discussed "exit strategies" for Greg while he is still aware and able to make these types of decisions. One of these exit strategies includes not treating his stage three prostate cancer. Greg's physician says that not treating the prostate cancer will most likely shorten his life, but Greg is okay with this because he would rather his life be shortened by the prostate cancer than by the Alzheimer's disease. Greg states that he is most afraid of the "in-between;" he loves living and he is not afraid to die, but he fears the middle portion, the loss of identity and independence, and dreads his family's suffering as they watch his slow decline.

Discussion Questions:

- Why is it important that individuals with Alzheimer's disease are diagnosed early?
 - When individuals are exhibiting signs of Alzheimer's disease, the people around them need to understand what is happening so they can be patient and react in an understanding way.
 - Being able to make important decisions about their care, including at the end of life, and finances while they are still able to make informed decisions.
- What are ways that Greg can maintain his independence as his Alzheimer's disease progresses?

- Going to the gym worries his family in case he gets lost on the way. A GPS app on his phone can alert his family to his location.
- Discuss the importance of end of life planning and role of public health in encouraging people to make plans.
- Discuss the importance of a strong social network and family support.
 - In one of the interviews, Greg talks about how where he lives is a small town where everyone knows everyone and their business. As word of his Alzheimer's disease spread and more people in his town knew about it, people eventually began introducing themselves to him when they began a conversation in order to help him identify them.
- Discuss the advantages and disadvantages of deciding not to treat stage-three prostate cancer as Alzheimer's disease progresses.

4- "Can Technology Ease the Burden of Caring for People with Dementia?" NPR (2015).

- **Audio/Transcript Link:**
<http://www.npr.org/templates/transcript/transcript.php?storyId=417205451>
- **Run Time:** 4:35 minutes (audio)
- **Key Terms:** care givers burden, financial burden, healthcare system, family support, technology, monitoring systems, long term care
- **Modules:** 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.

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

5- "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
- **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?
- 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?

6- "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?

7- "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
- **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?
- 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
- **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=yJTXN4xrI8>
- **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 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_na.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:

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_na_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, amnestic form, non-amnestic 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
- **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 clip 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 clip 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:

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.theconnexion.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 Cesrasoli (2012).

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

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IMAGE SOURCES

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